



# **PARLIAMENT OF VICTORIA**

**Family and Community Development  
Committee**

## **Inquiry into services for people with Autism Spectrum Disorder**

Final Report

Parliament of Victoria  
Family and Community Development Committee

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Ordered to be published

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VICTORIAN GOVERNMENT PRINTER  
June 2017

**PP No. 298, Session 2014-17**  
**ISBN 978 1 925458 94 7 (print version)**  
**978 1 925458 95 4 (PDF version)**

# Committee functions

The Family and Community Development Committee is constituted under section 11 of the *Parliamentary Committees Act 2003*.

The committee's functions are to inquire into, consider and report to the Parliament on:

- a. any proposal, matter or thing concerned with:
  - i. the family or the welfare of the family
  - ii. community development or the welfare of the community
- b. the role of Government in community development and welfare, including the welfare of the family.

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This report is available on the Committee's website.

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# Terms of Reference

## Inquiry into services for people with autism spectrum disorder

To the Family and Community Development Committee to inquire into, consider and report, no later than 31 May 2016\*, on services for people with autism spectrum disorder in Victoria, including but not limited to —

- (a) the prevalence of autism spectrum disorder in Victoria
- (b) the availability and adequacy of services provided by the Commonwealth, State and local governments across health, education, disability, housing, sport and employment services;
- (c) the adequacy of services to be provided under the National Disability Insurance Scheme (NDIS);
- (d) evidence of the social and economic cost of failing to provide adequate services; and
- (e) the projected demand for services in Victoria.

\*The reporting date was extended to 30 June 2017 by resolution of the Legislative Council on 12 April 2016.



## Chair's foreword

The diversity of people with Autism Spectrum Disorder (ASD) requires a diversity of services and service delivery models. It is common for autism to occur in a person with a co-existing disability, health or mental health condition, and services need to meet their varying individual needs. As the saying goes, 'if you've met one person with autism, you've only met one person with autism'. It is well known that the demand for services will increase in line with the increasing number of people being diagnosed with ASD, as evidenced, not just in Victoria, but across the globe.

Victoria faces many challenges with regard to government-funded services for people with ASD. The Committee heard frequently of the shortage of services, their high costs, and the poor integration of services, especially in rural and regional areas. The Committee found that there is a lack of assessment and diagnostic services, a shortage of qualified diagnostic clinicians, and a real lack of early intervention and behavioural support services. For both children and adults with ASD, access to education, health and mental health services and programs is limited, with long waiting times for support. There is also a lack of knowledge among education, health, mental health and disability service providers about autism. It is important that these professionals are provided with education and training to address the knowledge gap.

Participation in community, sporting and cultural activities and events is vital for people with ASD to prevent social isolation and discrimination. Raising community awareness and understanding of autism is essential to encourage inclusiveness and improved attitudes towards people with ASD. There are significant social costs in failing to be inclusive of people with autism, and a consequent loss of health and wellbeing for people with ASD. The Committee heard of many organisations delivering innovative and creative programs and services for people with ASD. However, delivery of these programs is often restricted to small numbers of people with ASD and they are often delivered in isolation. Investing in and expanding these services will mean more people with ASD can access these programs and services.

It is anticipated that many people with ASD will be supported through the NDIS. However, some people with ASD will not meet the eligibility criteria for the NDIS, but will still require services and support to enable them to live fulfilling lives. The Victorian Government's 2009 Autism State Plan provided the building blocks for addressing the needs of people with ASD. The Committee believes it is time to update this plan. An updated State Autism Plan will build upon the work of the former plan, and incorporate within it many of the findings and recommendations in this report. Some of the Committee's recommendations can be implemented quickly, while others will require time, effort and investment to develop and implement.

Throughout the Inquiry the Committee heard from people with ASD, families living with ASD and carers. What came through loud and clear is that any decisions made about services or programs for people with ASD must include their voices and experiences. The Committee appreciates the phrase it heard repeated across the Inquiry, 'Nothing about us without us'. On behalf of the Committee I acknowledge and

sincerely thank people with ASD and families living with ASD for their important contributions to the Inquiry. This final report has been prepared through the lens of their voices and experiences. On behalf of the Committee I would like to thank everyone who made written submissions to the Inquiry and appeared as witnesses at our public hearings. I would like to thank my fellow Committee Members for their commitment and contributions to this Inquiry that has spanned over 18 months, and for their work in the development of this report and its recommendations.

On behalf of the Committee I would also like to thank the dedicated and talented Committee Secretariat team: Research Officer, Ms Rachel Macreadie; Inquiry Assistant, Dr Pamie Fung; and Administration Officer, Ms Helen Ross-Soden, who have all worked tirelessly to assist the Committee in delivering this report. A special thank you to the Executive Officer, Dr Greg Gardiner, for his knowledge, direction and support to the Committee.

**Maree Edwards, MP**  
**Chair**

# Executive summary

Throughout the Inquiry the Committee heard evidence from people with Autism Spectrum Disorder (ASD) and families living with ASD, who told the Committee about their individual and family experiences, and whose accounts of living with ASD form the basis for this report. The Committee found that ‘living with autism’ means something different for every person diagnosed with ASD. The Committee also found that people with ASD are not content to have policies and programs in relation to ASD developed without their involvement. The Committee supports the core principle that people with ASD must be included in any such developments – by governments, service providers and agencies.

In the ten chapters of this report, the Committee examines the quality and adequacy of both mainstream and autism-specific services currently provided to people with ASD and families living with ASD in a range of areas. The Committee found that there are serious shortcomings in service access, quality and delivery in Victoria. These include: access to timely and affordable assessment and diagnosis, the availability of early childhood interventions, inclusive schooling options, and a shortage of trained health professionals, to name a few. In each chapter, the Committee makes recommendations to improve the access, availability and quality of services to people with ASD.

The roll out of the National Disability Insurance Scheme (NDIS) will occur across Victoria over the next few years. The Committee has found that, in its pilot phase in Victoria, participants in the scheme have experienced shortcomings and the Committee makes recommendations to address these issues. The Committee firmly believes that the Victorian Government has an ongoing, key role to play in improving and delivering services to people with ASD and families living with ASD.

## **Chapter One: Living with Autism**

The diversity of experiences of people with ASD is a challenge for public policy. The main challenge for governments is to ensure that people with ASD have access to the supports they need – either through specialised disability services or through mainstream services that are fundamentally inclusive. In this Inquiry, the Committee heard directly from people with ASD and from families living with ASD. First-hand accounts of living with ASD were a key source of evidence for this report. The chapter provides a brief history of ASD and the diagnostic process, an examination of ASD as a lifelong neurodevelopmental condition, and discusses the available data on the prevalence of ASD. The Committee found that for many families, the social, emotional and financial impacts of having a child with ASD has been immense.

The Committee makes a number of recommendations, beginning with a core principle that in the development of policies, services and supports for people with ASD, all service providers and professionals must consult and engage with people with ASD, their families and advocates. The Committee further recommends that families living with ASD be provided with proper supports, including respite care, to be available across the state. The Committee was keen to see the comprehensive

collection of data on all people diagnosed with ASD, to enable the analysis of the prevalence of ASD, both at the state level and nationally, to ensure appropriate planning for services to meet future demand. The Committee also identified the need for an audit of existing and ongoing service providers for people with ASD in Victoria.

## **Chapter Two: Policy Settings and Government-funded Services for People with ASD**

A focus of the Inquiry's terms of reference was the availability and adequacy of government-funded services for people with ASD. The Committee found that there are few government-funded services designed exclusively for people with ASD. People with ASD access mainstream services offered to the broader community, such as hospitals and health care, mental health services, schools, and social housing. The chapter outlines the legislative and policy frameworks at both Commonwealth and State levels that are relevant to the provision of services to people with ASD and their families, and their rights. It provides an overview of the disability service framework for people with ASD and their families, and provides details on autism-specific programs and services.

The Committee heard from people with ASD and their families about their frequently negative experiences of government-funded services. The evidence is clear that much needs to be done to make mainstream government services more inclusive of people with ASD, and for services to be better integrated. The Committee supports a policy framework that addresses the needs of people with ASD. The Committee recommends the development of a national strategy for people with autism, and at the state level, to create an updated State Autism Plan, which would build on the work of the previous 2009 Autism State Plan. The Committee recommends better integration of government-funded services for people with ASD and the removal of barriers to accessing services and information.

## **Chapter Three: The Early Years – Diagnosis and Intervention**

During the Inquiry, the Committee received substantial evidence from people with ASD and families living with ASD concerning children with ASD, especially the difficulties associated with obtaining a diagnosis and accessing appropriate early childhood intervention supports and services. A central concern for many of the Inquiry's stakeholders was access to timely, affordable assessment services for diagnosis, the lack of information available about appropriate early intervention services, and the cost of such services. More broadly, the Committee found that international best practice in the diagnosis of ASD consists of a multidisciplinary assessment involving a paediatrician or child and adolescent psychiatrist, a psychologist and a speech pathologist. Early diagnosis is important as it can pave the way for access to early intervention services, which has been strongly associated with better life outcomes for people with ASD.

The Committee makes a number of recommendations to improve Victoria's system for assessing children suspected of having ASD. Firstly, Victoria's Maternal and Child Health Nurses and General Practitioners need to be better trained in the surveillance of ASD and making appropriate referrals. Further, Victoria needs more speech pathologists, who can assess and treat ASD. Victoria needs to adopt a model for

assessment of ASD that is consistent with international best practice. Multidisciplinary assessment teams need to be established, based on and expanding upon existing services and infrastructure, such as the Child and Adolescent Mental Health Services Network (CAMHS), and form part of a state-wide ASD diagnostic service. These teams need to be available and accessible to all Victorians.

People with ASD and their families need to have access to clear information about evidence-based therapies, and practitioners of behavioural therapies need to be qualified. The Committee recommends the development in Victoria of a post-graduate diploma in behavioural therapies. The Committee also recommends that the Victorian Government make available up to 20 hours of optional, evidence-based therapy per week for children with ASD, who are ineligible for funded support under the NDIS.

## **Chapter Four: The School Years**

A key issue of the Inquiry has been the experience of students with ASD in the Victorian school system. A series of issues were raised both by parents of students with ASD and by students with ASD themselves. These related to: the lack of information for parents so that they are able to select an appropriate school for their child with ASD; some schools have refused to enrol children with ASD; and the limitations of the Program for Students with Disabilities (PSD).

The Committee also found that there was: a lack of understanding and knowledge in the school sector of ASD, coupled with poor or non-existent training of teachers; bullying; a lack of appropriate learning environments; and a lack of opportunity for academic achievement. The Inquiry's stakeholders consistently highlighted the need for an education system that is inclusive and welcoming of students with ASD.

The Committee found that, notwithstanding the recent efforts of the Victorian Government under its inclusive education agenda, mainstream schools in Victoria are not commonly providing an inclusive model of education for students with ASD and that, in general, the system lacks choice for students with ASD and their families. The chapter makes a number of recommendations to improve inclusiveness in Victorian schools, including: that the State Government adopt and fund all of the remaining four recommendations of the Review of the Program for Students with Disabilities; and that the Department of Education and Training and the Victorian Registration and Qualifications Authority monitor adherence to the Disability Standards for Education 2005, with respect to the enrolment of students with ASD in schools in Victoria.

The Committee recommends: that the Victorian Government fund a strategy for the inclusive education of students with ASD in all mainstream and specialist schools; the creation of new autism specialist schools in regional Victoria; the expansion of school-based autism outreach programs to all education regions of the state; doubling the number of funded scholarships for teachers to the Autism Teaching Institute, to take up a post-graduate diploma in teaching students with ASD; improvements to the training of both trainee and current teachers in ASD; and ensuring that students with ASD are able to have personal therapy and other supports provided to them within school settings.

## **Chapter Five: Services for Adults with ASD**

The chapter discusses the experiences of adults with autism and their families. The Committee heard directly from many adults with ASD about their experiences. The Committee found that some adults with ASD are being diagnosed late in life. These individuals often speak of their eventual diagnosis in adulthood as a ‘relief’ after a lifetime of confusion. However, many adults find the journey to diagnosis difficult, as there are no public ASD diagnostic assessment teams for adults, there is a lack of awareness amongst health and allied health professionals, and there are no targeted intervention therapies for adults with ASD. The chapter discusses the issues of diagnosis, underemployment and unemployment, parenting with ASD, the interface with the criminal justice system, and housing issues.

The Committee makes recommendations, including that: the current age cap of 13 years of age for the Medicare rebate for the diagnosis and assessment of ASD be removed entirely; adults have timely access to public ASD diagnostic assessment teams; training is provided to health professionals in identifying the traits and presentations associated with ASD in adults; the State Government develop an employment strategy for adults with ASD; and the Social Housing Growth Fund devote resources to provide for the housing needs of adults with ASD.

The Committee believes that the interface between the criminal justice system in Victoria and adults with ASD can be improved. A system for identifying and registering people with ASD who have contact with the criminal justice system needs developing, and Corrections staff need to be trained in engaging with adults with ASD. The policy landscape also needs to address the needs of adults with ASD, both at the state and federal level.

## **Chapter Six: People with ASD and the National Disability Insurance Scheme**

The National Disability Insurance Scheme (NDIS) was established by the *National Disability Insurance Scheme Act 2013* (Cth), and launched in 2013 at seven trial sites around Australia, including the Barwon trial site in Victoria. It is estimated that the scheme will provide support for approximately 460,000 people nationally, with more than 100,000 Victorians expected to benefit from the scheme. The scheme will eventually replace the main Commonwealth funded program for children with ASD – the Helping Children with Autism program (HCWA). The Committee heard both positive and negative commentary on the scheme, which is due to be fully rolled out in Victoria by 2019-20. At a public hearing held in Geelong, the Committee heard from people with ASD and families living with ASD about the scheme and its roll out in their region. Witnesses at public hearings outside Geelong expressed a lack of knowledge of the scheme and its implications for family members.

In the chapter, the Committee makes a number of recommendations, many of which are directed to the Victorian Government in its capacity as a participant in the COAG Disability Reform Council. The recommendations include: improving the provision of information to people with ASD; better training for scheme planners; more plan flexibility so that necessary changes can be more easily made; and supported travel costs. The Committee also wants to ensure that the national safeguarding framework



protects people with ASD, and that the NDIS has the capacity to meet the growth in demand for services in Victoria.

## **Chapter Seven: Gender and ASD**

The majority of children and adults diagnosed with ASD are male, and many programs designed for people with ASD are based on the assumption that it is an essentially male condition. The Committee received evidence that indicated that girls and young women have been under-represented in the available data. The Committee found that girls and women with ASD have often found accessing diagnosis, treatment and services to be particularly challenging. The Committee heard that an understanding of ASD in girls and women could broaden the general understanding of ASD.

The chapter discusses the gendered experiences of girls and women in obtaining a diagnosis and examines how females present with ASD. It examines the experience of girls in schools, social relationships and social media, and the experience of women with ASD through the lifecycle. The Committee heard evidence directly from women with ASD. Recommendations are made in relation to: better training to ensure health professionals and teachers have the skills to identify, treat and engage with girls and women with ASD; that the NDIS linkages program fund support groups for girls and women with ASD; a public education campaign to increase awareness of female ASD in the community; and that the State Government develop an employment strategy for women with ASD.

## **Chapter Eight: Health and Mental Health Services**

The chapter focuses on the experiences of people with ASD and families living with ASD accessing health and mental health services in Victoria. People with ASD told the Committee about their difficulties in accessing mainstream health and mental health services, including a lack of coordination between health professionals, and a lack of understanding about ASD across the health and mental health system. Some parents of children with ASD reported difficulties accessing services due to the heightened anxiety and sensory needs of their children.

The Committee makes a number of recommendations to improve health and mental health service delivery for people with ASD, which include: better training and education for health professionals, including dentists, in understanding, treating and managing patients with ASD; the provision of autism specialists throughout the public health system; all new hospitals to be designed with quiet rooms in emergency departments, and existing hospitals to be re-fitted with quiet spaces.

## **Chapter Nine: Services for People with ASD in Rural and Regional Victoria**

The chapter focuses on rural and regional experiences of accessing services for children, youths and adults with ASD. The Committee found that there were severe shortages of ASD services in rural and regional Victoria. The Committee heard that paediatricians, psychiatrists, psychologists, and allied health workers were in short supply, making access to diagnosis and early intervention services difficult, with long

waiting periods. The Committee found that there was a lack of inclusive school options in rural and regional areas for families and individuals with ASD.

The Committee makes a number of recommendations to address these shortcomings, including: that the Victorian Government establish centres for autism excellence in regional Victoria, providing specialist services and information for people with autism, including multidisciplinary diagnostic assessments, early intervention and therapy services; and that a rural and regional autism health and disability service network be created. The Committee also recommends the funding of scholarships to Indigenous students in the areas of allied health, psychology, speech pathology, social work and education to work in rural and regional Victoria.

With regard to education, the Committee is keen for the State Government to develop a strategy to address the shortage of inclusive school options for students with ASD in the regions. The Committee recommends that the Department of Education and Training draw on outreach models to enhance inclusive education. The Committee also recommends the expansion of the Mansfield Autism Statewide Services travelling teacher program, and the Dookie school model.

## **Chapter Ten: Social Inclusion, Community Participation and Sport**

The chapter discusses the barriers to social inclusion, community participation and access to sports and recreational activities for people with ASD. The Committee found that the lack of awareness of ASD in the community has left not only individuals with ASD but also their family members socially isolated. The chapter discusses leading initiatives that have emerged in the community to facilitate access for people with ASD to community-based activities and programs, and the role of self-advocates. The Committee found that there were substantial social costs of failing to include people with ASD in the community, and a loss of health and wellbeing for people with ASD and their families.

The Committee makes recommendations to improve the social inclusion of people with ASD, including: that the Victorian Government fund Creative Victoria to develop an autism inclusion strategy; and training for frontline Public Transport and Victoria Police officers to enable them to understand ASD and to engage with people with ASD.

The Committee views sport and recreation as vital for people with ASD given the barriers they face, and the Committee recommends the expansion of the Access All Abilities program to provide more sporting and recreation opportunities for children with ASD. The Committee also recommends funding for local governments to provide sporting and recreation opportunities for children with ASD. The Committee also heard of the need for a wide-reaching education campaign to educate and raise community awareness about ASD, for the inclusion of people with ASD and their families and carers in the community.

# Acronyms

<b>ABA</b>	Applied Behaviour Analysis
<b>ABS</b>	Australian Bureau of Statistics
<b>ADE</b>	Australian Disability Enterprises
<b>ADHD</b>	Attention Deficit Hyperactivity Disorder
<b>ADI-R</b>	Autism Diagnostic Interview – Revised
<b>ADOS</b>	Autism Diagnostic Observation Schedule
<b>AHMAC</b>	Australian Health Ministers’ Advisory Council
<b>ASD</b>	Autism Spectrum Disorder
<b>ASELCC</b>	Autism Specific Early Learning and Care Centre
<b>ATI</b>	Autism Teaching Institute
<b>Autism CRC</b>	Autism Cooperative Research Centre
<b>CAMHS</b>	Child and Adolescent Mental Health Services
<b>CALD</b>	Culturally and Linguistically Diverse
<b>CDC</b>	Center for Disease Control and Prevention (U.S.)
<b>COAG</b>	Council of Australian Governments
<b>CPD</b>	Continuing Professional Development
<b>Cth</b>	Commonwealth of Australia
<b>CYMHS</b>	Child and Youth Mental Health Services
<b>DDA</b>	<i>Disability Discrimination Act 1992</i> (Cth)
<b>DES</b>	Disability Employment Services
<b>DET</b>	Department of Education and Training (Victorian)
<b>DHHS</b>	Department of Health and Human Services (Victorian)
<b>DSC</b>	Disability Services Commissioner (Victorian)
<b>DSM</b>	Diagnostic and Statistical Manual
<b>DSS</b>	Department of Social Services (Commonwealth)
<b>ECEI</b>	Early Childhood Early Intervention (NDIS)
<b>ECIS</b>	Early Childhood Intervention Service
<b>ESDM</b>	Early Start Denver Model
<b>FaHSCIA</b>	Department of Families, Housing, Community Services and Indigenous Affairs (Commonwealth)
<b>GP</b>	General Practitioner
<b>HACC</b>	Home and Community Care
<b>HCWA</b>	Helping Children with Autism Program
<b>ICD</b>	International Classification of Diseases

<b>ID</b>	Intellectual Disability
<b>IFP</b>	Individually Funded Package
<b>ILC</b>	Information, Linkages and Capacity Building program
<b>IQ</b>	Intelligence Quotient
<b>ISP</b>	Individual Support Package
<b>MAV</b>	Municipal Association of Victoria
<b>MBS</b>	Medicare Benefits Schedule
<b>MCH</b>	Maternal and Child Health
<b>NICE</b>	National Institute for Health and Care Excellence (UK)
<b>NDIA</b>	National Disability Insurance Agency
<b>NDIS</b>	National Disability Insurance Scheme
<b>OCD</b>	Obsessive Compulsive Disorder
<b>OT</b>	Occupational Therapist
<b>OTARC</b>	Olga Tennison Autism Research Centre (La Trobe University)
<b>PBS</b>	Positive Behaviour Support
<b>PDD-NOS</b>	Pervasive Development Disorder-Not Otherwise Specified
<b>PEDS</b>	Parents' Evaluation of Developmental Status
<b>PSD</b>	Program for Students with Disabilities
<b>RACGP</b>	Royal Australian College of General Practitioners
<b>RACP</b>	Royal Australasian College of Physicians
<b>RANZCP</b>	Royal Australian and New Zealand College of Psychiatrists
<b>RCH</b>	Royal Children's Hospital
<b>RCN</b>	Raising Children Network
<b>RTO</b>	Registered Training Organisation
<b>SAC</b>	Social Attention and Communication study (La Trobe University)
<b>SDS</b>	Special Development School
<b>VASELCC</b>	Victorian Autism Specific Early Learning and Care Centre

# Glossary

## **Applied Behaviour Analysis (ABA)**

Applied Behaviour Analysis (ABA) is an approach to understanding and changing behaviour, which includes a range of different strategies and techniques to teach people with ASD new skills and reduce their difficult behaviour.<sup>1</sup> ABA is a style of early intervention that focuses on improving the social, communication and learning skills of children with ASD. Interventions based on ABA work to improve skills and behaviour by breaking complex tasks down into smaller, discrete steps, and teaching these tasks through repetition and positive refinement. There is a growing body of research that has found ABA therapies beneficial for children with ASD.<sup>2</sup>

## **Asperger's syndrome**

Asperger's syndrome (or Asperger's disorder) was previously understood as a distinct disorder from other types of autism. Following the release of the DSM-5, Asperger's is now considered part of the broad category of Autism Spectrum Disorder.<sup>3</sup>

## **Autism Spectrum Disorder (ASD)**

A lifelong, neurodevelopmental condition. ASD is usually diagnosed by health professionals using the DSM-5, which states that people with ASD have difficulties in two main areas:

- social communication and interaction; and,
- restricted or repetitive behaviours, interests and activities.

In addition, the DSM-5 outlines three 'severity levels' that can be used to describe the difficulties individuals have in relation to the key areas of social communication and restricted or repetitive behaviours:

- Level 3: Requiring very substantial support.
- Level 2: Requiring substantial support.
- Level 1: Requiring support.<sup>4</sup>

Prior to 2013, the DSM defined ASD as three separate disorders (Autistic Disorder, Asperger's Syndrome and Pervasive Developmental Disorder Not Otherwise Specified). These disorders are understood as part of a closely linked 'spectrum', with individuals displaying different levels of 'severity'.

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1 Raising Children Network, 'Applied Behaviour Analysis (ABA)', accessed 4 June 2017, <[raisingchildren.net.au/articles/applied\\_behaviour\\_analysis\\_th.html](http://raisingchildren.net.au/articles/applied_behaviour_analysis_th.html)>.

2 Ibid.

3 American Psychological Association, Diagnostic and statistical manual of mental disorders (5th ed.), Arlington, VA, American Psychiatric Publishing, 2013.

4 Ibid.

### **Diagnostic and Statistical Manual**

Standard diagnostic criteria for mental disorders developed by the American Psychiatric Association.<sup>5</sup> The criteria outlined in the DSM-5 (published in 2013) are most commonly used to diagnose ASD in Australia. The DSM-5 introduced new criteria for ASD, and combined Asperger's syndrome, Autistic Disorder and Pervasive Developmental Disorder – Not Otherwise Specified into one disorder: Autism Spectrum Disorder. The DSM-5 also created a separate diagnosis of Social Communication Disorder.

### **Disability Reform Council**

The Council of Australian Government's (COAG) Disability Reform Council oversees the trial and implementation of the NDIS. The Council consists of Commonwealth, State and Territory Ministers with responsibility for disability policy and treasury portfolios, as well as a representative from the Australian Local Government Association.

### **Early intervention services**

Early intervention services are designed to support children with a developmental delay, including those with ASD. Early intervention typically involves group or individual play-based sessions that focus on improving a child's behaviour, communication, or social skills. A range of different health professionals can be involved in providing early intervention services, such as psychologists, behavioural therapists, speech pathologists and occupational therapists.

### **International Classification of Diseases**

The International Classification of Diseases and Related Health Problems (ICD) is the standard international diagnostic tool for epidemiology, health management and clinical purposes, including mental disorders, maintained by the World Health Organisation. While it includes criteria for autism, it is not commonly used in Australia. The ICD is currently in its tenth revision (with ICD-11 in development and due to be released in 2018). Like the DSM, the ICD is revised periodically.

### **NDIS Early Childhood Intervention (ECEI) Approach**

A policy statement issued by the NDIS outlining how the scheme will fund early intervention services. The approach states that all children with developmental delay or disability will be eligible for early intervention services regardless of their diagnosis. The NDIS will establish a network of 'access partners' with expertise in early intervention, who will meet with families to determine the supports their child needs.

### **Neurodevelopmental disorders**

Conditions that are related to impairments of the growth and development of the brain or central nervous system. ASD is considered a neurodevelopmental disorder.

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5 Ibid.

**Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS)**

Like Asperger's syndrome, Pervasive Developmental Disorder – Not Otherwise Specified was previously a distinct diagnostic category. Following the release of the DSM-5, the disorder is now considered part of the broad category of Autism Spectrum Disorder.

**Sensory sensitivities**

People with ASD may have difficulty processing everyday sensory information. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment now forms part of the DSM-5 diagnostic criteria for ASD.

People with ASD may be hyper-sensitive or hypo-sensitive to sounds, smells, touch, light, textures, loud volume, and unexpected noises, which may trigger agitation, withdrawal, challenging behaviours or meltdowns.

**Social Communication Disorder**

A new diagnosis introduced by the DSM-5. People diagnosed with social communication disorder may have similar language difficulties as someone diagnosed with ASD, but they will not have the repetitive behaviours or restricted interests associated with autism.





# Summary of recommendations

## Chapter 1 – Living with Autism

<b>Number</b>	<b>Recommendation</b>
1.1	In the development of policies, programs, services and supports for people with ASD, or impacting on people with ASD, the Victorian Government, local governments, all service providers and professionals must consult and engage with people with ASD, their families and advocates.
1.2	The Victorian Government through the updated State Autism Plan ensure that families living with ASD are provided proper supports, including ongoing, viable and affordable respite care available across the state.
1.3	The Victorian Government through the updated State Autism Plan ensure that in the development of government-funded programs, services and policies that impact on families living with ASD, both by governments and by service providers, families living with ASD must be engaged and consulted.
1.4	The Victorian Government use its role on the Council of Australian Governments (COAG) Disability Reform Council to ensure the Australian Bureau of Statistics (in collaboration with the National Disability Insurance Agency) adopts a consistent and comprehensive approach to the national collection of data on people with ASD, including the prevalence of ASD and the prevalence of co-occurring conditions, and that this data be disaggregated to state and territory levels.
1.5	The Victorian Government develop and fund a process for the consistent and comprehensive collection of data on all people diagnosed with ASD, to enable the analysis of the prevalence of ASD and the prevalence of co-occurring conditions in the Victorian community.
1.6	In its collection of data on the prevalence of ASD in Victoria, the Victorian Government ensure that data on prevalence rates within CALD communities is also collected.
1.7	The Victorian Government in consultation with CALD communities support the development of a targeted information strategy for those communities to assist individuals and families in understanding ASD and the services available.
1.8	The Victorian Government fund enhanced training for all service providers engaging with people with ASD to develop cultural understanding on the specific needs of people with ASD from CALD backgrounds. <ul style="list-style-type: none"><li>• Develop specific training to build cultural awareness around assessment and diagnosis.</li></ul>
1.9	In its collection of data on the prevalence of ASD in Victoria, the Victorian Government ensure that data on prevalence rates within Aboriginal and Torres Strait Islander communities is also collected.

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- 1.10 The Victorian Government fund enhanced training for all service providers engaging with people with ASD to develop cultural understanding on the specific needs of people with ASD from Aboriginal and Torres Strait Islander backgrounds.
- Develop specific training to build cultural awareness around assessment and diagnosis.
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- 1.11 The Victorian Government through the Department of Health and Human Services conduct an audit of all existing and ongoing Victorian government-funded service providers for people with ASD in Victoria, and liaise with the NDIS to obtain information on all new registered providers under the NDIS. The audit to include details on location, service delivery models, organisational certifications and the skill sets of employees. This audit to occur on an ongoing basis.
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- 1.12 The Victorian Government actively support and fund research and development programs that are targeted to assist families living with ASD, as part of an overall strategy to improve services and reduce waiting lists, and more broadly, for the purpose of better understanding ASD.
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## Chapter 2 – Policy Settings and Government-funded Services for People with ASD

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### **Number Recommendation**

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- 2.1 The Victorian Government use its position on the COAG Disability Reform Council to ensure that the full suite of services currently provided by the Helping Children with Autism Program (HCWA) in Victoria be retained under the NDIS.
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- 2.2 The Victorian Government include, as a key element of the updated State Autism Plan, the integration and coordination of government-funded services for people with ASD. The Plan will highlight the need to remove unnecessary barriers to service access and information, such as agency policies that prevent integration.
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- 2.3 The Victorian Government use its position on the COAG Disability Reform Council to call for the development of a National Autism Strategy, a core principle of which will be the inclusivity of people with ASD.
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- 2.4 The Victorian Government update the 2009 Autism State Plan as a matter of priority to strategically address the ongoing needs of people with ASD and families living with ASD. A core principle of the Plan be the inclusivity of people with ASD.
- Any developments in policy, programs and services must involve the engagement and consultation of people with ASD.
  - The Victorian State Autism Plan be reviewed regularly in the national context.
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## Chapter 3 – The Early Years – Diagnosis and Intervention

Number	Recommendation
3.1	The Victorian Government provide funds and resources so that all current and future Maternal and Child Health Nurses are trained in the developmental surveillance of children with possible autism, and to support those children and families in referral for diagnosis.
3.2	The Victorian Government, in conjunction with peak bodies and the Royal Australian College of General Practitioners (Vic), facilitate the professional development of the state's general practitioners in the understanding and identification of ASD.
3.3	The Victorian Government work with the Royal Australian College of General Practitioners (Vic) to enable improved access to information and updated resources for the understanding and identification of ASD.
3.4	<p>The Victorian Government introduce a model of best practice in ASD diagnosis in Victoria, which consists of a multidisciplinary diagnosis involving, at minimum, a paediatrician or child and adolescent psychiatrist, a psychologist and a speech therapist, to be provided by the state's public health system.</p> <ul style="list-style-type: none"> <li>• A target to be set to ensure a multidisciplinary diagnosis will be conducted within three months of a referral for diagnosis.</li> </ul>
3.5	<p>The Victorian Government provide ongoing and increased funding to the Mindful Centre for Training and Research in Developmental Health, to support:</p> <ul style="list-style-type: none"> <li>• the education and training in the identification, diagnosis and treatment of ASD for all clinicians;</li> <li>• programs and initiatives that link to, facilitate, and manage ASD assessment and diagnosis;</li> <li>• overseeing early intervention and ongoing care and facilitate referral pathways to other services, and</li> <li>• the expansion of state-wide ASD coordinators.</li> </ul>
3.6	<p>The Victorian Government fund the Olga Tennison Autism Research Centre (OTARC) to:</p> <ul style="list-style-type: none"> <li>• provide training to Maternal and Child Health Nurses across all local government areas in developmental surveillance techniques designed to detect the signs of ASD in children aged 0-3, and make appropriate referrals, and</li> <li>• re-establish the Early Diagnostic Clinic (EDC) for ASD to enable the multidisciplinary diagnosis of ASD in children aged 0-3.</li> </ul>
3.7	The Victorian Government through the Department of Health and Human Services fund the development, coordination and delivery of state-wide ASD diagnostic services, which will provide access to an ASD diagnosis equally to all Victorians.

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3.8	<p>The Victorian Government support the development of an ASD state-wide diagnostic service and this be a key element of the Victorian Government’s updated State Autism Plan.</p> <ul style="list-style-type: none"> <li>• The Plan outline the fundamental features of the Service, namely: Surveillance, Training, Diagnosis and Post-Diagnosis.</li> <li>• The Plan outline the key partnerships and collaborations required to build and deliver the Service.</li> </ul>
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3.9	<p>The Victorian Government fund children with ASD who are not deemed to be eligible for participant funding under the NDIS for up to 20 hours of therapy per week according to need.</p> <ul style="list-style-type: none"> <li>• Ensure their families, carers and service providers are provided with accurate advice, information and support on childhood intervention therapies, including behavioural therapies, that are evidence-based.</li> </ul>
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3.10	<p>The Victorian Government use its position on the COAG Disability Reform Council to ensure that when the NDIA registers service providers of early childhood intervention therapies, including behavioural therapies, those therapies are evidence-based.</p> <ul style="list-style-type: none"> <li>• The NDIA ensure that practitioners of evidence-based behavioural therapies are qualified to deliver that therapy.</li> </ul>
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3.11	<p>The Victorian Government use its position on the COAG Disability Reform Council to ensure that the NDIA provides clear, unambiguous and accessible information about behavioural therapies to all scheme participants and their families, so that they can make informed decisions about the early childhood interventions that they choose for their child.</p>
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3.12	<p>The Victorian Government, in conjunction with the Office of the Skills Commissioner and key stakeholders, facilitate the development of a post-graduate diploma in behavioural therapies.</p>
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3.13	<p>The Victorian Government introduce a scholarship program for speech pathologists to work in rural and regional Victoria.</p>

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## Chapter 4 – The School Years

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<b>Number</b>	<b>Recommendation</b>
4.1	<p>As part of its inclusive schools agenda, the Victorian Government provide parents of children with ASD access to up-to-date, relevant, information and guidance on establishing the most appropriate school to enrol their child with ASD.</p> <ul style="list-style-type: none"> <li>• The Department of Education and Training update its website to better reflect how each local and or specialised school is able to support the needs of students with ASD.</li> </ul>
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4.2	<p>In developing the Inclusive Schooling Index, the Victorian Government ensure that the results of the Index are made publicly available and easily accessible to parents, so they can be better informed about their local schools, and the choices they have for the enrolment of their child with ASD.</p>

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- 4.3 The Victorian Government through the Department of Education and Training provide flexibility of service and programs to facilitate and support families who choose to home school their children with ASD.
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- 4.4 The Victorian Government adopt, implement and fund the remaining four recommendations of the Review of the Program for Students with Disabilities, namely Recommendations 14, 21, 22, and 23.
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- 4.5 The Victorian Government, through the Department of Education and Training and the Victorian Registration and Qualifications Authority, proactively monitor adherence to the Commonwealth Disability Standards for Education 2005, and the *Equal Opportunity Act 2010* (Vic), with respect to the enrolment of students with ASD in schools in Victoria.
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- 4.6 The Victorian Government through the Department of Education and Training conduct a state-wide information campaign for senior school staff, including school principals, to ensure that every school is aware of its legal responsibilities in relation to the admission of students with ASD.
- The campaign be conducted in collaboration with the Victorian Equal Opportunity and Human Rights Commission, and with the involvement of the non-government school sector and people with ASD and their families.
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- 4.7 The updated State Autism Plan clearly articulate:
- the rights of students with ASD to enrol and participate in mainstream schools on the same basis as other students, and
  - the responsibilities of educational authorities in Victoria to comply with the law.
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- 4.8 The Victorian Government fund the building of new autism specialist schools in regional Victoria, with a particular aim of servicing areas of high need.
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- 4.9 The Victorian Government retain, fund and expand autism outreach programs to other education regions of the state, including the role of autism outreach coordinators.
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- 4.10 In the design of all new special schools, the Victorian Government incorporate teacher training facilities to enable trainee teachers to be trained in autism.
- Partnerships with appropriate teacher training institutions be created where possible to deliver training at the schools.
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- 4.11 The Victorian Government's updated State Autism Plan include a strategy for the inclusive education of students with ASD in all mainstream and specialist schools, with key focus areas for funding to include:
- sensory and social environments;
  - specialised teacher training and professional development;
  - family participation;
  - policies to prevent bullying of students with ASD;
  - individualised learning plans;
  - behavioural and other therapy supports;
  - mixed classrooms with high staff to student ratios;
  - curriculum flexibility; and
  - appropriate transitions and structures.
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4.12	The Victorian Government enable the roll out of the school-wide Positive Behaviour Support program to all government mainstream and specialist schools, to manage behaviours of concern, as a matter of priority.
4.13	The Victorian Government at a minimum double the number of fully funded scholarships for teachers to the Autism Teaching Institute to 40 per year for the post-graduate diploma in teaching students with ASD.
4.14	In partnership with the Autism Teaching Institute, the Victorian Government develop and roll out a specifically targeted professional development program for existing teachers, in teaching students with ASD, that involves face-to-face learning, and class room experience, as well as online modules.
4.15	The Victorian Government use its position on the COAG Disability Reform Council to ensure that students with ASD who are funded participants in the NDIS are able to have personal therapy and other supports provided to them within school settings, as appropriate. <ul style="list-style-type: none"> <li>• This should not diminish access to therapy for students with ASD who are not eligible for the NDIS.</li> </ul>

## Chapter 5 – Services for Adults with ASD

Number	Recommendation
5.1	The Victorian Government use its position on the COAG Health Council to urge the Australian Health Ministers' Advisory Council (AHMAC) and the Commonwealth Department of Human Services to remove the age cap for the Medicare rebate for the diagnosis and assessment of ASD.
5.2	The Victorian Government make specific provision under the updated State Autism Plan to improve services for adults, including timely access to public ASD diagnostic assessment teams.
5.3	The Victorian Government collaborate with relevant professional and training bodies to: <ul style="list-style-type: none"> <li>• ensure that training is provided to health professionals in identifying the traits and presentations associated with ASD in adults, and</li> <li>• develop training programs for health professionals in the assessment and diagnosis of ASD in adults.</li> </ul>
5.4	The Victorian Government ensure that relevant autism networks and peak bodies are adequately funded to provide clear information both in relation to diagnostic services and support services post-diagnosis for adults with ASD.
5.5	The Victorian Government, in the updated State Autism Plan, develop strategic transition supports to meet the needs of people with ASD, throughout their lives.
5.6	The updated State Autism Plan contain a comprehensive employment strategy for adults with ASD.

5.7	Within the updated State Autism Plan the Victorian Government develop an education program for Victorian employers to encourage employment of people with ASD.
5.8	The Victorian Government collaborate with relevant organisations, such as the I CAN Network, Specialisterne and peak bodies, to develop capacity building for employers on how best to support employees with ASD.
5.9	The Victorian Government provide leadership in its own employment practices by employing people with ASD.
5.10	In the updated State Autism Plan, the Victorian Government include strategies to address the diverse needs of parents who have ASD.
5.11	<p>In the updated State Autism Plan, the Victorian Government include strategies to address the housing needs of adults with ASD.</p> <ul style="list-style-type: none"> <li>The Government collaborate with disability service providers, including new entrants to the market, on developing innovative housing solutions that match the needs and aspirations of people with ASD who need housing support.</li> </ul>
5.12	The Victorian Government include in its Social Housing Growth Fund initiative proposals and resources to provide specifically for the housing needs of people with ASD.
5.13	The Victorian Government direct the Department of Justice and Regulation, and Corrections Victoria, to develop a system for identifying and registering people with ASD who have contact with the criminal justice system, and who are incarcerated in Victorian prisons, with this data to be reported to the Minister.
5.14	<p>The Victorian Government fund Corrections Victoria to provide specific supports to people with ASD while incarcerated, based on an assessment of needs.</p> <ul style="list-style-type: none"> <li>Corrections staff be provided with training to develop the capacity to engage with people who have ASD, and understand their needs.</li> </ul>
5.15	As part of the updated State Autism Plan, the Victorian Government develop a specific housing strategy for people with ASD, in relation to the transition from prison to release into the community.
5.16	The Victorian Government use its position on the COAG Disability Reform Council to urge the NDIA to engage with Victorian criminal justice authorities to ensure that NDIS supports are made available to participants while incarcerated, and on their transition to the community on release.
5.17	The Victorian Government use its position on the COAG Disability Reform Council to support the development of specific strategies to address the needs of adults with ASD, within the National Autism Strategy.
5.18	The Victorian Government through the updated State Autism Plan develop specific strategies to address the needs of adults with ASD.



## Chapter 6 – People with ASD and the National Disability Insurance Scheme

Number	Recommendation
6.1	The Victorian Government use its position on the COAG Disability Reform Council to ensure the National Disability Insurance Agency improves its communication strategy for people with autism and families living with autism, carers and advocates to provide accurate, timely and clear information in an appropriate manner.
6.2	The Victorian Government use its position on the COAG Disability Reform Council to ensure the National Disability Insurance Agency develops a comprehensive training program, and ongoing professional development, for all scheme planners, so that they: <ul style="list-style-type: none"> <li>• are adequately equipped to engage and communicate with clients who have ASD;</li> <li>• understand the diverse needs of people with ASD, and</li> <li>• are able to provide consistent advice on supports and services, in the development of client plans.</li> </ul>
6.3	The Victorian Government use its position on the COAG Disability Reform Council to ensure the National Disability Insurance Agency provides a high level of plan flexibility to people with autism who are in the scheme.
6.4	The Victorian Government use its position on the COAG Disability Reform Council to ensure the National Disability Insurance Agency funds travel for clients and participants, and ensure that where travel funding is integral to the provision of the most appropriate service or support for a client, that funding be provided.
6.5	The Victorian Government carefully monitor the impacts of the NDIS on disability service provision at the local community level, and work with the Commonwealth Government, the NDIA, local governments and service providers to ensure that services for people with ASD are not diminished.
6.6	The Victorian Government closely monitor the roll out of the NDIS' Early Childhood Early Intervention scheme to ensure that services are adequately provided across Victoria, particularly in rural and regional areas.
6.7	The Victorian Government use its position on the COAG Disability Reform Council to strengthen the protections afforded by the NDIS Quality and Safeguarding Framework over time.
6.8	The Victorian Government monitor the impacts of the NDIS Quality and Safeguarding Framework in Victoria, in particular, to ensure that in the introduction and implementation of the National Framework in Victoria, none of the state's protections and processes for the prevention of abuse are diminished, or compromised in any form.
6.9	The Victorian Government use its position on the COAG Disability Reform Council to ensure the NDIS has the capacity to meet the growth in future demand for assessment and diagnosis of ASD, early interventions and ongoing service needs of people with ASD.



## Chapter 7 – Gender and ASD

<b>Number</b>	<b>Recommendation</b>
7.1	The Victorian Government ensure that training and professional development be provided to health professionals diagnosing ASD in the recognition of how girls present with ASD, including gender specific behaviours and symptoms.
7.2	The Victorian Government ensure that, as part of their training and professional development in ASD, teachers are provided with specific training to better understand how girls with ASD present, and the learning needs of girls with ASD.
7.3	The Victorian Government use its position on the COAG Disability Reform Council to advocate for the NDIA to provide grant funding opportunities under its Information, Linkages and Capacity Building program to community groups that specifically offer support programs and activities to girls and women with ASD.
7.4	The Victorian Government, in the updated State Autism Plan, and as part of the community education campaign aimed at raising awareness of ASD, include specific information on ASD in girls and women.

## Chapter 8 – Health and Mental Health Services

<b>Number</b>	<b>Recommendation</b>
8.1	The Victorian Government in conjunction with the Australian Dental Association – Victorian Branch develop education and training options to dental clinicians in understanding ASD and the way in which ASD presents in their clients.
8.2	In the updated State Autism Plan, the Victorian Government develop a strategy for public health and mental health services to accommodate the needs of people with ASD, including the roll out of autism specialists in the public health system. <ul style="list-style-type: none"> <li>• That people with ASD are identified on presentation to health services and that this information is recorded.</li> </ul>
8.3	The Victorian Government ensure all new and existing public hospitals and healthcare facilities have provision for dedicated quiet spaces for people with ASD in emergency departments and other inpatient and outpatient areas.
8.4	The updated State Autism Plan make provision for training and professional development of public hospital staff and public mental health clinicians in the awareness and understanding of ASD presentations.
8.5	The Victorian Government increase funding to public mental health services and community health services so they have the capacity to provide services for people with ASD with a co-occurring mental health condition.

## Chapter 9 – Services for People with ASD in Rural and Regional Victoria

Number	Recommendation
9.1	The Victorian Government through the Department of Health and Human Services support a state-wide ASD diagnostic service that expands ASD diagnostic services across the state and builds on existing rural and regional community health initiatives to enable a consistent model of care to be extended to rural and regional areas.
9.2	The Victorian Government support the establishment of a rural and regional autism health and disability service network to connect with ASD state-wide coordinators and regional coordinators.
9.3	<p>The Victorian Government support the establishment of centres for autism excellence in regional Victoria. The centres will provide specialist services for people with autism, including multidisciplinary diagnostic assessments, early intervention and therapy services, and provide information, resources and referral services.</p> <ul style="list-style-type: none"> <li>• The centres will act as the hubs for a ‘hub and spoke’ model of training and service delivery for rural and regional communities, and where appropriate be co-located with regional health services.</li> </ul>
9.4	<p>The updated State Autism Plan ensure affordable and ongoing training and mentoring opportunities for health professionals in identifying developmental delays, and diagnosing and treating children and adults with ASD.</p> <ul style="list-style-type: none"> <li>• Training be extended to health practitioners in rural and regional locations through the greater use of technologies such as telehealth.</li> <li>• The Plan explore alternative ideas and opportunities to ensure services are striving for inclusiveness.</li> </ul>
9.5	The Victorian Government collaborate with relevant tertiary campuses in rural and regional areas to develop strategies for the retention of graduate students in allied health, psychology, speech pathology, social work and education in rural and regional communities, and to maintain and grow relevant courses in rural and regional campuses.
9.6	The Victorian Government fund scholarships to Aboriginal and Torres Strait Islander students in the areas of allied health, psychology, speech pathology, social work and education – and to provide support to Aboriginal and Torres Strait Islander students to learn their profession in rural and regional communities.
9.7	The Victorian Government enable the Department of Education and Training to draw upon models of outreach success, both in the public and private school systems, to expand inclusive education and choice for students with ASD in rural and regional Victoria.
9.8	The Victorian Government fund the expansion of the “Mansfield Autism Statewide Services model” including the travelling teacher program, across regional Victoria.

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- 9.9 The Victorian Government fund and expand the “Dookie model” of education for students with ASD to provide specialist autism classes with high staff to student ratios in regional secondary colleges.
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- 9.10 The Victorian Government use its position on the COAG Disability Reform Council to ensure that the NDIA addresses potential market failures in the NDIS in rural and regional communities so that services in rural and regional communities are not diminished, particularly established services that have been found to be effective and reliable for people with ASD and their families.
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## Chapter 10 – Social Inclusion, Community Participation and Sport

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### Number Recommendation

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- 10.1 In the updated State Autism Plan, the Victorian Government make provision for a broad and extensive public education campaign to raise awareness about ASD and the inclusion of people with ASD, their families and carers in the community.
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- 10.2 The Victorian Government partner with local governments to provide more sporting and recreation opportunities for people with ASD through each LGA local Disability Action Plan.
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- 10.3 The Victorian Government fund Creative Victoria to develop an autism inclusion strategy for all publicly funded arts and cultural institutions and events in order to facilitate visitation and participation for people with ASD and their families.
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- 10.4 The Victorian Government in the updated State Autism Plan develop a strategy for the social inclusion of people with ASD across all government departments responsible for community, cultural and sporting events.
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- 10.5 In the updated State Autism Plan provision be made for the education and training of frontline public transport officers to understand and recognise ASD and to engage with people with ASD.
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- 10.6 The Victorian Government ensure the goals set out in the Victoria Police Accessibility Action Plan include an understanding of ASD including the diversity of presentation of people with ASD.
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- 10.7 The Victorian Government fund the expansion of the Access All Abilities program to provide more sporting and recreation opportunities for children with ASD in their communities.
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- 10.8 The Victorian Government fund autism specialists to liaise with local governments in the delivery of sport and recreation activities across the state for people with ASD.
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- 10.9 The Victorian Government use its position on the COAG Disability Reform Council to encourage the NDIS Information, Linkages and Capacity Building (ILC) component be expanded to support sporting programs for people with ASD.
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- 10.10 The Victorian Government fund the expansion of the coordinator positions of the I CAN network across the state to ensure the roll out of support and mentoring programs in primary and secondary schools; facilitate coordination of support camps; and training opportunities for mentors.
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- 10.11 The Victorian Government in the updated State Autism Plan develop strategies to build inclusion in the community for people with ASD in consultation with both people with ASD who are self-advocates and with ASD advocacy groups.
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# Introduction

The Parliament of Victoria's Legislative Council directed the Family and Community Development Committee to inquire into services for people with Autism Spectrum Disorder (ASD) on 6 May 2015. The Terms of Reference for the Inquiry were broad, requiring the Committee to examine the availability and adequacy of services provided by the Commonwealth, State and local governments across health, education, disability, housing, sport and employment services, as well as services to be provided under the National Disability Insurance Scheme (NDIS). The Committee was also directed to report on the prevalence of autism in the community. Each of the chapters of this report relate to one or more of the Terms of Reference for the Inquiry. The full Terms of Reference can be found on page ix.

From the outset, the Committee was determined to hear from people with ASD, and families living with ASD. In public hearings, site visits and through submissions, the Committee was able to hear directly from people with ASD and their families about their experiences, perspectives and recommendations. Having people with ASD and their families at the centre of this Inquiry has been fundamental to the Inquiry process and vital to the recommendations the Committee makes in the coming chapters.

The Inquiry also provided an opportunity for the Committee to hear evidence from autism advocacy and support groups, peak bodies, health professionals, educators, research and training institutes, disability service providers, government departments and agencies. The Committee thanks all those who contributed to this Inquiry.

## Conduct of the Inquiry

### Submissions

On 7 December 2015 the Committee released a call for submissions for the Inquiry. The call for submissions was advertised in over 30 Victorian metropolitan and regional newspapers. The call for submissions was also made on the Committee's website, and via a media release. The Committee also wrote to a wide range of individuals and organisations inviting them to make a submission to the Inquiry.

To assist those who wanted to make a written submission to the Inquiry, the Committee released a Submission Guide. This was published on the Committee's website and circulated to those who expressed an interest in submitting to the Inquiry. The Submission Guide outlined the scope of the Inquiry and the process for making a written submission. It provided an outline on the types of issues about which the Committee was seeking evidence. A copy of the Submission Guide can be found at Appendix Six.

The Committee also released the call for submissions and Submission Guide in an Easy English format. This document can be found at Appendix Seven.

The Committee received 154 written submissions including three supplementary submissions from a range of individuals and organisations. The authors of these submissions included:

- people with autism;
- family members and carers of people with autism;
- autism support groups;
- peak bodies and advocacy organisations;
- self-advocates;
- leading autism researchers;
- disability service providers;
- healthcare providers;
- local councils; and
- government departments and statutory bodies.

A full list of the submissions can be found at Appendix One.

## **Public hearings**

For this Inquiry the Committee held 11 public hearings – six in Melbourne and a further five hearings in the following regional cities:

- Geelong
- Bendigo
- Shepparton
- Morwell
- Swan Hill.

At these public hearings the Committee heard from over 120 witnesses, many of whom were people with autism and their families, who spoke candidly to the Committee about their experiences. The Committee also heard from school principals, speech pathologists, leading autism researchers, departmental secretaries, parent support groups, self-advocates, social enterprises, the National Disability Insurance Agency, community health services, and a robot, designed to engage with children with ASD in social and therapeutic activities. The full list of public hearings and witnesses can be found at Appendix Two.

## **Site visits**

In addition to the public hearings, the Committee conducted site visits. The main focus of the Committee's site visits for this Inquiry was education, and the Committee welcomed the opportunity to visit a number of schools both in Melbourne and in regional Victoria. The Committee's site inspections included visits to the Northern School for Autism in Reservoir, the Moomba Park Primary School in Fawkner,

Mansfield Autism Statewide Services in Mansfield, EdSpace Education and Training Centre in Benalla, Whittington Primary School in Geelong, and Kalianna School.

The Committee made an invaluable visit to the Olga Tennison Autism Research Centre at Latrobe University. The Committee also visited the headquarters of the Autism Cooperative Research Centre (Autism CRC) in Brisbane and met leading researchers of the program. The Committee thanks all of their hosts on these visits. A full list of the Committee's site visits is at Appendix Three.

### **Overseas study tour**

The Committee also conducted an overseas study tour to the USA, Denmark, Norway and Sweden, visiting a total of 34 organisations. The study tour provided the Committee with the opportunity to examine best practice in other jurisdictions. The Committee visited leading research institutes, and met with researchers, policy makers, autism service providers and peak bodies, government agencies, educators, ASD self-advocates and health professionals. The Committee's overseas study tour provided it with important insights into policy and practices in a range of service areas for people with autism. A list of the organisations visited during the study tour is at Appendix Four.

### **Social media**

Throughout the Inquiry, and with the assistance of the Parliament's Communications and Public Engagement team, the Committee made use of social media to provide updates on the Inquiry, and to advertise public hearings. This forum also provided followers of the Inquiry, including people with ASD, the opportunity to comment on the Inquiry's progress, provide feedback, and discuss issues.

### **National Disability Insurance Scheme**

The Committee's Inquiry took place as the National Disability Insurance Scheme (NDIS) was being rolled out across the country. The NDIS is one of the most significant social policy reforms of recent times, and will impact, directly and indirectly, on the lives of millions of Australians, including people with autism and families living with autism. The Committee has been particularly concerned with the roll out in Victoria, and heard evidence from both participants of the scheme, and those hoping to join the scheme. Many Victorians remain unaware of the scheme's features and their likely eligibility. The Committee sees this report as playing an important role in providing information on the NDIS to people with ASD and families living with ASD, and on how some of the shortcomings of the scheme that have emerged can be addressed.





# Chapter 1

## Living with Autism

### AT A GLANCE

#### Background

‘Living with autism’ will mean something different for every person diagnosed with Autism Spectrum Disorder (ASD). For some ASD is experienced as a disability that presents significant challenges for everyday living, for others ASD is part of the neurodiversity of humanity, a condition to be celebrated rather than ‘treated’. The diversity of experiences of people with ASD is a challenge for public policy. It means that governments cannot support people with ASD through a one-size-fits-all model. Each individual is impacted by ASD differently, and in addition, many will have other co-occurring conditions that will complicate how their ASD is experienced. The challenge is to ensure that people with ASD have access to the supports they need – either through specialised disability services or through mainstream services that are fundamentally inclusive.

#### Chapter overview

The Committee was eager to hear from people with ASD themselves and from families living with ASD. The Committee received 154 submissions, conducted eleven public hearings, and heard evidence from people living with ASD and their families and carers, as well as service providers, researchers, teachers, health professionals and others throughout the Inquiry. The Committee is keen for this report to reflect the interests of people with ASD. This chapter discusses the experiences of people with autism and their families and it also provides a brief history of ASD and the diagnostic process, an examination of ASD as a lifelong neurodevelopmental condition, the available data on the prevalence of ASD, and current research. This chapter looks at autism across the age spectrum, and contains commentary from people with ASD and families living with ASD of all ages. Following chapters will focus on the specific challenges faced by people with ASD, at different stages of the life cycle: early childhood, the school years, transitions, and adulthood.

This chapter addresses aspects of the following terms of reference:

- a) the prevalence of autism spectrum disorder in Victoria;
- b) the availability and adequacy of services provided by the Commonwealth, State and local governments across health, education, disability, housing, sport and employment services; and
- d) evidence of the social and economic cost of failing to provide adequate services.

This chapter highlights the diversity of the autism spectrum through the perspectives of people with ASD and families living with ASD. The Committee found that for many families, the social, emotional and financial impacts of having a child with ASD were immense.

The Inquiry provided an opportunity for people with Autism Spectrum Disorder (ASD) and their families to be heard, and coincides with the increasing diagnosis and awareness of ASD in the community. While the diagnosis of autism began to be developed in the 1940s, autism was traditionally considered a rare form of childhood schizophrenia, and was not understood as a more common developmental condition until after the 1980s. Knowledge about autism has accelerated over the last three decades, as rates of diagnosis have increased and the concept of the autism ‘spectrum’ has widened to include a larger group of people. Autism is now more visible than ever; both in terms of public culture and academic research. At the same time, the diversity of the autism spectrum is poorly understood – by service providers and the community at large – and stereotyped understandings of people with ASD endure.

‘Living with autism’ will mean something different for every person diagnosed with ASD: for some ASD is experienced as a disability that presents significant challenges for everyday living, for others ASD is part of the neurodiversity of humanity, a condition to be celebrated rather than ‘treated’. The diversity of experiences of people with ASD is a challenge for public policy. It means that governments cannot support people with ASD through a one-size-fits-all model. Each individual is impacted by ASD differently, and in addition, many will have other co-occurring conditions that will complicate how their ASD is experienced. The challenge is to ensure that people with ASD have access to the supports they need – either through specialised disability services or through mainstream services that are fundamentally inclusive.

This chapter will use evidence from submissions and public hearings to represent the lived experiences of people with ASD, and families living with ASD. This chapter relates to the following terms of reference:

- a) the prevalence of autism spectrum disorder in Victoria;
- b) the availability and adequacy of services provided by the Commonwealth, State and local governments across health, education, disability, housing, sport and employment services; and
- d) evidence of the social and economic cost of failing to provide adequate services.

This chapter looks at autism across the age spectrum, and contains commentary from people with ASD and families living with ASD of all ages. Following chapters will focus on the specific challenges faced by people with ASD, at different stages of the life cycle: early childhood, the school years, transitions, and adulthood.

## 1.1. What is autism?

I was not diagnosed with autism because I have special strengths; I was diagnosed, because I have specific difficulties in the areas of social communication and repetitive and restrictive behaviours. These things make interacting with the world very difficult for me, the same as any disability makes things difficult for people. That does not mean I cannot do anything, or that I do not have talents and skills to share with the world. It also does not mean that I do not have the same needs, hopes and desires as the average person... What it does mean is that I am going to need extra supports in some instances in order to enable me to have those needs met.<sup>6</sup>

Autism is a lifelong, neurodevelopmental condition that is usually first apparent in early life. People are born on the autism spectrum. Autism is not a disease and it cannot be cured, although the impact that ASD will have on an individual can vary significantly over their lifetime. The term 'Autism Spectrum Disorder' includes Autistic Disorder, Asperger's Syndrome and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS).<sup>7</sup> The word 'spectrum' in Autism Spectrum Disorder refers to the diversity of difficulties, symptoms and experiences that people on the autism spectrum may experience. In their submission to the Inquiry, Amaze states:

[N]o two people on the autism spectrum are alike. In practical terms this translates into each person having diverse needs for support in different areas of daily life to enable them to participate and contribute meaningfully to their community.<sup>8</sup>

The Diagnostic and Statistical Manual (DSM-5) states that people with ASD have difficulties in two main areas: social communication and interaction; and restricted or repetitive behaviours, interests and activities. Although every person with ASD is different, people with ASD will have difficulty interacting and communicating with others, narrow interests and repetitive behaviour. People with autism may also have sensory issues, that is, they may be sensitive to noise, lighting, smells, the feel of fabric and the texture of food.

As a lifelong condition, ASD impacts people in different ways throughout their lives. Many people with ASD have difficulty managing change, including key life stages and transitions between schools, and between education and work. Transitions will be discussed in more detail in the following chapters where they pertain to key life stages, such as the transition to primary and secondary school and post-school transitions. Many witnesses discussed the importance of constructing social stories to guide people with ASD through change and transitions, as discussed in Chapter Ten.

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6 Name withheld, submission no. 138B (supplementary submission), p. 2.

7 See Autism Speaks, 'DSM-5 Diagnostic criteria', accessed 16 May 2017, <[www.autismspeaks.org/what-autism/diagnosis/dsm-5-diagnostic-criteria](http://www.autismspeaks.org/what-autism/diagnosis/dsm-5-diagnostic-criteria)>.

8 Amaze, submission no. 139, p. 15.

### 1.1.1. Brief history of ASD

As noted above, autism was traditionally considered a rare form of childhood schizophrenia with the term ‘autistic’ used in relation to schizophrenia in the first and second editions of the Diagnostic and Statistical Manual (DSM). The diagnosis of autism began to be developed in the 1940s through the work, independently, of psychiatrist Leo Kanner and paediatrician Hans Asperger. In the 1950s, Leo Kanner’s observations, and the work of others such as Bruno Bettelheim, led to the emergence of a widely discarded theory that autism was caused by a lack of maternal warmth (‘refrigerator mother theory’). Mother and parent blaming attitudes prevailed from the 1950s to 1970s. It was not until the 1980s that autism was understood as a diagnosis separate from schizophrenia and a more common developmental condition.

### 1.1.2. Diagnosing autism

The Committee heard that one of the issues with diagnosing autism is that there is no uniform approach to diagnosing autism among health professionals and there is a lack of understanding of how autism presents.<sup>9</sup> Currently, there is also no consistency in applying the diagnostic tools for diagnosing ASD, although a national protocol is being developed by Autism CRC, discussed below.<sup>10</sup>

The criteria outlined in the Diagnostic and Statistical Manual (DSM-5) are most commonly used to diagnose ASD in Australia. However, autism may be diagnosed using the alternative criteria provided by the International Classification of Diseases (ICD-10). The ICD-10 has a broader aim than the DSM-5 – it provides standardised diagnostic criteria for all health conditions and diseases, including mental disorders. The ICD-10 is developed by the World Health Organisation and while it includes criteria for autism, it is not commonly used in Australia. Other tests include the Autism Diagnostic Observation Schedule (ADOS) which monitors child play and social interaction through a series of structured and semi-structured tasks, and the Autism Diagnostic Interview Revised which is a structured parent interview.

The DSM is published by the American Psychiatric Association and provides definitions and diagnostic criteria for all mental disorders. The first two versions of the DSM (DSM-I and DSM-II) classified children with autism as having ‘childhood schizophrenia’. The third version (DSM-III), released in 1980, added diagnostic criteria explicitly for autism. A revised version of the DSM-III increased the detail that should be considered in the diagnosis. The number of criteria that had to be met to receive a diagnosis was reduced in the DSM-IV. These changes have had implications for monitoring prevalence rates.<sup>11</sup>

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9 Mr Braedan Hogan, Policy and Advocacy Manager, Amaze, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 3.

10 L Taylor, P Brown, V Eapen, S Midford, J Paynter, L Quarmby, T Smith, M Maybery, K Williams and A Whitehouse, *Autism Spectrum Disorder Diagnosis in Australia: Are we meeting Best Practice Standards?* Autism Co-operative Research Centre, Brisbane, 2016; Mr Braedan Hogan, Policy and Advocacy Manager, Amaze, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 3.

11 Australian Bureau of Statistics, *Autism in Australia*, 2012, cat. no. 4428.0, Canberra, ABS, 2014.

Prior to 2013, the DSM-IV defined ASD as three separate disorders (Autistic Disorder, Asperger's Syndrome and Pervasive Developmental Disorder-Not Otherwise Specified). In 2013 a new edition of the DSM (DSM-5) was released, which presents these disorders as part of a closely linked 'spectrum', with individuals needing different levels of support, rather than three separate diagnoses. The DSM-5 also introduced the new diagnosis of 'Social Communication Disorder'. People diagnosed with social communication disorder may have similar language difficulties as someone diagnosed with ASD, but they will not have the repetitive behaviours or restricted interests associated with autism.

ASD in Victoria is usually diagnosed by health professionals using the DSM-5, which states that people with ASD have difficulties in two main areas:

- social communication and interaction; and
- restricted or repetitive behaviours, interests and activities.

In addition, the DSM-5 outlines three 'severity levels' that can be used to describe the difficulties individuals have in relation to the key areas of social communication and restricted or repetitive behaviours:

- Level 3: Requiring very substantial support.
- Level 2: Requiring substantial support.
- Level 1: Requiring support.

The diagnostic process can be quite complex. Ms Frances Saunders, the State-wide Autism Spectrum Disorder Coordinator at the Austin Child and Adolescent Mental Health Service, told the Committee at a public hearing in Melbourne that the severity levels are 'not enduring' and 'will go up and down over time, depending on the child's ability to cope with their environment and the stressors that are on the child'.<sup>12</sup> This is problematic when it comes to assessing a child's needs for funding purposes. The Living with Autism Spectrum Resource Support Group raised concerns in their submission over the ability of funding assessments to accurately assess a child's capacity, noting that a child may lose support if assessed on a 'good day'.<sup>13</sup>

Merri Health submitted to the Inquiry that 'parameters for diagnosis are quite unclear, subjective and often inconsistent, even amongst skilled paediatricians', which was also mentioned by other submitters.<sup>14</sup> They also noted that the prevalence of other disabilities and co-occurring conditions can also complicate diagnosis:

For example, some children diagnosed with auditory processing issues and sensory integrative disorders or Attention Deficit disorders are actually on the Autism Spectrum. Conversely some children diagnosed with ASD in their early

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12 Ms Frances Saunders, State-wide Autism Spectrum Disorder Coordinator, Mindful, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 13.

13 Living with Autism Spectrum Resource Support Group, submission no. 45, p. 1.

14 Merri Health, submission no. 37, p. 1. See also: Office of the Health Services Commissioner, submission no. 116, p. 2; Speech Pathology Australia, submission no. 136, p. 12.

years, actually have a developmental delay which does not become evident until at [sic] a later age.

Alternatively, so many of the issues for children on the spectrum manifest themselves initially as behavioural issues leading to years of investigations, misdiagnosis and incorrect treatment. Furthermore, as it is a spectrum, presentations can vary widely as no two children present with identical issues.<sup>15</sup>

The average age of diagnosis for children with ASD registered with the Helping Children with Autism (HCWA) package in Australia was four years and one month, with the most common age for diagnosis being five years and eleven months, when children enter school.<sup>16</sup> The Committee heard that there is increasing research indicating that diagnosis can be made at a younger age than initially thought.<sup>17</sup> Despite this, there seemed to be a reluctance among paediatricians and paediatric psychiatrists to diagnose autism under the age of three.<sup>18</sup> Mr Braedan Hogan, the Policy and Advocacy Manager at Amaze, told the Committee at a public hearing in Melbourne:

Present research is showing now we can actually diagnose from about 12 months, yet there is a hesitance within the public health system, preferring an option of 'wait and see' if this does develop into autism, where we see lost time.<sup>19</sup>

Mr Hogan also identified concerns about waiting lists and costs which delay the diagnosis process:

Other issues are long waiting lists for accessing diagnosis through the public health care system – up to two years in some cases; poor access to diagnosis in regional areas – these waiting lists are often exacerbated in regional areas; and then the cost of diagnosis through private diagnosticians due to the public system being inadequate. We have reports of costs of \$2750 for a diagnosis, yet recent research by the Autism cooperative research centre puts the mean cost to about \$580 per diagnosis. And also through the diagnostic process there is a lack of clear and concise information available to support the family as they investigate and navigate their way through this process.<sup>20</sup>

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15 Merri Health, submission no. 37, p. 2.

16 C Bent, C Dissanayake and J Barbaro, 'Mapping the Diagnosis of Autism Spectrum Disorders in children aged under 7 years in Australia, 2010-2012', *Medical Journal of Australia*, 202, no. 6, pp. 317-320, 2015.

17 Ibid.

18 Mr Braedan Hogan, Policy and Advocacy Manager, Amaze, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 4.

19 Ibid.

20 Ibid. See also Professor Cheryl Dissanayake, Founder and Director, Olga Tennison Autism Research Centre, La Trobe University, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 4; Ms Katie Koullas, Founder, Yellow Ladybugs, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 4; Ms Nicole Stephenson, Family and Community Development Committee public hearing – Geelong, 19 September 2016, transcript of evidence p. 2; Ms Susanna Flanagan, Family and Community Development Committee public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 3; Mr Angus Mackellar, submission no. 125, p. 2; Mr William Fidler, submission no. 129, p. 2; Speech Pathology Australia, submission no. 136, p. 9; Dr Anthony Engwirda, submission no. 153, p. 1.

### 1.1.3. Terminology

People with ASD may use the term ‘autistic’ or ‘Aspie’ to describe themselves. The Committee will use ‘people-first’ language, i.e. ‘people with autism’, as this language is traditionally used in the disability sector to emphasise the person rather than the disability and to avoid ASD becoming the primary, defining characteristic of an individual.

There is a building consensus that functioning labels, such as ‘high functioning’ and ‘low functioning’, are not helpful or appropriate terms to classify people with ASD. Words that are preferred are ‘high needs’ and ‘low needs’. Witnesses told the Committee that functioning labels are harmful and stigmatise individuals, and that they do not reflect reality.<sup>21</sup> Ms Stacey Smith, a 32-year-old woman with autism and mother of three daughters with ASD, told the Committee at a public hearing in Geelong:

I really hate any functioning labels whatsoever, because they do not represent individuals. High functioning just means without an intellectual disability. There is nothing more to it. If you want to talk about yourself or your child and your strengths and weaknesses, you focus on your strengths and weaknesses because that is going to tell the person more about you than the words ‘high’ or ‘low’ functioning. So I encourage every school and everybody I meet to not use that, because it does not give you any information. Does ‘high’ or ‘low’ tell you how to help the child or the adult? No, it does not.<sup>22</sup>

Functioning labels can mask the struggles and needs that individuals with ASD have. Ms Chloe Fitton, who was diagnosed with ASD at the age of 20, told the Committee at a public hearing in Bendigo:

[G]enerally as a community we reject functioning labels, as in labelling an Autistic high functioning or low functioning. It does not actually reflect reality. Somebody that is non-verbal is generally automatically regarded as low functioning and they are often shunted off. They do not get to experience much of the world because they are shunted away and treated like they are completely vacant – like they are not people. They do not get services, they do not get to access the world around them, they do not get to explore what it means to be anything. They just do not get that. Whereas on the other hand people like me are often labelled high functioning despite the fact that I have so many struggles, and people that are labelled high functioning may not actually be high functioning. A lot of them might need a lot of supports in place to keep things going. A lot of high-functioning Autistics may not ever be able to live independently.

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21 Ms Chloe Fitton, Family and Community Development Committee public hearing – Bendigo, 17 October 2016, transcript of evidence, pp. 6-7; Ms Susanna Flanagan, Family and Community Development Committee public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 6; Ms Rebecca Kelly, Co-Convenor, Bendigo Autistic Advocacy and Support Service, Family and Community Development Committee public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 3.

22 Ms Stacey Smith, Family and Community Development Committee public hearing – Geelong, 19 September 2016, transcript of evidence, p. 3.



The high-functioning and low-functioning split is a false dichotomy. The Autism spectrum is a spectrum. Everybody has different abilities and different strengths, and we need to cater for that. We need to drop the functioning labels from the way in which we treat Autistics in schools, in health, in everything. We kind of need a bit of a complete overhaul as to the protocol of how we deal with Autistics and help them.<sup>23</sup>

Within a disability framework, a 'strengths-based' view of autism is preferred by the disability sector that focuses on how all people with ASD can build upon their strengths and interests, regardless of the challenges of their ASD. There is a push to acknowledge that many people with ASD who appear 'high functioning' can often struggle to 'mask' their social and communication challenges, and may also require support at different times in their life.<sup>24</sup>

Importantly, the Committee heard that the strength-based mindset and discourse around disability could be problematic when it comes to asking for support and advocating for funding. Ms Shantelle Grant, a parent of a daughter with ASD, spoke to the Committee at a public hearing in Bendigo on behalf of the Macedon Ranges Autism Network and expressed concern about the language of diversity:

My fear with the change in language, and I have said this before, is that I understand the need of autistic adults wanting to be heard and not wanting to be called this, that and the other. Autism spectrum disorder is a disorder. It is a neurological disorder of the brain. That is the diagnosis. If we start changing language and changing things to diversity, when we look at supporting our families and supporting our children, if we take off those words, how are we going to get support from governments when we say, 'It's not really a disorder; it's not really a disability'? My fear as a parent, and this is the parent talking with you right at this point, is that if we change these languages and change these things, how can we expect governments to support us?<sup>25</sup>

Regarding the NDIS, Mr Geoff Barber, the Acting Coordinator of Care Services, Aged and Disability at the Greater Geelong City Council, told the Committee at a public hearing in Geelong:

[P]eople have been very much strength-based, as in the mental health sphere, not so much about my disability but what can I do. Then they have to go to NDIA and only speak about what they cannot do, especially when that is the worse situation. It is quite a different mindset to have, and I think that is where an

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23 Ms Chloe Fitton, Family and Community Development Committee public hearing – Bendigo, 17 October 2016, transcript of evidence, pp. 6-7.

24 See Ms Sally Smith, Family and Community Development Committee public hearing – Shepparton, 15 November 2016, transcript of evidence, p. 2; Broad Insight Group, Dianella Community Health, submission no. 132, p. 8; Autism Spectrum Australia (Aspect), submission no. 100, p. 5; Autism Family Support Association, submission no. 71, p. 15; Health and Community Services Union (HACSU), submission no. 43, p. 3; Ms Susanna Flanagan and Mr Martin Flanagan, submission no. 97, pp. 3-4; Aspergers Victoria, submission no. 141, p. 24.

25 Ms Shantelle Grant, Macedon Ranges Autism Network, Family and Community Development Committee public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 4.



advocate comes in really handy and probably will always do so in that insurance-based model, from my perspective anyway.<sup>26</sup>

The Committee heard that some people with ASD and families living with ASD preferred to use the word ‘condition’ rather than ‘disorder’.<sup>27</sup> Others advocated for a change of term from ASD to autism spectrum abilities.<sup>28</sup>

When relevant and applicable, throughout this report the Committee will refer to people with ASD as having either ‘low needs’ (what has previously been referred to as ‘high functioning’) or ‘high needs’ (what has previously been referred to as ‘low functioning’), in keeping with what the Committee has heard from people with autism and their families.

#### **1.1.4. The diversity of the spectrum**

The Committee has heard and seen that the autism spectrum is a wide and diverse spectrum and no two people with autism are alike. In their submission, Amaze quoted Dr Stephen Shore, advocate, researcher and a person with ASD, as saying:

If you’ve only met one person with autism, you’ve only met one person with autism.<sup>29</sup>

There is no homogeneity amongst people with ASD. Every individual with ASD shares broad challenges in the areas of social communication, restricted interests and behaviours, but the extent to which these attributes impact an individual vary considerably.<sup>30</sup> Some people with ASD experience ASD as a disability that presents significant challenges for everyday living, for others ASD is part of the neurodiversity of humanity, a condition to be celebrated rather than ‘treated’. The Committee heard from some people living with autism and families living with autism who are strongly opposed to genetic research into the causes of autism. There is also division on early behavioural intervention services (especially ABA) that some claim aim to mask or eliminate the ‘unique’ attributes and behaviours of people with ASD.<sup>31</sup> These views reflect the diversity of the autism spectrum.

Given the diversity of people with ASD it is difficult to speak of one ASD community. The lack of homogeneity is also problematic for service providers. Dr Sandra Radovini, the Director of Mindful – Centre for Training and Research in Developmental Health, spoke to the Committee at a public hearing in Melbourne about the diversity of autism and the difficulty this poses for service providers:

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26 Mr Geoff Barber, Acting Coordinator of Care Services, Aged and Disability, Greater Geelong City Council, Family and Community Development Committee public hearing – Geelong, 19 September 2016, transcript of evidence, p. 4.

27 Mr Stephen Williams, Family and Community Development Committee public hearing – Geelong, 19 September 2016, transcript of evidence, p. 2.

28 Miss Hayley Reed, submission no. 3, p. 2.

29 Amaze, submission no. 139, p. 14.

30 See Amaze, submission no. 139.

31 Ms Chloe Fitton, Family and Community Development Committee public hearing – Bendigo, 17 October 2016, transcript of evidence.

Children, young people and adults can be anywhere on those dimensions, and that adds to the complexity for service providers or the whole service system to be thinking about how you meet the needs of people who are going to be vastly different – so from children, young people and people who are very limited in their verbal capacity to people who are very fluent and from people who have severe intellectual disability to those who are in the average range when it comes to intellectual abilities. That is a key issue for us.<sup>32</sup>

Likewise, in their submission to the Inquiry, Merri Health told the Committee:

The diversity within ASD is problematic in itself, for example every child with ASD will present in different ways and with diverse needs. There is a need to do away with the ASD 'label' and work with the needs of children and families, a need for good individualised practical support. Service provision needs to be child and family centred.<sup>33</sup>

## 1.2. Living with ASD

People with ASD have a growing visibility in public culture, and are increasingly providing support to each other and speaking out about their needs. This section describes the experience of living with ASD from the perspective of young people and adults who are living with ASD. The Committee was keen to hear from people with ASD themselves, from families living with ASD and for this report to reflect the interests of people with ASD.

### Young people with ASD

The Committee heard from young people who used their experiences of ASD to advocate and support others in their schools. Mr Bryce Pace, a 17-year-old student in year 11, told the Committee at a public hearing in Melbourne that his autism was not a disability but had given him 'a lot of amazing and unique abilities'.<sup>34</sup> Mr Pace described his experience of coming to terms with his diagnosis:

I was diagnosed with autism when I was nine years old. Before I was diagnosed, I thought I was what most neuro-typical people would describe as normal. I was a happy kid who did not care what people thought of me. In primary school I had a rough time after my diagnosis, as my school did not know what or how they should teach me. To them I was just their kid with the disability label. They taught me life skills. Some of them, like reading a telephone book, were very last century, and I was living in this century. I wanted to move forward, but I felt they were holding me back. When I reached secondary school, I hid who I was as I wanted to be treated like everyone else. I did this for four years and only this year have started telling people of my diagnosis.

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32 Dr Sandra Radovini, Director of Mindful, Centre for Training and Research in Developmental Health, Department of Psychiatry, University of Melbourne, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, pp. 2-3.

33 Merri Health, submission no. 37, p. 3.

34 Mr Bryce Pace, Brauer College, I CAN Network, Family and Community Development Committee public hearing – Melbourne, 12 September 2016, transcript of evidence, p. 5.

That story is the reason why I am the person I am today. It is the story of many others with similar experiences; however, if it were not for my primary school's negative view of autism, I would probably not be so passionate about student voice.<sup>35</sup>

Likewise, Mr Dom Williams, a 12-year-old student in year 6, advised other students diagnosed with ASD to 'embrace it' rather than fight it as he said that most of his academic traits and strengths had come from the fact that he has autism.<sup>36</sup> Nonetheless, Mr Williams told the Committee that he had experienced bullying at school due to being different:

Probably the largest difficulty I have had is with, from my opinion, bullying because of ignorance. This was more prevalent in my second school, with some resolved bullying in my third one. In the second school – this is mainly in my third and fourth years of school – I came under fire from bullies who were sort of taking a jibe at the fact that I was different to other students. Certainly one of the main things that students use to bully me over is I am not very good at maths or spelling, so they would attack me over that. They attacked me over the fact that I was different.<sup>37</sup>

The Committee heard that bullying, isolation and alienation in schools was a common experience for people with ASD. Mr Ryan Kennedy, a 24 year old with ASD who was diagnosed at the age of 10 told the Committee at a public hearing in Melbourne:

One of the things that I think affected me was in primary school when I got the diagnosis. In primary school I got bullied. The programs were all about how socially you have to be able to stand up for yourself or whatever. The implied thing with that, in my opinion, was that it was saying that if you do not behave in the right way, you are asking to be bullied... When I went out of primary school there was less bullying, because I was able to go to the library and I actually found other autistic people to hang out with, which was good. But there are still issues that arise from it, like anxiety.<sup>38</sup>

The Committee heard evidence that bullying, alienation and isolation are experienced by students with ASD in rural and regional schools.<sup>39</sup> The challenges facing people with ASD in rural and regional areas are further discussed in Chapter Nine.

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35 Ibid.

36 Mr Dom Williams, Family and Community Development Committee public hearing – Melbourne, 10 October 2016, transcript of evidence, p. 6.

37 Ibid, p. 2.

38 Mr Ryan Kennedy, Family and Community Development Committee public hearing – Melbourne, 12 September 2016, transcript of evidence, p. 2.

39 Ms Natalie Owens, South Gippsland Autism Action Group, Family and Community Development Committee public hearing – Morwell, 5 December 2016, transcript of evidence p. 2; Mr Dom Williams, Family and Community Development Committee public hearing – Melbourne, 10 October 2016, transcript of evidence, pp. 2-4; Ms Carole Trotter, submission no. 55, p. 2; Ms Susanna and Mr Martin Flanagan, submission no. 97, p. 12; Ms Judith Horne, submission no. 120, p. 1.

## Adults with ASD

People with ASD continue to experience challenges after leaving school. The Committee heard from Ms Meaghan O'Brien, a 34 year old with Asperger's Syndrome and co-occurring anxiety and depression, on her struggle to gain employment and how this impacted her self-esteem:

I've never had a proper paid job, only many different volunteer ones with varied degrees of success and failures not turning into a paid job which has lead me to have low self-esteem and feeling like I am never going to [achieve] anything in life and feel I bring shame to my family who [brought] me up with a good work ethic. Sure volunteer work looks great on a resume but doesn't pay the bills or put money toward bigger things like a holiday overseas.

I applied for many jobs getting a few interviews here and there trying my absolute best in them getting my hopes up only to be disappointed in not getting the job. Getting a potential employer to understand why it is hard to engage in things like small talk is hard for me as it part of the Asperger's but it doesn't affect my work output where I am focussed on details and completing the work to a high standard in the allocated time given. I wish people would see these as positive traits to have in the workplace and totally outweigh my social shortfalls which I am working on improving all the time. I might be shy and quiet at first but after a while I am ok.<sup>40</sup>

Ms O'Brien argued that ideally there should be a focus on the positive attributes that employees with ASD bring to the workplace:

Diversity in the workplace is way more than different races and religions disability affects people of different races and religious beliefs too. Employers need to realise this and think outside the box when considering employing people. Australia is one of the worst in the OECD for disability employment 21 out of 25 countries. We put more effort to being the best in sports in than [sic] looking after people with disability if only the effort put on that instead the benefits across the board would be massive.<sup>41</sup>

Ms Stacey Smith described workplace challenges for people with ASD, including sensory issues, struggling with change, and the difficulty disclosing ASD to employers. She recounted her experience working in a customer service role to the Committee at a public hearing in Geelong:

To get by, I scripted everything I said. I realised I would have a script for this situation and a script for that situation, so I would find it very difficult if the information changed. I find it very difficult if there is a new product out; I would need to get a script together for that. If the situation changed, I have had instances where I actually cannot recognise people – facial blindness. So I would get myself into situations where I have served a customer and they have

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40 Ms Meaghan O'Brien, submission no. 109, pp. 1-2.

41 Ibid, p. 2.

come in in the afternoon and I forget who they were. There are so many issues, and that all adds to stress and anxiety and piles up.<sup>42</sup>

The Committee heard that people with autism can thrive in the workplace provided they have a supportive environment.<sup>43</sup> The Committee also heard that peer support groups and mentoring services play a major role in helping people with ASD navigate life changes. The Committee heard from Mr Chris Varney, the founder of the I CAN Network, about the success of I CAN's program which mentors adults with autism in employment.<sup>44</sup> Mr Varney told the Committee about his own experience with ASD:

I was diagnosed with Asperger's at the age of five. This was in the early 90s where very much parents walked into a room with one sense of their child and then went and sat down with someone from the medical field – my parents are both in the medical field, so I will just say that – and were given a totally different impression of what expectations to have around their kid. My mum walked into the room and being the unstoppable type of person that she is she said, 'Well, I'm not going to have a bar of lowering my expectations or thinking that he is going to have a life time of difficulty. I am going to have high expectations'. So I CAN was very much something I was raised with even though we found a lot of our people on the spectrum from the outside world tend to think, 'I can't do it like other people can'. I CAN was very much an ethos that I was raised within.<sup>45</sup>

While the majority of evidence received by the Committee pertained to the diagnosis of children, which will be discussed in Chapter Three, the Committee heard that for many adults the experience of being diagnosed with ASD late in life was a defining moment.

Ms Sally Smith was diagnosed with ASD at the age of 33 after her mother had been reading about ASD as Ms Smith's nephew was being assessed at the time. Ms Smith's mother suggested that Ms Smith also get assessed. Ms Smith had trained as a teacher but found herself unable to cope with teaching. She told the Committee at a public hearing in Shepparton that she wanted to share her story because it is important to recognise that people who may seem quite intelligent and able still do need support.<sup>46</sup> In her submission, she wrote:

It had been great to be diagnosed as it makes sense of so many things. I have a better understanding and feel better in myself. However I had to travel at least 2 hours to find anyone with the knowledge of ASD to diagnose me so there really is no support for me after diagnosis. There needs to be a lot more done for people

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42 Ms Stacey Smith, Family and Community Development Committee public hearing – Geelong, 19 September 2016, transcript of evidence, pp. 2-3.

43 Mr James Tucker, submission no. 9, p. 1.

44 Mr Chris Varney, Chief Enabling Officer and Founder, I CAN Network, Family and Community Development Committee public hearing – Melbourne, 12 September 2016, transcript of evidence, p. 3.

45 Ibid, p. 2.

46 Ms Sally Smith, Family and Community Development Committee public hearing – Shepparton, November 2016, transcript of evidence, p. 2.

who are diagnosed as adults as we often carry many scars from years of not understanding.<sup>47</sup>

Ms Chloe Fitton, who was diagnosed at the age of 20, told the Committee at a public hearing in Bendigo about her experience of being diagnosed after being misdiagnosed with bipolar disorder:

It is really hard trying to take your place in a world where all of a sudden — when I was diagnosed, it was like, ‘Wow! This makes so much sense. This fits me. This explains so much of my experience as a human being’, but I had pretty much nowhere to go after that. It is a very peculiar thing to experience, and we need to help people that are going through that. Especially as it is becoming more common for adults, and especially adult women, to be getting diagnosed, we need those supports in place. We need to be able to go to our schools, we need to be able to go to hospitals and just go about the world like everybody else without the fear of being warehoused or shuffled around the mental health system because nobody knows how to deal with us. We need to be able to feel safe in the world.<sup>48</sup>

Mr James Tucker explained in his submission to the Inquiry and at a public hearing in Melbourne that finding out that he had ASD late in life (at the age of 56) ‘was probably one of the most powerful moments’ of his life:

This late in life revelation has finally allowed me to make sense of my frustrating and very often disappointing life.<sup>49</sup>

Mr James Tucker told the Committee that his own experience of ASD allowed him to advocate more effectively for his son who also has ASD:

...with the help of my psychiatrist I can now deal with people and a world that I do not fully understand. Most importantly, I now advocate much more effectively for our son... People with ASD are as different from each other as they are from everyone else... There is no cure for ASD — not now... one person with ASD has quite different needs from any other person with ASD. Some of us need a great deal of help, and some of us just need a place to feel safe. Many of us need an advocate just to deal with the world, let alone with something as complex as the NDIS. It seems very strange to me that you could say to somebody, ‘You just go to this person and tell them all your needs and advocate for yourself and they will solve it’, when your biggest problem is communicating and advocating for yourself. But we all have something to offer. Einstein was ASD. He did not fit into the world. Thank God he was so smart that the world had to take him as he was. Most of us are not that lucky.<sup>50</sup>

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47 Ms Sally Smith, submission no. 83, p. 1.

48 Ms Chloe Fitton, Family and Community Development Committee public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 5.

49 Mr James Tucker, submission no. 9, p. 1; Mr James Tucker, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 3.

50 Mr James Tucker, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 3.

In a Melbourne public hearing, Ms Narelle McCaffrey described her experience as a mother with ASD and how this influenced the way she parented her children with ASD:

I am the mother of three autistic children. I feel I have an innate understanding of my children and their autism. I can understand and relate to their need to be away from people, the pain different noises can cause them and the need to immerse oneself in a special interest. I also understand the experience of being on the social outer because these are my experiences [too]. We might play or communicate differently from some others. We might process the world around us differently and maybe learn better in different ways. I truly believe that this is okay and do my best to teach my children this too. I love and embrace all that my children are and who they are. I can show my children how other people do it or how other people see things without expecting them to follow suit.<sup>51</sup>

Ms McCaffrey told the Committee that while there was a lot of resources and research around adults with ASD on the transition to adulthood, independent living and employment, there 'is a cohort being forgotten or ignored', which is mothers with ASD. Ms McCaffrey stated:

We exist and probably in numbers greater than can be predicted. Most of us have been diagnosed after the diagnoses of our children and at great personal expense, while others remain self-diagnosed because of this cost.

I and other autistic mothers face a number of unique difficulties. This may be in part due to societal expectations of mothers, the notion that autism affects more males than females and the idea that autistic parents, let alone mothers, are the exceptions to the rule, given that autism in adults is seemingly forgotten. Although we are all different, it would seem the difficulties autistic mothers experience are similar.<sup>52</sup>

Ms McCaffrey noted that many mothers with ASD struggle with executive functioning, feel misunderstood and do not feel comfortable asking for help out of fear of judgement.<sup>53</sup> Many mothers with ASD also experienced problems with executive functioning, which impacted organisation skills, prioritising and completing tasks, impulse control and self-regulation and the ability to plan. Ms McCaffrey told the Committee:

My house is a constant mess, so I end up feeling overwhelmed and anxious to the point of being unable to act. Although I am not a bad parent, I think that I could be better at it if I could maintain that order, have that order and have the help and support to do so... No matter what though, raising children, autistic or not, is really hard when you are dealing with your own issues. It is hard to juggle your own needs when juggling the those [sic] of your children. Services to help are non-existent... Our existence as autistic mothers needs to be acknowledged and services to help and support us need to be established.<sup>54</sup>

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51 Ms Narelle McCaffrey, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 2.

52 Ibid.

53 Ibid.

54 Ibid.



The experience of adults with ASD will be discussed in greater detail in Chapter Five.

### 1.2.1. ASD and identity

There is some tension between people who understand ASD within a ‘disability’ framework, and others who promote it as a central part of someone’s identity, which should be celebrated as an expression of their neurodiversity.<sup>55</sup> Ms Chloe Fitton told the Committee at a public hearing in Bendigo that she was proud to be autistic and would not want to be anything other than autistic:

Look, I am Autistic. I always have been and I always will be, and I am proud of this... we only started the process of diagnosing me with Autism when I was 20. It is quite odd being Autistic. My whole life thus far has been spent trying to fit in. I never will. I will always be odd. I will always be terrified of saying the wrong thing, doing the wrong thing, trying to guess what somebody means when they speak or trying to make sure that I do not make them uncomfortable by being visibly Autistic. It is quite exhausting. Despite this I do not want to be anything other than Autistic.

No neurotypical, which is somebody that is not Autistic, knows what it is like to be Autistic. Many organisations about awareness publish many kinds of media about what it is like to be Autistic. They do not capture it. All of these videos and other media tend to lull people into a false sense of authority about knowing what it means to be Autistic, which is quite dangerous. These videos and other media are all generally well meaning, but they do not help us.<sup>56</sup>

Ms Fitton’s comments correspond to a phrase which the Committee heard during its Inquiry: “nothing about us without us”. This phrase, frequently used in the context of the disability rights movement, was often spoken by people with ASD and their advocates, and emphasises the importance of including, engaging and consulting people with ASD in the development of any services, programs and supports that impact on people with ASD. Ms Fitton told the Committee:

It is not that we Autistics are not willing to speak about the issues we face and the barriers placed between us and getting any of the assistance we need to achieve our goals, and sometimes those goals can be as simple as: live, exist and be able to just keep on keeping on. We are willing to speak. Every time we try we tend to be shut down, ridiculed and silenced by neurotypicals, most often by our own parents, teachers, mentors or other people that are supposed to be on our side. We may not necessarily communicate like neurotypicals, but that does not mean that our voices should not be dismissed. Even the most seemingly vacant, non-verbal Autistic person has a rich inner world, and despite what some organisations will have you believe, we do have complex thoughts, feelings and Theory of Mind. We do not want a cure. We care not about the

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55 Amaze, submission no. 139; S Silberman, *Neurotribes: The legacy of autism and how to think smarter about people who think differently*, Allen & Unwin, Sydney, 2015; I CAN Network, submission no. 127; Aspergers Victoria, submission no. 141; Ms Chloe Fitton, Family and Community Development Committee public hearing – Bendigo, 17 October 2016, transcript of evidence; Ms Stacey Smith, Family and Community Development Committee public hearing – Geelong, 19 September 2016, transcript of evidence.

56 Ms Chloe Fitton, Family and Community Development Committee public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 2.



aetiology of Autism. We do care about the way the world works around us in ways that are not conducive to our existence. That is the issue here, not Autistics and the ways that we are different.<sup>57</sup>

The Committee also heard from some witnesses who objected to the inclusion of Asperger's in the autism spectrum in the DSM-5, rather than it being a separate diagnosis as it was previously under the DSM-IV. Ms Tasmin Jowett, the President of Aspergers Victoria, told the Committee at a public hearing in Melbourne:

We think that Aspergers have different needs to the rest of the spectrum. They have a different neurology. They are like an Apple computer versus a Microsoft computer, so their brains just work differently. They are differently wired. They do not have intellectual disability or impairment to be Aspergers, and they have strengths which are often overlooked. They have amazing innovative thinking – as Tony Attwood calls it, originality in problem solving. They come in at such a different angle on problems; no-one can anticipate their ideas. They usually have average to well above average IQ. They have language abilities; they are not in the part of the spectrum where language is an issue. However, they can interpret language literally, which restricts them. They have amazing factual knowledge and special interests.<sup>58</sup>

The Committee heard evidence from a range of different perspective from other people with ASD, and families and carers living with ASD. One submitter was highly critical of what they described as 'the current process of telling the whole world' you have autism as they believed it made it more difficult for society to understand the struggles of people for whom ASD is a significantly disabling condition, rather than a positive attribute.<sup>59</sup> For this submitter, the 'neurodiversity movement' presents 'a genius model of autism', which is 'profoundly rare', often sets people up for failure and puts 'undue pressure on children' with ASD.<sup>60</sup> They wrote:

That does not mean people do not have talents and strengths, they do, but they are no more genius than the average person. Equally one cannot deny that there are people who are profoundly disabled by their autism... I was not diagnosed with autism because I have special strengths; I was diagnosed, because I have specific difficulties in the areas of social communication and repetitive and restrictive behaviours. These things make interacting with the world very difficult for me, the same as any disability makes things difficult for people. That does not mean I cannot do anything, or that I do not have talents and skills to share with the world. It also does not mean that I do not have the same needs, hopes and desires as the average person... What it does mean is that I am going to need extra supports in some instances in order to enable me to have those needs met. That is a disability...

I'm constantly told I need to be proud of my autism, but that is not something I can understand. I'm proud of my achievements. Being diagnosed with autism is not an achievement; it is just something that happened. I'm not ashamed of it, if

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57 Ibid.

58 Ms Tasmin Jowett, President, Aspergers Victoria, Family and Community Development Committee public hearing – Melbourne, 12 September 2016, transcript of evidence, p. 3.

59 Name withheld, submission no. 138, p. 9.

60 Name withheld, submission no. 138B (supplementary submission), p. 2.

I was I would not speak to others about it, or actively advocate about things. To me autism, just is, the same as having any medical condition... Equally I am also told I need to love having autism. To this day I continue to have violent out of control meltdowns. To tell me I should love those things is insulting... My autism creates immense difficulties in my life, which I continually try to overcome and which are not that simple. I would love not to have those difficulties and fail to understand why anyone would want them.<sup>61</sup>

For some people with autism and their families, there is a perception that the major autism organisations privilege the views and experiences of people with autism who have low needs and no co-occurring intellectual disability. Some parents of children with ASD find this perspective alienating, particularly those struggling to manage children with challenging behaviours and no formal means of communication.<sup>62</sup> Some parents and carers argued that people who were severely impaired by ASD were neglected as those that had lower needs were more vocal.<sup>63</sup> Furthermore, the Committee heard that some parents were so busy looking after their children that they could not form advocacy and support groups and therefore their voices were not being heard.<sup>64</sup>

The Committee heard from many families whose lives were severely impacted by autism. Ms Elisabeth Appelgren-McIntyre, the mother of two adult sons with ASD and other co-occurring conditions, described in her submission the sensory triggers and the difficulty of challenging behaviours, particularly when her sons hurt themselves and broke furniture:

Words cannot describe how absolutely exhausting it is to live with a child with severe autism like my oldest son. Everything had to be exactly the same all the time to how he perceived it should be: you could not give him a different cup to drink out of, you could not enter the greengrocer's through a back door, you could not take a short cut in the car, etc, etc. All day we were faced with terrible meltdowns and blood pouring from his nose when he would hit it, or from his hand when he would bite it, in frustration... The other problem both our boys have is over acute hearing. It would send our oldest son into a rage if the phone rang or if we used any electrical appliance. Imagine the challenge when we had to use the washing machine, electric mixer, hairdryer, etc, etc. Even the sound of scissors when having to have a haircut would send our oldest son into a rage and it used to take four of us to hold him down.<sup>65</sup>

Evidence clearly indicates there is a wide diversity in symptoms and experiences of ASD and this is often further complicated by co-occurring conditions. The Committee recognises the diversity of people with autism and appreciates the different views on ASD of a community made up of individuals.

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61 Ibid, pp. 2, 5.

62 Amaze, submission no. 139; Yellow Ladybugs, submission no. 117; Name withheld, submission no. 138.

63 Ms Deirdre Wirth, Family and Community Development Committee public hearing – Geelong, 19 September 2016, transcript of evidence, p. 2.

64 Ibid.

65 Ms Elisabeth Appelgren-McIntyre, submission no. 95, p. 3.

Nevertheless, this Inquiry has provided the Committee with clear evidence that people with ASD must be engaged with, consulted and included in any discussions about them: a key phrase heard by the Committee during the Inquiry has been ‘nothing about us without us’. Governments, at all levels, need to be guided by this overarching principle of inclusivity in their development of policies and programs for people with ASD. This is both a philosophical and ethical issue and a practical matter: to exclude people with ASD from decision making will only lead to the development of flawed models and approaches.

In supporting people with ASD, the Committee is of the view that any changes to services for people with ASD must consult and engage with people with ASD, who are directly affected by these services. Accordingly, the Committee recommends that:

#### **RECOMMENDATION 1.1**

**In the development of policies, programs, services and supports for people with ASD, or impacting on people with ASD, the Victorian Government, local governments, all service providers and professionals must consult and engage with people with ASD, their families and advocates.**

### **1.3. Families living with ASD**

The Committee has heard from a large number of parents and carers of people with ASD about the impacts of ASD throughout the life cycle. Many parents have found the experience of diagnosis overwhelming and criticised the lack of practical information and support available to families during this time.<sup>66</sup> The long waiting lists and uncertainty that often precedes a diagnosis impacted the mental health of parents. The Committee is aware that long waiting lists for diagnosis are related to the lack of diagnostic services across the state, and qualified health professionals capable of diagnosing ASD, particularly in the regions. There is also a shortage of trained behavioural therapists. Professor Cheryl Dissanayake, the Founder and Director of the Olga Tennison Autism Research Centre (OTARC) told the Committee at a public hearing in Melbourne:

We are killing these parents. We are telling them early intervention is important, and then we are keeping them on waiting lists, so we are plunging them into mental health chaos, really.<sup>67</sup>

Professor Dissanayake told the Committee that early identification and diagnosis leads to a reduction in family stress and an increase in family wellbeing.<sup>68</sup> Despite

<sup>66</sup> Ms Jules Haddock, Family and Community Development Committee public hearing – Geelong, 19 September 2016, transcript of evidence, p. 4; Ms Cathy Talia-Parker, Family and Community Development Committee public hearing – Melbourne, 12 September 2016, transcript of evidence, pp. 2, 5; Ms Dianna Lane, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence; Ms Narelle McCaffrey, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 4; Ms Susan Pearce, submission no. 50.

<sup>67</sup> Professor Cheryl Dissanayake, Founder and Director, Olga Tennison Autism Research Centre, La Trobe University, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 7.

<sup>68</sup> Ibid, p. 2.

this, families of those with autism have the highest levels of stress and the lowest quality of life when compared to not only typically developing families but to other families of children with developmental disabilities.<sup>69</sup>

Even after receiving a diagnosis, parents spoke of feeling as though they had ‘entered an unknown world’ with little or no information or guidance on what to do for their children.<sup>70</sup> Many parents lamented the lack of a central agency to turn to, including Mrs Rebecca Spiteri who told the Committee that when her son was diagnosed at the age of seven, she found it overwhelming and devastating and described going through a grieving process.<sup>71</sup> Some parents spoke of having to continually investigate and apply for funding through a maze of rules and criteria.<sup>72</sup>

Ms Susan Pearce, the mother of a son with autism, told the Committee at a public hearing in Melbourne that there needed to be more support and information for parents, particularly addressing the blame that parents often feel:

It would be useful if there were some form of brochure that you handed to parents to take away to relieve some of these fears, not just explaining what ASD is but the process you go through and who to contact. It could contain referral points so parents could go to the internet and find the right information. If copies could be held with maternal health nurses or at doctors’ surgeries and kindergartens that might prompt parents if they notice the symptoms. They could read the brochure and say, ‘I must talk about my child’. It would help diagnosis early. One of the best things they could have in the brochure is a statement that says, ‘Parents, you have done nothing to cause your child’s ASD. Nothing you have done can cause it’. I know that is something that Darren and I found out with Simon and it would have been a big help to get us on the journey.<sup>73</sup>

### **1.3.1. The pressures on families living with ASD**

The Committee heard that parents of children with ASD had higher rates of mental illness, stress, anxiety, depression, relationship breakdowns and social isolation.<sup>74</sup> Dr Sandra Radovini, the Director of Mindful told the Committee at a public hearing in Melbourne that families needed support throughout the lifespan:

[P]arents of children with ASD have some of the highest mental health difficulties. The stress of being a parent of a child with autism is quite enormous, even when compared to children with a range of other disabilities – there has

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69 Ibid.

70 Ms Cathy Talia-Parker, submission no. 38; Ms Narelle McCaffrey, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 4.

71 Mrs Rebecca Spiteri, submission no. 16, p. 1.

72 Name withheld, submission no. 18, p. 2.

73 Ms Susan Pearce, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 2.

74 Ms Lisa Carr, Family and Community Development Committee public hearing – Melbourne, 21 November 2016, transcript of evidence; Mr Graeme Drysdale, submission no. 19; Name withheld, submission no. 119; Ms Shannon Leahy, submission no. 82; Illoura Early Childhood Intervention Services Inc, submission no. 35.

been quite a bit of research in this area — so we strongly believe that families need to be supported, again throughout the life span.<sup>75</sup>

Several witnesses acknowledged that having a child with ASD may involve lifelong caring responsibilities and that parents and families needed to be supported to prevent burn out. Ms Carole Trotter, the mother of a son with ASD, told the Committee at a public hearing in Shepparton:

As I talk with other country parents or read of their plight I have become aware of a common theme being expressed. Having an autistic child is a financial and emotional burden. There is usually no respite and no carers to relieve parents of the burden of caring for their child. The family is very often isolated and stressed. The lack of people contact as parents often isolates you to the child's antisocial tendencies, families break up or parents' self-esteem plummets as they become anxious and doubtful of their abilities.<sup>76</sup>

Many parents told the Committee that they felt isolated. Ms Dianna Lane in her written submission described her daughter's behaviour and anxiety as so severe that she and her family 'are confined to home because it is too difficult' to take her out and that they feel like 'prisoners' in their own home.<sup>77</sup> Several families spoke of feeling ostracised from friends, family and the community due to the challenging behaviours of their children with ASD.<sup>78</sup>

Caring responsibilities, including attending appointments and therapy sessions, can also contribute to difficulties maintaining employment and lead to further isolation. Many parents told the Committee that they had to resign from their jobs or reduce their workload significantly in order to care for their child.

Ms De'arne Treacy told the Committee at a public hearing in Shepparton that she had to go part time at work to pick her daughter up from school and to accommodate the occupational therapy sessions and different specialists that she was referred to for her daughter.<sup>79</sup>

Ms Shantelle Grant, a parent of a daughter with ASD, spoke to the Committee at a public hearing in Bendigo on behalf of the Macedon Ranges Autism Network and expressed the need to support parents:

We try to give parents those tools to educate themselves, because if there are mental health issues within parents, marriages suffer. My marriage unfortunately suffered, not 100 [per] cent because of the diagnosis, but it does make home life a little bit harder. It is about the education of parents and the supporting of parents through that journey and giving them the tools and the

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- 75 Dr Sandra Radovini, Director of Mindful, Centre for Training and Research in Developmental Health, Department of Psychiatry, University of Melbourne, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 3.
- 76 Ms Carole Trotter, Family and Community Development Committee public hearing – Shepparton, 15 November 2016, transcript of evidence, p. 2.
- 77 Ms Dianna Lane, submission no. 11, p. 1.
- 78 Ms Carole Trotter, submission no. 55.
- 79 Ms De'arne Treacy, Family and Community Development Committee public hearing – Shepparton, 15 November 2016, transcript of evidence, p. 3.

access to the things that they need to process and move through that journey of autism.<sup>80</sup>

The mental health and wellbeing of parents had an impact on the treatment and development of children. Ms Sarah Wilson, the Convenor of the ABA Parent Support Network, told the Committee at a public hearing in Melbourne:

Most importantly what is forgotten is that the effectiveness of any autism treatment hinges on the parents' mental, physical and emotional health. I was a wreck. When you are living with somebody who screams so much every day and you are just trying to get through the day it is very hard to make good choices about treatment. I, myself, saw a psychologist. Again I paid for that. I saw a psychologist for – I do not know – six months: every week for a few months and then every two weeks and then once a month, and finally she said, 'You're okay'. Because my daughter was getting better during that time as well, I started feeling better.<sup>81</sup>

In her submission to the Inquiry, Ms Shannon Leahy spoke of the impact of having three sons with ASD and other co-occurring conditions and, in particular, of the financial stress and marriage breakdown on the family's mental health:

We were and still remain a family in crisis with my energy taken up with trying to rundown leads on funding that will support us as a family - as a single parent carer my ability to financially support my children's extra needs as well as encourage social interaction with their limited community is a juggling act that stretches us to the breaking point.<sup>82</sup>

Families also had ongoing concerns about their children's future employment, housing and quality of life.<sup>83</sup> Parents also lived with anxiety about what would happen to their child when they were no longer around to care for them.<sup>84</sup>

The Committee heard that some families had positive experiences attending support groups which helped alleviate some of the pressures they faced.<sup>85</sup>

### **1.3.2. Respite**

Many families told the Committee that there was a lack of respite services available to families and that there were often long waiting lists. The Committee also heard that respite services often failed to adapt to the needs of people with ASD and their families and that there was a lack of appropriate training provided for respite

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80 Ms Shantelle Grant, Macedon Ranges Autism Network, Family and Community Development Committee public hearing – Bendigo, 17 October 2016, transcript of evidence, pp. 4-5.

81 Ms Sarah Wilson, Convenor, ABA Parent Support Network, Family and Community Development Committee public hearing – Melbourne, 10 October 2016, transcript of evidence, p. 4.

82 Ms Shannon Leahy, submission no. 82, p. 1.

83 Ms Rosemary Doherty, submission no. 12; Ms Dianna Lane, submission no. 11; Ms Janeane Baker, submission no. 14; Ms Joan Esser, submission no. 49; Ms Susan Pearce, submission no. 50; Name withheld, submission no. 18, p. 4.

84 Ms Joan Esser, submission no. 49; Ms Deirdre Wirth, Family and Community Development Committee public hearing – Geelong, 19 September 2016, transcript of evidence, p. 2.

85 Autism Family Support Association submission no. 71; Ms Dianna Lane submission no. 11.



workers. Ms Jules Haddock, the mother of a teenager son with autism, told the Committee that the respite they were using was not appropriate in terms of what their expectations were:

The staff that came around — their age and gender — it just did not work for him. He said, ‘Why have I got someone that smokes and sits around and watches television?’. In defence of the council, I think that is more of a systemic sort of issue, because it is hard to get a young person into HACC programs when they might only get an hour here and an hour there, but for us as a family we were hoping to get someone that was sort of more aligned with his age group, so to speak. He felt he was going out with grandma all the time, but in the end he could not do that because there was no mileage to cover any sort of out-of-home time — and we just put a halt to it because it was distressing him too much to have what he felt, and we could see what he meant, that age inappropriateness.<sup>86</sup>

The Committee also heard that respite staff were not always adequately trained in caring for a child or adult with ASD. Ms Nga Do, the Family and Volunteer Match and Program Coordinator at Extended Families Australia told the Committee about a Vietnamese family she was helping:

With that boy the council sent a worker to help, to give the mother respite. But one day he stayed and met me, and he said, ‘Can you help me with how to deal with him, because I have no idea?’. I asked him, ‘What about your training?’. He said, ‘I was trained to work in aged care’. That is why he had no idea, no understanding about this boy’s behaviour. In this case I believe that people who are interested in working in this field must be trained in how to help them and understand them.<sup>87</sup>

The Committee heard from many families about the significant lack of respite services during holiday periods and before and after school care. Ms Carmel Murphy, the mother of a teenager with ASD and Down Syndrome, emphasised the need for respite over school holiday periods when it is particularly difficult for children with ASD to be out of their routine to the Committee at a public hearing in Morwell:

Parents need a break from autism. It is draining, time consuming and highly demanding. We need to attract more staff with better pay. My respite team makes \$20 an hour. I have applied for 30 hours extra over the school holidays and I have been told I will be very lucky this year to get that due to lack of funding and staff. There will be no respite on weekends. My husband has never taken a carer's day from work in 14 years but these holidays I will need him to take a few days. I never look forward to the holidays and six weeks is a long time for any child to be out of their routine, let alone an autistic child.<sup>88</sup>

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86 Ms Jules Haddock, Family and Community Development Committee public hearing – Geelong, 19 September 2016, transcript of evidence, p. 3.

87 Ms Nga Do, Family and Volunteer Match and Program Coordinator, Extended Families Australia, Family and Community Development Committee public hearing – Melbourne, 21 November 2016, transcript of evidence, p. 4.

88 Ms Carmel Murphy, Family and Community Development Committee public hearing – Morwell, 5 December 2016, transcript of evidence, pp. 2-3.

Parents also found that the waiting lists for respite were too long. In her submission, Ms Deborah Ditchburn described her experience of getting her son diagnosed, moving from one waiting list to the next when it came to the diagnosis, early intervention and even respite:

My local Council service has a waitlist of up to 3 years. The area in which I live is one of the fastest, if not the fastest growth corridor in Victoria, with 120 families moving into the area each week. Couple this with the increased rate of diagnosis and it sees families missing out on this important service, and the pressure this places on a family unit is clear to see in statistics such as this one I came across a few years ago: the breakdown rate of autism-specific families is 80%. Without vital services like respite, that figure can only increase.<sup>89</sup>

The Committee also heard that there was a need for more residential schools. In her submission to the Inquiry, Ms Elisabeth Appelgren-McIntyre, the mother of two adult sons with severe ASD and other co-occurring conditions, described a residential school that her sons attended:

This particular residential school saved our family; it would have been impossible for our marriage to survive without the breaks the school gave my husband and I. There should be more residential autistic schools, but there particularly needs to be more non-residential schools for severely autistic children.<sup>90</sup>

The Committee consistently heard of the vital importance of respite services to families' wellbeing. Many parents and stakeholders called for increased respite services to support parents. Mr Christopher Reid told the Committee at a hearing in Melbourne that the limited availability of respite was particularly hard for children who were not with the same carer long enough to be comfortable without their parents:

Like other parents, I believe that the amount of respite care that our local council provides, which in my case is the City of Monash, is only 4 hours a month, and this is hopelessly inadequate. Children with autism often have severe separation anxiety and would not see carers long enough to be comfortable to be at home without their parents, particularly when the respite carer is not always the same person. Practically speaking also, 1 hour per week is not enough time for parents to be able to do much once you include travel time et cetera. In combination, these considerations effectively defeat the purpose of respite care.<sup>91</sup>

Respite remained important throughout the lifecycle. Ms Judith Horne, a speech pathologist with over 30 years' experience with children and adults with ASD in rural Victoria, submitted to the Inquiry that respite was particularly important for families of young adults with significant behaviours of concern:

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89 Ms Deborah Ditchburn, submission no. 21, p. 2.

90 Ms Elisabeth Appelgren-McIntyre, submission no. 95, p. 2.

91 Mr Christopher Reid, Family and Community Development Committee public hearing - Melbourne, 12 September 2016, transcript of evidence, p. 2.



Respite services for families are sparse and inadequate... Many families get to breaking point... Many families look at the option of relinquishing their young person so they can get emergency accommodation for them.<sup>92</sup>

As discussed in Chapter Two, local councils have been progressively withdrawing from providing respite services with the NDIS roll out.

The Victorian Government has a particular role in ensuring adequate supports are being provided to families living with ASD, and in particular, in ensuring that ongoing, viable and affordable respite care be available across the state.

Thus, the Committee recommends that:

### **RECOMMENDATION 1.2**

**The Victorian Government through the updated State Autism Plan ensure that families living with ASD are provided proper supports, including ongoing, viable and affordable respite care available across the state.**

### **1.3.3. Siblings**

Many parents expressed concern that the siblings of children with ASD were neglected because the attention of the parents was drawn to the child that had high needs. Some parents expressed concerns that their child or adult with ASD was aggressive to their siblings.<sup>93</sup> Some parents told the Committee that their other children had to grow up very quickly and even perform a caring role.

At a public hearing in Melbourne, the Committee heard from Mr Liam Parker, a 15 year old who spoke about his experience of having a brother with ASD:

It is definitely a different environment, growing up with a brother who has autism. You know, in social situations like in a supermarket my brother always used to have a lot of temper tantrums, quite often knocking shelves over with food and stuff like that. I am not really the expert on these things, on my brother's sort of support. I am just there to look after him as his brother, but as far as I have noticed, his school and the ABA is really the only thing that has held him up, and of course us as his family as well. Look, I just grew up to deal with it myself. I accepted it and I love him. Autism or not, it does not make a difference to me.<sup>94</sup>

Several parents drew attention to the lack of support for siblings. Ms Susan Pearce told the Committee at a public hearing in Melbourne:

92 Ms Judith Horne, submission no. 120, p. 3.

93 See, for example: Mr Ray Roney, submission no. 7.

94 Mr Liam Parker, Family and Community Development Committee public hearing – Melbourne, 12 September 2016, transcript of evidence, p. 6.

[T]here are no services for siblings of children with ASD. These siblings are left to their own devices or are required to help with the child with ASD. It is a balancing act for parents to make sure that both children feel special.<sup>95</sup>

Mr Shilo Wilson, the Manager of Respite and Support of Interchange Gippsland, told the Committee at a public hearing at Morwell:

We've had a lot of feedback from families that often the siblings without a disability miss out on a lot of opportunities because the parents' time is often consumed by the child with a disability or the child with a disability might have a variety of programs and supports in place for them but often the siblings miss out on that opportunity. So we feel that is a very important thing to offer to our families.<sup>96</sup>

The Committee is aware of some support services across Victoria available for siblings of people with ASD, but they are extremely limited.

### **1.3.4. Financial cost**

The Committee heard that there were numerous direct and indirect costs of supporting a child with autism. In their submission, Amaze cited a 2014 Western Australian study as estimating that the median family cost of autism is around \$34,900 per annum, with 90 per cent of that figure due to loss of income from employment.<sup>97</sup>

Children diagnosed prior to the age of six will be eligible for federal funding that ends when the child turns seven under the Helping Children with Autism (HCWA) package, discussed in detail in Chapter Three. This timeframe and long public waiting lists provide an incentive for many parents to choose private providers to conduct the diagnosis and speed up the diagnostic process so they are eligible and don't miss the timeframe for HCWA funding. However, many families end up getting a diagnosis through private providers at considerable expense.<sup>98</sup> Some families said that the cost of getting a diagnosis privately in Melbourne exceeded \$1,000.<sup>99</sup> Many people with autism diagnosed later miss out on funding altogether and rely on Medicare rebates under chronic disease management plans for allied health services or mental health plans.

Once diagnosed, the cost of treatment and therapies often exceed any funding that may be available to families. The Committee heard that some early intervention

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95 Ms Susan Pearce, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 2.

96 Mr Shilo Wilson, Manager, Respite and Support, Interchange Gippsland, Family and Community Development Committee public hearing – Morwell, 5 December, 2016, transcript of evidence, p. 2.

97 Amaze, submission no. 139, p. 63.

98 Ms Deirdre Wirth, Family and Community Development Committee public hearing – Geelong, 19 September 2016, transcript of evidence, p. 2; Speech Pathology Australia, submission no. 136.

99 Ms Nicole Stephenson, Family and Community Development Committee public hearing – Geelong, 19 September 2016, transcript of evidence, p. 2; Ms Deborah Morawetz, submission no. 27, p. 2. See also: Autism Spectrum Australia (Aspect), submission no. 100.

therapies, such as Applied Behaviour Analysis, can cost anything up to \$70,000 per year.<sup>100</sup> Dr Amanda Sampson, from the Autism Behavioural Intervention Association, spoke to the Committee at a public hearing in Melbourne about the lifetime costs of autism:

In the USA it is \$2.4 million for a lifetime cost for autism; in the UK, \$2.2 million – this is all in American dollars. If you were ASD with no intellectual disability, then the cost was much less at \$0.92 million. The largest cost components for children were the special education services and the parental productivity loss, and that is huge within the community. That applies to Australia as well, I have no doubt. During adulthood medical costs became much higher, and obviously living accommodation and individual productivity loss contributed greatly to higher costs.<sup>101</sup>

Many families struggled with the cost of particular therapies, such as ABA. Parents spoke about having to fundraise, sell their house, take up a second job, move in with parents, and claim their superannuation to fund in particular ABA therapy.<sup>102</sup> Other costs included the cost of travelling for therapies.<sup>103</sup> Parents also spoke about the cost of schooling as some parents opted to send their children to independent schools, Catholic schools and other private education providers due to lower teacher-student ratios and more support for their children.<sup>104</sup>

The Committee heard that parents of children with IQs above 70 but who had high needs often felt particularly disadvantaged because their children were not eligible to attend special schools. While their children may not have the same intellectual learning problems, many felt their children had the same therapy needs.<sup>105</sup>

The financial pressures of supporting a child or adult with ASD mean that many parents have to make difficult decisions about their own lives, place of residence, employment and career trajectory. Mr Christopher Reid, the parent of a daughter with ASD, moved countries and changed occupations to provide financially for his family. He told the Committee at a hearing in Melbourne about the tension between providing practical support by being available to help his child and the need to work to financially support his family:

Parents of children with special needs often have this dilemma. They can be practically supportive or financially supportive, but it is hard to be both sufficiently at the same time.<sup>106</sup>

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100 Dr Anna Middleton, submission no. 96, p. 2 (\$65,000-\$70,000/year); Mr Ben Snow, submission 103, p.1 (\$70,000/year).

101 Dr Amanda Sampson, Autism Behavioural Intervention Association, Family and Community Development Committee public hearing – Melbourne, 12 September 2016, transcript of evidence, p. 5.

102 Mrs Shelly Fleming, submission no. 41; ABA Parent Support Network, submission no. 51.

103 Mr Steve Ager, submission no. 57; Ms Shannon Leahy, submission no. 82; Mr Ben Snow, submission no. 103.

104 Ms De'arne Treacy, submission no. 76; Ms Shannon Leahy, submission no. 82;

105 See for example, Mr Angus Mackellar, submission no. 125.

106 Mr Christopher Reid, Family and Community Development Committee public hearing – Melbourne, 12 September 2016, transcript of evidence, p. 4.

The financial impact of having a child with autism can be lifelong. Many parents spoke about financially providing for their adult children who continued to have complex needs, experienced unemployment and were not able to live independently.<sup>107</sup> Parents also spoke about having to manage their children's finances and post-school transitions. In her submission, Ms Rosemary Doherty spoke about having to act 'like a personal assistant' to support her son in returning to tertiary study.<sup>108</sup> Ms Susan Rees told the Committee at a public hearing in Melbourne that she needed to prove that, despite her daughter's age, her daughter needed supervision in managing her disability pension:

I got a letter when my daughter turned 18 from the department of human services... Eighteen is the magical age when everybody is supposed to be an adult, but that is not the case. She was expected to manage her own disability pension, and they were questioning me as her parent as to whether I should be managing her money, so to speak. That was the nature of the letter. So I had to prove that she needed supervision with that money. That money she would go and spend on a truckload of lollies.<sup>109</sup>

The Committee is very concerned about families living with ASD and the often extreme pressures they face. The Committee heard that ASD presents a lifelong challenge for families and that many families benefit from a respite service. The Committee heard that there is a lack of respite services for families, that there were often long waiting lists and that there was a lack of appropriate training provided for respite workers.

The Committee is adamant that families living with ASD need better support from all levels of government and service providers. Across the chapters of this report the Committee will be making recommendations in a number of areas to improve supports for families living with ASD. However, the Committee believes that in the development of policies and programs for people with ASD, families living with ASD need to be, as far as is practicable, engaged and consulted.

Accordingly, the Committee recommends as a general principle that:

### **RECOMMENDATION 1.3**

**The Victorian Government through the updated State Autism Plan ensure that in the development of government-funded programs, services and policies that impact on families living with ASD, both by governments and by service providers, families living with ASD must be engaged and consulted.**

During the Inquiry, the Committee heard some evidence in relation to restrictive practices and restraints, in relation to people with ASD. Most of this evidence related

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107 Ms Rosemary Doherty, submission no. 12; Interchange Gippsland, submission no. 23; Ms Susan Rees, Family and Community Development Committee public hearing – Melbourne, 10 October 2016, transcript of evidence, p. 7.

108 Ms Rosemary Doherty, submission no. 12.

109 Ms Susan Rees, Family and Community Development Committee public hearing – Melbourne, 10 October 2016, transcript of evidence, p. 7.

to restrictive practices carried out in Victorian schools and the Victorian health system, subjects that are discussed in Chapters Four and Eight respectively.<sup>110</sup>

## 1.4. Prevalence

The Committee was tasked under Term of Reference (a) to look at the prevalence of ASD in Victoria. Looking at the available evidence, it is clear to the Committee that there is insufficient data on the prevalence of autism.

The Australian Bureau of Statistics' (ABS) 2015 Survey of Disability, Ageing and Carers (SDAC) showed that an estimated 164,000 Australians (approximately 0.68 per cent) had autism, which was a 42.1 per cent increase from the 115,400 people estimated to have autism in the previous survey in 2012.<sup>111</sup> The ABS survey also measured the prevalence of autism by state or territory of usual residence and showed that Victoria had a prevalence rate of 0.8 per cent.<sup>112</sup> In 2015, males were 4.1 times more likely than females to have ASD, with prevalence rates in the survey of 1.1 per cent and 0.3 per cent respectively.<sup>113</sup> In the previous ABS SDAC Survey in 2012 the estimated 115,400 Australians with autism represented 0.5 per cent of the population, which was a 79 per cent increase from the 64,400 people estimated to have autism in the previous survey in 2009.<sup>114</sup> The prevalence of ASD in Australia is thus rising, and this will have a consequent impact on the demand for services.

The prevalence rate estimated by the ABS is lower than the estimated rate of ASD in other studies. Professor Dissanayake told the Committee that OTARC's early diagnostic centre saw a referral rate from Maternal and Child Health nurses of 1-2 per cent of children indicating that 'between 1 to 2 per cent of the population will meet criteria for an autism spectrum condition'.<sup>115</sup> Results reported in 2016 from the ongoing Longitudinal Study of Australian Children of children recruited at kindergarten and birth for two-yearly 'waves' of assessment found that the prevalence of autism in these groups was between 1.5-2.5 per cent.<sup>116</sup> In other jurisdictions, such as the United States, the prevalence of ASD in school-aged children is estimated at 1 in 68 (14.6 per 1,000).<sup>117</sup> In South Korea, the prevalence

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110 One submission did relate to restrictive practices in disability services, see Ms Karen Burgess, submission no. 58.

111 See Australian Bureau of Statistics, *Autism in Australia*, 2012, cat. no. 4428.0, Canberra, ABS, 2014; and Australian Bureau of Statistics, *Autism in Australia*, 2015, cat. no. 4430.0, Canberra, ABS, 2017.

112 Australian Bureau of Statistics, *Autism in Australia*, 2015, cat. no. 4430.0, Canberra, ABS, 2017.

113 Ibid.

114 See Australian Bureau of Statistics, *Autism in Australia*, 2012, cat. no. 4428.0, Canberra, ABS, 2014.

115 Professor Cheryl Dissanayake, Founder and Director, Olga Tennison Autism Research Centre, La Trobe University, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 3.

116 M Randall, E Sciberras, A Brignell, E Ihsen, D Efron, C Dissanayake and K Williams, 'Autism spectrum disorder: Presentation and prevalence in a nationally representative Australian sample', *Australian and New Zealand Journal of Psychiatry*, Vol. 50, no. 3, 2016.

117 U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC), Prevalence and characteristics of autism spectrum disorder among children aged 8 years – Autism and developmental disabilities monitoring network, 11 sites, United States, 2012, *Morbidity and Mortality Weekly Report Surveillance Summaries*, vol. 65, no. 3, April 2016.

of ASD in a total population sample was estimated to be 2.64 per cent or 1 in 38 children.<sup>118</sup> The method of diagnosing ASD in these studies may differ which may affect the prevalence rates.

In 2007, MacDermott and colleagues published a report for the Australian Advisory Board on Autism Spectrum Disorder on the prevalence of ASD.<sup>119</sup> The report identified a lack of consistent data and noted that there were significant differences in the way children were diagnosed, directed to services and offered support. This is consistent with the evidence the Committee has received. The report strongly recommended that Australia gather reliable information about the prevalence of ASD for national, state and territory use:

Until a National approach to collection of prevalence data about autism is implemented, it is not possible to ensure that services are being provided to those who need them in a timely fashion and, as such, it is unlikely the potential of each individual with autism is being optimised. Opportunities to undertake useful research that has the potential to improve the lives of those affected and their families, are also being missed.<sup>120</sup>

The report noted that gathering this information required the development of additional data systems, which would need to gather information from both the private and public sector. The report suggested some possible pathways, including accessing Centrelink data, extending the Disability Services National Minimum Data Set<sup>121</sup> activity to other providers for ASD and into the private sector, and developing a virtual register of individuals with ASD, similar to the ASD online database funded by Autism Speaks in the United States.<sup>122</sup>

Several submissions received by the Committee pointed to the lack of consistent data and recommended that the government provide research funds to support the collection of empirical data on ASD prevalence.<sup>123</sup> In their submission, disability service provider Scope stated that there was a need to invest in prevalence data and research, noting that prevalence data is important in determining trends in ASD, assisting with planning services, in addition to informing policy and research.<sup>124</sup> Similarly, Speech Pathology Australia recommended to the Committee that the Victorian Government systematically gather, report and analyse prevalence data on the number of Victorians diagnosed with autism, including data on subgroups within

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118 Y S Kim, B Leventhal, Y Koh, E Fombonne, E Laska, E Lim, K Cheon, S Kim, Y Kim, H Lee, D Song, R Grinker, 'Prevalence of autism spectrum disorders in a total population sample', *American Journal of Psychiatry*, May 2011.

119 S MacDermott, K Williams, G Ridley, E Glasson and J Wray, *The prevalence of autism in Australia: Can it be established from existing data? A report prepared for Australian Advisory Board on Autism Spectrum Disorders*, 2007.

120 *Ibid*, p. 9.

121 Referred to in the report by its former name: the Commonwealth State/Territory Disability Agreement National Minimum Data Set.

122 S MacDermott, K Williams, G Ridley, E Glasson and J Wray, *The prevalence of autism in Australia: Can it be established from existing data? A report prepared for Australian Advisory Board on Autism Spectrum Disorders*, 2007, p. 62.

123 Distinctive Options, The Lab Network and Smart Communities, submission no. 77, p. 13; Speech Pathology Australia, submission no. 136, p. 17.

124 Scope, submission no. 36, p. 7.

this population, which can then be used for service planning and resource allocation decisions.<sup>125</sup>

The Royal Children's Hospital also called for more data on the prevalence of autism in their submission to the Inquiry:

To know the prevalence of autism in Victoria, in a way that will allow services to be provided to those who need them, we need more data. Underpinning the need for data is a need for excellence in services that identify, diagnose and manage individuals with autism and strong connections between them, particularly when connections across sectors, such as health, disability and education, are required.<sup>126</sup>

In a submission to the Inquiry, one parent told the Committee about their frustration with the lack of prevalence data on ASD:

I have asked this question at many Victorian Autism meetings and Forums. I have been given various statistics between - 1:110 or 1:100 or 1:68 - and not one person can back-up their stats. When I request them to provide me with the latest study, no one is forth coming.

Australians recognise that the prevalence of Autism is rising dramatically every year. The last study commissioned by the Government was awarded to Dr John Wray MB BS, FRACP, in 2004 to determine the Prevalence of Autism in Australia.

The figure of 1:160 was released in 2007 with birth cohorts between 1991/1992 to 1997/1998. My son was born in 2002 and has still not been counted. Autism organisations quoting 1:100 is only a guess/estimate; our children are worth more than a guess/estimate.<sup>127</sup>

The Committee heard that accurate prevalence data was particularly important for local councils working to improve support for people with ASD and their families in local communities.<sup>128</sup> Melton City Council stated in their submission:

Melton City Council has no accurate data on the prevalence of ASD within the municipality, but we do know that demand for services and information is rapidly increasing as indicated by the fact community based ASD information sessions and forums fill to capacity.<sup>129</sup>

Similarly, Hobsons Bay City Council in their submission suggested that the ABS figure is an underestimate and does not accord with the increasing demand for services in their region:

Based on the ABS data released in 2012, autism spectrum disorder affects around 0.7 per cent of Victorians, this equates to around 630 residents within Hobsons Bay. It is suggested that this is an underestimate of the actual number of residents. Locally, the number of people with autism is largely unknown,

125 Speech Pathology Australia, submission no. 136, p. 17.

126 Royal Children's Hospital, submission no. 143, p. 9.

127 Name withheld, submission no. 101, p. 2.

128 Hobsons Bay City Council, submission no. 80, p. 5; Melton City Council, submission no. 28, p. 4.

129 Melton City Council, submission no. 28, p. 4.



however the Western Autistic School based in Laverton has recently had to open up additional classes to deal with the demand, indicating an increase in people with autism spectrum disorder as well as an increasing demand for services.<sup>130</sup>

The Committee heard that out of all the states and territories, Western Australia had the most advanced system for registering the prevalence and incidence of ASD.<sup>131</sup> The Western Australian Register for Autism Spectrum Disorders, located at the Telethon Kids Institute, has collected information on newly diagnosed cases of ASD in Western Australia since 1999. The Register collects demographic and diagnostic information, including age, gender, primary language at home, the diagnostic criteria and methods used for the assessment, IQ and cognitive assessments, co-occurring conditions, language assessments, and adaptive behaviour.<sup>132</sup> This information is recorded in a data collection form for each new ASD case, which is completed by a clinician at the time of diagnosis and sent to the Register. The Register is bound by a confidentiality protocol and the method in which data is collected eliminates double entries of notifications to the Register.

On its study tour of the United States, the Committee was advised that the Centers for Disease Control (CDC) had estimated that 1 in 68 children in the U.S. have ASD, according to estimates from CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network.<sup>133</sup> The prevalence rate in the United States has risen dramatically, from 1 in 150 in 2000, to 1 in 68 in 2012. ASD is reported to occur in all racial, ethnic, and socioeconomic groups and is about 4.5 times more common among boys (1 in 42) than among girls (1 in 189). About 1 in 6 children in the United States had a developmental disability in 2006-2008, ranging from mild disabilities such as speech and language impairments to serious developmental disabilities, such as intellectual disabilities, cerebral palsy, and autism.<sup>134</sup>

On its study tour in Norway, the Committee was advised there was a prevalence rate of 1 in 125 for autism (on 2011 data) in the country, with a significant rise from 1 in 2,000 since the 1980s.<sup>135</sup> There can be a wide variation in prevalence rates across the country by county district, with some districts reporting a rate of 1 in 68, while others are low as 1 in 370. It is not clear what is driving this substantial variation. In general, ASD diagnoses are growing fast, and capacity building is regarded as essential.

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130 Hobsons Bay City Council, submission no. 80, p. 2.

131 Scope, submission no. 36, p. 7. Associate Professor Jill Sewell, Deputy Director, Centre for Community Child Health, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 6.

132 Western Australian Register for Autism Spectrum Disorders, 'Types of information collected', WA Register for ASD, accessed 24 March 2017, <[www.autismwa.org.au/moreinfo.html](http://www.autismwa.org.au/moreinfo.html)>.

133 Centers for Disease Control and Prevention, 'Autism Spectrum Disorder – Data and Statistics', US Department of Health and Human Services, accessed 24 April 2017, <[www.cdc.gov/ncbddd/autism/data.html](http://www.cdc.gov/ncbddd/autism/data.html)>.

134 Ibid.

135 See K Ozerk, 'The Issue of Prevalence of Autism/ASD', *International Electronic Journal of Elementary Education*, December 2016, pp. 263-306.



### 1.4.1. Increasing rates of ASD

In their submission, Amaze estimated that there are around 55,000 Victorians living with ASD.<sup>136</sup> It is clear that rates of ASD are increasing, both in Australia and internationally. According to Amaze:

Globally there have been a number of prevalence studies over a number of decades that have all shown an increase in the incidence of autism. The first was in the 1960's and produced a prevalence estimate of one in every 2,500 people (or 0.04% of the population) had autism. In the last decade, studies have continued to show a rise in prevalence ranging from 1 in 160 (or 0.62% of the population) through to a recent South Korean study that found a very high rate of 1 in 38 people (or 2.6% of the population).

The Centre for Disease Control in the United States has published all recent population based prevalence studies and states that "studies in Asia, Europe, Australia and North America have identified individuals with ASD with an average prevalence of between 1% and 2%".<sup>137</sup>

Researchers and peak bodies are of the view that this increase is related to a greater awareness of the condition within the community and changes to the diagnostic criteria for ASD. Many believe that there has not been an increase in ASD *per se* – instead, the medical establishment has expanded the concept of the autism spectrum to include people who would otherwise have not been considered autistic. This is consistent with a recent study by Professor Andrew Whitehouse and colleagues from the Autism CRC who found the increasing prevalence of ASD may be partly attributed to a shift toward diagnosing individuals with less severe behavioural symptoms.<sup>138</sup>

At a public hearing in Melbourne, Emeritus Professor Bruce Tonge from Monash University's Centre for Developmental Psychiatry and Psychology spoke to the Committee about the impact of the change in diagnostic criteria and growing awareness of ASD:

There is also genuinely an increase in prevalence, because the diagnostic criteria have relaxed over the past few years; therefore we are picking up more children. We are also picking up more children because of things like what we are doing, where people are picking up early signs and are making a diagnosis now in children who in the past would have not been diagnosed...<sup>139</sup>

At the same time, research into the biological and environmental causes of ASD has expanded rapidly, and there is a growing position that ASD is strongly related to genetic factors. A Victorian study which showed a ten fold increase over a 16-year period in the prevalence of autism also showed an increase in occurrence in siblings

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136 Amaze, submission no. 139, p. 12; Occupational Therapy Australia, submission no. 114, p. 3.

137 Amaze, submission no. 139, p. 16.

138 A Whitehouse, M Cooper, K Bebbington, G Alvares, A Lin, J Wray and E Glasson, 'Evidence of a reduction over time in the behavioural severity of autism disorder diagnoses', *Autism Research*, vol. 10, no. 1, 2017.

139 Emeritus Professor Bruce Tonge, Monash University Centre for Developmental Psychiatry and Psychology, Family and Community Development Committee public hearing – Melbourne, 6 March 2017, transcript of evidence, p. 12.

and relatives.<sup>140</sup> The Autism CRC and the Olga Tennison Autism Research Centre have been conducting genetic and biological research, discussed below and in Chapter Three.

Mr Braedan Hogan, the Policy and Advocacy Manager of Amaze, spoke to the Committee at a public hearing in Melbourne about the lack of prevalence data and the causes for the increase in prevalence:

The Olga Tennison Autism Research Centre... recently reported that 1 per cent of children in Victoria are on the autism spectrum, yet Australia-wide we have no accurate or up-to-date population-based prevalence data. We currently have some, which are based on ages, but no population-based prevalence data.

We also know that rates of diagnosis of autism have increased dramatically across the world over the recent decades. But rather than an autism epidemic, which we sometimes see reported in the media, this can be attributed to a number of factors, including the expansion of the diagnostic criteria of autism and the development of more sensitive autism diagnostic tools; an increase in awareness and understanding of autism within the community; a factor known as diagnostic substitution, where previously diagnoses of schizophrenia or mental health issues may have actually been primary diagnoses of autism; the availability of government assistance specific to children on the autism spectrum; as well as some level of a combination of environmental and genetic factors that scientists are working to pinpoint and quantify.<sup>141</sup>

The Committee heard that there was a lack of consistent data on the prevalence of autism, the age and incidence of autism diagnosis across Australia, and the prevalence of co-occurring conditions. While prevalence rates have fluctuated due to changes in the diagnostic criteria, accurate and ongoing data is important in the development of resources and service delivery.

The Committee views the ongoing collection of prevalence data on autism at the state and national level to be critical. Accordingly, the Committee recommends that:

#### **RECOMMENDATION 1.4**

**The Victorian Government use its role on the Council of Australian Governments (COAG) Disability Reform Council to ensure the Australian Bureau of Statistics (in collaboration with the National Disability Insurance Agency) adopts a consistent and comprehensive approach to the national collection of data on people with ASD, including the prevalence of ASD and the prevalence of co-occurring conditions, and that this data be disaggregated to state and territory levels.**

The Committee is also of the view that Victoria should move ahead to its own collection of data on the prevalence of ASD in this state. The Committee believes that the Victorian Government should take note of the model provided by the Western

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140 F Icasiano, P Hewson, P Machet, C Cooper and A Marshall, 'Childhood autism spectrum disorder in the Barwon region: A community based study', *Journal of Paediatric Child Health*, vol. 40, no. 12, 2004.

141 Mr Braedan Hogan, Policy and Advocacy Manager, Amaze, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 3.

Australian Register for Autism Spectrum Disorders, described above. It is important that any such register be bound by confidentiality protocols. Thus, the Committee recommends that:

### **RECOMMENDATION 1.5**

**The Victorian Government develop and fund a process for the consistent and comprehensive collection of data on all people diagnosed with ASD, to enable the analysis of the prevalence of ASD and the prevalence of co-occurring conditions in the Victorian community.**

## **1.5. Co-occurring (or co-morbid) conditions**

People with ASD are likely to have another co-occurring cognitive impairment, health condition or mental illness. ASD typically co-occurs with:

- intellectual disability;
- depression;
- anxiety;
- attention deficit hyperactivity disorder (ADHD);
- obsessive compulsive disorder (OCD);
- epilepsy; and
- chromosomal disorders (eg: fragile X or Down Syndrome).

Other conditions may include tuberose sclerosis, Tourette's Syndrome, immune disorders, post-traumatic stress disorder, macrocephaly, sleeping difficulties, and hearing or visual impairments.<sup>142</sup>

Having ASD and a co-occurring condition adds to the diversity and complexity of ASD. In policy terms, this means that services designed to support people with ASD must be attentive to the way that their co-occurring conditions impact their experiences. In her submission, Ms Carmel Murphy described her daughter with ASD and Down Syndrome in the following way:

We have a very complex girl, Meg does not fit into the Autism basket nor the Down Syndrome one, she is an individual person who we love & care for to the best of our ability.<sup>143</sup>

There is significant co-occurrence of ASD and intellectual disability, and ASD and mental illness, which impacts how education and health services should be

142 Speech Pathology Australia, submission no. 136; Amaze, submission no. 139, p. 15; Royal Australian & New Zealand College of Psychiatrists, submission no. 144; Victorian Disability Advisory Council, submission no. 146.

143 Ms Carmel Murphy, submission no. 20, p. 2.

delivered.<sup>144</sup> The Committee heard that co-occurring conditions such as anxiety, depression and eating disorders 'need to be treated in the context of autism'.<sup>145</sup>

The Committee heard that intellectual disability co-exists with ASD in 30-70 per cent of cases.<sup>146</sup> It has been estimated that up to 84 per cent of people with ASD have anxiety symptoms.<sup>147</sup>

The Committee heard that many children, especially girls, were diagnosed with a range of other conditions prior to being diagnosed with ASD. Ms Avigale Bischard told the Committee in her submission about the difficulty obtaining a diagnosis for her daughter:

My 17 year old daughter has only recently been given her diagnosis of Autism Spectrum Disorder by a Neuro-developmental Pediatrician. Seven years ago a young male teacher at her primary school diagnosed her but his opinion didn't carry any weight. He was in fact the real expert, his sister was Autistic. It took us the next six years of going from Psychologists, Doctors, Counsellors and Psychiatrists to finally get the correct cause of our daughter's problems. She was given labels for most of the co-morbid conditions of Autism, including school refusal, eating disorders, Social anxiety, Attachment Disorder, stress etc. Her health and meltdowns reached such a crisis point that we had to take her out of school and get her into Distance Education.<sup>148</sup>

Psychologists and psychiatrists told the Committee in public hearings in Melbourne that overshadowing and overlapping of ASD symptoms with other conditions made it difficult for diagnosis and treatment of ASD. Dr Sandra Radovini, the Director of Mindful, told the Committee at a public hearing in Melbourne:

Where we come in is also that we know that along the life span there is likely to be comorbid mental health issues for many people with ASD... What is tricky about that is sometimes being able to identify a mental health problem for somebody who has ASD. We talk about symptom overshadowing, so sometimes

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144 Amaze, submission no. 139; Australian Institute of Health and Welfare, submission no. 47; Royal Children's Hospital, submission no. 150 (supplementary submission); Royal Australian and New Zealand College of Psychiatrists (RANZCP) Victorian Branch Committee, submission no. 144; Emeritus Professor Bruce Tonge, Monash University Centre for Developmental Psychiatry and Psychology, Family and Community Development Committee public hearing – Melbourne, 6 March 2017, transcript of evidence, p. 3.

145 Ms Stacey Smith, Family and Community Development Committee public hearing – Geelong, 19 September 2016, transcript of evidence, p. 3.

146 E Dykens and M Lense, 'Intellectual disabilities and autism spectrum disorder: A cautionary note' in D Amaral, G Dawson and D Geschwind (eds) *Autism Spectrum Disorders*, New York, Oxford University Press, 2011; Raising Children Network, 'Conditions that can occur with autism spectrum disorder', accessed 6 June 2017, <raisingchildren.net.au/articles/autism\_spectrum\_disorder\_comorbidity.html#intellectual>. See also: Mr Stan Pappos, Senior Manager, High Risk Support Services, Australian Community Support Organisation, Family and Community Development Committee public hearing – Melbourne, 21 November 2016, transcript of evidence, p. 2; Ms Lisa Vale, Paediatric Occupational Therapist and Clinical Services Manager, Splash Occupational Therapy, Family and Community Development Committee public hearing – Melbourne, 6 March 2017, transcript of evidence, p. 8.

147 Raising Children Network, 'Conditions that can occur with autism spectrum disorder', Raising Children Network, accessed 15 March 2017, <raisingchildren.net.au/articles/autism\_spectrum\_disorder\_comorbidity.html#comorbidity>.

148 Ms Avigale Bischard, submission no. 15, p. 1.

people attribute everything to the ASD when in fact there is something else that is emerging and that requires a lot of training of the workforce and it requires supporting families and parents to understand. But I have to say parents usually know that something is different and something is wrong, and it is sometimes convincing the professionals that, 'No, this is not just autism'. That can be the challenge.<sup>149</sup>

Professor Nicole Rinehart, the Director of Deakin University Child Study Centre, also spoke about symptom overshadowing at a public hearing in Melbourne:

I think what can happen in the autism research field and in clinical practice is that when we see the word 'autism' it is such a big word that we think every struggle a child is having is to do with autism. I think that is a mistake because sometimes it is not autism. Sometimes it is an experience that the child has had, it is a comorbidity, it is something else. So I think we need to be very careful about that, just so that we do not miss that vital ingredient that might meet the needs of the child.<sup>150</sup>

Ms Frances Saunders, the Statewide Autism Spectrum Disorder Coordinator at Austin Child and Adolescent Mental Health Service, explained to the Committee at a public hearing in Melbourne about how a child ("Josh") with undiagnosed ASD might present to CAMHS with mental health issues:

We have lots of children with undiagnosed ASD that end up in high school, and often their first presentation is to CAMHS in crisis for suicidality or for self-harm. So this is where Leonie presents at A and E with her son, Josh, who is 13 years. Josh is lashing out at home and threatening to hurt himself and others. He commenced high school six months ago and has started refusing to go to school. Again, this is very common with our adolescents with ASD. Usually at around year 8 or 9 they start absolutely refusing. But Josh is having problems with the transition. He does not know he is on the spectrum. The school does not know he is on the spectrum, and clearly his mental health is deteriorating very quickly. His family is highly distressed, and this is a big problem for our accident and emergency departments, because often it is after the evening hour of tea and homework that suddenly there are these enormous meltdowns and the family has no idea what to do. As a last resort and as the behaviour gets extreme, they turn up at A and E.

This time Josh put his arm through a glass window, which kind of makes it easier to get through triage for him, I guess, but he is in distress. Leonie recalls seeing a paediatrician when Josh was five years old. She recalls the doctor, who talked about ASD and then referred Josh to a private speech pathologist and psychologist for further assessment. She did not follow this through. She could

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149 Dr Sandra Radovini, Director of Mindful, Centre for Training and Research in Developmental Health, Department of Psychiatry, University of Melbourne, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 3.

150 Professor Nicole Rinehart, Deakin University Child Study Centre, Family and Community Development Committee public hearing – Melbourne, 6 March 2017, transcript of evidence, p. 8.

not afford it at the time. He just seemed a bit odd, a bit quirky. He had some struggles with school, but he was okay.<sup>151</sup>

Ms Saunders went on to describe how the transition from primary school to secondary school can exacerbate mental health issues for children with ASD:

So this is quite typical — that lots of our high-functioning children will manage in a primary school that is supportive, but once they get to high school the transition, the multiple teachers, the demands and the different classrooms can really push them over the edge. Also when they have been in a supportive peer group that has known them since prep they get to high school and then we have those issues of bullying and marginalisation coming out. So it is very common for adolescent children — or adolescents — to have anxiety and depression with ASD.<sup>152</sup>

Health and mental health will be discussed in more detail in Chapter Nine.

## 1.6. Gender

The experience of ASD is inextricably linked to other factors, including gender. The Committee has heard that girls with ASD have been overlooked historically, due to the gender bias of standard diagnostic tools and the socialisation of girls to perform a more submissive gender role.<sup>153</sup> Yellow Ladybugs, an advocacy group supporting girls who attend mainstream schools, noted in their submission to the Inquiry:

Many people still have the misconception that Autism predominantly affects males. Researchers are finally highlighting the differences between males and females and why females commonly go under the radar or are diagnosed much later in life, but as a community, we are failing girls with Autism. Girls are often misdiagnosed, misunderstood or missed completely. The negative impacts caused by this, are life long, and come at not only a personal cost to our girls, but to the family, and our community as a whole.<sup>154</sup>

The experience of girls and women will be discussed in more detail in Chapter Six.

## 1.7. Rural and regional communities

The Committee heard that rural and regional communities face challenges in accessing services, and recruiting and retaining service providers, which will be discussed in more detail in Chapter Eight. Mr David Tennant, the Chief Executive Officer of FamilyCare, told the Committee at a public hearing in Shepparton:

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151 Ms Frances Saunders, Statewide Autism Spectrum Disorder Coordinator, Mindful, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 6.

152 Ibid.

153 Yellow Ladybugs, submission no. 117; Ms Stacey Smith, Family and Community Development Committee public hearing – Geelong, 19 September 2016, transcript of evidence, p. 2.

154 Yellow Ladybugs, submission no. 117, p. 1.

The supports that people need are often harder to find and to physically access when they live in regional areas, and for service providers as well the cost of providing services – exactly what is required when and where it is needed – is also higher than it might be in a metropolitan area and not something that our current funding and support system is particularly good at recognising.<sup>155</sup>

The Committee travelled to regional Victoria and was advised that regional communities lack access to diagnostic services, and trained health professionals including therapists, as well as early intervention therapies.

## 1.8. Culturally and Linguistically Diverse (CALD) communities

The Committee has also received evidence that ASD is little understood within some CALD communities leading to late diagnosis and social isolation.<sup>156</sup> Ms Nga Do, the Family and Volunteer Match and Program Coordinator at Extended Families Australia, told the Committee that many parents in CALD communities were particularly isolated with the language barrier and the lack of information. She spoke about her experience with the Vietnamese community and her concern over the mental health of parents:

I think the first thing is that when the parents just notice that their children have abnormal behaviour they are very worried, confused and lost. Then after they went to the doctor and then had been diagnosed with autism they feel very sad and hopeless. After that I know that the doctor refers them to go to the other services. But when they accept the services, they feel that it is very hard for them with the language barrier, and then it is uncomfortable for them to use the case letter because it is very difficult. It is something they talk about as very sensitive and upsetting, the case letter. I think the other thing that is very hard for the parents is their lack of knowledge about autism. They do not know how to handle the behaviour at home. It is very hard. Many mothers talk to me, crying and then they say, 'I don't know how to manage them'.

Also there is one family that had a boy who came to my playgroup when he was four years old. He seemed to me to be high functioning because he could talk and he understood very well all the instructions to do the activities. But after five years now he is nine years old, and I was assisting them one day and his mum said, 'Look at my house'. All the glasses were everywhere, broken, and then he broke the furniture and all the things, the lights and then the TV – everywhere. His mum said, 'I don't know that it may be one day coming I cannot handle it anymore. I think that maybe I put him in the institution'. When I heard that I feel very sad. Then at school, at her request, they send a psychologist to come to her house to observe and help him. But until now I do not think anything has improved. Then his behaviour was getting worse and worse. Mum said, 'Every

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155 Mr David Tennant, Chief Executive Officer, FamilyCare, Family and Community Development Committee public hearing – Shepparton, 15 November 2016, transcript of evidence, p. 2.

156 Extended Families Australia, submission no. 85.



day after school when I went to pick him up, I felt anxiety thinking about what could happen when he gets home. Every day is like this'.<sup>157</sup>

Ms Julie Langdon, the Chief Executive Officer of Extended Families Australia, told the Committee at a public hearing in Melbourne that anecdotally, there seemed to be a higher prevalence of ASD in CALD communities and that this enhanced the difficulties families faced with managing ASD:

I think the issues for CALD communities are the same as for everyone else, but I think they are just enhanced. It is plus plus. With ASD we already know that there are factors that create isolation. I think these are enhanced when you bring in the overlay of language and culture, and similarly finding supports around behaviour, self-worth and belonging.<sup>158</sup>

Ms Langdon also spoke about the NDIS and the need for CALD communities to receive assistance to access the services available:

Many families from a CALD background will need reassurance that the NDIS is a positive service that they can access and the assistance to do so. Our experience of other individualised funding packages, such as the Helping Children with Autism package is that most of our Vietnamese and other families were able to access the package, but what happened was that when something changed in the process, such as a speech therapist left or was not available, they did not end up spending their package or they did not end up getting linked back into the services.<sup>159</sup>

In their submission, Extended Families Australia also stated that families with a CALD background will need reassurance that the NDIS will be a positive service.<sup>160</sup>

In addition to the lack of nationally consistent prevalence data, there were gaps in prevalence data of ASD in CALD communities. In order to be able to provide adequate services and supports to CALD communities in Victoria living with ASD it is important that the Victorian Government have an understanding of the prevalence of ASD in these communities. The Victorian Government also needs to address the current lack of information on ASD available to CALD communities. Accordingly, the Committee recommends that:

## **RECOMMENDATION 1.6**

**In its collection of data on the prevalence of ASD in Victoria, the Victorian Government ensure that data on prevalence rates within CALD communities is also collected.**

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157 Ms Nga Do, Family and Volunteer Match and Program Coordinator, Extended Families Australia, Family and Community Development Committee public hearing – Melbourne, 21 November 2016, transcript of evidence, p. 4.

158 Ms Julie Langdon, Chief Executive Officer, Extended Families Australia, Family and Community Development Committee public hearing – Melbourne, 21 November 2016, transcript of evidence, p. 3.

159 Ibid, p. 5.

160 Extended Families Australia, submission no. 85.



**RECOMMENDATION 1.7**

The Victorian Government in consultation with CALD communities support the development of a targeted information strategy for those communities to assist individuals and families in understanding ASD and the services available.

The Victorian Government also needs to develop appropriate training and build cultural sensitivity for health professionals around the assessment and diagnosis of children and adults with ASD. Accordingly, the Committee recommends that:

**RECOMMENDATION 1.8**

The Victorian Government fund enhanced training for all service providers engaging with people with ASD to develop cultural understanding on the specific needs of people with ASD from CALD backgrounds.

- Develop specific training to build cultural awareness around assessment and diagnosis.

**1.9. Aboriginal and Torres Strait Islander communities**

The Committee heard that the lack of culturally appropriate services is also an issue for Aboriginal and Torres Strait Islander people with ASD.<sup>161</sup> Ms Rebecca Kelly from the Bendigo Autistic Advocacy Support Service (BAASS) spoke to the Committee at a public hearing in Bendigo about the difficult experience of Aboriginal people accessing autism information and the lack of cultural awareness:

Aboriginal presenters should deliver any Aboriginal Early Days autism information sessions. These should be held within local Aboriginal agencies.<sup>162</sup>

Ms Kelly spoke about Jackie French, an Aboriginal mother and Aboriginal Early Days presenter, and her experience accessing services:

Jackie lives in a rural town where services for autistic people are limited. Jackie stated that when her son was diagnosed she was very reluctant to disclose his diagnosis. She was afraid he would be treated differently because of the label given to him by a white person. She expressed the importance of cultural understanding when going through the diagnostic and assessment process and the importance of the same level of understanding in the therapeutic process. Her wish was for her child to have Aboriginal speech and occupational therapists, paediatricians and psychologists. In the Indigenous communities when specialists are invited into the home they ultimately become a part of the extended family. A lack of knowledge and understanding of culture creates fear and misinterpretation of Aboriginal home life. There is still an inherent fear of protective services getting involved amongst Aboriginal people. It is also

<sup>161</sup> Ms Rebecca Kelly, Co-convenor, Bendigo Autistic Advocacy and Support Service, Family and Community Development Committee public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 7.

<sup>162</sup> Ibid, p. 8.

important for all out-of-home services to be provided with an Indigenous-led service or co-op.<sup>163</sup>

Ms Kelly told the Committee that medical professionals dismissed the concerns of some parents in the Bendigo local Aboriginal and Torres Strait Islander community:

A constant worry is the loss of cultural identity by Aboriginal autistic people, and as advocates we have also witnessed firsthand the ignorance of the white community, especially healthcare professionals, towards Aboriginal families. When Aboriginal parents seek help for a diagnosis for their children, some children are brushed aside by doctors and the parents are told it is just bad behaviour or bad parenting.<sup>164</sup>

Mr Shilo Wilson from Interchange Gippsland told the Committee at a public hearing in Morwell that many Aboriginal families supported by Interchange were not aware of the services that are available to them or that they are entitled to particular services and supports:

You have to build relationships and trust with the community first before you can start to talk about services and put supports in place. So one way that we've been able to do that is each year we have an annual family camp for Aboriginal families that have a child with a disability. It is a chance for those families to get together for a fun weekend away and through that camp it is a great opportunity for us to build relationships with those families and towards the end of each of those camps we have an information session, we have a forum where we will have providers come in and talk about their supports and services and any family that wants to link in with appropriate supports and services, we will make those pathways for them. We will link them in where they need to be linked in... Often with the Aboriginal community we might have to meet with a family three or four times to develop a relationship before we will even start talking about what supports and services that we can link them in with or that is available to them.<sup>165</sup>

The Committee heard that there was a need for more training and understanding across the healthcare sector on the needs of Aboriginal and Torres Strait Islander children with ASD and their families. However, the Committee identified that data collection on the prevalence of ASD within Aboriginal and Torres Strait Islander communities is extremely limited. Accordingly, the Committee recommends that:

#### **RECOMMENDATION 1.9**

**In its collection of data on the prevalence of ASD in Victoria, the Victorian Government ensure that data on prevalence rates within Aboriginal and Torres Strait Islander communities is also collected.**

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163 Ibid, p. 7.

164 Ibid.

165 Mr Shilo Wilson, Manager, Respite and Support, Interchange Gippsland, Family and Community Development Committee public hearing – Morwell, 5 December, 2016, transcript of evidence, p. 6.

**RECOMMENDATION 1.10**

The Victorian Government fund enhanced training for all service providers engaging with people with ASD to develop cultural understanding on the specific needs of people with ASD from Aboriginal and Torres Strait Islander backgrounds.

- Develop specific training to build cultural awareness around assessment and diagnosis.

**1.10. State audit of ASD services**

Earlier in this chapter, the Committee made a number of recommendations around improving the collection of data on prevalence rates of ASD, both nationally and in Victoria.

It is also vitally important that the Victorian Government gain a clear understanding of the actual services that are provided to people with ASD in this state. The Committee is of the view that planning for the needs of people with ASD, particularly those with significant co-occurring conditions, will require a good understanding of the number and types of service providers providing services to people with ASD in Victoria. The Committee is also aware that with the development and roll out of the NDIS new service providers are entering the sector. Some of these new entrants will be organisations specialising in services for people with ASD.

It is also important for the Victorian Government to be aware of the qualifications and skills of new entrants. The State Government should liaise with the NDIS to obtain information on all new registered providers under the NDIS, and combine this knowledge with a survey of existing and ongoing Victorian providers.

Accordingly, the Committee recommends that:

**RECOMMENDATION 1.11**

The Victorian Government through the Department of Health and Human Services conduct an audit of all existing and ongoing Victorian government-funded service providers for people with ASD in Victoria, and liaise with the NDIS to obtain information on all new registered providers under the NDIS. The audit to include details on location, service delivery models, organisational certifications and the skill sets of employees. This audit to occur on an ongoing basis.

**1.11. Research into ASD**

The Committee heard from leading researchers in the field of ASD research in public hearings. As part of its Inquiry, the Committee also conducted site visits to key research institutes in Victoria and overseas, such as the Autism CRC in Brisbane, OTARC at La Trobe University, the Karolinska Institute in Sweden and the UC Davis MIND Institute in Sacramento. These site visits provided the Committee with an opportunity to learn about promising key developments in autism research.

Details on the research groups, institutes and organisations that have informed this Inquiry are contained through chapters in this report.

### **1.11.1. Research funding**

The Committee has received evidence of various successful research programs and projects for people with ASD and their families that have had their funding removed in recent years. State-wide Autism Spectrum Disorder Coordinator Ms Frances Saunders told the Committee at a public hearing in Melbourne that various successful programs had had their funding cut:

[T]he ACT-NOW has gone. Amaze certainly provides early day workshops, but ACT-NOW was an extensive program of training for parents of preschool children. The ReACT groups that provided really positive networks across sectors in each of the regions have gone because the funding for the coordinators has gone. The case consultant practitioners in DHHS have gone. The waiting list reduction initiatives all achieved the goals that were set, and now, five years later, we are finding that waiting lists are creeping up again.<sup>166</sup>

In following chapters, the Committee makes a number of recommendations in relation to funding support for specific programs undertaken by key research and training organisations in Victoria. The Committee regards the support of research into ASD as a vital part of an overall strategy to assist people with autism and their families. Accordingly, the Committee recommends that:

#### **RECOMMENDATION 1.12**

**The Victorian Government actively support and fund research and development programs that are targeted to assist families living with ASD, as part of an overall strategy to improve services and reduce waiting lists, and more broadly, for the purpose of better understanding ASD.**

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<sup>166</sup> Ms Frances Saunders, Statewide Autism Spectrum Coordinator, Mindful, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, pp. 3-4.

# Chapter 2

## Policy Settings and Government-funded Services for People with ASD

### AT A GLANCE

#### Background

A primary focus of the Inquiry's terms of reference is the availability and adequacy of government-funded services for people with Autism Spectrum Disorder (ASD). Services for people with ASD are funded by all tiers of government, and are always delivered under the umbrella of services for people with disability. There are few government-funded services that are designed exclusively for people with ASD unless research-funded; the major exception to this is the Commonwealth Government's Helping Children with Autism Program (HCWA), which is being phased out following the introduction of the NDIS. Some health services accessed by people with ASD are covered by Medicare. In addition, people with ASD access mainstream services offered to the broader community, such as hospitals and health care, mental health services, schools, and social housing.

#### Chapter overview

This chapter outlines the key legislative and policy frameworks at both Commonwealth and state levels that are relevant to the provision of services to people with ASD and their families, and the protection of their rights. It also provides an overview of the disability service framework for people with ASD and their families, and details on autism-specific programs and services. The Committee has heard from people with ASD and their families about their frequently negative experiences of government-funded services. These concerns are outlined in detail in the chapters that follow. The evidence is clear that much needs to be done to make mainstream government services more inclusive of people with ASD, and for services to be better integrated.

The ASD policy landscape, both federally and in Victoria, also needs reform, to better reflect the needs of people with autism, more recent understandings of ASD, and the emergence of ASD as a condition that affects significant numbers of Australians and their families. The Committee's study tour of the United States and Scandinavia also provided insights into legislation, policy and program developments overseas. This chapter addresses aspects of the following terms of reference:

- b) the availability and adequacy of services provided by the Commonwealth, State and local governments across health, education, disability, housing, sport and employment services; and
- c) the adequacy of services to be provided under the National Disability Insurance Scheme (NDIS).

A primary focus of the Inquiry's terms of reference is the availability and adequacy of government-funded services for people with Autism Spectrum Disorder (ASD). Services for people with ASD are funded by all tiers of government, and are always delivered under the umbrella of services for people with disability. There are few government-funded services that are designed exclusively for people with ASD unless research-based; the major exception to this is the Commonwealth Government's Helping Children with Autism Program (HCWA), which is being transitioned into the NDIS. In addition, people with ASD can access mainstream services offered to the broader community, such as hospitals and health care, mental health services, schools, and social housing.

While Victoria has its own legislative and policy framework for the provision of services to people with disability, including people with ASD, it is important to recognise the over-arching legislative and policy framework that exists federally. The key reform in this area is, of course, the creation of the National Disability Insurance Scheme (NDIS), which is discussed in detail in Chapter Six. This chapter outlines the key legislative and policy frameworks at both Commonwealth and state levels that are relevant to the provision of services to people with ASD and their families, and the protection of their rights. It also provides an overview of the disability service framework for people with ASD and their families, and details on autism-specific programs and services. The Committee's study tour of the United States and Scandinavia also provided it with insights into legislation, policy and program developments overseas.

Throughout this Inquiry the Committee has heard from people with ASD and their families about their frequently negative experiences of government-funded services. These concerns will be outlined in detail in the chapters that follow. However, the evidence is clear that much needs to be done to make government services more inclusive of people with ASD, for services to be better integrated, and for information about those services to be readily and easily accessible. The policy landscape, both federally and in Victoria, also needs reform, to better reflect the needs of people with ASD, more recent understandings of ASD, and the emergence of ASD as a condition that affects significant numbers of Australians and their families. The Committee makes recommendations to enhance national and state policy frameworks.

This chapter responds to terms of reference b) the availability and adequacy of services provided by the Commonwealth, State and local governments across health, education, disability, housing, sport and employment services; and c) the adequacy of services to be provided under the National Disability Insurance Scheme (NDIS).

## 2.1. Commonwealth Government

Australia ratified the *United Nations Convention on the Rights of Persons with Disabilities* (the CRPD) in 2008. The purpose of the CRPD is to ‘promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity’ (article 1). By ratifying the CRPD Australia accepts an obligation to recognise that people with disability enjoy legal capacity on an equal basis with others in all aspects of life, and that appropriate measures be provided to people with disability to enable their access to the support they require to exercise their rights and legal capacity.

The *Disability Discrimination Act 1992* (Cth) (the DDA 1992) implements Australia’s international human rights obligations under the CRPD, as well as obligations relating to non-discrimination under other treaties, including the International Covenant on Civil and Political Rights. The DDA 1992 makes it unlawful to discriminate against a person because of a disability or the disability of an associate, such as a friend, partner, carer or family member of the person. The DDA 1992 protects people with disability against discrimination in areas of public life, including: employment, education, accommodation, services and accessing public places.

Under the DDA 1992, the Attorney-General can make Disability Standards to specify rights and responsibilities about equal access and opportunity for people with a disability. The Standards can be made in relation to areas such as: employment, public transport, access to premises, and accommodation. Disability Standards for Education were introduced in 2005, which clarified the obligations of education and training providers and the rights of people with disability. These are discussed further in Chapter Four.

The Commonwealth Government’s National Disability Strategy 2010-2020 provides an over-arching framework for improving the lives of Australians with disability and their families and carers. The Strategy outlines a 10-year national policy framework to promote participation and create a more inclusive society. It is intended to guide public policy across all levels of government and to drive change in mainstream and specialist programs and services. It has six priority areas of action: inclusive and accessible communities; rights protection, justice and legislation; economic security; personal and community support; learning and skills; and health and wellbeing. The Strategy provides direction and funding to the Federal Government’s flagship autism program, Helping Children with Autism, which will transition into the NDIS.<sup>167</sup>

The Australian Government also funds the work of the Australian Advisory Board on Autism Spectrum Disorders, which is a national peak body for people with ASD and families living with ASD. The Board advises the government on policy, and has produced a guide for families and professionals to support people with ASD under the

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167 Department of Social Services, ‘National Disability Strategy’, Australian Government, accessed 31 March 2017, <[www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/government-international/national-disability-strategy](http://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/government-international/national-disability-strategy)>.



age of 25<sup>168</sup> Government-funded research being undertaken by the Autism CRC will continue to influence future policy.

### **2.1.1. Helping Children with Autism Program (HCWA)**

The major Commonwealth Government-funded program for people with ASD is the Helping Children with Autism Program (HCWA). The program includes a number of related initiatives:

- Funding for early intervention therapies;
- Eight Autism Specific Early Learning Centres across Australia (including the Olga Tennison Autism Research Centre in Melbourne);
- PlayConnect playgroups (autism-specific playgroups);
- Early Days family workshops;
- Professional development for teachers, school leaders and other school staff;
- Workshops and information sessions for parents and carers.

In Victoria, peak body Amaze (formerly Autism Victoria) has played a central role in administering individual HCWA early intervention funding through the Autism Advisors program, and has delivered Early Days workshops and other support services on behalf of the Commonwealth Government.<sup>169</sup> Autism Advisors provide advice and information about the most appropriate early intervention services, and are a link between diagnostic services and early intervention and support services. Amaze has supported over 12,000 families since beginning the service in 2008.<sup>170</sup> The Early Days program provides information workshops for parents of children aged 0-6 years who are on the spectrum, or who are being assessed. HCWA has also supported the Raising Children Network, a partnership of member organisations of Australia's early childhood agencies. The Raising Children website aims to provide evidence-based information for parents, including parents of children with ASD.<sup>171</sup>

Under the early intervention stream of the program children under the age of 7 are eligible to receive a total of \$12,000 for early intervention services, including speech therapy and occupational therapy. To obtain HCWA early intervention funding, the child must have a diagnosis of ASD, based on the criteria in either the Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV) or the Diagnostic and Statistical Manual of Mental Disorders 5 (DSM-5).

The Committee has heard extensive evidence about the deficiencies of the HCWA program and its age limitations and inadequate funding for early intervention.

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168 Australian Advisory Board on Autism Spectrum Disorders, *Supporting Individuals with Autism Spectrum Disorder. A guide for families and professionals*, Australian Government, 2013.

169 Amaze, submission no. 139, pp. 27-28.

170 Ibid, p. 27.

171 See, Raising Children Network, 'Children with Autism Spectrum Disorder', accessed 31 March 2017, <[raisingchildren.net.au/children\\_with\\_autism/children\\_with\\_autism\\_spectrum\\_disorder.html](http://raisingchildren.net.au/children_with_autism/children_with_autism_spectrum_disorder.html)>.



Ms Dianna Lane, who made a submission to the Inquiry and whose daughter has ASD, stated that:

Unfortunately for her, myself and the family, she did not qualify for the Helping Children With Autism Package HCWAP (which became available in 1996) as she had already turned 7 in 2006, too old, as it is for children 0-6. She did receive the Medicare sessions with an OT & speech therapist until 13 yo, which helped but for Chloe and her complex needs she will require on going OT, Speech and psychiatry sessions, which are very expensive. ... That's great offering the HCWAP but children with Autism do not suddenly get better...It is a life long condition. We have found that older children/ teenagers living with Autism are forgotten as the funding is not available and they are suddenly supposed to be 'normal' which is certainly not the case.<sup>172</sup>

Dr Anna Middleton, parent of a four-year-old child with autism who is enrolled in an intensive ABA early intervention program, stated in her submission to the Inquiry that:

The annual cost of my son's therapy program (accessed through a private provider) is \$65,000 - \$70,000. We drive an hour each way to access this therapy. The Helping Children with Autism (HCWA) Package has contributed a total of \$12,000. The remainder of the cost is covered by my husband and I and our extended family.

Given this, I see the offering of \$12,000 to be grossly inadequate.<sup>173</sup>

In their submission, Autism Spectrum Australia made the following points in relation to age limits and funding for early interventions:

Children can be reliably diagnosed with autism at around age 2. However a recent study utilising data from families accessing the HCWA package indicates that the average age of diagnosis in Australia is just over 4 years with the majority of children diagnosed closer to 6 years of age. In addition, based on these figures, and comparing them to the estimated prevalence of autism, it appears that approximately 25% of individuals with autism have not been identified prior to their 6th birthday. A delay in accessing diagnostic services is not only frustrating and stressful for families, but vital time is lost in commencing early intervention. Currently, there are long waitlists for state funded assessment services, sometimes in excess of 18 months. The NDIS will not be funding diagnostic assessments and the Medicare rebate covers less than 20% of the cost of most private providers.<sup>174</sup>

In their submission, Occupational Therapy Australia pointed to inconsistencies in the current funding models that apply in Victoria:

Funding opportunities for children with ASD in Victoria currently comprise of a matrix of schemes arising from different levels of government with different eligibility criteria. For example, the Commonwealth Helping Children with Autism (HCWA) Program enables children with autism funding for allied health assessment and treatment services until age seven. The eligibility criteria for this funding differs

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172 Ms Dianna Lane, submission no. 11, p. 1.

173 Dr Anna Middleton, submission no. 96, p. 2.

174 Autism Spectrum Australia, submission no. 100, p. 3.

widely from that of the Victorian state based Program for Students with Disabilities (PSD) funding. This results in a significant proportion of children who have received early intervention funding under the federal HCWA program being deemed ineligible for school support funding via Victoria's PSD as they commence primary school. The effect of these inconsistent funding criteria is that many children with ASD who have previously been eligible for funding for therapy services are no longer eligible. Of further concern is the additional effect that children who have not been diagnosed with ASD until school age often miss out on funding and therapy altogether as a result in Victoria.<sup>175</sup>

However, as the first Commonwealth program targeting ASD in Australia HCWA has been hugely significant at increasing accessibility to diagnosis and early intervention services. As the Commonwealth Department of Social Services pointed out in its submission, HCWA has assisted more than 46,000 children nationwide since its roll out in 2008, of whom 14,763 were in Victoria. Funding for the program nationally has totalled \$366 million on early intervention services, of which \$115 million was spent in Victoria since 2008. In Victoria, over 900 providers are approved to deliver services under the scheme.<sup>176</sup>

As the NDIS is introduced across Australia, the Helping Children with Autism package will be phased out. In this context, Amaze have argued in their submission that the long term role of programs within HCWA, such as the Autism Advisors, is currently unknown.<sup>177</sup>

The Committee believes it is vital that the full suite of services currently provided under the HCWA be maintained and enhanced under the NDIS, including information and support services for families living with ASD, such as the Autism Advisors. The roll-out of the NDIS and its implications for service delivery is discussed in Chapter Six. The Committee believes that the Victorian Government will need to carefully monitor the program impacts of the withdrawal of HCWA in Victoria, and ensure that services are not diminished.

Accordingly, the Committee recommends that:

### **RECOMMENDATION 2.1**

**The Victorian Government use its position on the COAG Disability Reform Council to ensure that the full suite of services currently provided by the Helping Children with Autism Program (HCWA) in Victoria be retained under the NDIS.**

## **2.1.2. Medicare**

In addition to funding for early intervention, HCWA provides for Medicare items for assessment, diagnosis and the creation of a treatment and management plan by a

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175 Occupational Therapy Australia, submission no. 114, pp. 3-4.

176 Department of Social Services, submission no. 72, p. 7.

177 Amaze, submission no. 139, p. 28.

consultant paediatrician (MBS item 135) or a psychiatrist (MBS item 289) for a child aged under 13 years.<sup>178</sup>

In addition, a child can be referred by a consultant paediatrician or psychiatrist for the following allied health services:

- Up to four diagnostic/assessment services from psychologists, speech pathologists, occupational therapists, audiologists, optometrists, orthoptists or physiotherapists to assist the referring practitioner with diagnosis or to contribute to a child's treatment and management plan (for a child under 13 years of age).
- Up to twenty treatment services from psychologists, speech pathologists, occupational therapists, audiologists, optometrists, orthoptists or physiotherapists (for a child under 15 years of age, providing a treatment and management plan is in place before their 13th birthday).<sup>179</sup>

People with autism can also access mental health care through the MBS Better Access program.<sup>180</sup>

## 2.2. Victorian Government

In Victoria, the *Charter of Human Rights and Responsibilities Act 2006* (the Charter) provides for the human rights of Victorians, including people with disability. The Charter prohibits discrimination on the basis of disability (see sections 3, 8, and 18). The Victorian *Equal Opportunity Act 2010* lists disability as an attribute in respect of which discrimination is prohibited (see section 6). Under section 15 organisations must take reasonable measures to eliminate discrimination, while sections 38 and 40 apply specifically to discrimination in education. These sections are further discussed in Chapter Four.

The Victorian Government recognised ASD as a neurological impairment under the *Disability Act 2006* in 2008 (see section 3 of the Act). Prior to this people with ASD who did not have an intellectual disability could not access disability services delivered or funded by the Department of Health and Human Services.<sup>181</sup> The *Disability Act 2006* requires the State Government to prepare a State Disability Plan, to be updated every four years. The *Disability Act 2006* also requires public authorities and local governments to prepare disability action plans.<sup>182</sup>

178 Department of Health, 'Autism – Helping Children with Autism Program', Australian Government, accessed 31 March 2017, <[www.health.gov.au/internet/main/publishing.nsf/Content/autism-children](http://www.health.gov.au/internet/main/publishing.nsf/Content/autism-children)>.

179 Raising Children Network, 'Helping Children with Autism (HCWA)', accessed 31 March 2017, <[raisingchildren.net.au/articles/hcwa\\_funding\\_partner.html](http://raisingchildren.net.au/articles/hcwa_funding_partner.html)>.

180 Department of Health, 'Better access to Psychiatrists, Psychologists and General Practitioners through the MBS (Better Access) initiative', Australian Government, accessed 31 March 2017, <[www.health.gov.au/mentalhealth-betteraccess](http://www.health.gov.au/mentalhealth-betteraccess)>.

181 Ms Amanda Cattermole, Deputy Secretary, Community Services Programs and Design Division, Department of Health and Human Services, Family and Community Development Committee public hearing – Melbourne, 7 November 2016, transcript of evidence, p. 3.

182 See sections 37 and 38, *Disability Act 2006* (Vic).

The current State Government has recently released the new State Disability Plan 2017-2020, titled 'Absolutely Everyone', which articulates government policy for people with disability, including people with ASD. This state plan supersedes the previous State Disability Plan (2013-2016). The new plan articulates five principles that underpin the plan: autonomy, opportunity, human rights, diversity, and accountability. The State Plan is designed to meet the State Government's obligations under the *Convention on the Rights of Persons with Disabilities*, the National Disability Strategy, and local Acts. In the State Plan the State Government commits to enhancing assessment, diagnostic services and early intervention for children and young people with ASD, stating that, 'We will complement this with funding to deliver autism-specific training in assessment, diagnosis and early intervention.'<sup>183</sup> In the State Budget 2017-2018, the State Government allocated \$4.9 million towards the implementation of the State Disability Plan 2017-2020.<sup>184</sup> In 2009 the then Victorian Government released the Autism State Plan, which is discussed below. People with ASD can access the full range of mainstream services delivered by the Victorian Government, including hospital and general health care, housing, and services for children and families. People with ASD may also be eligible for specialist disability services such as supported residential accommodation and day programs, and additional support in government schools.

### 2.2.1. Department of Health and Human Services

As mentioned, ASD is covered by the definition of 'disability' in the *Disability Act 2006* (Vic) (section 3 of the Act), and as such people with autism can access disability support services offered by the Department of Health and Human Services (DHHS), including supported accommodation, personal care and day programs. However, disability support services are funding-dependent and needs-based, and a diagnosis of ASD is not sufficient to access DHHS services. DHHS stipulates that a person seeking disability support must have a disability that impacts on 'mobility, communication, self-care or self-management'.<sup>185</sup> Once DHHS confirms a person's need for support they are placed on the Disability Support Register, which the Department claims 'is used to allocate these supports in a fair and efficient manner when funding or vacancies become available'.<sup>186</sup> In this way, the recognition that a person is eligible for support does not guarantee that supports will be available.

Currently, DHHS provides disability supports to people in two main ways:

- Short-term supports – such as respite services, behaviour supports, care management and therapy;

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183 Victorian Government, *Absolutely Everyone - State Disability Plan 2017-2020*, 2017, p. 35.

184 Victorian Government, *Getting on with the job, Victorian Budget 17/18 Service Delivery, Budget Paper no. 3*, p. 85, accessed 7 May 2017, <[s3-ap-southeast-2.amazonaws.com/budgetfiles201718.budget.vic.gov.au/BP3\\_2017-18\\_ServiceDelivery.pdf](https://s3-ap-southeast-2.amazonaws.com/budgetfiles201718.budget.vic.gov.au/BP3_2017-18_ServiceDelivery.pdf)>;

185 Department of Health and Human Services, 'Access and planning', Victorian Government, accessed 17 November 2016, <[www.dhs.vic.gov.au/for-service-providers/disability/access-and-planning](http://www.dhs.vic.gov.au/for-service-providers/disability/access-and-planning)>.

186 Department of Health and Human Services, 'Disability Support Register', Victorian Government, accessed 17 November 2016, <[www.dhs.vic.gov.au/for-individuals/disability/start-here/disability-support-register](http://www.dhs.vic.gov.au/for-individuals/disability/start-here/disability-support-register)>.

- Ongoing supports – such as supported residential accommodation and Individual Support Packages (ISPs).

Generally, disability support services are ‘block-funded’ by DHHS, that is, funding is allocated to community service organisations rather than to individuals. DHHS fund a range of disability services that people with ASD can access. There are four community service organisations that receive funding from DHHS that primarily deliver services to people with ASD and their families. In 2015-16, these organisations were allocated over \$14 million.

The Victorian Government has provided support funding over a long period of time. Mansfield Autism Statewide Services deliver community-based respite, flexible support packages, outreach, supported accommodation, case management and behaviour support.<sup>187</sup> DHHS also funds peak body Amaze to provide information and advice to people with ASD and their families. In addition, the government funds Autism Spectrum Australia (Aspect) to deliver ISPs, respite, and behaviour support. The government also provides funding to disability service provider Autism Plus.

Victorian Government funding is also provided to Mindful – Centre for Training and Research in Developmental Health, to deliver a state-wide ASD coordination role. As mentioned, people with ASD also access supports to address their needs from other funded community organisations and from DHHS itself. These supports can include case management, behaviour support, and residential support.

Individual Support Packages (ISPs) provide funding tied to an individual, and allow that individual to identify which services are most appropriate to their needs. In 2015-16, 15,205 people with disability were in receipt of an ISP in Victoria, of whom over 1,700 people with ASD as a recorded primary diagnosis were allocated an ISP.<sup>188</sup> Approximately two-thirds of these recipients also had an intellectual disability. The total value of this funding for individuals with ASD was \$70.7 million. Individuals holding ISPs can purchase services, for example the Futures for Young Adults funding program,<sup>189</sup> which can be used to purchase supports to develop school leavers’ independence. Respite and day programs are examples of other services which can be purchased under an ISP.

In essence, the NDIS’ Individual Funded Packages (IFPs) are an extension of the ISP model of self-directed support and choice in service providers. It is anticipated that

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187 Ms Amanda Cattermole, Deputy Secretary, Community Services Programs and Design Division, Department of Health and Human Services, Family and Community Development Committee public hearing – Melbourne, 7 November 2016, transcript of evidence, p. 4.

188 Ibid.

189 Futures for Young Adults (FFYA) program, provides supports for young people needing disability assistance during the day and skills development to participate in the community after they leave school, and is now designed to support young people with a disability, until their transition into the National Disability Insurance Scheme. See Department of Health and Human Services, *Transition support for young people with a disability leaving school (incorporating Futures for Young Adults and Transition to Employment): a handbook 2015*, Victorian Government, accessed 16 May 2017, <[www.dhs.vic.gov.au/\\_\\_data/assets/pdf\\_file/0009/916632/Transition-support-for-young-people-with-a-disability-leaving-school-handbook.pdf](http://www.dhs.vic.gov.au/__data/assets/pdf_file/0009/916632/Transition-support-for-young-people-with-a-disability-leaving-school-handbook.pdf)>.

anyone who currently receives an ISP will not be disadvantaged in the move to the NDIS. This issue is discussed further in Chapter Six.

## 2.2.2. Autism State Plan

The 2009 Autism State Plan (the Plan) was a significant public policy that built on extensive consultation with people with ASD and their families.<sup>190</sup> The Plan involved consultation with almost 1,000 Victorians with ASD and their families, as well as contributions from Amaze and the Department of Education and Early Childhood Development. It was developed in response to the growing prevalence of ASD in Victoria and increased demand for ASD-specific services. The Plan outlined a ten-year vision to support people with ASD and included six priority areas:

1. Make it easier to get support
2. Strengthen the ASD expertise of the workforce
3. Extend and link key services and support especially during transitions
4. Enhance and provide appropriate educational opportunities
5. Facilitate successful participation in the community
6. Develop a robust evidence base about ASD.

The Plan provided funding for a range of programs including: the Autism Teaching Institute at the Western Autistic School; transition support for students with ASD entering primary school; an increase in diagnostic services offered by Child and Adolescent Mental Health Services (CAMHS); leadership and new resources for ASD diagnosis through Mindful; and a number of employment and sporting programs. Throughout the Inquiry the Committee heard support for the Autism State Plan and concern that action on the Plan had stalled. Many of the Inquiry's stakeholders were consulted by DHHS during the creation of the Plan, and there is a feeling that this work should not be 'wasted' by the State Government. In particular, peak body Amaze questioned the apparent disappearance of the Plan, especially given the extensive consultation that was involved in its development.<sup>191</sup>

At a public hearing held in Melbourne, the Committee heard from Ms Amanda Cattermole, Deputy Secretary, Community Services Programs and Design Division, DHHS. Ms Cattermole stated that the State Disability Plan 2013-2016 incorporated key focus areas and strategies from the Autism State Plan, and that there were actions relating to ASD in the State Disability Plan with strong synergies with the priority areas of the Autism State Plan. She further stated that reporting on implementation of the State Disability Plan in 2014 included reporting on six specific autism actions, and that there was a continued focus on delivering improved

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190 Department of Health and Human Services, 'Autism State Plan', Victorian Government, accessed 17 November 2016, <[www.dhs.vic.gov.au/about-the-department/plans,-programs-and-projects/plans-and-strategies/disability-services/autism-state-plan](http://www.dhs.vic.gov.au/about-the-department/plans,-programs-and-projects/plans-and-strategies/disability-services/autism-state-plan)>.

191 Amaze, submission no. 139, p. 16.



outcomes.<sup>192</sup> Victoria remains the only state to have developed an autism strategic plan.<sup>193</sup>

## 2.3. Local government

Under the *Local Government Act 1989* (Vic) councils have a statutory responsibility ‘to improve the overall quality of life of people in the local community’ and ‘to ensure that services and facilities provided by the Council are accessible and equitable’ (Section 3C(c)(e)).

As mentioned above, the *Disability Act 2006* also requires local governments to develop disability action plans. Typically, councils achieve this through the implementation of disability and inclusion plans focused on improving access to mainstream services and supporting community wellbeing. Examples of inclusive local practices include: swimming classes, sport and recreation activities for children with ASD, playgroups and parent groups, quiet spaces at community festivals and events, and sensory story times in libraries.

For example, Hobsons Bay City Council has a Disability Access and Inclusion Strategy 2013-17, under which a number of initiatives and programs are designed to support people with ASD. These include: the Laverton Children's Centre PlayConnect playgroup; partnering with the Western Autistic School to deliver programs; promoting the Train Supreme, Autistic Physical Development and Exercise Training, based in Altona Meadows; the Inside the Brick program at community centres; the Bayfit Leisure Centre, which runs classes for children with ASD; the Laverton Swim and Fitness Centre which is connected to the Rainbow Club and delivers specific classes for children with ASD; and the South Kingsville Community Centre.<sup>194</sup>

Historically, local government has also provided respite and disability support services through the Commonwealth-funded Home and Community Care program (HACC). For example, the Darebin City Council Aged and Disability Department

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192 Ms Amanda Cattermole, Deputy Secretary, Community Services Programs and Design Division, Department of Health and Human Services, Family and Community Development Committee public hearing – Melbourne, 7 November 2016, transcript of evidence, pp. 3-4. The six autism actions for 2013-14 were: Provide support to children, adults, families and carers who are dealing with autism spectrum disorder in a more coordinated and complementary approach across government; Provide training and advice to disability support professionals over two years to better equip them to meet the needs of people with autism, their families and carers; Use the Department of Education and Early Childhood Development's regional autism spectrum disorder annual implementation plans to support an integrated early years and school approach through identifying regional priority areas such as professional learning and transition support; Release operational guidelines for child adolescent mental health services to help improve the assessment and treatment of children, young people and adults with complex presentations of autism spectrum disorder; Implement and evaluate a new behaviour support service to test an approach that provides more effective and early support for young people with autism who display behaviours of concern, and their families and carers; and, Provide training sessions to mental health clinicians across child, youth and adult mental health services that help to increase their knowledge and skills in assessment, diagnosis and early intervention for autism spectrum disorder and mental illness. See, NSW Parliamentary Research Service, *Autism Spectrum Disorder*, Briefing Paper No 5, 2013, pp. 24-25.

193 The other states have state disability plans, similar to the Victorian State Disability Plan 2017-20. For example, see Government of South Australia, *Disability Access and Inclusion Plan 2014-2018*, Department of Communities and Social Inclusion, 2015.

194 Hobsons Bay City Council, submission no. 80, p. 3.

provides support services (respite, home and personal care) through the HACC program, and approximately 150 people receiving this service have a diagnosis of ASD. In its submission to the Inquiry, the Council states that, 'The majority of these clients are under 18 years of age, indicating that primarily access to the HACC program by families is for respite services.'<sup>195</sup>

The Committee has heard from parents disappointed with the limited availability of respite services in their local area. Early childhood intervention service the Broad Insight Group stated in their submission that:

Access to in-home respite care for families where carers have identified that they are experiencing severe carer stress is very limited. Some families are unable to receive respite where HACC services are already fully extended or where children are excluded due to their behaviours of concern. Other respite services provide short-term programs only. Council respite services can, at times, be inflexible and may not provide families with the hours of support required or at the times desired by the family. For example, Hume City Council has announced that from May 2016 the Council are planning to withdraw weekend respite services. Some families also experience judgemental attitudes towards their requests for service where the provider deems they are requiring too little or too much support.<sup>196</sup>

In 2016 the HACC program underwent significant change – respite services for people with disability will gradually be transferred to the NDIS. Services for older people, aged 65 years and over, will be funded by the Commonwealth, under the Commonwealth Home Support Programme (CHSP).<sup>197</sup> The HACC Program for Younger People (HACC-PYP) will continue and be funded and managed by DHHS, for people under 65 years, to provide basic supports and maintenance to help people with disabilities to remain living at home. However, it is expected that some clients of this program will transfer to the NDIS. In the State Budget 2017-2018, the State Government announced funding of \$2.9 million for the HACC-PYP program, to provide individuals with a disability with basic community care services such as domestic assistance, personal care, home nursing, allied health services and social support.<sup>198</sup>

The Committee has heard some evidence that local councils are withdrawing from services for people with disability. In addition to the reference above to the Darebin City Council, the Committee heard from the City of Greater Geelong that it was withdrawing from service supports for people with disability, apart from delivered meals and home maintenance. Mr Geoff Barber, Acting Coordinator, Care Services, Aged and Disability, City of Greater Geelong, said at the hearing held in Geelong that the withdrawal was in relation to the NDIA unit cost structure:

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195 Darebin City Council, submission no. 99, p. 2.

196 Broad Insight Group, Dianella Community Health, submission no. 132, p. 2.

197 Department of Health and Human Services, 'Home and Community Care in Victoria', Victorian Government, accessed 17 November 2016, <[www2.health.vic.gov.au/ageing-and-aged-care/home-and-community-care](http://www2.health.vic.gov.au/ageing-and-aged-care/home-and-community-care)>.

198 Victorian Government, *Getting on with the job, Victorian Budget 17/18 Service Delivery, Budget Paper no. 3*, pp. 78, 82, accessed 7 May 2017, <[s3-ap-southeast-2.amazonaws.com/budgetfiles201718.budget.vic.gov.au/BP3\\_2017-18\\_ServiceDelivery.pdf](http://s3-ap-southeast-2.amazonaws.com/budgetfiles201718.budget.vic.gov.au/BP3_2017-18_ServiceDelivery.pdf)>;



Unfortunately we are not able to charge a top-up fee. The NDIA unit cost is set; you cannot change it. We were not able to meet that cost, we were not able to break even, so we had to present that financial position to the administrators and they made a decision on 16 August that it was not something that we could continue in so we decided we had to transition those people to other providers. I think that reflects what other local governments are considering and looking at.<sup>199</sup>

The withdrawal of local government services is further discussed in Chapter Six.

Local government also works in partnership with the State Government in managing Victoria's maternal child and health services.<sup>200</sup> The Committee has heard that maternal child and health (MCH) nurses can play a pivotal role in the early identification and surveillance of ASD in children, an issue which is pursued in Chapter Three.

## 2.4. Service integration and coordination

In their submission, Occupational Therapy Australia stated that:

Currently, there is poor coordination and integration of Commonwealth and state funding arrangements and services for individuals with ASD. This has resulted in service gaps, inequity, inconsistency and fragmentation of services. People with ASD and their families are required to self-advocate and navigate their pathway to funding and services with little support or guidance, resulting in a lottery of opportunities.<sup>201</sup>

Throughout the Inquiry, the Committee has heard about the lack of integration and coordination of services for people with ASD and families living with ASD delivered by the different levels of government, and also within levels of government. In their submission, Speech Pathology Australia report their members saying that:

Members report parents expressing frustration at; having to navigate a complicated and complex service system; being placed on waiting lists; having to retell their "story" each time they see a new professional; encountering barriers that prevent collaboration of health professionals; having to wait for a service when they transfer across from a different service; having to reapply for funding and meet different eligibility criteria when they enter a new service or system; and feeling like they have to fight for every "ounce" of support their child receives.<sup>202</sup>

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199 Mr Geoff Barber, Acting Coordinator, Care Services, Aged and Disability, City of Greater Geelong, Family and Community Development Committee public hearing – Geelong, 19 September 2016, transcript of evidence, pp. 2-3.

200 Department of Health and Human Services, 'Maternal and child health services', Victorian Government, accessed 17 November 2016, <[www.betterhealth.vic.gov.au/health/healthyliving/maternal-and-child-health-services](http://www.betterhealth.vic.gov.au/health/healthyliving/maternal-and-child-health-services)>. See also, Municipal Association of Victoria (MAV), 'Maternal and Child Health', accessed 28 March 2017, <[www.mav.asn.au/policy-services/social-community/children-families/maternal-child-health/Pages/default.aspx](http://www.mav.asn.au/policy-services/social-community/children-families/maternal-child-health/Pages/default.aspx)>.

201 Occupational Therapy Australia, submission no. 114, p. 8.

202 Speech Pathology Australia, submission no. 136, p. 14.

Stakeholders report that this lack of integration and coordination occurs at both governmental and sector levels. In their submission, Merri Health reported that:

There is a lack of integration and communication across government and community services. Relationships are usually dependent upon the strength of personal connections as opposed to clarity of expectations regarding collaboration, service partnerships and referral pathways between sectors and services.<sup>203</sup>

The Committee was frequently told of the existence of ‘silos’ between government services that prevented clients from gaining adequate access and information. In their submission, the Austin Child and Adolescent Mental Health Service (CAMHS) advised the Committee that:

Government services are poorly integrated and appear to maintain strong boundaries around their identified clientele. This was reported by many clinicians and seems particularly evident between Disability Client Services and the Mental Health Sector where there is strong push back between the services for those with a dual diagnosis. It seems very difficult for families to access both services simultaneously despite meeting eligibility criteria for both. For families already engaged in mental health services it can be difficult to access additional services available only through Disability services.<sup>204</sup>

Given the nature and characteristics of ASD, it is imperative that agencies and services work with one another to achieve good outcomes. However, the reverse often appears to be the case, as the Mindful Centre for Training and Research in Developmental Health advised the Committee in their submission that:

ASD assessment and treatment should be a seamless process that can occur across government services to meet the needs of the individual child or young person who presents at a primary, secondary or tertiary agency. Currently there are local agencies such as community health centres and early intervention agencies whose policies prevent professionals working together across and within agencies to provide a comprehensive multidisciplinary assessment at the service of first contact. In some regional areas these policy barriers have been overcome and as a consequence children and their families receive more timely diagnosis.<sup>205</sup>

Local councils were also aware of the lack of integration across services. The City of Melton advised the Committee in its submission that it had conducted a consultation process with 150 local parents and carers of people with ASD on services for people with ASD.<sup>206</sup> On the issue of integration of services, participants in the consultation advised there were a number of issues that needed to be addressed, including: the need for closer collaboration between multicultural services and disability/ASD services; a need for consistent and shared information across government

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203 Merri Health, submission no. 37, p. 3.

204 Austin Child and Mental Health Services, submission no. 113, p. 3.

205 Mindful Centre for Training and Research in Developmental Health, submission no. 134, p. 5.

206 See, City of Melton, submission no. 28, p. 2.

organisations, particularly around the needs of the CALD community; and better understanding of ASD amongst Victoria Police.<sup>207</sup>

The Commonwealth Department of Social Services advised the Committee that effective service integration between the NDIS and other service systems, such as education and health, was critical in avoiding cost shifting, duplication and service gaps.<sup>208</sup> The issue of NDIS integration with existing state services will be discussed in Chapter Six.

Following chapters of this report contain further evidence of the lack of integration of services within and between sectors and levels of government. Parents and carers frequently describe their frustrating experiences as a ‘merry-go-round’ of attempts to gain access to reliable information and service provision, involving seemingly endless requests to repeat their stories.

The Committee found that there is a lack of integration and coordination of government-funded services for people with ASD and their carers, both between levels of government and within sectors. The Committee is of the view that an updated state autism plan (discussed below) will incorporate as a key aim of the strategy the need for, and implementation of, better integration and coordination of services across the state. Accordingly, the Committee recommends that:

#### **RECOMMENDATION 2.2**

**The Victorian Government include, as a key element of the updated State Autism Plan, the integration and coordination of government-funded services for people with ASD. The Plan will highlight the need to remove unnecessary barriers to service access and information, such as agency policies that prevent integration.**

## **2.5. Other jurisdictions**

In 2009 the United Kingdom passed the *Autism Act 2009*, which was the first disability-specific legislation to be passed in the UK. It is estimated that more than half a million people in England have autism.<sup>209</sup> The *Autism Act 2009* committed the UK Government to producing a national strategy for adults with autism, and the first autism strategy was released in 2010. The strategy was updated in 2014. The strategy focuses on five core areas of activity: increasing awareness and understanding of autism among frontline professionals; developing a clear pathway for diagnosis, to be followed by personalised needs assessment; improving access to services and supports to enable independent living; helping adults into work; and enabling local authorities to plan and develop services to meet identified needs. The

<sup>207</sup> See, *Ibid*, p. 6.

<sup>208</sup> Department of Social Services, submission no. 72, p. 9.

<sup>209</sup> House of Commons Library, *Autism – overview of UK policy and services*, Briefing Paper Number CBP 07172, 2016, pp. 3-6.

UK Government announced 4.5 million GBP of funding to support the objectives of the strategy in 2014.<sup>210</sup>

New Zealand launched the NZ Autism Spectrum Disorder Guideline in 2008, and the document, which now stands at over 300 pages, operates as a living guideline with regular updates. The guideline acknowledges the whole of a person's life – from early intervention and diagnosis, to community living for adults, and is intended to provide guidance on ASD in both children and adults in New Zealand. It is an evidence-based summary that covers the identification and diagnosis of ASD, and ongoing assessment and access to interventions and services for individuals with ASD, and is intended for use by primary care practitioners, education professionals, policy makers, funders, parents, carers, specialists and any others who make provision for individuals with ASD. It is estimated that about 40,000 people or approximately 0.9% of New Zealand's population has ASD.<sup>211</sup>

In the United States, the federal Individuals with Disabilities Education Act (IDEA) provides rights and protections to children with disabilities and to their parents. Autism is a recognised disability under the IDEA Act. Amended several times since Congress first passed it in 1975, the essential purpose of IDEA is, firstly, to ensure students with disabilities have access to a free and appropriate public education. Schools are required to provide special education in the least restrictive environment, and teach students with disabilities in general education classrooms, whenever possible. And secondly, under IDEA, parents have a say in the educational decisions the school makes about their child. The law gives parents specific rights and protections, known as procedural safeguards.<sup>212</sup>

Under the IDEA students have an Individualised Education Plan (IEP) developed. The Act provides for school age children with disabilities to receive specifically designed instruction to meet each child's unique needs. In theory, as a federal law IDEA allows students to maintain their IEPs regardless of where they live in the country. On its study tour the Committee heard, however, that gaining IEPs could be difficult, and that individual states have different requirements for the IEP criteria. U.S. education services for children with ASD are further discussed in Chapter Four.

On its study tour the Committee learnt that, at a public policy level, the U.S. has a number of key lead organisations to develop policy and research on autism. The Office of Autism Research Coordination (OARC) is part of the National Institute of

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210 Ibid.

211 Ministries of Health and Education, *New Zealand Autism Spectrum Disorder Guideline*, Wellington, Ministry of Health, 2016, pp. 2-3, 11. However, according to the Guideline, there is no definitive information on the prevalence and incidence of ASD in NZ.

212 See, Understood, 'How IDEA Protects You and Your Child', Understood, accessed 24 April 2017, <[www.understood.org/en/school-learning/your-childs-rights/basics-about-childs-rights/how-idea-protects-you-and-your-child](http://www.understood.org/en/school-learning/your-childs-rights/basics-about-childs-rights/how-idea-protects-you-and-your-child)>.

Mental Health (NIMH) and the National Institutes of Health (NIH).<sup>213</sup> OARC coordinates and manages the Interagency Autism Coordinating Committee (IACC) and related cross-agency autism spectrum disorder activities, programs, and policies. The IACC is a federal advisory committee created by Congress to coordinate federal activities and provide advice to the Secretary of Health and Human Services on issues related to ASD. The IACC's Strategic Plan is framed around seven consumer-based areas: screening and diagnosis; biology; risk factors; treatments; services; lifespan; and, infrastructure.<sup>214</sup>

Another important office is that of the National Autism Coordinator, which is responsible for ensuring implementation of ASD activities across the Department of Health and Human Services (HHS) and serves as the department's liaison with external groups on matters related to autism. A large part of this role focuses on transition – the time between youth and adulthood where there has been the least development of research and interventions. The Committee learnt that there was a pressing need to conduct research and establish interventions that will support youths with ASD to transition to adulthood.<sup>215</sup>

The Committee also learnt that different states have different programs and policy frameworks for people with ASD. For example, California has a state-wide system of Regional Centres, which provide or coordinate services for individuals with developmental disabilities. The state Department of Developmental Disabilities oversees the Regional Centres, which are non-profit private corporations contracted by the department. California has 21 regional centres.<sup>216</sup> The Regional Centres can evaluate and assess an infant or toddler (age 0 to 36 months) to determine eligibility for early intervention services. However, from three years of age, public school districts provide services and supports to children with developmental disabilities.

Broadly speaking, the Committee was informed by peak body and advocacy group known as the Arc for People with Intellectual and Developmental Disabilities that the U.S. service system for people with disabilities was a patchwork system of care, with few programs that are condition-specific and most programs and services based on

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213 OARC provides assistance to the IACC by: communicating information about the IACC and federal ASD research activities to Congress, other government agencies, and the public; planning meetings, conferences, and other venues for interaction between the IACC and the public; assisting the IACC in its strategic planning and ASD research monitoring activities; conducting analyses and preparing reports for the IACC and Congress; and, developing and disseminating information to the public about ASD. See National Institute of Mental Health, 'Office of Autism Research Coordination', U.S. Department of Health and Human Services, accessed 24 April 2017, <[www.nimh.nih.gov/about/organization/od/office-of-autism-research-coordination-oarc.shtml](http://www.nimh.nih.gov/about/organization/od/office-of-autism-research-coordination-oarc.shtml)>.

214 See, Interagency Autism Coordinating Committee (IACC), 'About IACC', U.S. Department of Health and Human Services, accessed 24 April 2017, <[iacc.hhs.gov](http://iacc.hhs.gov)>.

215 See, Interdisciplinary Technical Assistance Center on Autism and Developmental Disabilities, 'Secretary Burwell Names Dr. Thomas E. Novotny New HHS Autism Coordinator', accessed 24 April 2017, <[www.aucd.org/itac/detail/news.cfm?news\\_id=11899&parent=646&parent\\_title=News&url=/itac/template/page.cfm?id%3D646](http://www.aucd.org/itac/detail/news.cfm?news_id=11899&parent=646&parent_title=News&url=/itac/template/page.cfm?id%3D646)>.

216 For a list of the centres, see: California State Department of Developmental Disabilities, 'Regional Centres Directory', Department of Developmental Disabilities, accessed 18 April 2017, <[www.dds.ca.gov/RC/RCList.cfm](http://www.dds.ca.gov/RC/RCList.cfm)>.

functional needs.<sup>217</sup> Other U.S. federal programs targeted at people with ASD will be discussed in further chapters.

On its study tour of Scandinavia, the Committee learnt about the Scandinavian welfare model, which includes a large public sector supporting vulnerable citizens, high government taxes which aim to safeguard free health care, education and social services, and a policy to try to keep both parents in employment. The legal and policy framework in Scandinavia focuses primarily on disability rather than autism specifically. However, there are specific programs and bodies dedicated to 'special needs' children and adults who are on the spectrum.

In Denmark the Committee met with representatives from the National Board of Social Services, who advised the Committee that over 90 per cent of children attend public or private child nursery or kindergarten from the age of one, and all families are continuously followed during pregnancy and after delivery by healthcare professionals. Under this universal system there was thus a greater preparation for families in pregnancy for anything that could occur later in the child's development.

The Norwegian Directorate for Children, Youth and Family Affairs advised the Committee that it dealt with autism as part of their work with intellectual disabilities and learning disabilities, with a primary focus on the consequences of disability, inclusion and discrimination. In Norway, there had been a paradigm shift in both ideology and policy around disability to one of normalisation, integration, inclusion, empowerment, anti-discrimination and equality. In 1975, legislation was passed to ensure mainstream schooling: 'one school for all'. In 1991, there was a deinstitutionalisation for people with intellectual disabilities. Every person who needs long-term, coordinated services is entitled to an 'individual plan'. The purpose of an individual plan is to provide a complete, coordinated and individually tailored set of services and to ensure that one professional has the main responsibility for follow-up and coordination at all times.

In Norway, a guaranteed place in kindergarten begins at the age of one. There are three kindergarten employees for every nine children, with at least one person trained and who has the responsibility of identifying learning impairments, such as the early signs of ASD. In Norway, all children who have special needs have the right to special needs education and it is the responsibility of the school to draw up an individual syllabus (which is drawn up by a special needs educationalist, teachers and parents).

In Sweden, the Committee met with representatives of the Swedish Agency for Participation, and learnt about disability policy and the inclusion framework from the Agency, which is a small government agency of about 60 staff under the Ministry for Social Affairs and Health. Disability policy is 'cross-cutting policy' in the sense that it cuts across different sectors but is coordinated under the Agency. The Agency noted that there are increasing numbers of people being diagnosed with ASD in Sweden. Sweden has disability legislation (such as the LSS – see below) and support services but the results, according to the Agency, are not uniform or satisfying. For families

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217 The Arc, 'The Arc – For people with intellectual and developmental disabilities', accessed 24 April 2017, <[www.thearc.org](http://www.thearc.org)>.



living with ASD in Sweden it can be difficult to navigate systems, and support services are not well coordinated.

The Committee also met with the Autism and Aspergers Association's Ombudsman, who advised the Committee about the Law regulating Support and Services to Persons with Certain Functional Disabilities (LSS). The LSS is the national law for people with disabilities in Sweden which aims to provide a high standard of care for people with disabilities including autism, ensure that people don't live in institutions, and creates the same rights for everyone. It is a law of rights. There are ten forms of assistance in accordance with clause 9 of the LSS, as follows:

- Advice and other personal support to ensure persons with functional disabilities and their relatives access to professional, coordinated and permanent assistance from several areas of competence.
- Personal assistance for persons who have considerable need of personally designed care in everyday life.
- Companion service for persons who need help to get out to leisure or cultural activities, or to participate in social life otherwise.
- Contact person - who gives personal support and functions as a friend.
- Relief service, which means that a person comes to the family home in order to take care of the person with functional disabilities.
- Short-term stays away from home to provide persons with functional disabilities with recreation and to give relief to relations.
- Short-term care for school children over 12 – care before and after the school day and during school holidays for school children over 12 years old with functional disabilities.
- Living in family homes or housing with special services for children and young people. As a complement to, or to replace the family home, children and young people can live with another family or in housing with special services.
- Housing with special services for adults or other specially adapted housing for adults – can be specially adapted housing, service housing or group housing.
- Daily activities for persons with intellectual disabilities, autism or functional disabilities. The operation can be carried out at a day centre or at another place of work.<sup>218</sup>

However, the Committee was advised that the legislation is currently under investigation as the current Swedish Government considers that it is too costly to implement. Examples of specific policy areas and programs for people with ASD in Scandinavia are covered in following chapters.

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218 Habilitering & Halsa, Stockholms Lans Landsting, 'LSS - the Law regulating Support and Services to Persons with Certain Functional Disabilities – in brief', accessed 25 April 2017, <[www.publicerat.habilitering.se/sites/pubhab.wklive.net/files/product-files/kort-om-lss-2014-engelska\\_0.pdf](http://www.publicerat.habilitering.se/sites/pubhab.wklive.net/files/product-files/kort-om-lss-2014-engelska_0.pdf)>.

## 2.6. Policy settings

The Committee heard evidence from people with autism, their families and the autism sector who questioned the apparent disappearance and lack of implementation of the 2009 Autism State Plan.<sup>219</sup> The Plan provided a policy framework, under which funding was provided for a range of programs and projects, some of which have been discontinued due to their funding having been subsequently withdrawn. The Committee appreciates that the State Disability Plans have incorporated focus areas from the Autism State Plan, and that specific autism actions are still being undertaken, and reported on, as described above by DHHS.

However, the Committee is of the view that the Autism State Plan provided an important policy platform for the Victorian Government, funded services and agencies, and people with autism and their families. It delivered significant advances in project and program development, which had positive outcomes, such as reductions in waiting lists for assessments and diagnosis. As Chapter One illustrated, the prevalence of diagnosed autism is rising in Victoria. The NDIS have reported that a significant proportion of those entering the scheme are doing so with a primary diagnosis of ASD.

The various policy models that the Committee heard about first hand on its study tour, or has reviewed through the literature, provide different approaches to policy formulation for people with ASD by governments. The United States has a broad based policy approach conducted at the federal level for people with ASD, involving coordination bodies, offices and committees. The states retain significant capacity themselves, both legislatively and in terms of policies and programs, as the Californian model of regional centres attests. In Scandinavia, the welfare model is designed to support people with ASD, through their lifetimes, in a broad based social commitment to people with disabilities. New Zealand and the UK both have national policies designed specifically for people with ASD, although the latter policy is targeted at adults with ASD.

In the jurisdictions reviewed, and notwithstanding their significant differences, the general trend in recent years has been towards the creation of specific policy frameworks for people with autism: such frameworks address autism as an area requiring specific, tailored and targeted programs and policies across government levels, agencies and the disability service sector. A policy framework specifically designed and articulated for people with ASD will raise the profile of autism in the community, create a common set of aims for policy makers, service providers, departments and agencies, and provide targets and expected outcomes against which progress can be reviewed.

In reviewing policy frameworks both here and overseas, and through the information gleaned from its study tour to the United States and Scandinavia, the Committee has also formed the view that Australia should move in the direction of developing and

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219 See for example: Dr Sandra Radovini, Director of Mindful, Centre for Training and Research Developmental Health, Department of Psychiatry, the University of Melbourne, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 3; Autism Family Support Association Inc., submission no. 71, p. 13-14; Amaze, submission no. 139, p. 16.



adopting a national strategy for people with ASD. The Victorian Government can use its role on the COAG Disability Reform Council to urge its counterparts and the Commonwealth to create such a strategy to provide for the needs of people with ASD across the country. This is particularly relevant in the context of the roll-out of the National Disability Insurance Scheme, under which national standards have been, and are being, developed for the disability sector. Accordingly, the Committee recommends that:

### **RECOMMENDATION 2.3**

**The Victorian Government use its position on the COAG Disability Reform Council to call for the development of a National Autism Strategy, a core principle of which will be the inclusivity of people with ASD.**

The Committee believes that the state requires a stand-alone strategic plan that is specifically devoted to the needs of people with ASD and families living with ASD. Victoria is well-placed to follow the emerging trend in other jurisdictions in developing specific state plans for people with autism, having already launched its own plan in 2009. An updated plan will: provide a policy framework for the provision of government-funded services for people with ASD; announce clear goals, aims and targets; and articulate key underpinning principles. The plan can build upon the consultative process undertaken for the 2009 plan, the Autism State Plan itself, the outcomes of this report, and engage with current stakeholders. Central to such a plan will be the expression of the principle of inclusivity.

Accordingly, the Committee recommends that:

### **RECOMMENDATION 2.4**

**The Victorian Government update the 2009 Autism State Plan as a matter of priority to strategically address the ongoing needs of people with ASD and families living with ASD. A core principle of the Plan be the inclusivity of people with ASD.**

- **Any developments in policy, programs and services must involve the engagement and consultation of people with ASD.**
- **The Victorian State Autism Plan be reviewed regularly in the national context.**



# Chapter 3

## The Early Years – Diagnosis and Intervention

### AT A GLANCE

#### Background

The Committee received a substantial amount of evidence concerning the early years of living with ASD, especially the difficulties associated with obtaining a diagnosis and accessing appropriate early intervention supports. This chapter examines the central concerns for many of the Inquiry's stakeholders in access to timely and affordable assessment services for diagnosis, the lack of information available about how to choose an appropriate early intervention service, and the high out-of-pocket costs associated with some therapies.

There is broad agreement amongst experts in ASD, such as the Autism CRC, that best practice consists of a multidisciplinary assessment that takes place over a number of sessions involving, at minimum, a paediatrician or child and adolescent psychiatrist, a psychologist and a speech pathologist. An early diagnosis is considered essential as it paves the way for access to early intervention services, which are strongly associated with better educational outcomes and higher rates of employment and community participation later in life. The Committee is of the view that access to early diagnosis and intervention services is critical to ensuring the future support and success of children with ASD.

#### Chapter overview

The Committee heard from people with ASD and many families living with ASD about their experience accessing a diagnosis and early intervention. This chapter will begin by giving voice to the experiences of families and carers in obtaining a diagnosis. The chapter will then examine best practice in diagnosis and the barriers to achieving best practice in Victoria; the development of a national standard for diagnosing ASD in Australia; current national and international research, the Child and Adolescent Mental Health Services Network (CAMHS); the criticality of early intervention; and the role of evidence-based therapies. This chapter addresses the following terms of reference:

- a) the prevalence of autism spectrum disorder in Victoria; and
- b) the availability and adequacy of services provided by the Commonwealth, State and local governments across health, education, disability, housing, sport and employment services.

The Committee received a substantial amount of evidence concerning the early years of living with ASD, especially the difficulties associated with obtaining a diagnosis and accessing appropriate early intervention supports. A central concern for many of the Inquiry's stakeholders was access to timely and affordable assessment services for diagnosis. During the Inquiry, witnesses identified a number of barriers to achieving best practice diagnosis, including:

- A lack of awareness of ASD on the part of health professionals, especially General Practitioners (GPs);
- The absence of agreed national guidelines for diagnosis;
- Poor understanding of how girls with ASD present;
- Difficulties accessing publicly funded diagnostic services due to high demand;
- High cost of private services;
- Lack of services in rural and regional areas, and in Melbourne's west;
- Poor understanding of ASD in culturally and linguistically diverse communities and Aboriginal and Torres Strait Islander communities; and
- Inadequate numbers of speech pathologists, paediatricians and psychologists trained in ASD assessment.

The Committee heard that long journeys towards diagnosis and missed opportunities for the provision of appropriate care and services were the norm for parents and carers. Delays and misdiagnoses contributed to increased stress in families, as well as lost opportunities for addressing developmental delays in children. There is no agreed national standard for diagnosing ASD in Australia, or Victoria, nor is there a clear pathway for families seeking an assessment for their child. The Autism CRC is driving research into best practice standards for Australia.<sup>220</sup> International best practice for diagnosis is considered to be an assessment by a multidisciplinary team of clinicians, including a paediatrician (or child and adolescent psychiatrist), a psychologist and a speech pathologist.<sup>221</sup> Typically, individuals will visit these professionals over a number of different sessions and they will then confer on whether a child meets the criteria for a diagnosis of ASD under the DSM-5; this can be a time-intensive, costly and logistically difficult process. Individuals can also be diagnosed by a single practitioner, usually a private paediatrician.

This chapter addresses the following terms of reference: a) the prevalence of autism spectrum disorder in Victoria; and b) the availability and adequacy of services provided by the Commonwealth, State and local governments across health, education, disability, housing, sport and employment services.

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220 L Taylor, P Brown, V Eapen, S Midford, J Paynter, L Quarmby, T Smith, M Maybery, K Williams and A Whitehouse, *Autism Spectrum Disorder diagnosis in Australia: Are we meeting best practice standards?* Autism CRC, Indooroopilly, 2016.

221 For example, see: National Institute for Health and Care Excellence (NICE), *Autism: Recognition, referral and diagnosis of children and young people on the autism spectrum (Clinical Guidelines)*, 2011, accessed 4 May 2017, <[www.nice.org.uk/guidance/cg128/evidence/full-guideline-pdf-183228447](http://www.nice.org.uk/guidance/cg128/evidence/full-guideline-pdf-183228447)>.

### 3.1. ‘Has my child got ASD?’ The experience of families and carers in obtaining a diagnosis

A large amount of evidence received by the Committee came from parents and carers of children with ASD who spoke about their experiences with accessing and obtaining a diagnosis. While parents had varied experiences with health professionals and service providers, there were common themes that emerged in the evidence, including long waiting lists in the public system, a lack of service providers to facilitate assessment, high costs associated with accessing services, and a lack of information pre- and post-diagnosis.

Many families spoke about little follow-up post-diagnosis.<sup>222</sup> In a submission, one parent described their son’s diagnosis in 1992-93 at the Austin Hospital at the age of two and a half:

The diagnosis was very matter of fact and the delivery appalling. After telling us that our son will be disabled and the way he is for the rest of his life with no hope of a cure, we were left to go home in tears. Hopefully things have improved since then.<sup>223</sup>

In her submission, Ms Susan Pearce described the first signs of autism in her son at about two years old, such as appearing to give a blank stare, walking on his tiptoes, not interacting with other children, running away from crowds, struggling with social situations and not sleeping until very late.<sup>224</sup> The diagnosis was made after seeing two paediatricians, following a meeting with his preschool teachers who discussed the possibility of autism with Ms Pearce and her husband. Ms Pearce wrote in her submission:

We were at a loss as to what we need to do as there was no guide or information pack telling how to help your child. In a lot of ways the process involves parents trying to find out what is need [sic] and the paediatrician helping or guiding where possible. We read what information was available and contacted various organisations to find out what Simon would need. The local council facility was overwhelmed. It took three phone calls and six months for them to contact me by which time I had organised help for Simon. Our best support came from the 3 and 4 year old pre-school teachers who organised additional support to help Simon when he was in classes and a shoulder for me to cry on when needed.<sup>225</sup>

Ms Pearce’s son improved in a supportive and understanding preschool environment:

Fortunately, we had a very understanding pre-school community. An aid [sic] was arranged funded by the Council for all the kids with special needs in his group. A letter was sent to all the parents of the kids in Simon’s group, explaining his

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222 Name withheld, submission no. 108.

223 Name withheld, submission no. 18, p. 1.

224 Ms Susan Pearce, submission no. 50, p. 1.

225 Ibid.

condition from his perspective, assisting the other parents to explain to the kids about Simon, after which Simon felt accepted and blossomed.<sup>226</sup>

In her submission, Mrs Rebecca Spiteri spoke about her experience of her son's diagnosis at the age of two:

It was incredibly overwhelming and devastating. We felt bombarded by information and opinions – not just from family, but from both public and private organisations. In a sense, this was a time we were grieving a child we felt we had lost. This is the only way I can describe our feelings.<sup>227</sup>

Mrs Spiteri noted that parents needed a step-by-step guide of early intervention in the beginning, and also to have knowledge of what funding they were entitled to because, she notes, 'It is very difficult to take in so much information in the early months'.<sup>228</sup> In her submission, she wrote:

Now we embrace and celebrate our son's points of difference. We nurture his strengths and help him to develop and manage his not-so-strong points. This came through the help of some wonderful occupational therapists, speech therapists, GPs and transition workers. But it was hard to know which services to approach in the beginning.<sup>229</sup>

In her submission, Ms Deborah Ditchburn, the mother of a nine-year-old son with ASD, wrote of her journey towards a diagnosis for her son and the long waiting time before a formal diagnosis was made:

At first, the Speech Therapist and Paediatrician indicated that it was likely my son suffered from developmental delay rather than any disorder. He was suffering regular ear infections and it was assumed that this alone was impeding his language development. I sought the care of an Ear Nose Throat Specialist and he underwent what would be the first of four operations for the insertion of tympanostomy tubes. His speech didn't improve at the expected rate and the sensory seeking behaviours grew stronger. I was advised to begin the process of applying for an early intervention service. We were on a waiting list of more than 12 months and as he neared the age of 2, our Paediatrician observed that it was likely my son had a form of PDD-NOS (Pervasive development disorder not otherwise specified). This was a kind of no-man's land in terms of assistance with the cost of therapies and any form of funding so we were removed from the intervention waiting list (the qualifying criteria for intervention is a delay in 3 or more areas and our son was displaying only 2). As the gap between the development of a typical toddler and my little boy grew wider, the Paediatrician conducted the Childhood Autism Rating Scale test. My son was formally diagnosed with moderate autism aged 2 years and 8 months, with the Paediatrician, Psychologist and Speech Therapist now all concurring.<sup>230</sup>

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226 Ibid, p. 2.

227 Mrs Rebecca Spiteri, submission no. 16, p. 1.

228 Ibid, p. 2.

229 Ibid, p. 1.

230 Ms Deborah Ditchburn, submission no. 21, p. 1.

In her submission, Ms Ditchburn spoke of the ‘intricate web’ of early intervention funding, and how difficult it was for ‘an already overwhelmed parent’ to make sense of, and navigate, state and federal funding. She wrote:

A diagnosis changes everything, but it also changes nothing. It changed the way I parented him, how I helped him understand the world, and it opened many more doors with regards to funding, but it never change the way I loved him.<sup>231</sup>

At a public hearing in Melbourne, Ms Florence Mclver told the Committee:

Our son was diagnosed at age two and a half, and he is now 25. It was like we had to reinvent the wheel on our own. After talking to other parents, I do not think we are on our own. We have been faced with being our son’s only advocate, and we have had to seek funding for most of his life to cover most of his basic needs. Starting with education – kinder, primary, secondary and tertiary – every time, funding had to be sought and, every time, in a different bucket. This bucket runs out, and this one needs to be filled up. And every time, it involved a lot of research and determination and time on our part.<sup>232</sup>

It was not uncommon for parents to report a diagnosis being made after seeing many different health professionals. Ms Sarah Wilson told the Committee at a public hearing in Melbourne:

My story is my daughter was diagnosed at two years old – nearly three years old. At 18 months I had taken her to a private paediatrician in Sydney, a very well-respected paediatrician, who told me that this is definitely not autism, which shocked me because I was just like, ‘Oh, my goodness, that’s autism’. I did not expect that. We did see a speech pathologist when she was two because she had some words and then dropped them, and we thought she might have had hearing difficulties, which we checked out. The speech pathologist put us onto a developmental paediatrician, and the developmental paediatrician diagnosed autism over a year after I had first seen that first paediatrician.<sup>233</sup>

Ms Donna Milne described, in her submission, the experience of her son’s diagnosis at the age of four (in 2004) which was, for her and her husband, ‘quite a shock and a steep learning curve’:

Our first contact with a government agency was with the local council’s maternal health nurse service who performed a test on my son and established that there were some warning signs. Then a lady from the council came and carried out more testing in our house and then we were referred to a paediatrician. We were also referred to Early Intervention and it was here that a cognitive and autism assessment was carried out. We were very grateful for all the support that we

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231 Ibid.

232 Ms Florence Mclver, Family and Community Development Committee public hearing – Melbourne, 12 September 2016, transcript of evidence, p. 2.

233 Ms Sarah Wilson, Convenor, ABA Parent Support Network and president, ABIA, Family and Community Development Committee public hearing – Melbourne, 10 October 2016, transcript of evidence, p. 2.



received from these health and disability services and we were also lucky enough that it didn't cost us any money.

In the early days there was no private occupational therapist (Now there are 3 in Mildura) and so after our stint at Early Intervention (that finished when my son went to school) we did travel to Adelaide. Going to school meant for us that now we had to fund our child's therapy. It is still ongoing and we are still paying.<sup>234</sup>

For some parents, the presentation of ASD was not as apparent in their children and the diagnosis of ASD came as a shock. In her submission, Ms Cathy Talia-Parker, the mother of a son with autism, recalled:

It was only by accident through my then local doctor when I took my son to see him regarding a nasty cold that he had observed more to worry about than I ever had thought! And that's when our long frustrating journey began in the world of Autism!! My son was then 3 years old.<sup>235</sup>

Parents, such as Ms Talia-Parker, spoke of the vital need for medical and health professionals to be provided with the necessary training to pick up signs of ASD:

After all of our visits to see our local Health and Maternal nurses...Why had not one of them noticed that something was not quite right!? Should they be equipped with further knowledge and skills in relation to identifying any autistic features/traits that babies and toddlers are displaying?? Many mothers that I have come to know have asked the same question! This was and is a problem in the system!<sup>236</sup>

### **3.1.1. Issues contributing to the delays in diagnosis**

Many stakeholders highlighted the importance of early diagnosis for access to early intervention services because of the age cap on government-funded intervention services. To be eligible for the Helping Children with Autism (HCWA) funding package a child must be diagnosed before the age of six, and the funding ceases at the age of seven. The long waiting time for diagnosis can mean that children miss out on the HCWA funding packages. In her submission, consultant paediatrician Dr Deborah Morawetz, who works in the western region of Melbourne, wrote:

The reported wait time for a public multidisciplinary assessment for ASD (the gold standard diagnostic assessment which includes an ADOS assessment) is anywhere between 12-18 months, which is unacceptably long. For a child presenting age 4½ years this means that many miss out on intensive early intervention, and some may miss the 6 year old 'cut-off' for accessing FaHCSIA funding.<sup>237</sup>

At a public hearing in Melbourne, Professor Cheryl Dissanayake from the Olga Tennison Autism Research Centre (OTARC) said that there was a need for greater

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234 Ms Donna Milne, submission no. 91, p. 1.

235 Ms Cathy Talia-Parker, submission no. 38, p. 1.

236 Ibid.

237 Dr Deborah Morawetz, submission no. 27, p. 2.

awareness of the very early signs, not just amongst parents but also amongst professionals:

[A] paediatrician saying this child is too young to diagnose with autism is not uncommon. GPs and paediatricians continue to think that this is not possible in very early life, so I think we need to change that. Of course you get pockets of excellence but across the board it is not recognised that very early diagnoses are possible.<sup>238</sup>

For some families, multiple attempts to gain an accurate diagnosis and experiences of misdiagnoses meant lost opportunities for appropriate care and therapies. As discussed in Chapter One, the long waiting lists and uncertainty that often precedes a diagnosis impacts the mental health and wellbeing of parents and families who are told that early intervention is important, and yet face long delays in obtaining a diagnosis.<sup>239</sup> The Committee heard that early identification and diagnosis leads to a reduction in family stress and an increase in family wellbeing.<sup>240</sup>

Speech Pathology Australia noted that waiting lists for publicly funded services had reduced following the launch of the Victorian Autism State Plan in 2009, however these waiting times have increased again and were around 12-24 months in 2016.<sup>241</sup> In their submission, Speech Pathology Australia stated:

Many children prior to a diagnosis of ASD will first access a speech pathology service through their local community health centre. They will often have to wait (sometimes up to 12 months) to access this service. If concerns that the child may have ASD are raised by the Community Health speech pathologist, then the child will be placed on the waiting list for an Assessment Team and / or an Early Childhood Intervention Service. Another lengthy wait of between 12 to 18 months will likely follow before they actually receive this specialised service.<sup>242</sup>

In their submission, Mindful – Centre for Training and Research in Developmental Health ('Mindful') noted that there is inequity in access to diagnostic services and intervention in rural areas and in the western region of Melbourne. For example, in the western region, families often encounter waiting lists of over 12 months (despite having several dedicated ASD assessment teams at the Royal Children's Hospital (RCH), Melton Health Service and Sunshine Hospital) in contrast to waiting lists of 1-6 months in the eastern and southern areas of Melbourne.<sup>243</sup> Mindful noted:

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238 Professor Cheryl Dissanayake, Founder and Director, Olga Tennison Autism Research Centre, La Trobe University, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 3.

239 Ibid, p. 7.

240 Ibid, p. 2.

241 Speech Pathology Australia, submission no. 136, p. 9.

242 Ibid, p. 10.

243 Mindful – Centre for Training and Research in Developmental Health, submission no. 134, p. 4. See also, the Centre for Research Excellence in Child Language submission to the Senate Community Affairs Reference Committee, *Inquiry into the Prevalence of different types of speech, language and communication disorders and speech pathology in Australia*, 2014 (submission no. 161, p. 10). This submission maps the location of public and private speech pathology and early intervention services against areas of language and cognitive skill vulnerability, showing inequity of service distribution across Melbourne and few services in West.

From waiting list data collected across the state from the ASD coordinators of the tertiary neurodevelopmental assessment teams there is a very clear inequity of access to services with significantly longer waiting lists in Western Region of metropolitan Melbourne and in rural areas... This reflects a high need for western region clients to have access to publically funded clinics due to significant socio economic disadvantage and large numbers of CALD families requiring access to interpreters, not readily available in the private sector assessments. These issues are also evident in regional areas with high waiting lists such as Shepparton and Bendigo.<sup>244</sup>

In their submission, the Royal Children's Hospital stated:

Access to quality diagnostic services is variable in the state and often inequitably distributed with difficulties for regional children and those unable to access private services. There is also an artificial disjuncture between diagnostic and intervention services, fracturing the system even further.<sup>245</sup>

In their submission, Speech Pathology Australia noted that many individuals with ASD cannot access the specific services they require, such as services that are culturally appropriate and geographically available:

For some individuals with ASD their needs will be complex. They may have a co-occurring intellectual disability and a mental health disorder, or the severity of their impairments may be high. These individuals require the support only available from a specialist autism specific service. Many parents and carers report frustration about not being able to access these services because they do not exist in their geographical location (e.g., autism specific schools). Compounding this problem in accessing specialised autism services is the overlay of clinical complexity found for children from culturally and linguistically diverse communities or indigenous children who require culturally appropriate and specialised autism services.<sup>246</sup>

The diagnostic process can be further complicated by the existence of co-occurring mental health issues, such as anxiety, depression, ADHD and OCD, and high rates of intellectual disability experienced by people with ASD.<sup>247</sup> It may be difficult for clinicians unfamiliar with ASD to differentiate between symptoms associated with autism and those related to a co-occurring condition or mental illness. In their submission, Austin Child and Adult Mental Health Services (CAMHS) wrote:

[A]t Austin CAMHS, approximately 50% of adolescents referred over an 18 month period for assessment within the Community Mental Health Team with ASD type

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244 Mindful – Centre for Training and Research in Developmental Health, submission no. 134, p. 4. See also, the Centre for Research Excellence in Child Language submission to the Senate Community Affairs Reference Committee, *Inquiry into the Prevalence of different types of speech, language and communication disorders and speech pathology in Australia*, 2014 (submission no. 161, p. 10).

245 Royal Children's Hospital Melbourne, submission no. 143, p. 2.

246 Speech Pathology Australia, submission no. 136, p. 10.

247 Amaze, submission no. 139, p. 15; Speech Pathology Australia, submission no. 136; Royal Australian & New Zealand College of Psychiatrists, submission no. 144; Victorian Disability Advisory Council, submission no. 146.

behaviours were ultimately diagnosed with other disorders such as Attachment Disorder, Social Anxiety Disorder or Social Communication Disorder. The Autism Spectrum Disorder Assessment programme accepts referrals from paediatricians for clarification of the diagnosis in children aged 3-12 yrs. Similarly between 35 -40% of cases were not given an ASD diagnosis during the 12 months of 2015. These high rates of non diagnosis suggest complex presentations and the need for thorough assessment. The rigour and reliability of differential assessment and diagnosis appears highly variable across the sectors of disability, mental health and private practice where differing knowledge and standards of assessment occur. Assessment processes vary from a single practitioner to multi-disciplinary team assessments with varying degrees of collateral information, ranging from developmental assessments and standardised screening tools being applied. The reliability of diagnosis appears particularly problematic for young people where normal intelligence, more subtle presentations of ASD and mental health problems are evident.<sup>248</sup>

The Committee heard from many parents of children who were diagnosed later and missed out on early intervention funding. Ms Sara Cartwright, the mother of a six-year-old daughter, spoke about the difficulty with the early intervention funding cut off, in her submission to the Inquiry:

She has only recently been diagnosed (she turns 7 in a few days) because it wasn't until she started school that it became apparent that it wasn't just 'Terrible Twos' (and threes and fours and fives) that was causing the behaviour. She was already 6 when the diagnosis occurred, so we have missed out on a great deal of government funding which could help her drastically - psychologist, occupational therapists, speech pathologists - these things are all things that she needs, regardless of when she was diagnosed. So why is it that the day she turns 6, the government believes that she no longer needs these things?<sup>249</sup>

Many families were critical of the age capped funding. Ms Dianna Lane, whose 16-year-old daughter was diagnosed at the age of seven and therefore was ineligible for funding, wrote in her submission:

That's great offering the HCWAP but children with Autism do not suddenly get better...It is a life long condition. We have found that older children/ teenagers living with Autism are forgotten as the funding is not available and they are suddenly supposed to be 'normal' which is certainly not the case. In fact Chloe has regressed as she approached puberty and her anxiety and behaviour have become extremely challenging as she is frustrated, angry and lacks the communication and ability to regulate her emotions.<sup>250</sup>

In his submission, Mr James Tucker, an adult with ASD who also has a son with ASD, both diagnosed late, wrote:

ASD treatments are considered most successful if they are provided early in life (before 7 and preferably before 5 years of age), and the majority of current

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248 Austin Child and Adolescent Mental Health Service (CAMHS), submission no. 113, pp. 1-2.

249 Ms Sara Cartwright, submission no. 124, p. 2.

250 Ms Dianna Lane, submission no. 11, p. 1.

government support is targeted this way. However, many people [do not] "present" with ASD symptoms until later in life. And since ASD is incurable, some form of on-going support may also be needed.<sup>251</sup>

Many parents of daughters with ASD spoke of a long and complicated process towards diagnosis with many professionals dismissing a diagnosis of ASD due to not understanding how ASD presents in girls. Ms Avigale Bischard, a parent of a 17-year-old daughter, wrote in her submission:

My 17 year old daughter has only recently been given her diagnosis of Autism Spectrum Disorder by a Neuro-developmental Pediatrician. Seven years ago a young male teacher at her primary school diagnosed her but his opinion didn't carry any weight. He was in fact the real expert, his sister was Autistic. It took us the next six years of going from Psychologists, Doctors, Counsellors and Psychiatrists to finally get the correct cause of our daughter's problems. She was given labels for most of the co-morbid conditions of Autism, including school refusal, eating disorders, Social anxiety, Attachment Disorder, stress etc.<sup>252</sup>

Mr Graeme Drysdale gave similar evidence of the challenge of getting girls diagnosed and illustrated the impact on individuals, families and the wider community. In his submission, Mr Drysdale stated that it took seven years for his 17-year-old daughter to be diagnosed, which he described as 'too long', noting that her education and social life were profoundly affected during that time:

For seven years my daughter saw various counsellors, psychiatrists, and psychologists. None of these people had the skills, experience or understanding of aspergers in girls to recognise my daughter's condition. We tried seeing psychiatrists but their fees are mercenary.<sup>253</sup>

Ms Narelle McCaffrey told the Committee at a public hearing in Melbourne:

Prior to [my daughter being diagnosed] I had seen two different paediatricians who both said, 'No, she's just shy. She'll blossom'. Clearly they did not know much about girls and autism. So we saw this developmental paediatrician a number of times. We took her to have an assessment with a speech pathologist. I do not know why he did not send us to a psychologist; we saw an OT instead. It took a few months, that whole process.<sup>254</sup>

Similarly, Ms Jo Backway told the Committee in her submission that her 11-year-old daughter exhibited signs of autism at kindergarten but that these traits were classed as "quirky" rather than 'autistic'. At primary school, these traits became more evident, but her daughter was only diagnosed at the age of eight after being on a

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251 Mr James Tucker, submission no. 9, p. 1.

252 Ms Avigale Bischard, submission no. 15, p. 1.

253 Mr Graeme Drysdale, submission no. 19, p. 1.

254 Ms Narelle McCaffrey, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 4.

waiting list to see a local paediatrician for eight months.<sup>255</sup> The experience of girls with ASD is discussed in detail in Chapter Seven.

## 3.2. The diagnostic process

While the DSM-5 provides the classification standard for establishing a diagnosis of ASD, it is not an actual test for ASD. There is, in fact, no single test for ASD and no diagnostic test which provides ‘a definitive answer’.<sup>256</sup> Diagnosis is based on observation of a child’s behaviour and interaction with others, assessment of developmental delays, interviews with parents and reviewing a child’s developmental history. Many stakeholders, such as Speech Pathology Australia, advocated for a consistent approach to the diagnostic process for ASD.<sup>257</sup> Speech Pathology Australia considered that many individuals with ASD encounter inconsistencies in the approaches used by health professionals to diagnose ASD. In their submission, they stated:

In Australia, there is no standard approach to the diagnosis of ASD. This is despite there being strong agreement, particularly internationally, as to best practice guidelines for ASD assessment.<sup>258</sup>

In a 2015 Autism CRC survey of health professionals conducting ASD assessments, around half of participants in the survey used the Autism Diagnostic Observation Schedule (ADOS), which monitors child play and social interaction through a series of structured and semi-structured tasks. Only thirty per cent used both the ADOS and the Autism Diagnostic Interview Revised (ADI-R) which is a structured parent interview.<sup>259</sup> The report noted:

The results confirmed that there is a lack of consistency in diagnostic practices across Australia and that some professionals may not be practicing in a way that is consistent with international best practice guidelines for ASD diagnosis.<sup>260</sup>

The survey also found that while there were more multidisciplinary assessment teams in the public sector than in the private sector, ‘sole practitioners rarely collaborate with other professionals to make diagnostic decisions’.<sup>261</sup> In their submission, Speech Pathology Australia noted that there was a lack of funding to support private practitioners to work in a collaborative way, as the Medicare Helping

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255 Ms Jo Backway, submission no. 59, p. 1.

256 K Bull and S Radovini, *A guide to identification, diagnosis and treatment of autism spectrum disorder in Victorian mental health services*, Mindful Centre for Training and Research in Developmental Health, Melbourne, 2013, p. 49. See also Dr Neil Coventry, Chief Psychiatrist, Department of Health and Human Services, Family and Community Development public hearing – Melbourne, 7 November 2016, transcript of evidence, p. 6.

257 Speech Pathology Australia, submission no. 136.

258 Ibid, p. 12.

259 L Taylor, P Brown, V Eapen, S Midford, J Paynter, L Quarmby, T Smith, M Maybery, K Williams and A Whitehouse, *Autism Spectrum Disorder diagnosis in Australia: Are we meeting best practice standards?* Autism CRC, Indooroopilly, 2016, p. 5.

260 Ibid.

261 Ibid.



Children with Autism assessment item number 82020 can only be claimed for a face-to-face service with the client.<sup>262</sup>

As noted above, one of the reasons that there are delays in the diagnostic process is because diagnoses are subjective and behaviourally based. In their submission to the Inquiry, Austin CAMHS stated:

Interpretation of the criteria for diagnosis is highly subjective and ultimately clinical in nature. Although the statistical results of standardised tools are used to make a diagnosis, their small print always refers to clinical knowledge and expertise overriding statistical results. Consideration for differential diagnosis seems to rely on the experience, knowledge and framework within which the diagnosing practitioner works.<sup>263</sup>

### 3.2.1. Tests for diagnosing ASD

This section examines the diagnostic process, best practice multidisciplinary diagnostic teams, the role of speech pathologists in diagnosing ASD, the work of CAMHS and the development of a national standard for diagnosing ASD. As described in Chapter One, the DSM-5 and the ICD-10 are the international classification standards for establishing a diagnosis of ASD. The DSM-5, a manual for mental health professionals, is more commonly used by clinicians in Australia. ASD is diagnosed based on two areas: difficulties in social communication and restricted, repetitive behaviour or interests. Professionals can also rank the severity of ASD using the DSM-5.<sup>264</sup>

A diagnostic assessment for young children may include a comprehensive medical assessment, including hearing and vision tests and tests for genetic disorders.<sup>265</sup> Clinicians generally use a combination of tests in diagnosing autism. The Autism Diagnostic Observation Schedule (ADOS-2) is used to assess and diagnose ASD across age, developmental level and language skills from the age of one year onwards. ADOS-2 is a semi-structured assessment, which uses special toys, pictures and prompts to elicit behaviours. ADOS-2 consists of four modules to cater for different ages and can be used to assess and diagnose ASD in children and adults.<sup>266</sup>

The Autism Diagnostic Interview-Revised (ADI-R) is a structured interview conducted with the parents or carers of an individual being assessed for ASD. The interviews

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262 Speech Pathology Australia, submission no. 136, p. 12.

263 Austin Child and Adolescent Mental Health Service, submission no. 113, pp. 1-2.

264 American Psychological Association, *Diagnostic and statistical manual of mental disorders* (5<sup>th</sup> ed.), Arlington, VA, American Psychiatric Publishing, 2013.

265 K Bull and S Radovini, *A guide to identification, diagnosis and treatment of autism spectrum disorder in Victorian mental health services*, Mindful Centre for Training and Research in Developmental Health, Melbourne, 2013, p. 54.

266 Australian Council for Educational Research, 'Autism Diagnostic Observation Schedule – Second Edition (ADOS-2)', accessed 5 June 2017, <[shop.acer.edu.au/autism-diagnostic-observation-schedule-second-edition-ados-2](http://shop.acer.edu.au/autism-diagnostic-observation-schedule-second-edition-ados-2)>.



cover the full developmental history of the child and can be used for a child with a mental age of at least 18 months.<sup>267</sup>

Other diagnostic tests which may be used, depending on the age of the child and the clinicians involved, include the following:

- Psycho-Educational Profile – Third Edition (PEP-3);
- Wechsler Pre-School and Primary Scale of Intelligence – Third Edition (WPPSI-III);
- Vineland Adaptive Behavioural Scales (VABS-II);
- Clinical Evaluation of Language Fundamentals - Fourth Edition (CELF-4 Australian);
- Preschool Language Scale, Fourth Edition (PLS-4);
- Developmental Behaviour Checklist;
- Childhood Autism Rating Scale (CARS);
- Other assessments to investigate sensory problems, motor planning and coordination.<sup>268</sup>

There are various screening tools used by GPs, Maternal and Child Health nurses and early childhood educators during regular encounters with young children to monitor development and elicit concerns from parents, such as the Parents' Evaluation of Developmental Status (PEDS), which is a ten-item questionnaire for parents.<sup>269</sup> The questionnaire takes a few minutes to complete and score.

Autism screens are particularly important for 'at risk' groups such as siblings of children with ASD, children with a developmental delay, children with emotional and behavioural problems, and children with genetic syndromes or other developmental problems.<sup>270</sup> As noted by Dr Kerry Bull and Dr Sandra Radovini from Mindful:

Screens are not diagnostic, but sort out those who are likely to have the condition from those who are likely not to. Screening instruments can provide valuable information about a child's development and behaviour and can provide a structure for parents and professionals to talk about their understanding of the child in different settings. This is an important 'first step' in informing parents and professionals of the need for referral for further assessment.<sup>271</sup>

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267 Autism Genetic Resource Exchange, 'Autism Diagnostic Interview-Revised (ADI-R), Autism Speaks, accessed 5 June 2017, <[research.agre.org/program/aboutadi.cfm](http://research.agre.org/program/aboutadi.cfm)>.

268 K Bull and S Radovini, *A guide to identification, diagnosis and treatment of autism spectrum disorder in Victorian mental health services*, Mindful Centre for Training and Research in Developmental Health, Melbourne, 2013, p. 54.

269 Ibid, pp. 38-39.

270 Ibid, p. 41.

271 Ibid.

Screening tools currently used in Victoria include the Checklist for Autism in Toddlers (ChAT), the Modified Checklist for Autism in Toddlers (M-ChAT), the Developmental Behaviour Checklist (DBC) and the Brigance (Developmental Assessment Tool).<sup>272</sup>

### 3.2.2. Referral pathways

In their guidebook, Bull and Radovini note that referral and support should take place as soon as there is concern about a child's behaviour and development, stating that 'It is not necessary to wait for a diagnosis'.<sup>273</sup> However, they note that in Victoria, there are a number of referral pathways, which 'makes it confusing for parents and professionals alike'.<sup>274</sup> These referral pathways include: a primary health practitioner (GP, Maternal and Child Health Nurse); an Early Childhood Intervention Service (ECIS); a Community Health Service; and allied health practitioners.<sup>275</sup>

#### Maternal and child health nurses

The Maternal and Child Health Service (MCH) is provided in partnership with the Municipal Association of Victoria (MAV), local governments and the Department of Education and Training (DET) as a universal primary care service for all Victorian families with children from birth to school age. The Service focuses on health promotion, prevention, early detection and intervention for physical, emotional and social factors affecting young children and their families.<sup>276</sup>

The Maternal and Child Health Service promotes regular contact between the Service and the child and family through the recommended schedule of contact in the Key Ages and Stages Framework, including an initial home visit and consultations at two weeks, four weeks, eight weeks, four months, eight months, 12 months, 18 months, 2 years and 3.5 years.<sup>277</sup> Alongside the universal MCH Service, which is available to all Victorian families in rural and metropolitan areas, there is also an 'Enhanced Maternal and Child Health Service' which provides, in addition to the universal service, a more intensive level of support for children, mothers and families at risk of poor health and wellbeing.<sup>278</sup> There is also a Maternal and Child Health Line, which provides 24-hour telephone support, advice, information, counselling and referral for families with children from birth to school age.<sup>279</sup>

MCH nurses must be 'registered with the Nurses Board of Victoria as Registered Nurses Division 1, registered midwives holding an accredited post-graduate qualification in maternal and child health nursing'.<sup>280</sup> All Maternal and Child Health Nurses in Victoria must have the following qualifications:

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272 Ibid, pp. 41-42.

273 Ibid, p. 45.

274 Ibid.

275 Ibid, pp. 45-47.

276 Department of Education and Early Childhood Development (DEECD), *Maternal and Child Health Service Program Standards*, Melbourne, DEECD, 2009, p. 15.

277 Ibid.

278 Ibid, p. 9.

279 Ibid.

280 Ibid, p. 35.

- Bachelor of Nursing (three year degree)
- Midwifery training (either included in general training of a four year degree or as a separate post graduate one year course)
- Graduate Diploma in Family Child and Community Health Nursing (postgraduate course at university).<sup>281</sup>

MCH nurses are trained in developmental concerns during their tertiary education and are 'highly skilled with assessment for developmental delays and communication disorders'.<sup>282</sup> MCH nurses are required to complete 40 hours of continuing professional development (CPD) as part of their registration with the Australian Health Practitioner Regulation Agency.<sup>283</sup>

The Committee heard that MCH nurses can also receive additional training from government departments, such as DET, MAV, various local autism services providers, such as Gippsland Autism Professionals, and universities, such as La Trobe's Social Attention and Communication study (SAC trial).<sup>284</sup> In 2011, the Department of Education and Early Childhood Development (DEECD) also funded Monash University's Centre of Developmental Psychiatry and Psychology to deliver the Autism Secondary Consultation and Training Strategy (ACT-NOW), which included professional development for MCH nurses by the ACT-NOW training group.<sup>285</sup>

MCH nurses often use the Brigance (Developmental Assessment Tool) as a secondary screen and as a tool to refer a child to other services, predominantly a GP and speech pathologist as 'first line of referral'.<sup>286</sup> If there is an active ECIS in their area that accepts direct referral from MCH nurses, the MCH nurses use this referral pathway.<sup>287</sup> MCH nurses reported that other referral pathways include a community health service for speech and occupational therapy review, an audiologist, a paediatrician, a physiotherapist, or a psychologist.<sup>288</sup> MCH nurses may also refer families to services in their area that provide opportunities for the child to develop skills and interact with peers, such as a supported playgroup, the Mother Goose Program, library services such as Rhyme Time, the Home Interaction Program for Parents and Youngsters (HIPPY), and parenting support programs to assist parents in managing problematic behaviours.<sup>289</sup>

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281 Victorian Association of Maternal and Child Health Nurses (ANMF Vic), correspondence, dated 24 April 2017.

282 Ibid.

283 Ibid.

284 Ibid.

285 Department of Education, 'Resources for MCH Nurses', Victorian Government, accessed 16 May 2017, <[www.education.vic.gov.au/childhood/professionals/support/Pages/nurses.aspx](http://www.education.vic.gov.au/childhood/professionals/support/Pages/nurses.aspx)>.

286 Victorian Association of Maternal and Child Health Nurses (ANMF Vic), correspondence, dated 24 April 2017.

287 Ibid.

288 Ibid.

289 Ibid.

MCH resources and referral forms, including referral forms for ASD, are available on the Department of Education and Training website.<sup>290</sup> There are also ‘tip sheets’ (developed by Monash University’s ACT-NOW) for MCH nurses to conduct the Parents’ Evaluation of Developmental Status (PEDS) screening tool at eight, 12, 18 months and two and three-and-a-half years during consultations to screen for ‘red flags’ for autism. As noted on the website:

These small red flags alert the MCH nurse to the prompts on these PEDS tip sheets that are important not only from a developmental point of view but also relate to some early signs of autism and form the basis of a thorough surveillance protocol.<sup>291</sup>

The reverse side of these tip sheets provide further information for MCH nurses to identify ‘red flags’ in the responses given by parents, which may indicate early signs of autism relevant to that particular age and stage and may warrant further surveillance.<sup>292</sup>

The Committee believes that Maternal and Child Health nurses have a critical and central role in developmental surveillance and can act as a key referral pathway to diagnosis. The work of OTARC, which is discussed later in this chapter, demonstrates how effective this model is, building on a well-regarded free community service that most parents access. The Committee believes that key training programs for Maternal and Child Health nurses, such as ACT-NOW and the SAC trial, are important to ensuring that nurses have the skills and capacity to perform this role in the early detection of possible ASD. As detailed below, these training programs are no longer funded.

Accordingly, the Committee recommends that:

### **RECOMMENDATION 3.1**

**The Victorian Government provide funds and resources so that all current and future Maternal and Child Health Nurses are trained in the developmental surveillance of children with possible autism, and to support those children and families in referral for diagnosis.**

#### **General Practitioners**

General Practitioners (GPs) are often the first point of contact for many families with concern over their child’s behaviour and development. Hence, GPs play a key surveillance role in determining whether a young child might require further screening and referral for an ASD assessment to a paediatrician, child psychiatrist or ASD assessment team. As noted above, GPs can use several different screening tools,

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290 Department of Education, ‘Resources for MCH Nurses’, Victorian Government, accessed 16 May 2017, <[www.education.vic.gov.au/childhood/professionals/support/Pages/nurses.aspx](http://www.education.vic.gov.au/childhood/professionals/support/Pages/nurses.aspx)>.

291 Ibid.

292 Ibid.

such as M-ChAT and DBC, which are not diagnostic but can indicate whether a referral is necessary.<sup>293</sup>

In their position statement on ASD, the Australian Medical Association (AMA) note that there are currently no Australian clinical guidelines concerning the identification of ASD in general practice.<sup>294</sup> Accordingly, the AMA recommend, in addition to comprehensive clinical guidelines or minimum national standards, that all health professionals who interact with children be encouraged to develop and maintain their understanding of the early signs and symptoms of ASD.<sup>295</sup>

At a public hearing in Melbourne, Mr Braedan Hogan, Policy and Advocacy Manager of Amaze, described the need for greater understanding of autism among GPs and other medical professionals:

In 2008, when the Helping Children with Autism package was developed federally, there was an element of that package to actually develop and increase the understanding of autism through an on-line training module, which was owned by the AMA and the RACGP as well – to increase the capacity of the medical professionals, particularly primary health care professionals, so general practitioners, and increase their understanding and knowledge of autism. I guess with anything within the medical profession it does require a prolonged, sustained approach, and these things do take a long time. I guess from the general practitioner's perspective there are 100 things coming in the door that they need to be across. Because we are a state body and the AMA and the general college are federal bodies, we are not currently doing anything with them.<sup>296</sup>

The Committee received evidence that some GPs are not sufficiently knowledgeable about ASD and how to refer people for assessment. Some parents reported that their GP was critical to suggesting the possibility that their child had ASD, while for many parents their local doctor has not had the capacity or skills to recognise the features, characteristics or behaviours of ASD.<sup>297</sup> The Committee believes that GPs should be part of the early surveillance of the signs of ASD in children, and a key referral pathway to diagnosis, and be trained accordingly. As explained below, the Mindful – Centre for Training and Research in Developmental Health has trained over 1,000 clinicians, and developed a practice guide for the identification of ASD. Similarly, the Royal Children's Hospital also undertakes training for clinicians and others in the identification of ASD.

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293 B Tonge and A Brereton, 'Autism Spectrum Disorders', *Australian Family Physician*, vol. 40, no. 9, September 2011, p. 3.

294 Australian Medical Association, 'Position Statement: Autism Spectrum Disorder – 2016', AMA, 7 December 2016, accessed 16 May 2017, <[ama.com.au/position-statement/autism-spectrum-disorder-2016](http://ama.com.au/position-statement/autism-spectrum-disorder-2016)>.

295 Ibid.

296 Mr Braedan Hogan, Policy and Advocacy Manager, Amaze, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 8.

297 Ms Katie Koullas, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 2. Ms Christine Lyons, Family and Community Development Committee public hearing – Melbourne, 12 September 2016, transcript of evidence, p. 6; Ms Stacey Smith, Family and Community Development Committee public hearing – Geelong, 19 September 2016, transcript of evidence, p. 3.

The Victorian Government needs to support the training of the state's GPs in the identification of ASD. The Royal Australian College of General Practitioners should be supported to introduce training for GPs in the identification of ASD, in the form of a professional development course, that is accessible and cost effective, and to be delivered by the state's leading experts in ASD training.

Accordingly, the Committee recommends that:

### **RECOMMENDATION 3.2**

**The Victorian Government, in conjunction with peak bodies and the Royal Australian College of General Practitioners (Vic), facilitate the professional development of the state's general practitioners in the understanding and identification of ASD.**

### **RECOMMENDATION 3.3**

**The Victorian Government work with the Royal Australian College of General Practitioners (Vic) to enable improved access to information and updated resources for the understanding and identification of ASD.**

## **Paediatricians**

Paediatricians play an important role in the diagnosis and management of children and young people with ASD, and are an important part of a multidisciplinary team.<sup>298</sup> The Royal Australasian College of Physicians (RACP) has 609 practicing paediatricians on record in Victoria, which includes 247 general paediatricians and 72 community child health specialists.<sup>299</sup> There are approximately 53 paediatricians practicing in rural and regional Victoria.<sup>300</sup>

In 2008, the RACP prepared a statement titled 'A consensus approach for the paediatrician's role in the diagnosis and assessment of autism spectrum disorders in Australia', to 'clearly enunciate current paediatric medical opinion about the best approach to the diagnosis and assessment of suspected ASD'.<sup>301</sup> The statement details the principles and objectives guiding paediatricians in diagnosis and assessment of ASD, including the importance of early identification of ASD and early intervention, considering differential diagnoses and co-occurring conditions, and the importance of multidisciplinary assessment and management of ASD.<sup>302</sup>

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298 The Royal Australasian College of Physicians (RACP) Paediatrics and Child Health Division, 'A consensus approach for the paediatrician's role in the diagnosis and assessment of autism spectrum disorders in Australia', RACP, 2008, accessed 17 May 2017, <[www.racp.edu.au/docs/default-source/advocacy-library/pa-pol-a-consensus-approach-for-the-paediatricians-role-in-the-diagnosis-and-assessment-of-autism.pdf](http://www.racp.edu.au/docs/default-source/advocacy-library/pa-pol-a-consensus-approach-for-the-paediatricians-role-in-the-diagnosis-and-assessment-of-autism.pdf)>.

299 The Royal Australasian College of Physicians (RACP), correspondence, dated 19 April 2017.

300 Ibid.

301 The Royal Australasian College of Physicians (RACP) Paediatrics and Child Health Division, 'A consensus approach for the paediatrician's role in the diagnosis and assessment of autism spectrum disorders in Australia', RACP, 2008, accessed 17 May 2017, <[www.racp.edu.au/docs/default-source/advocacy-library/pa-pol-a-consensus-approach-for-the-paediatricians-role-in-the-diagnosis-and-assessment-of-autism.pdf](http://www.racp.edu.au/docs/default-source/advocacy-library/pa-pol-a-consensus-approach-for-the-paediatricians-role-in-the-diagnosis-and-assessment-of-autism.pdf)>.

302 Ibid.

All RACP general paediatricians and community child health paediatricians are trained over a six-year specialist program, which includes training in ASD and other complex neurodevelopmental disorders. Paediatricians also take part in continuing professional development (CPD), and other formal and informal professional development, related to the assessment and management of ASD. General paediatricians undertake developmental training over a six-month period, which includes skills and knowledge in ASD diagnostic criteria and co-occurring conditions, assessment tools, medication and management methods.<sup>303</sup>

Community child health paediatricians are trained to perform comprehensive assessments of a child's development, behaviour, learning and emotion.<sup>304</sup> They are also trained in classification systems such as the ICD-10 and DSM-5, and in using diagnostic tools such as the ADI-R, CARS, and ADOS-2.<sup>305</sup> The Victorian Training Program in Community Child Health at the Royal Children's Hospital is a 12-month fellowship, which provides Fellows with clinical experience at the Royal Children's Hospital, Monash Medical Centre, and specialist services in Geelong, Shepparton and Sunshine regions.<sup>306</sup> The program includes detailed training in ASD assessments and management, and over the last 35 years, the program has trained over 250 fellows.<sup>307</sup>

### Speech pathologists

Speech pathologists are an essential part of the multidisciplinary diagnostic, intervention and support team for individuals with ASD. Speech pathologists trained in Victoria generally complete four to five years of tertiary education.<sup>308</sup> The course curriculums include clinical experience and training in developmental language and speech disorders.

In their submission, Speech Pathology Australia explained the role of the speech pathologist in the assessment and diagnostic process:

The speech pathology assessment process involves multiple assessment sessions typically of one hour duration (generally two or three sessions) as the speech pathologist seeks to observe and assess the individual in a range of contexts (for example, clinic, home and/or educational setting) and in a range of communication

303 See learning objective 2.7.4: 'Assess and manage children and young people with autism spectrum disorder (ASD)' in The Royal Australasian College of Physicians (RACP) *General Paediatrics: Advanced Training Curriculum*, RACP, Sydney, December 2013, p. 40.

304 See learning objective 4.2.2: 'Describe assessment of development and learning' in The Royal Australasian College of Physicians (RACP) *Community child health: Advanced Training Curriculum*, RACP, Sydney, December 2013, p. 40.

305 Ibid.

306 Royal Children's Hospital, 'Victorian Training Program in Community Child Health fellowship', accessed 17 May 2017, <[www.rch.org.au/ccch/training-dev/Victorian\\_Training\\_program\\_in\\_Community\\_Child\\_Health\\_fellowship](http://www.rch.org.au/ccch/training-dev/Victorian_Training_program_in_Community_Child_Health_fellowship)>.

307 The Royal Australasian College of Physicians (RACP), correspondence, dated 19 April 2017.

308 Speech Pathology Australia grants accreditation to speech pathology programs. Speech Pathology Australia, 'Accreditation of university programs', Speech Pathology Australia, accessed 17 May 2017, <[www.speechpathologyaustralia.org.au/spaweb/Document\\_Management/Public/Become\\_a\\_Speech\\_Pathologist.aspx](http://www.speechpathologyaustralia.org.au/spaweb/Document_Management/Public/Become_a_Speech_Pathologist.aspx)>.



situations (e.g. structured and unstructured) and with a range of communication partners (e.g., family versus peers versus unfamiliar etc.)

An important role of a speech pathologist in the diagnostic process for individuals with ASD will be the differential diagnosis of ASD and other communication related disorders; including specific language impairment, social (pragmatic) communication disorder, language disorder, speech sound disorder (e.g., childhood apraxia of speech, and specific learning disorder (e.g. dyslexia).<sup>309</sup>

Speech Pathology Australia stated that the majority of assessments, especially diagnostic assessments, require two, three or more consultations with a speech pathologist.<sup>310</sup> Speech Pathology Australia further explained:

Other individuals with ASD will have speech and language skills within the normal range and their communication deficits will be in understanding language (e.g. they may not understand the subtleties of language and interpret language in a concrete way or literally, making the understanding of jokes, irony and sarcasm difficult). In particular, some may have difficulties using and understanding social communication (e.g., they may engage in one-sided monologues, they may not respond when someone is talking to them or interrupt inappropriately, they may stand too close to others or they may not use appropriate eye contact or gestures).<sup>311</sup>

In their submission, Mindful noted:

An assessment of language and social communication skills is a critical component of an ASD assessment. Therefore, the lack of access to speech pathology is a major problem for agencies attempting to provide diagnostic services without this essential component.<sup>312</sup>

Some children have been diagnosed without the multidisciplinary team approach, often without a speech pathologist.

As reflected in international standards, speech pathologists perform an important role in diagnosing ASD, and in ruling out other communication and speech disorders. They also serve an important function in early intervention treatments. The Committee is concerned that the level of training amongst the state's speech pathologists is not sufficient to meet the needs of the state-wide standard outlined above. The Committee has heard that there is currently a shortage of such trained speech pathologists, and notes that this situation will only be exacerbated by the increasing prevalence of ASD. The training of health professionals, including speech pathologists, is addressed below.

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309 Speech Pathology Australia, submission no. 136, p. 7.

310 Ibid, p. 5.

311 Ibid, p. 6.

312 Mindful – Centre for Training and Research in Developmental Health, submission no. 134, p. 6.

### 3.2.3. Best practice multidisciplinary diagnosis and the barriers to achieving it

The Autism CRC recently reported on the need for minimum national standards for ASD diagnosis across Australia to enable more consistent diagnostic practices across states and territories and ensure that future diagnostic assessments are in keeping with best practice guidelines.<sup>313</sup> In their submission to the Inquiry, Austin CAMHS discussed the problems with inconsistency in the way diagnoses are carried out, particularly for young people with more subtle presentations of ASD:

The rigour and reliability of differential assessment and diagnosis appears highly variable across the sectors of disability, mental health and private practice where differing knowledge and standards of assessment occur. Assessment processes vary from a single practitioner to multi-disciplinary team assessments with varying degrees of collateral information, ranging from developmental assessments and standardised screening tools being applied. The reliability of diagnosis appears particularly problematic for young people where normal intelligence, more subtle presentations of ASD and mental health problems are evident.<sup>314</sup>

During the Inquiry, the Committee heard that best practice in ASD diagnosis was a multidisciplinary diagnosis involving, at minimum, a paediatrician or child and adolescent psychiatrist, a psychologist and a speech therapist. This is consistent with key international and national guidelines on the assessment of ASD, such as the National Institute for Health and Care Excellence (2014) (NICE) and Autism Victoria's Diagnostic Process for Children, Adolescents and Adults Referred for Assessment of ASD (2010).<sup>315</sup> The agreed criteria for the diagnosis of ASD is defined by the DSM-5.<sup>316</sup>

NICE is an international leader in producing clear recommendations, based on the best available evidence. As stated in a report prepared by Roberts and Williams and funded by the NDIA about evidence-based support provided to preschool children, their families and carers:

All diagnosis and assessment guidelines require children to be assessed by a paediatrician or a child and adolescent psychiatrist, a psychologist and a speech pathologist and for a consensus diagnosis to have been reached in accordance with existing classification systems ... All recommend that consideration be given to detailed profiling of strengths and difficulties, beyond what may be needed for making a diagnosis, to enable tailoring of intervention and management strategies.

313 L Taylor, P Brown, V Eapen, S Midford, J Paynter, L Quarmby, T Smith, M Maybery, K Williams and A Whitehouse, *Autism Spectrum Disorder diagnosis in Australia: Are we meeting best practice standards?* Autism CRC, Indooroopilly, 2016.

314 Austin Child and Adolescent Mental Health Service, submission no. 113, p. 2.

315 National Institute for Health and Care Excellence (NICE), *Autism: Recognition, referral and diagnosis of children and young people on the autism spectrum (Clinical Guidelines)*, 2011, accessed 4 May 2017, <[www.nice.org.uk/guidance/cg128/evidence/full-guideline-pdf-183228447](http://www.nice.org.uk/guidance/cg128/evidence/full-guideline-pdf-183228447)>. See also: National Institute for Health and Care Excellence (NICE), *Autism Spectrum Disorder in under 19s: Recognition, referral and diagnosis (Clinical Guidelines)*, 2011, accessed 4 May 2017, <[www.nice.org.uk/guidance/cg128/resources/autism-in-under-19s-recognition-referral-and-diagnosis-35109456621253](http://www.nice.org.uk/guidance/cg128/resources/autism-in-under-19s-recognition-referral-and-diagnosis-35109456621253)>.

316 Mindful – Centre for Training and Research in Developmental Health, submission no. 134, p. 4.

Under DSM-5, the severity of ASD symptoms and level of functioning should be specified along with the presence of co-morbid conditions.<sup>317</sup>

There are significant barriers to the provision of multidisciplinary diagnosis by the public and private health system and a corresponding difficulty for parents and caregivers for their children seeking best practice assessment and diagnosis. Currently, parents' access to diagnosis is a difficult and protracted process. There are no obvious pathways to source a diagnosis, and there can be long waiting lists for publicly funded diagnostic services.<sup>318</sup> Parents can choose to source private professionals to assess and diagnose their child, however parents have reported high costs of private assessments, and spoken about needing to do so because of the long wait in the public system.<sup>319</sup>

Best practice guidelines recommended by NICE have a waiting period for diagnosis and assessment of ASD of no greater than three months but many individuals with ASD wait longer than 12 months to access a publicly funded service.<sup>320</sup> In their submission, Amaze noted that 'the average age of diagnosis in Australia is currently 49 months' for children receiving the HCWA program, 'with the most frequently reported age being 71 months'.<sup>321</sup> Amaze stated:

Given that research suggests a reliable and accurate diagnosis is possible for many children with autism at 24 months, this finding represents a possible average delay of 2 years and with common delays of up to 4 years...<sup>322</sup>

At a public hearing in Melbourne, Professor Dissanayake stated that the average age of diagnosis would be older than the average of 49 months as the paper citing the average age of diagnosis in Australia is based on data from the HCWA.<sup>323</sup> According

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317 J Roberts and K Williams, *Autism spectrum disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers*, 2016, report funded by the NDIA, p. 18. See also: Royal Children's Hospital Melbourne, submission no. 143, p. 5.

318 Austin Child and Adolescent Mental Health Service, submission no. 113, p. 2.

319 See for example, Ms Sarah Wilson, convenor, ABA Parent Support Network and president, ABIA, Family and Community Development Committee public hearing – Melbourne, 10 October 2016, transcript of evidence, p. 2; Ms Donna Milne, submission no. 91, p. 1; Mr Graeme Drysdale, submission no. 19, p. 1.

320 National Institute for Health and Care Excellence (NICE), *Autism: Recognition, referral and diagnosis of children and young people on the autism spectrum (Clinical Guidelines)*, 2011, accessed 4 May 2017, <[www.nice.org.uk/guidance/cg128/evidence/full-guideline-pdf-183228447](http://www.nice.org.uk/guidance/cg128/evidence/full-guideline-pdf-183228447)>. See also: Speech Pathology Australia, submission no. 136, p. 9; L Taylor, P Brown, V Eapen, S Midford, J Paynter, L Quarmby, T Smith, M Maybery, K Williams and A Whitehouse, *Autism Spectrum Disorder diagnosis in Australia: Are we meeting best practice standards?* Autism CRC, Indooroopilly, 2016, p. 20.

321 Amaze, submission no. 139, p. 18.

322 Ibid.

323 Professor Cheryl Dissanayake, Founder and Director, Olga Tennison Autism Research Centre, La Trobe University, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 2. See also: C Bent, C Dissanayake and J Barbaro, 'Mapping the diagnosis of autism spectrum disorders in children aged under 7 years in Australia, 2010-2012', *The Medical Journal of Australia*, 2015, vol. 202, no. 6, pp. 317-320.

to Professor Dissanayake: ‘we know this is an actual underestimate because it is only under seven-year-olds that access the HCWA package’.<sup>324</sup>

In their submission, peak body Amaze discussed many of the obstacles to accessing diagnostic services within Victoria in a timely manner, including:

- Lack of understanding of autism and its presentations by primary healthcare professionals such as local GPs or community nurses;
- Early signs of autism are not identified by family members but by other professionals such as a day care worker, a preschool teacher or another person closely involved in the care of children;
- Having to eliminate other possible causes of the developmental delay before reaching a hypothesis of autism;
- Lack of understanding of presentation of girls on the autism spectrum;
- A reluctance of paediatricians and paediatric psychiatrists to diagnosis autism under the age of three;
- Waiting lists for accessing diagnosis through the public health care systems;
- Limited access to diagnosticians in regional areas;
- Financial constraints for those seeking diagnosis through private diagnosticians, generally not wanting to wait for the public system;
- Lack of clear and concise information and support for family in navigating the diagnosis pathway;
- Parents and families have to fight the system to get a diagnosis and getting confirmation of what they already suspect requires a great deal of persistence; and
- Parents having conflicting views of potential developmental delays.<sup>325</sup>

The Committee supports the introduction in Victoria of the international model of best practice in ASD diagnosis, which is a multidisciplinary diagnosis involving a paediatrician or child and adolescent psychiatrist, a psychologist and a speech pathologist. The evidence received by the Committee in this Inquiry, including on its overseas study tour, is that a multidisciplinary approach to ASD diagnosis will provide the best and most enduring outcome for children with ASD, and families living with ASD. This also assists service providers and other authorities to provide better services.

An enormous amount of time, money and emotional effort has been expended by Victorian families in trying to obtain an assessment for their child. The diagnostic process should be timely, affordable, conducted to a state-wide standard, and available and accessible in the state’s public health system. In keeping with best practice, once a referral for assessment is made, a diagnosis should be conducted in

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324 Professor Cheryl Dissanayake, Founder and Director, Olga Tennison Autism Research Centre, La Trobe University, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 2.

325 Amaze, submission no. 139, pp, 18-19.

no more than three months from referral.<sup>326</sup> A multidisciplinary diagnosis must also be equally available to all Victorians – rural and regional communities, and the Western suburbs of Melbourne, must have equality of access to this resource.

The Committee also supports the introduction of a national standard in ASD diagnosis, and recommends on this later in this chapter. However, the Committee believes that the Victorian Government need not wait for the full development of a national standard prior to rolling out its own state-wide standard.

Accordingly, the Committee recommends that:

#### **RECOMMENDATION 3.4**

**The Victorian Government introduce a model of best practice in ASD diagnosis in Victoria, which consists of a multidisciplinary diagnosis involving, at minimum, a paediatrician or child and adolescent psychiatrist, a psychologist and a speech therapist, to be provided by the state's public health system.**

- **A target to be set to ensure a multidisciplinary diagnosis will be conducted within three months of a referral for diagnosis.**

#### **3.2.4. Mindful – Centre for Training and Research in Developmental Health**

Mindful – Centre for Training and Research in Developmental Health (Mindful) is the Victorian unit responsible for the delivery of postgraduate courses, training programs, professional development and research programs in child and adolescent mental health. Mindful is jointly hosted by the University of Melbourne and Monash University and is funded by a Victorian Department of Health and Human Services grant. Mindful offers training for all public and private sector clinicians, including CAMHS/CYMHS staff, psychiatrists, paediatricians, psychologists, speech pathologists, occupational therapists, social workers, teachers and family support workers. An estimated 250 CAMHS/CYMHS clinicians will attend Mindful training in 2017.<sup>327</sup>

Over the last five years, Mindful has trained over 1000 clinicians.<sup>328</sup> Mindful also developed a practice guide for the identification, diagnosis and treatment of ASD within Victorian mental health services.<sup>329</sup> As part of the 2009 Autism State Plan,

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326 National Institute for Health and Care Excellence (NICE), *Autism: Recognition, referral and diagnosis of children and young people on the autism spectrum (Clinical Guidelines)*, 2011, accessed 4 May 2017, <[www.nice.org.uk/guidance/cg128/evidence/full-guideline-pdf-183228447](http://www.nice.org.uk/guidance/cg128/evidence/full-guideline-pdf-183228447)>. See also: Speech Pathology Australia, submission no. 136, p. 9; L Taylor, P Brown, V Eapen, S Midford, J Paynter, L Quarmby, T Smith, M Maybery, K Williams and A Whitehouse, *Autism Spectrum Disorder diagnosis in Australia: Are we meeting best practice standards?* Autism CRC, Indooroopilly, 2016, p. 20.

327 Victorian Department of Health and Human Services, correspondence, questions on notice, dated 10 May 2017.

328 Mindful – Centre for Training and Research in Developmental Health, submission no. 134, p. 2.

329 K Bull and S Radovini, *A guide to identification, diagnosis and treatment of autism spectrum disorder in Victorian mental health services*, Mindful Centre for Training and Research in Developmental Health, Melbourne, 2013.

Mindful received funding for four years to develop a training program for ongoing professional development workshops in assessment and treatment of ASD and neurodevelopmental disorders. As part of the Autism State Plan, Mindful has established a network of regional ASD coordinators based in child and adolescent mental health services who were responsible for coordinating ASD assessment and linking with other services, such as paediatricians, disability services and early childhood intervention programs.<sup>330</sup>

Mindful conducts several postgraduate courses, such as:

- Child and Adolescent Psychiatry Course (CAPC) – a two-year full-time course for psychiatry registrars, psychiatrists and paediatric registrars comprising weekly seminars, supervised clinical work and supervision of child, adolescent, parent and family therapy. One seminar in Semester 1 is devoted to ‘Autistic Disorders’.<sup>331</sup>
- Child & Youth Mental Health – Intro to Assessment – a three-day training course for professionals working in clinical settings, which is a prerequisite to the Developmental Psychiatry Course (DPC).
- Developmental Psychiatry Course (DPC) – a one-year part-time course for those with a relevant undergraduate qualification and employment within a service that provides access to infants, children, adolescents and/or their families. According to Mindful’s website, the DPC course ‘builds a foundational knowledge in normal and abnormal development across the developmental stages, and builds competency in assessment, diagnosis, formulation, and treatment planning.’<sup>332</sup> On completion of the clinical and seminar components, participants are awarded a certificate of successful completion.
- Certificate in Child, Adolescent and Family Therapies – a two-year part-time course for graduates with a relevant undergraduate degree (for example, psychology, occupational therapy, speech pathology, general or psychiatric nursing, social work, medicine, education, or other similar disciplines) and with sufficient experience and/or prior training in conducting assessments and working with children, adolescents and families.<sup>333</sup> The Certificate offers two streams, one in theory and one in theory and clinical practice, the latter for students offering therapy who ‘want a strong foundation in theory as well as supervision in how to put this into practice’ in clinical supervision.<sup>334</sup>

330 Mindful – Centre for Training and Research in Developmental Health, submission no. 134, p. 3.

331 A Certificate of Satisfactory Completion in Child and Adolescent Psychiatry is awarded by the RANZCP when registrars have completed the requirements of the course. Mindful, ‘Child and Adolescent Psychiatry Course (CAPC)’, Mindful website, accessed 16 May 2017, <[www.mindful.org.au/Post-Grad-Courses/Child-and-Adolescent-Psychiatry-Course.aspx](http://www.mindful.org.au/Post-Grad-Courses/Child-and-Adolescent-Psychiatry-Course.aspx)>.

332 Mindful, ‘Developmental Psychiatry Course (DPC)’, Mindful website, accessed 16 May 2017, <[www.mindful.org.au/PGrad-Courses/Developmental-Psychiatry-Course-\(DPC\).aspx](http://www.mindful.org.au/PGrad-Courses/Developmental-Psychiatry-Course-(DPC).aspx)>.

333 The Certificate can be undertaken ‘in-house’ at Mindful or as part of a University of Melbourne Graduate Certificate, Graduate Diploma or Masters Degree. Mindful, ‘Certificate in Child, Adolescent and Family Therapies’, Mindful website, accessed 16 May 2017, <[www.mindful.org.au/PGrad-Courses/Certificate-in-Child,-Adolescent---Family-Therapie.aspx](http://www.mindful.org.au/PGrad-Courses/Certificate-in-Child,-Adolescent---Family-Therapie.aspx)>.

334 Trainees learn about the theory and principles of cognitive behaviour, psychodynamic and family therapies for working with children, adolescents, families and parents. Mindful, ‘Certificate in Child, Adolescent and Family Therapies: Brochure’, Mindful website, accessed 16 May 2017, <[www.mindful.org.au/Documents/2017-CAFT-Brochure.aspx](http://www.mindful.org.au/Documents/2017-CAFT-Brochure.aspx)>.



- Advanced Training in the Psychotherapies – a two-year course leading to the Certificate in Psychiatry – Psychotherapies for psychiatry registrars and psychiatrists.<sup>335</sup>

### **ASD coordinators**

There are ASD coordinators in each of the CAMHS and CYMHS across Victoria. The Committee heard from Dr Sandra Radovini at a public hearing in Melbourne that the ASD coordinators are the ‘go-to people within that service’ and they facilitate ASD assessment and diagnosis, oversee early intervention and ongoing care and facilitate referral pathways to other services.<sup>336</sup> The coordinators also link in with key service providers in their local areas, such as disability services, early childhood services, paediatricians and student support services.<sup>337</sup>

Despite the ASD coordinators having recurrent state funding, the Committee heard that funding for other programs, such as ACT-NOW, ReACT, and the DHHS case consultant practitioners, had been lost or decreased.<sup>338</sup> Other programs such as the positive behavioural support workshops and Mindful’s Statewide ASD Coordinator has been given short-term and time-limited funding.<sup>339</sup> The supports for schools implemented under the 2009 Autism State Plan, such as the regional coaches who provided support, training and consultation to individual schools, have also ceased.<sup>340</sup> Ms Frances Saunders told the Committee at a public hearing in Melbourne that Mindful’s state funding for training had also gone.<sup>341</sup> In their submission, Mindful stated that funding for many positive initiatives, which have ‘brought about improvements in the lives of children and young people with ASD’ have unfortunately been short-term:

Building a highly skilled workforce requires quality training and relative ease of access to training. It is our experience, as ASD coordinators, that capacity building relies on continuous funding streams to maintain an ASD skilled workforce.<sup>342</sup>

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- 335 The core seminars in the first six months of the course cover four modalities of individual psychodynamic therapy; CBT, Family therapy or group therapy, after which trainees specialise in their chosen modality. Mindful, ‘Advanced Training in the Psychotherapies’, Mindful website, accessed 16 May 2017, <[www.mindful.org.au/PGrad-Courses/Advanced-Training-in-the-Psychotherapies-\(VIC\).aspx](http://www.mindful.org.au/PGrad-Courses/Advanced-Training-in-the-Psychotherapies-(VIC).aspx)>.
- 336 Dr Sandra Radovini, Director, Mindful, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 2.
- 337 Mindful – Centre for Training and Research in Developmental Health, submission no. 134, p. 3.
- 338 Ms Frances Saunders, Statewide Autism Spectrum Disorder Coordinator, Mindful, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, pp. 3-4.
- 339 Ms Frances Saunders, Statewide Autism Spectrum Disorder Coordinator, Mindful, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 4; Mindful – Centre for Training and Research in Developmental Health, submission no. 134, p. 3.
- 340 Ms Frances Saunders, Statewide Autism Spectrum Disorder Coordinator, Mindful, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 4.
- 341 Ibid.
- 342 Mindful – Centre for Training and Research in Developmental Health, submission no. 134, p. 5.



Ms Saunders noted recurrent funding meant that assessment teams could continue in ‘a quality way’:

One of the good things in terms of child and adolescent mental health is the ASD coordinators for each mental health region are still there. Because it had recurrent funding it has been able to maintain that profile within each service. If a young person comes in with complexity or needs assessment, in each of those services we know there is an expert person there who has a team of appropriate professionals around them providing appropriate diagnostic services and advice about treatment options. So that has been one really positive thing to do with funding that continues that allows the retention of skills and the retention of good service in the mental health area.<sup>343</sup>

In their submission, Mindful stated that major issues of concern identified by their metropolitan ASD coordinators were around access to quality services, lack of integration across government services, training and workforce issues and continuity of past positive initiatives for children, young people and adults.<sup>344</sup> By contrast, the major issues of concern identified by Mindful regional ASD coordinators were around the lack of access to allied health disciplines, limited access to private or public services for ongoing care and treatment, few paediatricians and child and adolescent psychiatrists, and difficulties maintaining a skilled workforce.<sup>345</sup> To work around the lack of speech pathologists in regional areas, some regional CAMHS/CYMHS teams formed partnerships with private speech pathologists, or even private paediatricians ‘to ensure children receive a comprehensive assessment’.<sup>346</sup>

Mindful is a key organisation in the education and training in the identification, diagnosis and treatment of ASD for all public and private sector clinicians, including psychiatrists, paediatricians, psychologists, speech pathologists, occupational therapists, social workers, and teachers in Victoria. It also manages an extensive network of coordinators across the state who play a central role in facilitating ASD assessment and diagnosis, overseeing early intervention and ongoing care and providing referral pathways. The Committee is concerned that some of the programs previously conducted, or supported, by Mindful are no longer funded, as outlined above. The Committee believes that the training of health professionals is critical to creating a viable diagnostic and treatment regime for people with ASD and their families. The Committee believes that Mindful should be provided with ongoing, recurrent funding to perform, and expand upon, its key tasks as outlined above.

Accordingly, the Committee recommends that:

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- 343 Ms Frances Saunders, Statewide Autism Spectrum Disorder Coordinator, Mindful, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 4.
- 344 Mindful – Centre for Training and Research in Developmental Health, submission no. 134, p. 4.
- 345 Ibid, p. 6.
- 346 Ibid, p. 5; Ms Frances Saunders, Statewide Autism Spectrum Disorder Coordinator, Mindful, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 5.

### **RECOMMENDATION 3.5**

The Victorian Government provide ongoing and increased funding to the Mindful – Centre for Training and Research in Developmental Health, to support:

- the education and training in the identification, diagnosis and treatment of ASD for all clinicians;
- programs and initiatives that link to, facilitate, and manage ASD assessment and diagnosis;
- overseeing early intervention and ongoing care and facilitate referral pathways to other services, and
- the expansion of state-wide ASD coordinators.

#### **3.2.5. Child and Adolescent Mental Health Services (CAMHS) and Child and Youth Mental Health Services (CYMHS)**

In Victoria, families wishing to obtain a diagnosis or paediatricians seeking diagnostic clarification will often be referred to a Child and Adolescent Mental Health Service (CAMHS) or Child and Youth Mental Health Service (CYMHS) in their area, or the Royal Children’s Hospital Mental Health Service. The Child and Adolescent Mental Health Services (CAMHS) provide comprehensive services for children and adolescents up to the age of 18 experiencing mental health problems. The Child and Youth Mental Health Services (CYMHS) provide services for children and youth up to the age of 25. Both CAMHS and CYMHS are state government-funded to conduct multidisciplinary assessments and diagnosis of ASD and have assessment teams in metropolitan and regional areas. Each CAMHS/CYMHS team has a senior clinician to coordinate the ASD assessment and diagnostic process. At least 585 children received an assessment for ASD from CAMHS/CYMHS in 2015-16.<sup>347</sup>

The Amaze website lists a number of government-funded teams that specialise in the assessment and diagnosis of ASD:

- Alfred CYMHS – Developmental Assessment Service in Moorabbin;
- Austin CAMHS – Developmental Assessment Program in Heidelberg;
- Barwon Children’s Health Service (CAMHS) in Belmont;
- Bendigo CAMHS – Autism Assessment Team;
- Eastern Health CYMHS in Ringwood;
- Gippsland Autism & Related Disorders Assessment Clinic in Traralgon;
- Goulburn Valley CYMHS – GV Autism Spectrum Assessment Team in Seymour and Shepparton;
- Grampians Region Autism Assessment and Diagnostic Team in Ballarat;
- Melton Health – Autism Spectrum Assessment Clinic in Melton;

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347 Victorian Department of Health and Human Services, correspondence, questions on notice, dated 10 May 2017.

- Monash Developmental Disabilities Clinic – Paediatrics in Clayton;
- Northern Mallee CYMHS – Autism Spectrum Support & Evaluation Team (ASSET) in Mildura;
- Royal Children’s Hospital Mental Health Services – Autism Spectrum Assessment Team in Flemington;
- Warrnambool CAMHS in Warrnambool;
- Western Health, Children’s Allied Health Services in St Albans.<sup>348</sup>

Practitioners usually make a referral to the CAMHS/CYMHS closest to the child’s place of residence.<sup>349</sup> There is variation in the referral processes and target ages of the CAMHS/CYMHS teams in each region.<sup>350</sup> The ASD assessment team at Austin CAMHS, for example, is a service which is only available to children aged 3-12.<sup>351</sup> There are also significant differences in waiting times across each of the regions in which CAMHS/CYMHS operate. For example, Eastern Health CAMHS has a waiting list of just one to two months, in contrast to Goulburn Valley CYMHS, which has a waiting list of 24 months.<sup>352</sup>

The combined submission of clinicians and parents associated with the Autism Spectrum Disorder Assessment Program (ASDAP) within Austin CAMHS noted that: ‘There is a gap in access for families seeking diagnosis in older children without mental health difficulties’.<sup>353</sup> The Austin CAMHS ASDAP operates one day per week and, as noted in their submission, the program ‘does not have the capacity to provide ongoing support, advice nor management strategies for struggling families’.<sup>354</sup>

The Committee heard that CAMHS are over-stretched, with significant waiting-lists in most areas and patients are prioritised by urgency.<sup>355</sup> Therefore, the majority of the CAMHS service is devoted to supporting people experiencing acute mental health crises, rather than more routine ASD assessments.<sup>356</sup>

The Committee believes that the CAMHS/CYMHS services are integral to the state’s diagnostic services for ASD, but are currently unable to meet the demand for assessments. The current waiting lists in some regions of Victoria are not defensible. The Committee believes that the development of a multidisciplinary diagnosis must be matched by the resources and personnel to provide such diagnoses. The current

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348 Amaze, ‘Autism Assessment Teams in Victoria’, May 2016, Amaze, accessed 9 May 2017, <[www.amaze.org.au/uploads/2016/05/Autism-Assessment-Teams-in-Victoria-May-2016.pdf](http://www.amaze.org.au/uploads/2016/05/Autism-Assessment-Teams-in-Victoria-May-2016.pdf)>.

349 Ibid.

350 Ibid.

351 Austin Child and Adolescent Mental Health Service, submission no. 113, p. 2.

352 Victorian Department of Health and Human Services, correspondence, questions on notice, dated 10 May 2017.

353 Austin Child and Adolescent Mental Health Service, submission no. 113, p. 2.

354 Ibid, p. 2.

355 Ms Frances Saunders, Statewide Autism Spectrum Disorder Coordinator, Mindful, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 6.

356 K Bull and S Radovini, *A guide to identification, diagnosis and treatment of autism spectrum disorder in Victorian mental health services*, Mindful Centre for Training and Research in Developmental Health, Melbourne, 2013, p. 57.

CAMHS/CYMHS network does provide an existing infrastructure and service model to support the implementation of best practice multidisciplinary diagnosis, provided it is funded accordingly. The Committee thus supports increased funding for existing CAMHS/CYMHS, to enable them to manage demand, and provide high quality services in a timely manner.

The Committee is of the view that the Victorian Government needs to build on the existing expertise in the community. The capacity of CAMHS and some mainstream community health services can be increased to enhance their existing role in the assessment and diagnosis of ASD, thereby reducing waiting lists and enabling children diagnosed with ASD to receive early intervention in a timely manner.

### **3.2.6. Royal Children's Hospital (RCH)**

In partnership with the University of Melbourne and the Murdoch Childrens Research Institute, the Royal Children's Hospital provides clinical care, training, and research in ASD. The RCH also provides content for the Raising Children Network website.<sup>357</sup>

As part of their clinical care, the RCH provides a public multidisciplinary assessment clinic for children living in the North West region of Melbourne, with a focus on children aged two to six, or prior to school entry.<sup>358</sup> According to the RCH website, the Developmental and Autism Assessment intake does not accept referrals for children aged over six years.<sup>359</sup>

As part of their training program, the RCH is involved in training university students, hospital and community-based professionals 'across health, education and disability and all relevant disciplines'.<sup>360</sup> In their submission, the RCH stated:

We have a particular capacity for clinical training, and use online and in-person approaches. We also provide education for parents and carers (referred to from now on as parents) of children and young people with autism. Training spans identification, diagnosis and management.<sup>361</sup>

As noted above, the Royal Children's Hospital facilitates the Victorian Training Program in Community Child Health, which is a 12-month fellowship providing paediatricians with clinical experience and includes detailed training in ASD assessments and management.<sup>362</sup> In their submission, the Royal Children's Hospital noted:

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357 Royal Children's Hospital, submission no. 143, p. 4.

358 Royal Children's Hospital, 'Autism assessment aged 0-6', accessed 17 May 2017, <[www.rch.org.au/autism/autism\\_assessment/Autism\\_assessment\\_ages\\_0-6](http://www.rch.org.au/autism/autism_assessment/Autism_assessment_ages_0-6)>.

359 Royal Children's Hospital, 'Autism assessment ages 6 and over', accessed 17 May 2017, <[www.rch.org.au/autism/autism\\_assessment/Autism\\_assessment\\_ages\\_6\\_and\\_over](http://www.rch.org.au/autism/autism_assessment/Autism_assessment_ages_6_and_over)>.

360 Royal Children's Hospital, submission no. 143, p. 4.

361 Ibid.

362 Royal Children's Hospital, 'Victorian Training Program in Community Child Health fellowship', accessed 17 May 2017, <[www.rch.org.au/ccch/training-dev/Victorian\\_Training\\_program\\_in\\_Community\\_Child\\_Health\\_fellowship](http://www.rch.org.au/ccch/training-dev/Victorian_Training_program_in_Community_Child_Health_fellowship)>. The Royal Australasian College of Physicians (RACP), correspondence, dated 19 April 2017.

[B]uilding a well trained workforce and ongoing opportunities for professional development, through teamwork and formal education, will be crucial to the success of any services developed to improve the lives of individuals with autism. This has been recognised by both the disability and education sector. Good work in this domain is occurring, with national reach and locally, but is currently poorly coordinated with the risk for inconsistent messages. RCH is committed to training and education, with a particular role in training paediatricians and allied health professionals, and with its training partners has access to state-of-the art training expertise and technology. We're ready to join in a more coordinated effort for training.<sup>363</sup>

In terms of research, the RCH and its partners are involved in research ‘that estimates the prevalence of autism, explores possible causes, assesses identification and diagnostic accuracy, evaluates interventions using best methods and seeks to understand the outcomes for children who are diagnosed with autism, including their quality of life and the mental health and well-being of their families’.<sup>364</sup>

In their submission, the Royal Children’s Hospital addressed the need for ongoing research into prevalence, causation, accurate surveillance and diagnosis, effective interventions, and management, noting that although there are significant research efforts into autism across various institutions in Victoria, they are ‘fragmented’.<sup>365</sup> The RCH recommended the establishment of a state-wide Victorian autism research network to increase collaboration and coordination, facilitate research, assist with dissemination of research findings and build upon Victoria’s strengths in health research. Their submission articulated their commitment to being part of a Victorian strategy and joining a coordinated effort for training and research in ASD:

RCH is currently involved in all types of research necessary to build a better future for individuals with autism, and is delivering clinical care and developing population health strategies, in a way that can make a difference. We are already working with colleagues across Victoria and are ready to be part of a strategy that supports these endeavours in a more coordinated way.<sup>366</sup>

### 3.2.7. Olga Tennison Autism Research Centre (OTARC)

The Olga Tennison Autism Research Centre (OTARC) was established in 2008 as a partnership between La Trobe University and Autism Victoria (now Amaze), with funding from the university and philanthropist Olga Tennison. The Centre’s mission is to research the cause and nature of ASD and develop evidence-based strategies to support people with ASD and their families.<sup>367</sup>

OTARC receives federal government funding under the HCWA package to conduct Early Days information and skills workshops for parents and families of children

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363 Royal Children’s Hospital, submission no. 143, pp. 12-13.

364 Ibid, p. 4.

365 Ibid, p. 13.

366 Ibid, p. 13.

367 La Trobe University, ‘About OTARC: Mission and objectives’, accessed 5 June 2017, <[www.latrobe.edu.au/otarc/about/mission-and-objectives](http://www.latrobe.edu.au/otarc/about/mission-and-objectives)>.

recently diagnosed with ASD and to deliver early intervention programs to children (up to 6 years) at the Victorian Autism Specific Early Learning and Care Centre (ASELCC).<sup>368</sup> OTARC is also a key member of the Autism CRC.<sup>369</sup>

OTARC conducted landmark research into the early detection and diagnosis of ASD, in partnership with Victorian Maternal and Child Health centres. The research project, the Social Attention and Communication study (SAC), trained over 300 Victorian Maternal and Child Health nurses across 17 local government areas in metropolitan Melbourne in developmental surveillance techniques designed to monitor key social and communication behaviours (such as pointing, waving and eye contact) as part of routine childhood check-ups.<sup>370</sup> Maternal and Child Health nurses were able to identify the very early signs of autism during their routine check-ups at 12, 18 and 24 months.<sup>371</sup> Over 30,000 babies were monitored within the Victorian Maternal and Child Health system.<sup>372</sup>

Professor Cheryl Dissanayake told the Committee at a public hearing in Melbourne that the early signs of ASD are ‘very subtle’ and can often be missed. However, these can be used as markers to identify autism prospectively, and diagnosis of autism is possible from as young as 18 to 24 months of age.<sup>373</sup>

[E]arly identification and diagnosis enables early intervention, which we know promotes much better developmental outcomes in young children. What we do know is that early intervention really is able to increase the learning capacity of children with autism and there are consistent findings now of gains in cognitive functioning following access to early intervention.<sup>374</sup>

The project found it was possible to identify the key characteristics of ASD from 12 months, and to confirm a diagnosis by two years, which is significantly earlier than the national average age of approximately four years. Eighty one per cent of the children referred to OTARC by these nurses received a diagnosis of autism by 24 months of age.<sup>375</sup> Professor Dissanayake told the Committee that these nurses were

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368 La Trobe University, ‘About OTARC: History’, accessed 5 June 2017, <[www.latrobe.edu.au/otarc/about/history](http://www.latrobe.edu.au/otarc/about/history)>.

369 La Trobe University, ‘About OTARC: CRC for living with autism’, accessed 5 June 2017, <[www.latrobe.edu.au/otarc/researchers/crc-for-living-with-autism-spectrum-disorders](http://www.latrobe.edu.au/otarc/researchers/crc-for-living-with-autism-spectrum-disorders)>.

370 Professor Cheryl Dissanayake, Founder and Director, Olga Tennison Autism Research Centre, La Trobe University, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 3. See also: J Barbaro and C Dissanayake, ‘Prospective identification of autism spectrum disorders in infancy and toddlerhood using developmental surveillance: The social attention and communication study’, *Journal of Developmental & Behavioral Pediatrics*, vol. 31, no. 5, June 2010.

371 See also: J Barbaro and C Dissanayake, ‘Prospective identification of autism spectrum disorders in infancy and toddlerhood using developmental surveillance: The social attention and communication study’, *Journal of Developmental & Behavioral Pediatrics*, vol. 31, no. 5, June 2010.

372 Professor Cheryl Dissanayake, Founder and Director, Olga Tennison Autism Research Centre, La Trobe University, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 2.

373 Ibid.

374 Ibid.

375 Ibid, pp. 2-3.



very successful in identifying the early signs of autism and other developmental delays:

Seventy-five per cent of children referred to us met criteria for autism. The remainder had either a language or developmental delay, so once again, just as with our studies, we were not seeing typically developing children being referred to us. Generally, when we saw children, we were always referring them for further services.<sup>376</sup>

The Committee heard from Professor Dissanayake that these early diagnoses were crucial to ensuring better cognitive outcomes for children as these children were able to access early intervention and support when it was most beneficial.<sup>377</sup>

The success of this study in prospectively identifying infants and toddlers via routine developmental surveillance led to the establishment of Australia's first Early Diagnostic Clinic (EDC) for ASD at OTARC, which focuses on children under the age of three years.<sup>378</sup> This clinic, established in July 2011, was funded by the RE Ross Trust as a 'one stop shop' multidisciplinary diagnostic approach with children being able to access a number of diagnosticians on the same day under the same roof.<sup>379</sup> Despite its success, the Committee heard that the early diagnosis clinic was closed in 2015 due to lack of funding.<sup>380</sup>

Based on their research of assessing the social and communication behaviours of children aged between 11 and 30 months, OTARC also developed a free phone app called ASDetect that empowers parents and caregivers to identify the early signs of autism. The app, which is suited to children from 11-30 months of age, is 'video-led' where parents see videos of a typically developing child and an atypically developing child and are then asked whether their child rarely or mostly shows those behaviours. On completion, they are informed immediately whether their child has a high likelihood or a low likelihood of developing autism, and encourages parents to take the results to a medical professional for a formal developmental assessment.<sup>381</sup>

As a key member of the Autism CRC, OTARC is a lead organisation for research into children with ASD. However, the Committee was particularly interested in how OTARC developed its training program into the early detection and diagnosis of ASD with the Victorian Maternal and Child Health centres. The Social Attention and Communication study (SAC) was, by any measure, a success, and when combined with the establishment of the Early Diagnostic Clinic (EDC) for ASD at OTARC provided Victoria with a model for both the surveillance and diagnosis of children with ASD under the age of three. As the Committee has been made aware, early diagnosis does provide one pathway to early intervention, with potentially lifelong positive effects.

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376 Ibid, p. 4.

377 Ibid, p. 2.

378 Amaze, submission no. 139, p. 21.

379 Ibid.

380 Professor Cheryl Dissanayake, Founder and Director, Olga Tennison Autism Research Centre, La Trobe University, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 4.

381 Ibid.



The Committee believes the Victorian Government should fund the restart of the SAC study and the re-establishment of the EDC at OTARC. With regard to the latter, the CAHMS/CYMHS network will not be sufficient on its own to provide diagnostic coverage for the whole state. The re-establishment of the EDC at OTARC would provide an important resource to supporting that coverage, while at the same time being focused on the unique area of the 0-3 years age group. The SAC study can have significant benefits and outcomes for a relatively low investment. The Maternal and Child Health Nurses have received training in ASD detection from other programs, but the SAC program has had significant results and can be used to augment other training.

Accordingly, the Committee recommends that:

### **RECOMMENDATION 3.6**

**The Victorian Government fund the Olga Tennison Autism Research Centre (OTARC) to:**

- **provide training to Maternal and Child Health Nurses across all local government areas in developmental surveillance techniques designed to detect the signs of ASD in children aged 0-3, and make appropriate referrals, and**
- **re-establish the Early Diagnostic Clinic (EDC) for ASD to enable the multidisciplinary diagnosis of ASD in children aged 0-3.**

## **3.3. Study tour: assessment and diagnosis**

Early detection of ASD is a priority in the U.S. as it is elsewhere. At the Center for Autism Research (CAR) in Philadelphia the Committee heard that the regular ‘well-child visits’ are opportunities for families and professional health workers, including paediatricians, to identify developmental delays in young children.<sup>382</sup> CAR also conducts diagnosis for its research participants, including comprehensive differential diagnoses of ASD from other developmental disorders and mental health conditions.

The American Academy of Paediatrics (AAP) recommends that all children receive autism-specific screening at 18 and 24 months of age – in addition to broad developmental screening at nine, 18, and 24 months.<sup>383</sup> While parents and caregivers are likely to be the first to identify developmental concerns, medical doctors, day-care and kindergarten teachers are also key to detecting developmental delays in children.

At a meeting organised by the Office of Autism Research and Coordination (OARC) in Washington D.C., which included representatives from the National Institute of Health

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382 The Center for Autism Research (CAR) is a joint effort between the Children’s Hospital of Philadelphia (CHOP) and the University of Pennsylvania. See: the Center for Autism Research, ‘About CAR’, accessed 16 May 2017, <[www.centerforautismresearch.org/about](http://www.centerforautismresearch.org/about)>.

383 American Academy of Pediatrics (AAP), ‘Recent Information’, accessed 16 May 2017, <[www.aap.org/en-us/about-the-aap/Committees-Councils-Sections/Council-on-Children-with-Disabilities/Pages/Recent-Information.aspx](http://www.aap.org/en-us/about-the-aap/Committees-Councils-Sections/Council-on-Children-with-Disabilities/Pages/Recent-Information.aspx)>.

and the federal Department of Health, among other agencies, the Committee heard about a program developed by the Center for Disease Control and Prevention (CDC) – ‘Learn the Signs, Act Early’. The program has national reach. It aims to ‘improve early identification’ of ASD and other developmental disabilities by empowering parents and other caregivers to learn the signs and act early.<sup>384</sup> The program works by developing and disseminating research-based materials to support parents and professional health and education workers to monitor the development of children from zero through to five years of age.

According to the CDC, if a parent has concerns they are advised to request a referral from their medical doctor to see a specialist. Typically, they are referred to one of the following lead specialists: developmental paediatricians, child neurologists (who specialise in the brain, spine and nerves) and child psychiatrists or psychologists.<sup>385</sup> In the U.S., a typical diagnostic evaluation involves a multidisciplinary team of clinicians including a paediatrician (particularly a developmental behavioural paediatrician), psychologist, speech and language pathologist, and occupational therapist.

In New York City, the Committee met with representatives of the leading national autism science and advocacy organisation, Autism Speaks. In their *100 Day Kit for Newly Diagnosed Families of Young Children*, Autism Speaks advises parents that a thorough diagnosis helps ‘create a roadmap for treatment by identifying your child’s specific strengths and challenges’.<sup>386</sup> Parents are advised to request a comprehensive report from their lead diagnostician that includes the diagnosis in writing as well as recommended treatments. At the UC Davis Mind Institute in Sacramento, California, the Committee heard that diagnosis is now easier to access in the community and the Institute’s clinical services now have a greater emphasis on treatment. The Mind Institute also offers a multidisciplinary assessment and diagnosis service. Patients can pay privately or through their health insurance for diagnosis and or treatment services.<sup>387</sup>

When the Committee visited the Yale Child Study Centre’s Developmental Disabilities Clinic, they learnt about their multidisciplinary diagnosis services.<sup>388</sup> Over two days, a multidisciplinary team that spans psychology, psychiatry, and speech and language assesses a child. In New York City, the Committee heard of the Autism Speaks’ Autism Treatment Network (ATN), which is a collaborative network of thirteen leading health services in the U.S. and Canada that can provide high quality diagnosis and

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384 Center for Disease Prevention and Control, ‘Learn the Signs Act Early Factsheet’, accessed 16 May 2017 <[www.cdc.gov/ncbddd/actearly/pdf/parents\\_pdfs/ltsae-factsheet\\_508.pdf](http://www.cdc.gov/ncbddd/actearly/pdf/parents_pdfs/ltsae-factsheet_508.pdf)>.

385 Center for Disease Prevention and Control, ‘If you’re concerned’, accessed 16 May 2017, <[www.cdc.gov/ncbddd/actearly/concerned.html](http://www.cdc.gov/ncbddd/actearly/concerned.html)>.

386 Autism Speaks, *100 Day Kit for Newly Diagnosed Families of Young Children*, Autism Speaks, 2014, p. 2.

387 The UC Davis Mind Institute, ‘Built by Families for Families’, accessed 17 May 2017, <[www.ucdmc.ucdavis.edu/mindinstitute](http://www.ucdmc.ucdavis.edu/mindinstitute)>.

388 Autism Program at Yale, ‘Yale Developmental Disabilities Clinic’, Yale School of Medicine, accessed 17 May 2017, <[childstudycenter.yale.edu/autism/clinical\\_services/yaledevelopmentaldisabilitiesclinic.aspx](http://childstudycenter.yale.edu/autism/clinical_services/yaledevelopmentaldisabilitiesclinic.aspx)>.

treatment services.<sup>389</sup> Parents and caregivers in the U.S. need to navigate different systems, legislation and insurance requirements to access services. Lead advocacy organisations, such as The Arc for People with Intellectual and Developmental Disabilities, play an important role as providers of information, advice and advocacy services to support individuals and families to navigate the systems.

The Committee heard that the average age of diagnosis in the U.S. is four to four-and-a-half years of age.<sup>390</sup> They heard that a reduction in the average age would be beneficial to children and their families by ensuring that children can develop the skills necessary for their health and wellbeing. Autism Speaks highlights one of the challenges to earlier detection and diagnosis, 'Unfortunately parents' concerns are sometimes not taken seriously by their doctor and as a result, a diagnosis is delayed.'<sup>391</sup> Girls and women are also not being diagnosed, on average, until a later age.<sup>392</sup> The Autistic Self Advocacy Network (ASAN) in Washington D.C. highlighted the need to do more to ensure that surveillance and diagnostic gaps for underserved populations are addressed.<sup>393</sup> There are also not enough expert clinicians to diagnose adults.<sup>394</sup>

In Scandinavia, nearly all children are in care at the age of one year old, and thus subject to surveillance at an early age for a range of conditions, including neurodevelopmental delay. At the Center for Autisme in Copenhagen, the Committee learnt that a team of three psychologists, each with a different specialisation, conducts diagnostic assessments for ASD.<sup>395</sup> In Norway, ASD diagnoses are conducted by multidisciplinary teams supervised by a specialist physician or psychiatrist, for the purpose of educational needs assessments and support.

The diagnostic process in Sweden involves a multidisciplinary team made up of paediatricians, psychologists and others, and assessments are conducted over time. During the Committee's study tour, the Committee visited the Early Autism Sweden (EASE) at the Karolinska Institutet Center of Neurodevelopmental Disorders, Uppsala University, to hear from clinical psychologists and researchers conducting longitudinal research on infants at risk for autism.<sup>396</sup> The Committee heard that in one of their projects, Projekt Smasyskon at the Uppsala Child and Babylab, the researchers followed babies at intervals from as early as 5 months and 10 months to 36

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389 Autism Speaks 'Find an ATN', accessed 16 May 2017, <[www.autismspeaks.org/science/resources-programs/autism-treatment-network/where-can-i-find-atn-location](http://www.autismspeaks.org/science/resources-programs/autism-treatment-network/where-can-i-find-atn-location)>.

390 See also, Center for Disease Prevention and Control, 'Autism Spectrum Disorders', accessed 16 May 2017, <[www.cdc.gov/ncbddd/autism/data.html](http://www.cdc.gov/ncbddd/autism/data.html)>.

391 Autism Speaks, 100 Day Kit for Newly Diagnosed Families of Young Children, Autism Speaks, 2014, p. 2.

392 Center for Disease Prevention and Control, 'Learn the Signs Act Early Factsheet', accessed 16 May 2017 <[www.cdc.gov/ncbddd/actearly/pdf/parents\\_pdfs/ltsae-factsheet\\_508.pdf](http://www.cdc.gov/ncbddd/actearly/pdf/parents_pdfs/ltsae-factsheet_508.pdf)>.

393 Autistic Self Advocacy Network (ASAN), 'ASAN's statement on the CDC's new prevalence data', accessed 16 May 2017, <[autisticadvocacy.org/2015/11/asan-statement-on-cdcs-new-autism-prevalence-data](http://autisticadvocacy.org/2015/11/asan-statement-on-cdcs-new-autism-prevalence-data)>.

394 Autism Speaks, Is it Autism and If So, What Next? A Guide for Adults, March 2015, p. 10.

395 Center for Autisme, 'About Us', Center for Autisme, accessed 17 May 2017, <[translate.google.com.au/translate?hl=en&sl=da&u=<www.centerforautisme.dk/&prev=search](http://translate.google.com.au/translate?hl=en&sl=da&u=<www.centerforautisme.dk/&prev=search)>.

396 Karolinska Institutet, 'The Project EASE', accessed 17 May 2017, <[ki.se/en/kind/the-project-ease](http://ki.se/en/kind/the-project-ease)>.

months.<sup>397</sup> They measured early communication and reactivity to stimulus through eye tracking and semi-structured interaction with an experimenter, who interacts with the baby while the baby is on the mother’s lap.

### 3.4. Coordination for ASD diagnostic state-wide services

In reviewing the evidence received by the Committee on the provision of diagnostic services for people with ASD and families living with ASD in Victoria, the Committee has concluded that the current models of diagnostic service provision are inadequate to the task of providing timely, affordable and high standard diagnoses for ASD to the community. The Committee has therefore made a number of recommendations above to address the current lack of services and training.

The Committee believes that unless a coordinated approach to diagnostic services in the state is taken, the recommendations it has made may have limited effect. The Victorian Government, through the agency of the Department of Health and Human Services, should take the lead in coordinating and collaborating with, the various service providers, agencies, organisations, and research centres that are involved in the detection and/or diagnosis of ASD, and the training of professionals. The state’s ‘ASD Diagnostic State-wide Service’, will be based on the following components:

- The adoption of a state-wide standard of ASD diagnosis, comprising of multidisciplinary teams;
- The service will build on, enhance, and extend existing infrastructure and services across the state; and
- The multidisciplinary diagnostic service will be accessible in all health regions of the state, including rural and regional Victoria.

Accordingly, the Committee recommends that:

#### **RECOMMENDATION 3.7**

**The Victorian Government through the Department of Health and Human Services fund the development, coordination and delivery of state-wide ASD diagnostic services, which will provide access to an ASD diagnosis equally to all Victorians.**

#### **Surveillance**

In the updated State Autism Plan, surveillance will be a key to developing early diagnoses and early interventions. The role of Maternal and Child Health Nurses across the state is critical to the surveillance of ASD, and making timely referrals. General Practitioners and other allied health professionals are important to picking up the ‘red flags’ and creating the recognised pathways that can become the basis of referral.

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397 Ibid.

## **Training**

The training of health and allied health professionals in understanding and detecting the signs and behaviours associated with ASD, and in diagnosing ASD, is critical to the success of the Diagnostic State-wide Service. The Committee notes the statement of the Royal Children's Hospital above that they are 'ready to be part of a strategy that supports these endeavours in a more coordinated way'. The State Autism Plan will outline key partnerships necessary to build on, and enhance, current training offerings to deliver a suite of tailored programs for all health and allied health professionals in the state. ASD coordinators will play an important role in providing information and creating networks across the state: networks that bring together families, local communities, health professionals, and health services.

## **Diagnosis**

Multidisciplinary diagnostic teams will build upon and enhance current multidisciplinary teams working through the CAMHS and CYHMS networks. They can also be created in collaboration with regional hospitals and local community health centres. Each region of the state will be serviced by a multidisciplinary team, with several 'hubs' established in regional centres that will provide regular outreach to rural and remote communities. (Rural and regional diagnostic services are discussed in more detail in Chapter Nine).

## **Post-diagnosis**

The Committee is aware of the real challenges that families have faced in obtaining clear information on therapy and intervention options once a diagnosis has been made. While it is clear that the NDIS will be providing early childhood intervention services to NDIS participants, this does not negate the need for an information service to be provided to Victorian individuals and families after a diagnosis is made. The post-diagnostic service will be provided to assist with support after diagnosis and with information on evidence-based intervention options, and contact with the NDIS, including NDIS Early Childhood Partners.

The Committee is aware that the creation and coordination of a state-wide service that addresses the current shortfalls in diagnosis will involve a significant increase in expenditure in this area. However, the Committee is confident that with appropriate funding and cross-sector collaboration the above model can be implemented across Victoria, and thus permanently eliminate the long waiting lists, high costs and the deferrals of much needed early interventions that currently plague the system.

The updated State Autism Plan will articulate the key components necessary to create a state-wide service of this kind. The Committee recommends that:

**RECOMMENDATION 3.8**

The Victorian Government support the development of an ASD state-wide diagnostic service and this be a key element of the Victorian Government's updated State Autism Plan.

- The Plan outline the fundamental features of the Service, namely: Surveillance, Training, Diagnosis and Post-Diagnosis.
- The Plan outline the key partnerships and collaborations required to build and deliver the Service.

**3.5. The critical importance of early intervention**

Early intervention is considered fundamental to managing the challenges faced by people with ASD. Early intervention services are designed to support children with a developmental delay, including those with ASD. Early intervention typically involves group or individual therapy based sessions that focus on improving aspects of a child's behaviour, communication, or social skills. A range of different health professionals can be involved in providing early intervention services, such as psychologists, speech pathologists and occupational therapists. There is widespread agreement that effective early intervention can address many of the social and economic costs associated with ASD, and improve quality of life for people with ASD and their families.<sup>398</sup>

At a public hearing in Melbourne, Professor Cheryl Dissanayake described the reasons why early intervention was imperative to ensure that children continue to learn from their social environment and to change the way the brain develops at an early age:

Intervention is important because you can change the way the brain develops. The reason why the typically developing child learns and develops so quickly, so seamlessly and so easily is because that baby comes into the world with their sensory systems already tuned to other human beings – towards their faces, towards their eyes. We know babies at birth process the human voice more than they process the sound of mechanical objects. We know they will preferentially look at eyes; we know that they will preferentially look at faces. If a baby is born without their sensory systems tuned in towards other people, you are going to immediately impact their learning, because how babies learn is from other people ... If you are not looking at faces, that specialty is not going to develop. If you are more tuned into objects, if you are not motivated to look and engage with other people, that is going to impact your learning. So the sooner you can get a child identified and diagnosed and start working with that child, and get that child back into the social loop, the child can begin to learn from other people.

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398 For example, see: Amaze, submission no. 139; Royal Children's Hospital, submission no. 143; Speech Pathology Australia, submission no. 136; Autism Behavioural Intervention Association, submission no. 60; Professor Cheryl Dissanayake, Founder and Director, Olga Tennison Autism Research Centre, La Trobe University, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence.

That is really what good early intervention does. It basically rewires that brain that is not processing the social world. We do not want to change autism ... What we want to change is the impact autism can have on the ability to learn. So the sooner you get in you can prevent intellectual disability from happening in many children.<sup>399</sup>

Early Childhood Intervention Australia (ECIA) is the national peak body for early childhood intervention (ECI) in Australia, which represents professionals and organisations providing services for young children with disability and developmental delays, including ECI professionals working in government-funded agencies. In April 2016, ECIA released their *National Guidelines for Best Practice in Early Childhood Intervention*, developed following two years of extensive consultations and workshops with ECI service providers and government, including the NDIA, and a review of current international and Australian literature.<sup>400</sup> The Guidelines are intended to be used by ECI practitioners 'as a framework for excellence in service delivery, and to help prepare for the NDIS rollout'.<sup>401</sup> The rationale for the development of the Guidelines is set out in the Guidelines themselves:

Current practices in ECI in Australia vary across and within states and territories. As a national scheme, the NDIS requires national guidelines for best practice that may be consistently applied in all states and territories.

The purpose of these guidelines and recommendations is to provide a framework for universal and equitable high quality ECI based on best practice for children with disability and/or developmental delay whether they attend government, non-government, large, small, sole non-for-profit service providers or private providers, anywhere in Australia.<sup>402</sup>

These industry developed Guidelines set out eight key best practices in early childhood intervention around four key quality areas of family, inclusion, teamwork and universal principles, which are:

- 1) Family-Centred and Strength-Based Practice;
- 2) Culturally Responsive Practice;
- 3) Inclusive and Participatory Practice;
- 4) Engaging the Child in Natural Environments;
- 5) Collaborative Teamwork Practice;
- 6) Capacity-Building Practice;
- 7) Evidence Base, Standards, Accountability and Practice; and

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399 Professor Cheryl Dissanayake, Founder and Director, Olga Tennison Autism Research Centre, La Trobe University, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 8.

400 Early Childhood Intervention Australia, *National guidelines for best practice in early childhood intervention*, ECIA, April 2016, accessed 12 May 2017, [www.ecia.org.au](http://www.ecia.org.au).

401 Early Childhood Intervention Australia, 'ECIA National Guidelines for Best Practice', ECIA, accessed 12 May 2017, <[www.ecia.org.au/documents/item/186](http://www.ecia.org.au/documents/item/186)>.

402 Early Childhood Intervention Australia, *National guidelines for best practice in early childhood intervention*, ECIA, April 2016, accessed 12 May 2017, <[www.ecia.org.au/documents/item/186](http://www.ecia.org.au/documents/item/186)>, p. 5.



8) Outcome Based Approach.<sup>403</sup>

The Guidelines stated that the early childhood years ‘lay the foundation for all future development’, and that ECI supports ‘a child’s development of functional skills that would enable them to participate meaningfully in everyday activities alongside typically developing peers’.<sup>404</sup>

The Committee consistently heard about the critical importance of early intervention in supporting children in their development through the lifecycle in submissions, public hearings and on its study tour of the United States, Denmark, Norway and Sweden. This section addresses the barriers to accessing early intervention services, the role of behavioural therapies, and the NDIS early intervention program, which will also be discussed in Chapter Six. Some aspects of this section will also be addressed in later chapters, for example, a lack of early intervention service providers in rural and regional areas will be discussed in Chapter Nine.

### Autism advisors

Part of the support provided by the HCWA program includes a national Autism Advisor Service, which assists families and carers of children who are diagnosed with ASD in accessing the HCWA funding. There are eight Advisor Services in Australia and in Victoria, Amaze is funded to provide that service. There are approximately 8.8 FTE Advisors at Amaze.<sup>405</sup> In the financial year 2015-16, the Department of Social Services provided \$847,000 to Amaze to implement the Autism Advisor Service in Victoria.<sup>406</sup>

In Victoria, parents and carers apply for HCWA funding through the Autism Advisor Service at Amaze and once the application has been processed, an Autism Advisor will contact the parents and carers to organise a time to discuss the funding and answer questions.<sup>407</sup> The Autism Advisor is the point of contact for any questions related to funding for the entire time that a child has access to the HCWA package. Importantly, Autism Advisors cannot provide individualised advice about services and they are not ‘case managers’. The Committee heard that some parents were frustrated by the inability of Autism Advisors to provide advice and support around particular therapy options.<sup>408</sup>

In their submission, Amaze recommended that the role of Autism Advisors be expanded so that the service is accessible for all newly diagnosed people on the autism spectrum, regardless of age.<sup>409</sup> About the service, they stated:

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403 Ibid, p. 7.

404 Ibid, pp. 4, 5.

405 ARTD Consultants, *Evaluation of the Helping Children with Autism Package (FaHCSIA components)*, Technical report, Sydney, 2012, p. 112.

406 Department of Social Services, submission no. 72, p. 27.

407 Amaze, ‘Autism Advisor program Victoria: Information pack’, accessed 18 May 2017, <[www.amaze.org.au/uploads/2011/10/Helping-children-with-autism-Information-Booklet.pdf](http://www.amaze.org.au/uploads/2011/10/Helping-children-with-autism-Information-Booklet.pdf)>.

408 Mr Steve Ager, submission no. 57, p. 2.

409 Amaze, submission no. 139, p. 7.

We provide this service to all families who have a child diagnosed under seven. Amaze has been running this service since 2008 and to date has supported over 12,000 families in Victoria. Since 2008, diagnosticians have increasingly been providing details of Amaze to newly diagnosed families as their next point of contact... this can be a traumatic and confusing time for families and Amaze provides a 'safe and soft place to land' for these families. The Autism Advisors take the time to explain what the diagnosis means, for them and their child, what the next steps are for supports and services, provide independent and evidence based information and answer questions – whilst also arranging access to the Early Intervention funding available. This process may take a number of hours over a number of phone calls. A 2010 evaluation of the 'Helping Children with Autism' program found a 90% satisfaction rate with the service provided by the Autism Advisors.<sup>410</sup>

In their submission, Amaze noted that with the transition to the NDIS and the cessation of the HCWA program 'the role of the Autism Advisors in the long term is unknown'.<sup>411</sup> Amaze stated in their submission:

Amaze is of the view that the Autism Advisor program is hugely valuable in assisting families following diagnosis and needs to continue once the NDIS is rolled out.

The role of Autism Advisors has also now organically grown to provide information regarding the NDIS to families as they have initial contact and also from families who may not have been in contact with an Advisor for many years.<sup>412</sup>

A 2012 federally-funded evaluation of the HCWA found that the Advisor services had 'good reach' to the population of children with autism, but families from outer regional and remote areas, and those from CALD backgrounds, remain under-represented in client registration data. The report also found that overall most families were satisfied with the support the Advisors provided, however many families and some stakeholders thought that Advisors should provide additional supports. The report noted:

Advisors are not in a position to meet some of these identified needs, in particular individualised advice about services. But they could potentially provide a follow-up and exit appointment—something most families (>80%) surveyed would like. These are more aligned with Advisors' role and would help address issues identified during the evaluation. A follow-up appointment would help because some families find it difficult to take in all the information in the initial appointment, and survey data shows some are unaware of (or do not remember being informed about) particular components of the Package. An exit appointment to inform families about ongoing service options may help support families that feel anxious about the end of the funding period.<sup>413</sup>

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410 Ibid, p. 28.

411 Amaze, submission no. 139, p. 28.

412 Ibid, p. 27.

413 ARTD Consultants, *Evaluation of the Helping Children with Autism Package (FaHCSIA components, summary report, Sydney, 2012, pp. 30-31.*

## State budget

In the 2017/18 Victorian State Budget, funding for early childhood intervention services was extended for over 500 children over two years until those children transition to the NDIS.<sup>414</sup> There is also funding for the Kindergarten Inclusion Support program to assist children with significant disabilities to participate in kindergarten, such as through providing specialist consultancy, training and additional staff in kindergartens.<sup>415</sup>

### 3.5.1. The barriers to accessing early intervention services

There are many barriers to accessing early intervention services, such as delays in diagnosis, waiting lists for early intervention services, a lack of service providers, and insufficient publicly funded programs. As with barriers to a timely diagnosis, many stakeholders expressed concern about the lack of allied health professionals trained to provide early intervention services.<sup>416</sup>

The Committee heard that many parents were frustrated with the lack of information available guiding parents on how to choose an appropriate early intervention service, and the high out-of-pocket costs associated with some therapies, especially Applied Behaviour Analysis (ABA). At a public hearing in Melbourne, Ms Sarah Wilson told the Committee that the lack of information about therapies and the ‘wait-and-see’ approach of some practitioners left parents ‘really desperate’:

When there is this wait-and-see attitude parents get really, really desperate. They try things that are not evidence-based, things like diets or other therapies, and they feel that their lives are hard... So parents get desperate to try anything. I was ready to try anything, and luckily for me it was ABA. But we should have the right to make an informed choice, and an informed choice means that all of the therapies are laid out in front of you: these are the ones that are evidence-based; these are the ones that are not; this is how much they cost. But I think GPs and paediatricians are a bit afraid of presenting those choices, especially when the best one comes with such a huge price tag.<sup>417</sup>

While the Commonwealth-run Raising Children Network (RCN) website<sup>418</sup> does provide information about the evidence-base of the different early intervention therapies available, few parents seem aware of this resource, and those parents that were aware of the RCN website found the information on the website hard to navigate. Dr Anna Middleton, mother of a 4-year-old son with ASD, told the Committee at a public hearing in Melbourne:

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414 Department of Treasury and Finance, *Victorian Budget 17/18: Service Delivery (Budget Paper No. 3)*, Melbourne, Victorian Government, p. 54.

415 Ibid.

416 ABA Parent Support Network, submission no. 51; Autism Behavioural Intervention Association, submission no. 60; AMAZE, submission, no. 139; Speech Pathology Australia, submission no. 136.

417 Ms Sarah Wilson, Convenor, ABA Parent Support Network, Family and Community Development public hearing – Melbourne, 10 October 2016, transcript of evidence, p. 4.

418 Raising Children Network, ‘Children with Autism Spectrum Disorder’, accessed 4 May 2017, <[raisingchildren.net.au/children\\_with\\_autism/children\\_with\\_autism\\_spectrum\\_disorder.html](http://raisingchildren.net.au/children_with_autism/children_with_autism_spectrum_disorder.html)>.

When he was diagnosed, despite that at the time I was a trainee general practitioner, I was quite confused about how to start going about getting help for him, and I had read a lot about how important it was to get to an early diagnosis and early intervention, but I did not really know what that was or where to find it. So I ended up looking at websites such as the Raising Children Network, which did have a list of what seemed to be thousands of different therapies, with the advice that not every therapy is right for every child. So we still felt quite lost with that.<sup>419</sup>

The types of interventions for ASD listed on the RCN Parent Guide to Therapies on the RCN website include:

- behavioural interventions, such as Applied Behaviour Analysis (ABA), Discrete Trial Training, and Positive Behaviour Support;
- developmental interventions, such as Developmental Social-Pragmatic Model and Relationship Development Intervention;
- combined interventions, such as Early Start Denver Model and TEACCH
- family-based intervention, such as the More Than Words program;
- therapy-based interventions, such as speech therapy, occupational therapy, sign language and Picture Exchange Communication System;
- medical interventions that address problems seen in children with ASD such as hyperactivity, anxiety, obsessive compulsive behaviour, self-harming behaviour and sleep disorders; and
- alternative interventions, such as chelaton, elimination diets, secretin and yeast overgrowth management.<sup>420</sup>

The RCN Parent Guide to Therapies gives each therapy a 'research rating' to indicate how much research support and evidence there is for a particular therapy.<sup>421</sup> The Guide also has a safety rating, and an estimation of cost per session and time involved in delivering the therapy.

In their submission, Echuca Regional Health and Kyabram District Health Service noted that once families receive their funding, it is their responsibility to arrange private therapy, which many families report can be 'a difficult, overwhelming process':

Often families receive their package in the mail, but do not fully understand what it means, or where to next. It should also be noted that in rural areas not all required allied health services are available in the private sphere.<sup>422</sup>

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419 Dr Anna Middleton, Family and Community Development public hearing – Melbourne, 10 October 2016, transcript of evidence, p. 2.

420 Raising Children Network, 'Children with Autism Spectrum Disorder: Types of interventions for children with autism spectrum disorder', accessed 4 May 2017, <[raisingchildren.net.au/articles/autism\\_spectrum\\_disorder\\_intervention\\_types.html/context/978](http://raisingchildren.net.au/articles/autism_spectrum_disorder_intervention_types.html/context/978)>.

421 Raising Children Network, 'Children with Autism Spectrum Disorder', accessed 4 May 2017, <[raisingchildren.net.au/children\\_with\\_autism/children\\_with\\_autism\\_spectrum\\_disorder.html](http://raisingchildren.net.au/children_with_autism/children_with_autism_spectrum_disorder.html)>.

422 Echuca Regional Health and Kyabram District Health Service, submission no. 33, p. 2.

As the above quote reflects, the difficulties faced by many parents was compounded for those who lived in rural, regional and remote areas where there was a lack of paediatricians, allied health services and other service providers. Families living in regional areas often found it difficult to access therapies and many had to travel to Melbourne.<sup>423</sup> The challenges faced by these parents will be discussed in more detail in Chapter Nine, as will the ‘hub and spoke’ model of capacity building in regional areas.

Many parents told the Committee that they quickly reached the funding threshold of services and needed more services because the assessment was incomplete or they see the benefits of intervention but cannot continue to access intervention because they have ‘used all of the funding streams available to them’.<sup>424</sup> Speech Pathology Australia made a submission to the Inquiry in which they reported the barriers to accessing speech therapists:

Many parents report being offered short blocks of therapy (e.g. six sessions) by publically funded services with long breaks in between blocks of therapy. Others are asked to choose between more frequent group sessions and less frequent individual sessions. Recent research has suggested that decisions regarding the frequency of therapy offered by a publically funded organisation are being made on the need to ration services due to long waiting lists rather than best practice evidence. Many parents of individuals with ASD report having to spend large amounts of money on private interventions to ‘fill the gap’ in publicly funded services.<sup>425</sup>

In addition, Speech Pathology Australia identified several workforce issues limiting the availability and accessibility of speech pathologists in the ‘system of services’ for people with ASD in Victoria that will affect others:

- An uneven distribution of speech pathology positions across Victoria, particularly in areas of greatest need and in regional and rural locations;
- Insufficient numbers of speech pathologists within publicly funded services to meet the current and future demands of Victorians with ASD;
- Workforce sustainability undermined by time-limited funding of programs (i.e. initiatives which are discontinued when funding runs out or disbanded when there is a change of government);
- Allied health practitioners working with people with ASD not routinely included in evaluation of services, which compromises the quality of the evaluations of intervention effectiveness and acts as a barrier to embedding evidence based practice within the sector;
- Speech pathologists working in publicly funded services having little or no access to professional training budgets or clinical supervision, and limited opportunities for team based training and education; and

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423 Mr Ben Snow, submission no. 103.

424 Speech Pathology Australia, submission no. 136, p. 13.

425 Ibid, p. 12.

- Limited research into innovative or “non-traditional” models of service delivery.<sup>426</sup>

In their submission, Speech Pathology Australia stated that there were many families ‘who go without essential diagnostic or early intervention while they wait to access a publicly funded service because they cannot afford private speech pathology fees’.<sup>427</sup> The Committee was concerned by reports that many individuals with ASD cannot access both publically and privately funded services at the same time. Speech Pathology Australia also stated:

Speech Pathology Australia members report parents being told that they cannot continue to access publically funded services (and that they will be placed at the bottom of the waiting list) if they continue to access private services.<sup>428</sup>

Speech Pathology Australia suggested the possibility of ‘dual or multiple servicing’ and argued that ‘no individual with ASD should be prevented from accessing a publicly funded service simply because they are also accessing a private service’.<sup>429</sup> In their submission, they cited an economic evaluation of speech and language therapies for children with ASD undertaken in the UK in 2010, which found that every £1 GBP invested in speech and language therapies generates £1.46 GBP through lifetime cost savings and productivity gains.<sup>430</sup>

### 3.6. The role of evidence-based therapies

While speech pathology and occupational therapy are common evidence-based therapies used in early intervention, the Committee heard about other early intervention therapies, particularly Applied Behaviour Analysis (ABA), which is a range of techniques and strategies used to teach people with ASD new skills and reduce difficult behaviour.

Some supporters of ABA (and related early intervention therapies) consider that they can ‘virtually cure’ ASD. There are examples of children who have undertaken intensive early intervention who do not require integration aides in mainstream schools. For example, at a public hearing in Melbourne, the Committee heard from Ms Sarah Wilson, the Convenor of the ABA Parent Support Network, whose 10-year-old daughter was diagnosed with ASD at age 2-3 and after accessing a few years of ABA, her daughter is now in a mainstream school without support:

So we invested in it, and we did ABA for three and a half years. We started at 40 hours a week. We were told that the more hours that you do, the more effective the treatment is, so we thought, ‘Great, we’ve got the money. Let’s do it. We’ll do 40

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426 Ibid, p. 14.

427 Ibid, pp. 9-10.

428 Ibid, p. 10.

429 Speech Pathology Australia, submission no. 136, p. 10, citing K Marsh, E Bertranou, H Suominen and M Venkatachalam, An Economic Evaluation of Speech and Language Therapies: Final Report, Matrix Evidence, 2010 ([www.optimityadvisors.com/sites/default/files/research-papers/45-Speech-and-Language.pdf](http://www.optimityadvisors.com/sites/default/files/research-papers/45-Speech-and-Language.pdf)).

430 Speech Pathology Australia, submission no. 136, pp. 15-16.

hours a week'. We started at 20 and we just wanted to see how much she could cope with it. She loved the therapy, so we just kept going. We just kept adding hours until it was completely full. She did therapy from about a couple months after diagnosis until she was six years old when she was at school. The last six months was therapy in a mainstream school. She still attends this school. She has no aides; nothing is required. Her teachers treat her like any other regular child in the class, and she copes just fine.<sup>431</sup>

Ms Wilson described starting her own ABA parent support group as she felt that she could not share her daughter's progress in a regular autism support group:

I tried a regular autism support group, but it was a bit sad. I did not feel I could share the gains that she was making. She was making a lot of progress. She was starting to talk and starting to interact more and play with other children. I felt bad sharing these experiences when their children were not having the same gains.

So I started my own ABA parent group with some friends that I met, and we got together and we talked about things that are specific to ABA – things like: how do you get the money; where do you get the money; where do you get therapists; how do you hire a therapist; how do you know what a good therapist looks like; what kinds of programs are you doing; or we are running across this particular difficulty – how do we manage that? It was that kind of thing. Now we have a Facebook page for ABA parents. We have today, I think, 224 members, and some of those members are outside of Victoria but most of them are within Victoria. It sits under the auspices of the ABIA.<sup>432</sup>

When Ms Cathy Talia-Parker's son was diagnosed with ASD, she described the experience as like 'entering an unknown world'.<sup>433</sup> At a public hearing in Melbourne, she told the Committee that ABA was beneficial for her son, but it was very expensive and the intensity of the program made it difficult for her to stay in the workforce. Eventually Ms Talia-Parker became ABA-trained to help her son:

Once the diagnosis was made, it was really very, very tricky to know which path to take... We received a little bit of information about what we call ABA therapy, applied behaviour analysis. It was very little at that time, so we were quite confused and did not have much direction in terms of what we were to expect in the coming years, how we were to help our son – we really had no idea how we were to help our son – and what directions to take. It was really because my husband was quite proactive at that time and the internet had become much more useful and it was at our doorstep that we researched ABA, and we found that there was a lot of data and evidence to say that children with autism who participated in an ABA program were likely to have some success and maybe a great deal of success, and that was the path we decided to go down.<sup>434</sup>

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431 Ms Sarah Wilson, Convenor, ABA Parent Support Network, Family and Community Development public hearing – Melbourne, 10 October 2016, transcript of evidence, p. 3.

432 Ibid.

433 Ms Cathy Talia-Parker, submission no. 38, p. 1.

434 Ms Cathy Talia-Parker, Family and Community Development public hearing – Melbourne, 12 September 2016, transcript of evidence, p. 2.



Ms Talia-Parker described the gains her son made with ABA:

The program for us was a success, really. It gave our son many different skills. We were able to work on such little things, including noticing his environment and being able to point. Up until that point he did not know how to even point. Being able to listen and look at the same time is a big challenge for our children with autism, so there is a lot that goes into that program that starts that off for these children. Socially we were able to work on social interaction, and we were able to work on behaviours that we wanted to reduce – stims, which are stimulatory behaviours – and we were able to give him communication, starting with picture-word exchange and then leading even to some computer apps that had recently come out that our children can access. It did lead to our son speaking, even though he still struggles with that. But the main thing is that he knows how to communicate if he cannot get his words out. A lot of children his age have not been able to get to that point, unfortunately. So we are very happy with the way that went.<sup>435</sup>

In their submission, the ABA Parent Support Network described some parents as having ‘sold their home, taken a second job or accessed their superannuation’ to afford ABA therapy for their children, but they argued that the benefits of ABA for children with ASD and their families far outweigh the costs.<sup>436</sup> They write:

[I]n a wealthy, developed country like Australia is it simply not fair that wealthy families can access an effective and known intervention but poorer families cannot. Nor is it fair that parents with a special needs child correspondingly face massive financial consequences.<sup>437</sup>

In her submission, Mrs Shelley Fleming described having to claim her superannuation to pay for ABA therapy:

The governments Early Intervention Program was offered (about 1.5 hours a week and the waiting list was over 12 months long... which then wouldn't have been “early intervention” so we started to investigate other options. After consultation with Child Psychologists, our GP and various other people in the child health field, we then invested in [ABA] and, living in the Western suburbs of Melbourne, not only had to make the trips to Essendon to have meetings, but the therapists had to travel (often quite impressive distances) to us. ABA therapy cost us approximately \$30,000 per year, and Matt was receiving 4 hours of therapy 5 days a week. This really did wonders for him- his speech improved immeasurably... Though we believe that Matt's improvements are priceless, we soon realised that selling the house would be a likely solution if we wanted to continue Matt's therapy; otherwise we simply wouldn't be able to. So in 2008, I claimed my superannuation, which was sitting at approximately \$90,000. \$25,000 of that was then claimed by the government in taxes. The \$6,000 a year for two years, from the government was

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435 Ibid, p. 3.

436 ABA Parent Support Network, submission no. 51, p. 2.

437 Ibid, p. 2.

helpful (the ‘children with disabilities’ fund), but was gone within the first 2-3 months of therapy.<sup>438</sup>

At a public hearing in Melbourne, Associate Professor Jill Sewell, the Deputy Director of the Centre for Community Child Health at the Royal Children’s Hospital, spoke about the need for further research into effective and realistic interventions, noting that the cost of ABA is prohibitive for many families:

I think the focus on research should be effective intervention. We already know about some things that have been shown to be effective, but we have got to be realistic about intervention as well. For example, ABA, applied behavioural analysis, has been shown to be effective for kids with severe autism. You need about 40 hours a week to do it. You are talking about maybe 1 per cent of the autism community who can afford that. What about the others? What can we do that is a bit more realistic for ordinary everyday people in the street, and what is the most effective way to change the outcome for those sort of people? So I think it is about realistic intervention evaluation. That is what we need much more research about.<sup>439</sup>

Dr Anna Middleton, a General Practitioner and the parent of a 4-year-old son with ASD, described feeling very confused, despite her training as a doctor, about how to help her son post-diagnosis. She and her husband took her son to a few speech therapy and occupational therapy sessions, which she said were not helpful because her son was unable to interact with the therapist. She described the positive changes in her son’s development as a result of their accessing an intensive ABA-based intervention program:

During the diagnosis period I had also read about ABA... Given that there was some evidence behind it, we decided to give it a try, so we contacted a behaviour analyst, who came to our house to do an assessment of our son. As soon as she started her assessment, probably within the first minute or few, I knew that ABA was the answer and was going to work for our family. In the 3 hours that she spent with my son he followed instructions, he listened, he played games, he did puzzles and he actually spoke with the therapist, and these were all things that up until that point I had no idea that he could do. For the first time I saw that my son had the ability and the intelligence to learn and with a bit of help would one day be able to sit and learn in a classroom with other children.

Fast-forward to today. It is now two and a half years later. Among numerous other things he has achieved those school-readiness skills and will be attending a mainstream primary school for prep next year. We are, however, planning to send an ABA therapist with him to school part time at probably an estimated cost of \$8000 per term. Although he now has the skills to learn effectively in a classroom environment he still has high levels of anxiety, and I worry that without the

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438 Mrs Shelley Fleming, submission no. 41, p. 1.

439 Associate Professor Jill Sewell, Deputy Director, Centre for Community Child Health, Royal Children’s Hospital, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 6.

additional support of a behaviour therapist at school he might get too anxious and start refusing to go.<sup>440</sup>

While education will be discussed in the following Chapter, it is important to note that some schools in Australia and in the United States incorporate ABA in their educational approach. In Victoria, Moomba Park Primary School is a school that embeds ABA and behavioural therapists in classrooms.<sup>441</sup>

The principles of ABA and other behavioural therapies have been incorporated into the approach of some early learning centres. The Committee visited the Victorian Autism Specific Early Learning and Care Centre (VASELCC) at La Trobe University's Olga Tennison Centre and learnt about their research into the efficacy of the Early Start Denver Model (ESDM), which is a play-based, 'naturalistic' group therapy that extends the principles of ABA.<sup>442</sup> While ESDM was originally developed to be applied on a one-to-one basis, the VASELCC use ESDM in a child care setting with the principle that children learn best in interactive social contexts, where they can learn from peers. The VASELCC is one of six Autism Specific Early Learning and Care Centre in Australia and provides support to children aged 0-6 in a long day care setting.

The UC Davis Mind Institute in the U.S. offers training in the ESDM. At the Mind Institute, the Committee received information of research projects that take evidence-based interventions into the community. One such study, the Parents and Toddlers at Home (PATH) Study, evaluated the effects of coaching parents of young children with ASD aged 12 to 36 months on the use of ESDM strategies to increase their children's social communication and developmental skills and to reduce problem behaviours. One outcome of this project has been a parent-friendly training package for professionals and parents to learn techniques used in the ESDM.<sup>443</sup>

Some of the Inquiry's stakeholders are strongly averse to ABA as it is seen to suppress children's natural autistic urges and can elicit almost 'robotic' responses from children.<sup>444</sup> Although Ms Chloe Fitton, who was diagnosed at the age of 20, did not go through ABA, she expressed criticism of ABA at a public hearing in Bendigo:

I do not think my parents would have put me through ABA anyway, but it is something that I really feel needs to be brought up, because there are several organisations represented in this inquiry that are about promoting ABA, and I disagree with ABA. Even a quick Google search can tell you that it is cruel and often

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440 Dr Anna Middleton, Family and Community Development public hearing – Melbourne, 10 October 2016, transcript of evidence, p. 2. See also: Dr Anna Middleton, submission no. 96.

441 Moomba Park Autism Inclusion Parents, submission no. 90.

442 G Vivanti, C Dissanayake and the Victorian ASELCC Team, 'Outcome for children receiving the Early Start Denver Model before and after 48 months', *Journal of Autism and Developmental Disorders*, March 2016; G Vivanti, J Paynter, E Duncan, H Fothergill, C Dissanayake, S Rogers and the Victorian ASELCC Team, 'Effectiveness and feasibility of the Early Start Denver Model implemented in a group-based community childcare setting', *Journal of Autism and Developmental Disorders*, June 2014.

443 The UC Davis Mind Institute, 'Research', accessed 17 May 2017, <[ucdmc.ucdavis.edu/mindinstitute/centers/cedd/cedd\\_research.html](http://ucdmc.ucdavis.edu/mindinstitute/centers/cedd/cedd_research.html)>.

444 Ms Chloe Fitton, Family and Community Development public hearing – Bendigo, 17 October 2016, transcript of evidence; Ms Susanna Flanagan, Family and Community Development public hearing – Bendigo, 17 October 2016, transcript of evidence; Ms Susan Rees, Family and Community Development public hearing – Melbourne, 10 October 2016, transcript of evidence.

traumatic enough that most people subjected to it end up with post-traumatic stress disorder. A lot of the markers for how successful ABA is are based on parent satisfaction and not on the wellbeing of the child, which I think is also unacceptable. One of the main goals of ABA is to normalise behaviour – to bleach an Autistic person of any Autistic behaviour and to force them to pretend to be neurotypical.<sup>445</sup>

Ms Fitton relayed to the Committee what adults who had gone through ABA as children had said in online forums, citing one adult as writing:

I went through ABA. In my opinion, I was trained like a dog, and the exclusive focus on learning to 'pass' as neurotypical set me up for a lifetime of shame and isolation. When you pass, you make every human interaction a lie. You imbibe the lie that who you are is not acceptable, and the thing you fear most is that you will fail in your effort to mimic social behaviours that are not natural for you and that you largely are unable to perceive (or even perceive how that effort is being received by others), so you slowly accumulate a burden of shame and self-loathing, and anxiety that someone will see who you are. All the while you are dying inside because you want someone to know who you are. You need it – Autistics are human and need human contact and love like everyone else. And yet, we are trained to make ourselves invisible.

It denigrates you as an Autistic... In my opinion, ABA addresses the needs of neurotypicals by rendering Autistics invisible. It also shifts the entire burden to people who are already struggling with the disabilities that come with sensory integration dysfunction and the resulting difficulties with social interaction. It forces us to add a layer of cognitive effort on top of ... trying to decipher communication that has a substantial portion of the content missing. That is profoundly ableist and – and frankly selfish.<sup>446</sup>

Ms Susan Rees, the mother of an 18-year-old daughter with ASD and an intellectual disability, told the Committee at a public hearing in Melbourne about her decision not to use ABA therapy on her daughter:

[W]e did not feel that was suitable for our daughter. To get her to do something that she did not want to do was not an option. Plus it was super expensive. You had to pay out of your own pocket for that, an hourly rate for round-the-clock educators to come into your home and do that privately. It did not gel with my style of parenting, with our style of parenting, I suppose too – making someone sit down and do tasks over and over and over again repeatedly until it was rote. It was learning by rote. I do not know, maybe in hindsight she would have benefited from that, but I do not know.<sup>447</sup>

While the Committee heard similar views expressed by representatives at the Autistic Self-Advocacy Network (ASAN) in the U.S., the Committee also learnt of the

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445 Ms Chloe Fitton, Family and Community Development public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 5.

446 Ibid.

447 Ms Susan Rees, Family and Community Development public hearing – Melbourne, 10 October 2016, transcript of evidence, p. 5.

widespread use and availability of behavioural analysis and behavioural therapies across the U.S. The Committee also heard about professionally accredited behavioural analysts – Board Certified Behaviour Analysts (BCBAs) who work in a range of settings including schools and disability service settings. BCBAs are nationally accredited behavioural analysts with a graduate degree (often in related areas such as speech therapy, education/ special education and psychology). BCBAs supervise other staff administering behaviourally based interventions in their workplaces.<sup>448</sup> The Committee heard that the BCBAs work with a wide range of clients who engage in self-injurious behaviours and not just individuals with autism.

In the U.S., there is a national Behaviour Analyst Certification Board (BACB) – a non-profit corporation accredited to offer training in behavioural analysis and to people wanting to become BCBAs. At the Southern Connecticut State University, which offers a Master’s Degree in Science for special education teachers to specialise in ASD – students can elect to undergo the additional BCBA qualification.<sup>449</sup> The Committee was impressed with the widespread availability of different evidence-based behavioural therapies, which are not as common or accessible in Australia. The Committee is concerned that there is a lack of therapists trained in delivering behavioural therapies in Victoria, particularly in regional areas.<sup>450</sup>

Discrete Trial Training and Pivotal Response Training techniques are not therapies but are teaching techniques that are based on ABA principles and are considered components of ABA therapy. Both techniques are focused on children from the 2 – 6 year old age group but they have been used with adults with ASD. As stated on the Raising Children’s Network site about Discrete Trial Training (DTT):

It involves breaking skills down to their most basic parts and teaching those skills to children, step by step. All achievements are rewarded, which encourages children to learn.<sup>451</sup>

DTT is used to teach children (or adults) with ASD skills, for example: daily living skills, and because it ‘works on changing behaviour, DTT can also be used to teach parents how to manage children’s difficult behaviour’.<sup>452</sup>

Pivotal Response Training is a set of teaching techniques that are based on the principle of ‘naturalistic teaching’ and focuses on understanding what children are motivated by and their interests in order to work with children to improve children’s social, communication and play skills and their behaviour.<sup>453</sup>

In relation to the number of hours per week that is required for an early intervention program of therapy to be successful, the Committee heard that ABA was

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448 Behaviour Analyst Certification Board (BACB), ‘BCBA’, 18 April 2017, <[bacb.com/bcba](http://bacb.com/bcba)>.

449 Southern Connecticut State University, ‘Graduate Programs’, accessed 17 May 2017, <[www.southernct.edu/academics/schools/education/departments/specialeducationreading/graduateprograms.html](http://www.southernct.edu/academics/schools/education/departments/specialeducationreading/graduateprograms.html)>.

450 Mr Ben Snow, submission no. 103.

451 Raising Children’s Network, ‘Discrete Trial Training’, accessed 18 May 2017, <[raisingchildren.net.au/articles/discrete\\_trial\\_training\\_th.html](http://raisingchildren.net.au/articles/discrete_trial_training_th.html)>.

452 Ibid.

453 Raising Children’s Network, ‘Pivotal Response Treatment (PRT)’, accessed 5 June 2017, <[raisingchildren.net.au/articles/prt\\_th.html](http://raisingchildren.net.au/articles/prt_th.html)>.

time-intensive, and requires up to 40 hours per week.<sup>454</sup> However, in the report by Roberts and Williams, commissioned by the NDIA, mentioned above, the researchers critically evaluated the effectiveness of different therapies and recommended that children who have received a diagnosis of autism receive 20 hours per week of early intervention ‘that involves interaction with them’.<sup>455</sup>

Mr Peter De Natris, strategic adviser at the National Disability Insurance Scheme, told the Committee at a public hearing in Geelong that the report ‘did not state that [the 20 hours of intervention] had to be specialist’, noting that the report ‘went on to clearly indicate that that intervention should be, wherever possible, family and participatory based’.<sup>456</sup> He went on to say that:

We are using that as a guideline, but what we are more interested in from a diagnosis point of view is the functional impact of the diagnosis – so, what is the impact, in what domains, for that young person, that child? And how are we best constructing reasonable and necessary plans to respond to that? We would like to think that there is a rich evidence base, indeed led by the early childhood intervention sector here in Victoria, that clearly states that family-centred practice, the practice that involves the child in activities that are very focused on inclusion and respects the fact that children live, grow, play and develop best with other children and with their families than in therapists’ rooms and those sorts of things.

It is about getting that balance right. But yes, we do use that as a guidance; it is not a hard-and-fast rule.<sup>457</sup>

The Committee supports the view, expressed to it by other participants to the Inquiry, that evidence-based therapies need to be delivered in a manner, and for periods of time appropriate to each child with ASD and their needs.

There is also a need to provide support for children deemed not eligible to be funded under the NDIS.

Accordingly, the Committee recommends that:

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454 Associate Professor Jill Sewell, Deputy Director, Centre for Community Child Health, Royal Children’s Hospital, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 6.

455 J Roberts and K Williams, *Autism spectrum disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers*, report funded by the NDIA, 2016, p. 11.

456 Mr Peter De Natris, Strategic Adviser, National Disability Insurance Scheme, Family and Community Development public hearing – Geelong, 19 September 2016, transcript of evidence, p. 4.

457 Ibid, pp. 4-5.



### RECOMMENDATION 3.9

The Victorian Government fund children with ASD who are not deemed to be eligible for participant funding under the NDIS for up to 20 hours of therapy per week according to need.

- Ensure their families, carers and service providers are provided with accurate advice, information and support on childhood intervention therapies, including behavioural therapies, that are evidence-based.

#### Non evidence-based therapies

In submissions and public hearings, the Committee heard about a range of other therapies, such as art therapy,<sup>458</sup> hydrotherapy,<sup>459</sup> music and dance therapy,<sup>460</sup> drama therapy,<sup>461</sup> and massage therapy.<sup>462</sup>

At a public hearing in Melbourne, Ms Lisa Carr told the Committee that her two sons participation in St Martins Youth Arts Centre had improved their confidence and helped them to feel included. Her sons both benefited from an 'inclusion scholarship' offered by St Martins drama therapy to children and young people experiencing disability or learning difficulties, cultural and linguistic difference and/or economic or educational disadvantage.<sup>463</sup> Ms Carr told the Committee:

St Martins do not tell them off. They can be silly. They are, again, just happy to participate... They have a support teacher in there. They are all unique kids. I do not know if they are all on the spectrum. The teacher just draws them in. They include them all. They praise and are positive about their participation.<sup>464</sup>

Ms Nicole Stephenson told the Committee at a public hearing in Geelong that her son with ASD loves art and benefits from art classes but the NDIA will not fund his art classes because, they say, 'It is not ASD-specific'.<sup>465</sup> Ms Stephenson is critical of the NDIA discourse around mainstreaming and she said that she had been fighting for six months to get his art classes approved by the NDIA, noting that they were helping her son interact with society and communicate with people:

In regard to the art therapy and it not being ASD-specific, they said it is not actually considered a therapy as such, which it is, because there has now been a childcare centre in Geelong that has actually put that as an NDIA-approved program. I could

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458 Ms Nicole Stephenson, Family and Community Development public hearing – Geelong, 19 September 2016, transcript of evidence, p. 2.

459 Ms Lisa Carr, Family and Community Development public hearing – Melbourne, 21 November 2016, transcript of evidence, p. 6.

460 Ibid.

461 Ibid, p. 8.

462 Mr Brenten Hogan, Family and Community Development public hearing – Swan Hill, 14 February 2017, transcript of evidence, p. 4.

463 St Martins Youth Arts Centre, 'Inclusion Scholarship', St Martins, accessed 18 May 2017, <[stmartinsyouth.com.au/page/scholarship](http://stmartinsyouth.com.au/page/scholarship)>.

464 Ms Lisa Carr, Family and Community Development public hearing – Melbourne, 21 November 2016, transcript of evidence, p. 8.

465 Ms Nicole Stephenson, Family and Community Development public hearing – Geelong, 19 September 2016, transcript of evidence, pp. 2-3.



not understand why the art therapy he was going to would not have been considered the same. He does not communicate very well with others, and halfway through the session they all put in a gold coin and they get fish and chips, and it might not seem like a big thing for everybody else, but he actually comes back and goes, ‘Mum, I socialised with the kids. I asked’ — such and such — ‘how is your painting going?’, and he would never do that. So this sort of thing is a necessity, an absolute necessity, and I just feel like I am fighting tooth and nail and getting absolutely nowhere.<sup>466</sup>

At a public hearing in Swan Hill, Mr Brenten Hogan told the Committee about an alternative massage therapy that their 12-year-old son with ASD has. The cost of the therapy and travelling to Adelaide, where the therapist is located, costs around \$12,000 a year.<sup>467</sup> Mr Hogan said that the therapy calmed their son, that they saw improvements in his demeanour, which also meant that they could ‘do a lot more things socially now as a family’.<sup>468</sup>

Medication was sometimes used to manage behaviours of concern and/or co-occurring mental health conditions.<sup>469</sup> Regarding medication, the Raising Children Network states that while medication is ‘not a cure’ for ASD, medications can help with challenging behaviours associated with ASD, such as hyperactive behaviour or overactivity, anxiety, obsessive or repetitive behaviour, tics, aggressive behaviour, sleep problems and seizures.<sup>470</sup>

Ms Rosemary Doherty told the Committee at a public hearing in Melbourne that her adult son with ASD was on medication to lessen anxiety.<sup>471</sup> Ms Susan Rees told the Committee at a public hearing in Melbourne about her 20-year-old daughter’s experience with medication (antidepressants and antipsychotics), which ‘made a massive difference’ in helping her manage her co-occurring schizophrenia.<sup>472</sup>

While some parents and caregivers talked about the need to medicate in order to manage behaviours of concern and or co-occurring mental health conditions, other parents described medication as unhelpful or damaging. Ms Susanna Flanagan and Mr Martin Flanagan are two parents with ASD who have three children with ASD. They spoke to the Committee at a public hearing in Bendigo about their experiences with medication, including needing to medicate their then 5-year-old to cope with the anxiety of attending school. Mr Flanagan said:

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466 Ibid.

467 Mr Brenten Hogan, Family and Community Development public hearing – Swan Hill, 14 February 2017, transcript of evidence, p. 4.

468 Ibid.

469 Mr Phil Lipshut, Committee member, Autism Family Support Association, Family and Community Development public hearing – Melbourne, 12 September 2016, transcript of evidence, p. 9; Ms Dianna Lane, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 2.

470 Raising Children Network, ‘Medication and autism spectrum disorder’, accessed 18 May 2017, <[raisingchildren.net.au/articles/autism\\_spectrum\\_disorder\\_medications.html/context/978](http://raisingchildren.net.au/articles/autism_spectrum_disorder_medications.html/context/978)>.

471 Ms Rosemary Doherty, Family and Community Development public hearing – Melbourne, 12 September 2016, transcript of evidence, p. 3.

472 Ms Susan Rees, Family and Community Development public hearing – Melbourne, 10 October 2016, transcript of evidence, p. 8.

It is not acceptable that [an education] system be so deficient as to have children requiring medication and experiencing trauma in order to attend. A system that operates in this fashion and views this as even remotely acceptable holds no value and will continue to disadvantage and fail individuals and communities.<sup>473</sup>

The Committee also heard that some people with ASD had negative experiences with medication. Ms Chloe Fitton, an adult with ASD, described at a public hearing in Bendigo how the medication she was given for misdiagnosed bipolar disorder ‘absolutely destroyed’ her body.<sup>474</sup> Ms Florence McIver also told the Committee at a public hearing in Melbourne that ‘every single medication’ that her son has been on ‘has sent him absolutely nuts’.<sup>475</sup>

In their submission, the Lizard Centre, which offers a range of ABA programs and social skills development programs, argued that parents need to be informed about the types of ‘fad treatments’ and unestablished therapies available.<sup>476</sup> In their submission, they wrote:

Given the prevalence of ASD and the demand for treatment, the intervention market is booming. As government investments into autism treatment are increasing, so too are fad treatments. Primary care, allied health, social care, and education professionals have critical responsibility to protect families and individuals affected by ASD from fad and ineffective, controversial, or potentially dangerous interventions that are touted by self-proclaimed autism experts who are looking for financial gain (Dillenburger et al., 2014).<sup>477</sup>

The Lizard Centre also stated that ‘several unestablished interventions *continue to be widely recommended* by primary care, allied health, social care, and education professionals in Victoria, often at a high cost’.<sup>478</sup> They said, in their submission, that ‘primary care, allied health, social care, and education professionals are not doing enough to protect consumers from fad and ineffective, controversial, or potentially dangerous interventions’.<sup>479</sup>

### 3.7. NDIS early intervention program

Information provided to the Committee by the NDIA showed that at 31 March 2017, the percentage of children (0-18) who were NDIS participants with an active plan and diagnosed with ASD was 45.2 per cent. As discussed in Chapter Six, the NDIS will eventually replace a range of programs currently operated by the Commonwealth Department of Social Services, including the Helping Children with Autism (HCWA)

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473 Mr Martin Flanagan, Family and Community Development public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 3.

474 Ms Chloe Fitton, Family and Community Development public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 5.

475 Ms Florence McIver, Family and Community Development public hearing – Melbourne, 12 September 2016, transcript of evidence, p. 5.

476 The Lizard Centre, submission no. 52.

477 Ibid, p. 1.

478 Ibid, p. 2.

479 Ibid.

package. The NDIS Early Childhood Early Intervention (ECEI) approach will replace the HCWA.

The NDIS has stated that all children with developmental delay<sup>480</sup> or disability will be eligible for early intervention services regardless of whether they have received an official diagnosis. While a formal diagnosis will not be necessary, diagnosis will remain a useful tool as it can provide parents and service providers with detailed information about a child's support needs.

The ECEI approach promotes a family-centred practice and timely, well-integrated early intervention. The approach is informed by a report commissioned by the NDIA,<sup>481</sup> in addition to other research.<sup>482</sup>

As mentioned above, the report by Roberts and Williams, commissioned by the NDIA, critically evaluated the effectiveness of different therapies and recommended that children who have received a diagnosis of autism receive 20 hours per week of early intervention 'that involves interaction with them'.<sup>483</sup> For Mr Peter De Natris, strategic adviser at the National Disability Insurance Scheme, the report 'did not state that [the 20 hours of intervention] had to be specialist', rather, that the time period for intervention should be more broadly interpreted to involve therapists and family and be participatory based.<sup>484</sup> This accords with the Committee's understanding that each child with ASD requires an individualised plan that caters for their individual needs. Nevertheless, the Committee is aware that for some parents there is confusion about how many hours of therapy should be delivered only by therapists, or by a combination of therapists and family members.

As detailed in Chapter Six, the NDIS will establish a network of 'access partners' with expertise in early intervention, who will meet with families to determine the supports their child needs. There are six Early Childhood Partners appointed across Victoria, which will be the first contact point for families.<sup>485</sup> The Early Childhood Partner will discuss with the family the most appropriate supports that would benefit the child, tailoring the supports to the child and the family's individual needs and circumstances. The NDIS Early Childhood Partner may provide information and referral to other support services.

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480 As defined in the Commonwealth *National Disability Insurance Scheme Act 2013*.

481 J Roberts and K Williams, *Autism spectrum disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers*, report funded by the NDIA, 2016.

482 KPMG, *Reviewing the evidence on the effectiveness of early childhood intervention*, report to the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), September 2011; Family & Community Services, *Strengthening supports for children and families 0-8 years: Now and into the future*, NSW Government, 2015; Department of Education and Early Childhood Development (DEECD), DEECD Early Childhood Intervention Reform Project: Literature review, Victorian Government, 2009.

483 J Roberts and K Williams, *Autism spectrum disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers*, report funded by the NDIA, 2016, p. 11.

484 Mr Peter De Natris, Strategic Adviser, National Disability Insurance Scheme, Family and Community Development public hearing – Geelong, 19 September 2016, transcript of evidence, p. 4.

485 The six Early Childhood Partners appointed across Victoria are listed in Chapter Six.

The NDIS announced the following eligibility requirements for access to funded early intervention:

- if you have an impairment or condition that is likely to be permanent and
- there is evidence that getting supports now (early interventions) will help you by:
  - reducing how much help you will need to do things because of your impairment in the future **and**
  - improving or reducing deterioration of your functional capacity or
  - helping your family and carers to keep helping you **and**
  - those supports are most appropriately funded through the NDIS, and not through another service system.

OR

- you are a child aged under 6 years of age with developmental delay which results in:
  - substantially reduced functional capacity in one or more of the areas of self-care, receptive and expressive language, cognitive development or motor development and
  - results in the need for a combination and sequence of special interdisciplinary or generic care, treatment or other services which are of extended duration, and are individually planned and coordinated; **and**
- those supports are most appropriately funded through the NDIS, and not through another service system.<sup>486</sup>

It is anticipated that not all children who access early intervention services under the NDIS will require a funded package once they are adults. This is in-line with emerging research on early intervention, which affirms that early intervention can reduce ongoing health care, social and economic costs associated with ASD, and improve an individual's ability to 'cope' in the mainstream.<sup>487</sup>

In their submission, Amaze stated that they are supportive of the ECEI approach of putting in place interventions before the need for a diagnosis, but Amaze reiterated that diagnosis should not be delayed:

However, of concern is the lack of clarity within the ECEI approach regarding the point at which a diagnosis of autism will be obtained. Whilst there is a clear benefit in children who are showing signs of developmental delay to enter the ECEI to receive services that previously weren't available to them, it is unclear what steps will be taken if the initial presentation of developmental delay progresses to

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486 NDIS, 'Access Requirements', NDIS, 2017, accessed 11 May 2017, <[www.ndis.gov.au/people-disability/access-requirements.html](http://www.ndis.gov.au/people-disability/access-requirements.html)>.

487 Amaze, submission no. 139, p. 31; J Roberts and K Williams, *Autism spectrum disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers*, 2016, report funded by the NDIA; National Guidelines, Best Practice in Early Childhood Intervention, Early Childhood Intervention Australia, 2016 (release on 19 April 2016).

autism, and when a diagnosis will be sought. Amaze recognises the benefits of the ECEI putting interventions in place before a diagnosis of autism, however it doesn't remove the need for a diagnosis to be made if there is a clear presentation of autism. The risks of a delayed diagnosis are a delay in improvement at a time when the child is most receptive to intervention.<sup>488</sup>

Throughout the Inquiry, the Committee heard from many service providers who seemed unsure of what the change to the NDIS meant for them and their clients. Speech pathologist Ms Lyn Nicol expressed hope that the NDIS allows access to children beyond the current capped age of seven years. At a public hearing in Morwell, Ms Lyn Nicol stated:

I guess one of the things with the NDIS that I have great hopes for it is that at the moment most of our funding occurs through ECIS, which finishes at the start of school for helping children with autism, which does allow us to support, within the school system, up to the age of seven. We have a fairly close relationship with a number of local schools where we continue to support the children. However, what we find is that at age seven funding for assistance stops and it seems to be a little bit unequal at the moment. We have some parents who seem to be able to organise lots of different funding for lots of different services, sources, and other parents who struggle with it a little bit. So a number of parents have already asked, you know, how is the NDIS going to impact, to which I can't answer generally. My answer is to make sure that they have whatever they can in place so that their child is noted as the NDIS roll out comes in. My hope is that those children from the age of seven onwards will be getting a little bit more support because that is very difficult.<sup>489</sup>

The NDIS ECEI is discussed in Chapter Six. It is anticipated with the roll out of the NDIS many new providers of services for people with ASD will enter the market. The Committee is aware that the NDIS is undertaking a registration process in order for new entrants to become part of the scheme, and be eligible to provide supports, (including behavioural therapy), to participants of the scheme. However, unlike the United States, Australia does not have a national accreditation system for therapies, such as ABA. In fact, practitioners of ABA do not need formal qualifications to practise ABA therapy in Australia. There is an international certification board, which accredits practitioners as Board Certified Behaviour Analysts, and while this accreditation is widely used in the United States, it is not yet the national standard of accreditation in Australia.<sup>490</sup>

The Committee believes that the NDIS should ensure that service providers of therapies to participants in the scheme are offering evidence-based therapies that are grounded in science. Second, the NDIS needs to ensure that individuals providing therapy supports to participants, such as behavioural therapy, are qualified to deliver those supports. Lastly, the NDIS needs to provide clear, accessible and critical information on evidence-based therapies to all participants and their families, so that

488 Amaze, submission no. 139, p. 57.

489 Ms Lyn Nicol, Speech Pathologist, Gippsland Lakes Community Health, Family and Community Development public hearing – Morwell, 5 December 2016, transcript of evidence, p. 6.

490 Raising Children Network, 'Applied Behaviour Analysis', accessed 19 May 2017, <raisingchildren.net.au/articles/applied\_behaviour\_analysis\_th.html>.

they can make informed decisions about the early childhood interventions that they choose for their child.

The Committee understands that early intervention will be the responsibility of the NDIS for eligible children with ASD, however, there is a role for the Victorian Government in ensuring a smooth pathway for children from initial diagnosis to early intervention. The Victorian Government should also provide clear and consistent information for parents pre- and post-diagnosis.

Accordingly, the Committee recommends that:

### **RECOMMENDATION 3.10**

**The Victorian Government use its position on the COAG Disability Reform Council to ensure that when the NDIA registers service providers of early childhood intervention therapies, including behavioural therapies, those therapies are evidence-based.**

- **The NDIA ensure that practitioners of evidence-based behavioural therapies are qualified to deliver that therapy.**

### **RECOMMENDATION 3.11**

**The Victorian Government use its position on the COAG Disability Reform Council to ensure that the NDIA provides clear, unambiguous and accessible information about behavioural therapies to all scheme participants and their families, so that they can make informed decisions about the early childhood interventions that they choose for their child.**

The Committee heard that there is currently a shortage of therapists to deliver services to people with ASD. There is a shortage of allied health professionals, particularly in the area of speech pathology. It is anticipated with the roll out of the NDIS the demand for services will increase, and the need for qualified speech pathologists and other allied health professionals, trained in behavioural therapies, will also grow.

The ability to reduce the average age of diagnosis is dependent on the availability of clinicians. Likewise, the ability to provide early intervention for children with ASD is dependent on the availability of clinicians. There are concerns with the rollout of the NDIS that many families will not be able to use their packages because of the lack of allied health professionals and early intervention service providers, particularly in rural and regional areas.

The Committee believes that the Victorian Government will need to take a lead in addressing this shortfall. Firstly, provision needs to be made to support the training of more speech pathologists, particularly to cover the lack of speech pathology services in rural and regional Victoria. Secondly, the State Government needs to address the lack of a tertiary-based course in evidence-based behavioural therapies, which could provide qualified practitioners in behavioural therapies to work in a range of sectors with people with ASD. This course would be particularly beneficial to health professionals and allied health professionals, such as psychologists, occupational therapists and speech pathologists.

The Committee believes that the Victorian Government, in consultation with key stakeholders outlined in the updated State Autism Plan and registered training organisations, should support and fund the development of a post-graduate diploma in behavioural therapies. Secondly, the State Government should provide funding to support more places to be available in speech pathology in Victorian universities, and examine the option of a scholarship program for speech pathologists to work in rural and regional Victoria.

Accordingly, the Committee recommends that:

**RECOMMENDATION 3.12**

The Victorian Government, in conjunction with the Office of the Skills Commissioner and key stakeholders, facilitate the development of a post-graduate diploma in behavioural therapies.

**RECOMMENDATION 3.13**

The Victorian Government introduce a scholarship program for speech pathologists to work in rural and regional Victoria.





# Chapter 4

## The School Years

### AT A GLANCE

#### Background

One of the key issues of this Inquiry has been the experience of students with ASD in the Victorian school system. Parents raised the following issues: a lack of information and guidance on establishing the best school for the enrolment of their child; schools that refuse to enrol their child with ASD; the limitations of the Program for Students with Disabilities (PSD); a lack of understanding and knowledge in the school sector of ASD; a lack of appropriate learning environments, including appropriate sensory spaces; poor or non-existent training of teachers in ASD; and a lack of opportunity for academic achievement.

#### Chapter overview

Currently mainstream schools are not commonly providing an inclusive model of education that would encourage parents of children with ASD to enrol their child. The Committee is aware that many parents are choosing special or specialist schools or home schooling for their child over mainstream school enrolment. This chapter examines the school experiences of students with ASD and families living with ASD, the Program for Students with Disabilities and its Review, the Special Needs Plan and other programs that support inclusion, the issue of schools denying ASD students entry, and how to build a more inclusive school culture for students with ASD. This chapter relates primarily to the following terms of reference:

- (b) the availability and adequacy of services provided by the Commonwealth, State and local governments across health, education, disability, housing, sport and employment services; and
- (c) the adequacy of services to be provided under the National Disability Insurance Scheme (NDIS).

One of the central issues raised by families living with ASD and people with ASD in this Inquiry has been their experiences of the Victorian school system. Many parents reported to the Committee their struggles in attempting to find appropriate schooling for their child, and their often negative experiences of the school system. While the criticism of schools was broad in scope, much of the commentary rested on failures within the mainstream Victorian state school system.

The evidence suggests that currently mainstream schools are not commonly providing an inclusive model of education that would encourage parents of children with ASD to enrol their child. The Committee is aware that many parents are choosing special or specialist schools, or home schooling, for their child over mainstream school enrolment. This chapter examines the school experiences of students with ASD and families living with ASD, the Program for Students with Disabilities and its Review, the Special Needs Plan and other programs that support inclusion, the issue of schools denying ASD students entry, and how to build a more inclusive school culture for students with ASD. This chapter relates primarily to the following terms of reference:

(b) the availability and adequacy of services provided by the Commonwealth, State and local governments across health, education, disability, housing, sport and employment services; and c) the adequacy of services to be provided under the National Disability Insurance Scheme (NDIS).

## **4.1. The school experience for students with ASD and their families**

One submitter to the Inquiry, who has ASD, described her experience of school as follows:

I hated school, had no idea of what was going on, could not follow the teacher or understand the children. I had significantly delayed motor skills, had no useable speech, and was continually mocked by the other children. I was not yet independently toileting, and in fact did not achieve that until I was almost 9. I was severely bullied. I was also constantly disciplined by the teachers, at that time by being smacked. I would be smacked because I was not paying attention, but I didn't know what I was supposed to be doing. I did not know for example, that when they said, everyone look at the board that it included me. I would constantly get told "don't do that again" but I never understood what they were referring to.<sup>491</sup>

According to the Australia Bureau of Statistics, in Australia in 2012, of the children with ASD who attended school, 95 per cent experienced some form of educational restriction.<sup>492</sup> Six per cent of children with ASD were not able to attend school because of their disability, while 44 per cent needed to attend either a special class

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491 Name withheld, submission no. 138, p. 1.

492 Australian Bureau of Statistics, *Autism in Australia – 2012*, 4428.0, 2014, accessed 11 May 2017, <[www.abs.gov.au/AUSSTATS/abs@.nsf/Latestproducts/4428.0Main%20Features52012?opendocument&tabname=Summary&prodno=4428.0&issue=2012&num=&view](http://www.abs.gov.au/AUSSTATS/abs@.nsf/Latestproducts/4428.0Main%20Features52012?opendocument&tabname=Summary&prodno=4428.0&issue=2012&num=&view)>.

in a mainstream school, or a special school.<sup>493</sup> For children with ASD who were attending school, 86 per cent reported ‘having difficulty’ at school, ‘the majority of whom had difficulty with fitting in socially, learning and communication.’<sup>494</sup> The rate of post-school qualification for people with ASD was relatively low, at 19 per cent of the total.<sup>495</sup>

Peak body Amaze conducted a survey as part of a consultation process with people with ASD and families living with ASD in Victoria in preparation for their submission to this Inquiry. Amaze received 500 responses to their detailed survey.<sup>496</sup> The results of the survey included that: 15 per cent of respondents had no, or partial school attendance; 68 per cent stated they were not supported in school to achieve their potential; and 50 per cent received no additional support.<sup>497</sup> The majority who did receive support said that it was not adequate to their needs. According to Amaze, 8 in 10 students with ASD do not complete school.<sup>498</sup>

In 2012, the Victorian Equal Opportunity and Human Rights Commission released its report, titled *Held Back*, on students with disability and the Victorian school system. While directed at all students with disability, the findings of the report were relevant to students with ASD. Those findings included: students being refused enrolment in a school; being denied participation in external assessments; being denied equal access to attend excursions, or school camps; student support group meetings taking place infrequently or haphazardly; individual learning plans not being properly developed; struggling to find accessible transport; and discriminatory attitudes.<sup>499</sup> Bullying was also a significant issue. The Commission argued for the development of an inclusive culture in Victorian schools to address discrimination and provide genuine opportunity to students with disability.<sup>500</sup>

Throughout this Inquiry people with ASD and parents of students with ASD have described to the Committee their experiences of the Victorian school system. The issues of concern to parents are manifold. They include: a lack of information and guidance on establishing the best school for their child; schools that actually refuse to enrol their child with ASD; the limitations of the Program for Students with Disabilities (PSD) funding model; a lack of understanding and knowledge in the school sector of ASD and how it presents in students; a lack of appropriate learning

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493 Ibid.

494 Ibid.

495 Ibid. See also Amaze, submission no. 139, and the Victorian Disability Advisory Council, submission no. 146.

496 Amaze, submission no. 139, p. 5.

497 Ibid, p. 38.

498 Ms Fiona Sharkie, Chief Executive Officer, Amaze, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, pp. 2, 4.

499 Victorian Equal Opportunity and Human Rights Commission, *Held Back – The experiences of students with disabilities in Victorian schools*, 2012, p. 10.

500 Ibid, p. 11. Other recent reports on students with disability and education, which are relevant include: Senate Standing Committee on Education and Employment, *Access to real learning: the impact of policy, funding and culture on students with disability*, Commonwealth of Australia, 2016; Children with Disability Australia, *Inclusion in education – towards equality for students with disability*, Children and Families Research Centre, Macquarie University, 2013.

environments, including appropriate sensory spaces; poor or non-existent training of teachers in ASD; and a lack of opportunity for academic achievement.<sup>501</sup>

The Committee also heard evidence of the bullying of students with ASD; the use of inappropriate restrictive practices; an inability of schools to manage behaviours of concern; a lack of facilities, including appropriate technologies; and the prevalence of co-occurring conditions in children with ASD that prevent them from engaging in school, such as anxiety.

### **Assistance with school choice**

Parents have consistently advised the Committee of the difficulties they have faced in their search for an appropriate school for their child. Parents of students with ASD have told the Committee of the lack of support and information they have received in this process, describing their experience as one involving a frustrating round of school visits and contacts with often unsatisfactory results. For many parents, choosing the right school also involves assessing the differences, advantages and disadvantages between mainstream schooling and special schooling. In their submission to the Inquiry, support group Extended Families Australia told the Committee about the experiences families of students with ASD faced in finding the right school:

Families report struggling to find an appropriate school setting for their child. We have observed a common pattern of families moving their child between schools to find a more appropriate environment. Parents often feel unsupported in trying to find information about the options and make those choices. They are often unsatisfied with what is on offer and many have said they have had to make compromises on what they believe the ideal education setting would be for their child due to a lack of options.<sup>502</sup>

At a public hearing in Morwell, members of the South Gippsland Autism Action Group told the Committee about the difficulty of finding appropriate schools for their children. Ms Michelle Hackett, mother of a 10-year-old boy with ASD, told the Committee about her search for a secondary school for her son:

We have already gone to the Catholic secondary school in Leongatha and it doesn't seem promising. We thought we would start the process now because our boys would go there in two or three years and we just walked away going, "No, that doesn't sound promising at all." They are not going to change anything.<sup>503</sup>

Member of the South Gippsland Autism Action Group Ms Tona O'Connor, mother of a 9-year-old boy with ASD told the Committee that:

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501 See for example, Extended Families Australia, submission no. 85, p. 4 and Ms Lisa Hamling, Facilitator, The Treehouse, Family and Community Development Committee public hearing – Geelong, 19 September 2016, transcript of evidence, p. 3.

502 Extended Families Australia, submission no. 85, p. 4.

503 Ms Michelle Hackett, South Gippsland Autism Action Group, Family and Community Development Committee public hearing – Morwell, 5 December 2016, transcript of evidence, p. 8.

From what we hear the funding even drops off even more once they hit secondary and the secondary college — our boys don't have that executive functioning to be able to navigate around the school or — I just know that we would not cope at all in the secondary college so Mary Mackillop was the secondary college, was the only real option because he can't go to the specialist school. When we approached them, and I told her exactly the story of how my son is, she said, "You may want to look at other schooling options." I said, "There are no other schooling options."<sup>504</sup>

Ms Cathy Talia-Parker, mother of a 13-year-old boy with ASD, told the Committee at a public hearing in Melbourne that:

Unfortunately mainstream school was very difficult. We had a good year in prep, but then there was a decline halfway through grade 1, and that probably had to do with a lot of factors. We perhaps did not choose the right school there. Also there were much bigger grade sizes. There were 28 children in that group — a lot for inexperienced teachers to deal with who did not really have any background on autism or on what it would be like to teach a child with autism or even have them participate within the classroom.<sup>505</sup>

After a 'stressful year', the family decided to look at special education. Ms Talia-Parker stated that:

[W]e got towards the end of that year and decided that we would look at special education, even though we were very reluctant to do that because we wanted our son to participate in mainstream. However, after we did go to special education, we found Katandra School in Ormond that would fit our son's needs. After some assessing, he was able to enter that school before the school year ended and become settled and ready to start the following year. They were smaller groups. Teachers that were special-education trained were able to understand our son and his needs a little better. It turned out that he wanted to go to that school, so we were very happy about that.<sup>506</sup>

However, as her son progressed through the school it became apparent to the family that his needs were not being met. Ms Talia-Parker stated that:

That is a higher functioning school, and as our son got older, because his verbal language had not increased — they are a more academic school — we had to look at what was going to happen to our son afterwards. That school would go until the age of 12, similar to a grade 6. The following year our son was going to be in a grade 5/6 class, and he was not really coping academically. His needs were not being met, so we then had to think about which school we were going to look at for our son. We also wanted to look at schooling that would enable him to stay on in a secondary situation, at least until the age of 18. That was a very tricky one. There were not a lot of special education schools that we were able to choose from within our area. Also visiting a lot of these schools does not necessarily lead you to

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504 Ms Tona O'Connor, South Gippsland Autism Action Group, Family and Community Development Committee public hearing – Morwell, 5 December 2016, transcript of evidence, p. 8.

505 Ms Cathy Talia-Parker, Family and Community Development Committee public hearing – Melbourne, 12 September 2016, transcript of evidence, p. 3.

506 Ibid.

believe that your child is going to fit into that school. So we ended up choosing a school that was out of our zone, and we were happy with that – Bayside Special – and our son has been very happy there.<sup>507</sup>

Ms Talia-Parker told the Committee that this choice of a school outside their zone did, however, come at a cost:

However, because of that, we were not able to access buses. They have an amazing bus access that is funded by the department of education, but because we were out of the zone, even after trying to access that in different ways – writing and speaking and all sorts of things – we were not able to access that.<sup>508</sup>

As indicated, many parents begin with enrolment of their child in a mainstream school, only to find that the lack of facilities, training and support for their child create an intolerable, negative and unsustainable experience. Some of these parents are forced to move their children to special schools (where, according to some parents, academic aspirations for students are lower), or decide to home school their children.<sup>509</sup>

The Department of Education and Training (DET) maintains a disabilities coordinator in each of its education regions, who can assist parents with choosing the right school for their child with ASD. DET also maintains a website that provides overall information to parents of school-age children with ASD.<sup>510</sup> However, while the website provides relevant general information it does not elaborate on the specific supports or programs that the local school can offer students and families living with ASD. Likewise, the disabilities coordinators can provide advice to families, but as the Committee understands it, this advice role is a reactive, rather than a proactive one.<sup>511</sup>

The Committee believes that parents of children with ASD need to have access to current, relevant information and guidance on establishing the best school for their child. As part of its schools inclusion agenda, the Victorian Government should establish a collaborative network of advisors, involving advocacy and support groups and peak bodies, to work with DET to provide a proactive service to inform parents of their choices. This will include an updating of the DET website, to better reflect how each local school is able to support the needs of students with ASD.

In the 2016 Review of the Program for Students with Disabilities (PSD) led by former Commonwealth Disability Commissioner Graeme Innes, to be discussed in detail below, a recommendation was made to create a new Inclusive Schooling Index, for all schools to self-assess and measure inclusivity. This recommendation was accepted

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507 Ibid.

508 Ibid, pp. 3-4.

509 See for example, Name withheld, submission no. 108, p. 4. Parents who have had to home school their children with ASD, see, Ms Susanna and Mr Martin Flanagan, submission no. 97, p. 10.

510 Department of Education and Training, 'Autism Friendly Learning', Victorian Government, accessed 20 May 2017, <[www.education.vic.gov.au/about/programs/needs/Pages/autism.aspx?Redirect=1](http://www.education.vic.gov.au/about/programs/needs/Pages/autism.aspx?Redirect=1)>.

511 Department of Education and Training, Correspondence, Follow up questions on notice – 21 March 2017.



by the government in its response to the Review. The Committee supports the development of the index, and believes that one element of this tool should be that its results are made available to parents, in order that they can be better informed about their local schools, and the right school to enrol their child.

Accordingly, the Committee recommends that:

#### **RECOMMENDATION 4.1**

**As part of its inclusive schools agenda, the Victorian Government provide parents of children with ASD access to up-to-date, relevant, information and guidance on establishing the most appropriate school to enrol their child with ASD.**

- **The Department of Education and Training update its website to better reflect how each local and or specialised school is able to support the needs of students with ASD.**

On the issue of the Inclusive Schooling Index, the Committee recommends that:

#### **RECOMMENDATION 4.2**

**In developing the Inclusive Schooling Index, the Victorian Government ensure that the results of the Index are made publicly available and easily accessible to parents, so they can be better informed about their local schools, and the choices they have for the enrolment of their child with ASD.**

### **Classroom learning environments**

Ms Narelle McCaffrey, a woman with ASD and mother of three autistic children, related to the Committee at a public hearing in Melbourne, the experience of an eight-year-old boy with ASD at a mainstream school:

He was determined to have language skills at a level deeming him ineligible for PSD funding, so he attended a mainstream school. He has struggled from his very first day at school. Meltdowns were frequent and his mother was called to collect him early most days. She reports that one time she had not even made it out of the school building when that call was made. His teacher was not equipped to work with him. The school asked that this boy's hours spent at school each day be reduced. Without being aware of any options, she agreed, so he was effectively for about half a year [sic]. Since then, things have continued to be a struggle.

We fast forward to this year. When allocating classrooms, this child's sensory needs were not considered. As a result, he effectively removed himself from his peer group into an adjoining room. The door was open. His behaviour spoke volumes of his struggle. He felt alienated and misunderstood and definitely not accepted. It was put to his mother that he might not be ready to participate in

school camp – that he might make unsafe choices, putting himself, peers and staff at risk. He often spoke about killing himself.<sup>512</sup>

Ms Susan Pearce, mother of a nine-year-old son with ASD, told the Committee at a public hearing in Melbourne about the issue of poor support in mainstream schools:

The problem is with mainstream schools, we understand, you have got 30 kids to a class; special schools have got 8 to 9. Putting them through the mainstream, yes it would be lovely and great – if you have got the aides, if you have got the funding, if you have got the teachers that understand ASD.<sup>513</sup>

Ms Pearce told the Committee about the consequences of this for her son's, and other ASD children's academic development:

Another big area of concern, and my major point, is that there are no facilities for children with high-functioning ASD or autism. Unfortunately parents have to put them into a special school. They are great, by the way. They are great for their social disability, but it means that their intellectual prowess is compromised because they are stuck with kids that have intellectual disabilities as well. While the environment is important to improve the social skills, unfortunately it means that the academic development of high-functioning children is compromised. Rather than reaching their full potential as future leaders and thinkers they settle for achievements that are less than what they could achieve.<sup>514</sup>

Ms Katie Koullas, founder of girls support group Yellow Ladybugs, and mother of a girl with ASD, described to the Committee at a public hearing in Melbourne the experience of one of the Yellow Ladybug girls at a mainstream school:

I will give you an example of one of the Yellow Ladybugs girls who absconds from school often daily due to anxiety, and even though her language is above what you would expect for a student of her age and her IQ is high, she is not able to perform to the best of her ability because she has got such extreme anxiety. She does not have any aide or support because of those issues. So this is a real issue for our community, and it is not just this one example – it is many, many, many stories from our parents.<sup>515</sup>

In their submission to the Inquiry, the Yellow Ladybugs provided commentary from their members about their experiences of the school system. One member quotes a teacher at her daughter's mainstream school to illustrate the school's inability to address her needs:

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512 Ms Narelle McCaffrey, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 3.

513 Ms Susan Pearce, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 5.

514 Ibid, p. 3.

515 Ms Katie Koullas, Founder, Yellow Ladybugs, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 3.

A comment from her teacher was " I can't treat her any different I have to treat her the same as their [sic] are other children with more visible needs". Just because hers is not physically obvious does not mean she isn't impaired.<sup>516</sup>

At a public hearing in Geelong, the parent support group the Treehouse told the Committee about their experience of mainstream schools:

I think the most important question is: can a mainstream school really endeavour to cater for students with ASD? In its current model, no. An ASD child often has a high IQ, but through slow processing speeds and executive functioning problems, when learning in a mainstream environment it is difficult, if not impossible, to reach their full potential.

The classroom environment should be such as to minimise sensory overload. The noise, colours, lighting and classroom configurations can be unbearable to an ASD student, compromising their learning potential and often leading to meltdown. This could lead to defiant behaviour, learning difficulties, being ostracised from their classmates, as well as creating a difficult environment for a teacher to control. The reality is we are made to deal with a mainstream model catered for neurotypical children. Classrooms are social environments that rely heavily on being able to interact, socialise and communicate with others. This can intensify the anxiety students on the spectrum experience. Research shows the importance of understanding the link between academic and social and emotional wellbeing. Inclusion is about being proactive in identifying the barriers for our ASD kids and then removing those barriers. It is about meeting the needs of all children to ensure they get a quality education. There are a number of barriers to providing better and appropriate support in the classroom for our ASD kids. These include funding, lack of knowledge and training, lack of specialist support staff and class sizes. It is not enough to give teachers professional development on autism; they need additional help from specialist staff to put adjustments in place in our classrooms.<sup>517</sup>

For the Treehouse, the result of the current incapacity of mainstream schools to accommodate students with ASD has led to school exclusion:

ASD children are getting excluded from school because of their behavioural needs, while other children refuse to go to school. Often ASD children are seen as poorly behaved or troublemakers. Better education would show that often the child is easily led or is acting out sensory overload.<sup>518</sup>

Not all the criticism of parents was directed at mainstream schools. While many parents reported positively to the Inquiry about their children's experience of special schools (or specialist autism schools), some parents were not impressed by their experience of their child's special school. One submitter to the Inquiry described the teachers at their child's special school as babysitters:

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516 Yellow Ladybugs, submission no. 117, p. 2.

517 Ms Lisa Hamling, Facilitator, The Treehouse, Family and Community Development Committee public hearing – Geelong, 19 September 2016, transcript of evidence, p. 3.

518 Ibid.

The staff seemed to consider their jobs to be babysitting. [Her child] didn't learn anything at this school. Some other parents and I decided to start a fundraising committee, which didn't exist at the time. The Principal took no interest in what we were doing and only contributed after I notified the Education Department of her lack of interest. We were having various problems with the school so saw the psychologist at the school. The conclusion she made was that we were troublemakers and we should "go elsewhere".<sup>519</sup>

Ms Cathy Talia-Parker described to the Committee at a public hearing in Melbourne her experiences of both mainstream and special schools. In choosing a special school for her son, a key issue was access to the school for her son's therapist:

I guess we were looking for a school that would accept children with challenges. All children have challenges, but obviously there were more in this case. We wanted a school where our therapist could attend the school, and this school was quite accepting of that. That is not always the case at all schools. Some schools do not like outsiders coming in.<sup>520</sup>

## **Bullying**

At a public hearing in Melbourne, Mr Ryan Kennedy, who has ASD, described his experience of being bullied at school:

I have had a fair bit of experience with various things. One of the things that I think affected me was in primary school when I got the diagnosis. In primary school I got bullied. The programs were all about how socially you have to be able to stand up for yourself or whatever. The implied thing with that, in my opinion, was that it was saying that if you do not behave in the right way, you are asking to be bullied...<sup>521</sup>

Mr Kennedy described the inability of the school to defend him:

I feel that regarding the current idea of teachers being out there to supervise, there is nothing particularly there to make sure they stop the bullying. It is all focused on the individual level, and there is no idea about the teachers having to be involved there. From my experience teachers are purely there so that if something happens, they can go and give first aid. There is nothing to say, 'Okay, there are students who need assistance'. I was not very good socially at school, so when they said, 'You need to stand up for yourself', I could not do that. It did not help that basically the rest of the year level saw me as the weird kid. I got picked on for being the weird kid, in acting out in autistic ways that I did not necessarily know were autistic at the time, and also for the fact that I have got red hair.<sup>522</sup>

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519 Name withheld, submission no. 108, p. 4.

520 Ms Cathy Talia-Parker, Family and Community Development Committee public hearing – Melbourne, 12 September 2016, transcript of evidence, p. 6.

521 Mr Ryan Kennedy, Family and Community Development Committee public hearing – Melbourne, 12 September 2016, transcript of evidence, p. 2.

522 Ibid, p. 3.

Mr Kennedy stated that there should be clear guidelines for schools to handle bullying of this nature, but he doubted the willingness of schools to implement anti-bullying strategies:

I think in pressing for good schools with no tolerance of bullying, in some cases there is also a focus on trying to sweep whatever they can under the rug to make it seem like there is no bullying so they can get more money and more funding. That seems to be one of those potential issues that needs to be dealt with. I think that occurred a bit.<sup>523</sup>

School student Mr Dom Williams, who has ASD, told the Committee at a public hearing that he was bullied at school because he was different to other students:

Probably the largest difficulty I have had is with, from my opinion, bullying because of ignorance. This was more prevalent in my second school, with some resolved bullying in my third one. In the second school — this is mainly in my third and fourth years of school — I came under fire from bullies who were sort of taking a jibe at the fact that I was different to other students. Certainly one of the main things that students use to bully me over is I am not very good at maths or spelling, so they would attack me over that. They attacked me over the fact that I was different.<sup>524</sup>

Mr Graeme Drysdale, parent of a girl with ASD, told the Committee in his submission to the Inquiry that school can be a place of intimidation to some students with ASD:

At school she was at times given various instructions and useless suggestions, the most destructive was "to be resilient"; when in fact it was the inadequate training of teachers (a very few of which actually bullied her); conversely we had compassionate teachers attempt to make her time at school bearable, yet neither they nor we knew what we were dealing with. Throughout this entire time her twin-brother has been her primary care giver, whilst this has had positive implications on his personal development as a person it has also weighed heavily on him in other ways. For some children on the autism spectrum school can be a place of intimidation and bullying; via some students, some staff, and the very nature of the school environment. I work in a primary school and see the same things.<sup>525</sup>

For Mr Martin and Ms Susanna Flanagan, parents of children with ASD, it is the 'love of learning' that is critically missing in the school system's education of their children. Mr Flanagan told the Committee at a public hearing in Bendigo that:

I guess that through school and all of these things the biggest thing that we are trying to get in our children at the moment is a love of learning, and that is where we have really struggled with our middle child. Even after trying with two different schools, we just could not get that love of learning. We did have some good teachers along the way that really worked, but I guess overall that system really did

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523 Ibid.

524 Mr Dom Williams, Family and Community Development Committee public hearing – Melbourne, 10 October 2016, transcript of evidence, p. 2.

525 Mr Graeme Drysdale, submission no. 19, p. 1.

not work the way we needed it to because it is trying to make you fit into a mould that does not fit everyone.<sup>526</sup>

To ensure that parents of students with ASD have choice around education options, the Committee recommends:

### **RECOMMENDATION 4.3**

**The Victorian Government through the Department of Education and Training provide flexibility of service and programs to facilitate and support families who choose to home school their children with ASD.**

#### **Stakeholder views**

Other stakeholders to the Inquiry reinforced the views of some people with ASD and parents of students with ASD. Consulting group Lancaster Consulting Australia advised the Committee in their submission that they had observed a widespread lack of understanding of ASD in teachers and support staff across primary and secondary schools. They stated that this is demonstrated in many different ways:

- Teachers who openly report that they have not received any training in ASD, and feel lost in how to support students with a diagnosis in their classrooms. ...
- Teachers who have a very superficial understanding of ASD and will often “diagnose” students themselves based on traits such as lining up toys and not making eye contact. ...
- Teachers who have been informed that they have a student with ASD in their classroom, but report that they do not have the time or resources to implement supports and appropriate modifications in the classroom. ...
- Teachers who implement strategies based on “gut instinct” rather than evidence based practise.<sup>527</sup>

In their submission, the Austin Child and Adolescent Mental Health Service (CAMHS) commented on the poor understanding of ASD in the school system and the limited support facilities:

For young people with ASD and normal intelligence, limited facilities within the education sector as well as a poor understanding of the needs of this population only serves to increase distress and contributes to escalating anxiety and mental health problems. Although schools have access to the Language Support Programme, the availability of this programme varies widely across networks and does not seem to be offered [in] some areas. In the experience of the writer, mainstream schools as a general rule, have only a cursory understanding of ASD and would benefit from more education and support. The provision of support to

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526 Mr Martin Flanagan, Family and Community Development Committee public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 9.

527 Lancaster Consulting Australia, submission no. 88, p. 6.

academically bright ASD students in schools is limited and these students are not eligible for integration funding...<sup>528</sup>

In their submission Victorian Advocacy League for Individuals with Disability Inc (VALID) and the Behaviours of Concern Peer Action Group, stated that both mainstream and specialist schools were failing students with ASD:

The inability for teachers both in mainstream and specialist settings to support and provide education programs that enable children with ASD and behaviours of concern to grow, develop and feel a part of the school community, only serves to escalate behaviours and further marginalise and isolate these vulnerable and lonely children. The experience of school can mark people for life – in this case the system marks children with ASD and behaviours of concern for exclusion and sets them on a career of rejection from most aspects of community life. Ineffective supports and commitment to some sort of developmental plan in the school system exacerbates behaviours which further stigmatise children and their families.<sup>529</sup>

In their submission, the Autism Family Support Association (AFSA) stated that, ‘While there are one or two relatively “good news” stories sprinkled around the system, the sense is that many schools are struggling either through lack of sufficient skilled resources or finding it is “all too hard”’.<sup>530</sup> AFSA is particularly concerned about students exhibiting challenging behaviours:

There are some individuals with ASD with challenging behaviours who are mostly attending the special school system, who currently do not get the support they need to be educated. There is a risk that many of these individuals in the special school system will be channelled into generic disability day services (which are typically under resourced and often provide little more than “childminding” for adults) and not given other opportunities.<sup>531</sup>

AFSA argue that the DET workforce needs upskilling to the unique needs of students with ASD:

More intense therapeutic intervention should be given to all ASD children in the school system. Collaboration between therapists within the DET system and private practice is a must for the benefit of the individual. Some schools have a reluctance to embrace this collaboration. These school years, provide the building blocks to set children up for a good and productive life.<sup>532</sup>

The importance of a teacher workforce that is suitably trained was emphasised by Ms Mary Thomson, Principal of the Western Autistic School, and CEO of the Autism Teaching Institute, at a public hearing in Melbourne:

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528 Austin Child and Adolescent Mental Health Service (CAMHS), submission no. 113, pp. 3-4.

529 Victorian Advocacy League for Individuals with Disability Inc (VALID) and the Behaviours of Concern Peer Action Group, submission no. 137, p. 8.

530 Autism Family Support Association, submission no. 71, p. 10.

531 Autism Family Support Association, submission no. 71, p. 10.

532 Ibid, p. 11.



It can often be a counterintuitive process to teach children with autism, and teachers require specialist knowledge. Even accomplished teachers can be baffled by their students with ASD in their grade and struggle to appreciate the meaning of the behaviour and learning style of the children. The capacity to make a reasonable adjustment and modification for students with ASDs in schools is based on understanding the impact autism has on each individual student. It is common to hear students with ASD described as naughty children, but when teachers are trained to look at behaviours through the lens of ASD, they can appreciate that when the student calls out the answers in class, for example, or questions the accuracy of what the teacher is saying, that is likely due to their autism. Skills have to be explicitly taught to children with autism that typical children pick up naturally.<sup>533</sup>

In research conducted by the Autism CRC, the role of co-occurring anxiety in students with ASD was the subject of their recent paper, *Autism, Anxiety and School Functioning*. The Autism CRC outlined the issue in this way:

Anxiety is commonly experienced by children on the autism spectrum, with approximately half of children on the spectrum having such high anxiety levels that they also meet criteria for an anxiety disorder. Anxiety causes many challenges for these children, as it furthers a child's impairment and leads to additional problems of aggression, oppositional behaviour, and poorer social skills relative to children on the spectrum who do not have anxiety. For this reason, we urgently need interventions that can effectively address anxiety for children on the spectrum. In particular, interventions are needed that can address the child's anxiety at school, as school is where anxiety is frequently experienced because it requires social, communication, and flexibility skills that are characteristic of autism. For example, a substitute teacher, field trip, or pop quiz can trigger emotional distress or outbursts that obstructs social and academic functioning. These problems are likely to further heighten anxiety, and limit the learning and academic outcomes of children on the spectrum.<sup>534</sup>

In a recent separate study undertaken by the Autism CRC, published in 2016, an autism educational needs analysis was completed. In their study, which involved a nation-wide survey, the Autism CRC identified the social and emotional needs of students on the spectrum as having the most impact on their learning, and requiring the highest level of support. This was followed by behavioural, communication and sensory needs. The sensory issue identified as having the most impact on the ability to participate was noise. The co-occurring condition that had the most impact on learning was anxiety. A range of other factors that impacted the learning environment were identified, including lack of specialist support, lack of specialist training, lack of support around daily transitions, and low social connectedness to the school.<sup>535</sup> The survey found that for students with ASD there were a number of difficult daily activities at school. Overall, the challenges rated highest as difficulties by students

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533 Ms Mary Thomson, Principal of the Western Autistic School, and CEO of the Autism Teaching Institute, Family and Community Development Committee public hearing – Melbourne, 21 November 2016, transcript of evidence, p. 3.

534 Autism CRC, *Executive Summary - Autism, Anxiety and School Functioning*, 2016, p. 2.

535 Autism CRC, *Australian Autism Educational Needs Analysis – What are the needs of schools, parents and students on the autism spectrum? 2016*, pp. 2-3.

with ASD were executive function, social and emotional challenges and fine motor challenges.<sup>536</sup>

This study concluded that an inclusive school culture and learning environment was a priority for all schools.<sup>537</sup>

## 4.2. Victorian state schools

At a public hearing in Melbourne, the Acting Secretary of the Department of Education and Training (DET), Ms Katy Haire, advised the Committee that DET delivers education to approximately 580,000 students, in over 1,500 government schools.<sup>538</sup> It is estimated that between 55,000 and 80,000 students in these schools require adjustments due to a disability. Of the government school student population, 25,000 students (4.2 per cent of the entire student population) are identified as having moderate to severe disabilities. These latter students are supported by the disability funding program known as the Program for Students with Disabilities (PSD).<sup>539</sup>

Of this group, more than 5,000 students with ASD receive support through the PSD, approximately 0.9 per cent of the total school population. Of the 25,000 students supported by the PSD, approximately half are enrolled in mainstream schools and half are enrolled in special schools. The obligations of Victorian Government schools in relation to students with disabilities are defined by the *Disability Discrimination Act 1992* (Cth), and other Acts. Students with disabilities have an explicit right to participate in mainstream schools on the same basis as other students.<sup>540</sup>

For this Inquiry, the Committee visited and met senior staff and students at Whittington Primary School in Geelong, Moomba Park Primary School in Fawkner, the Northern School for Autism in Reservoir, Kalianna School in Bendigo North, and Bendigo Special Developmental School in Kangaroo Flat. The Committee also visited some private school campuses. In addition to site visits, the Committee heard from a number of school principals and educationists at public hearings, including: Mr Peter Bush, Principal of Kalianna School; Ms Britt Holmberg, Autism Connect and inclusion coordinator, Kalianna School; Mr Graeme Scoberg, recent former principal, Swan Hill Specialist School; Ms Mary Thomson, Principal, Western Autistic School, and CEO, Autism Teaching Institute; and Ms Nancy Sidoti, Principal, Baltara Special School.

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536 The top ten rated daily difficulties rated were: planning for assignments; working as part of a group; handwriting and being neat; coping with change; coping with bullying or teasing; the speed at which they completed handwriting; copying information from the board; doing homework; staying calm when other kids annoyed them; and staying calm when the classroom is very noisy. See Autism CRC, *Australian Autism Educational Needs Analysis – What are the needs of schools, parents and students on the autism spectrum?*, 2016, p. 4.

537 Autism CRC, *Australian Autism Educational Needs Analysis – What are the needs of schools, parents and students on the autism spectrum?*, 2016, p. 7.

538 Ms Katy Haire, Acting Secretary, Department of Education and Training, Family and Community Development Committee public hearing – Melbourne, 10 October 2016, transcript of evidence, pp. 2-3.

539 Ibid.

540 See section 1.2.6 below.

The Committee also received submissions from: the Northern School for Autism; the parent group Moomba Park Autism Inclusion Parents; and from a wide range of parents of students with ASD, and people with ASD, who related their experiences of the school system. At public hearings, both parents and people with ASD spoke passionately about their interactions with the school sector.

#### 4.2.1. State school options

Students with ASD have essentially three broad schooling options within the state school system, provided they meet certain criteria. The options are: a local mainstream school; an autism-specific specialist school (of which there are currently seven in Victoria); or a specialist school that caters for students with an intellectual disability and ASD, and other disabilities. According to Mr Peter Bush, President of the Association of Specialist Schools in Victoria, there are 81 special schools in Victoria.<sup>541</sup> About 70 per cent of students supported under the autism category of the PSD attend a mainstream school.<sup>542</sup>

To gain entry to an autism-specific specialist school, a student with ASD must have a diagnosis of ASD and be eligible for funding under the ASD criteria of the Department's PSD. This criteria includes a diagnosis of ASD, significant deficits in adaptive behaviour and significant deficits in language skills. It is important to note that many students with a diagnosis of ASD are not deemed eligible under the criteria for PSD funding. The ASD PSD criteria are further discussed in more detail below.<sup>543</sup> For specialist government schools there can also be different additional entry requirements. For example, there are specialist schools for students with intellectual disability across Victoria. The two main types are known as:

- 'special schools' for students with a mild intellectual disability; and
- 'special development schools' for students with a moderate to severe intellectual disability.

There are also specialist government schools for:

- eligible students who are deaf or hearing impaired;
- eligible students who are blind or vision impaired; and
- students with a physical disability and/ or significant health impairment.<sup>544</sup>

Some students with ASD also have an intellectual disability, and may be assessed under this category for PSD support. Broadly, a student whose IQ is scored between 50 and 70 on psychological testing will be eligible for entry to a 'special school', designed to accommodate students with a mild intellectual disability. Those students

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541 On the number of special schools in Victoria, see, Mr Peter Bush, Principal of Kalianna School Bendigo and President of the Association of Special Schools in Victoria, Family and Community Development Committee – Melbourne, 7 November 2016, p. 4.

542 Ms Katy Haire, Acting Secretary, Department of Education and Training, Family and Community Development Committee public hearing – Melbourne, 10 October 2016, transcript of evidence, p. 4.

543 See, Northern School for Autism, submission no. 30, pp. 2-3.

544 Association for Children with a Disability, 'Government Specialist Schools and Units', accessed 6 June 2017, <[acd.org.au/government-specialist-schools-units](http://acd.org.au/government-specialist-schools-units)>.

who score below 50 on such a test can be eligible for entry to a 'special development school' (SDS), which can accommodate students with moderate to profound intellectual disabilities.<sup>545</sup> The Committee has learnt through this Inquiry that the IQ categories and scores related to entry to special schools and SDSs are sometimes confused by stakeholders with the testing regime for the ASD category.

Each of the seven specialist schools for students with ASD have taken a different approach to educating students on the autism spectrum, as the following list shows. The following list of the specialist schools for autism was current at the time of the Inquiry:

- Bulleen Heights School (Prep to Year 12). Bulleen Heights School has a teaching and learning curriculum that has been developed within the framework of AusVELS. The additional programs they offer include, among others, developing effective communication systems, sensory integration, play skills and ABA-based teaching.<sup>546</sup>
- Northern School for Autism (Prep to Year 12).<sup>547</sup> The Northern School for Autism implements a structured teaching approach that has been informed by the Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH) approach from the U.S. Students have been grouped according to their developmental and educational needs in the school.<sup>548</sup>
- Jacana School for Autism (Primary and secondary age groups).<sup>549</sup> Jacana School for Autism has adopted programs that are informed by current research and evidence-based practice. At the secondary level, their specialist programs provide students with the opportunities to explore the arts, food technology, and health and physical education.<sup>550</sup>
- Eastern Ranges School (Foundation to Year 10 and transitioning to provide education up to Year 12). Enrolment into the Eastern Ranges School is dependent on a diagnosis of ASD, an intellectual disability and a language disorder.<sup>551</sup> The Eastern Ranges School uses the TEACCH approach.<sup>552</sup>
- Southern Autistic School (Early education to secondary).<sup>553</sup> The Southern Autistic School's early education program implements strategies from the Early

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545 See, Association for Children with a Disability, 'Applying for government specialist schools or units', accessed 5 May 2017, <[acd.org.au/applying-government-specialist-schools-units](http://acd.org.au/applying-government-specialist-schools-units)>.

546 Bulleen Heights School, 'Primary Overview', accessed 6 June 2017, <[www.bulleenheights.vic.edu.au/?page\\_id=86](http://www.bulleenheights.vic.edu.au/?page_id=86)>.

547 Northern School for Autism, submission no. 30, p. 1.

548 Ibid; Northern School for Autism, 'School Overview', accessed 6 June 2017, <[www.northernautism.vic.edu.au/?page\\_id=365](http://www.northernautism.vic.edu.au/?page_id=365)>.

549 Jacana School for Autism, 'Homepage', accessed 17 February 2017, <[www.jacanaschoolforautism.vic.edu.au](http://www.jacanaschoolforautism.vic.edu.au)>.

550 Jacana School for Autism, 'Learning and Teaching', accessed 6 June 2017, <[www.jacanaschoolforautism.vic.edu.au/?page\\_id=748](http://www.jacanaschoolforautism.vic.edu.au/?page_id=748)>.

551 Eastern Ranges School, 'Homepage', accessed 17 February 2017, <[easternrangesschool.vic.edu.au](http://easternrangesschool.vic.edu.au)>.

552 Eastern Ranges School, 'About our School', accessed 6 June 2017, <[easternrangesschool.vic.edu.au/about-our-school/#structured](http://easternrangesschool.vic.edu.au/about-our-school/#structured)>.

553 Southern Autistic School, 'About Our School', Southern Autistic School, accessed 17 February 2017, <[www.southernautistic.vic.edu.au/about](http://www.southernautistic.vic.edu.au/about)>.

Start Denver Model (ESDM). The school receives training on the ESDM from staff at La Trobe University.<sup>554</sup> The school considers parents as partners and teachers are available to provide parents with ideas on how they can support their children’s development at home.<sup>555</sup>

- Western Autistic School (Prep to grade three).<sup>556</sup> The school operates a short-term intensive program for early years primary students at the Laverton and Niddrie campuses, as well as offering limited places in specialist programs for upper primary and secondary students.<sup>557</sup> Leadership and staff at the school established the Autism Teaching Institute, which provides specialist training for teachers. The school has been recognised by DET as a centre of excellence in education for students with ASD.<sup>558</sup>
- Jennings Street School (Prep to Year 12). The school opened in 2015. It is closely located to the Western Autistic School in Laverton.<sup>559</sup> The purpose-built school has been designed with flexible learning spaces to cater for the diverse educational needs of students with autism. Underpinning their curriculum and pedagogy is the Social, Communication, Emotional Regulation and Transactional Support (SCERTS) Model – a model that prioritises developing social and communication skills, emotional regulation, and support of the student in educating students with ASD.<sup>560</sup>

#### 4.2.2. Special Needs Plan

As part of the Victorian Government’s new Education State policy the Department of Education and Training developed a Special Needs Plan in 2015 to promote inclusive practices in schools and better support students with disabilities, such as ASD. The Special Needs Plan has a number of steps, including:

- a comprehensive review of the Program for Students with Disabilities;

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554 Southern Autistic School, ‘Teaching and Learning’, accessed 6 June 2017, <[www.southernautistic.vic.edu.au/classes](http://www.southernautistic.vic.edu.au/classes)>.

555 Southern Autistic School, ‘Parents as Partners’, accessed 6 June 2017, <[www.southernautistic.vic.edu.au/parents-as-partners](http://www.southernautistic.vic.edu.au/parents-as-partners)>.

556 Ms Mary Thomson, Principal of the Western Autistic School, and CEO of the Autism Teaching Institute, Family and Community Development Committee public hearing – Melbourne, 21 November 2016, transcript of evidence. Western Autistic School, ‘About us’, accessed 17 February 2017, <[www.westernautisticschool.vic.edu.au/about-us](http://www.westernautisticschool.vic.edu.au/about-us)>.

557 Western Autistic School, ‘About us’, accessed 6 June 2017, <[www.westernautisticschool.vic.edu.au/about-us](http://www.westernautisticschool.vic.edu.au/about-us)>.

558 Ms Mary Thomson, Principal of the Western Autistic School, and CEO of the Autism Teaching Institute, Family and Community Development Committee public hearing – Melbourne, 21 November 2016, transcript of evidence, p. 3. Western Autistic School, ‘About us’, accessed 6 June 2017, <[www.westernautisticschool.vic.edu.au/about-us](http://www.westernautisticschool.vic.edu.au/about-us)>.

559 Jennings Street School, ‘About us’, accessed 17 February 2017, <[www.jenningsstreetschool.vic.edu.au/about\\_us.html](http://www.jenningsstreetschool.vic.edu.au/about_us.html)>. Ms Mary Thomson, Principal of the Western Autistic School, and CEO of the Autism Teaching Institute, Family and Community Development Committee public hearing – Melbourne, 21 November 2016, transcript of evidence, p. 9.

560 Jennings Street School, ‘About us’, accessed 6 June 2017, <[www.jenningsstreetschool.vic.edu.au/about\\_us.html](http://www.jenningsstreetschool.vic.edu.au/about_us.html)>.

- a \$10 million Inclusive Schools Fund to assist schools to build new infrastructure, such as outdoor sensory areas, quiet areas and more inclusive classrooms;
- the new role of Principal Practice Leader (Education), who will work with the Office of the Senior Practitioner (Disability) to promote the use of positive behaviour support programs and oversee the use of restraint and seclusion in schools;
- new requirements for pre-service teachers to learn about teaching students with disabilities as part of their training (tied to registration with the Victorian Institute of Teaching);
- in-service teachers to undertake professional development in the area of inclusive education in order to maintain their registration with the Victorian Institute of Teaching;
- introducing an Outstanding Inclusive Education Award;
- introducing an early years screening program for learning disorders which commenced in March 2017. The screening program is not designed to screen for autism. However, the screening aims to identify students who demonstrate significant and pervasive learning and language delays. The English Online Interview is the key assessment tool used to assess all Prep children's literacy abilities in government primary schools when they start school in the screening program;<sup>561</sup>
- phasing in the use of the Ability Based Learning and Education Support (ABLES) program; and
- establishing a new Independent Panel for School Dispute Resolution to resolve complex complaints that have already been considered by both the school and the regional office.<sup>562</sup>

The government states that all of the initiatives in the Special Needs Plan have now been delivered.<sup>563</sup>

### 4.2.3. Program for Students with Disabilities (PSD)

The Program for Students with Disabilities (PSD) is the Victorian Government's program that provides supplementary funding to schools to support students with

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561 Department of Education and Training, Correspondence, Follow up questions on notice – 21 March 2017. See also, Department of Education and Training, 'Early Years Screening', Victorian Government, accessed 6 June 2017, <[www.education.vic.gov.au/about/department/Pages/earlyyearscreening.aspx](http://www.education.vic.gov.au/about/department/Pages/earlyyearscreening.aspx)>.

562 Department of Education and Training, 'Special Needs Plan', Victorian Government, accessed 5 May 2017, <[www.education.vic.gov.au/about/department/Pages/specialneeds.aspx](http://www.education.vic.gov.au/about/department/Pages/specialneeds.aspx)>.

563 Ms Katy Haire, Acting Secretary, Department of Education and Training, Family and Community Development Committee public hearing – Melbourne, 10 October 2016, transcript of evidence; Department of Education and Training, 'Special Needs Plan', Victorian Government, accessed 5 May 2017, <[www.education.vic.gov.au/about/department/Pages/specialneeds.aspx](http://www.education.vic.gov.au/about/department/Pages/specialneeds.aspx)>.



disabilities.<sup>564</sup> The PSD is a funding allocation that schools receive in addition to the base level of funding that is allocated on a per student basis. The PSD has two main components:

- targeted funding to support students with ‘moderate to high needs’; and
- funding for specialist schools and specific programs to support teachers to assist students with disabilities.

The bulk of PSD funding (70 per cent; \$460 million in 2015) is targeted funding that is used to support the needs of individual students.<sup>565</sup> Under the PSD schools apply to the government for extra funding to support the needs of students with disabilities within their school. Broadly, to be eligible for PSD funding students must have a diagnosed physical, intellectual, visual, hearing, behavioural or severe language disability, or be on the autism spectrum. However, a diagnosis of ASD alone is not sufficient to qualify a student for extra funding. Students with ASD are only eligible for PSD funding if they also meet certain criteria. As mentioned above, a student with diagnosed ASD must also have significant deficits in adaptive behaviour and language. The criteria is as follows:

- A diagnosis of Autism Spectrum Disorder; and
- Significant deficits in adaptive behaviour established by a composite score of two standard deviations or more below the mean on an approved standardised test of adaptive behaviours; and
- Significant deficits in language skills established by a comprehensive speech pathology assessment demonstrating language skills equivalent to a composite score of two standard deviations or more below the mean.<sup>566</sup>

Multidisciplinary evidence provided by professionals with experience and knowledge in the assessment of Autism Spectrum Disorder is required in order to meet the criteria. This multidisciplinary diagnosis will include a comprehensive report from a child psychiatrist or paediatrician, and concurring reports from a psychologist (including a comprehensive report of a Vineland Adaptive Behaviour Scale assessment), a speech pathologist (including a comprehensive language/pragmatic language assessment), and where appropriate an occupational therapist.<sup>567</sup>

The Vineland Adaptive Behaviour Scale assessment is usually administered by a psychologist and measures the personal and social skills of individuals by asking someone familiar with the individual to describe his or her activities. The four main domains measured are Communication, Daily Living Skills, Socialisation and Motor

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564 Department of Education and Training, ‘Program for Studies with Disabilities’, Victorian Government, accessed 14 June 2017, <[www.education.vic.gov.au/about/programs/needs/Pages/disabilityprogram.aspx](http://www.education.vic.gov.au/about/programs/needs/Pages/disabilityprogram.aspx)>.

565 Department of Education and Training, *Review of the Program for Students with Disabilities*, Victorian Government, 2016, p. 13.

566 Department of Education and Training, *Program for Students with Disabilities – operational guidelines for schools 2017*, Victorian Government, 2016, p. 23.

567 A Student Support Group should be established and personalised learning and support planning undertaken for any student with an Autism Spectrum Disorder, regardless of whether they meet the eligibility criteria. See Department of Education and Training, *Program for Students with Disabilities – operational guidelines for schools 2017*, Victorian Government, 2016, p. 23.



Skills. The composite scores from each four domains combine to form the adaptive score, and the results are compared to people of the same age. Vineland can be used with a student that is non-verbal.<sup>568</sup>

The speech pathology assessment process involves multiple assessment sessions typically of one hour duration as the speech pathologist seeks to observe and assess the individual in a range of contexts (for example, clinic, home and/or educational setting) and in a range of communication situations (e.g., structured and unstructured) and with a range of communication partners. There is no single test used to assess significant deficits in language skills.<sup>569</sup>

Typically, children need to be diagnosed with ASD and score below 70 on both the Vineland adaptive behaviour test and a language skills test. If a student is identified as eligible for targeted PSD funding this funding is allocated to the school, not to the individual and their family. It is then the prerogative of individual schools to decide how to use their funding allocation. PSD funding is often pooled and used to fund education support staff (aides), specialist staff (such as a Special Needs Coordinator, occupational therapists, speech pathologists), professional development activities, specialist equipment and learning materials.<sup>570</sup>

The Committee has heard a significant amount of evidence about the Program for Students with Disabilities. There is a high level of confusion around the program and its criteria. For example, as alluded to above, some parents believe that eligibility for students is tied to their IQ, whereas the criteria are linked to a communication assessment by a speech pathologist and a behavioural assessment by a psychologist. Many parents are frustrated that funding under the program is not tied to their child in the form of an aide; rather, school principals decide how to manage funding across the entire school community.<sup>571</sup>

The Committee also heard that there is a group of students with ASD that are not eligible for PSD funding, but nevertheless find mainstream classrooms overwhelming in terms of their social anxieties and sensory needs. These children often score high on the language assessment test, so are not able to access PSD funding. Some children have had their enrolment refused because they are not eligible for PSD funding as there is no additional funding to support their sensory needs. There is evidence that a minority of these children seek PSD funding under the 'severe behaviour disorder' category.<sup>572</sup> This issue is discussed further below.

The Department also has a network of Students Support Services Officers (SSSOs) to 'assist children and young people faced with learning barriers to achieve their

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568 Community-University Partnership for the Study of Children, Youth, and Families, *Review of the Vineland Adaptive Behavior Scales -Second Edition (Vineland -II)*, Edmonton, Alberta, Canada, 2011, accessed 20 May 2017, <[cloudfront.ualberta.ca/-/media/ualberta/faculties-and-programs/centres-institutes/community-university-partnership/resources/tools--assessment/vinelandjune-2012.pdf](http://cloudfront.ualberta.ca/-/media/ualberta/faculties-and-programs/centres-institutes/community-university-partnership/resources/tools--assessment/vinelandjune-2012.pdf)>.

569 Speech Pathology Australia, submission no. 136, p. 7.

570 Department of Education and Training, *Program for Students with Disabilities: operational guidelines for schools*, 2018, Victorian Government, p. 11.

571 See for example, Mr Steve Ager, submission no. 57, p. 3.

572 Ms Janeane Baker, submission no. 14, p. 1.

educational and developmental potential'.<sup>573</sup> SSS officers can be psychologists, guidance officers, speech pathologists, social workers or visiting teachers, and offer both individual and group-based support for students. Some students with ASD received support from SSS staff. The Department created a new regional model in March 2016, which established 17 new areas within the Department's existing four regions.<sup>574</sup> A feature of the model is the establishment of multidisciplinary teams in each of the 17 new areas. These teams provide a range of services in relation to student wellbeing, health and disability coordination. From January 2017, Student Support Services were embedded in area-based multidisciplinary teams to:

- support the delivery of quality universal services for all students, with extra effort directed to ensuring education and health and wellbeing services are accessible to, and inclusive of, the most vulnerable and disadvantaged
- target the delivery of individual support services to those who require specialised expertise, assessment and intervention in order to overcome barriers to learning develop the capability of schools to design health, learning, development and wellbeing strategies that focus on improving education and health and wellbeing outcomes
- collaborate with multidisciplinary professional practice teams and build partnerships with community services to meet the needs of schools and students and their health, wellbeing and learning goals
- respond to critical incidents involving students, staff and school communities.<sup>575</sup>

#### **4.2.4. Review of Program for Students with Disabilities (PSD)**

As part of the Special Needs Plan, the Victorian Government commissioned a review of the PSD in 2015, led by former Commonwealth Disability Commissioner Graeme Innes. One of the Review's terms of reference was to examine 'the future capacity of the government school system, including the role of the PSD, to meet the specific needs of students with Autism Spectrum Disorder and dyslexia'.<sup>576</sup> The Review consulted widely with parents, teachers, current and former students, principals and teacher associations, and peak bodies. The Review made 25 recommendations and made the following key findings:

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573 Department of Education and Training, 'Student Support Services Officers', Victorian Government, accessed 16 May 2017, <[www.education.vic.gov.au/school/principals/health/Pages/ssso.aspx?Redirect=1](http://www.education.vic.gov.au/school/principals/health/Pages/ssso.aspx?Redirect=1)>.

574 Ms Katy Haire, Acting Secretary, Department of Education and Training, Family and Community Development Committee public hearing – Melbourne, 10 October 2016, transcript of evidence, pp. 13-14; Department of Education and Training, 'Strengthening Regional Support', Victorian Government, accessed 16 May 2017, <[www.education.vic.gov.au/about/educationstate/Pages/regions.aspx](http://www.education.vic.gov.au/about/educationstate/Pages/regions.aspx)>.

575 Department of Education and Training, 'Student Support Services Officers', Victorian Government, accessed 16 May 2017, <[www.education.vic.gov.au/school/principals/health/Pages/ssso.aspx?Redirect=1](http://www.education.vic.gov.au/school/principals/health/Pages/ssso.aspx?Redirect=1)>.

576 See, Department of Education and Training, *Review of the Program for Students with Disabilities*, Victorian Government, 2016, p. 10.

- the PSD has significant weaknesses in its design, implementation and accountability and the current PSD funding model is not sufficiently transparent;
- Victoria does not adequately support inclusive education and lacks a clear inclusive education policy and framework;
- inclusive education requires sustained investment in the education workforce and professional development;
- a more effective approach to identify and support students with disabilities is required;
- the current PSD criteria with its deficit-focused approach doesn't adequately support all children with disabilities; and
- a lack of support for students who lose PSD funding prior to their transition to high school.<sup>577</sup>

The Review made three recommendations specifically in relation to students with ASD:

- to develop options to support specialist schools to become centres of expertise;
- to make available ongoing autism-specific disability training and access to specialist schools and expertise; and
- to consider providing additional resources to schools to better meet the needs of students with autism.<sup>578</sup>

In April 2016 the Victorian Government released its response to the review of the PSD. The government has endorsed 21 of the review's recommendations.<sup>579</sup> In particular, the government addressed the three specific autism related recommendations by committing \$17 million to funding the support needs of children with autism and dyslexia who are not currently funded under the PSD; with a \$3 million funding boost to support students transitioning to year 7; and through a \$2 million dyslexia and learning difficulties strategy. The government will also investigate the role that specialist schools, including autism-specific schools, can play in supporting teachers at mainstream schools. Other funding commitments include support for an increase in professional development for teachers.<sup>580</sup> The four recommendations that the Victorian Government has not adopted relate to proposals for a new funding model to support students with disabilities. These were:

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577 See, *Ibid*, pp. 24-28; Department of Education and Training, *Inclusive Education for All Students with Disabilities and Additional Needs: The Government's Response to the Review of the Program for Students with Disabilities*, Victorian Government, 2016, p. 8; Ms Katy Haire, Acting Secretary, Department of Education and Training, Family and Community Development Committee public hearing – Melbourne, 10 October 2016, transcript of evidence, pp. 3-4.

578 Ms Katy Haire, Acting Secretary, Department of Education and Training, Family and Community Development Committee public hearing – Melbourne, 10 October 2016, transcript of evidence, p. 4.

579 Department of Education and Training, *Inclusive Education for All Students with Disabilities and Additional Needs: The Government's Response to the Review of the Program for Students with Disabilities*, Victorian Government, 2016.

580 *Ibid*, p. 9.

- Recommendation 14, which states, ‘Design and implement a new funding model, based on functional needs, that removes the requirement for the Year 6–7 review process’;
- Recommendation 21, which states, ‘Develop a new tiered funding model based on a strength-based functional needs approach to meet the needs of all students with disabilities, which includes: Base funding—allocated to all schools for all students; Teaching and learning loading—allocated to schools to support students with disabilities who require reasonable adjustments; Targeted funding—allocated to schools to support students with disabilities and high education adjustment needs’;
- Recommendation 22, which states, ‘Develop a formal relationship with the National Disability Insurance Agency to ensure maximum alignment with the NDIS as it evolves, including consistency and sharing of information and professional insight where possible’; and
- Recommendation 23, which states, ‘Develop and implement a strengths-based, functional needs approach to assessing student need, to support the achievement and participation of students with disabilities.’<sup>581</sup>

The State Government has indicated that these recommendations will be considered in conjunction with the recent Review of School Funding conducted by the Hon. Steve Bracks, the ongoing Gonski negotiations with the Commonwealth Government and the roll out of the NDIS.<sup>582</sup> Issues surrounding the roll out of the NDIS and its interface with the school sector will be addressed later in this chapter.

The Government released its response to the Bracks review in September 2016.<sup>583</sup> The Government response focused on four reform directions that were major themes in the Review, which were in brief: improving outcomes for all students; better information for all about school funding; targeting funding and resources to students in need; and strengthening the school system. The State Government accepted the proposition that schools should be funded according to need, and stated that, ‘The four recommendations in the PSD Review that relate to funding will be considered alongside the funding recommendations in the Government Schools Funding Review as part of the 2017/18 budget.’<sup>584</sup>

### **State Budget 2017/18**

In the 2017/18 State Budget the Victorian Government committed to spend \$58.4 million to meet new demand for the Program for Students with Disabilities in

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581 Ibid, p. 24.

582 Ibid. The Bracks Review was required to consider: how government school funding is currently allocated and used; Commonwealth contributions to government school funding in Victoria; how the Student Resource Package is calculated, constructed and distributed; and, how to make sure the system is clear and transparent for principals and school communities on school funding and how it is determined. See, Department of Education and Training, ‘Schools Funding Review’, Victorian Government, accessed 6 May 2017, <[www.education.vic.gov.au/about/department/Pages/fundingreview.aspx](http://www.education.vic.gov.au/about/department/Pages/fundingreview.aspx)>.

583 Department of Education and Training, ‘Schools Funding Review’, Victorian Government, accessed 6 May 2017, <[www.education.vic.gov.au/about/department/Pages/fundingreview.aspx](http://www.education.vic.gov.au/about/department/Pages/fundingreview.aspx)>.

584 Ibid.

2018, and \$44.4 million to upgrade six special schools.<sup>585</sup> An additional 2,600 students will be supported by the Program for Students with Disabilities in the 2018 school year, in response to growth in school enrolments. Overall funding for 'Support for Students with Disabilities' in 2017-18 will be \$975.1 million. The Support for Students with Disabilities output covers the program for students with disabilities, transport, welfare and support services for students with special needs.<sup>586</sup> Six schools that support students with special needs will receive funding for upgrades to provide facilities that will improve educational outcomes over the next four years.<sup>587</sup> Bayside Special Developmental School, in Moorabin, will be completely rebuilt, while the new North Geelong Special Developmental School will be constructed on the former Western Heights College site.<sup>588</sup> Funded earlier, and due to open in 2017, the new inclusive school the Armstrong Creek Education Precinct will provide new facilities, combining both primary (P-6) and special (P-12) school elements under one governance model.<sup>589</sup>

#### 4.2.5. Stakeholder views of the PSD

The evidence received by the Committee demonstrated a widespread dissatisfaction with the PSD amongst stakeholders, including parents of students with ASD, and students with ASD. Ms Fiona Sharkie, Chief Executive Officer of peak body Amaze, told a public hearing in Melbourne that:

We also need to review the funding to support autistic students. In 2015, \$659 million was spent on the program for students with disability. We do not believe that funding is well spent. It is outmoded and outdated, and it needs a complete overhaul to create a strengths-based and functional needs-based model. So that money could be better spent, and there are ways to do that.<sup>590</sup>

Amaze was advised by people with autism and their families that there was a lack of accountability surrounding the PSD:

Thirdly, what our community told us very loud and clear through the PSD review was: accountability, accountability, accountability. How are we checking the progress and achievement of autistic students who are receiving disability funding and reporting on their educational outcomes? For students with disability we know the data is collected, but we never see it reported. We do not see any transparency

585 See Department of Education and Training, 'State Budget Highlights', Victorian Government, accessed 7 May 2017, <[www.education.vic.gov.au/about/educationstate/Pages/budget.aspx](http://www.education.vic.gov.au/about/educationstate/Pages/budget.aspx)>.

586 Victorian Government, *Getting on with the job, Victorian Budget 17/18 Service Delivery, Budget Paper no. 3*, p. 194, accessed 7 May 2017, <[s3-ap-southeast-2.amazonaws.com/budgetfiles201718.budget.vic.gov.au/BP3\\_2017-18\\_ServiceDelivery.pdf](http://s3-ap-southeast-2.amazonaws.com/budgetfiles201718.budget.vic.gov.au/BP3_2017-18_ServiceDelivery.pdf)>.

587 Ibid, p. 64.

588 ABC News, 'Melbourne special school to be completely demolished, finally given chance to start again', accessed 30 May 2017, <[www.abc.net.au/news/2017-05-01/run-down-melbourne-special-school-gets-chance-to-start-again/8487154](http://www.abc.net.au/news/2017-05-01/run-down-melbourne-special-school-gets-chance-to-start-again/8487154)>.

589 Department of Education and Training, 'Planning and Building Inclusive New Schools', March 2016, Victorian Government, accessed 6 June 2017, <[www.education.vic.gov.au/about/department/Pages/inclusivenewschools.aspx](http://www.education.vic.gov.au/about/department/Pages/inclusivenewschools.aspx)>.

590 Ms Fiona Sharkie, Chief Executive Officer, Amaze, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 4.

around there, and it is absolutely critical at the student level, at the school level, at the region level and at the state level. So the call for accountability was very strong.<sup>591</sup>

Ms Narelle McCaffrey told the Committee at a public hearing in Melbourne that the model underpinning the PSD was wrong:

The second issue I wish to address is education, in particular the way autistic students are supported in mainstream schools. My issues are as follows. The PSD funding allocation is determined by a deficit-based model for eligibility and is not based on needs. For example, my son is currently in grade 1. He has excellent language skills, so he does not qualify for funding. Yet his needs are not being met. They are complex in nature and will take significant effort from all involved to work through, address and support. He dislikes school and school refusal is becoming an issue – and he has only just turned seven. I guess you could consider him as a student at risk of disengagement.<sup>592</sup>

Ms Rebecca Kelly, from the Bendigo Autistic Advocacy and Support Service, and mother of two school-aged children with ASD, advised the Committee that her group supported recommendations made by the PSD Review. In particular, Ms Kelly said that there was a need for a new tiered funding model based on a strength-based functional needs approach, including: base funding – allocated to all schools for all students; teaching and learning loading – allocated to schools to support students with disabilities who require reasonable adjustments; and targeted funding – allocated to schools to support students with disabilities and high education adjustment needs.<sup>593</sup>

Ms Kelly recommended that the current years 6 to 7 PSD review process ‘be scrapped and for autistic students funded under the PSD to receive their review from years 7 to 8’, and further that, ‘the Victorian state government accept the four current recommendations from the PSD review that are currently under consideration’.<sup>594</sup>

Ms Janeane Baker is the mother of a 15-year-old boy with ASD and a founding member of a group called ‘Change The Criteria’ – a group of parents, carers and friends concerned about the lack of accessibility to education support funding for students with ASD in Victoria.<sup>595</sup> In her submission to the Inquiry, Ms Baker advised the Committee that:

There is a major problem with the funding for education assistance within the ASD category of the Program for Students With Disability. The problem is that of the three criteria that need to be met to obtain funding, one is a significant language deficit. The reality is that many children at the higher end of the Autism Spectrum,

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591 Ibid, pp. 4-5.

592 Ms Narelle McCaffrey, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 3.

593 Ms Rebecca Kelly, Co-convenor, Bendigo Autistic Advocacy and Support Service, Family and Community Development Committee public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 3.

594 Ibid, p. 8.

595 Ms Janeane Baker, submission no. 14, p. 1.



such as my son, do not have what the criteria classes as a 'language deficit'. However, their 'Autistic traits' (for want of a better term) are still extremely strong, making the classroom/school ground/social expectations a veritable nightmare for them to negotiate.<sup>596</sup>

Ms Baker discussed her own son's case, where he failed to obtain ASD funding under the 2013 PSD funding review, 'despite the fact that since grade Prep in 2006 he had attended the specialist setting, and had never been considered to be an appropriate candidate for integration into mainstream setting.'<sup>597</sup>

At his mandatory funding review in year six (which I was unaware he was going to be having), I was advised that despite meeting two criteria, he didn't meet the language criteria. Therefore, he would be unable to continue to attend specialist setting in his high school years, and would not attract any support funding at a mainstream high school. At all.<sup>598</sup>

Ms Baker advised the Committee that in order to attract PSD funding she was forced to meet the criteria for her son under the separate category of 'Severe Behaviour Disorder'. She told the Committee that, 'in order to do this, I had to advise that my son's 'bad behaviour' was NOT related to his autism (it is).'<sup>599</sup>

As parents of children on the Autism spectrum, we spend a lot of time encouraging our children to 'be who they are', to be 'proud of who they are'. I personally spend a lot of time telling my son that yes, he has autism, but that this is not something to be embarrassed or ashamed about. However, when push came to shove, it was ME who had to deny my son's autism, and on paper have him marked down as a 'naughty boy' so that he was allowed to remain in the specialist setting that he so desperately needed.<sup>600</sup>

In her submission to the Inquiry, the Principal of the Northern School for Autism, Ms Anna Rigoni, advised the Committee that the Severe Behaviour Disorder (SBD) category was being used to gain funding for students with ASD.

There is a cohort of students with autism who are not eligible for funding under the PSD - ASD category. These students often access funding via the Severe Behaviour Disorder (SBD) category. This is unjust as generally the difficulties these children and young people face in regulating their emotions and behaviour are largely because of the impact of autism upon their development. The reason that we observe students exhibiting severe challenging behaviour in some settings is because they require a different teaching approach and educational environment to successfully access school. Many students with autism are excluded from mainstream schools (for severe/challenging behaviour), or indeed self-exclude (school refusal), due to high anxiety. There appears to be an expectation of those working in general education settings that people with autism adapt to our schools, rather than the schools and the adults working within them adapting their

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596 Ibid.

597 Ibid.

598 Ibid.

599 Ibid.

600 Ibid, p. 2.



behaviour, environment and teaching approach to meet the needs of these students. There are students who are not eligible for PSD funding who require additional support and do receive such support, however, there is also a cohort of learners who have significant levels of need for whom the avenue to access funding support in the Victorian State Government school system is not available.<sup>601</sup>

According to Communication Rights Australia, the PSD is too limited in its scope. They state in their submission that:

It is frequently reported by parents, educators and allied health professionals alike that the PSD is too limited and too many students are assessed as not meeting the criteria, and therefore not able to access the valuable supports it can provide. This has consequences for students in the short term - having to struggle unsupported day after day - and also for those students and society more broadly in the longer term.<sup>602</sup>

In their joint submission, Distinctive Options, the Lab Network and Smart Communities, advised the Committee that there was an important distinction between expressive and receptive language skills:

Further compounding the issues confronting students with Autism has been the implementation of the Program for Students with a Disability (PSD) and the narrow criteria for access to the funding supports provided by the program. A key criteria for access to support funding is the assessment of students in both receptive and expressive language skills. This requires potential students undertaking language testing measuring both expressive and receptive language skills and then averaging the outcome. This has led to many students who require support being ineligible due to their high rating for expressive language skills comparative to their poor receptive language skills. In essence students with Autism may have an extensive vocabulary and can demonstrate high level oral competency but lack the receptive language skills necessary to function well in a learning environment.<sup>603</sup>

In their submission, consulting group, Lancaster Consulting Australia also advised the Committee about the shortcomings of the language test for students with ASD:

There are also significant issues in the requirements for Program for Students with Disabilities (PSD) funding for students with ASD, where the student must score 2 standard deviations below the mean on a standardised language assessment to be provided additional funding within Department of Education schools. This requirement implies that only those students with an ASD and a language disorder require additional support at school, and supports our observations of the dearth in understanding of the underlying deficits in ASD, which have implications for all areas of learning and the school experience.<sup>604</sup>

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601 Northern School for Autism, submission no. 30, p. 3.

602 Communication Rights Australia, submission no. 54, p. 6.

603 Distinctive Options, the Lab Network and Smart Communities, submission no. 77, p. 18.

604 Lancaster Consulting Australia, submission no. 88, p. 6.

In their submission, Speech Pathology Australia advised the Committee that the organisation had made a submission to the Review of the Program for Students with Disability. It urged the Government to ensure that, 'funding is equitable for all students with disability (including students with ASD) in Victorian government schools'.<sup>605</sup>

The Victorian Disability Advisory Council in their submission strongly supported the findings of the Review of the PSD and urged the Committee to support each of its recommendations. The Council reiterated the Review's findings as follows:

While the Program for Students with Disabilities (PSD) provides targeted funding for most students with autism, not all students on the autism spectrum meet the eligibility guidelines. The PSD criteria for autism require a diagnosis in addition to two indicators of student need, and demonstrated deficits in adaptive behaviour and language skills. Children and young people who are assessed as being on the autism spectrum can have a wide variety of strengths and needs, despite having the same diagnosis. Up to 90 per cent of children and young people with autism may have additional conditions (co-morbidity), such as attention deficit hyperactivity disorder, epilepsy and obsessive compulsive disorder. ... While the majority of students with autism are currently captured within the existing PSD eligibility criteria (0.9 per cent of all student enrolments), not all students with autism receive targeted PSD support because the focus of the PSD is on students with moderate to high educational adjustment needs. This results in a number of students who have a diagnosis of autism but do not meet the existing eligibility criteria (such as students with stronger adaptive behaviour or language skills). However, these students may still require additional support in school to achieve their potential.<sup>606</sup>

The Committee believes that the evidence is clear that the criteria for PSD funding for students with ASD is in need of reform, in line with the recommendations of the PSD Review. The Committee appreciates that the Victorian Government has accepted, and acted on, 21 of the 25 recommendations made by the PSD Review. It also understands that there is a broader context surrounding the funding of education, which includes the role of the Federal Government, and the Gonski model of funding. The Committee also recognises that the Victorian Government has developed an inclusive schools program, which is fundamentally aligned with the notion of needs-based schooling and service support for students with disability, and has provided funding to that end. The Committee appreciates the work in this area.

However, as the above evidence from families and stakeholders attests, the PSD model of funding does not currently meet the needs of students with ASD and their families. As critics of the PSD funding argue, the criteria are too narrow and restrictive, and fail to take into account key distinctions in the behaviour, skills and capacities of individuals with ASD. Parents of children with ASD should not be placed in the position of being forced to apply for PSD funding support under the category of Severe Behaviour Disorder because of the inadequacies of the PSD's ASD criteria.

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605 Speech Pathology Australia, submission no. 136, p. 11.

606 Victorian Disability Advisory Council, submission no. 146, pp. 15-16.

The Committee concurs with Recommendation 14 of the Review, that the new funding model based on functional needs will remove the requirement for the current Year 6-7 review. At the very least, students and families should not be placed in the position of conducting this review at a critical point of transition from primary to secondary schools. As Ms Rebecca Kelly, cited above, suggests, if this review is retained it could more appropriately occur at years 7 to 8.

A revised PSD funding model should also recognise that many students with ASD have often strong expressive skills in language, but that these skills do not preclude the same students experiencing often profound barriers to participation in a learning environment. A revised funding model will focus on needs based assessments, and as Recommendation 21 says, will include base funding for schools, a teaching and learning loading to support students who require reasonable adjustments, and targeted funding to support students with disabilities and high adjustment needs.

Recommendation 22 of the Review of the PSD, which concerns the relationship of the Victorian Government with the NDIS will be discussed further below. Nevertheless, the Committee can foreshadow its support for this recommendation. The Committee supports the approach articulated in Recommendation 23 of the Review, that a strengths-based, functional needs approach is essential. The Committee urges the Government to accept and implement the outstanding recommendations of the PSD Review as outlined above. Accordingly, the Committee recommends that:

#### **RECOMMENDATION 4.4**

**The Victorian Government adopt, implement and fund the remaining four recommendations of the Review of the Program for Students with Disabilities, namely Recommendations 14, 21, 22, and 23.**

#### **4.2.6. ‘Gatekeeping’: Denying enrolment to students with ASD**

I had four schools say they were full and turn me away – my local schools – but then I found a school that was willing to accept her and say, ‘Yes, we can’, because the Catholic system has a different funding model and they have kept that funding for children with language above 70.<sup>607</sup>

As mentioned in Chapter Two, the Commonwealth *Disability Discrimination Act 1992* (the DDA 1992) makes it unlawful to discriminate against a person because of a disability and protects people with disability against discrimination in areas of public life, including education. Section 22 of the DDA 1992 states:

- (1) It is unlawful for an educational authority to discriminate against a person on the ground of the person’s disability:
  - (a) by refusing or failing to accept the person’s application for admission as a student; or

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607 Ms Katie Koullas, Founder, Yellow Ladybugs, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 6.

- (b) in the terms or conditions on which it is prepared to admit the person as a student.
- (2) It is unlawful for an educational authority to discriminate against a student on the ground of the student's disability:
- (a) by denying the student access, or limiting the student's access, to any benefit provided by the educational authority; or
  - (b) by expelling the student; or
  - (c) by subjecting the student to any other detriment.
- (2A) It is unlawful for an education provider to discriminate against a person on the ground of the person's disability:
- (a) by developing curricula or training courses having a content that will either exclude the person from participation, or subject the person to any other detriment; or
  - (b) by accrediting curricula or training courses having such a content.
- (3) This section does not render it unlawful to discriminate against a person on the ground of the person's disability in respect of admission to an educational institution established wholly or primarily for students who have a particular disability where the person does not have that particular disability.

The obligations of Victorian schools in relation to students with disabilities are clearly defined by the DDA 1992. Students with disabilities have an explicit right to participate in mainstream schools on the same basis as other students. Section 31 of the DDA 1992 empowers the Federal Minister to create Disability Standards for Education, and section 32 makes it unlawful to not comply with these standards. The Disability Standards for Education were introduced in 2005, and these clarified the obligations of education and training providers and the rights of people with disability.<sup>608</sup>

The Standards apply to all education providers: preschools and kindergartens, public and private schools, all education and training providers and tertiary institutions. The Standards state that all education providers must make 'reasonable adjustments' to support students with disabilities. While the Standards do not refer specifically to people with ASD, the condition is covered by the DDA 1992's definition of disability. A breach of the Standards can be the subject of a complaint to the Australian Human Rights Commission (AHRC), or in the event that complaint is not successfully conciliated by the AHRC, legal proceedings can be commenced in the Federal Court.<sup>609</sup>

As also mentioned in Chapter Two, the *Charter of Human Rights and Responsibilities Act 2006* (Vic) (the Charter) prohibits discrimination on the basis of disability (see sections 3, 8, and 18). The Victorian *Equal Opportunity Act 2010* lists disability as an attribute in respect of which discrimination is prohibited (section 6), and under section 15 organisations must take reasonable measures to eliminate discrimination.

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608 See, Department of Education and Training, *Disability Standards for Education 2005*, Australian Government, accessed 3 May 2017, <[education.gov.au/disability-standards-education](http://education.gov.au/disability-standards-education)>.

609 Ibid.

Sections 38 and 40 of the *Equal Opportunity Act 2010* apply specifically to discrimination in education. Section 38 states that:

- (1) An educational authority must not discriminate against a person—
  - (a) in deciding who should be admitted as a student; or
  - (b) by refusing, or failing to accept, the person's application for admission as a student; or
  - (c) in the terms on which the authority admits the person as a student.
- (2) An educational authority must not discriminate against a student—
  - (a) by denying or limiting access to any benefit provided by the authority; or
  - (b) by expelling the student; or
  - (c) by subjecting the student to any other detriment.

The *Equal Opportunity Act 2010* covers all education institutions, including schools, colleges, universities and education and training providers. Section 40 addresses how education authorities must make reasonable adjustments for a person with disability:

- (1) This section applies if a person with a disability requires adjustments in order to participate in or continue to participate in or derive or continue to derive any substantial benefit from an educational program of an educational authority.
- (2) The educational authority must make reasonable adjustments unless the person could not participate in or continue to participate in or derive or continue to derive any substantial benefit from the educational program even after the adjustments are made.

The *Equal Opportunity Act 2010* gives an example of compliance, where an educational authority can make reasonable adjustments for a person with a disability by 'providing a teacher's aide or particular software packages for computers', or by 'moving a particular course or event from an inaccessible venue to an accessible one'. The Victorian Equal Opportunity and Human Rights Commission can receive complaints for breaches of the law under the *Equal Opportunity Act 2010*.<sup>610</sup> Under the *Victorian Education and Training Reform Act 2006*, all students of compulsory school age are entitled to be enrolled in their designated neighbourhood government school, subject to sufficient accommodation.<sup>611</sup>

The Committee is concerned by evidence it has received that some Victorian schools are refusing to enrol students with ASD. In the quote that heads this section, Ms Katie Koullas, founder of ASD support group, Yellow Ladybugs, relates her experience in trying to enrol her daughter, who has ASD, in local schools, stating that four of them advised her that they were full and could not take her daughter. At a

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610 See, Victorian Equal Opportunity and Human Rights Commission, 'The Law – Victorian laws administered by the Commission', accessed 3 May 2017, <[www.humanrightscscommission.vic.gov.au/home/the-law](http://www.humanrightscscommission.vic.gov.au/home/the-law)>.

611 See, *Education and Training Reform Act 2006*, sections, 2.2.13 and 2.2.14.

public hearing in Melbourne, Ms Koullas advised the Committee that, earlier, her daughter was misdiagnosed with general anxiety and her behaviour was not understood by the school she was enrolled in at the time. Ms Koullas told the Committee that:

She was misunderstood at school. She was considered naughty. I was often called in to pick her up, because she was defiant. Also, she was just having sensory overload at the time. The school did not understand what was going on and so she was considered naughty. Even after diagnosis, the public school we went to, one of the first things they said to me was, 'You won't get any funding'. Straightaway, that was basically the answer: 'You're not going to get any funding. There's nothing we can do'. And it was a really hard battle for me to have an understanding that they would support us through it with or without funding.<sup>612</sup>

At a public hearing in Melbourne, the Committee heard from Ms Lisa Carr, mother of two boys with ASD, about the extraordinary lengths she and her husband had gone to secure appropriate schooling for their sons. She stated that:

What I want to tell you about, as well as my boys, is the kids for whom there is no adequate educational placement in Victoria – those children not accepted by private schools, those who do not qualify for special schools and specialised settings, those who are not behaviourally challenged so do not fit into alternative educational settings and those who do not qualify for aided funding in mainstream government schools. That is my boys, and I am sure we are not the only ones.<sup>613</sup>

Ms Carr advised the Committee that she had visited or contacted at least 17 schools, public and private, in her search for appropriate schools for her sons. She related her experience as follows:

Independent schools receive a certain percentage of funding to cater to children with special needs, but from our experience independent schools do not take these children, so it is left to government schools to take them, but they do not receive adequate or proportionate funding. A fellow from Blackburn High said 60 per cent of kids with special needs end up in high schools because independent schools will not take them. I have evidence of that from our experience this year. This is just my knowledge of the funding.<sup>614</sup>

Ms Carr quoted the various responses she had received from different private schools on inquiring about entry for her sons:

We are a private school and we can choose who we want.

We query whether the boys would cope with the academic rigours required by the school.

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612 Ms Katie Koullas, Founder, Yellow Ladybugs, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 3.

613 Ms Lisa Carr, Family and Community Development Committee public hearing – Melbourne, 21 November 2016, transcript of evidence, p. 2.

614 Ibid, p. 3.

Not sure whether this is the right school for the boys.

We have a very VCE-focused program. This may not be where their future lies.

Our staff skill set is non-existent or rusty in the area of autism. To have expertise in this area takes time. We have not got that. It takes people with finesse and nuance to get the best out of kids, and our staff doesn't have that depth of experience with those who are different.<sup>615</sup>

At one point, Ms Carr considered moving her family interstate to obtain appropriate schooling. Their boys are now enrolled at a public high school.

In their submission to the Inquiry, the early childhood intervention service, the Broad Insight Group advised the Committee that, 'Parents have been discouraged from enrolling their children in some mainstream schools, the stated reason being that schools already have too many children with additional needs.'<sup>616</sup> The Group suggested in their submission that parents of students with ASD were put under pressure by mainstream schools to withdraw their children if behavioural issues arose, while some schools suggest to parents reducing their child's hours of attendance at school due to the difficulty in meeting their needs.<sup>617</sup> According to the Group, some specialist ASD schools are at capacity, which diminishes parent choice on appropriate schooling. The Group recommend, 'That school enrolment patterns of children with ASD be scrutinised to identify why certain schools are attracting high numbers of children with ASD and why others have adopted a 'burden-shifting' approach.'<sup>618</sup>

According to advocacy organisation VALID, there is a form of educational exclusion occurring for children with ASD, which has profound impacts on their lives. In their submission VALID stated that:

The experience of school can mark people for life – in this case the system marks children with ASD and behaviours of concern for exclusion and sets them on a career of rejection from most aspects of community life. Ineffective supports and commitment to some sort of developmental plan in the school system exacerbates behaviours which further stigmatise children and their families.

For many children this meant that no school in their area would take them – in some cases this resulted in families, usually mothers resorting to home schooling of their child.<sup>619</sup>

The Committee is disturbed by evidence that suggests that some Victorian schools are engaged in the practice known as 'gatekeeping', whereby mainstream schools discourage parents from enrolling children with ASD and often direct them to inquire at other or special schools. This practice is clearly in breach of the DDA 1992 and

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615 Ibid, pp. 3-4.

616 Broad Insight Group, submission no. 132, p. 8.

617 Ibid.

618 Ibid, p. 9.

619 Victorian Advocacy League for Individuals with Disability Inc (VALID) and the Behaviours of Concern Peer Action Group, submission no. 137, p. 8.



Commonwealth Education Standards outlined above, and the Victorian *Equal Opportunity Act 2010* and the *Education and Training Reform Act 2006*.

According to the Victorian Department of Education and Training, parents who have a complaint about a government school refusing to enrol their child can take that complaint in the first instance to the regional disabilities coordinator of the Department in their region. If this process fails to secure an outcome, a formal complaint to the Department can be lodged through DET's parent complaint process.<sup>620</sup> The recently established Independent Office for School Dispute Resolution could become involved in such a case provided the matter is regarded as 'complex' and has not been resolved by the above mechanisms.<sup>621</sup>

In relation to independent schools, parents can make a complaint about a school refusing to enrol their child by, firstly, utilising the school's complaints process. Complaints can also be made to a school's Board. The Victorian Registration and Qualifications Authority (VRQA) is the body responsible for accreditation, registration, certification and quality of all Victorian schools, and all Victorian independent schools must comply with relevant laws and VRQA standards. A parent could take a complaint of this nature about an independent school to the VRQA, which has the power to order a school to comply with relevant standards.<sup>622</sup>

However, a complaint in relation to a Catholic school needs to be referred to the Catholic Education Commission of Victoria.<sup>623</sup> For both the government sector and the non-government sector, a parent with a complaint concerning a refusal to enrol their child can take that complaint to the Victorian Equal Opportunity and Human Rights Commission.

The Committee accepts that there are mechanisms available for parents of children with ASD to lodge a complaint in regard to a school refusing to enrol their child, as outlined above. However, the evidence received by the Committee makes it clear that at least some schools in Victoria are avoiding their legal responsibilities by urging parents to have their children with ASD enrolled elsewhere.

The evidence suggests that the whole enrolment process for students with ASD needs to be reviewed, and the Committee makes recommendations to this effect. The Committee believes that the Victorian Government has a duty to ensure that the school system in this state is not abrogating the law by denying entry to students on the basis of their disability. Parents of students with ASD should not be placed in the position of being educational beggars, who must plead with mainstream schools to have their child enrolled. The law is quite clear that it is incumbent on the school to make the necessary and reasonable adjustments to accommodate students with disabilities. In this respect, school principals of mainstream schools, whether public

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620 See, Department of Education and Training, 'Parent Complaints – Government Schools', Victorian Government, accessed 3 May 2017, <[www.education.vic.gov.au/school/parents/complaints/Pages/default.aspx](http://www.education.vic.gov.au/school/parents/complaints/Pages/default.aspx)>.

621 See, Independent Office for School Dispute Resolution, 'About Us', accessed 3 May 2017, <[www.schoolresolution.vic.gov.au/Pages/default.aspx?Redirect=1](http://www.schoolresolution.vic.gov.au/Pages/default.aspx?Redirect=1)>.

622 See, Victorian Registration and Qualifications Authority, 'Which agency investigates my complaints', accessed 3 May 2017, <[www.vrqa.vic.gov.au/complaints/Pages/schtype.aspx](http://www.vrqa.vic.gov.au/complaints/Pages/schtype.aspx)>.

623 See, Victorian Registration and Qualifications Authority, 'Other Complaints Agencies', accessed 3 May 2017, <[www.vrqa.vic.gov.au/complaints/Pages/otheragencies.aspx#H3N100F8](http://www.vrqa.vic.gov.au/complaints/Pages/otheragencies.aspx#H3N100F8)>.

or private, have no right to deter or deflect a parent who wishes to enrol their child on the basis of the child's disability, and that to do so is to break the law.<sup>624</sup>

The Committee understands that the Victorian Government is primarily responsible for the delivery of education through the state school system. However, the VRQA is a statutory authority established under Chapter 4 of the *Education and Training Reform Act 2006*, and has responsibilities that bridge the government and non-government sectors. The Minister is empowered to issue directions to the VRQA.<sup>625</sup>

The Committee believes that the Victorian Government should play a more proactive role in ensuring that the Disability Standards for Education 2005 are being adhered to in Victoria. There is scope for the State Government, through the agency of the Department of Education and Training and the VRQA, to proactively monitor adherence to the Commonwealth Standards to ensure that parents can challenge the attitudes of principals who do not want to accept a child at their school, on the basis of his or her disability. Accordingly, the Committee recommends that:

#### **RECOMMENDATION 4.5**

**The Victorian Government, through the Department of Education and Training and the Victorian Registration and Qualifications Authority, proactively monitor adherence to the Commonwealth Disability Standards for Education 2005, and the *Equal Opportunity Act 2010* (Vic), with respect to the enrolment of students with ASD in schools in Victoria.**

The Committee recommends that:

#### **RECOMMENDATION 4.6**

**The Victorian Government through the Department of Education and Training conduct a state-wide information campaign for senior school staff, including school principals, to ensure that every school is aware of its legal responsibilities in relation to the admission of students with ASD.**

- **The campaign be conducted in collaboration with the Victorian Equal Opportunity and Human Rights Commission, and with the involvement of the non-government school sector and people with ASD and their families.**

The Committee recommends that:

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624 See, Department of Education and Training, 'Parent Complaints – Government Schools', Victorian Government, accessed 3 May 2017, <[www.education.vic.gov.au/school/parents/complaints/Pages/default.aspx](http://www.education.vic.gov.au/school/parents/complaints/Pages/default.aspx)>.

625 See, Victorian Registration and Qualifications Authority, 'Legal Framework', accessed 3 May 2017, <[www.vrqa.vic.gov.au/about/Pages/legalframework.aspx](http://www.vrqa.vic.gov.au/about/Pages/legalframework.aspx)>.

**RECOMMENDATION 4.7**

The updated State Autism Plan clearly articulate:

- the rights of students with ASD to enrol and participate in mainstream schools on the same basis as other students, and
- the responsibilities of educational authorities in Victoria to comply with the law.

**4.3. Non-government schools**

The non-government school sector comprises Independent schools and Catholic schools. In 2014, there were 208 Independent schools and 489 Catholic schools in Victoria. Both Independent and Catholic schools receive funding from the state and federal governments, and some support for students with disability. However, the Program for Students with Disabilities (PSD) is not available in the non-government sector. Around 3.4 per cent of the Independent student population have a disability, while the figure for the Catholic school system is approximately 4 per cent of the total.<sup>626</sup>

In the Independent sector most students with disability attend mainstream schools, but there are also special schools which cater for students with disability. About 1 in 5 students with disability attend one of these schools. Independent schools argue that they are more constrained than the Catholic sector in supporting students with disability because they cannot access support from a system authority, due to their autonomous nature.<sup>627</sup>

The Catholic school system does have a more systemic approach to supporting students with disability, including students with ASD. For example, under the federally supported Literacy, Numeracy and Special Learning Needs Program (LNSLN) Catholic schools are able to meet the needs of students with disabilities by employing specialist aides as support staff within the classroom. This support is centrally administered by the Catholic Education Commission of Victoria (CECV), and at a regional level. A number of parents of students with ASD told the Inquiry that it was this capacity to provide an aide in the classroom, or have extra support, that encouraged them to enrol their child at a Catholic school.<sup>628</sup> The Committee heard from Ms Katie Koullas at a public hearing that:

Unfortunately it is a similar situation for many of our community members, where they either have to take them out of state school and go to a Catholic school to be able to get given an aide or have to home school because the children have school

626 Independent Schools Victoria, 'School and Student Numbers' accessed 7 May 2017, <[www.is.vic.edu.au/managing-a-school/facts-figures-funding/school-and-student-numbers](http://www.is.vic.edu.au/managing-a-school/facts-figures-funding/school-and-student-numbers)>.

627 Independent Schools Council of Australia, 'Students with Disability' accessed 7 May 2017, <[isca.edu.au/about-independent-schools/students-with-disability](http://isca.edu.au/about-independent-schools/students-with-disability)>.

628 Ms Tona O'Connor, Ms Michelle Hackett, and Ms Natalie Owens, South Gippsland Autism Action Group, Family and Community Development Committee public hearing – Morwell, 5 December 2016, transcript of evidence; Ms Katie Koullas, Founder, Yellow Ladybugs, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 3.

refusal. That is what we actually did. We took my daughter out of state school and we went to a Catholic school, even though we are not Catholic, because now she has got an aide in the classroom. To paint the picture, last year before we moved she had anxiety every day and was throwing up every day before school and at school for six months, and that did not qualify for any support in the classroom.<sup>629</sup>

The Committee also heard from Ms Mary Thomson, CEO of the Autism Training Institute (ATI), that teachers from the Catholic school sector do receive training at the ATI, and that in 2016, 15 teachers from Catholic schools undertook the certificate level course, with a mix of government and CECV funding.<sup>630</sup>

The Committee also visited several non-government schools and services that specialised in providing services to students and young people with ASD. The Committee visited and met with staff at the Mansfield Autism Statewide Services (MASS), which began as family camps, offering parents of children with ASD the opportunity to come together and learn more about their children's needs in a relaxed setting. MASS now aims to prepare children to integrate into schools, home and the community through a coordinated, wraparound approach to service provision.

MASS runs a number of other services both locally and more broadly in regional Victoria, including the Mansfield Autism Practitioners (MAPs) - an outreach service of teachers and other professionals, who travel out to families and schools across the state, providing advice and advocacy both in family homes and at schools. MASS also runs the Dookie Campus, which is a small secondary school with a maximum enrolment of twelve students (ages 11–18), with two full-time staff. The Committee visited the campus at Dookie, meeting staff and students, and was highly impressed with the work of the school.

The Committee also visited the EdSpace Education and Training Centre in Benalla, and met with senior staff, students and parents. EdSpace is an independent therapeutic school for children aged 11 to 18 who have developmental disorders, including ASD, which have impacted on their ability to succeed in previous schools. The school offers a wraparound approach to service provision and students are supported by a multidisciplinary team of health and education professionals. The Committee saw, first-hand, the benefits of this program, and heard how it had improved students' confidence and self-esteem. The Committee was impressed with EdSpace and the work being undertaken there. Both MASS and EdSpace are located in rural and regional Victoria and they are discussed in more detail in Chapter Nine.

The Committee is limited in making recommendations that can impact the non-government school sector. However, the sector can provide cases of programs

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629 Ms Katie Koullas, Founder, Yellow Ladybugs, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 3. See also Ms Loretta Krelle and Mr Rob Krelle, Family and Community Development Committee public hearing – Melbourne, 21 November 2016, transcript of evidence; Ms Tona O'Connor, Ms Michelle Hackett, and Ms Natalie Owens, South Gippsland Autism Action Group, Family and Community Development Committee public hearing – Morwell, 5 December 2016, transcript of evidence.

630 Ms Mary Thomson, Principal of the Western Autistic School, and CEO of the Autism Teaching Institute, Family and Community Development Committee public hearing – Melbourne, 21 November 2016, transcript of evidence, p. 5.

and approaches that could be studied by the government sector. For example, the Mansfield Autism Practitioners (MAPs) outreach service is similar in approach to that of the Autism Connect program, which is run by DET's North Western region.

The use of animal therapy at EdSpace provides an excellent example of how to reduce student anxiety levels within an educational setting. The intensive integration program at MASS illustrates that a short-term highly focused program can enable students to re-enter mainstream schools. The Committee believes that the school sector should be open to innovative programs, practices and approaches that are evidence-based and successful, regardless of their origin.

#### 4.4. Inclusive schools

The question of inclusive school education was taken up by the Australian Research Alliance for Children and Youth (ARACY), in a study prepared for the Commonwealth Department of Education, Employment and Workplace Relations in 2013. In its review of international and national sources, the ARACY report showed that there was a global trend towards inclusive education for students with disability, even while many regions maintain some form of separate special education. The ARACY report states that inclusive education can be a contentious term, with various meanings attached to it. However, the group did find that the global and Australian evidence indicates a range of similar practices:

The key approaches adopted in Australia focus on whole-school practice and in-class support. At a whole, school level good practices include adjustments to cultures, policies, and practices, development of support structures, regimes of funding support, and the provision of and access to equitable learning opportunities. At an in-class level, differentiating curriculum or introducing alternative curricula, the application of universal design, use of information technologies, individual planning through the individual education plan (IEP), and a focus on quality teaching for all students are the most prominent practices.<sup>631</sup>

For peak body Children with Disability Australia, definitions of 'inclusive education are rapidly changing'.<sup>632</sup> In their issues paper, *Inclusion in education*, Children with Disability Australia express their concern about the usage of the term as follows:

However, a troubling ambiguity is that the term inclusive education is often used to describe only placement in a mainstream classroom, rather than a child's full participation in all aspects of the educational setting. Being physically present in a mainstream setting does not automatically result in inclusion.<sup>633</sup>

At a public hearing in Melbourne, the Acting Secretary of DET, Ms Katy Haire, outlined the approach to inclusive education in Victoria as follows:

631 Australian Research Alliance for Children and Youth (ARACY), *Inclusive Education for Students with Disability – A review of the best evidence in relation to theory and practice*, ARACY, 2013, p. 5.

632 Children with Disability Australia, *Inclusion in education – towards equality for students with disability*, Children and Families Research Centre, Macquarie University, 2013, p. 13.

633 Ibid.

The government has made a commitment to establish Victoria as the education state, which is a vision for a fairer and more inclusive education system. Part of the work of the education state is to promote inclusive schooling and inclusive practices across schools. It is important to establish what we mean by inclusive schooling. There are many definitions in the education literature, which I imagine you may have considered, but they all focus on all members of every school community belonging and being valued and supported to fully participate, learn, develop and succeed within an inclusive school culture. Schooling is a universal service. Ensuring children and young people with disabilities and additional needs participate on the same basis as other students requires the department to build a strong culture of inclusion within schools. Schools best meet diverse needs through a personalised learning approach, one that builds on each child's strengths while addressing their individual support needs.<sup>634</sup>

Ms Haire described how the government was delivering on inclusive education as follows:

To deliver on inclusion, schools and systems need to support the diverse needs of children and young people. To do this there are some fundamental building blocks that need to be established, and I will outline some of these. We are currently undertaking major reform of provision of services to schools and students with disabilities. The reform underway seeks to transform the culture, policy and practice of Victorian schools to be fully inclusive of all students. The reform direction focuses on developing a personalised approach to learning for students with disabilities and additional needs. The flagship policies driving this reform agenda are largely set out in the government's special needs plan of 2015 and the Victorian government response to the review program for students with disabilities, which is titled *Inclusive Education for all Students with Disabilities and Additional Needs*. Together these policies aim to strengthen the capacity of Victoria's school system to meet the learning needs of all Victorian students and to deliver inclusion, participation, access and achievement of all students, especially those with additional needs.<sup>635</sup>

The Victorian Government describes inclusive education as 'central to the Victorian Government's vision of equity and excellence in the Education State', and built upon, 'clear policy commitments, positive school culture, high quality teaching and strength-based approaches to student learning.'<sup>636</sup> Spending initiatives and programs under the Government's Special Needs Plan, and program announcements and funding initiatives by the government in response to the PSD review, were outlined above.

In addition, the Government has announced further funding under the schools infrastructure program, the Inclusive Schools Fund, with round three applications

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634 Ms Katy Haire, Acting Secretary, Department of Education and Training, Family and Community Development Committee public hearing – Melbourne, 10 October 2016, transcript of evidence, p. 2.

635 Ibid, p. 3.

636 See, Department of Education and Training, 'Inclusive education for all students with disabilities and additional needs', Victorian Government, accessed 17 May 2017, <[www.education.vic.gov.au/about/departments/Pages/inclusive-education-for-all.aspx](http://www.education.vic.gov.au/about/departments/Pages/inclusive-education-for-all.aspx)>.



open in March 2017. This fund, which totals spending of \$20 million over four years, has supported projects in 75 schools. Examples of the type of projects funded include; indoor inclusive learning spaces, outdoor sensory areas, and quiet and supportive re-engagement spaces.<sup>637</sup> In the State Budget 2017-2018, the Government announced several measures to enhance learning and development for pre-school children, including \$10 million for Early Childhood Development facilities.<sup>638</sup> There were also measures to support children with disabilities to participate in kindergarten, including funding for additional speech therapists.<sup>639</sup>

Notwithstanding these commitments from government to inclusive education, the Committee heard from witnesses and submitters to the Inquiry that Victoria has a long way to go to establishing an inclusive culture and practice in its schools. Ms Narelle McCaffrey, mother of autistic children, told the Committee at a public hearing in Melbourne that:

Creating an inclusive culture in some schools is going to be a real uphill battle. The mindset of school leadership will need to shift significantly. Teachers will need more support in running an inclusive classroom, more than a few PD sessions – and one is mostly relied on – can offer. They are inundated with these modules to complete, so another one will just be one more. This is a real disservice to our kids.<sup>640</sup>

Ms Bronwyn Carter, from Aspergers Victoria, told the Committee at a public hearing that inclusiveness needed to be underpinned by the notion of ‘neurodiversity’:

Yes, a neurodiversity policy that acknowledges that children learn differently and some students have sensory sensitivities, and when they withdraw or they do not attend school or they have flare-ups, that this is caused by anxiety and sensory sensitivities, it is not bad behaviour, because when that is misinterpreted it compounds the problem instead of being inclusive.<sup>641</sup>

Ms Tracey Hayes, committee member of the Autism Family Support Association, and mother of sons with autism, told the Committee that at the secondary level there are few inclusive options:

I am looking at secondary school for my boys, and we are transitioning at the moment. There are no schools out there in secondary that are very inclusive, especially in the mainstream. Especially with my boys, with little to no language, you are looking at really just the special schools. I want an inclusive school, where

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637 See, *Ibid.*

638 These facilities are co-located at new primary schools, and designed to enable stable transition for children from early learning services into primary school, see Victorian Government, *Getting on with the job, Victorian Budget 17/18 Service Delivery, Budget Paper no. 3*, pp. 59-60, accessed 7 May 2017, <[s3-ap-southeast-2.amazonaws.com/budgetfiles201718.budget.vic.gov.au/BP3\\_2017-18\\_ServiceDelivery.pdf](https://s3-ap-southeast-2.amazonaws.com/budgetfiles201718.budget.vic.gov.au/BP3_2017-18_ServiceDelivery.pdf)>.

639 *Ibid.*, pp. 53-54.

640 Ms Narelle McCaffrey, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 3.

641 Ms Bronwyn Carter, Volunteer Consultant to the Board, Aspergers Victoria, Family and Community Development Committee public hearing – Melbourne, 12 September 2016, transcript of evidence, p. 8.



my boys can get role models from people who are neurotypical. I have seen a big difference with my boys just going to mainstream already. Yes, it is complex with their behaviours, but they are greatly reduced now, having communication, and also, looking at the education, looking at the curriculum, instead of in special schools where we seem to do life skills. My boys were exhibiting huge big behaviours and anxiety. Put them into mainstream and they are actually following a curriculum, and that has made a huge difference, especially for my little boys, who are now reading and writing.<sup>642</sup>

Mr Murray Dawson-Smith, Chief Executive Officer at disability service provider, Distinctive Options, told the Committee at a hearing in Bendigo, that the onus should be on school principals to ensure inclusion was developed in schools:

Likewise government has consistently, over a number of governments of both persuasions, talked about inclusive schools. We would argue again quite simply that we should be putting one of the KPIs of the principal as the development of an inclusive school system, and the principal should be able to demonstrate that as part of his criteria to meet his performance indicators. Again there is no cost to government to do that, but what it does demand is that the school from the principal down starts taking inclusion as a serious part of its school system.<sup>643</sup>

#### **4.4.1. Moomba Park Primary: Case study in inclusion**

Throughout the Inquiry, the Committee heard of the need for parents to have educational options that genuinely included and engaged students with ASD. As the submission from the Moomba Park Autism Inclusion Parents stated:

Above all, families want **options** in educational settings. Our children are not set in stone and we need to know that there are options available. Our children need more than to be welcomed by a school (though many families do not even have this). They need to be educated, challenged and have high expectations held for them.<sup>644</sup>

The Committee visited the Moomba Park Primary School in the northern metropolitan suburb of Fawkner, and met with senior staff and toured the school. In addition to the submission from the parent group, Moomba Park Autism Inclusion Parents, the Committee also received a submission from a parent of a student with ASD who attends Moomba Park, Mr Ben Snow.<sup>645</sup> Mr Snow also met with the Committee and

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642 Ms Tracey Hayes, Committee Member, Autism Family Support Association, Family and Community Development Committee public hearing – Melbourne, 12 September 2016, transcript of evidence, p. 11.

643 Mr Murray Dawson-Smith, Chief Executive Officer, Distinctive Options, Family and Community Development Committee public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 3.

644 Moomba Park Autism Inclusion Parents, submission no. 90, p. 5. Emphasis in the original submission.

645 Ibid; Mr Ben Snow, submission no. 103.

gave evidence at a public hearing held in Shepparton.<sup>646</sup> The Committee also received a submission from Mrs Shelley Fleming, whose son attends the school.<sup>647</sup>

From 2010, Moomba Park Primary was involved in the Department of Education and Training's Autism Inclusion Schools project. Fifteen mainstream schools across the state eventually took part in the project and each school developed their own approach to support students with ASD, tailored to the specific needs of each school's community.<sup>648</sup>

Moomba Park Primary chose to work with a private provider of behavioural therapy – Autism Partnerships Australia, which implemented learning strategies across the whole school based on the therapy Applied Behaviour Analysis (ABA). The program is titled 'Innovative Developments in the Education of Children with Autism' (IDEA).<sup>649</sup>

As part of the partnership, each student with ASD has an individualised plan developed in collaboration with school staff and a psychologist from Autism Partnerships Australia. The plans outline the individualised support needs and the learning goals of each student and they are monitored and updated to respond to changing needs.<sup>650</sup> Each plan is different and includes goals designed for each specific child: e.g. learning to follow instructions, learning particular social skills, etc.

Autism Partnerships Australia's psychologists and behavioural therapists attend the school to deliver the program, in collaboration with staff. IDEA focuses on three broad goals of achievement: academic, behavioural and social. The program method is to provide the level of ABA support specific to the needs of each individual child, and at a staff to student ratio that is needs-based. The school maintains a close relationship with its parent community.

The school has been able to continue the program by pooling together the funds they receive for students who are eligible for PSD funding, in conjunction with other school funding. At the time of the Committee's visit, there were 37 students diagnosed with ASD attending the school who were in receipt of a PSD Student Resource Package out of a total enrolment of 260 students. During the Committee's visit to the school, the Committee was advised that the school was about to receive five prep students with ASD in the coming year. The school receives one to two inquiries on average a week from families who have school age children with ASD.

In their submission to the Inquiry, the Moomba Park Autism Inclusion Parents described the benefits for students with ASD at the school when teachers are trained in autism and behavioural interventions.<sup>651</sup> There were small group learning and 'pull

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646 Mr Ben Snow, Family and Community Development Committee public hearing – Shepparton, 15 November 2016, transcript of evidence.

647 Mrs Shelley Fleming, submission no. 41.

648 Ms Katy Haire, Acting Secretary, Department of Education and Training, Family and Community Development Committee public hearing – Melbourne, 10 October 2016, transcript of evidence, pp. 4, 10.

649 Autism Partnerships Australia, 'The IDEA Program', accessed 17 February 2017, <[www.autismpartnership.com.au/the\\_idea\\_program](http://www.autismpartnership.com.au/the_idea_program)>.

650 Ibid.

651 Moomba Park Autism Inclusion Parents, submission no. 90, p. 1.

out' sessions that offered focused support to students on a range of skills and facilitated 'transitions between settings'.<sup>652</sup>

The parent group also described benefits for families at a school that integrates ABA therapy. It has alleviated the need for parents to coordinate private therapy and reduced the cost for families.<sup>653</sup> The availability of integrated ABA offers a seamless transition for students who have already undertaken ABA in their early years. According to the Moomba Park Autism Inclusion Parents, it has also ensured that children are being accommodated in the least restrictive environment as the therapy supports their children to manage their behaviours of concern.<sup>654</sup> Some families travel great distances so their children can attend the school, while some have relocated to Melbourne from regional areas. In their submission, the Moomba Park Autism Inclusion Parents stated:

Teachers at Moomba Park Primary are not just trained in autism and behaviour intervention. Their teaching is observed by the specialist ABA Program Supervisor and they are coached in their practice. This builds teacher capability across the school, a key goal of the Education Department's Special Needs Plan. The coaching is not restricted to outcomes for the autistic student but to the whole student body.<sup>655</sup>

During the Inquiry, the Committee heard that some families had chosen to bear the economic and social costs associated with relocating their homes to access the IDEA program at Moomba Park Primary School. Mr Ben Snow advised the Committee of the need to set up a second home in Melbourne for his wife and children during the week so that his son can attend Moomba Park. Mr Snow continues to work in his profession in Shepparton.<sup>656</sup> According to Mr Snow this has been necessary for his son who started receiving ABA shortly after his diagnosis at three years of age. There were no known providers in the Shepparton region. At a public hearing in Shepparton, Mr Snow described the services in Shepparton:

The choices for services in Shepparton in my opinion are just not enough. The ECIS, which we were entitled to at about two and a half for Bailey, was wonderful ... We were also under the guidance of Peter Eastaugh, who is a very well known paediatrician in the area. He has a lot of experience and is great with kids with autism. Again, he put us onto additional speech and OT-type services, but you are getting 2 hours a week at best. It is just not going to cut it; it is never going to cut it ...<sup>657</sup>

Prior to enrolling at Moomba Park the family had chosen, 'after significant research and deliberation, to engage Bailey in a centre based ABA therapy in North Melbourne

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652 Ibid.

653 Ibid, p. 2. Mr Ben Snow, Parent, Family and Community Development Committee public hearing – Shepparton, 15 November 2016, p. 4.

654 Moomba Park Autism Inclusion Parents, submission no. 90, p. 4.

655 Ibid, p. 3.

656 Mr Ben Snow, submission no. 103, p. 2.

657 Mr Ben Snow, Family and Community Development Committee public hearing – Shepparton, 15 November 2016, transcript of evidence, p. 3.

at a significant cost of \$70,000 per annum as well as accommodation and travel cost in excess of \$25,000 per annum.<sup>658</sup>

Since starting at the school the family has not needed to undertake privately funded ABA therapy. Mr Snow stated that:

As of when he started at Moomba Park, he does not do the ABA anymore, mainly because the therapy is built into their IDEA program. If it was not, we would certainly be doing hours outside.<sup>659</sup>

Mr Snow also gave evidence of the program at the school. He stated:

Bailey is only in prep, so we are still coming to terms with how it sort of works from being one on one to him now being in a public school setting ... each day the children that are on the spectrum and some of the other additional-needs children are extracted out into a specialty group for an hour at a time and given a social interaction type of activity or program to do ... Bailey needs less and less of that as we go along, and I understand that is happening with all of the kids ...<sup>660</sup>

The Snow family is very pleased with their son's progress at the school, and the ABA-based program it offers, but the decision to enrol their son at the school has come at a cost. As Mr Snow says in his submission:

So for our family, this has meant my family are now based in Melbourne 5 days a week, apart from myself who has to work in Shepparton to support our choices. It puts additional strain on relationships and means my wife has little support around her and the kids certainly miss their Dad. Michelle is an educated and experienced child care worker and kinder teacher and at times has ran a local child care facility and worked for a local kinder, both areas our region has a shortage of workers in. I am also under pressure to find means to spend more time in Melbourne to support my family and I could imagine the brain drain on the Goulburn Valley does not stop with our family.<sup>661</sup>

Other parents of children attending Moomba Park travelled long distances each day to take their child to school. Mrs Shelley Fleming stated in her submission that:

Matt is not severely autistic, and we felt that an autistic school might limit his learning, so instead we searched for a school that would cater more to his needs. We eventually came across Moomba Park Primary. With assisted learning in the 'Foundation Room', they have ABA therapy integrated into their system - perfect for Matt. The only issue happened to be that we live in Werribee, and the school is in Faulkner [sic] 45 kms trips twice a day, for my husband and I, now going in to our 7<sup>th</sup> year is not only expensive but can have a detrimental effect on the whole family. (The western ring road can be dreadful for traffic).<sup>662</sup>

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658 Mr Ben Snow, submission no. 103, p. 1.

659 Mr Ben Snow, Family and Community Development Committee public hearing – Shepparton, 15 November 2016, transcript of evidence, p. 4.

660 Ibid, p. 5.

661 Mr Ben Snow, submission no. 103, p. 2.

662 Mrs Shelley Fleming, submission no. 41, p. 1.

At the time of the Inquiry, the Committee heard that Moomba Park Primary School remained a unique initiative for mainstream primary schools in the state. As mentioned above, 14 other mainstream schools participated in the Autism Inclusion Schools project, which concluded in 2014. At a public hearing the Acting Secretary of DET, Ms Katy Haire, advised the Committee that:

Each project school's individual approach was developed and implemented in the context of their school community. What we learnt from this project was that while each school needed to develop its own tailored approach to respond to local need, the following essential elements are a constant: first, a focus on the child and the young person first; second, the importance of leadership of the principal and the school leadership team; third, the promotion of inclusion at a whole-school level; fourth, the provision of coordinated and extensive professional development; fifth, meaningful communication and collaboration between all the people involved in the child's education, with an emphasis on families and parents; sixth, the need for continual review and implementation of evidenced-based pedagogy and curriculum; and seventh, the consideration of physical aesthetic elements that constitute an autism-friendly environment. This project, which was concluded in 2014, provided the department with a range of models and learning to assist all schools to strengthen the inclusiveness of the school environment, and all schools across the state have access to the resources and lessons that this project delivered, which is on our website on the autism-friendly learning page.<sup>663</sup>

In response to follow-up questions on notice from the Committee, DET advised the Committee that while the Department does not have a comprehensive list of schools that run specific autism inclusive programs, the fifteen Autism Inclusion Schools that were involved in the project, do continue to offer students on the autism spectrum an inclusive environment, with staff who have undertaken training and professional learning about autism.<sup>664</sup>

The 15 schools are: Ballarat High School, Carwatha College P-12, Coburn Primary School, Highton Primary School, Kennington Primary School, Lucknow Primary School, Moomba Park Primary School, Mooroolbark East Primary School, Mount Alexander College, Newcomb Secondary School, Officer Primary School, Sunbury College, Trafalgar Primary School, Williamstown North Primary School, and Wodonga South Primary School. In 2016, the Victorian Education Excellence Award for Outstanding Inclusive Education was awarded to one of these schools - Williamstown North Primary School.<sup>665</sup>

The Committee became aware through the Inquiry that many parents of students with ASD, chose to send their child to a special school, rather than a mainstream school, because that school better met the needs of their child. The Committee is of the view

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663 Ms Katy Haire, Acting Secretary, Department of Education and Training, Family and Community Development Committee public hearing – Melbourne, 10 October 2016, transcript of evidence, p. 4.

664 Department of Education and Training, Correspondence, Follow up questions on notice – 21 March 2017.

665 Ibid.

that there will continue to be an ongoing and important role played by special schools and specialist autism schools in the school system.

#### 4.4.2. Autism specialist schools

During the Inquiry the Committee received a submission from the Northern School for Autism and it visited the Northern School for Autism's Early and Middle Years campus in Reservoir to discuss the program with leading staff and observe the school's purpose-built facilities for students with ASD.<sup>666</sup> The Committee also heard from Ms Mary Thomson, Principal of the Western Autistic School and CEO of the Autism Teaching Institute (ATI) at a hearing in Melbourne. Ms Thomson briefly described the program at the Western Autistic School, which caters for students aged from prep to grade three. As mentioned above, there are seven specialist schools for autism. To be admitted, students need to have approved PSD funding under the ASD category. Each of the specialist schools for students with ASD have taken a different approach to educating students on the autism spectrum.<sup>667</sup>

The Committee received evidence of the role that specialist schools for autism play in providing training and professional development opportunities to teachers and therapists (speech and occupational therapists) who work in all settings.<sup>668</sup> The Committee also heard of the benefits of certain key supports in place at the specialist schools for autism, which would benefit students with ASD in all settings. These supports included:

- The development of Individual Learning Plans and goals.
- The use of evidence-based teaching and learning practices and teachers to be trained in implementing these evidence-based practices.
- The integration of speech and occupational therapists into the classroom so that therapists work with teachers to develop individualised plans and support student learning.
- An emphasis on the development of the social and communication skills of students, given that students with ASD experience particular challenges in these areas.
- Adaptation of the Victorian curriculum.<sup>669</sup>

According to Ms Anna Rigoni, Principal of the Northern School for Autism, the school has implemented a structured teaching approach based on the TEACCH approach

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666 Northern School for Autism, submission no. 30.

667 See for example, *Ibid*: Ms Mary Thomson, Principal of the Western Autistic School, and CEO of the Autism Teaching Institute, Family and Community Development Committee public hearing – Melbourne, 21 November 2016, transcript of evidence, p. 3.

668 Northern School for Autism, submission no. 30, p. 1. Ms Mary Thomson, Principal of the Western Autistic School and CEO of the Autism Teaching Institute, Family and Community Development Committee public hearing – Melbourne, 21 November 2016, transcript of evidence, p. 3.

669 Northern School for Autism, submission no. 30.

developed at the University of North Carolina.<sup>670</sup> In the school's submission, Ms Rigoni stated:

All staff members are trained and work in accordance with the autism specific NSA Teaching and Learning Protocols. The school delivers the Victorian Curriculum (predominately Levels A-D) as well as an autism specific supplementary curriculum. The autism specific component of the curriculum builds on students' strengths and skills, within a supportive environment ...<sup>671</sup>

The Western Autistic School relies on a 'toolbox of evidence-based teaching strategies', developed from their long experience in the provision of early intervention therapies and early education.<sup>672</sup>

The Northern School for Autism and the Western Autistic School have integrated speech and occupational therapists into their programs. Ms Rigoni described how the Northern School for Autism's therapists work in a collaborative 'push in' model 'rather than a withdrawal or "pull out" model' and support is provided inside the classroom.<sup>673</sup> According to Ms Rigoni, the program has enabled students at the Northern School for Autism to learn how to implement strategies in the school setting.<sup>674</sup> It has also meant that their students receive therapy, regardless of whether a teacher makes a referral for therapy.<sup>675</sup> The Western Autistic School employs speech and occupational therapists from their PSD funding and the therapists work with the school teachers to develop Individual Learning Plans for their students. As Ms Thomson stated:

The model is a consultative model, so it is not clinical as such. The speech pathologists and OTs work collaboratively with the teachers in terms of the design and development of the individual learning programs. That does require at times clinical assessment, but only inasmuch as it informs how the teacher comes to understand the sensory needs of the children or the language needs, the social communication needs, of the student. They are part of the team that writes and develops the ILP.<sup>676</sup>

Following the department's review of the PSD, the key ASD recommendations have included: developing options to support specialist schools to become 'centres of expertise'; making available ongoing autism-specific disability training and access to specialist support and expertise; and the inclusion of allied health professionals or specialist teachers in new multidisciplinary teams to support schools and

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670 Ibid, p. 2.

671 Ibid, p. 2.

672 Ms Mary Thomson, Principal of the Western Autistic School, and CEO of the Autism Teaching Institute, Family and Community Development Committee public hearing – Melbourne, 21 November 2016, transcript of evidence, p. 3.

673 Northern School for Autism, submission no. 30, p. 4.

674 Ibid.

675 Ibid.

676 Ms Mary Thomson, Principal of the Western Autistic School, and CEO of the Autism Teaching Institute, Family and Community Development Committee public hearing – Melbourne, 21 November 2016, transcript of evidence, p. 10.



individuals.<sup>677</sup> At a hearing in Melbourne, Ms Katy Haire, the Acting Secretary for DET, gave evidence that DET is also investigating ways to enable therapists to enter schools where students with disabilities require greater support.<sup>678</sup> DET has also provided resources to assist teachers on aspects that include creating Individual Learning Plans and effective goal setting via their website.<sup>679</sup>

The Committee supports the expansion of the role and number of autism specialist schools, and notes that currently there is no regionally based autism specialist school. The seven current autism specialist schools are based in Melbourne or surrounding suburbs. New autism specialist schools need to be built in regional Victoria, particularly in relation to areas of high need. The Committee appreciates the need for choice in schooling options, and accordingly, the Committee recommends that:

#### **RECOMMENDATION 4.8**

**The Victorian Government fund the building of new autism specialist schools in regional Victoria, with a particular aim of servicing areas of high need.**

#### **4.4.3. Autism Connect: Case study in supporting inclusion**

The Committee heard evidence about Autism Connect in the North-Western region. Autism Connect is an initiative that connects mainstream schools with six specialist schools in the region. Specialist schools act as hub schools by providing assistance and advice to mainstream schools in the region; specialist schools also offer opportunities for staff in mainstream schools to visit the school to learn how to implement practices that support students with ASD.<sup>680</sup>

In 2012, federal funding was provided to each region in Victoria for a three-year period under the More Support for Students with Disabilities Program and each region chose to use the funding in different ways.<sup>681</sup> In the North-Western region educators identified that they were getting increased requests for assistance from schools with students who have ASD. The region covers metropolitan Fitzroy, Glenroy and Coburg and includes the regional centre of Bendigo and the rural cities of

677 The Department of Education and Training, *Inclusive education for all students with disabilities and additional needs: The government's response to the review of the Program for Students with Disabilities*, Melbourne, 2016, p. 20.

678 Ms Katy Haire, Acting Secretary, Department of Education and Training, Family and Community Development Committee public hearing – Melbourne, 10 October 2016, transcript of evidence, p. 7.

679 Department of Education and Training, 'Autism-Friendly Environments', Victorian Government, accessed 22 February 2017. <[www.education.vic.gov.au/school/teachers/teachingresources/diversity/Pages/asdfriendly.aspx](http://www.education.vic.gov.au/school/teachers/teachingresources/diversity/Pages/asdfriendly.aspx)>.

680 The Department of Education and Training (DET), *Review of the Program for Students with Disabilities*, Melbourne, 2016, p. 108.

681 S Hosking, *The Measures that Contribute to Effective Inclusion of Autism Spectrum Disability Students in Mainstream Schools*, Parliamentary Internship Report, 2016, pp. 18 – 19.

Mildura and Swan Hill.<sup>682</sup> The funding is the equivalent of a two-day full-time teacher and the program has secured DET funding for 2017.<sup>683</sup>

Kalianna School is one of the six hub schools to provide assistance to mainstream schools in the region under the initiative. Kalianna School students have a mild intellectual disability. The Committee visited Kalianna School to observe the facilities and learn about the school's teaching practices. The Committee observed the visual supports and the use of flexible learning spaces that supported Kalianna's students. The Committee also learned about the individual plans that are developed to support students at the school who are displaying behaviours of concern as part of the school-wide Positive Behaviour Support. At the time of the Inquiry, the school had 91 students diagnosed with ASD in addition to intellectual disability and it had a total enrolment of 265 students.<sup>684</sup>

At a public hearing in Melbourne, Ms Britt Holmberg, Autism Connect Inclusion Coordinator, stated:

Through Autism Connect we support about 10 schools at the moment. We have been operating Autism Connect for the past three years, and I have been coordinator of the program for this year and last year. The sort of support we provide to schools within our region consists of really focusing on those whole-school approaches to schools and involving the coordination of leadership teams to make sure that those practices I help implement are effective.

A lot of the initiatives that we focus on through Autism Connect include implementation of PBS frameworks – positive behaviour support; making sure that whole-school practices are happening, such as visual supports and clear structures and routines; having whole-school reward systems; and ensuring that we provide schools with professional development centred around what autism is, what it looks like for students and how we can effectively support those students in our classrooms through the use of visuals and reward systems. Often that will include the coordination of the zones of regulation as well.<sup>685</sup>

As the Inclusion Coordinator for Autism Connect, Ms Holmberg travels across the region, from Romsey to Echuca. Ms Holmberg described to the Committee what frequently occurs when she responds to a support request in the region:

Historically what happens with a support request is it will start off as one or two students and then the realisation is, after you have met with the leadership teams, they think, 'That support would be great for our whole school', and it usually gets rolled out throughout the whole school. Why that happens also is because the most

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682 Mr Peter Bush and Ms Britt Holmberg, Kalianna School Bendigo, Family and Community Development Committee public hearing – Melbourne, 7 November 2016, transcript of evidence, p. 3. See also, S Hosking, *The Measures that Contribute to Effective Inclusion of Autism Spectrum Disability Students in Mainstream Schools*, Parliamentary Internship Report, 2016, p. 18.

683 Mr Peter Bush, Principal, Kalianna School Bendigo, Family and Community Development Committee public hearing – Melbourne, 7 November 2016, transcript of evidence, p. 3.

684 Ibid, p. 2.

685 Ms Britt Holmberg, Autism Connect and Inclusion Coordinator, Kalianna School Bendigo, Family and Community Development Committee public hearing – Melbourne, 7 November 2016, transcript of evidence, p. 3.

effective strategy is going to be whole-school approaches, such as a positive behaviour support framework, making sure the resources are consistent from classroom to classroom. Leadership teams will see that it will be effective to involve their whole staff. So it might just be a couple of students that they flag that they need to have some really serious support and help with and some advice. Then the realisation comes that these students will move from this teacher to that teacher, so we would like to train our whole staff in best practice around working with children with ASD.<sup>686</sup>

Specific strategies such as Positive Behaviour Support (PBS) have benefited the entire school community including students with ASD. According to Mr Peter Bush, Principal of Kalianna School, since implementing school-wide PBS at his school, there has been a significant reduction in the behaviours of concern within the school.<sup>687</sup> Ms Holmberg is the school's coordinator of its PBS framework, and has had extensive training and professional development in this area. Ms Holmberg and Mr Bush supplied further details on how specialist schools have been supporting and upskilling mainstream schools in the region:

- Schools are able to make an initial support request through the DET's regional office in Coburg. The request will be triaged to see if the service provided through Autism Connect is suitable. The support request will be referred on to the hub school that is closest.
- The Autism Connect Inclusion Support staff contact the school to understand their needs and develop a service plan. The plan involves identifying and setting appropriate goals for the school staff to support an individual student with ASD or to implement whole-school practices such as PBS.<sup>688</sup>
- As part of the program, the specialist schools also host visits from teachers and staff members of mainstream schools; this provides an opportunity for professional development.<sup>689</sup>

Autism Connect Service Support staff have been selected for their expertise and 'exemplary practice in the field of supporting students with ASD'.<sup>690</sup> Autism Connect Service Providers have provided a range of supports that include professional development opportunities, advice on the development of Individualised Learning Plans and behaviour management plans and teacher mentoring so that schools have a range of strategies to include students with ASD.<sup>691</sup> Crucially, the initiative has not

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686 Ibid, p. 5.

687 Mr Peter Bush, Principal, Kalianna School Bendigo, Family and Community Development Committee public hearing – Melbourne, 7 November 2016, transcript of evidence, p. 8.

688 Mr Peter Bush and Ms Britt Holmberg, Kalianna School Bendigo, Family and Community Development Committee public hearing – Melbourne, 7 November 2016, transcript of evidence, pp. 3-4.

689 Ibid, pp. 3-5.

690 The Department of Education and Training (DET), *Review of the Program for Students with Disabilities*, Melbourne, 2016, p. 108.

691 Ibid.

been limited to students who have a diagnosis of ASD and the support is designed to build school capacity and inclusiveness.<sup>692</sup>

The Autism Connect program relies on the expertise already available in specialist schools and the Committee heard of how it has represented a cost-effective way to assist and upskill mainstream schools.<sup>693</sup> While teachers have been provided with online resources that include information and guidance on autism-inclusion practices, the Committee heard of the need for teachers and principals to connect with expertise in their region. Autism Connect however remains limited to the North-Western region of the state.

Mr Bush also advised the Committee that the employment of teacher aides by themselves is not the best model to use.<sup>694</sup> He described the team teaching model that was being developed at Kalianna:

The really important thing that we are going to change is the old model of one teacher, one classroom and one teacher, one aide is not going to happen. We are going to team teach. At the moment we are looking at three teachers being in the one classroom, so a bigger number of students in each classroom, and then two or three assistants in the room as well. That will enable the two teachers and three assistants to focus on teaching. Then there will be one teacher – so again going back to that professional person – to give one-on-one instruction or it might be welfare or they might be able to go around and visit a home. So there is a teacher free to do that, and it will not be the one teacher all the time. It will be one of the three teachers; that is why we are really pushing for the team teaching model so that we can use our resources better.<sup>695</sup>

Mr Bush told the Committee that at Kalianna one measure of success at his school was its capacity to transition students back into mainstream schooling:

I see that as a success of our school if we can transition students back to mainstream. It is really difficult when parents come to the school because special schools have got a stigma. We tell parents that enrolling them at our school does not mean they have to stay there forever. We might skill their child up and then they can go back to mainstream. Or they might start off dual enrolled, so at mainstream and our school as well. There are all different models. One of the successes would be for them to go back to mainstream, especially for those students who are travelling the long distances on the bus from Wedderburn and Heathcote.<sup>696</sup>

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692 Mr Peter Bush and Ms Britt Holmberg, Kalianna School Bendigo, Family and Community Development Committee public hearing – Melbourne, 7 November 2016, transcript of evidence, p. 5.

693 Ibid, p. 3.

694 Mr Peter Bush, Principal, Kalianna School Bendigo, Family and Community Development Committee public hearing – Melbourne, 7 November 2016, transcript of evidence, p. 5.

695 Ibid, p. 6.

696 Ibid.

Mr Bush also advised the Committee that at Kalianna school staff work with students well before they leave school to develop their skills so that they can successfully transition to either the workforce or to TAFE:

But, as best we can, we can make a judgement of what skills they have and what skills will be useful to them when they graduate from Kalianna. We focus on those, whether that is extensive work experience or they start a TAFE course with us or they do a school-based apprenticeship, which they can continue on when they do leave. The clientele at our school are more than likely to succeed out there, or have the ability to get full-time employment.<sup>697</sup>

The Committee was impressed with the Autism Connect model of enhancing school capacity and addressing the special needs of students with ASD. In its response to the Committee's follow up questions on notice, DET stated that the Autism Connect program would continue to be funded in 2017 for the North Western Victoria Region. The Department is currently evaluating a number of other collaborative arrangements to provide evidence-based supports that will cover a range of inclusion needs, including those of students with ASD.<sup>698</sup>

The Committee is of the view that the expertise that exists in specialist and special schools needs to be drawn upon to enhance the capacity of mainstream schools. The Autism Connect program is a successful, evidence-based program specifically tailored for students with ASD and their needs, but having demonstrable value to the whole school. The Committee supports its retention and expansion and thus recommends that:

#### **RECOMMENDATION 4.9**

**The Victorian Government retain, fund and expand autism outreach programs to other education regions of the state, including the role of autism outreach coordinators.**

The Committee believes the Victorian Government needs to expand the teacher-training role of special schools and autism specialist schools. Both the Western Autistic School and Kalianna School provide models of practice for such schools acting as potential teacher training hubs.

When developing new special schools, the Victorian Government should examine the feasibility of incorporating within them teacher training facilities, and create linkages with appropriate teacher training institutions, such as universities and the Autism Teaching Institute, to deliver training on autism to trainee teachers in situ.

Accordingly, the Committee recommends that:

<sup>697</sup> Ibid, p. 13.

<sup>698</sup> Department of Education and Training, Correspondence, Follow up questions on notice – 21 March 2017.

## RECOMMENDATION 4.10

In the design of all new special schools, the Victorian Government incorporate teacher training facilities to enable trainee teachers to be trained in autism.

- Partnerships with appropriate teacher training institutions be created where possible to deliver training at the schools.

### School-wide Positive Behaviour Support (PBS)

In addition to Kalianna, the Committee visited several mainstream and specialist schools, which had implemented School-Wide Positive Behaviour Support (PBS) the evidence-based approach to reinforcing positive behaviours and addressing behaviours of concern. The schools included: Whittington Primary School, Bendigo Specialist School, and the Northern School for Autism.

The Committee heard evidence about the benefits for all students, including students with ASD, when PBS is implemented by school leadership teams.<sup>699</sup> PBS focuses on the school as the primary site of change and leadership to address behaviours of concern and promote positive behaviours across the school community. According to expert researchers, PBS is one element of a set of features that contribute to educational best practice for students with ASD.<sup>700</sup> At present, DET provides teachers with online resources to guide schools on how to implement PBS.<sup>701</sup> DET's website states that it will be helping Victorian schools to implement PBS over the next two years.<sup>702</sup> Developed in the U.S., Positive Behaviour Support (PBS) is a person-centred approach that helps individuals replace their behaviours of concern with socially meaningful behaviours. The ultimate goal is to achieve quality of life for the person involved. The key features of PBS include the following:

- a Functional Behavioural Assessment conducted by a trained behavioural analyst, which identifies the key reasons behind a behaviour of concern;
- the development of a behaviour management plan that uses evidence-based practices to tailor a plan that meets the individual's needs. PBS plans often entail environmental modifications to remove any factors that are reinforcing a behaviour of concern; and
- consultation with the individual and their key persons (parents/ carers, therapists, teachers or employers) throughout the assessment process and the development of their intervention plan.<sup>703</sup>

699 Gateways Support Services, submission no. 87, p. 4. Autism Spectrum Australia (Aspect), submission no. 100, p. 4. Amaze, submission no. 139, pp. 40 – 41. Mr Peter Bush and Ms Britt Holmberg, Kalianna School Bendigo and Autism Connect, Family and Community Development Committee public hearing – Melbourne, 7 November 2016, transcript of evidence, p. 3.

700 J Roberts, 'Autism and Education in Australia', *Australian Clinical Psychologists*, vol. 1, issue. 2, 2015, p. 24.

701 Department of Education and Training, 'Whole School Organisation', Victorian Government, accessed 22 February 2017, <[www.education.vic.gov.au/school/teachers/teachingresources/diversity/Pages/wholeschoolorg.aspx](http://www.education.vic.gov.au/school/teachers/teachingresources/diversity/Pages/wholeschoolorg.aspx)>.

702 Ibid.

703 Autism Spectrum Australia, 'What is PBS', Autism Spectrum Australia, Melbourne, accessed 22 February 2017. <[www.autismspectrum.org.au/content/what-pbs](http://www.autismspectrum.org.au/content/what-pbs)>.

In PBS, the school leadership team establishes three tiers of supports to promote positive behaviour in their school community. Tier One is designed to provide basic preventative support across the school and includes practices such as:

- Using Data-based Decision Making
- Developing a Simple Set of Behavioural Expectations
- Teaching Behavioral Expectations
- Acknowledging Appropriate Behaviours.<sup>704</sup>

Tiers Two and Three are designed for students who are not responding to the primary level of supports. Tier Two provides targeted group support for some students, such as group mentoring and social skills training.<sup>705</sup> Tier Three involves targeted and individual support for a few students who have not responded to Tier One and Tier Two interventions.<sup>706</sup> At the public hearing in Melbourne, Ms Holmberg stated:

Our individual student profiles were implemented at the end of term 3 this year as a consistent way of making sure every classroom had up-to-date information on every single student within our school. This was to ensure that we were involving all the people that worked with certain students so we had up-to-date information ... That can be simple things from contact phone numbers right through to ... different information such as specialists they might work with and different types of behaviours, like tier 1 – so low level behaviours ... and to give hints to CRTs and to different teachers about what to do in those situations ...<sup>707</sup>

Mr Bush and Ms Holmberg also described other standard features of PBS including the use of a central database at Kalianna School to record incidents of concern and inform school-wide strategies.<sup>708</sup> The Committee heard of the benefits to the entire school community when PBS is implemented alongside other practices that engage students with ASD at the school, and provide teachers with the support they need to teach students with ASD. The Committee heard of the need for the Victorian Government to be more proactive in ensuring that effective PBS approaches are implemented widely in schools. According to DET's Whole School Engagement and Strategies Support webpage, in 2014, 70 schools received grants to implement PBS.<sup>709</sup>

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704 The Technical Assistance Center on Positive Behavioural Interventions and Supports, 'Tier 1, Case Examples', accessed 21 February 2017. <[www.pbis.org/school/tier1supports/case-examples](http://www.pbis.org/school/tier1supports/case-examples)>.

705 The Technical Assistance Center on PBIS, 'Tier 2, Support', Technical Centre on PBIS, U.S., accessed 21 February 2017. <[www.pbis.org/school/tier2supports](http://www.pbis.org/school/tier2supports)>.

706 The Technical Assistance Centre on PBIS, 'Tier 3 Supports', Technical Centre on PBIS, U.S., accessed 21 February 2017. <[www.pbis.org/school/tier-3-supports](http://www.pbis.org/school/tier-3-supports)>.

707 Ms Britt Holmberg, Autism Connect and Inclusion Coordinator, Kalianna School Bendigo, Family and Community Development Committee public hearing – Melbourne, 7 November 2016, transcript of evidence, p. 10.

708 Mr Peter Bush and Ms Britt Holmberg, Kalianna School Bendigo, Family and Community Development Committee public hearing – Melbourne, 7 November 2016, transcript of evidence.

709 Department of Education and Training, 'Whole School Engagement Strategies and Support', Victorian Government, accessed 24 February 2017. <[www.education.vic.gov.au/school/principals/participation/Pages/wholeschoolengage.aspx](http://www.education.vic.gov.au/school/principals/participation/Pages/wholeschoolengage.aspx)>.



## The New York ASD Nest Program

On its study tour of the USA, the Committee learnt about the ASD Nest Support Program, which is the largest inclusion project for students with autism in the U.S. public education system. The ASD Nest Project serves 1,200 students in the New York City school district, and exists in 39 'regular education' schools. The program is a partnership between the New York City Department of Education (NYCDOE), and New York University's ASD Nest Support Project. The program serves students in a reduced class size model that involves two teachers per class – one special education teacher and one general education teacher – and a mix of ASD students and typically developing students. The state government and education department fund the ASD Nest Project.<sup>710</sup>

The ASD Nest Project leaders work with the NYC Department of Education to help identify children that need to attend ASD Nest schools and there is a close partnership with the department in order to fill their classes. No educator goes into an ASD Nest class without training. At the elementary school level, teachers access two autism-specific courses. The ASD Nest Project has a partnership with Hunter College and New York City University. Teachers develop expertise on autism based on tiers of education that lead progressively to greater knowledge of autism and increasing sophistication in teaching practices. One of the strategies teachers receive training in is known as Social Development Intervention (SDI), which is an evidence-based program that supports the social and emotional needs of ASD Nest students.<sup>711</sup>

Teachers who have undergone extensive training and experience in the ASD Nest classes can become onsite autism coaches in their school. The ASD Nest Project supports the development of self-sustaining programs at the schools. Therapists (speech and occupational) also receive autism-specific training. There are weekly meetings in schools with the nest classes, which include the ASD Nest consultant, teaching staff and therapists to 'case conference' students. The project adheres to a wrap-around service model for students. By high school, the ratio of students with autism and neurotypical students is 4 to 6 ASD students and 22 neuro-typical students, and the project staff continue to work closely with the education department to assist in identifying students who would benefit from ASD Nest classes. All ASD Nest students access intervention therapies to support their social skills development. While extra training is provided to teachers upfront, ASD Nest Project leaders have found that less and less training is required over time. Classrooms are designed to meet the sensory needs of students with ASD. High achieving typically developing students are not withdrawn from ASD Nest classes, rather the program considers a balance of children and ability levels is required in the class for educational success. They have found parents of neurotypical children who

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710 NYU Steinhardt, 'About the Department of Education ASD Nest Program', accessed 22 May 2017, <[steinhardt.nyu.edu/asdnest/about/doe](http://steinhardt.nyu.edu/asdnest/about/doe)>.

711 NYC Department of Education, *Autism Spectrum Disorder Programs*, accessed 22 May 2017, <[schools.nyc.gov/NR/ronlyres/DD51680F-EA30-469A-9C9B-52DD8854A1E6/0/ASDProgramInfoforFamilies\\_102315.pdf](http://schools.nyc.gov/NR/ronlyres/DD51680F-EA30-469A-9C9B-52DD8854A1E6/0/ASDProgramInfoforFamilies_102315.pdf)>.

initially baulked at having their child learning with ASD students but the small class sizes have become attractive for many parents.<sup>712</sup>

## 4.5. Creating more inclusive schools for students with ASD

The evidence received by the Committee, outlined in detail above, suggests that currently mainstream schools are not commonly providing an inclusive model of education that would encourage parents of children with ASD to enrol their child. The Moomba Park Primary example shows the lengths, including re-location and commuting long distances, to which some parents will go to secure an inclusive education for their child in a mainstream school environment.

The Committee is aware that many parents are choosing special or specialist schools for their child with ASD over mainstream school enrolment. For many parents the option of sending their child to one of these schools will be the most appropriate choice for their child. The philosophy of inclusive schooling does not exclude the important role that special and specialist schools can play in meeting the needs of students with ASD. As discussed above, these schools can have a positive impact and influence on mainstream schools that enhances their ability to be inclusive.

The Committee also believes that at least part of the reason for some parents making this choice is because of the failure of many mainstream schools to meet the needs of students with ASD. The absence of inclusive practices and programs for students with ASD in mainstream schools can therefore act not just as a limitation on parent choice, but also as a driver of parent choice.

Given the programs and initiatives outlined above under the government's schools inclusion agenda, what further changes can the Victorian Government implement to make Victorian schools more inclusive for students with ASD? The Committee understands that Victorian schools have a certain level of autonomy to pursue individual approaches to their school culture. This was reflected in how the 15 schools participating in the Autism Inclusion Schools project, described above, developed and implemented an individual approach in the context of their school community.

As noted above, the Acting Secretary Ms Haire advised the Committee that essential elements emerged from the Autism Inclusion Schools project which were: a focus on the child and the young person first; the importance of leadership of the principal and the school leadership team; the promotion of inclusion at a whole-school level; the provision of coordinated and extensive professional development; meaningful communication and collaboration between all the people involved in the child's education, with an emphasis on families and parents; the need for continual review and implementation of evidenced-based pedagogy and curriculum; and the

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712 NYU Steinhardt, 'About the Department of Education ASD Nest Program', accessed 22 May 2017, <[steinhardt.nyu.edu/asdnest/about/dae](http://steinhardt.nyu.edu/asdnest/about/dae)>; NYC Department of Education, *Autism Spectrum Disorder Programs*, accessed 22 May 2017, <[schools.nyc.gov/NR/ronlyres/DD51680F-EA30-469A-9C9B-52DD8854A1E6/0/ASDProgramInfoforFamilies\\_102315.pdf](http://schools.nyc.gov/NR/ronlyres/DD51680F-EA30-469A-9C9B-52DD8854A1E6/0/ASDProgramInfoforFamilies_102315.pdf)>.

consideration of physical aesthetic elements that constitute an autism-friendly environment.<sup>713</sup>

The Committee supports the Government's inclusive school agenda for mainstream and specialist schools, and recognises that all students with disability need to be catered for in an inclusive school culture. Nevertheless, the Committee believes that the Victorian Government should adopt a more proactive approach to the development of an inclusive culture in mainstream schools that is welcoming and supportive of students with ASD, and which incorporates the learnings from the Autism Inclusion Schools project. Many students with ASD require a classroom environment that is adapted to their needs, both in terms of the sensory and physical environment, and the social and emotional environment. Transitions through the day need to be carefully managed, structures of learning need to be systematic and routine and provide visual supports where necessary.<sup>714</sup>

Families of students with ASD need to be involved, particularly around creating individual student plans. The curriculum for students with ASD needs to be flexible enough to allow for adjustments. Importantly, each student with ASD requires an individualised learning plan, that incorporates academic goals, behaviours and therapy supports, unique preferences, and learning styles.<sup>715</sup> In order to participate effectively, students with ASD need to have a sense of connectedness to their school, be protected from bullying, and have the support of, and access to, specialist staff, therapists, and general staff who are suitably trained. Ideally, class sizes should be small and the teacher to student ratio high.<sup>716</sup>

In the updated State Autism Plan, a program for inclusive education for students with ASD in mainstream schools should be articulated. The program will outline key areas of focus in making Victorian schools ASD friendly, including: sensory and social environments; specialised teacher training and professional development; family participation; policies to prevent bullying of students with ASD; individualised learning plans; behavioural and other therapy supports; mixed classrooms with high staff to student ratios; curriculum flexibility; and transitions and structures. Accordingly, the Committee recommends that:

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713 Ms Katy Haire, Acting Secretary, Department of Education and Training, Family and Community Development Committee public hearing – Melbourne, 10 October 2016, transcript of evidence, p. 4.

714 Autism CRC, *Australian Autism Educational Needs Analysis – What are the needs of schools, parents and students on the autism spectrum?* 2016.

715 Amaze, submission no. 139, pp. 40-41; Autism CRC, *Australian Autism Educational Needs Analysis – What are the needs of schools, parents and students on the autism spectrum?* 2016.

716 Autism CRC, *Australian Autism Educational Needs Analysis – What are the needs of schools, parents and students on the autism spectrum?* 2016.

**RECOMMENDATION 4.11**

The Victorian Government's updated State Autism Plan include a strategy for the inclusive education of students with ASD in all mainstream and specialist schools, with key focus areas for funding to include:

- sensory and social environments;
- specialised teacher training and professional development;
- family participation;
- policies to prevent bullying of students with ASD;
- individualised learning plans;
- behavioural and other therapy supports;
- mixed classrooms with high staff to student ratios;
- curriculum flexibility; and
- appropriate transitions and structures.

**4.6. Restrictive practices**

In her submission to the Inquiry, disability advocate Ms Julie Phillips stated that the Victorian school system was historically overly reliant on restrictive practices in relation to students exhibiting behaviours of concern, many of whom have ASD.<sup>717</sup> In her submission, Ms Phillips cites case studies of students in Victorian schools who have been subject to various forms of restraint. While recognising that DET had introduced new procedures and guidelines on the use of restrictive practices in 2015, Ms Phillips stated that, in her experience, many teachers remained unaware of the new procedures. She stated that:

Since these policies and procedures have been brought in, a number of teachers have reported to the writer that they have not read them. Teachers are not required to sign off as having read these (or other) policies. As a result, it would be safe to say that in many schools, these policies are not being followed. Given their flaws, this is not altogether disappointing, however one of the few improvements in the policies was the banning of prone restraint. The failure of staff to adhere to that policy puts the lives of children at risk.<sup>718</sup>

Ms Phillips supports the role of trained and certified behavioural therapists in schools to work effectively with students with autism. She points to the U.S. as providing examples of schools that have a level of professionalism and qualification 'incomparable to that of Australia'.<sup>719</sup> The issue of restrictive practices in some Victorian schools has also been the subject of media reportage.<sup>720</sup> At a public hearing

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717 Ms Julie Phillips, submission no. 70.

718 Ibid, pp. 5-6.

719 Ibid, p. 8.

720 See for example, Henrietta Cook, 'Allegations of students in cage-like structures triggers investigation', *the Age*, September 22, 2015, accessed 5 June 2017, <[www.theage.com.au/victoria/allegations-of-students-in-cagelike-structures-triggers-investigation-20150921-gjrnd8.html](http://www.theage.com.au/victoria/allegations-of-students-in-cagelike-structures-triggers-investigation-20150921-gjrnd8.html)>.

in Melbourne, Ms Katy Haire, Acting Secretary of DET, outlined the Department's policy on restrictive practices as follows:

We have a new policy. We have released last year a new policy on restraint and seclusion. ... As part of the special needs plan the principal practice leader was appointed. The principal practice leader reports to the senior disability practitioner in DHHS, and the senior disability practitioner, as I expect you know, has a statutory role under the Disability Act to monitor and report on the use of restraint and seclusion in disability services. We are drawing on that expertise and professional insight through employing the principal practice leader in our Department to support the development of policy and to support schools, in a positive and constructive way, to address behaviours of concern.<sup>721</sup>

Ms Haire stated that under the new policy the use of restraint was now not supported, except in the circumstance, 'where the child is in immediate danger to themselves or others, and only in that momentary circumstance, and it must be immediately documented and the department must take steps at once to investigate the circumstances.'<sup>722</sup> Ms Haire stated that the new policy had been extensively communicated to all schools and in particular to the principals of all special schools.

The Principal Practice Leader (Education) was established in 2015, and works for DET under the direction and guidance of the Senior Practitioner (Disability). The role of the Principal Practice Leader is to: examine and assess existing legislation, policies and guidelines; advise the Department on how to improve and align policy and processes with best practice; assess how the Department collects and reports on data; advise on the need for professional learning and training; identify trends and opportunities to reduce the use of restraint, using the Department's data; and provide reports summarising data and advice, including recommendations for how the Department and schools could improve approaches to challenging behaviours.<sup>723</sup>

The Committee is completely opposed to the use of restraints and seclusion as a method of managing behaviours of concern being demonstrated by students with ASD. The Committee supports the upskilling of the Victorian teaching workforce to provide them with the skills, capacity and judgement to effectively deal with behaviours of concern without resorting to the illegal practice of involuntary restraint. Teacher training is the subject of the following section. The Committee has heard that some schools are dealing more effectively with behaviours of concern through the implementation of the School-Wide Positive Behaviour Support (PBS) program. In response to follow-up questions on notice from the Committee, DET informed the Committee that at the end of 2015, 229 schools had officially commenced training and roll out of PBS, and that a state-wide coordinator for PBS had been appointed to focus on ensuring consistency of approach and implementation across the state in government schools. It is anticipated that in 2017 a mapping of schools involved in

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721 Ms Katy Haire, Acting Secretary, Department of Education and Training, Family and Community Development Committee public hearing – Melbourne, 10 October 2016, transcript of evidence, p. 9.

722 Ibid.

723 Department of Education and Training, *Principal Practice Leader (Education) Fact Sheet*, Victorian Government, 2015.

PBS will be undertaken, alongside a training needs analysis, to support PBS uptake across the state.<sup>724</sup>

The Committee appreciates that the introduction of the office of Principal Practice Leader (Education) is a step in the right direction towards eliminating restrictive practices in Victorian schools. However, the Committee believes that change must come at the school level in order to be effective. For this reason, the Committee urges the Department to roll out the PBS initiative as a priority to all schools that manage students who can exhibit behaviours of concern. Accordingly, the Committee recommends that:

#### **RECOMMENDATION 4.12**

**The Victorian Government enable the roll out of the school-wide Positive Behaviour Support program to all government mainstream and specialist schools, to manage behaviours of concern, as a matter of priority.**

### **4.7. Workforce capacity**

In their submission to the Inquiry, peak body Amaze addressed the issue of workforce capacity in the school sector as follows:

Amaze is regularly informed by both parents and educators of the lack of autism expertise within schools to meet the specific educational needs of students on the autism spectrum. In many cases, this involves inadequate knowledge of the individual student, developing individual learning plans, putting in place supports and adjustments to ensure opportunities for learning, all of which represent a major barrier in students on the autism spectrum in reaching their educational outcomes. There is evidence of good practice in some schools, modelling effective inclusive practice that are achieving greater educational outcomes for students on the autism spectrum. There is a need to harness these pockets of good practice, model and profile it across all schools to demonstrate the positive impact it has, not only for those students but for the entire school community.<sup>725</sup>

The Autism Teaching Institute (ATI) has been operating as a registered training provider for 10 years, and in that time has trained and accredited around 400 teachers.<sup>726</sup> The ATI provides two fee-based courses of post-graduate study: a Graduate Diploma of Teaching Students with Autism Spectrum Disorder (ASD), and a Graduate Certificate in Teaching Students with Autism Spectrum Disorder (ASD). At a public hearing in Melbourne the CEO of the ATI, Ms Mary Thomson, described a key feature of the courses:

What distinguishes the ATI courses from other credentialled studies is the practicum component. All of our students get some academic input in a

724 Department of Education and Training, Correspondence, Follow up questions on notice – 21 March 2017.

725 Amaze, submission no. 139, p. 45.

726 Ms Mary Thomson, Principal of the Western Autistic School, and CEO of the Autism Teaching Institute, Family and Community Development Committee public hearing – Melbourne, 21 November 2016, transcript of evidence, p. 3.



combination of lectures and tutorials from ATI staff. The practicum consists of applying that information in their own classroom setting and being observed and assessed and assisted by a travelling assessor employed by Western Autistic School. Since 2015 the course has been delivered in three semesters over 18 months. In the certificate year, each teacher enrolled in the course comes out of their classroom for 10 days for a supervised practicum in a classroom at Western Autistic School or one of the ATI partner schools to observe best practice teaching by an experienced peer, and an ATI assessor-coach visits the teacher in his or her classroom for five days. ... What is the impact of the training? Individual teachers develop specialist knowledge and practice. There are the development of school-wide approaches for students with ASD and improved wellbeing and learning outcomes for students with autism.<sup>727</sup>

Approximately 20 scholarships are funded by DET and are offered each year for study at the ATI.<sup>728</sup> According to DET, there are 38 teachers enrolled in the ATI Graduate Diploma in 2017. More broadly, following the introduction of the Special Needs Plan, all new teachers were required as part of their tertiary studies to complete a special needs component of their course, and existing teachers were required to undertake special needs training as part of ongoing professional development.<sup>729</sup> DET have also rolled out an online course for teachers focused on inclusion, and understanding ASD. The Department advised the Committee that over 4,000 teachers from over 700 schools have so far completed the training, which consists of two hours per week for a school term, and three face-to-face sessions.<sup>730</sup>

In response to the Committee's follow-up questions on notice, DET stated that the Department was currently drafting a Workforce Capability Strategy to build the capacity of the school workforce to deliver evidence-based teaching and learning programs for students with disability, including students with ASD. The Strategy will consider the need for further teaching courses.<sup>731</sup>

The Abilities Based Learning and Education Support (ABLES) program helps teachers personalise learning programs for students with disability. ABLES is an online curriculum, assessment and reporting program developed by DET and the University of Melbourne, which has been designed to help teachers to assess students' learning readiness in four areas: English, Speaking and Listening, Reading and Writing, Personal Learning and Interpersonal Development. ABLES also provides teachers with tools and resources so that they can develop appropriate learning goals and plans for students with disabilities that tie in with the state curriculum and enable teachers to track students' progress along the curriculum.<sup>732</sup> The government has recognised the benefits of the ABLES assessment and teaching tool. One of the nine

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727 Ibid, p. 4.

728 Ms Katy Haire, Acting Secretary, Department of Education and Training, Family and Community Development Committee public hearing – Melbourne, 10 October 2016, transcript of evidence, p. 8.

729 Ibid, p. 3.

730 Ibid, p. 5.

731 Department of Education and Training, Correspondence, Follow up questions on notice – 21 March 2017.

732 Department of Education and Training, 'Research behind ABLES', Victorian Government, accessed 5 June 2017, <[www.education.vic.gov.au/school/teachers/support/diversity/Pages/ablesresearch.aspx](http://www.education.vic.gov.au/school/teachers/support/diversity/Pages/ablesresearch.aspx)>.



commitments of the Special Needs Plan is to increase the use of ABLES across all schools. During the Inquiry, the Committee heard from several teachers and parents who stated that there were schools who were not being proactive in adopting ABLES and other interventions to support students with disabilities including ASD. At a hearing in Bendigo, Ms Susanna Flanagan, representing the Bendigo Autistic Advocacy and Support Services, stated:

ABLES is available to every school to assess the requirements and needs of disabled children, yet most families we have recommended it to have never even heard of it. It is a tool that should be used across the board, not just when an informed parent requests it.<sup>733</sup>

Ms Rebecca Kelly of the Bendigo Autistic Advocacy and Support Services recommended:

[T]hat every autistic student in every Victorian school should automatically be assessed with ABLES, not just the students whose parents request it.<sup>734</sup>

The Northern School for Autism also recommended the use of ABLES in all schools to monitor the progress of students with disabilities and to ensure that learning goals reflect students' capacities for further development.<sup>735</sup>

In response to the Committee's follow-up questions on notice, DET advised the Committee that in 2017 all Victorian Government schools will have access to ABLES via the Insight Assessment Portal, and that it is expected that over the next 18 months all schools will increase their use of the program.<sup>736</sup>

The Committee appreciates that the Victorian Government is doing more to upskill and enhance the capacity of its teaching workforce, with the programs and courses listed above, and that it is currently engaged in developing its Workforce Capability Strategy. To that end, the Committee believes that the Government should prioritise the creation of further scholarships to the ATI to support teachers taking up the opportunity of a graduate certificate or diploma in teaching students with autism.

The Committee understands that online courses are an expedient method of targeting a high number of teachers for professional development in teaching students with disability, including students with ASD. However, the evidence received by the Committee is that face-to-face learning, class room experience and theoretical knowledge forms the best basis for creating qualified and capable teaching staff.

As mentioned above, the Committee was advised that, as part of its review of workforce capability, the Government was considering the need for further training

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733 Ms Susanna Flanagan, Co-convenor, Bendigo Autistic Advocacy Support Service, Family and Community Development Committee public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 6.

734 Ms Rebecca Kelly, Co-convenor, Bendigo Autistic Advocacy Support Service, Family and Community Development Committee public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 8.

735 Northern School for Autism, submission 30, p. 5.

736 Department of Education and Training, Correspondence, Follow up questions on notice – 21 March 2017.

courses. In Chapter Three of this report the Committee recommended that the Victorian Government develop and fund a post-graduate diploma in behavioural therapies, in partnership with an appropriate tertiary institution. The Committee believes that the Government should examine the feasibility of such a course applying not just to the health and disability sector, but also to the education sector, as a further means of enhancing teacher capability.

For these reasons, the Committee recommends that:

#### **RECOMMENDATION 4.13**

**The Victorian Government at a minimum double the number of fully funded scholarships for teachers to the Autism Teaching Institute to 40 per year for the post-graduate diploma in teaching students with ASD.**

#### **RECOMMENDATION 4.14**

**In partnership with the Autism Teaching Institute, the Victorian Government develop and roll out a specifically targeted professional development program for existing teachers, in teaching students with ASD, that involves face-to-face learning, and class room experience, as well as online modules.**

## **4.8. The NDIS and supports in schools**

The Committee was advised by DET that it is working with the NDIA to develop a model and guidelines for how personal supports and therapies can be provided in school settings. This issue has been raised by many parents, both in relation to schools allowing access to personally funded (or ISP funded) speech and other therapists, and therapists who may be funded under the NDIS.

Some parents reported that there were currently barriers to such access in some schools. As Ms Lisa Hamling from support group Treehouse told the Committee at a hearing in Geelong concerning the Barwon trial, 'At present, it is difficult to access NDIS-funded therapy in school environments because of the separation of what is NDIS-funded and what is defined as state education responsibilities.'<sup>737</sup> Ms Fiona Sharkie, CEO of Amaze, told the Committee at a hearing in Melbourne that:

It is critical that the education department develop a formal relationship with the NDIA to maximise the alignment. We can see trouble coming down the road when autistic students will be given supports, therapeutic supports, that will or will not be allowed into the classroom, and unless the schools adjust to support autistic students, it is very likely that the investment by the NDIS into autistic students will not be maximised, because the NDIA will get the students to the school gate, but once they get into the school there needs to be that support carried through, and we are not seeing a great deal of cooperation at that level to date.<sup>738</sup>

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737 Ms Lisa Hamling, Facilitator, The Treehouse, Family and Community Development Committee public hearing – Geelong, 19 September 2016, transcript of evidence, p. 3.

738 Ms Fiona Sharkie, Chief Executive Officer, Amaze, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 4.

Ms Katy Haire, Acting Secretary of DET, told the Committee at a hearing in Melbourne that:

We are also undertaking in the meantime specific actions working with the NDIA, including working together on phasing in our programs into the NDIS, such as the disability transport program and personal care in schools; and writing to parents with students who will be clients of both to provide additional advice to support their entry into the NDIS. Our staff are co-presenting information sessions with the NDIA for parents of students with disabilities and for school principals as the NDIS is rolled out across Victoria, and we are providing schools with information about the process. Consistent with our commitment to maximise the benefits of the NDIS, we are also developing guidelines and licensing agreements to help school principals accommodate NDIS-funded support staff at schools where necessary.<sup>739</sup>

Ms Haire told the Committee that in addition, ‘we are leading a national project here in Victoria with the NDIA to determine the scope and working arrangements for the NDIS-funded personal care in schools, and we have commenced doing that in partnership with the NDIA.’<sup>740</sup>

In follow-up questions on notice from the Committee, the NDIA advised that the National Mainstream Interface Working Arrangements, which include interface principles with regard to personal care in schools, was being reviewed, in collaboration with the Victorian Government. This project will inform how delivery of therapy can be provided in the school setting outside of what the current education systems maintain responsibility for.<sup>741</sup> At the time of writing, the Committee was advised that new guidelines will be issued in May 2017. It is critical that students with ASD who are funded as participants of the NDIS are able to have their funded supports available to them within the school environment, and where relevant or appropriate, within school teaching hours. The principle of inclusion must involve the notion that students with ASD are not presented with barriers to their individualised therapies occurring within school settings, but rather, they should form part of the Individual Learning Plan for the student. The Committee makes a recommendation about access to therapy for children who are not eligible for the NDIS in Chapter Three (see recommendation 3.9). Accordingly, the Committee recommends that:

#### **RECOMMENDATION 4.15**

**The Victorian Government use its position on the COAG Disability Reform Council to ensure that students with ASD who are funded participants in the NDIS are able to have personal therapy and other supports provided to them within school settings, as appropriate.**

- **This should not diminish access to therapy for students with ASD who are not eligible for the NDIS.**

739 Ms Katy Haire, Acting Secretary, Department of Education and Training, Family and Community Development Committee public hearing – Melbourne, 10 October 2016, transcript of evidence, p. 5.

740 Ibid.

741 NDIA, Correspondence, Follow up questions on notice, Ref. no. SQ17-000007, 17 March 2017.



# Chapter 5

## Services for Adults with ASD

### AT A GLANCE

#### Background

ASD is a lifelong neurological condition that can impact people in different ways throughout their lives. The majority of research into ASD has focused on children. Likewise, most support services cater only for children, leaving young adults and adults without support.

The Committee heard evidence that some adults with ASD are being diagnosed late in life, and some following the diagnosis of their children. Some adults have been diagnosed following a long period of mental health issues, or incorrect diagnoses. These individuals often speak of their eventual diagnosis in adulthood as a 'relief' after a lifetime of confusion. However, many adults find the journey to diagnosis difficult as there are no public ASD diagnostic assessment teams for adults, there is a lack of awareness amongst health and allied health professionals, and there are no targeted intervention therapies for adults with ASD. Adults with ASD face limited employment opportunities, but nevertheless can be gainfully employed.

#### Chapter overview

This chapter discusses the experiences of adults with autism and their families. The Committee heard from many adults with ASD about their experiences. This chapter begins with accounts of people with ASD receiving a late diagnosis, evidence on the lack of support available to adults with ASD and post-school transitions. This chapter then looks at underemployment and unemployment, the experiences of adults with ASD in employment and seeking employment, as well as social enterprise employment organisations and disability employment services. It also examines parenting with ASD, the interface with the criminal justice system, and housing issues. This chapter addresses aspects of the following terms of reference:

- b) the availability and adequacy of services provided by the Commonwealth, State and local governments across health, education, disability, housing, sport and employment services;
- c) the adequacy of services to be provided under the National Disability Insurance Scheme (NDIS); and
- d) evidence of the social and economic cost of failing to provide adequate services.

The Committee heard from many adults about their experiences living with ASD and the way ASD influenced their social interactions and relationships. The Committee received evidence from adults with ASD in submissions and at public hearings about their experience of late diagnoses, post-school transitions, education, employment, the criminal and youth justice system, parenthood, housing, healthcare, support services, community attitudes and mental health (the latter is dealt with in Chapter Eight). The Committee heard that there was a lack of services for adults and that adults with ASD had poor employment outcomes when compared with other disabilities and people without disabilities. The Committee is of the view that much more needs to be done to support adults with ASD, particularly in the areas of diagnostic assessment, education, employment support, and housing.

There is limited research on adults with ASD and many adults told the Committee that they felt 'forgotten' by service providers, including disability service providers which tended to cater more for individuals with intellectual disabilities. For adults with ASD, difficulties with social communication, repetitive behaviours, the need for routine and structure, and the challenges they experienced with particular sensory sensitive environments continued throughout their lives. Ms Stacey Smith illustrated the difficulties in managing the sensory environment in day-to-day life at a public hearing in Geelong:

You do not grow out of autism. Things are just as hard. Like the lighting in this room is horrible. I wish I had a hat. If I was in here all day, that would have an effect on me. These things do not get spoken about...<sup>742</sup>

This chapter addresses aspects of the following terms of reference:

b) the availability and adequacy of services provided by the Commonwealth, State and local governments across health, education, disability, housing, sport and employment services; c) the adequacy of services to be provided under the National Disability Insurance Scheme (NDIS); and d) evidence of the social and economic cost of failing to provide adequate services.

## 5.1. Late diagnosis

The Committee heard from many adults who were not diagnosed with ASD until late in life. For many adults, a diagnosis was made only after the diagnosis of their children. The Committee heard that for many adults the experience of being diagnosed with ASD late in life was a defining moment.

At a public hearing in Bendigo, the Committee heard from parents of children with ASD who were both diagnosed after their children. Ms Susanna Flanagan described her experience:

For me, I had a dogged determination to find out because the more I saw it in our children – and other people just did not get us, whereas I just intuitively knew and provided. I came around to realising, 'Oh, right, so when I collected spark plugs as

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742 Ms Stacey Smith, Family and Community Development public hearing – Geelong, 19 September 2016, transcript of evidence, p. 3.

a kid, when I collected this, when I did that, when I cannot cope with that' — so it was very validating. It was a huge relief. It was very empowering, and it also gave us that road to assist our children and things as well and the broader autistic community.<sup>743</sup>

Ms Sally Smith was diagnosed with ASD at the age of 33. Sally's mother had been reading about ASD as Sally's nephew was being assessed at the time. Sally's mother suggested that Sally also be assessed.<sup>744</sup> In her submission, she wrote:

It had been great to be diagnosed as it makes sense of so many things. I have a better understanding and feel better in myself. However I had to travel at least 2 hours to find anyone with the knowledge of ASD to diagnose me so there really is no support for me after diagnosis. There needs to be a lot more done for people who are diagnosed as adults as we often carry many scars from years of not understanding.<sup>745</sup>

Mr James Tucker explained in his submission to the Inquiry and at a public hearing in Melbourne that finding out that he had ASD late in life (at the age of 56) 'was probably one of the most powerful moments' of his life:

This late in life revelation has finally allowed me to make sense of my frustrating and very often disappointing life...<sup>746</sup>

[W]ith the help of my psychiatrist I can now deal with people and a world that I do not fully understand.<sup>747</sup>

The Committee heard that for some adults, they were finally diagnosed with ASD after many years of being diagnosed or misdiagnosed with other conditions, particularly mental health conditions. Ms Chloe Fitton, who was diagnosed at the age of 20, told the Committee at a public hearing in Bendigo about her experience being diagnosed with ASD after being misdiagnosed with bipolar disorder. She spoke of the lack of service and supports for adults post-diagnosis:

It is really hard trying to take your place in a world where all of a sudden — when I was diagnosed, it was like, 'Wow! This makes so much sense. This fits me. This explains so much of my experience as a human being', but I had pretty much nowhere to go after that.<sup>748</sup>

The Committee heard that there are no publicly-funded adult ASD assessment clinics in Victoria. In order to obtain a diagnosis, adults had to see private psychologists and psychiatrists. Many witnesses drew attention to the high cost of obtaining an adult

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743 Ms Susanna Flanagan, parent, Family and Community Development public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 8.

744 Ms Sally Smith, Family and Community Development public hearing – Shepparton, 15 November 2016, transcript of evidence, p. 3.

745 Ms Sally Smith, submission no. 83, p. 1.

746 Mr James Tucker, submission no. 9, p. 1.

747 Mr James Tucker, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 3.

748 Ms Chloe Fitton, Family and Community Development public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 5.



diagnosis and the lack of specialists.<sup>749</sup> Ms Stacey Smith told the Committee at a public hearing in Geelong:

The cost of assessment is so hard because generally, if you are an autistic adult who is a parent, you generally have autistic children. Being in my age group, a lot of us are getting diagnosed later in life because we did not have the awareness to diagnose earlier. So you have got parents that are struggling to pay for their children's diagnosis and then they put themselves last. There is a lot of impact with mental health on the parent who is autistic, because they are just wearing so many hats and it is very hard to manage.<sup>750</sup>

In their submission, the Office of the Health Services Commissioner reported that adults with ASD had complained about not being taken seriously when presenting to health services providers.<sup>751</sup> The Committee heard of this occurring in the context of adults seeking a diagnosis but being met by psychiatrists who were unwilling to provide a diagnosis. Ms Chloe Fitton described her experience to the Committee of being 'shunted around different mental health facilities' until she finally found a clinical psychologist who was 'willing to listen'. She stated:

I finally found a mental health professional that was able to kind of work with me, and then that is how we ended up coming to the conclusion that I am Autistic... After seeing that clinical psychologist for a while I ended up having another follow-up appointment with my psychiatrist ... I said to him that we had discovered that I was actually Autistic, and the psychiatrist's response was, 'How?'. Imagine being asked, if you are neurotypical, how you are neurotypical? It is not really something that you can just kind of rattle off an answer to, because being Autistic is so encompassing. It just is. I do not know anything else. So when I was lost for words when he asked me how I was Autistic, he dismissed me, and then my discharge letter said that after all those years and after all the suffering and all the trauma that I went through they did not know what was wrong with me, which was horrifying, to say the least.

The lack of education about the huge variety of experiences of Autism is why all but two of the mental health professionals that I have had dealings with disputed the incorrect diagnoses that I had. That is why it took so long to get diagnosed, because nobody knows what it looks like. It is different in women. It is different for each person.<sup>752</sup>

In their submission, Aspergers Victoria stated:

Lack of diagnostic services is a significant problem, especially for adults, as diagnostic services currently available tend to focus on assessment of children. An experience still not uncommonly reported by our members is that of health professionals appearing unable to recognise Aspergers and offer referral to a

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749 Miss Hayley Reed, submission no. 3, p. 1.

750 Ms Stacey Smith, Family and Community Development public hearing – Geelong, 19 September 2016, transcript of evidence, p. 2.

751 Office of the Health Services Commissioner, submission no. 116, p. 2.

752 Ms Chloe Fitton, Family and Community Development public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 3.

specialist, especially for adults, even when patients themselves are expressing significant concerns, or are recognising signs of Aspergers in their children or partners. Adults who are now middle aged or older, as well as older children and teenagers, who have missed earlier diagnosis, also need access to information and diagnosis, as well as therapeutic intervention.<sup>753</sup>

## 5.2. Lack of support

Adults with ASD repeatedly told the Committee that there was a lack of services for adults, stretching from a lack of diagnostic services to a paucity of specialists who understand adults with ASD. Adults with ASD also found services to be lacking in employment assistance, housing and therapeutic aids, such as weighted blankets suitable for adults. Ms Chloe Fitton communicated her concerns to the Committee about the barriers for diagnosing ASD in adults:

One barrier to diagnosing Autism is that the Medicare rebates for assessment for Autism have an age cap... Autism has no age cap. Somebody that is Autistic is going to be Autistic for their entire life, so I do not understand why – especially when there are so many women that fall through the cracks and do not get diagnosed until, like me, they are about 20, or like many others, until they are even in their 40s or 50s – we have an age cap on Medicare rebates for diagnosis, assessment of somebody's skills and what they need from other services. Because of this, I had to use my 10 sessions from the Better Access initiative, which is the 10 mental health sessions per year that are rebated by Medicare, just for the process of diagnosing Autism.

Diagnosing Autism is a process that does take more than a couple of hours. It is an ongoing thing that takes a lot of time. For myself and many other Autistic people, there is a huge comorbidity with conditions like depression and anxiety, so it is really important to be able to access the Better Access initiative rebates and Medicare, because I really need those. Like many people with Autism, I do not earn a whole lot of money in terms of being able to just afford to go to mental health professionals. That is one really big thing that is an issue for people like me.<sup>754</sup>

Once diagnosed, adults with ASD continue to be met with a lack of services appropriate for adults, Ms Chloe Fitton explained:

Another issue is that when we are diagnosed there are no services for adults. There is nothing. There is nothing that I can reach out to, no service that I can go to and say, 'I'm Autistic. I need help. I'm not quite sure what I need help with, but here I am. These are the areas I struggle with in my life, and I am not sure where to go from here'. There is nowhere that I can really go to that can help me with things like that.<sup>755</sup>

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753 Aspergers Victoria, submission no. 141, p. 18.

754 Ms Chloe Fitton, Family and Community Development public hearing – Bendigo, 17 October 2016, transcript of evidence, pp. 3-4.

755 Ibid, p. 4.

The Committee heard that services for adults were very limited, particularly if an adult had a diagnosis of ASD and no co-occurring intellectual disability.<sup>756</sup> This, however, did not mean that an adult with ASD and an intellectual disability would be provided support that was responsive and sensitive to their needs. In their submission to the Committee, Emeritus Professor Bruce Tonge and Dr Avril Brereton from Monash University's Centre for Developmental Psychiatry and Psychology raised many of these issues:

The biggest gaps in services for individuals with an ASD are for adults and the elderly. There is a lack of clear and effective pathways for young people with an ASD into post school options. Paradoxically services are better if the young person also has an intellectual disability because of the range of generic services available for people with a disability. However adult disability services may lack special skills and training necessary to respond to the specific needs, symptoms and emotional and behavioural problems presented by people with an ASD.<sup>757</sup>

In their submission to the Inquiry, Echuca Regional Health and Kyabram District Health Service drew attention to their inability to provide services for adults with a diagnosis solely of ASD:

Neither ERH nor KDHS has a funded capacity to provide service to adult clients based on a diagnosis solely of ASD. If a client requires goal directed care, they are eligible for a community health service for short term input. The service is especially limited for adults with a diagnosis of ASD. Those adults residing in our community with ASD can only access our services via a triage system with certain criteria. Examples of appropriate use of community health could be home assessments for safety concerns, mobility and /or transfer assistance, and carer support... Young adults with a diagnosis of ASD are particularly disadvantaged, as they are often housed with the elderly either in aged care facilities or supported accommodation... There are significant barriers to treatment including delays in diagnosis, travel requirements, access to appropriately skilled clinicians, costs associated with accessing care and a lack of suitable care options particularly for adults.<sup>758</sup>

The Health and Community Services Union also identified a gap in services for adults:

Many of the services provided by the Commonwealth, local governments and particularly by the State of Victoria seem to cater to the needs of children with autism spectrum disorder in a more superior way than they do for adults. For example, the Aspect Vic Positive Behaviour Support Program is funded through the Department of Human Services and is offered free to parents/carers only of children and young adults diagnosed with autism aged 6–25 years of age and living at home. The demographic for adults in the disability sector with autism spectrum disorder are adults over the age of 25 years old, and living in a

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756 Dr Sandra Radovini, Director of Mindful, Centre for Training and Research in Developmental Health, Department of Psychiatry, University of Melbourne, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence.

757 Professor Bruce Tonge and Dr Avril V Brereton, submission no. 48, p. 2.

758 Echuca Regional Health and Kyabram District Health Service, submission no. 33, pp. 2-3, 4.

Government funded, or a Not for Profit care facility, under ... the care and support of our disability support members.<sup>759</sup>

In their submission, Occupational Therapy Australia, the professional association and peak representative body for occupational therapists in Australia, called for a review and an expansion of the funding of services for adults:

Funding and availability of therapy services for the adult population with ASD in Victoria needs to be reviewed and expanded. Adults comprise approximately 75% of the population of people with ASD, yet attention is rarely paid towards services to support their participation in employment housing/independent living, and also sport and leisure-focused programs.<sup>760</sup>

The lack of services for adults with ASD was particularly noticed by practitioners who were at a loss when needing to refer clients with ASD onto other services. For example, Ms Johanna Rouse, senior occupational therapist and ASD coordinator at Orygen Youth Health, which sees young people aged 15-24, told the Committee at a public hearing in Melbourne that primary mental health services such as Orygen 'find it very difficult to discharge people with ASD and refer them to appropriate follow-up services, as they do not exist'.<sup>761</sup>

In a joint submission, Distinctive Options, The Lab Network and Smart Communities drew attention to both the lack of support for adults to achieve quality of life outcomes and the lack of training for staff:

A significant number of adults in the support service system whether in one to one support or the group models including Shared Supported Accommodation and Day Services are not able to access appropriately targeted support to achieve quality of life outcomes. Again the training of staff does not, in most certificate courses, include Autism as a core unit and as a result successful outcomes for this group of individuals is by accident or simply through the experiential learning of staff rather than by design.<sup>762</sup>

Addressing the Committee's term of reference (c), Connect and Relate for Autism, a national organisation that provides autism services and is made up of speech pathologists, occupational therapists, psychologists, educators and autism specialists, noted in their submission:

Older clients, teenagers and adults, with ASD who do not fit into the Early Childhood Intervention age group, require the same long term remediation and intervention as young children, to minimize the devastating impact of ASD. NDIS services for older clients are given as 10 hours for specialized assessment and therapy/intervention... There is a very high cost to society in mental health, social

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759 Health and Community Services Union (HACSU), submission no. 43, p. 4.

760 Occupational Therapy Australia, submission no. 114, p. 5.

761 Ms Johanna Rouse, Senior Occupational Therapist and Autism Spectrum Disorders Coordinator, Orygen Youth Health, Family and Community Development public hearing – Melbourne, 6 March 2017, transcript of evidence, p. 5.

762 Distinctive Options, The Lab Network and Smart Communities, submission no. 77, p. 5.

welfare and carers requirements when ASD teenagers and adults are not targeted with specific remediation programs to improve their quality of life outcomes.<sup>763</sup>

In their submission, Autism Spectrum Australia (Aspect) noted that in a recent survey undertaken by 40 young adult Aspect participants, the most common areas where participants felt they needed more support were preparing and supporting participants to find and obtain work, to develop meaningful relationships and friendships and to have greater independence in the community.<sup>764</sup> They stated:

Post-school life and employment outcomes for people with autism are often poor. Research into the outcomes for adults on the autism spectrum universally show poor employment, social and life outcomes (Howlin & Moss, 2012; Howlin et al, 2004; Baldwin, Costley & Warren, 2014; Cimera & Cowan, 2009; Taylor & Seltzer, 2011). The results of the most recent study in the US, the *National Autism Indicators Report: Transition into Young Adulthood* (Roux et al, 2015), highlights the poor outcomes for young adults with autism; 28% being unemployed, 26% having received no services after leaving school, only 19% were living independently of their parents. Parents involved in this study, referred to the reduction of services post-school as akin to “falling off a cliff”.<sup>765</sup>

In Chapter Three the Committee outlined its proposals for improving diagnostic services for children and teenagers with ASD. From the evidence that the Committee has received, there is a lack of diagnostic services for adults with ASD across the state; a lack which is even more profound than the current lack of diagnostic services for children.

The Committee is adamant that this situation needs to be improved so that adults with ASD are able to access affordable and timely assessments. One way of providing a more affordable diagnosis for adults with ASD is to broaden the scope of the current Medicare rebate to include adults. The Committee has formed the view that the age-capped Medicare rebate for diagnosis and assessment referred to both in this chapter and in Chapter Two should be reviewed to ascertain the feasibility of removing the cap. Accordingly, the Committee recommends that:

### **RECOMMENDATION 5.1**

**The Victorian Government use its position on the COAG Health Council to urge the Australian Health Ministers' Advisory Council (AHMAC) and the Commonwealth Department of Human Services to remove the age cap for the Medicare rebate for the diagnosis and assessment of ASD.**

The Committee believes that it is incumbent upon the Victorian Government to ensure that diagnostic services are available and accessible to adults with ASD in this state. The Committee therefore recommends that:

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763 Connect and Relate for Autism, submission no. 92, p. 2.

764 Autism Spectrum Australia (Aspect), submission no. 100, p. 3.

765 Ibid, p. 2.

**RECOMMENDATION 5.2**

**The Victorian Government make specific provision under the updated State Autism Plan to improve services for adults, including timely access to public ASD diagnostic assessment teams.**

The Committee is also of the view that health professionals require training in identifying the traits and presentations associated with ASD in adults. The Committee is aware that there is a lack of trained health professionals in diagnosing ASD in adults. The Committee recommends:

**RECOMMENDATION 5.3**

**The Victorian Government collaborate with relevant professional and training bodies to:**

- **ensure that training is provided to health professionals in identifying the traits and presentations associated with ASD in adults, and**
- **develop training programs for health professionals in the assessment and diagnosis of ASD in adults.**

The Committee believes that adults with ASD require access to clear information, both in relation to diagnostic services and support services post-diagnosis. The Committee believes that the role of peak bodies is central in relation to outreach and information provision. The Committee therefore recommends that:

**RECOMMENDATION 5.4**

**The Victorian Government ensure that relevant autism networks and peak bodies are adequately funded to provide clear information both in relation to diagnostic services and support services post-diagnosis for adults with ASD.**

### 5.3. Post-school transitions

As previous chapters have noted, transitions are often very difficult for people with ASD. Some of the most significant transitions that a person with ASD will encounter are in adulthood, such as post-school transitions, employment transitions and independent living transitions, during which time there is a concurrent reduction in support. In their submission, Autism Spectrum Australia (Aspect) stated:

Young people with autism at the point of transition to adult life often leave school without a clear route towards a fulfilling and productive adult life. Services are often limited for school leavers on the autism spectrum.<sup>766</sup>

In their submission, Professor Bruce Tonge and Dr Avril Brereton wrote:

There is some Victorian evidence that at least 30% of young adults with an ASD who do not have an intellectual disability have no employment or support and are essentially at home going nowhere. Employment services are usually not able to

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<sup>766</sup> Autism Spectrum Australia (Aspect), submission no. 100, p. 4.

provide mentoring and on the job support to enable a person with an ASD to manage the complex transition into a workplace even if they have the necessary skills to undertake that work.<sup>767</sup>

Ms Dianna Lane, the mother of a 16-year-old daughter with ASD, expressed concern about her daughter's post-school transition, where her daughter will mostly likely attend a day program with people up to the age of 65:

Transitioning from school is a crucial time in any young adults life and is particularly challenging for young people on the autism spectrum. Young people and their families have been significantly under resourced during this important life stage.<sup>768</sup>

At a public hearing in Melbourne, Ms Lane argued that children attending special schools should have the option of staying until age 21 or, alternatively, that services for young adults with ASD (18-30) could be developed to support this transition:

[C]hildren with disabilities do not graduate with the same skill set as their peers so to expect them to transition into adulthood at the same age seems quite unrealistic... This type of 18 to 25 to 30-year-old setting could cater for their specific needs in real-life literacy and numeracy – to still continue what they do at the school – their personal development, computer, industry and work-related areas and have an integrated approach to their development. It would just make more sense – because at 18 they are coping with their puberty and hormones and having these extreme mood swings and things like that – than to throw in a transition where they leave their school that they love at that age. In America they actually stay at their specialist settings until they are all 21. It is the same with England – they are all there until they are 21. Even another three years at the school would be ideal. So that is our next biggest hurdle to face. We found that at 13 there was a really big jump. Services tended to stop for us. Maybe if you were lucky and you had your plan together you could have still accessed some services until they were 15, and now we are finding that as they are reaching adulthood as well.<sup>769</sup>

In her submission to the Inquiry, Ms Carole Trotter, the mother of a 52-year-old son with ASD, argued that there remains a significant need for a change in public attitudes towards people with ASD to make schools and workplaces inclusive of children and adults with ASD:

As our children leave school and try to enter the workforce they are faced with ongoing difficulties as there is no assistance provided for this transition [which is] both bewildering and frightening for these young adults. If by chance they approach the employment agencies they are offered unsuitable employment or are just kept on the books by people who have no understanding of their needs.

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767 Professor Bruce Tonge and Dr Avril V Brereton, submission no. 48, p. 2.

768 Ms Dianna Lane, submission no. 11, p. 2.

769 Ms Dianna Lane, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 2.



Is it any wonder that these unsupported young adults become depressed or so anxious that they withdraw from the community and then, more often than not, enter the Mental Health System where they are given psychotropic medication to control their disorder? At what cost to the system?<sup>770</sup>

Many parents of children with ASD found their child's transition into adulthood difficult because of the cessation of support and the expectations that once a child was an adult they no longer needed parental involvement in aspects of their life. The Committee heard that this was particularly difficult for both parents and their children with ASD when adolescent or adult children with ASD were undergoing medical treatment. Health and mental health will be discussed in more detail in Chapter Eight. Similarly, some parents also noted that their adult children needed support in managing finances. Ms Susan Rees told the Committee at a public hearing in Melbourne that she needed to prove that, despite her daughter's age, her daughter needed supervision in managing her disability pension:

I got a letter when my daughter turned 18 from the department of human services... Eighteen is the magical age when everybody is supposed to be an adult, but that is not the case. She was expected to manage her own disability pension, and they were questioning me as her parent as to whether I should be managing her money, so to speak. That was the nature of the letter. So I had to prove that she needed supervision with that money. That money she would go and spend on a truckload of lollies.<sup>771</sup>

On its study tour of the United States, the Committee heard from the National Autism Coordinator, responsible for ensuring implementation of ASD activities across the Department of Health and Human Services (HHS).<sup>772</sup> A large part of the coordinator's role focuses on transition between youth and adulthood. The Committee was advised that there was a pressing need to conduct research and establish interventions that will support youths with ASD to transition to adulthood, and that half a million youths in the US with autism are expected to transition to adulthood in the near future.

In Chapter Four the Committee addressed the needs of students with ASD as they transition from one level of school to another, and from school to post-school. However, the issue of transitions for people with ASD is not just tied to the school experience, as the above evidence indicates. In developing a state autism plan for people with autism, a key element of such a plan will be the recognition of the transition support needs of people with ASD, throughout the lifespan. As the U.S. experience indicates, the transition from youth to adulthood is critical, and as in Australia, with rising levels of ASD prevalence, a growing number of young people with ASD will require transition support. Governments at all levels, service providers, employers and local authorities need to make provision for the transition needs of

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770 Ms Carole Trotter, submission no. 55, pp. 2-3.

771 Ms Susan Rees, Family and Community Development public hearing – Melbourne, 10 October 2016, transcript of evidence, p. 7.

772 U.S. Department of Health and Human Services (HHS), 'Our Commitment to Supporting Individuals on the Autism Spectrum and their Families', HHS, accessed 27 April 2017, <[www.hhs.gov/programs/topic-sites/autism/autism-support/index.html](http://www.hhs.gov/programs/topic-sites/autism/autism-support/index.html)>.

their clients, employees and patients with ASD. Thus, the Committee recommends that:

#### **RECOMMENDATION 5.5**

**The Victorian Government, in the updated State Autism Plan, develop strategic transition supports to meet the needs of people with ASD, throughout their lives.**

### **5.4. Underemployment and unemployment**

In their submission, Amaze noted that people with ASD experience poorer post-school outcomes compared to people with other disabilities and those without disabilities.<sup>773</sup> The Committee heard that unemployment rates for people with ASD are higher than for other people with disability.<sup>774</sup>

According to the most recent Australian Bureau of Statistics data for Autism in Australia, the labour force participation rate for people with autism was 42 per cent. In contrast, the labour force participation rate for people with disabilities is 53 per cent and 83 per cent for people without disabilities. The ABS states:

This has implications for the economic security of people with autism. Without jobs, they lack the financial freedom to make decisions about their lives and miss out on other aspects of working such as the social networks that people develop through work. These help to give a person the resources to cope with the challenges they may face in life. The National Disability Strategy notes “Employment contributes to mental health, personal well being and a sense of identity”. These are issues with which people with autism may already be struggling with; lower labour force participation can further restrict their ability to participate and contribute.<sup>775</sup>

In their submission, Occupational Therapy Australia stated:

Importantly, government initiatives to engage the adult population of people with ASD in the workforce will have the economic benefit to re-focus on the unmeasured, but likely to be significant, pool of talent that is currently being overlooked by employers. It will also have the effect to increase the productivity for individuals who previously may not have contemplated a work career, whilst decreasing reliance on social services for these same individuals.<sup>776</sup>

In addition to the benefits of employment for people with autism, Specialisterne, an organisation which assists companies to recruit people with ASD, told the Committee at a public hearing in Melbourne that there were many benefits for employers hiring people with autism:

The autism advantage is what we are about... our fundamental view is that in fact autistic people have a magnificent contribution to make, particularly in an evolving

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773 Amaze, submission no. 139, p. 49.

774 Specialisterne Australia, submission no. 64; Amaze, submission no. 139.

775 Australian Bureau of Statistics, *Autism in Australia, 2012*, cat. no. 4428.0, Canberra, ABS, 2014.

776 Occupational Therapy Australia, submission no. 114, p. 6.

workplace that requires innovation, flexibility and development. We are backed by research that has been done at Harvard University and in other places that finds that this ability to manage what are called the outliers is a very valuable thing for any organisation to do, to learn how to make a diverse workforce.<sup>777</sup>

In his submission, Mr Angus Mackellar wrote that the support available to adults with ASD 'is almost non-existent' and that support with employment is also negligible, which is problematic as 'ASD does not disappear in adulthood':

While there is reasonable adjustment available for people with disabilities, this is very difficult in an ASD context. What is required for adults with ASD to maintain employment is recognition that people with ASD process information differently, are more literal, may take more time to perform tasks etc. The solution is a balance between the employer recognising that the ASD person is different and will have different competencies; and the employee having appropriate qualifications/skills to perform jobs where the autistic traits are minimised and do not interfere with the job.<sup>778</sup>

In their submission, Occupational Therapy Australia argued that:

Existing employment supports are commonly targeted for individuals with intellectual disabilities. Although some people with ASD and intellectual disabilities can be eligible for this type of support, commonly those individuals who are classed as having 'higher functioning ASD', are left with little to no employment services support. These individuals may experience significant challenges in areas such as the social aspects of work environments, but can often be highly focused and skilled at niche tasks. These are often also the group of people with ASD who have completed a high level of education, and have developed knowledge and skills that, in theory, equip them to enter the workforce. Appropriate strength-focused supports devoted to this group of individuals can ensure that talented people who have valuable skills to offer to the workforce are not overlooked.<sup>779</sup>

At a public hearing in Melbourne, Occupational Therapy Australia recommended that occupational therapists be contracted to work alongside employment consultants to perform job assessments and make recommendations to improve the likelihood of safe and successful engagement and sustained employment in the workforce.

Ms Johanna Rouse, Senior Occupational Therapist and Autism Spectrum Disorders Coordinator at Orygen Youth Health, stated:

In making this recommendation OT Australia is identifying that there is a need for individualised attention for young adults with ASD, particularly in periods of life transition. Individuals with ASD often possess extensive skills and qualities which lead them to have significant vocational potential. A university or vocational service's access to OT expertise can be the crucial factor which perhaps supports a person to display less behaviours of concern or might impact positively on their

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777 Mr John Craven, Chair, Specialisterne Australia, Family and Community Development public hearing – Melbourne, 10 October 2016, transcript of evidence, p. 3.

778 Mr Angus Mackellar, submission no. 125, p. 2.

779 Occupational Therapy Australia, submission no. 114, pp. 5-6.

social skills deficits to help them adapt to their mild intellectual impairment. This can set them on a path to meaningful work and economic participation in the future. Services such as Orygen Youth Health recognise that this in turn gives an individual a sense of purpose and can be an important preventative influence for illnesses such as depression and other mental health conditions.<sup>780</sup>

Ms Rouse explained the role of an occupational therapist in working with people with ASD:

Some of the roles performed by occupational therapists working with people with ASD may include: providing information about sensory, social and emotional issues impacting on work performance; exploring interests, vocational histories and experiences, and goals; identifying barriers to employment performance and developing collaborative plans to address these; performing environmental assessments of workplaces, including sensory environments and social culture; and also support systems of the workplaces. It also includes referring to and liaising with employment specialists and clinical teams and providing education and consultancy to other professionals in regard to the impact of disability on employment.<sup>781</sup>

One submission, from parents of a young adult with ASD, details their experiences trying to find suitable employment options for their son through supported employment, employment agencies and 'normal employment'. The latter they describe as relying 'entirely on the good heart of the owner who may have a sense of social justice'.<sup>782</sup> They describe their son's experience in supported employment:

[T]he closest [supported employment option] available was in Lilydale (nursery, more than 1.5 hr each way on public transport) with a pay packet of \$8 a day. This was totally unacceptable for a number of reasons: It felt like exploitation, it costed twice as much for public transport, it did not give him any sense of self-worth.<sup>783</sup>

They noted that there was little incentive for employment agencies to secure more than eight hours a week of work for their son because the employment agency would not receive a government subsidy for additional hours. They also noted that many parents were reluctant to seek employment for their children due to the risk of losing the Disability Support Pension:

Working has the negative effect of risking the loss of the Disability Support Pension. Many parents prefer to stop their children from working as they fear the loss of the pension. It is also thought that once it is lost, it will not be reinstated. That's because, from afar and on paper, it looks like one is able to work and therefore not disabled any more. This is not the case at all. What is important to recognise (and is supported by our experience) is that the jobs we have secured for our son are heavily reliant on the good will of the manager at the time. This has

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780 Ms Johanna Rouse, Senior Occupational Therapist and Autism Spectrum Disorders Coordinator, Orygen Youth Health, Family and Community Development public hearing – Melbourne, 6 March 2017, transcript of evidence, p. 5.

781 Ibid.

782 Name withheld, submission no. 18, p. 4.

783 Ibid, p. 3.

been true for us for both the Council and Coles's positions that [our son] held. Once these people moved onto other employments, new managers had different philosophies and [our son] lost his jobs. We agree with the loss of Disability pension /assistance whilst he is working but we cannot afford to be in a position where his pension cannot be reinstated. This fear gets worst as we age and ponder about his future without us. It is constant juggle to keep his hours below the threshold.<sup>784</sup>

Nonetheless, they spoke of their hope that their son would gain employment for many reasons, including to give their son a sense of self-worth, keep him active and social in the community, enhance his mental and physical health, allow him to 'be more like everyone else' and to contribute to society.<sup>785</sup>

The Committee heard from Ms Meaghan O'Brien on her struggle to gain employment and how this impacted her self-esteem:

I've never had a proper paid job, only many different volunteer ones with varied degrees of success and failures not turning into a paid job which has lead me to have low self-esteem and feeling like I am never going to [achieve] anything in life and feel I bring shame to my family who bought me up with a good work ethic... I applied for many jobs getting a few interviews here and there trying my absolute best in them getting my hopes up only to be disappointed in not getting the job. Getting a potential employer to understand why it is hard to engage in things like small talk is hard for me as it part of the Asperger's but it doesn't affect my work output where I am focussed on details and completing the work to a high standard in the allocated time given. I wish people would see these as positive traits to have in the workplace and totally outweigh my social shortfalls which I am working on improving all the time. I might be shy and quiet at first but after a while I am ok.<sup>786</sup>

Ms O'Brien argued that ideally there should be a focus on the positive attributes that ASD employees bring to the workplace:

Diversity in the workplace is way more than different races and religions disability affects people of different races and religious beliefs too. Employers need to realise this and think outside the box when considering employing people.<sup>787</sup>

Ms Stacey Smith described workplace challenges for people with ASD, including sensory issues, struggling with change, and the difficulty disclosing ASD to employers. She recounted her experience working in a customer service role to the Committee at a public hearing in Geelong:

To get by, I scripted everything I said. I realised I would have a script for this situation and a script for that situation, so I would find it very difficult if the information changed. I find it very difficult if there is a new product out; I would need to get a script together for that. If the situation changed, I have had instances where I actually cannot recognise people — facial blindness. So I would get myself

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784 Ibid, p. 3.

785 Ibid, pp. 2-3.

786 Ms Meaghan O'Brien, submission no. 109, pp. 1-2.

787 Ibid, p. 2.

into situations where I have served a customer and they have come in in the afternoon and I forget who they were. There are so many issues, and that all adds to stress and anxiety and piles up.<sup>788</sup>

Ms Stacey Smith also told the Committee that adults were more likely to experience 'shutdowns' rather than meltdowns and that this was particularly difficult in a workplace environment:

Most adults have shutdowns rather than meltdowns where they cannot speak, they cannot do anything. They cannot do the housework. They need quiet, they need to be alone, they need to be away from people. If I got to the point where I was coming to a shutdown, how do I express that to people at work? How can I even verbalise it if I am not verbal?<sup>789</sup>

The Committee heard that people with autism can thrive in the workplace provided they have a supportive environment.<sup>790</sup>

At a public hearing in Melbourne, Ms Rosemary Doherty gave evidence with Chris, her 28-year-old son with ASD, who was not diagnosed until the age of 24. In her submission, Ms Doherty stated that Chris struggled in high school, feeling isolated and experiencing severe headaches which caused him to miss a significant amount of school time. During this time Chris saw a range of specialists, including at the Royal Children's Hospital, but none diagnosed Chris with ASD. At the age of 24 Chris was diagnosed with ASD, after friends suggested Ms Doherty consider an assessment for him. In addition to ASD, he was also diagnosed with migraines and a sleep disorder, and he began treatment with a psychologist and neurologist. Ms Doherty expressed disappointment with the lack of services for adults with ASD and is very concerned about her son's future. She described the sorts of accommodations that he would need in the workplace:

We know that he needs a structured, good routine working environment. We know that if he does get a job somewhere, that the support is going to have to be exceptional. Chris does not know how good he is. He does not really know what is possible. He does not feel the drive and the urge and the instinct, as other people do, to want more for his future, but we feel that he will only see this and know what it means and understand his potential and capacity when he actually is working. Chris will need an understanding work environment as he will misunderstand usual, everyday comments and directions that he has not experienced before. He is very trusting and very literal when he is interacting with people.<sup>791</sup>

#### **5.4.1. Disability Employment Services**

The Committee heard from the Commonwealth Department of Social Services about the Commonwealth Disability Employment Services (DES). The DES is a program

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788 Ms Stacey Smith, Family and Community Development public hearing – Geelong, 19 September 2016, transcript of evidence, pp. 2-3.

789 Ibid, p. 2.

790 Mr James Tucker, submission no. 9.

791 Ms Rosemary Doherty, Family and Community Development public hearing – Melbourne, 12 September 2016, transcript of evidence, p. 3.



which assists ‘people for whom disability is assessed as their primary impediment to gaining employment in the open labour market’, including people with ASD.<sup>792</sup> According to the Department of Social Services, 134 organisations are funded through grants and contracts to help people with disability to increase their capacity to work. This includes two organisations in Western Australia (the Autism Association of Western Australia in Perth) and Queensland (NQ Competitive Employment Service in Townsville) which have been contracted specifically to provide specialised assistance to people with ASD.<sup>793</sup> The AIM Employment Program, through the Autism Association of Western Australia, is a free service which supports people with ASD seeking employment. A ‘dedicated employment consultant’ assists people with ASD in Perth with looking for employment, writing resumes and applications, and attending interviews.<sup>794</sup> Other support includes pre-vocational and vocational counselling, support in accessing further education and planning career progression, and support in learning transport routes and catching public transport.<sup>795</sup> This employment consultant also helps employers and co-workers understand ASD, explains the financial incentives available to employers and provides on-the-job support and guidance.<sup>796</sup>

The DES program includes a range of assistance for people with disability and employers, such as work experience, resume and interview help, support for employers to recruit staff (i.e. wage subsidies, disability awareness training, and workplace adjustments). Four per cent (6,300) of DES participants have ASD listed as their primary disability, with Victoria accounting for 19 per cent of these DES participants (1,186).<sup>797</sup>

In their submission to the Inquiry, the Commonwealth Department of Social Services noted that current DES contracts are due to expire in March 2018 and that the decisions about the future of the DES in light of the NDIS and changes to the provision of social services are being reviewed by the Disability Employment Taskforce.<sup>798</sup>

#### 5.4.2. Specialisterne Australia

Specialisterne, which means ‘The Specialists’ in Danish, is a not-for-profit organisation established in Denmark in 2004 to harness and develop the skills of people with autism. In 2008, the Specialisterne Foundation was formed with the aim of creating one million job opportunities for people with autism globally. The Specialisterne model has been successfully implemented in the U.S., Canada, the

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792 Department of Social Services, submission no. 72, p. 18.

793 Ibid, p. 18.

794 Autism Association of Western Australia, ‘For Job Seekers: Are you seeking help to find employment?’, accessed 6 June 2017, <[www.autism.org.au/our-services/employment-support/looking-for-a-job](http://www.autism.org.au/our-services/employment-support/looking-for-a-job)>. NQ Employment, ‘Recruitment for Employers’, accessed 6 June 2017, <[www.nqemployment.org.au](http://www.nqemployment.org.au)>.

795 Autism Association of Western Australia, ‘For Job Seekers: Are you seeking help to find employment?’, accessed 6 June 2017, <[www.autism.org.au/our-services/employment-support/looking-for-a-job](http://www.autism.org.au/our-services/employment-support/looking-for-a-job)>.

796 Ibid.

797 Department of Social Services, submission no. 72, p. 18.

798 Ibid, p. 19.



UK, Australia, Poland, Switzerland, Spain, South America, Norway, Iceland and Germany. Specialisterne Australia was established in 2015.

In their submission to the Inquiry, Specialisterne Australia highlighted that employment is a critical issue for people with ASD, who have the highest rates of unemployment of any people with disability (Specialisterne Australia claim that up to 70 per cent of adults with ASD are unemployed).<sup>799</sup> Specialisterne Australia argued that existing disability employment services, such as the Australian Government's Disability Employment Service (discussed above) and the Jobactive program, have a limited understanding of the needs of people with ASD, in particular the difficulty people have negotiating the social and communication demands of a traditional interview process. In their submission they stated:

Employment Services for people with Autism in Victoria are currently inadequate. Specialist support services for people with Autism have a limited focus on employment and in many cases have a limited understanding of the unique needs and opportunities of Autistic people... The Autism "Industry", although it acknowledges that Autistic people may have advanced skills for the workplace, is not equipped to provide a platform for Autistic people to be able to showcase these talents. As a result, the talents of Autistic people are not visible to employers or the wider community, and many very talented people are often only engaged in low-skill jobs at best.<sup>800</sup>

Their submission noted that many people with ASD who have experienced employment have done so with little or inadequate support which has often had 'very damaging and long lasting consequences' for that person.<sup>801</sup> This is often due to a lack of understanding of ASD by the employer and employment service workers and the person with ASD being placed in unsuitable employment with little or no support. Their submission cited a 2011 internal study by Victorian based DES provider Alpha Autism,<sup>802</sup> which detailed the employment experience of their registered clients with ASD, finding that:

- it took an average of around 35 applications before gaining an interview;
- it took 5-15 interviews before a person with ASD was successful in gaining employment;
- the standard interview process was confusing for the person with ASD;
- less than 10 per cent of all people with ASD received feedback from unsuccessful job interviews;
- employment service providers generally sought low-skill, low hours (underemployment) to encourage people with ASD into applying for work;

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799 Specialisterne Australia, submission no. 64, p. 4.

800 Ibid, p. 3.

801 Ibid, p. 4.

802 In 2014, Alpha Autism was integrated into Autism Spectrum Australia (Aspect)'s Choose & Connect program for adults.

- many people with ASD felt the job application and interview process was 'pointless', and rarely led to job outcomes.<sup>803</sup>

In their submission, Specialisterne Australia noted unemployment and underemployment of people with ASD has a range of lifelong consequences including a loss of confidence, lowered self-esteem, increased mental health concerns, and dependence on government financial support:

In Victoria, the Autism "Industry" is founded on diagnosis, specifically Early Intervention of detection and treatment; supply of support services, with the lowest denominator being placement into employment... Of all disabilities, those people living with Autism and in receipt of employment assistance are some of the most underserved participants in these programmes of support. This can be attributed to a general lack of awareness of Autism in the employment industry to effectively assist job seekers with Autism.<sup>804</sup>

Specialisterne Australia takes a unique approach to recruitment by organising workshops where people with ASD can demonstrate their skills to employers without the anxiety of a formal interview process. The organisation also offers consulting services to business and government to assist them to recruit, train and manage people with ASD. One of the projects Specialisterne has worked on is the Dandelion Program with Hewlett Packard, which has supported people with ASD to harness their strengths and work within the IT sector. Specialisterne Australia argued that government can take a leadership role by employing people with ASD and developing initiatives to support organisations to employ more people with ASD.<sup>805</sup>

On their study tour of Scandinavia, the Committee visited the Specialisterne Foundation in Denmark and heard a presentation from Specialisterne about the services they offer to encourage employers to hire people with ASD and support people with ASD in finding employment. The Committee heard that people with ASD recruited into the Specialisterne program are loyal employees and have a high retention rate in comparison to other employees.

### 5.4.3. I CAN Network

The I CAN Network describes itself as the 'first social enterprise founded by people with Autism'.<sup>806</sup> The organisation aims to change perceptions about people with ASD from a 'deficit approach' to a 'strengths-based approach' that focuses on what people with ASD can contribute.<sup>807</sup>

At least 50 per cent of the I CAN Network – including its board, management team and volunteers – must be on the spectrum. The organisation delivers a fee-for-service peer-mentoring program that builds self-confidence and social connections for young

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803 Specialisterne Australia, submission no. 64, pp. 4-5.

804 Ibid, p. 4.

805 Ibid; Mr John Craven, Chair, Specialisterne Australia, Family and Community Development public hearing – Melbourne, 10 October 2016, transcript of evidence.

806 I CAN Network, submission no. 127, p. 1.

807 Ibid.

people with ASD, youth leadership camps to train young people with ASD to be mentors, and also runs a general speaking program for schools, businesses and other organisations.

Their submission states that ‘the single greatest thing that Government could achieve from the Committee’s Inquiry is sending a signal to the community that it will pursue, at all levels, greater space for people with Autism to inform government decisions made on Autism services’.<sup>808</sup> The organisation argues that people with ASD have ‘all the answers’ to increasing their participation in the community, and the I CAN Network is an example of the enterprising abilities and passion of people on the spectrum.<sup>809</sup>

The I CAN Network suggests that government promote initiatives that encourage ASD-friendly workplaces, and programs that prepare people with ASD to succeed at work. Their submission also emphasised the importance of supporting people with ASD through life ‘transitions’, such as from school to work. The organisation believes that the transition to higher education and work is a significant challenge for people on the spectrum, and has developed peer support networks at a number of TAFEs and universities to support students. The I CAN Network also argues that more can be done to encourage educators to understand ASD and support the talents of their students.<sup>810</sup>

Their submission stated that the I CAN Network has experienced rapid growth in rural and regional areas, which is testament to the lack of services in these areas. The organisation has developed two strong networks in Warrnambool and Ballarat, which deliver support and mentoring programs to schools in the area.<sup>811</sup>

The Committee heard that peer support groups and mentoring services play a major role in helping people with ASD navigate life changes. The Committee heard from Mr Chris Varney, the Chief Enabling Officer and Founder of the I CAN Network, about the success of I CAN’s program which mentors adults with autism in employment.<sup>812</sup> Chris told the Committee about his own experience with ASD:

I was diagnosed with Asperger’s at the age of five. This was in the early 90s where very much parents walked into a room with one sense of their child and then went and sat down with someone from the medical field – my parents are both in the medical field, so I will just say that – and were given a totally different impression of what expectations to have around their kid. My mum walked into the room and being the unstoppable type of person that she is she said, ‘Well, I’m not going to have a bar of lowering my expectations or thinking that he is going to have a life time of difficulty. I am going to have high expectations’. So I CAN was very much something I was raised with even though we found a lot of our people on the

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808 Ibid, p. 2.

809 Ibid.

810 Ibid.

811 Ibid, p. 7.

812 Mr Chris Varney, Chief Enabling Officer and Founder, I CAN Network, Family and Community Development public hearing – Melbourne, 12 September 2016, transcript of evidence.

spectrum from the outside world tend to think, 'I can't do it like other people can'. I CAN was very much an ethos that I was raised within.<sup>813</sup>

The value of social enterprises to Victoria is recognised in the State Government's Social Enterprise Strategy, which has a strong emphasis on 'inclusive growth'.<sup>814</sup> On its study tour the Committee heard about employment programs for adults from New York Collaborates for Autism (NYCA).<sup>815</sup> NYCA's work on Project Search – a transitional employment program for people with developmental disabilities, which was originally developed at the Cincinnati Children's Hospital Medical Centre. The program involves training youths and adults with autism to develop skills and experience in employment settings. Participants receive training and support that includes meetings in the morning before they go to work, and the program teaches a range of skills that include customer relations and social skills. It starts in the final years of high school and youths participate on three lots of ten-week internships, for four hours a day. Each participant has a job coach to support his or her transition throughout the program. There are currently 15 different internships under Project Search at the New York Presbyterian Hospital (NYPH). These internships include placements in information technology, phlebotomy, the billing department, the kitchen and cafeteria, the pharmacy, shipping and receiving. The hospital has its own upholstery shop which has also employed Project Search for Autism participants.

In Bethesda, Maryland, the Committee heard from support group the Autism Society. The Autism Society of Indiana, its affiliate body, is an approved provider for the state government's Ticket to Work Program, which provides support to adults with disabilities to find and retain employment. The program provides three years of tapering support services.<sup>816</sup>

In Scandinavia, the Committee heard about the Centre for Autisme's 13-week training program for people aged 18-50 years old, which allows adults with ASD to build life and employment skills. The Centre offers a range of programs, such as music, woodwork, photography, art, filmmaking, sewing, a girls group, yoga, cooking, sport, and the opportunity for the students to sell their products, such as wheat bags made in the sewing group, and their services, such as filmmaking. This program was regarded as valuable in building social skills and confidence in people with ASD.<sup>817</sup>

All of these programs listed above from the study tour are either fully supported or part supported by government funding.

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813 Ibid, p. 2.

814 See, Department of Economic Development, Jobs, Transport and Resources, 'Social Enterprise Strategy', Victorian Government, accessed 26 April 2017, <[economicdevelopment.vic.gov.au/about-us/overview/strategies-and-initiatives/social-enterprise](http://economicdevelopment.vic.gov.au/about-us/overview/strategies-and-initiatives/social-enterprise)>.

815 New York Collaborates for Autism is in the process of changing its name to NEXT for Autism, See NEXT for Autism, 'Always Innovating', accessed 26 April 2017, <[www.nyc4a.org](http://www.nyc4a.org)>.

816 Autism Society, 'Autism Society', accessed 26 April 2017, <[www.autism-society.org](http://www.autism-society.org)>.

817 Center for Autisme, 'Center for Autisme', accessed 26 April 2017, <[www.centerforautisme.dk](http://www.centerforautisme.dk)>; and, <[translate.google.com.au/translate?hl=en&sl=da&u=http://www.centerforautisme.dk/&prev=search](http://translate.google.com.au/translate?hl=en&sl=da&u=http://www.centerforautisme.dk/&prev=search)>.

The Committee understands that the Disability Employment Taskforce has been established by the Australian Government's Department of Social Services to review the entire disability employment system, including DES, Australian Disability Enterprises (ADEs) and other government-funded programs that provide employment assistance to people with disability. The Taskforce will develop a new national Disability Employment Framework for a staged implementation from 2018, in line with the philosophy of the NDIS to deliver better choice and control to people with disability.<sup>818</sup>

While the Committee understands the disability employment system is under review by the Commonwealth Taskforce, it believes that the Victorian Government does have a role in supporting employment for people with ASD. The Committee believes that a renewed State Autism Plan should contain a comprehensive employment strategy for adults with ASD in Victoria. The Committee believes that local and overseas experience shows that governments retain a necessary role in supporting the employment opportunities for people with ASD, and that they can successfully partner with businesses and funded agencies to create or support innovative programs.

The Committee also believes that it would be highly valuable to conduct an education campaign for Victorian employers so that they can appreciate the value of employing people with ASD. To support employers, the Government should collaborate with relevant groups, such as the I CAN Network, Specialisterne and peak bodies, in developing capacity building for employers on how best to support employees with ASD. The Committee also believes that the Victorian Government itself should provide leadership in the employment of people with ASD, as the NDIA is currently doing, with its target of 15 per cent of agency employees having a disability.<sup>819</sup>

Consequently, the Committee recommends that:

#### **RECOMMENDATION 5.6**

**The updated State Autism Plan contain a comprehensive employment strategy for adults with ASD.**

In regard to employer education, the Committee recommends that:

#### **RECOMMENDATION 5.7**

**Within the updated State Autism Plan the Victorian Government develop an education program for Victorian employers to encourage employment of people with ASD.**

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818 Department of Social Services, 'Disability Employment Framework Consultation', Australian Government, accessed 19 April 2017, <[www.dss.gov.au/our-responsibilities/disability-and-carers/programmes-services/disability-employment-services/disability-employment-framework-consultation](http://www.dss.gov.au/our-responsibilities/disability-and-carers/programmes-services/disability-employment-services/disability-employment-framework-consultation)>.

819 Ms Louise Glanville, Deputy Chief Executive Officer, Stakeholder Relations and Organisational Capability, National Disability Insurance Agency, Family and Community Development Committee public hearing – Geelong, 19 September 2016, transcript of evidence, p. 9.

**RECOMMENDATION 5.8**

**The Victorian Government collaborate with relevant organisations, such as the I CAN Network, Specialisterne and peak bodies, to develop capacity building for employers on how best to support employees with ASD.**

In terms of its own hiring practices, the Committee believes that the Victorian Government should emulate the employment practices of the NDIA, in relation to the hiring of people with ASD. Thus, the Committee recommends that:

**RECOMMENDATION 5.9**

**The Victorian Government provide leadership in its own employment practices by employing people with ASD.**

**5.5. Parenting with ASD**

The Committee heard from parents with ASD who had children on the spectrum. Despite the potential challenges and the lack of support, some parents described their experiences of ASD as allowing them to parent in a way that was more accommodating to their child's sensory needs and need for routine.

One parent with ASD wrote in her submission to the Inquiry that she did not know her son had ASD until he entered school and was exposed to triggers in his environment.<sup>820</sup> She wrote that she had 'always been able to avert the situations' that might lead to a meltdown because she understood 'what it meant to be overwhelmed by the neurotypical world':

Unknowingly, and more by luck than design, I had created a life for him that actually prevented him from commonly experiencing meltdown. But I didn't know that because my own (then undiagnosed) 'Aspieness' had always informed my parenting. I knew that clothing tags are uncomfortable (I had always cut my own tags off) so I cut [my son's] tags. I knew that change was difficult for [my son] because change had always been difficult for me. I knew that [my son] would have a lot of anxiety at school because I felt anxiety at school. I made sure all fabrics were soft and not tight, encouraged rocking knowing how soothing I found repetitive physical action to be. I knew [my son] was super sensitive that he needed a very gentle, compassionate, flexible, nurturing and non judgemental teacher, someone "low triggering", because I had needed these things to feel okay and safe to ask and re-ask questions. I knew that processing directions would be hard for him because I found that so hard at school. None of these behaviours came as any shock to me ... they were completely within the realms of my expectations and experiences. I didn't know that I myself was 'on the spectrum' so I didn't anticipate anything unusual or traumatic. But my parenting style had largely buffered [my son] from many of the overwhelming elements of a neuro-typical world, without even realising it.<sup>821</sup>

820 Name withheld, submission no. 119.

821 Ibid, p. 2.

The Committee heard that many parents with ASD were able to advocate more effectively for their children with ASD. Mr James Tucker explained at a public hearing in Melbourne how his own experience of ASD allowed him to advocate more effectively for his son who also has ASD:

As a result of this discovery we now have had our son tested, and he is also on the spectrum – surprise, surprise – which, I might add, my parents still do not get. But at 85 I do not think they need to... Most importantly, I now advocate much more effectively for our son. In fact I have a lot of discussions with my psychiatrist about how to deal with issues for him. But I am one of the lucky ones, and I truly believe that I am one of the lucky ones. People with ASD are as different from each other as they are from everyone else. We put our son, without really understanding why, in a school – not a special school – which has very low class sizes and very good teachers. We pay through the nose for it – and we can afford to – and he gets the kind of help he needs.<sup>822</sup>

Many parents with ASD (and those without) spoke about the challenges in advocating for their children. Parents Ms Susanna and Mr Martin Flanagan, both diagnosed late in life, told the Committee about their struggles to be heard and valued when advocating for their children with ASD, how it acted as an impetus for them to receive their diagnosis and how it gave them validation in advocating. Mr Flanagan told the Committee at a public hearing in Bendigo:

That is probably why we also went and got our diagnosis. That gives us a bit more validation for people to actually listen when we advocate for our kids now too, whereas other people are just like, 'You're the parent; we're the teachers', and that sort of stuff. We have had to do a bit of that as well so that people will take us a bit more seriously when we say, 'We actually know this stuff. We live this stuff'. Yes, we live with these kids too and we are all different, but we have had to do a bit of that, which has been at a reasonable cost in itself to be able to get that behind us. You have to get letters from someone else to say the same thing that you are trying to explain.<sup>823</sup>

There has been little research into the experiences of parents with ASD and there is a lack of services in Victoria to support parents with ASD. In their submission to the Inquiry, Aspergers Victoria stated:

Support with parenting is a particular need of adults with Aspergers and their partners, this need is recognised around the world by Asperger support groups and authors, but this recognition is not reflected in the level of services available in Victoria... There is an urgent need for adults who have missed diagnosis in childhood, in particular those adults who are now parents themselves, to access diagnostic and therapeutic services, in order to prevent and treat mental health

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822 Mr James Tucker, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 3.

823 Mr Martin Flanagan, Family and Community Development public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 7.



complications and problems with parenting, which result from delayed diagnosis and delayed therapeutic intervention.<sup>824</sup>

At a Melbourne public hearing, Ms Narelle McCaffrey told the Committee that while there was a lot of resources and research around adults with ASD on the transition to adulthood, independent living and employment, there 'is a cohort being forgotten or ignored', which is mothers with ASD. Ms McCaffrey stated:

We exist and probably in numbers greater than can be predicted. Most of us have been diagnosed after the diagnoses of our children and at great personal expense, while others remain self-diagnosed because of this cost.<sup>825</sup>

Ms McCaffrey noted that mothers with ASD face 'a number of unique difficulties' which 'may be in part due to societal expectations of mothers, the notion that autism affects more males than females and the idea that autistic parents, let alone mothers, are the exceptions to the rule, given that autism in adults is seemingly forgotten'.<sup>826</sup> Ms McCaffrey noted that many mothers with ASD feel misunderstood and do not feel comfortable asking for help out of fear of judgment.<sup>827</sup> Many mothers with ASD also experienced problems with executive functioning, which impacted organisation skills, prioritising and completing tasks, impulse control and self-regulation and the ability to plan. Ms McCaffrey told the Committee:

My house is a constant mess, so I end up feeling overwhelmed and anxious to the point of being unable to act. Although I am not a bad parent, I think that I could be better at it if I could maintain that order, have that order and have the help and support to do so... No matter what though, raising children, autistic or not, is really hard when you are dealing with your own issues. It is hard to juggle your own needs when juggling the those of your children. Services to help are non-existent... Our existence as autistic mothers needs to be acknowledged and services to help and support us need to be established.<sup>828</sup>

Ms Sally Smith told the Committee, at a public hearing in Shepparton, of the impact of ASD in her ability to manage competing tasks:

Even as a mother, there are days when I cannot manage to prepare a healthy meal for my family at the end of the day because I have done too many other things, and by that time of day I am just overwhelmed... so we have takeaway or whatever.<sup>829</sup>

This section shows the unique challenges that parents, who have ASD, have in raising their children (either with or without ASD). This is an area that is largely unaddressed in terms of research, policy or specific services or supports for parents with ASD. The Committee believes that in any public campaign to raise awareness of autism in the

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824 Aspergers Victoria, submission no. 141, p. 14.

825 Ms Narelle McCaffrey, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 2.

826 Ibid.

827 Ibid.

828 Ibid.

829 Ms Sally Smith, Family and Community Development public hearing – Shepparton, 15 November 2016, transcript of evidence, pp. 5-6.

community, the role of parents with ASD needs to be highlighted. Chapter Ten of this report addresses the issue of a public campaign around ASD.

Services, such as health services and the school sector, need to be informed and their staff trained in understanding the particular challenges that parents who have ASD face, in their role as parents of children attending school, or as patients or clients. Thus the Committee recommends that:

#### **RECOMMENDATION 5.10**

**In the updated State Autism Plan, the Victorian Government include strategies to address the diverse needs of parents who have ASD.**

## **5.6. Housing issues for adults with ASD**

Some witnesses drew attention to the lack of housing for individuals with ASD, but overall, the evidence received by the Committee on this issue was limited. A key area that the Committee did hear about was from parents, who spoke of their ongoing worry about what will happen to their children when they can no longer care for them. One submission, from parents of a young adult with ASD, stated:

We are in our 50's [and] are reasonably healthy but what will happen to [our son] if something was to happen earlier than expected and when we get older. This is a very common worry for parents of children with disabilities. [Who] will care for our children, advocate for them and give the care we feel they need and are entitled to?

There are a number of people out there who have funded, built and organised the long-term accommodation and supervision of their children in purpose-built housing due to the shortage of available government accommodation. It is costly, time consuming and exhausting. Some will manage, many won't.<sup>830</sup>

The lack of housing for people with ASD was particularly stressful for ageing parents who were unable to provide appropriate care. In her submission, Ms Joan Esser wrote:

There is an urgent need for residential services for older adults with autism. These people have been living with their parents, sometimes but not always receiving day programs, but now their parents are becoming frail and unable to provide appropriate care. People with autism have a normal life expectancy so may well survive their parents by thirty years, and need supervised residential care with appropriate social programs.<sup>831</sup>

In calling for increased respite for families at 'breaking point', Ms Judith Horne, a speech pathologist with over 30 years experience with children and adults with ASD in rural Victoria, submitted to the Inquiry that many parents living with autistic adults had to endure difficult behaviours, which made some families consider the option of

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830 Name withheld, submission no. 18, p. 4.

831 Ms Joan Esser, submission no. 49, pp. 1-2.

relinquishing their young person so they could get emergency accommodation for them:

In rural areas there are major issues with many young adults [the majority being male] with autism and significant behaviours of concern who are living at home. Issues with parents trying to maintain employment but having to leave at a minutes notice to assist with the behaviour of their young person at the centre they attend due to assaults, property damage, etc... Issues with elderly parents waiting for permanent accommodation for their young person.<sup>832</sup>

In his submission, Mr Phil Gluyas, who was diagnosed with Asperger's Syndrome in 1997 at the age of 31, discussed the difficulties he has had finding housing that caters for his needs for solitude:

Housing hits a very strong chord with me right now. I am on the Public Housing waiting list and have been since 2002. I have been on the receiving end of some serious contempt for my needs in housing over the years, to the point that I felt it was needed to take the matter into the arbitration system and ultimately into VCAT under disability discrimination. It failed due to a dangerous precedent – housing that doesn't exist is not subject to discrimination. I am under pressure to stop demanding needs that are common for Autistics relating to housing in order to gain an affordable rental arrangement. This involves isolation – distance from neighbours and in a small town rather than a large city. Autistics are solitary people that need space from others in general. Public Housing does not provide this sort of housing as a general rule, and this has to change.<sup>833</sup>

At a public hearing in Swan Hill, the Committee heard from Ms Nicole Doolan, services manager at Murray Human Services, about their 'KeyRing' model of housing for people with disability. Ms Doolan described the program which is currently offered in Echuca and aims to support people with a disability to live independently in the local communities by allowing a small number of residents with disabilities to share a unit with a full-time carer. Murray Human Services plan to offer this type of supported living in neighbouring areas including Swan Hill, Kerang, Cohuna, Rochester and Kyabram. Ms Doolan stated:

The name KeyRing comes from the fact that there is one house that acts as a hub and then different houses where people live come off that. So there is the picture of a keyring in the middle and other keys coming off that. The hub generally provides 24/7 support for people who require that level of support, so there are always staff at that house when anyone is living within the KeyRing. They are your highest support clients.

Then those that live coming off that hub can live more independently and may need support, for example, for a couple of hours per day, or if they contact the staff person during the night and just might need transient support for rolling or for some sort of personal care, and then the staff can go back to the hub house... the positive thing about the KeyRing model is that any person can come and join the KeyRing and they rent or own their own home within that KeyRing. So it meets the

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832 Ms Judith Horne, submission no. 120, p. 2.

833 Mr Phil Gluyas, submission no. 79, p. 2.

changing needs of clients very well, or if they can, they can purchase their own home. They can stay there, for example, if they need transition training for independent living. We can provide that training and then ideally they go and live independently with no support.<sup>834</sup>

On the Committee's study tour of Scandinavia, the Committee visited Specialområde Autisme (Special Area Autism) in Denmark. Specialområde Autisme provides a range of innovative, flexible housing options for adults diagnosed with ASD, including housing for young women with ASD at Dannebrogsgade, housing at Bækkeoften for adults with ASD and severe disability, the AtHome flexible housing concept for adults with ASD, and Seniors Housing in Hinnerup.<sup>835</sup>

Young people in Denmark usually leave home at around 18-20 years of age (including people with disabilities). The Committee heard that under the Danish welfare model, the public sector was responsible for looking after the most vulnerable members of society, which included finding housing for people with ASD, particularly young people. Specialområde Autisme's housing takes into account visual stimuli, is 'autism friendly' in its design and aims to allow adults with ASD to increasingly engage with others by having flexible, moveable houses. The Committee heard that a particular advantage of this housing model was its flexibility and the way the housing has the capacity to constantly develop to accommodate different needs.<sup>836</sup>

On its study tour of the United States, the Committee met with the President and representatives of Chapel Haven, in New Haven, Connecticut, which is a residential housing program for people with developmental disabilities, including ASD.<sup>837</sup> The program was developed by parents in 1972, who chose six family homes on Chapel Street in New Haven and created a residential program for adults with developmental disabilities. The programs at Chapel Haven continue to work towards supporting adults with autism to live independently. Chapel Haven is an approved special education provider in the state. Programs run for two years, and the total number of participants is 250. The Committee heard that Chapel Haven admits participants who are behaviourally safe to live with for a roommate. This is a privately run service with significant fees. The Committee heard that Chapel Haven's alumnae tend to stay in the area by renting or purchasing accommodation in New Haven, and alumnae have also been responsible for funding improvements and refurbishments to the Chapel Haven buildings.<sup>838</sup>

In New York, the Committee heard from disability service provider Quality Services for Autism Community (QSAC) that thousands of people were waiting for group homes in

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834 Ms Nicole Doolan, Services Manager, Murray Human Services, Family and Community Development public hearing – Swan Hill, 14 February 2017, transcript of evidence, pp. 3-4.

835 Specialområde Autisme, 'About Us', accessed 27 April 2017, <[www.sau.rm.dk/om-os/about-us](http://www.sau.rm.dk/om-os/about-us)>.

836 Specialområde Autisme, 'Our physical frameworks', accessed 27 April 2017, <[www.sau.rm.dk/om-os/about-us/physical-framework](http://www.sau.rm.dk/om-os/about-us/physical-framework)>.

837 See, Chapel Haven, 'Chapel Haven', accessed 26 April 2017, <[www.chapelhaven.org](http://www.chapelhaven.org)>.

838 On Chapel Haven's programs see Chapel Haven, 'Chapel Haven - How our program works', accessed 26 April 2017, <[www.chapelhaven.org/chapel-haven-how-our-program-works](http://www.chapelhaven.org/chapel-haven-how-our-program-works)>.

New York.<sup>839</sup> QSAC advised the Committee that most of their clients needed to live with their parents due to this shortage of options. This view of a general housing shortage for people with ASD was underlined by peak body Autism Speaks.<sup>840</sup> Autism Speaks told the Committee that 50,000 children with autism were becoming adults each year, compounding the need for housing solutions that are suitable to people with autism. Autism Speaks also spoke about the concerns of elderly parents who are worried that they will pass away before their adult child, leaving their child without care. Autism Speaks favours a combined public and private sector effort as one potentially effective solution to the housing problem.<sup>841</sup>

In her submission, Ms Maree Maxfield articulated her concerns about housing in old age and finding somewhere sensitive to her needs and sensory sensitivities:

I am an ageing adult who is diagnosed as being on the autism spectrum. I care for my adult daughter who is also on the spectrum.

I fear my old age as I watched my ageing mother receiving inadequate and resultant cruel treatment in aged care until she died. Much of this was because people didn't understand her needs. She did not have dementia and was very frail, but people didn't understand her needs such as her love of solitude, her prolific reading, her dislike of loud amplified noise, her fire independence and self sufficiency, a distinct dislike of contact and her particular ways of doing things...

I would like to be part of something that helps to design such integrated communities. I have lived a very unusual but vibrant, self sufficient life, tasting all sorts of things. I do not want to be institutionalised in a stark place with no originality and people who do not understand me. I want to be part of a community that I have some say in designing in preparation for my old age so that I can age gracefully in the community with comfortable surroundings that cater for what other people like to call my quirks. I would like to go somewhere where I can fill in a comprehensive profile of the things that actually scare the hell out of me that other people just take for granted and don't worry about. For example how I like to be showered and how the touch of water on my skin the wrong way almost sends me into a meltdown. Or how I may like to stay up at all hours of the night and early morning and then sleep later in the morning and get up when I feel like it. If I am old that should not worry anyone. And if I want to wear the same comfortable clothes every day that are not necessarily in fashion that should be okay as well.<sup>842</sup>

The NDIA has stated that it understands that, 'Affordable, stable housing is needed to support people with disability in achieving their life goals and aspirations.'<sup>843</sup> The NDIS will provide ongoing supports for daily living, but 'has not been designed to take

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839 See, QSAC Quality Services for the Autism Community, 'QSAC', accessed 26 April 2017, <[www.qsac.com](http://www.qsac.com)>.

840 For the role of Autism Speaks see, Autism Speaks, 'Autism Speaks', accessed 26 April 2017, <[www.autismspeaks.org](http://www.autismspeaks.org)>.

841 For the services provided by Autism Speaks, see, Autism Speaks, 'Adult services', accessed 26 April 2017, <[www.autismspeaks.org/family-services/adults](http://www.autismspeaks.org/family-services/adults)>.

842 Ms Maree Maxfield, submission no. 53, p. 1.

843 See National Disability Insurance Scheme (NDIS), 'What help can I get?', NDIS, accessed 21 April 2017, <[www.ndis.gov.au/people-disability/what-help-can-i-get.html#housing](http://www.ndis.gov.au/people-disability/what-help-can-i-get.html#housing)>.

responsibility for the housing needs of participants. The NDIA recognises that housing policy is a matter for governments.<sup>844</sup>

Given the limited nature of NDIS funding for housing for people with ASD, it will remain critical for state and federal governments to support the housing needs of people with disability. The Committee is aware of the current shortage of quality housing for people with disability, including people with ASD, around the state. The foregoing evidence shows the real concerns of ageing parents of adult children with ASD, in relation to both the current and future housing needs of their children.<sup>845</sup>

The Committee is impressed with the innovative housing solutions provided by the example of Specialomrade Autisme in Denmark, particularly in its provision of housing for elderly people with ASD. The Committee also regards the KeyRing housing project identified by Murray Human Services as an important example of a successful housing model, notwithstanding the fact that this model operates for people with disability in general.<sup>846</sup> Other examples from the study tour listed above also show that housing shortages for people with ASD, and the challenges of ageing and housing, are not restricted to Victoria.<sup>847</sup>

The Committee believes that while the NDIS can provide supports for people with ASD who are funded participants to live independently and within group settings, such as in residential accommodation, the Victorian Government does have an ongoing role and responsibility to support the housing needs of people with disability, including the particular needs of people with ASD. The State Government should work with disability service providers, including new entrants to the market, on developing innovative housing solutions that match the needs and aspirations of people with ASD who need support.

The levels of housing support that people with ASD will require will vary significantly from low need of support to high levels of daily support, particularly for people with ASD who have significant co-occurring conditions. The Committee believes that a renewed state plan for autism should reflect these housing responsibilities and aims for people with ASD. Accordingly, the Committee recommends that:

### **RECOMMENDATION 5.11**

**In the updated State Autism Plan, the Victorian Government include strategies to address the housing needs of adults with ASD.**

- **The Government collaborate with disability service providers, including new entrants to the market, on developing innovative housing solutions that match the needs and aspirations of people with ASD who need housing support.**

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844 Ibid.

845 See, Urban Development Institute of Australia, 'Melbourne faces a housing shortage' accessed 20 May 2017, <[www.udiavic.com.au/News/Media/Melbourne-faces-a-housing-shortage](http://www.udiavic.com.au/News/Media/Melbourne-faces-a-housing-shortage)>.

846 Ms Nicole Doolan, Services Manager, Murray Human Services, Family and Community Development public hearing – Swan Hill, 14 February 2017, transcript of evidence, pp. 3-4.

847 For example, the Committee was advised by the disability provider, Quality Services for the Autism Community (QSAC) that there was a severe housing shortage for people with ASD in New York.



The Committee is aware that the Victorian Government has announced a \$1 billion social housing fund to be rolled out over the next four years.<sup>848</sup> The Committee believes that the parameters for that fund should include housing that is reflective of, and directed towards, the housing needs of people with ASD. Accordingly, the Committee recommends that:

### **RECOMMENDATION 5.12**

**The Victorian Government include in its Social Housing Growth Fund initiative proposals and resources to provide specifically for the housing needs of people with ASD.**

## **5.7. Adults with ASD and the criminal justice system**

While not strictly within the Committee's terms of reference, the Committee did receive some evidence in relation to people with ASD who have contact with the criminal justice system. The Committee believes this is an issue which warrants its attention. The Committee heard from Ms Loretta and Mr Rob Krelle, parents of their 34-year-old son, who has ASD and an intellectual disability and is currently in the Marlborough Unit at Port Philip Prison. At the time of the public hearing, their son was due to have his case reviewed by the Parole Board, and the Krelles were very concerned about the lack of suitable accommodation available to their son, should he be released. At a public hearing held in Melbourne Mr Krelle explained that:

He was given five and half years jail. One was taken off, and then two years were served together. He had a four and a half year jail term and remand after two years. He has been in there nearly three, and the main reason that he cannot get out and he cannot take advantage of the parole period is that there is no housing available. He cannot go back to Geelong. He was being harassed. It is not appropriate, and we need him closer to us. I am approaching retirement at some point. We will look after him to a degree, but he needs his own house, and it is not there.<sup>849</sup>

The Krelles explained to the Committee the strenuous efforts that they had made to ensure their son would have adequate housing on release, but to no avail. They advised the Committee that their son was effectively being held in prison while awaiting appropriate housing:

Yes, the tentative parole date can either be put back if accommodation becomes available, or else if it rocks around to 13 February and nothing is available, it can just be postponed until something becomes available. We have been quite emphatic that we will advocate as much as we can to get suitable accommodation, because that is in his interests, it is in our family's interests – because it has been a nightmare – and it is in the community's interests. It is a rights issue in that he does have a right to a stable life; he may not have that insight or capacity to

<sup>848</sup> Department of Health and Human Services, 'Victorian Social Housing Growth Fund', Victorian Government, accessed 24 May 2017, <dhhs.vic.gov.au/victorian-social-housing-growth-fund>.

<sup>849</sup> Mr Rob Krelle, Family and Community Development public hearing – Melbourne, 21 November 2016, transcript of evidence, p. 4.



verbalise it like that, but he does. Now, you may say it is not ignoring someone's right or it is not a disability discrimination issue because, if something is not there or if there is no housing, you are not discriminating by not giving him a place. But the fact is that there should be housing for him and people like him.<sup>850</sup>

The Krelles mentioned the work being undertaken by the Marlborough Unit with their son. The Marlborough Unit is a 35 bed unit that runs the Joint Treatment Program, a program for male prisoners with cognitive impairment. The Program addresses offending behaviours and social skills deficits, and utilises a therapeutic approach to promote pro-social behaviour of offenders.<sup>851</sup> While the Krelles were impressed with the work done by the unit with their son, they expressed their fears that if appropriate accommodation and support is not found for him on release, that he will relapse into re-offending:

We are very positive about the Marlborough experience that he has had, and in fact it is a wonderful program; it is a wonderful initiative. ... The program there is very much routine based, which has a great appeal. They have prison mentors who have been wonderful, and our son has actually seen that, okay, he might have a disability, but there is no shame in that. ... But what happens on release? And the staff express that concern too. You sort of need a non-institutionalised model of Marlborough out in the community, because a lot of people just come back, and that must be so disheartening if you are working there, because you address a lot of the needs and for some people it can become home.<sup>852</sup>

At a public hearing in Melbourne the Committee heard from the Australian Community Support Organisation (ACSO), a support service provider that provides a range of supports and services to people in contact with, or in danger of coming into contact with, the criminal justice system. A small percentage of ACSO's clients have ASD, nevertheless ACSO has developed a good understanding of the needs of people with ASD in contact with the system. Mr Stan Pappos, Senior Manager, High Risk and Support Services at ACSO, told the Committee that:

We often see the participants we work with interfacing with the criminal justice system, and that occurs for a whole range of reasons. There is not any concrete evidence as to why people with autism spectrum disorders interface with the criminal justice system, but some of the research, particularly by Guy Hall at Murdoch University, points to the deficits in communication, in social skills and in sensory and perception skills.<sup>853</sup>

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850 Ms Loretta Krelle, Family and Community Development public hearing – Melbourne, 21 November 2016, transcript of evidence, p. 6.

851 See, Corrections, Prisons and Parole, 'The Joint Treatment Program', Department of Justice and Regulation, accessed 19 April 2017, <[www.corrections.vic.gov.au/utility/publications+manuals+and+statistics/the+joint+treatment+program](http://www.corrections.vic.gov.au/utility/publications+manuals+and+statistics/the+joint+treatment+program)>.

852 Ms Loretta Krelle, Family and Community Development public hearing – Melbourne, 21 November 2016, transcript of evidence, p. 5.

853 Mr Stan Pappos, Senior Manager, High Risk and Support Services, Australian Community Support Organisation, Family and Community Development public hearing – Melbourne, 21 November 2016, transcript of evidence, p. 2.

Mr Pappos spoke about the common issue of misdiagnosis amongst people with ASD within the criminal justice system:

Certainly one of the things that we have become accustomed to seeing is people with autism spectrum disorders, when they do come across the criminal justice system and mainstream services, having their diagnosis mistaken for other things, including mental illness and substance use, and that is problematic in that when people with autism spectrum disorders are interfacing with these services, quite often there is not an awareness around how to interact or how to engage. A lot of the issues or behavioural presentations are seen as problematic rather than linked to the person's anxiety or lack of understanding and ability to make the connection around the supports or the services that they are interfacing with.<sup>854</sup>

Mr Pappos also stated that Victoria Police had made advances with upskilling their members in engaging more appropriately with people with intellectual disabilities or mental illness, but 'I think autism spectrum disorder is one of those things that still has not evolved to that level.'<sup>855</sup> Mr Pappos confirmed the level of specific housing support for people with ASD who are released from prison was limited and problematic. He stated that people with ASD tend to have to access the same mainstream housing services as everybody else coming out of prison.<sup>856</sup>

Both the Krelles and Mr Pappos commented on the issue of NDIS funding while participants were in jail. The Krelles advised that their son had started as a participant of the NDIS prior to entering prison, that this funding ceased when he entered prison, but would be re-instated on his release.<sup>857</sup> Mr Pappos stated that the NDIA had made it clear that criminal justice needs will not be funded under the scheme, which would make successful transition for those on release 'incredibly problematic' with no supports in place for them.<sup>858</sup>

According to advice the Committee received from the Department of Justice and Regulation, the Commonwealth Government has acknowledged that the interface between the criminal justice system and the NDIS is complex. The Department of Justice and Regulation advised that the NDIS and the justice system are working together to plan and coordinate services for people who require both justice and disability services, and that there is a focus on improving transition from custodial settings to the community. However, none of these elements have been implemented in the correctional system.<sup>859</sup> The Department of Justice and Regulation has also advised the Committee that specific data is not available on the number of people with ASD who are prisoners in Victorian custodial settings. Each Victorian prison does have a staff member assigned as a 'Disability Portfolio Holder' who assists prisoners

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854 Ibid.

855 Ibid, p. 4.

856 Ibid, p. 3.

857 Ms Loretta Krelle, Family and Community Development public hearing – Melbourne, 21 November 2016, transcript of evidence, p. 5.

858 Mr Stan Pappos, Senior Manager, High Risk and Support Services, Australian Community Support Organisation, Family and Community Development public hearing – Melbourne, 21 November 2016, transcript of evidence, p. 3.

859 Department of Justice and Regulation, correspondence, dated 11 January 2017.

with a disability. Corrections Victoria also runs a re-integration pathway program, designed to assist prisoners' transitional needs.<sup>860</sup>

While the Committee has received limited information in relation to contact between people with ASD and the criminal justice system, it is concerned by the evidence that it has heard. The Committee is concerned by the apparent lack of housing post-release for former prisoners who have ASD. While the Committee applauds the work being undertaken in the Joint Treatment Program, it would like to see programs of this nature more widely available in the system, and for such programs to also specifically target prisoners with ASD. The Committee believes that it is crucial for the corrections system to understand, in the first instance, how many people with ASD are actually incarcerated in Victoria. The Committee also believes that the Victorian Government should use its position on the Disability Reform Council to urge the NDIA to engage with criminal justice authorities to ensure that NDIS supports are made available to participants while incarcerated, particularly in relation to their transition to the community on release.

On the issue of the number of people with ASD who are in custodial settings, the Committee recommends that:

#### **RECOMMENDATION 5.13**

**The Victorian Government direct the Department of Justice and Regulation, and Corrections Victoria, to develop a system for identifying and registering people with ASD who have contact with the criminal justice system, and who are incarcerated in Victorian prisons, with this data to be reported to the Minister.**

On the issue of the services provided to people with ASD in prison, the Committee recommends that:

#### **RECOMMENDATION 5.14**

**The Victorian Government fund Corrections Victoria to provide specific supports to people with ASD while incarcerated, based on an assessment of needs.**

- **Corrections staff be provided with training to develop the capacity to engage with people who have ASD, and understand their needs.**

On the issue of housing post-release, the Committee recommends that:

#### **RECOMMENDATION 5.15**

**As part of the updated State Autism Plan, the Victorian Government develop a specific housing strategy for people with ASD, in relation to the transition from prison to release into the community.**

On the issue of the interface between the NDIS and the criminal justice system, the Committee recommends that:

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860 Ibid.

**RECOMMENDATION 5.16**

The Victorian Government use its position on the COAG Disability Reform Council to urge the NDIA to engage with Victorian criminal justice authorities to ensure that NDIS supports are made available to participants while incarcerated, and on their transition to the community on release.

**5.8. Public policy for adults with ASD**

As detailed in Chapter Two, in terms of public policy, the United Kingdom is now a leader in developing a national policy designed for adults with autism.<sup>861</sup> *Think Autism* highlights the role that local authorities and NHS bodies should have in planning services for adults with autism. *Think Autism* stipulates that people with autism need to have access to a clear pathway to diagnosis and know that this pathway is aligned with care and support assessments, and that there is post-diagnostic support available. The policy covers a wide range of areas including health, local government services, employment, and criminal justice. The collection of high quality data is held to be critical to the delivery of the policy, including data that is disaggregated by gender and ethnicity.<sup>862</sup> Local authorities and the NHS are required to provide autism awareness training to all frontline staff who are in contact with adults with ASD.<sup>863</sup>

On its study tour to the U.S., the Committee heard from peak body Autism Speaks about the lack of services and support for adults with autism in the U.S.<sup>864</sup> The Office of People with Developmental Disabilities (OPWDD)<sup>865</sup> is primarily responsible in each state for services to adults with autism, and the OPWDD will develop a plan that is similar to the Individualised Education Plans (IEPs) that school districts are mandated to develop for students with special needs. However, Autism Speaks advised in discussion that there is no federal law to keep the requirement intact for adults. The Committee heard from other agencies about the ad hoc nature of services for adults with ASD in the U.S.<sup>866</sup> The Autistic Self Advocacy Network (ASAN) in Washington D.C. highlighted the need to do more to ensure that diagnostic gaps for underserved

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861 See, Social Care, Local Government and Care Partnership Directorate, Department of Health, *Progress Report on Think Autism: the updated strategy for adults with autism in England*, Department of Health, 2016.

862 Ibid, pp. 11-15.

863 See, Ibid, p. 16. There are also provisions for students with ASD in higher education, and a self-assessment process which allows for people with ASD and their families to rate the services they receive. The policy is overseen by a National Autism Programme Board, which includes autism self-advocates and family members living with ASD.

864 Autism Speaks, 'Autism Speaks', accessed 26 April 2017, <[www.autismspeaks.org](http://www.autismspeaks.org)>.

865 See, the Office of People with Developmental Disabilities (OPWDD), 'Office of People with Developmental Disabilities', New York State, accessed 26 April 2017, <[opwdd.ny.gov](http://opwdd.ny.gov)>.

866 For a description of the services provided by The Arc, see The Arc, 'For people with intellectual and developmental disabilities', accessed 20 May 2017, <[www.thearc.org](http://www.thearc.org)>.

populations are addressed.<sup>867</sup> According to Autism Speaks, there are not enough expert clinicians to diagnose adults.<sup>868</sup>

Similarly, the policy and service landscape in Scandinavia for adults with ASD varied significantly. The Swedish law, the LSS, discussed in Chapter Two of this report, is highly commendable in terms of its aspirations, but has now come under focus due to the high cost of implementation. The Scandinavian welfare model is, in theory, designed to support people with disabilities, including adults with ASD, through their lifetimes. But the Committee heard in discussion with agencies that there was a lack of uniformity and availability of services.<sup>869</sup>

The Committee is of the view that in the development of public policy for people with ASD, the specific needs of adults with ASD need to be addressed. The U.S. experience suggests that policy can drive change, but only where it is regionally supported. The Scandinavian model is a broad social welfare model, but it lacks focus at the policy level for adults with ASD. The UK experience indicates that one way forward is to explicitly address adult autism as an area requiring specific, tailored and targeted programs and policies, across government levels and the disability service sector. While no guarantee that services will match expectations, a policy framework specifically designed and articulated for adults with ASD will raise the profile of adults in the community with ASD, and create a common set of aims for policy makers, service providers, departments and agencies.<sup>870</sup>

As this chapter shows, adults with ASD in Victoria have been marginalised and ignored, and services tailored to their needs are limited, or non-existent. In addition to the specific goals and actions outlined in this chapter to improve services and supports for people with ASD, the Committee believes that both the national and state strategies recommended in Chapter Two must take into account the specific needs of adults with autism, and articulate a policy framework to address those needs.

Accordingly, the Committee recommends that:

### **RECOMMENDATION 5.17**

**The Victorian Government use its position on the COAG Disability Reform Council to support the development of specific strategies to address the needs of adults with ASD, within the National Autism Strategy.**

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867 Autistic Self Advocacy Network (ASAN), 'ASAN's statement on the CDC's new prevalence data', accessed 16 May 2017, <[autisticadvocacy.org/2015/11/asan-statement-on-cdcs-new-autism-prevalence-data](http://autisticadvocacy.org/2015/11/asan-statement-on-cdcs-new-autism-prevalence-data)>.

868 Autism Speaks, *Is it Autism and If So, What Next? A Guide for Adults*, March 2015, p. 10.

869 For a description of the work of the Swedish Agency for Participation, see Swedish Agency for Participation, 'Swedish Agency for Participation', accessed 20 May 2017, <[www.mfd.se/other-languages/english](http://www.mfd.se/other-languages/english)>.

870 Social Care, Local Government and Care Partnership Directorate, Department of Health, *Progress Report on Think Autism: the updated strategy for adults with autism in England*, Department of Health, 2016.



**RECOMMENDATION 5.18**

The Victorian Government through the updated State Autism Plan develop specific strategies to address the needs of adults with ASD.





# Chapter 6

## People with ASD and the National Disability Insurance Scheme

### AT A GLANCE

#### Background

The National Disability Insurance Scheme (NDIS) is one of the most significant social policy reforms in recent history. The scheme was established by the *National Disability Insurance Scheme Act 2013* (Cth), and launched in 2013 at seven trial sites around Australia, including the Barwon trial site in Victoria. The scheme is expected to be fully rolled out by 2019-20. Once rolled out, it is estimated that the scheme will provide support for approximately 460,000 people nationally. The National Disability Insurance Agency (NDIA) is the statutory authority responsible for implementing the NDIS.

#### Chapter overview

The Committee heard both positive and negative commentary on the scheme and its roll out. At the public hearing held in Geelong the Committee heard from stakeholders, families living with ASD, participants in the scheme and officers from the NDIA. A common reaction of witnesses at public hearings outside Geelong has been to express a lack of knowledge or understanding of the scheme and its implications for family members.

The Committee believes that the experience of the NDIS roll out in Victoria can be used to enhance the scheme to the benefit of people with ASD. The Committee makes a number of recommendations to this end, mainly directed to the Victorian Government in its capacity as a participant in the COAG Disability Reform Council.

The chapter addresses terms of reference:

- c) the adequacy of services to be provided under the National Disability Insurance Scheme (NDIS); and
- e) the projected demand for services in Victoria.

The National Disability Insurance Scheme (NDIS) is one of the most significant social policy reforms in recent history. The scheme was established by the *National Disability Insurance Scheme Act 2013* (Cth), and launched in 2013 at seven trial sites around Australia, including the Barwon trial site in Victoria. The scheme is expected to be fully rolled out by 2019-20. Once rolled out, it is estimated that the scheme will provide support for approximately 460,000 people nationally. The National Disability Insurance Agency (NDIA) is the statutory authority responsible for implementing the NDIS.

At a public hearing in Geelong the Committee heard from officers of the NDIA and local participants in the scheme. Through submissions and public testimony, the Committee has heard both positive and negative commentary on the scheme and its roll out. A common reaction of witnesses at public hearings outside Geelong has been to express a lack of knowledge or understanding of the scheme and its implications for family members. The Committee is aware that, following the trial period's conclusion, the scheme has now moved into a transition phase, with the roll out in Victoria expected to be completed by mid-2019. It is projected that more than 100,000 Victorians will directly benefit from the scheme.

The Committee is of the view that a number of areas require the attention of the NDIA as the scheme is further rolled out, in order to enhance the scheme to benefit people with ASD. The Committee makes recommendations in relation to these areas. Two areas of concern stand out: the need for enhanced communications from the NDIA to potential participants and participants; and the need for enhanced training and professional development for scheme planners to adequately engage and support people with ASD.

This chapter addresses terms of reference c) the adequacy of services to be provided under the National Disability Insurance Scheme (NDIS); and e) the projected demand for services in Victoria.

## **6.1. National Disability Insurance Scheme (NDIS)**

The National Disability Insurance Scheme (NDIS) is one of the largest social policy reforms of recent times. The National Disability Insurance Agency (NDIA) is the statutory authority responsible for implementing the National Disability Insurance Scheme (NDIS). The NDIA is governed by a board of management, which reports to the COAG Disability Reform Council. The Commonwealth Department of Social Services is responsible for the overarching design and development of the NDIS. The NDIS was launched in 2013 and is expected to be fully rolled out by 2019-20. Once rolled out, it is estimated that the scheme will provide support for approximately 460,000 people nationally. More than 100,000 Victorians are expected to directly benefit from the scheme.<sup>871</sup> The scheme was established by the *National Disability Insurance Scheme Act 2013* (Cth).

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871 Department of Social Services, submission no. 72, pp. 13-14.

At the end of December 2016 there was a total of 61,215 participants in the scheme with approved plans, 9,370 of whom were Victorian funded participants.<sup>872</sup> A total of \$5.1 billion had been committed to the total number of participants across Australia.<sup>873</sup> Nationally, people with a diagnosis of autism as their primary condition were the second largest group of funded participants with an approved plan, at 28.4 per cent of the total. Those with an intellectual disability made up 37.6 per cent of participants with an approved plan.<sup>874</sup> By 31 December there was a total of 5,110 service providers who were registered under the scheme, of whom 1,476 approved provider services were in Victoria.<sup>875</sup> A total of 2,267 children nationally have been referred to the Early Childhood Early Intervention (ECEI) gateway.<sup>876</sup>

### **NDIS funded plans**

There are two essential components to the NDIS: first, the program of individual funded packages (IFPs) that will support individuals with approved plans; and second, the Information, Linkages and Capacity Building (ILC) program, which supports capacity building for the community and individuals.

The NDIS will provide individualised supports for people with significant and permanent disability under the age of 65. The NDIS will cover reasonable and necessary supports that enable a participant to complete everyday activities and work towards their goals. Examples of the kinds of supports funded include personal care, transport to access the community, equipment, and home modifications. According to the NDIS website, to be eligible for a funded plan from the NDIS, participants need to meet the following disability requirements:

- you have an impairment or condition that is likely to be permanent (i.e. it is likely to be lifelong) and
- your impairment substantially reduces your ability to participate effectively in activities, or perform tasks or actions unless you have:
  - assistance from other people or
  - you have assistive technology or equipment (other than common items such as glasses) or
  - you can't participate effectively even with assistance or aides and equipment and
- your impairment affects your capacity for social and economic participation and
- you are likely to require support under the NDIS for your lifetime.

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872 National Disability Insurance Agency, *National Disability Insurance Scheme COAG Disability Reform Council Quarterly Report 31 December 2016*, National Disability Insurance Agency, 2017, p. 59.

873 Ibid, p. 69.

874 Ibid, p. 64.

875 Ibid, p. 43.

876 Ibid, p. 10.

An impairment that varies in intensity e.g. because the impairment is of a chronic episodic nature may still be permanent, and you may require support under the NDIS for your lifetime, despite the variation.<sup>877</sup>

In the NDIS Operational Guidelines (List A), autism is listed as a condition which is likely to meet the disability requirements under section 24 of the *National Disability Insurance Scheme Act 2013* (Cth).<sup>878</sup> The NDIS states the following in relation to autism as such a condition:

Autism diagnosed by a specialist multi-disciplinary team, pediatrician, psychiatrist or clinical psychologist experienced in the assessment of Pervasive Developmental Disorders, and assessed using the current Diagnostic and Statistical Manual of Mental Disorders (DSM-V) diagnostic criteria as having severity of Level 2 (*Requiring substantial support*) or Level 3 (*Requiring very substantial support*).<sup>879</sup>

It is important to note that a diagnosis of ASD is not sufficient to meet the eligibility requirements for an NDIS Plan. It must be demonstrated that the ASD ‘substantially reduces’ the ability of an individual to participate in daily activities and tasks, and restricts social and economic participation, and that the individual requires either ‘substantial support’ or ‘very substantial support’. Given that the experience of people on the spectrum is diverse, each person with ASD needs to be considered on an individual basis – there is no blanket eligibility for people with ASD. NDIS participants will go through a planning process to identify the supports they require in an agreed Plan.<sup>880</sup> The NDIS will fund supports that address impairments associated with an individual’s disability – any general health and education needs will continue to be delivered by mainstream services.

The NDIS Operational Guidelines (List C), also state that clients of Victorian schemes, such as Individual Support Packages (ISPs) and the Disability Support Register, ‘will generally be considered to satisfy the disability requirements without further evidence being required’.<sup>881</sup>

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877 National Disability Insurance Scheme (NDIS), ‘Access requirements’, accessed 13 April 2017, <[www.ndis.gov.au/people-disability/access-requirements.html](http://www.ndis.gov.au/people-disability/access-requirements.html)>. For the full list of eligibility requirements see sections 17-30 of the *National Disability Insurance Scheme Act 2013* (Cth) and the *National Disability Insurance Scheme (Becoming a Participant) Rules 2016* (Cth). See also NDIS operational guidelines, provided for each area of the scheme, including access: National Disability Insurance Scheme (NDIS), ‘Operational Guidelines’, NDIS, accessed 13 April 2017, <[www.ndis.gov.au/about-us/operational-guidelines](http://www.ndis.gov.au/about-us/operational-guidelines)>.

878 See National Disability Insurance Scheme (NDIS), ‘Access – Disability Requirements’, accessed 13 April 2017, <[www.ndis.gov.au/about-us/operational-guidelines/access-disability-requirements.html](http://www.ndis.gov.au/about-us/operational-guidelines/access-disability-requirements.html)>.

879 Ibid.

880 On the planning process see National Disability Insurance Scheme (NDIS), ‘My NDIS Pathway’, accessed 13 April 2017, <[www.ndis.gov.au/participants/planning-process](http://www.ndis.gov.au/participants/planning-process)>.

881 See National Disability Insurance Scheme (NDIS), ‘Access – Disability Requirements’, accessed 13 April 2017, <[www.ndis.gov.au/about-us/operational-guidelines/access-disability-requirements.html](http://www.ndis.gov.au/about-us/operational-guidelines/access-disability-requirements.html)>.

The average annualised committed support to funded participants with a primary diagnosis of autism (excluding participants with shared accommodation supports) is currently running at approximately \$30,000 per annum at the national level.<sup>882</sup>

### Information, Linkages and Capacity Building

In addition to funded support packages for individuals, the NDIS is developing supports known as 'Information, Linkages and Capacity Building'. In November 2016, the NDIA released the updated version of the *Information, Linkages and Capacity Building (ILC) Commissioning Framework* (the ILC Policy). The ILC Policy describes five kinds of activities that will be funded in the ILC in the future:

- Information, linkages and referrals
- Capacity building for mainstream services
- Community awareness and capacity building
- Individual capacity building, and
- Local area coordination.<sup>883</sup>

Broadly, the information, linkages and capacity building stream aims to link people to existing mainstream services, and improve the capacity of mainstream services to be inclusive of people with disabilities. This part of the NDIS will provide individuals who do not qualify for a funded plan with access to information and support to engage with mainstream services. The ILC Policy states that the four activity areas can be broken down into two groups – those that focus on developing the capacity of people with disability (capability) and those that focus on developing the capacity of the mainstream and community (opportunity).<sup>884</sup> The budget for the ILC will build over time, with a full budget estimate of \$132 million by 2019-20.

The ILC will fund a range of activities, and will include assistance for people with disability who do not have an NDIS plan. Examples of the types of activities to be funded include: a website that provides information on particular disabilities; a 'yarning circle' for Aboriginal women run by an Aboriginal organisation; a community awareness program to increase employment opportunities for people with disability; and a project that connects young people with disability in rural areas via social media.<sup>885</sup> The ILC Policy contains a grants process open for organisations, with two tiers of grants – grants under \$10,000 and those over \$10,000.<sup>886</sup> In order to be funded, the NDIA will look for proposals that demonstrate a strong evidence of need,

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882 National Disability Insurance Agency, *National Disability Insurance Scheme COAG Disability Reform Council Quarterly Report 31 December 2016*, National Disability Insurance Agency, 2017, pp. 78, 80.

883 National Disability Insurance Agency, *Information, Linkages and Capacity Building Commissioning Framework*, November 2016, National Disability Insurance Agency, 2016, p. 7.

884 Ibid, p. 9.

885 Ibid, p. 18.

886 Ibid, p. 24.

fit within the ILC activity areas, assist people who do not have an NDIS plan, assist families and carers, and/or deliver ILC outcomes.<sup>887</sup>

The NDIA has advised the Committee that a focus area for ILC investment will be rural and remote areas. The ILC will not fund systemic advocacy, which is covered by the separate National Disability Advocacy Program.

### **Productivity Commission and NDIS costs**

In January 2017, the Treasurer, Mr Scott Morrison, announced that the Productivity Commission had been requested to undertake a study into the National Disability Insurance Scheme costs, reporting no later than 15 September 2017. In February, the Productivity Commission released an Issues Paper – *National Disability Insurance Scheme (NDIS) Costs* – which outlines the scope of the study and emerging cost pressures. The paper states that, according to the NDIA, the projection of total scheme costs based on updating the Commission’s 2011 projections ‘remain the most reliable available’.<sup>888</sup> That projection states total scheme costs as \$22 billion per annum, based on 460,000 participants by 2019-20.

### **Federal Budget 2017/18**

The Treasurer, Mr Morrison, announced that, ‘To secure the Commonwealth’s contribution to funding the NDIS, from 1 July 2019 the Medicare levy will increase by half a percentage point from 2 to 2.5 per cent of taxable income.’<sup>889</sup> The Commonwealth Government announced it will direct one-fifth of the money raised by the Medicare levy, along with NDIS underspends and other selected savings to a special NDIS Savings Fund. The Commonwealth Government is also providing \$209 million to establish an independent NDIS Quality and Safeguards Commission to oversee the delivery of quality and safe services.<sup>890</sup>

### **State Budget 2017/18**

In the Victorian Government’s State Budget for 2017-2018, the Government announced funding to support the state’s transition to the full roll out of the NDIS. The Government said that, ‘This funding will prepare for and facilitate the implementation of the scheme and support the disability sector to prepare for the scale and pace of the transition to the NDIS.’<sup>891</sup> This includes \$36.3 million to prepare staff, service providers, and systems for this transition to the National

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887 Ibid, p. 20.

888 See, Productivity Commission, *National Disability Insurance Scheme (NDIS) Costs - Productivity Commission Issues Paper*, Australian Government, February 2017, p. 11.

889 The Hon Scott Morrison, Treasurer of Australia, ‘Guaranteeing the essentials Australians rely on’, 9 May 2017, accessed 10 May 2017, <[sjm.ministers.treasury.gov.au/media-release/049-2017](http://sjm.ministers.treasury.gov.au/media-release/049-2017)>.

890 Ibid.

891 Victorian Government, *Getting on with the job, Victorian Budget 17/18 Service Delivery, Budget Paper no. 3*, p. 83, accessed 7 May 2017, <[s3-ap-southeast-2.amazonaws.com/budgetfiles201718.budget.vic.gov.au/BP3\\_2017-18\\_ServiceDelivery.pdf](http://s3-ap-southeast-2.amazonaws.com/budgetfiles201718.budget.vic.gov.au/BP3_2017-18_ServiceDelivery.pdf)>.

Disability Insurance Scheme (NDIS).<sup>892</sup> The Budget also included funding of \$19.9 million for an additional 256 packages under the Futures for Young Adults (FFYA) program, which provide supports for young people needing disability assistance during the day and skills development to participate in the community after they leave school. This funding is designed to support young people with a disability, until their transition into the National Disability Insurance Scheme.<sup>893</sup> Other Victorian Government budget initiatives are detailed below.

### 6.1.1. The Barwon Trial

The initial trial sites for the NDIS included the Barwon trial site in Victoria, which comprised the Greater Geelong, Surf Coast Shire, Queenscliff and Colac-Otway local government areas. The trial commenced in July 2013 and was completed on 30 June 2016, at which point the scheme moved into transition mode. The North East Melbourne region, comprising Banyule, Darebin, Nillumbik, Whittlesea and Yarra local government areas, commenced transition to the scheme on 1 July 2016, and the Central Highlands region, comprising Ararat, Ballarat, Golden Plains, Hepburn, Moorabool and Pyrenees local government areas, commenced transition to the scheme on 1 January 2017. The Loddon region, comprising Campaspe, Central Goldfields, Greater Bendigo, Loddon, Macedon Ranges and Mount Alexander local government areas, commenced transition to the scheme on 1 May 2017, with other regions to follow with expected full roll out in Victoria by mid-2019.<sup>894</sup>

At the completion of the Barwon trial there was a total of 5,284 participants in the NDIS with approved plans in Victoria. Twenty-two per cent of participants with an approved plan had a primary diagnosis of ASD.<sup>895</sup> As of 30 June 2016, the average annualised cost of approved support packages for people with ASD across the whole of the NDIS was \$26,475.<sup>896</sup>

The Committee held a public hearing in Geelong and heard from local participants in the NDIS Barwon trial, and from the NDIA itself. The Committee also received a number of submissions that related to the Barwon trial. At the public hearing, Ms Louise Glanville, Deputy Chief Executive Officer, of the National Disability Insurance Agency (NDIA) stated that:

It is very pleasing actually today that our minister has released the results at the end of trial, so that is as at 30 June 2016. What those results show in our actuarial report for that period, that last quarter, is that we now have over 30 000 people in the scheme around the country. Very importantly, as Ms Faulkner was referring to,

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892 Victorian Government, *Getting on with the job, Victorian Budget 17/18 Rural and Regional Information Paper*, p. 16, accessed 7 May 2017, <[www.budget.vic.gov.au/budget-papers](http://www.budget.vic.gov.au/budget-papers)>.

893 Ibid, pp. 78, 83.

894 See, National Disability Insurance Scheme, *Victoria roll out – Participant Information Pack*, 2016, p. 1. Ms Louise Glanville, Deputy Chief Executive Officer, Stakeholder Relations and Organisational Capability, National Disability Insurance Agency, Family and Community Development Committee public hearing – Geelong, 19 September 2016, transcript of evidence, p. 2.

895 National Disability Insurance Agency, *Quarterly Report to COAG Disability Reform Council 30 June 2016*, National Disability Insurance Agency, 2016, pp. 33-34.

896 Ibid, p. 55.



it indicates that we have hit our targets here in Barwon, which is incredibly pleasing and a tribute in part to her leadership. We see that those results have meant not only that we have the numbers coming into the scheme that were predicted but that we are within budget. That is very clear from our figures. Also we continue to have high levels of satisfaction from participants in our scheme. That is not to say of course that there are not issues that we have to address all the time, and probably that is the bit that I am most engaged with – trying to look at what is happening where things are not going as well as what we would like and really understanding what the participant and the provider experience is in terms of our systems and our processes.<sup>897</sup>

In terms of the supports that people are entitled to under the scheme, Ms Glanville stressed the importance of tailoring to particular needs, and how plans should be focused over time:

It is really important to say that the reasonable and necessary supports that people or individuals or children are entitled to as a result of the national disability insurance scheme have to be tailored to meet their particular needs. That is the whole point of the scheme. In instances where in someone's plan perhaps something has been included which has proven not to be particularly useful over time, or where sometimes in a plan review we may see that some resources have not been expended, the transition site now would interrogate that pretty thoroughly to get a sense of that and whether that was wrongly targeted and something else is actually needed, or was there not a provider that could be utilised for that purpose so was it a market deficiency in some way. But it is particularly important for plans to be very much focused on what the needs of those individuals are.<sup>898</sup>

Ms Glanville went on to say that there were two main concerns held by people with disability during the trial: 'one, would the money run out?', and 'two, when will it be my turn to come in?'.<sup>899</sup> She added that with people now moving into the scheme quite quickly, a greater level of certainty was emerging amongst people with disability about the scheme.<sup>900</sup>

In the Geelong public hearing, and via submissions, the Committee heard both positive and negative commentary from local participants and stakeholders about their experiences of the scheme. Consulting group Lancaster Consulting Australia are contracted by DHHS to provide Positive Behaviour Support (PBS) training to departmental staff, and were established as a provider for the NDIA Barwon pilot area. In their submission, the group commented on the impact of the NDIS on services for ASD in the region, stating that:

In our work in the Barwon Region, we have seen firsthand how the implementation of the NDIS has impacted services for ASD. The NDIS has introduced a number of benefits. In particular, the ability to use different accommodation options (e.g.

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897 Ms Louise Glanville, Deputy Chief Executive Officer, Stakeholder Relations and Organisational Capability, National Disability Insurance Agency, Family and Community Development Committee public hearing – Geelong, 19 September 2016, transcript of evidence, p. 3.

898 Ibid, p. 4.

899 Ibid.

900 Ibid.

private builds and rentals) opens up the possibilities to explore what option suits the individual's needs. The NDIS also has a proactive approach towards service provision, which is extremely important for all individuals with disabilities, as opposed to the more reactive tendency seen in past years when additional supports, including assessment and training, are only implemented when there is a crisis, a time when they are least effective.<sup>901</sup>

The group also reported on their observation of 'failed models' of support during the trial, stating that:

In contrast, we have also observed multiple failed models of support as agencies struggle to come to grips with unique needs of individuals on the spectrum. This has included implementation of risk management policies that pull out/remove supports as individuals show signs of anxiety unsurprisingly leading to significant incidents within the community; and an inability to effectively assess an individual's capacity as they lack the knowledge of the cognitive triad to understand the implications for problem solving, initiation/motivation, planning and decision making. Many agencies claim to have "autism specific" supports or staff trained in this area, but observations of practice continually demonstrate this knowledge is still very superficial and far more training and support is required across the sector.<sup>902</sup>

At the public hearing in Geelong the Committee heard from parent Ms Jules Haddock, who described the difficulties she had faced around the usage of the NDIS for her son. Ms Haddock listed five key areas of concern: a lack of plan flexibility, poor information provision through the NDIS portal, a lack of relevant skills and capacity of care planners, a respite model that did not suit their needs, and no allowance for travel funding in the plan.<sup>903</sup> Ms Haddock also commented on the process whereby her family was required 'to prove' the need for specialist support, stating that:

He is, like many kids on the spectrum, often the butt of bullying, particularly on buses where there are uncontrolled environments. So we thought we would get a speech pathologist back in to help him sort of read the scene a little bit and develop some of his autism skills. But the onus was on us to prove whether we needed a specialist or not. How do we prove that, other than the school backing us? It was only when we got the paediatrician to write a very stern letter that we got a response to that. It took a lot of work, and I felt – understanding, having worked in the system myself for years – I had got my head around the service sector, but I thought at the time that if you were a parent that did not understand your rights and could not advocate well, that probably would not have happened. But even as someone that does understand the system, I was getting pretty frustrated.<sup>904</sup>

Family support group, the Treehouse Geelong, told the Committee that there were mixed results coming out of the trial, stating that:

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901 Lancaster Consulting Australia, submission no. 88, pp. 8-9.

902 Ibid, p. 9.

903 Ms Jules Haddock, Family and Community Development Committee public hearing – Geelong, 19 September 2016, transcript of evidence, p. 2.

904 Ibid.

In our experience, the NDIS has a positive impact on encouraging and funding social activity and community participation options for people with autism. At present, it is difficult to access NDIS-funded therapy in school environments because of the separation of what is NDIS-funded and what is defined as state education responsibilities.<sup>905</sup>

The Committee heard that there was some confusion for participants over the types of services that would be funded under the NDIS. Parent Ms Nicole Stephenson told the Committee at Geelong that she was advised that art therapy for her son would not be funded:

He is not very social and loves to do art classes. He goes to Geelong Fine Art School. I note that when the NDIA were talking, and they were talking about mainstreaming, it actually made me laugh a little because their response to me wanting him to do those art classes was, 'It is not ASD-specific, therefore it is not covered by the NDIA'. I found that very, very interesting.<sup>906</sup>

The confusion was compounded when Ms Stephenson discovered that a child care centre in Geelong had added art therapy as an NDIA-approved program to its services.<sup>907</sup>

The issue of specialist availability and travel funding was raised by local parent, Mr Steve Ager, whose son has ASD. Mr Ager stated that:

As I alluded to in our submission, the other ones in our local area are not NDIA registered; therefore, unless you are paying for it yourself, it is hard to find a specialist, and if we have to fund it ourselves, both my wife and I are war veterans, both retired from the workforce, so we do not have a lot of disposable income to splash around on things, even though we deem them to be important. In that way it has become a little bit difficult to get him the help that he needs in Geelong, which is not even really classed as regional Victoria.<sup>908</sup>

Mr Ager described the NDIA travel budget allocated to his son's specialists for them to travel to his school as just adequate. On access to specialists and travel funding Mr Ager told the Committee that:

So my easy answer is: throw more money at it and give the travel vote more money, or make the providers under NDIA more accessible so that they can make the employment conditions for therapists more flexible – that they do not have to live in Melbourne or work in Geelong, or if they do that they can deliver the therapies at a time that is convenient for both the client and them as well as their organisation.<sup>909</sup>

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905 Ms Lisa Hamling, Facilitator, The Treehouse, Family and Community Development Committee public hearing – Geelong, 19 September 2016, transcript of evidence, p. 3.

906 Ms Nicole Stephenson, Family and Community Development Committee public hearing – Geelong, 19 September 2016, transcript of evidence, p. 2.

907 Ibid.

908 Mr Steve Ager, Family and Community Development Committee public hearing – Melbourne, 10 October 2016, transcript of evidence, p. 3.

909 Ibid, p. 5.

Geelong disability service provider, Gateways, advised the Committee in their submission that one impact of the NDIS on their service had been a significant reduction in government funding for autism assessment – the provider was continuing to provide the assessment service, but was now funding it through Victorian mental health funding, donations and grants.<sup>910</sup>

In Chapter Two, the Committee outlined concerns raised in relation to the withdrawal of services for people with ASD by local governments. As mentioned, Mr Geoff Barber, Acting Coordinator, Care Services, Aged and Disability, City of Greater Geelong, told the Committee about the cost pressures on councils created by the NDIA unit cost structure. Mr Barber also observed that there would be a strong need for advocacy support with the NDIS due to, ‘the kind of combative nature of trying to get what you want’.<sup>911</sup> In relation to the quality of service under the NDIS, Mr Barber stated that he thought that this would suffer, given lower wages and less supervision.<sup>912</sup>

### **Stakeholder concerns regarding the NDIS**

The concerns of participants in the Barwon trial were mirrored in commentary about the NDIS from submitters to the Inquiry, who also raised other issues. On the issue of travel funding, the Autism Family Support Association (AFSA) said in their submission that:

Transport to and from services that is tailored to the individual needs of a person with ASD is often a critical component for the wellbeing of both client and parents/carers/family. While unaccompanied taxi travel can work for some with ASD it is not safe for others. Affordable and appropriate transport options need to be provided for people with ASD.<sup>913</sup>

There was considerable comment made by submitters about the lack of clear information about the NDIS available to potential participants, and the complexity of the system. In their submission, support provider Extended Families Australia stated that:

Based on conversations and feedback from families involved with our organisation, our experience is that many families have little or no understanding of the NDIS, what it means, what they will need to do and how it will impact their family. This is starting to be addressed in the North East Melbourne area who will be phased in first, as our organisation and many others have commenced information sessions. We are finding that families want and need extra support to help them be ready to transition into the NDIS.<sup>914</sup>

Advocacy group the Victorian Advocacy League for Individuals with Disability Inc (VALID) stated in its submission that information about the NDIS ‘has been to this

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910 Gateways Support Services, submission no. 87, p. 1.

911 Mr Geoff Barber, Acting Coordinator, Care Services, Aged and Disability, City of Greater Geelong, Family and Community Development Committee public hearing – Geelong, 19 September 2016, transcript of evidence, p. 4.

912 Ibid.

913 Autism Family Support Association, submission no. 71, p. 16.

914 Extended Families Australia, submission no. 85, p. 3.

point confusing and complex', and that it was critical that families be reassured that they will not be disadvantaged under the transition to the NDIS.<sup>915</sup>

A number of submitters to the Inquiry were concerned that in the NDIS transition phase potential inequities could emerge to disadvantage people with ASD. The Victorian Disability Advisory Council stated in its submission that:

As the NDIS gets rolled out access to disability services will vary greatly across Victoria. Given that current disability services are inadequate for children and adults with autism the NDIS is likely to create new inequities with NDIS recipients potentially being able to access more, high-quality services than people with autism who live in areas without the NDIS. It is critical that DHHS Victoria consider ways to improve on current systems, including access to ISPs, to ensure that people with autism that do not have access to the NDIS for some years receive high quality services and supports.<sup>916</sup>

The role of the State Government in managing the transition was also highlighted by disability providers Distinctive Options, the Lab Network and Smart Communities in their combined submission. In discussing potential limits to funding packages under the NDIA, their submission questioned what the role of the State Government would be in supporting individuals who have clearly demonstrated needs for support to function effectively in the community, but are unable to meet the funding parameters of the NDIS.<sup>917</sup> The combined submission states, 'Will the State Government be expected or required to step in to provide the support or will they simply direct concerns to the NDIA and the Commonwealth?'<sup>918</sup> These sentiments were echoed by National Disability Services Victoria (NDS), who stated in their submission that:

The role of the Victorian government in relation to people with disability is changing but continues to be critical. Whilst the NDIS is being delivered by the NDIA, the Victorian Government will continue to have significant ongoing responsibility to support people with disability, including those with ASD. This is as both a co-funder and co-designer of the NDIS, and in relation to ongoing direct responsibility for mainstream services and the broader Victorian community.<sup>919</sup>

NDS identified four critical areas requiring ongoing state action: advocacy to the NDIS, the interface between the NDIA and mainstream services, implementation of local disability strategies to create an inclusive state, and accessibility of mainstream services, including education and health.<sup>920</sup>

In conducting public hearings in regional Victoria, the Committee frequently heard from families living with ASD and people with ASD that they were either not informed, or not fully informed about the general parameters of the NDIS, or, in particular, whether they or their family members would be eligible for support, and what level of

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915 Victorian Advocacy League for Individuals with Disability Inc (VALID) and the Behaviours of Concern Peer Action Group, submission no. 137, p. 13.

916 Victorian Disability Advisory Council, submission no. 146, p. 21.

917 Distinctive Options, The Lab Network and Smart Communities, submission no. 77, p. 32.

918 Ibid, p. 33.

919 National Disability Services Victoria, submission no. 133, p. 3.

920 Ibid, pp. 3-4.

support that might entail. At the Morwell public hearing, parent Ms Carmel Murphy told the Committee that her daughter was currently in receipt of an ISP from the State Government to fund speech therapy, and had been on a wait list for three years with DHHS for a larger package. It was her view that this process would be put on hold until the NDIS was rolled out:

Because we are the last for it to be rolled out I believe that Yooralla are starting to contact people. I certainly heard of one family that has been contacted in Morwell just recently. We have not been contacted. We get regular newsletters and updates but I'm just waiting to have that initial first contact, I suppose. I have been told it is January 2019 so Meg will be 16 by then. Our needs will be totally different to what we want now to what we need then. I can't get my head around it until such time as we are contacted.<sup>921</sup>

A similar picture emerged at the Swan Hill public hearing, where parents of children with ASD advised the Committee that they did not know if they would be eligible for NDIS support, and were not informed of its details.<sup>922</sup>

### **NDIA responses to concerns regarding the NDIS**

At the Geelong public hearing the Committee put a number of concerns from stakeholders to the NDIA, and later requested further information from the NDIA in follow-up questions on notice.<sup>923</sup> In relation to the reviewing of plans and plan flexibility, the NDIA advised the Committee that a participant can request a review of their plan at any time if their circumstances changed. The normal process is for a review to be conducted every 12 months, but for children in the Early Childhood Early Interventions the period of review was every six months.<sup>924</sup> At the hearing, Ms Glanville from the NDIA described how the trial had led to a greater level of plan flexibility, with participants having more control over how their reasonable and necessary supports can be met, within the three categories of core supports, capacity supports, and capital supports. This had led to much greater choice of control than when the trial started in 2013.<sup>925</sup>

In terms of the types of activities and supports that may be funded under the NDIS, such as the art therapy mentioned above, the NDIA advised the Committee that the approach was to provide each individual with supports that were individualised and

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921 Ms Carmel Murphy, Family and Community Development Committee public hearing – Morwell, 5 December 2016, transcript of evidence, p. 6.

922 See for example, Ms Jane McLean, Family and Community Development Committee public hearing – Swan Hill, 14 February 2017, transcript of evidence.

923 The NDIA responded to the Committee's follow up questions on notice with correspondence received on 17 March 2017 (Ref. no. SQ17-000001) and 2 May 2017 (Ref. no. SQ17-000057).

924 See Ms Chris Faulkner, Regional Manager, Victoria West, National Disability Insurance Agency, Family and Community Development Committee public hearing – Geelong, 19 September 2016, transcript of evidence, p. 3.

925 Ms Louise Glanville, Deputy Chief Executive Officer, Stakeholder Relations and Organisational Capability, National Disability Insurance Agency, Family and Community Development Committee public hearing – Geelong, 19 September 2016, transcript of evidence, p. 4. The review of plans and review decisions under the *National Disability Insurance Scheme Act 2013* is covered by sections 47-50, and by sections 99-103 respectively.



necessary.<sup>926</sup> The legal parameters for reasonable and necessary supports are set out in section 34 of the *National Disability Insurance Scheme Act 2013*. Supports will vary depending on the needs and goals of the participant, but in order to be considered reasonable and necessary, a support must: be related to the participant's disability; not include unrelated day to day living costs; represent value for money; be beneficial and effective; and take into account other informal supports. Supports are not funded if they are not related to the disability, or they duplicate other supports already funded by a different mechanism. In relation to the example of art therapy, the NDIA advised the Committee that it would not generally fund an art class, but would consider funding any additional costs that may be incurred in attending the classes that relate to the person's disability, such as the need for a support worker to assist the person to attend the recreation class.

In relation to funding for travel, the Committee was advised that funding for travel was part of participant packages,<sup>927</sup> based on an assessment of the impact of the participant's impairment on their functional capacity to travel independently, or use public transport. Transport supports that may be funded include: training and support to use public transport; modification to vehicles; costs associated with innovative transport options; taxi costs for those who cannot travel independently; and transport to and from school in certain circumstances.

On the issue of access to information, the NDIA acknowledged that in the early phase of the trial there were challenges related to the scheme's ICT systems, which caused problems for some participants.<sup>928</sup> In relation to the skills sets and capacity of planners, the NDIA advised that the planning process had been improved and changed as the trial went on based on the experiences of people in the scheme.<sup>929</sup> The NDIA has established a specialist technical team to assist planners and partners, including assistance to identify and respond to the needs of people with ASD. All planning staff undergo professional development.

In relation to local government involvement in disability service provision, the NDIA has advised the Committee that it is aware of a number of Victorian local governments that have announced that when the NDIS transitions to their area, they will not register to be an NDIS service provider. In 2015, the Victorian and Commonwealth Governments signed an agreement – *the Transitioning Responsibilities for Aged Care and Disability Services in Victoria* – which commits both governments to ensuring service stability over the three years of the NDIS roll out to mid-2019.<sup>930</sup>

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926 Ms Chris Faulkner, Regional Manager, Victoria West, National Disability Insurance Agency, Family and Community Development Committee public hearing – Geelong, 19 September 2016, transcript of evidence, p. 8.

927 Ms Louise Glanville, Deputy Chief Executive Officer, Stakeholder Relations and Organisational Capability, National Disability Insurance Agency, Family and Community Development Committee public hearing – Geelong, 19 September 2016, transcript of evidence, p. 10.

928 Ibid, p. 3.

929 Ibid, p. 7.

930 Department of Health and Human Services, *National Disability Insurance Scheme - Fact Sheet on the bilateral agreements for transition to the NDIA and transitioning of responsibilities for aged care and disability services*, Victorian Government, 2016, p. 1.



As noted in Chapter Two, in 2016 the Home and Community Care program (HACC) underwent significant change, but will continue to be provided by local government on behalf of the Victorian Government, albeit in a more limited form. Services for younger people will be funded solely by the Victorian Government until the NDIS is in full operation. The agreement also covers continuity of support, safeguards, and workforce readiness.<sup>931</sup>

The NDIA advised the Committee that it is working with the Victorian Government and the Municipal Association of Victoria (MAV) to identify regions at risk of participants not receiving disability support services during the transition phase. This work includes: identifying alternative providers, progressively transitioning clients to those alternative providers, and assisting to find those providers for clients. The NDIA maintains that it has not received specific feedback on pricing issues from the MAV or local governments. The NDIA note that all levels of government have committed to no person being disadvantaged by the introduction of the NDIS.

The interface between the NDIS and the delivery of mainstream services, including therapy services in education settings, is discussed in Chapter Four.

The Committee appreciates that Barwon was an NDIS trial site, and thus designed, in part, to be an early roll out of the scheme, which would contain a number of 'learnings' for policy makers. The NDIA at the Geelong public hearing did suggest in their responses that the scheme was, in part, in a learning phase during the pilot period, and that the scheme overall would benefit from the experiences of participants. The Committee also appreciates that officers of the NDIA have been tasked with implementing the largest social policy reform of recent times, and in what amounts to a relatively tight timetable for full implementation. The Committee is appreciative of the work of all those involved in the initial roll out phase of the NDIS, which has already seen over 60,000 Australians receive direct funding support through the scheme.

Nevertheless, the Committee is persuaded by the evidence presented to it in this Inquiry that the ongoing roll out of the scheme can be improved for people with autism. The Committee sees two key areas in which the NDIA can improve its performance: first, the provision of clear and timely information to participants; and second, the provision of skilled, knowledgeable and consistent planning support to participants. In addition to these two broad areas, the Committee has a number of other concerns that it believes need to be addressed.

In relation to the provision of information and people with ASD, the Committee is of the view that in the pilot phase the provision of information to potential participants and to participants themselves has been inadequate. The Committee appreciates that there were early ICT issues which did impede the delivery of timely and accurate information from the NDIA. However, overall the scheme has not promoted itself sufficiently well to the group that require it most: people with ASD and families living with ASD. The NDIS website remains confusing and complex. In regional Victoria the

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931 Ibid, p. 2.

provision of information has been, in some instances, negligible or non-existent, particularly in regional areas.

The Committee acknowledges that in the transition phase information provision will follow the pattern of the roll out. However, the Committee believes that there is substantial anxiety in the community around the implementation of the scheme, and that this can only be addressed by comprehensive outreach to people with ASD and families living with ASD, involving digital information, person to person contact, and information sessions. It is important that peak bodies be supported to provide information to people with ASD and families living with ASD state-wide.

Accordingly, the Committee recommends that:

### **RECOMMENDATION 6.1**

**The Victorian Government use its position on the COAG Disability Reform Council to ensure the National Disability Insurance Agency improves its communication strategy for people with autism and families living with autism, carers and advocates to provide accurate, timely and clear information in an appropriate manner.**

In relation to the skills sets and capacity of planners, the Committee appreciates that the planning process has improved as the scheme has rolled out, and that the NDIA has established a specialist technical team to assist planners and partners, including assistance to identify the needs of people with ASD.

However, given that participants to the scheme who have a primary diagnosis of ASD now represent almost 30 per cent of participants, and are the second largest group of participants overall, it is critical that planners have a high level of skills and capacity to engage with clients who have ASD. The Committee believes that the evidence it has received indicates that this has not been consistently the case and that further improvements in the training and professional development of scheme planners needs to take place.

The Committee therefore recommends that:

### **RECOMMENDATION 6.2**

**The Victorian Government use its position on the COAG Disability Reform Council to ensure the National Disability Insurance Agency develops a comprehensive training program, and ongoing professional development, for all scheme planners, so that they:**

- **are adequately equipped to engage and communicate with clients who have ASD;**
- **understand the diverse needs of people with ASD, and**
- **are able to provide consistent advice on supports and services, in the development of client plans.**

The Committee appreciates the advice of the NDIA that the normal process for a review of client plans is for it to be conducted every 12 months, and for children in the Early Childhood Interventions every six months. The Committee understands that

as the scheme has unfolded a greater level of plan flexibility has emerged, with participants having more control over how their reasonable and necessary supports can be met, compared to when the trial started in 2013.

However, the Committee has heard evidence that contradicts the advice of the NDIA. Some participants to the scheme have remarked on the inflexibility of their plans, which has led in some instances to participants having to endure services or supports that are inappropriate or inadequate. The Committee believes that in this transition phase of the scheme, which entails a high number of new and untested service providers entering the market, it is critically important for the NDIA to provide as much flexibility for client plans as is feasible. Where serious failures of service occur, participants to the scheme need to be provided with a timely review of that element of their plan, bearing in mind that it is intended that the whole plan is reviewed on an annual basis.

Accordingly, the Committee recommends that:

### **RECOMMENDATION 6.3**

**The Victorian Government use its position on the COAG Disability Reform Council to ensure the National Disability Insurance Agency provides a high level of plan flexibility to people with autism who are in the scheme.**

The Committee was disturbed to hear from witnesses that funding for travel has in some instances been refused. There appears to be a contradiction between the advice provided to the Committee on the funding of travel for participants, and the experiences of some participants.

The Committee believes that the NDIA needs to clarify its funding for travel advice to potential clients and participants, and ensure that where travel funding is integral to the provision of the most appropriate service or support for a client, that that funding be provided. NDIA clients should not be placed in a position of having to receive an inferior, inadequate or inappropriate service due to a lack of travel funding support.

The Committee recommends that:

### **RECOMMENDATION 6.4**

**The Victorian Government use its position on the COAG Disability Reform Council to ensure the National Disability Insurance Agency funds travel for clients and participants, and ensure that where travel funding is integral to the provision of the most appropriate service or support for a client, that funding be provided.**

The Committee appreciates that the approach to the types of activities, supports and services that are funded is based on providing each individual with supports that are individualised and necessary. However, the Committee believes that this aspect of the scheme needs to be better communicated to potential participants and participants, so that clients are fully aware of the parameters involved in the making of plan decisions. This advice should be part of the improved communication strategy mentioned above.

The Committee notes with concern the withdrawal from disability service provision by local governments in Victoria, a fact acknowledged by the NDIA. The Committee understands the commitment of the Victorian Government under the agreement reached with the Commonwealth Government to ensure service stability over the three years of the NDIS roll out to mid-2019. The Committee also acknowledges the concerns expressed to it by both submitters and witnesses to the Inquiry about the future role of the State Government in the provision of disability services.

This will be particularly relevant in relation to supporting those individuals who have clearly demonstrated needs for support to function effectively in the community, but are unable to meet the funding parameters of the NDIS. The Committee believes that the Victorian Government must carefully monitor the impacts of the NDIS in relation to the provision of services at local government level, and work with the Commonwealth Government, the NDIA, local governments and service providers to ensure that services are not diminished. The Committee believes that current respite services for people with ASD, and families living with ASD are particularly at risk.

Accordingly, the Committee recommends that:

#### **RECOMMENDATION 6.5**

**The Victorian Government carefully monitor the impacts of the NDIS on disability service provision at the local community level, and work with the Commonwealth Government, the NDIA, local governments and service providers to ensure that services for people with ASD are not diminished.**

### **6.1.2. The Early Childhood Early Intervention (ECEI) Approach**

As mentioned in Chapter Two, the NDIS will replace a range of programs currently operated by the Commonwealth Department of Social Services, including the Helping Children with Autism (HCWA) package. HCWA is being replaced by the NDIS Early Childhood Early Intervention (ECEI) approach, as the NDIS is rolled out. The NDIS has stated that all children with developmental delay or disability will be eligible for early intervention services regardless of whether they have received an official diagnosis.<sup>932</sup> The NDIS are establishing a network of ‘Early Childhood Partners’ (also referred to as ‘Access Partners’) with expertise in early intervention, who will meet with families to determine the supports their child needs. The NDIS has announced the following eligibility requirements for potential access to funded early intervention:

You may meet the early intervention requirements:

- if you have an impairment or condition that is likely to be permanent and
- there is evidence that getting supports now (early interventions) will help you by:
  - reducing how much help you will need to do things because of your impairment in the future and

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932 National Disability Insurance Scheme, ‘Access requirements’, accessed 17 December 2016, <[www.ndis.gov.au/people-disability/access-requirements.html](http://www.ndis.gov.au/people-disability/access-requirements.html)>; and information provided to the Committee via correspondence dated 2 May 2017 (Ref. no. SQ17-000058).

- improving or reducing deterioration of your functional capacity or
- helping your family and carers to keep helping you and
- those supports are most appropriately funded through the NDIS, and not through another service system.

OR

- you are a child aged under 6 years of age with developmental delay which results in:
  - substantially reduced functional capacity in one or more of the areas of self-care, receptive and expressive language, cognitive development or motor development and
  - results in the need for a combination and sequence of special interdisciplinary or generic care, treatment or other services which are of extended duration, and are individually planned and coordinated; and
- those supports are most appropriately funded through the NDIS, and not through another service system.<sup>933</sup>

While a child is defined under the *National Disability Insurance Scheme Act 2013* (Cth) as a person under 18 years, 'developmental delay' is defined as meaning delay in the development of a child under 6 years (see section 9).<sup>934</sup> For children aged 0-6 years, presenting with developmental delay, access to early intervention support will occur regardless of whether there is a diagnosis of ASD, or where the child is on the pathway for an ASD assessment, or in the case that they have been found not to have ASD following an assessment.<sup>935</sup> The NDIS summarise the ECEI approach as follows:

- Family meets with experienced early childhood intervention service provider (access partner) to discuss their needs
- The access partner determines the appropriate supports for the child and family - this may include a number of actions:
  - Information services, emotional support or referral to a mainstream service
  - Short to medium-term supports or longer term intensive supports.
- The access partner will assist a child and their family if they need more intensive supports. The access partner will complete a support plan and submit it to the NDIA for approval

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933 National Disability Insurance Scheme, 'Access requirements', accessed 17 December 2016, <[www.ndis.gov.au/people-disability/access-requirements.html](http://www.ndis.gov.au/people-disability/access-requirements.html)>.

934 The NDIS Act 2013 uses the same age grouping, and very similar concepts and language to define developmental delay as the Victorian *Disability Act 2006*, see section 3.

935 National Disability Insurance Scheme, 'Access requirements', accessed 17 December 2016, <[www.ndis.gov.au/people-disability/access-requirements.html](http://www.ndis.gov.au/people-disability/access-requirements.html)>; and NDIA Correspondence dated 2 May 2017 (Ref. no. SQ17-000058).

- Once the plan is approved, the family can choose the early intervention provider(s) they wish to work with and the support begins.<sup>936</sup>

At the public hearing in Geelong, the NDIA explained that it was partnering with early childhood intervention specialists to work as the access or gateway partner into the scheme. Mr Peter De Natris told the Committee that:

So the concept is that we will partner with the early childhood intervention provider, who will then work with the family around looking at the functional impact of delay if there is no diagnosis. So developmental delay, where you may have a significant deficit in one domain that requires an interdisciplinary response for a significant period of time, is a threshold of entry into the scheme. But that does not mean it should be an all-or-nothing proposition.<sup>937</sup>

The NDIA stressed the role of evidence-based interventions, family-centred practice, and the need for families to have access to clear information to make good evidence-based decisions.<sup>938</sup> The NDIA's Early Childhood Partners will form a national network, and the Autism Cooperative Research Centre will provide advice on best practice. The ECEI approach utilises the existing pathways for referral, through maternal and child health care, paediatricians and general practitioners. The gateway is also designed to support children to access mainstream services in the event that they do not meet the criteria. In addition to information, support and planning, the Early Childhood Partners will also be able to provide intervention services to families.

It is also anticipated that not all children who access early intervention services under the NDIS will require a funded package once they are adults. This is in line with emerging research on early intervention, which affirms that it can reduce ongoing health care, social and economic costs associated with ASD, and improve an individual's ability to participate in the mainstream. In terms of national guidelines for early childhood intervention, the early childhood intervention sector has produced its own set of national guidelines following industry and workshop consultations.<sup>939</sup> Recent research commissioned by the NDIS has critically evaluated the effectiveness of different therapies for children with ASD.<sup>940</sup> In response to the Committee's follow-up questions on notice, the NDIA advised the Committee that the following Early Childhood Partners have so far been appointed in Victoria:

- North East Melbourne Region: (Local Government areas: Banyule, Darebin, Nillumbik, Whittlesea and Yarra) - **Brotherhood of St Laurence**

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936 National Disability Insurance Scheme, *NDIS Early Childhood Early Intervention (ECEI) Approach*, NDIS, 26 February 2016, p. 4.

937 Mr Peter De Natris, Strategic Adviser, National Disability Insurance Agency, Family and Community Development Committee public hearing – Geelong, 19 September 2016, transcript of evidence, p. 5.

938 Ibid, pp. 5-6.

939 See Early Childhood Intervention Australia, 'National Guidelines – Best Practice in Early Childhood Intervention', ECIA, accessed 12 April 2017, <[www.ecia.org.au/resources/best-practice-guidelines](http://www.ecia.org.au/resources/best-practice-guidelines)>.

940 J Roberts and K Williams, *Autism spectrum disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers*, 2016, accessed 27 April 2017, <[www.ndis.gov.au/html/sites/default/files/Early%20Intervention%20for%20Autism%20research%20report.pdf](http://www.ndis.gov.au/html/sites/default/files/Early%20Intervention%20for%20Autism%20research%20report.pdf)>.



- Central Highlands Region: (Local Government Areas: Ararat, Ballarat, Golden Plains, Hepburn, Moorabool and Pyrenees) - **Latrobe Community Health Service**
- Barwon Region: (Local Government Areas: City of Greater Geelong, Colac Otway, Surfcoast, Borough of Queenscliff) - **Barwon Child Youth and Family**
- Ovens Murray Region: (Local Government Areas: Alpine, Benalla, Indigo, Mansfield, Towong, Wangaratta, Wodonga) - **Merri Community Health Service**
- Loddon Region: (Local Government Areas: Campaspe, Central Goldfields, Greater Bendigo, Loddon, Macedon Ranges, Mount Alexander) - **Intereach**
- Wimmera South West Region: (Local Government Areas: Alpine, Benalla, Indigo, Mansfield, Towong, Wangaratta, Wodonga) - **Latrobe Community Health Service**
- Inner East Melbourne: (Local Government Areas: Boroondara, Manningham, Monash, Whitehorse) - **Link Health and Community**
- Outer East Melbourne: (Local Government Areas: Knox, Maroondah, Yarra Ranges) - **Link Health and Community**
- Inner Gippsland: (Local Government Areas: Bass Coast, Baw Baw, Latrobe, South Gippsland) - **Link Health and Community.**

Peak body Amaze has raised some concerns in relation to the ECEI. In its submission, Amaze stated that while it recognised the value of putting interventions in place before diagnosis, this did not remove the need for a diagnosis to be made, and that diagnoses should not be delayed.<sup>941</sup> Amaze were also keen to see that ECEI access partners were suitably qualified to perform their role, and that access partners should not be registered providers of supports. Another issue has been the higher than expected level of children participants to the scheme, during the South Australian NDIS trial, which focused on access for children under thirteen. Nearly half the total number of participants with approved plans at the end of the South Australian trial had a primary diagnosis of ASD.<sup>942</sup> According to the NDIS, the percentage of children (0-18 years) who are currently participants in the whole scheme with an active plan, and who have been diagnosed with ASD, represents 45.2 per cent of the total of active children participants in the NDIS.<sup>943</sup>

The Committee welcomes the commitment in the 2017-2018 State Budget where the Government announced further funding of \$7.2 million to extend Early Childhood Intervention Services (ECIS) to over 500 children over two years until they transition to the National Disability Insurance Scheme (NDIS).<sup>944</sup> The Government also announced funding of \$10 million over four years for the planning and construction

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941 Amaze, submission no. 139, pp. 57-58.

942 Occupational Therapy Australia, submission no. 114, p. 9; National Disability Insurance Agency, *Quarterly Report to COAG Disability Reform Council 30 June 2016*, National Disability Insurance Agency, 2016, p. 34.

943 NDIA, Correspondence dated 2 May 2017 (Ref. no. SQ17-000058).

944 Victorian Government, *Getting on with the job, Victorian Budget 17/18 Service Delivery, Budget Paper no. 3*, p. 54, accessed 7 May 2017, <[s3-ap-southeast-2.amazonaws.com/budgetfiles201718.budget.vic.gov.au/BP3\\_2017-18\\_ServiceDelivery.pdf](https://s3-ap-southeast-2.amazonaws.com/budgetfiles201718.budget.vic.gov.au/BP3_2017-18_ServiceDelivery.pdf)>; Victorian Government, *Getting on with the job, Victorian Budget 17/18 Rural and Regional Information Paper*, accessed 7 May 2017, <[www.budget.vic.gov.au/budget-papers](http://www.budget.vic.gov.au/budget-papers)>.



of Early Childhood Development facilities co-located at new primary schools. The funding will enable a stable transition for children from early learning services into primary school.<sup>945</sup>

The Committee supports the principle that children demonstrating developmental delay should receive early intervention support services regardless of whether they have received a diagnosis, or are in the process of obtaining an assessment. The evidence clearly supports this approach, as was shown in Chapter Three of this report. The Committee therefore applauds the approach being taken by the NDIS and the State Government to early childhood intervention.

The Committee is, however, concerned that in the roll out of the NDIS, adequate levels of early intervention service support will be available across the state. The Committee is particularly concerned, as reflected in Chapter Nine, about whether early intervention services will meet the needs of Victorian families in rural and regional areas, where there has been a distinct lack of such services to date.

The Committee appreciates that there are, and will be, new entrants to the market, who will be funded under the insurance scheme. It believes that the Victorian Government will need to monitor the roll out of the scheme to ensure that early childhood interventions services are adequately distributed and provided across Victoria, so that rural and regional families are not discriminated against, simply by virtue of where they live.

Accordingly, the Committee recommends that:

#### **RECOMMENDATION 6.6**

**The Victorian Government closely monitor the roll out of the NDIS' Early Childhood Early Intervention scheme to ensure that services are adequately provided across Victoria, particularly in rural and regional areas.**

### **6.1.3. The NDIS Quality and Safeguarding Framework**

The COAG Disability Reform Council released the National Disability Insurance Scheme (NDIS) Quality and Safeguarding Framework (the Framework) in December 2016.<sup>946</sup> The objectives of the Framework are to ensure NDIS funded supports:

- uphold the rights of people with disability, including their rights as consumers
- facilitate informed decision making by people with disability

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945 Victorian Government, *Getting on with the job, Victorian Budget 17/18 Service Delivery, Budget Paper no. 3*, p. 60, accessed 7 May 2017, <[s3-ap-southeast-2.amazonaws.com/budgetfiles201718.budget.vic.gov.au/BP3\\_2017-18\\_ServiceDelivery.pdf](https://s3-ap-southeast-2.amazonaws.com/budgetfiles201718.budget.vic.gov.au/BP3_2017-18_ServiceDelivery.pdf)>.

946 See, Department of Social Services, *NDIS Quality and Safeguarding Framework*, Australian Government, 2016.

- are effective in achieving person-centred outcomes for people with disability in ways that support and reflect their preferences and expectations
- are safe and fit for purpose
- allow participants to live free from abuse, violence, neglect and exploitation, and
- enable effective monitoring and responses to emerging issues as the NDIS develops.<sup>947</sup>

The principles underpinning the Framework include: the presumption of capacity to exercise choice and control; national consistency; proportionality and risk responsiveness; and efficiency and effectiveness.<sup>948</sup> The Framework creates a national NDIS Complaints Commissioner with powers to investigate complaints and serious incidents, and a national NDIS Registrar with responsibility for registering providers and managing the NDIS practice standards and certification scheme.<sup>949</sup> There is no formal mandatory reporting system in the Framework as such, but there is a requirement for all registered providers to report 'serious incidents' to the NDIS Complaints Commissioner. Serious incidents are defined as:

- incidents involving fraud
- incidents of alleged physical or sexual assault of a participant committed by an employee
- incidents of alleged physical or sexual assault of a participant committed by another participant while in the care of the provider
- culpable neglect
- serious unexplained injury
- death of a participant (irrespective of cause), and
- unauthorised use of restrictive practices.<sup>950</sup>

In relation to serious incidents, the Complaints Commissioner is empowered to:

- receive and assess serious incident reports
- work with providers to develop a positive reporting culture
- build provider capability to prevent and respond to serious incidents, including working with providers to develop a service response to incidents if necessary
- recommend compliance action to the NDIS registrar when required
- refer matters to worker screening units, the NDIS registrar, the NDIS senior practitioner or other relevant authorities, and coordinate the response

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947 See, *Ibid*, p. 11.

948 *Ibid*, pp. 11-13.

949 *Ibid*, pp. 15-18.

950 *Ibid*, p. 52.

- review serious incident reporting data to identify systemic issues to be addressed, and
- report publically on the level of serious incidents and prevention strategies.<sup>951</sup>

The Framework also creates the role of NDIS Senior Practitioner. The NDIS Senior Practitioner will be established to provide clinical leadership in positive behaviour support, and to reduce and eliminate the use of restrictive practices in the NDIS.<sup>952</sup>

In its previous Inquiry into abuse in disability services in Victoria, the Committee made a number of recommendations to improve the safeguarding system in this state, and made further recommendations in relation to a national safeguarding framework.<sup>953</sup> Establishment of a mandatory reporting scheme was a key recommendation of this Inquiry, as was the principle of zero tolerance of abuse. Both of these elements were accepted by the Victorian Government in its response to the Inquiry.<sup>954</sup>

The Committee welcomes the adoption of the NDIS Quality and Safeguarding Framework by the COAG Disability Reform Council. It supports the creation of the national NDIS Complaints Commissioner, the national NDIS Registrar, and the Senior Practitioner, and other elements of the Framework designed to protect people with disability from abuse, such as worker screening. The Committee appreciates that the Framework does provide a nationally based framework for the prevention of abuse, which can be augmented and enhanced over time.

The Committee also appreciates that the Framework has been developed in the context of a national insurance scheme, and as such, is driven, in part, by the market-based philosophy that underpins the NDIS. The Framework balances the need for ‘appropriate protections that meet governments’ duty of care obligations with the need to enable participants to take reasonable risks so they can reach their goals’.<sup>955</sup> However, the Committee is concerned that in its current form the national Framework may not provide for the level of protection from abuse for people with disability, including people with ASD, that the community has demanded. The Committee is concerned that the definition of abuse is potentially confused by the division of reports into categories of ‘complaints’ and ‘serious incidents’. The Committee adheres to the view that any instance of abuse should be the subject of a mandatory report, without exception. The Committee notes that the Framework does not adopt the principle of the zero tolerance of abuse.

In its response to the Committee’s Final Report into Abuse in Disability Services, the Victorian Government showed itself to be a leader in the development of policies to

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951 Ibid, p. 53.

952 Ibid, p. 73.

953 Family and Community Development Committee, *Inquiry into Abuse in Disability Services*, Parliament of Victoria, 2016.

954 Minister for Housing, Disability and Ageing, *Zero tolerance of abuse of people with a disability – Response to the Inquiry into Abuse in Disability Services*, Victorian Government, 2016.

955 Department of Social Services, *NDIS Quality and Safeguarding Framework*, Australian Government, 2016, p. 11.

prevent the abuse of people with disability.<sup>956</sup> In the 2017-2018 State Budget, the Government announced that funding for strengthening oversight to prevent abuse in disability services would be provided. The Government stated that:

The Government will strengthen safeguards to prevent and respond to abuse of vulnerable people with a disability prior to implementation of the National Disability Insurance Scheme and its Quality and Safeguarding Framework. This includes additional resourcing to support the Disability Services Commissioner's (DSC) enhanced role to conduct an annual review of deaths in disability services, conduct own motion investigations, establish a mandatory reporting scheme for registered disability service providers to report abuse, and develop training resources to support professional development of the sector.<sup>957</sup>

Specifically, \$8.7 million will be allocated to strengthen the safeguards and oversight powers of the Disability Services Commissioner.<sup>958</sup>

Accordingly, the Committee recommends that:

#### **RECOMMENDATION 6.7**

**The Victorian Government use its position on the COAG Disability Reform Council to strengthen the protections afforded by the NDIS Quality and Safeguarding Framework over time.**

In relation to Victoria, the Committee recommends that:

#### **RECOMMENDATION 6.8**

**The Victorian Government monitor the impacts of the NDIS Quality and Safeguarding Framework in Victoria, in particular, to ensure that in the introduction and implementation of the National Framework in Victoria, none of the state's protections and processes for the prevention of abuse are diminished, or compromised in any form.**

The Committee is also concerned whether the NDIS will have the capacity and resources to meet the growing demand for diagnosis, early intervention and service delivery that will occur in Victoria as a natural consequence of the growing prevalence of ASD. Accordingly, the Committee recommends that:

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956 See, Minister for Housing, Disability and Ageing, *Zero tolerance of abuse of people with a disability – Response to the Inquiry into Abuse in Disability Services*, Victorian Government, 2016.

957 Victorian Government, *Getting on with the job, Victorian Budget 17/18 Service Delivery, Budget Paper no. 3*, p. 83, accessed 7 May 2017, <[s3-ap-southeast-2.amazonaws.com/budgetfiles201718.budget.vic.gov.au/BP3\\_2017-18\\_ServiceDelivery.pdf](https://s3-ap-southeast-2.amazonaws.com/budgetfiles201718.budget.vic.gov.au/BP3_2017-18_ServiceDelivery.pdf)>.

958 Victorian Government, *Getting on with the job, Victorian Budget 17/18 Rural and Regional Information Paper*, accessed 7 May 2017, <[www.budget.vic.gov.au/budget-papers](http://www.budget.vic.gov.au/budget-papers)>.

**RECOMMENDATION 6.9**

The Victorian Government use its position on the COAG Disability Reform Council to ensure the NDIS has the capacity to meet the growth in future demand for assessment and diagnosis of ASD, early interventions and ongoing service needs of people with ASD.

# Chapter 7

## Gender and ASD

### AT A GLANCE

#### Background

The Committee heard that the majority of children and adults diagnosed with ASD are male, and that many programs designed for people with ASD are based on the assumption that it is an essentially male condition. However, the Committee also heard that girls and young women have significant rates of ASD and have been under-represented in the available data. It has been suggested that this is linked to the different ways in which females present with ASD compared to males. This chapter will address the gendered dimension of the experiences of people with ASD.

This chapter focuses on the experience of girls and women with ASD, but it is not intended to detract from the experiences of boys and men. ASD affects all genders and all genders experience issues with diagnosis, treatment and accessing services. As a spectrum, boys and men with ASD clearly have particular and diverse needs, as do girls and women. An understanding of ASD in girls and women will broaden the general understanding of ASD.

#### Chapter overview

This chapter discusses the experiences of girls and women in obtaining a diagnosis and examines how females present. The chapter also examines the experience of girls in schools, social relationships and social media, and the experience of women with ASD through the lifecycle. This chapter relates primarily to the following terms of reference:

- (b) the availability and adequacy of services provided by the Commonwealth, State and local governments across health, education, disability, housing, sport and employment services; and
- (c) the adequacy of services to be provided under the National Disability Insurance Scheme (NDIS).

The Committee heard that the majority of children and adults diagnosed with ASD are male, and that many programs designed for people with ASD are based on the assumption that it is an essentially male condition. The most widely reported ratio of boys diagnosed with ASD to girls is 4:1. However, the Committee also heard that girls and young women have significant rates of ASD and have been under-represented in the available data. It has been suggested that this is linked to the different ways in which females present with ASD compared to males. This chapter discusses the experiences of girls and women in obtaining a diagnosis and examines how females present. The chapter also examines the experience of girls in schools, social relationships and social media, and the experience of women through the lifecycle.

This chapter focuses on the experience of girls and women with ASD, but it is not intended to detract from the experiences of boys and men. ASD affects all genders and all genders experience issues with diagnosis, treatment and accessing services. As a spectrum, boys and men with ASD clearly have particular and diverse needs, as do girls and women. More generally, an understanding of ASD in girls and women broadens and deepens the understanding of ASD. It can also assist in providing appropriate and targeted services. This chapter relates primarily to the following term of reference:

(b) the availability and adequacy of services provided by the Commonwealth, State and local governments across health, education, disability, housing, sport and employment services; and (c) the adequacy of services to be provided under the National Disability Insurance Scheme (NDIS).

## **7.1. Girls and ASD**

Throughout the Inquiry, the Committee heard that girls and women face particular obstacles in getting assessed and diagnosed for ASD, obtaining funding and finding appropriate treatments. Witnesses explained that this is largely because autism presents differently in girls than in boys and there is a lack of understanding of the presentation of girls with ASD. The Committee also heard that because ASD has historically been considered a male condition and research has focused on male presentations of ASD, there are gender biases in diagnostic practices, treatment and service delivery. Furthermore, girls and women adapted to some aspects of ASD and had better social imitation skills, resulting in females often ‘flying under the radar’.

Yellow Ladybugs, an advocacy group supporting girls who attend mainstream schools, noted in their submission to the Inquiry:

Many people still have the misconception that Autism predominantly affects males. Researchers are finally highlighting the differences between males and females and why females commonly go under the radar or are diagnosed much later in life, but as a community, we are failing girls with Autism. Girls are often misdiagnosed, misunderstood or missed completely. The negative impacts caused by this, are life long, and come at not only a personal cost to our girls, but to the family, and our community as a whole. We need to invest in programs which address these issues,



so that girls and women can get a timely, affordable diagnosis, the correct support in therapy, school and work.<sup>959</sup>

Natalie G, the Yellow Ladybugs Secretary, stated in their submission:

It's so hard it to identify autism in girls. My six-year-old son Nathan was diagnosed with ASD relatively quickly. But that was not the case for my eight-year-old daughter Emma. With Emma, we noticed from a young age the symptoms were there, just not as intense, every time we approached a professional to talk about it, it was always dismissed as she's just shy. Or she'll be fine." Emma had repetitive behaviours and an overwhelming fear of people. She was eventually diagnosed with ASD, but much later and missed out on a lot of critical early intervention support.<sup>960</sup>

According to U.S. autism researcher Sheila Wagner, girls are socialised to perform a more submissive gender role and are often overlooked by health professionals because they may come across as shy or having a passive personality rather than a social impairment.<sup>961</sup>

There are many consequences for girls with ASD being misdiagnosed, diagnosed late or not diagnosed at all. Girls often miss out on funding and receiving the support they need through misdiagnosis. They may also undergo many other unnecessary treatments and therapies. In their submission, Amaze drew attention to issues girls encounter in accessing a diagnosis through evidence gathered in consultations they conducted with people with ASD in Victoria. The following quotes are from participants to their consultation:

There seems to be low awareness of how ASD presents in girls, preventing early diagnosis and meaning that girls miss out on funding.

It is very generous of the government to provide the funding for early intervention. But many children with Asperger's, and girls with ASD, are diagnosed after the age of 7. This means they get no funding, which is a shame.<sup>962</sup>

In separate submissions, parents Mr Graeme Drysdale and Ms Avigale Bischard advised the Committee that it took up to seven years to get a diagnosis for each of their respective daughters.<sup>963</sup> Many diagnoses were only made once girls were at school.<sup>964</sup> The Committee also heard evidence from several women who were only diagnosed with autism in adulthood.<sup>965</sup> Girls seeing a general psychologist were often diagnosed or misdiagnosed with a range of other conditions, such as general anxiety,

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959 Yellow Ladybugs, submission no. 117, p. 1.

960 Ibid, p. 3.

961 S Wagner, 'Educating the female student with Asperger's', in T. Attwood and T. Grandin (eds) *Asperger's and Girls*, Future Horizons, Inc., Arlington, Texas, 2006, p. 19.

962 Amaze, submission no. 139, pp. 19, 29.

963 Mr Graeme Drysdale, submission no. 19; Ms Avigale Bischard, submission no. 15.

964 Ms Sara Cartwright, submission no. 124; Ms Avigale Bischard, submission no. 15.

965 Ms Katie Koullas, Founder, Yellow Ladybugs, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence; Ms Elissa Plumridge, Director and Program Facilitator, Creating Connections Australia, Family and Community Development public hearing – Swan Hill, 14 February 2017, transcript of evidence, p. 4.

depression, eating disorders, bipolar disorder, multiple personality disorders and schizophrenia.<sup>966</sup> Ms Sherri Cincotta from Creating Connections Australia told the Committee at a public hearing in Swan Hill that her oldest daughter was not diagnosed until she was 13 ‘because it was not as obvious’:

She just tended to fit in and mimic a lot of what her friends were doing, until it become obvious to me, when I started to look, that a lot of her issues were anxiety based.<sup>967</sup>

At a public hearing in Bendigo, another parent, Mr Martin Flanagan, drew attention to the missed opportunities to support his daughter following a late diagnosis:

What we have found is that with girls it is harder to diagnose some of this stuff. Then when we did find those things, we have missed out on funding, we have missed out on other things, and there is so much stuff that we could have done differently to better support her and her anxiety through all these years, particularly as she transitioned, went through puberty, started high school – all those massive changes that you need to go through that you do not quite know how to navigate; you may not pick up all the other cues that other kids are probably sending.<sup>968</sup>

Ms Stacey Smith, a mother with ASD of three girls who also have ASD, told the Committee at a public hearing in Geelong that there is a lack of psychologists who understand how women with ASD present:

Women are underdiagnosed, due to the lack of professionals specialising in the female profile and how they present differently. When you encounter psychologists, not all of them know about autism. That is your first barrier, whether you are an adult or a parent. You finally get into a psychologist, and it might be six months, a year, and nothing is happening, because that person has not done all the work to really know what they are talking about. Then for girls it is harder again, or for women, because they do not specialise in seeing beyond the mask. There is only a handful of people Australia wide that are psychologists that understand and have the level of qualifications that women need to access support.<sup>969</sup>

Likewise, Mr Ben Snow, the father of a son diagnosed with ASD and a two-year-old daughter who has been exhibiting ‘red flags’, emphasised the importance of getting a diagnosis. He told the Committee at a public hearing in Shepparton that there needed to be more awareness and training about how girls present:

Girls on the spectrum still obviously have a large degree of being left out because they present differently, and that has got its own challenges. Clearly diagnosis is

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966 Amaze, submission no. 139, pp. 19, 29; Ms Katie Koullas, Founder, Yellow Ladybugs, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 3. Ms Sally Smith, Family and Community Development public hearing – Shepparton, 15 November 2016, transcript of evidence, p. 3.

967 Ms Sherri Cincotta, Director and Program Facilitator, Creating Connections Australia, Family and Community Development public hearing – Swan Hill, 14 February 2017, transcript of evidence, p. 5.

968 Mr Martin Flanagan, Family and Community Development public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 7.

969 Ms Stacey Smith, Family and Community Development public hearing – Geelong, 19 September 2016, transcript of evidence, p. 2.

the key behind everything. Until you have got a diagnosis or at least an understanding that you are dealing with an ASD matter, you really have no grounding, no floor to work off. That is clearly your key point. The continued awareness of autism, the training and having appropriate paedies and the public system here in Shepparton to allow that analysis to happen – whether it is done like La Trobe do at their early diagnostic clinic or whether it is something a bit broader – certainly needs to be brought to the fore.<sup>970</sup>

On its overseas study tour the Committee heard about the research being conducted at the Yale Developmental Disabilities Clinic, and its ‘Initiative for Girls and Women with Autism Spectrum Disorder’, which aims to understand the unique needs of teens and young women with ASD.<sup>971</sup> As the Yale project states:

ASD interventionists and researchers have begun to appreciate that the development of socialization and communication processes for girls and women is quite different from that of boys and men. Unfortunately, the research and intervention implications of these differences have not been systematically addressed for girls and women with ASDs.<sup>972</sup>

## 7.2. Gender bias in screening and assessing for ASD

The Committee heard that girls and women with ASD present differently to boys and men with ASD. A dominant theory in the field of autism studies, which is being increasingly challenged, is that autism is a manifestation of an “extreme male brain”. The theory began in 1944 when Hans Asperger suggested that the autistic personality is ‘an extreme variant of male intelligence’, and that ‘In the autistic individual, the male pattern is exaggerated to the extreme’.<sup>973</sup>

Simon Baron-Cohen, from the Autism Research Centre at Cambridge University, has continued this research, arguing that in autism we see more pronounced male characteristics with the male brain ‘defined psychometrically as those individuals in whom systemising is significantly better than empathising, and the female brain is defined as the opposite cognitive profile’.<sup>974</sup> The ‘extreme male brain’ theory has been criticised by many scholars and has had an impact on the assessment and diagnosis of females. In a joint submission to the Inquiry, Distinctive Options, The Lab Network and Smart Communities all stated:

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970 Mr Ben Snow, Family and Community Development public hearing – Shepparton, 15 November 2016, transcript of evidence, p. 7.

971 See, Autism Program at Yale, ‘Initiative for Girls and Women with Autism Spectrum Disorder’, Yale School of Medicine, accessed 12 May 2017, <[childstudycenter.yale.edu/autism/clinical\\_services/initiative](http://childstudycenter.yale.edu/autism/clinical_services/initiative)>.

972 See, Autism Program at Yale, ‘Initiative for Girls and Women with Autism Spectrum Disorder’, Yale School of Medicine, accessed 12 May 2017, <[childstudycenter.yale.edu/autism/clinical\\_services/initiative](http://childstudycenter.yale.edu/autism/clinical_services/initiative)>.

973 H Asperger, ‘Die autistischen psychopathen’ im Kindesalter’, *Arch Psychiatr Nervenkr*, vol. 117, pp. 76-136 (trans. Uta Frith).

974 S Baron-Cohen, ‘The extreme male brain theory of autism’, *TRENDS in Cognitive Sciences*, vol. 6, no. 6, 2002, p. 248.

A number of research projects have concluded current assessment tools have a gender bias and the subtle nature of Autism in girls is not being recognised through the assessment process.<sup>975</sup>

For some women with ASD, the lack of understanding of ASD in girls is directly linked to the male narrative that persists in the literature of autism. Amy Gravino, a U.S. woman with ASD, and an activist and autism specialist, states that:

Girls and women on the autism spectrum face unique and specific challenges that are often misunderstood and rarely addressed. A clinical emphasis on boys with autism, as well as a dominant male narrative in autism literature, means that girls and women with ASD struggle to have their voices heard and acknowledged.<sup>976</sup>

### 7.2.1. Prevalence of ASD in boys and girls

The most widely reported ratio of boys diagnosed with ASD to girls is 4:1, however the Committee heard from others, such as Mr Murray Dawson-Smith, the Chief Executive Officer of Distinctive Options, who also argued that the 4:1 ratio is not a true reflection of the female rate of autism:

A lot of the research that has been taking place in Europe is now suggesting that the assessment tools we use around diagnosing autism are gender biased towards males and do not pick up females, and so again, despite the traditional notional view that it is 4 to 1, we would argue that it is not 4 to 1 – the diagnostic rates – but that it is much closer to 1 to 1 than we predicted.<sup>977</sup>

Many witnesses addressing the issue of girls and ASD referred to the research of clinical psychologist Professor Tony Attwood, who has suggested that the prevalence ratio is probably closer to 2 to 1.<sup>978</sup> Among girls with moderate to severe learning disabilities, the ratio is closer to 2:1.<sup>979</sup> However, in intellectually able girls, the ratio is around 10:1.

The DSM-5 entry on ASD states that females with ASD without an accompanying intellectual impairment or language delay may go unrecognised ‘perhaps because of subtler manifestations of social and communication difficulties’.<sup>980</sup> This is reflected in clinical settings where intellectually able boys are being referred for assessment at

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975 Distinctive Options, The Lab Network and Smart Communities, submission no. 77, p. 12.

976 NYU Steinhardt ASD Nest Support Project, ‘Amy Gravino on Girls & ASD’, accessed 12 May 2017, <[steinhardt.nyu.edu/asdnest/video/girls](http://steinhardt.nyu.edu/asdnest/video/girls)>.

977 Mr Murray Dawson-Smith, Chief Executive Officer, Distinctive Options, Family and Community Development public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 2.

978 Ms Sally Smith, Family and Community Development public hearing – Shepparton, 15 November 2016, transcript of evidence, p. 2; Ms Katie Koullas, Founder, Yellow Ladybugs, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 2.

979 Nasen, *Girls and autism: Flying under the radar. A quick guide to supporting girls with autism spectrum conditions*, Nasen, Staffordshire, 2016, p. 2.

980 American Psychological Association, *Diagnostic and statistical manual of mental disorders* (5<sup>th</sup> ed.), Arlington, VA, American Psychiatric Publishing, 2013; T Rivet and J Matson, ‘Review of gender differences in core symptomatology in autism spectrum disorders’, *Research in Autism Spectrum Disorders*, vol. 5, no. 3, pp. 957–976, 2011.

ten times the rate of intellectually able girls because their symptoms are more obvious. Tony Attwood discusses this in the book *Asperger's and Girls*:

We have a stereotype of typical female and male behaviour. Girls are more able to verbalise their emotions and less likely to use physically aggressive acts in response to negative emotions such as confusion, frustration and anger. We do not know if this is a cultural or constitutional characteristic, but we recognise that children who are aggressive are more likely to be referred for a diagnostic assessment... A consequence of this referral bias is that not only are more boys referred, clinicians and academics can also have a false impression of the incidence of aggression in this population.<sup>981</sup>

In their submission, the Victorian Disability Advisory Council drew attention to a recent guide from the United Kingdom which questioned whether the extreme gender difference is real, arguing that the difference in prevalence may be due to protective and compensatory factors in females; gender bias in existing screening and referral processes, diagnostic criteria and tools; and gender-specific differences in presentation of Autism Spectrum Disorder.<sup>982</sup>

### 7.3. How autism presents in girls

Research has indicated that girls with equivalently high levels of 'autistic-like traits' are less likely than boys to meet the diagnostic criteria for ASD.<sup>983</sup> This may be due to gender bias in diagnosis or 'genuinely better adaption/compensation in girls'.<sup>984</sup> Ms Michelle Anderson, the facilitator of the Pink Musketeers (Treehouse Geelong), a social group for girls with ASD, noted:

[Girls] do not really fit within the guidelines of the diagnosis as it was created, because it was created so long ago in a time when it really was predominantly a male diagnosis...

... they have quite good social imitation skills. Quite often you will hear them being called chameleons, because they can kind of hide their difficulties and hide that they are not understanding and blend in with everything else.<sup>985</sup>

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981 T Attwood, 'The pattern of abilities and development of girls with Asperger's Syndrome', in Attwood, T and Grandin, T (eds) *Asperger's and Girls*, Future Horizons, Inc., Arlington, Texas, 2006, p. 3. See also: T May, K Cornish and N Rinehart, 'Gender Profiles of Behavioral Attention in Children with Autism Spectrum Disorder', *Journal of Attention Disorders*, vol. 20, no. 7, pp. 627-635.

982 Victorian Disability Advisory Council, submission no. 146, p. 3, citing Nasen, *Girls and autism: Flying under the radar. A quick guide to supporting girls with autism spectrum conditions*, Nasen, Staffordshire, 2016.

983 K Dworzynski, A Ronald, P Bolton and F Happé, 'How different are girls and boys above and below the diagnostic threshold for autism spectrum disorders?', *Journal of the American Academy of Child & Adolescent Psychiatry*, vol. 51, iss. 8, 2012, pp. 788-797.

984 Ibid.

985 Ms Michelle Anderson, Facilitator, Pink Musketeers, Treehouse, Family and Community Development public hearing – Geelong, 19 September 2016, transcript of evidence, pp. 4, 5.

In their submission, Aspergers Victoria drew attention to the tendency of females to learn social skills through observation.<sup>986</sup> In her submission, Ms Meaghan O'Brien stated that females learn to blend in to gain acceptance from others.<sup>987</sup> Similarly, Ms Susan Rees, the mother of a girl with ASD, told the Committee:

Girls with autism often slip through the cracks because they are naturally more sociable than boys.<sup>988</sup>

ASD researchers Andersson, Gillberg and Miniscalco have suggested that current screening methods may not be reliable for identifying autism in females.<sup>989</sup> The Committee heard from many witnesses that girls are better communicators, they imitated their peers and had higher language skills, they tend to internalise anxiety rather than exhibit challenging behaviours and the special interests they had, which forms part of the diagnostic criteria, often did not raise suspicions. For example, girls with ASD may be interested in animals, reading or music, which may be typical of their peers.<sup>990</sup> The systematising, fixated and obsessive way in which girls with ASD may approach those interests may be different from the way their peers engage with the same interests but these may be not as obvious to parents and health professionals. Tony Attwood writes:

When involved with solitary play with dolls, the girl with Asperger's Syndrome has total control and can script and direct the play without interference and having to accept outcomes suggested by others. The script and actions can be an almost perfect reproduction of a real event or scene from a book or film. While the special interest in collecting and playing with dolls can be assumed to be an age-appropriate activity and not indicative of psychopathology, the dominance and intensity of the interest is unusual.<sup>991</sup>

The Committee heard that constructing social scripts and mimicking the behaviour of others can conceal autistic traits. In the Yellow Ladybugs' submission, Tess, a Yellow Ladybugs member, said the following about her daughter:

She seems too social and empathetic to be on the spectrum my daughters 'special interest' is copying and imitating what older girls say and how they act.... She is a Chameleon and it is exhausting for her.<sup>992</sup>

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986 Aspergers Victoria, submission no. 141, p. 9.

987 Ms Meaghan O'Brien, submission no. 109, p. 2.

988 Ms Susan Rees, Family and Community Development public hearing – Melbourne, 10 October 2016, transcript of evidence, p. 5.

989 G Andersson, C Gillberg and C Miniscalco, 'Pre-school children with suspected autism spectrum disorders: Do girls and boys have the same profiles?' *Research in Developmental Disabilities*, vol. 34, pp. 413-422.

990 See also, J Gould and J Ashton-Smith, 'Missed diagnosis or misdiagnosis? Girls and women on the autism spectrum', *Good Autism Practice*, 2011, vol. 12, no. 1, pp. 34-41.

991 T Attwood, 'The pattern of abilities and development of girls with Asperger's Syndrome', in Attwood, T and Grandin, T (eds) *Asperger's and Girls*, Future Horizons, Inc., Arlington, Texas, 2006, p. 5.

992 Yellow Ladybugs, submission no. 117, p. 3.



Girls often become ‘quite adept at camouflaging their difficulties’.<sup>993</sup> According to Tony Attwood, girls also tend to receive help from their peers and are “mothered” by other girls in their social circle, unlike boys who may be teased, ignored or bullied for being different.<sup>994</sup>

Notwithstanding these mimicking and camouflaging techniques, recent research conducted at the UC Davis Mind Institute suggests that behavioural differences between girls with autism and typically developing girls are actually much larger than the differences between boys with autism and typically developing boys.<sup>995</sup>

One researcher at the Olga Tennison Autism Research Centre has concluded from her study into girls with ASD and restricted and repetitive behaviours (RRBs) that:

As RRBs are more easily observed in the early years than social attention and communication deficits, it is possible therefore that ASD in girls can be missed considering that they display less of them. It is also possible that girls may not come to a diagnostician’s attention because the social and behavioural deficits observed in ASD may be more acceptable in girls than boys or may be more noticed in boys because of the current gender bias – that is parents and other carers of young children expect ASD to affect more boys than girls and therefore may not be so concerned about girls. It seems therefore that mis- or under diagnosis in girls may occur not because ASD symptoms are different in boys and girls, but because they are more noticeable in boys.<sup>996</sup>

### 7.3.1. Girls in schools

Several witnesses noted that girls are often overlooked in schools because they tend to internalise anxiety.<sup>997</sup> They may fall behind in school and often do not get access to an aide due to being less disruptive in the classroom.<sup>998</sup> In their submission, Yellow Ladybugs argued that ‘as a community, we are failing girls with autism’. They noted that some girls with ASD are often very functional, have high IQs and can excel in subjects, but they really struggle in the classroom and are often not eligible for funding.<sup>999</sup> Ms Katie Koullas, the founder of Yellow Ladybugs, noted:

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993 T Attwood, ‘The pattern of abilities and development of girls with Asperger’s Syndrome’, in Attwood, T and Grandin, T (eds) *Asperger’s and Girls*, Future Horizons, Inc., Arlington, Texas, 2006, p. 3.

994 Ibid.

995 UC Davis Health, ‘UC Davis MIND Institute research finds differences in the brains and behavior of girls and boys with autism’, accessed 12 May 2017, <[www.ucdmc.ucdavis.edu/publish/news/newsroom/9818](http://www.ucdmc.ucdavis.edu/publish/news/newsroom/9818)>.

996 Olga Tennison Autism Research Centre, ‘Autism spectrum disorder in girls’, accessed 12 May 2017, <[otarc.blogs.latrobe.edu.au/autism-spectrum-disorder-in-girls](http://otarc.blogs.latrobe.edu.au/autism-spectrum-disorder-in-girls)>.

997 Ms Katie Koullas, Founder, Yellow Ladybugs, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 3.

998 Ibid.

999 Yellow Ladybugs, submission no. 117, p. 1.



Often girls with Autism, who are attending mainstream school, do not have access to any funding, because their language score is above 70. Their needs may be hard to pick up on, and 'invisible' so they miss out on critical support.<sup>1000</sup>

Ms Koullas drew attention to the key issues affecting the ability of girls with ASD to succeed in school, which include class rules, working collaboratively and working with peers.<sup>1001</sup> In their submission, Yellow Ladybugs noted:

The research and anecdotal evidence both clearly show that teachers are often unaware of the typical female presentation and they very often present as quiet and withdrawn, masking their need for support and therefore do not attract the help that they so desperately need. There are countless stories from parents of having to remove their daughters with ASD from the mainstream school system as they aren't understood or accommodated.<sup>1002</sup>

Michelle, a Yellow Ladybugs member, stated:

I had to pull my daughter out of public school and put her in Catholic (despite being an atheist) because she didn't qualify for an aide. She's entitled to one under the Catholic system. Girl's [sic] often present with much better vocab and communication skills so their learning issues are masked. My daughter's teacher kept saying she was 'exactly where she should be' academically. At the end of Grade 3 however, it became increasingly apparent that this wasn't the case. She tested in the 5th percentile for maths and the 12th for English. She was in the 97th percentile for vocabulary. In other words, she's brilliant at making the teachers think she understands what's [sic] happening in the classroom. She's a chameleon.<sup>1003</sup>

The Committee was told that girls struggled with social relationships at school. Ms Christine Lyons, the acting CEO of Speech Pathology Australia, told the Committee that:

[A] lot of girls will slip through the system, and it will not be until they actually reach perhaps grade 3 or 4 when issues with friendship groups start to emerge or concerns about either them being accused of bullying – or vice versa, that they are being bullied by their peers – and that often has a lot to do with their difficulties with social relationships.<sup>1004</sup>

The Committee heard that many girls were expending enormous energy to appear 'normal' and hide their anxiety at school, resulting in meltdowns after school. In her submission, Ms Sara Cartwright, whose daughter missed out on funding because she

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1000 Ibid.

1001 Ms Katie Koullas, Founder, Yellow Ladybugs, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 4.

1002 Yellow Ladybugs, submission no. 117, p. 4.

1003 Ibid, p. 2.

1004 Ms Christine Lyons, Acting Chief Executive Officer, Speech Pathology Australia, Family and Community Development public hearing – Melbourne, 12 September 2016, transcript of evidence, p. 7.

was diagnosed at the age of six, describes a day in the life of her six-year-old daughter:

She did okay in the classroom in the morning, and sat quietly because she knows she has to do that. She fidgeted a little bit, but then got told off for doing that. She doesn't like getting in trouble. Then she started making noises, because she does that sometimes when she's concentrating. She got in trouble for that, too... Tegan knows how she is supposed to behave - she's a very good actress. She spends all day trying her best to please everybody. Sometimes she slips up at recess and lunch time, and she might hurt somebody. She feels extremely bad about it afterwards, but at the time she can't control it.

By the time she gets home, her stress hormones are in overdrive, and she loses control. There's no way we can stop the inevitable meltdown.<sup>1005</sup>

Another member of Yellow Ladybugs, Natasha E, was quoted in their submission on how, at her daughter's school, she was often the only girl in the ASD skills groups:

Also that if girls are put in speech therapy or social skills groups at school odds are that they will be the only girl in the group. My daughter likes boys and plays with them well, but she's getting a bit sick of pirate ships and lego building (with no pretend play afterwards). I'd like her to learn skills with girls and boys. There are issues for girls right across the spectrum.<sup>1006</sup>

### 7.3.2. Social relationships and social media

The Committee heard that social media is an important outlet and often a special interest for many people with ASD who may struggle with face-to-face interactions and social relationships. For girls with ASD, however, many parents expressed concern that girls may be particularly naïve and susceptible to bullying and vulnerable to exploitation in online interactions. The Committee heard from Ms Leah Thomson, the mother of a girl with ASD, on the need to teach girls with ASD how to interpret and understand what people say, how to understand emotions and how to respond appropriately. Ms Thomson identified that this is particularly difficult with social media:

In the autistic world it is either you are a friend or you are not. On Facebook you have got 236 friends. Regardless of where they are on your friend tree, it is a minefield, and it is really scary as a parent to know that my daughter is talking to someone from America because he is a friend of a friend, and because it says 'friend', he is a friend. Disclosing that information of what you would disclose to your close personal friend, after three days they are your close personal friend, because you have had a close conversation. That really scares me ... we can help to teach these girls what to say, how to say it, what is appropriate, what it means when you have got your hair spread out against the pillow and your lips pouted. They do not think that that means anything, so I have to explain to my daughter that you are going to get a few boys responding to that and why. What message is

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1005 Ms Sara Cartwright, submission no. 124, p. 1.

1006 Yellow Ladybugs, submission no. 117, p. 2.

that sending out? Yes, it is really scary, even just for neurotypical girls let alone autistic ones.<sup>1007</sup>

Similarly, Ms Sarah Hayden, the mother of a girl with ASD, told the Committee that her daughter's 'whole world is social media':

She is very, very naive and vulnerable and will often get people requesting private videos or conversations with her online, and she will do it straightaway. I will say to her, 'How do you know that it's a mum with two kids?', and she will say, 'Because they told me that they are'. It is beyond her comprehension that anybody would lie or that anybody could put up a fake profile picture. For her it is that vulnerability and naiveté which is really concerning. Even as a 19-year-old she just takes everybody at face value. She will say to me, 'But Mum, why would they say they were a mum with two ASD kids if they were not? What else would they want?'. She is a beautiful-looking girl, and she says, 'What else would they want?'. She does not understand.

She also often talks about how hard it is for her to understand emotions, even when face to face with somebody. It is so much harder for her without seeing a face and with there just being words on the screen. She is often attacked on social media. She will often get people commenting on blog posts and stuff now that she is getting a little bit viral. The keyboard warriors come in with comments like, 'You're just pretending to be autistic so you can get attention', and things like that. People can get quite nasty, and they do not realise that she will go into 12 hours of meltdowns and crying and being really upset. She cannot understand the meanness or all of the things that come with social media.<sup>1008</sup>

Ms Hayden described the centrality of social media for her daughter:

In the early days I and other people would say, 'Why don't you just take her off that?', but what they do not understand is that for a lot of ASD people that is their world. She does not work. She spends most of her time in her room – in her safe place – and her entire world of friendships and communicating is social media. If we take that away from her, what has she got? It is about trying to create some kind of safe space where she has got friends and people she can communicate with and where she can use this public platform to be a really great advocate for somebody living with ASD, but it is also about attempting to protect her from the people in the world who are not going to be very nice or who may want something from her other than what she is there thinking that she is giving. There is just that naiveté around it, so it is about education, I think.<sup>1009</sup>

Despite these concerns, some women with autism have used the internet as a way to build online support groups. Ms Stacey Smith told the Committee about a predominantly online support group called Sisterhood of the Autistic Woman with 287 members in Australia that 'provides a safe place for autistic women to access

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1007 Ms Leah Thomson, Family and Community Development public hearing – Geelong, 19 September 2016, transcript of evidence, p. 2.

1008 Ms Sarah Hayden, Family and Community Development public hearing – Geelong, 19 September 2016, transcript of evidence, p. 4.

1009 Ibid.

support from their peers’ and acknowledges ‘the different presentations in autistic females and the common barrier we face together’.<sup>1010</sup> Ms Smith told the Committee that while predominantly online, the support group organised local catch-ups in Melbourne and Geelong and provided a unique place where members ‘finally feel like they belong’ and was connected to another group with 1100 members worldwide:

Autistic women and girls are in a minority within a minority, and we desperately need a voice.<sup>1011</sup>

Likewise, Ms Sally Smith, who was diagnosed at the age of 34, connected with a Facebook group of women with Asperger’s which she found very helpful in the absence of in-person support:

This Facebook group is a place where you can say what you are feeling and share. Different subjects come up, and there is just that feeling of connection and being understood.<sup>1012</sup>

Ms Chloe Fitton, an adult with autism who was diagnosed in her twenties, told the Committee that online groups were a place where people with ASD could support each other:

There is a huge online presence on most social platforms of Autistic people getting together and talking about their experiences, posting questions and just getting hundreds of responses from people that society generally depicts as antisocial. It is really great for people to be able to talk with people like us. It is really refreshing to not have to put up that face of having to think through everything I say before I say it, because a lot of the things I say do not come out right. So being able to network some Autistics especially in a place like Bendigo and other regional centres where we can get together and just be ourselves is really important.<sup>1013</sup>

### 7.3.3. Gender and ASD through the life cycle

As this chapter has illustrated, the Committee heard from many women who were diagnosed as adults. Ms Tamsin Jowett, the President of Aspergers Victoria, noted that many of the people coming to their organisation are women who are diagnosed later as adults, at a point in their lives where they have struggled in school, dropped out of university and have experienced employment challenges:

We are finding they are coming to us disempowered by the community, not empowered to use these amazing strengths that they have got. So they fall through the cracks. They feel disabled... We have got this wasted talent.<sup>1014</sup>

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1010 Ms Stacey Smith, Family and Community Development public hearing – Geelong, 19 September 2016, transcript of evidence, p. 2.

1011 Ibid.

1012 Ms Sally Smith, Family and Community Development public hearing – Shepparton, 15 November 2016, transcript of evidence, p. 4.

1013 Ms Chloe Fitton, Family and Community Development public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 8.

1014 Ms Tamsin Jowett, President, Aspergers Victoria, Family and Community Development public hearing – Melbourne, 12 September 2016, transcript of evidence, p. 4.

Many women were not diagnosed until their children were diagnosed. Ms Narelle McCaffrey told the Committee that while there was a lot of resources and research around adults with ASD on the transition to adulthood, independent living and employment, there 'is a cohort being forgotten or ignored', which is mothers with ASD. Ms McCaffrey stated:

We exist and probably in numbers greater than can be predicted. Most of us have been diagnosed after the diagnoses of our children and at great personal expense, while others remain self-diagnosed because of this cost.

I and other autistic mothers face a number of unique difficulties. This may be in part due to societal expectations of mothers, the notion that autism affects more males than females and the idea that autistic parents, let alone mothers, are the exceptions to the rule, given that autism in adults is seemingly forgotten. Although we are all different, it would seem the difficulties autistic mothers experience are similar.

Work carried out at the Autism Research Centre at Cambridge in the UK found that autistic mothers are more likely to have trouble with time management, multi-tasking, domestic duties – we can be awesome mums but pretty hopeless housekeepers – organising play dates and other social opportunities for children, speaking with health and other relevant professionals about their children and advocating for their children and themselves, or more so than their typical peers.<sup>1015</sup>

Ms McCaffrey noted that many mothers with ASD struggle with executive functioning, feel misunderstood and do not feel comfortable asking for help out of fear of judgment.<sup>1016</sup> Problems with executive functioning impact organisational skills, prioritising and completing tasks, impulse control and self-regulation, and the ability to plan. Ms McCaffrey told the Committee:

My house is a constant mess, so I end up feeling overwhelmed and anxious to the point of being unable to act. Although I am not a bad parent, I think that I could be better at it if I could maintain that order, have that order and have the help and support to do so... No matter what though, raising children, autistic or not, is really hard when you are dealing with your own issues. It is hard to juggle your own needs when juggling the those of your children. Services to help are non-existent... Our existence as autistic mothers needs to be acknowledged and services to help and support us need to be established.<sup>1017</sup>

Ms Sally Smith told the Committee at a public hearing in Shepparton of the impact of ASD on her ability to manage competing tasks:

Even as a mother, there are days when I cannot manage to prepare a healthy meal for my family at the end of the day because I have done too many other things, and

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1015 Ms Narelle McCaffrey, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 2.

1016 Ibid.

1017 Ibid.

by that time of day I am just overwhelmed, and I do not, so we have takeaway or whatever.<sup>1018</sup>

A large-scale survey, conducted by Autism Spectrum Australia, identified two main ‘gender gaps’ in the life experiences of adults with ASD: a higher proportion of women (83 per cent) than men (67 per cent) reported having a mental health condition and male respondents tended to be more positive about their social life with only around half of women stating that they were happy with their current level of social activities and friendships.<sup>1019</sup>

Other aspects related to gender differences raised by several witnesses were the lack of services catering for girls and women with ASD throughout the life cycle, and the need for diversity in program design for both males and females. Witnesses told the Committee that women attending community groups were often the only women in the group and felt that they did not fit in.<sup>1020</sup> Likewise, parents expressed concern that their daughters were not given opportunities to socialise with girls:

... if girls are put in speech therapy or social skills groups at school odds are that they will be the only girl in the group. My daughter likes boys and plays with them well, but she's getting a bit sick of pirate ships and lego building (with no pretend play afterwards). I'd like her to learn skills with girls and boys.<sup>1021</sup>

The Committee also heard some evidence from women with ASD and their difficulties obtaining suitable employment. In her submission, Ms Meaghan O'Brien told the Committee about her struggle to gain employment throughout her life:

I've never had a proper paid job, only many different volunteer ones with varied degrees of success and failures not turning into a paid job which has lead me to have low self-esteem and feeling like I am never going to [achieve] anything in life and feel I bring shame to my family who brought me up with a good work ethic... I applied for many jobs getting a few interviews here and there trying my absolute best in them getting my hopes up only to be disappointed in not getting the job.<sup>1022</sup>

At a public hearing in Geelong, Ms Stacey Smith told the Committee about the workplace challenges for women with ASD, including sensory issues, struggling with change, and the difficulty of disclosing ASD to employers. She recounted her experience working in a customer service role to the Committee at a public hearing in Geelong, where she needed to create a ‘script’ beforehand for each situation she

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1018 Ms Sally Smith, Family and Community Development public hearing – Shepparton, 15 November 2016, transcript of evidence, pp. 5-6.

1019 The Australia-wide survey ascertained the views of over 300 adults with ASD and no co-occurring intellectual disability. Autism Spectrum Australia (Aspect), *We belong: The experiences, aspirations and needs of adults with Asperger's disorder and high functioning autism*, Autism Spectrum Australia (Aspect), 2013, accessed 1 June 2017, <[www.autismspectrum.org.au/sites/default/files/Autism\\_Spectrum\\_WE\\_BELONG\\_Research\\_Report-FINAL\\_LR\\_R.pdf](http://www.autismspectrum.org.au/sites/default/files/Autism_Spectrum_WE_BELONG_Research_Report-FINAL_LR_R.pdf)>, pp. 16, 37.

1020 Ms Chloe Fitton, Family and Community Development public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 8.

1021 Yellow Ladybugs, submission no. 117, p. 2.

1022 Ms Meaghan O'Brien, submission no. 109, pp. 1-2.

thought she might encounter at work. Part of her issues had to do with facial recognition and memory:

If the situation changed, I have had instances where I actually cannot recognise people – facial blindness. So I would get myself into situations where I have served a customer and they have come in in the afternoon and I forget who they were. There are so many issues, and that all adds to stress and anxiety and piles up.<sup>1023</sup>

Ms Smith also told the Committee about the ‘shutdowns’ she experienced, which impacted her home and working life:

Most adults have shutdowns rather than meltdowns where they cannot speak, they cannot do anything. They cannot do the housework. They need quiet, they need to be alone, they need to be away from people. If I got to the point where I was coming to a shutdown, how do I express that to people at work? How can I even verbalise it if I am not verbal?<sup>1024</sup>

One submitter, a woman with ASD, told the Committee about her struggles to become employable, her interactions with disability employment services, and the myriad of short-term employment she has experienced:

I have utilised the services of 9 Disability Employment Services, all initially said this would be easy and then kicked me out saying I was too complex and was not employable. I am now banned by Centrelink for accessing Disability Employment services on the basis of the last report written by one which said “the best we could hope for is an employer willing to tolerate having her around.” None of them had even a basic understanding of autism, none of them could comprehend my strengths versus my difficulties, they initially focussed on the strengths, and then could not work out where the difficulties came in and the problems they were going to cause if they were not accommodated. I have done close to 30 different jobs, primarily voluntary a few short paid jobs, but none lasted. People expected me to know more than I did and to have better social skills. They also could not comprehend the difficulties I have in what is often referred to as executive functioning deficits. Truth is I would need support to work and while I can do that with what is funded by the Disability Employment Services they actually have to be capable of providing it. I have each one of these services to give examples of what support they could offer me and they just kept saying we can support you, I said doing what, I was never answered. I asked for an example of what they had done with other people with autism to be told, we support many people with autism, when again I asked how, they never answered. All the jobs I have had were found by me without their support. A few have placed me in voluntary work, but it never lasted, largely because it was never supported.<sup>1025</sup>

Employment issues for adults with ASD were discussed in Chapter Five.

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1023 Ms Stacey Smith, Family and Community Development public hearing – Geelong, 19 September 2016, transcript of evidence, pp. 2-3.

1024 Ibid, p. 2.

1025 Name withheld, submission no. 138, p. 6.



While this chapter has focused on the experience of girls and women with ASD, this is not to detract from the experiences of boys and men. ASD affects all genders and all genders experience issues with diagnosis, treatment and accessing services. Every individual with autism has particular and diverse needs. An understanding of ASD in girls and women broadens and deepens an understanding of ASD more generally. There will be an ongoing need to understand the needs of boys and men as distinct from girls and women and to provide services that are relevant to their individual needs. Notwithstanding these differences, there will continue to be a need for a range of services, particularly mainstream, which will be equally applicable to both males and females.

This chapter has not examined the experiences of people with ASD who identify as gender diverse, but it was suggested to the Committee that people with autism may be represented in greater numbers in asexual and transgender communities compared with the general population.<sup>1026</sup>

From the evidence received, the Committee has formed the view that girls and women with ASD have particular needs as distinct from males and that these are currently insufficiently recognised, or not being met by health professionals, educators and service providers. The lack of understanding of the experience of girls and women with ASD impacts on diagnosis, intervention, schooling, employment, service delivery models and parenthood. It is also clear to the Committee that more research needs to be done to establish the characteristics and presentation of ASD in girls and women.

In relation to diagnosis of ASD in girls the Committee is of the view that health professionals require specific training to enable them to identify ASD behaviours and symptoms in girls in order to gain an accurate diagnosis, and to support early intervention.

Accordingly, the Committee recommends that:

### **RECOMMENDATION 7.1**

**The Victorian Government ensure that training and professional development be provided to health professionals diagnosing ASD in the recognition of how girls present with ASD, including gender specific behaviours and symptoms.**

In relation to the schooling of girls with ASD, the Committee is of the view that teachers require a greater awareness and understanding of how girls with ASD present in the classroom and the learning needs of girls with ASD. School environments need to better accommodate the particular learning needs of girls with ASD. Accordingly, the Committee recommends that:

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<sup>1026</sup> Mr Ryan Kennedy, Family and Community Development public hearing – Melbourne, 12 September 2016, transcript of evidence, p. 5.

## **RECOMMENDATION 7.2**

**The Victorian Government ensure that, as part of their training and professional development in ASD, teachers are provided with specific training to better understand how girls with ASD present, and the learning needs of girls with ASD.**

Given the evidence it has received, the Committee is of the view that girls and women with ASD benefit greatly from the work of community groups, such as the Yellow Ladybugs, that are focused specifically on their needs. Such groups generally lack funding support, which inhibits the range of support services they can provide. The Committee believes that the Information, Linkages and Capacity Building (ILC) of the NDIS is well suited under its grant scheme to fund community groups such as those created to support girls and women with ASD. Accordingly, the Committee recommends that:

## **RECOMMENDATION 7.3**

**The Victorian Government use its position on the COAG Disability Reform Council to advocate for the NDIA to provide grant funding opportunities under its Information, Linkages and Capacity Building program to community groups that specifically offer support programs and activities to girls and women with ASD.**

The Committee received limited evidence in relation to women with ASD and employment. However, in the evidence it did receive it was clear that the needs of women with ASD do not appear to be being met, either by disability employment services, or potential employers. As outlined in Chapter Five, the Committee believes that, as part of an updated State Autism Plan, an employment strategy for people with ASD will be needed, and will include specific provision for the needs of women with ASD. From the evidence received, it is clear to the Committee that there is limited community awareness of the needs of girls and women with ASD. The State Government can enhance community awareness of girls and women with ASD and the issues they face through a community awareness program delivered through an updated State Autism Plan.

Accordingly, the Committee recommends that:

## **RECOMMENDATION 7.4**

**The Victorian Government, in the updated State Autism Plan, and as part of the community education campaign aimed at raising awareness of ASD, include specific information on ASD in girls and women.**

# Chapter 8

## Health and Mental Health Services

### AT A GLANCE

#### Background

The Committee heard that there are many barriers to accessing mainstream health and mental health services, including a lack of understanding by health practitioners of ASD, communication difficulties, and sensory sensitivities. Health professionals also reported that communication difficulties, challenging behaviours, diagnostic overshadowing and the heterogeneity within ASD made it difficult to diagnose and treat health and mental health conditions.

People with ASD accessing mainstream health and mental health services reported confusion, a lack of coordination between health professionals working with the same individual, and a lack of understanding about ASD across the health and mental health system. Some parents of children with ASD reported difficulties ensuring that their children had access to mainstream health and dental services due to their heightened anxiety and sensory needs.

#### Chapter overview

This chapter focuses primarily on the experiences of people with ASD and families living with ASD accessing health services and the lack of coordination between health professionals working with the same individual. Issues covered include: access to mainstream health, mental health, hospital emergency and dental services; creating quiet rooms and addressing sensory needs; enhanced awareness/training of ASD amongst mainstream health professionals including hospital staff; and coordination and integration of health and mental health services for people with ASD.

This chapter relates primarily to the following terms of reference:

- (b) the availability and adequacy of services provided by the Commonwealth, State and local governments across health, education, disability, housing, sport and employment services; and
- (d) evidence of the social and economic cost of failing to provide adequate services.

The Committee heard that there are many barriers to accessing mainstream health and mental health services, including a lack of understanding by health practitioners of ASD, communication difficulties, and sensory sensitivities.<sup>1027</sup> Health professionals also reported that communication difficulties, challenging behaviours, diagnostic overshadowing and the heterogeneity within ASD made it difficult to diagnose and treat health and mental health conditions. People with ASD accessing mainstream health and mental health services reported confusion, a lack of coordination between health professionals working with the same individual, and a lack of understanding about ASD across the health and mental health system. Some parents of children with ASD reported difficulties ensuring that their children had access to mainstream health and dental services due to their heightened anxiety and sensory needs. This chapter focuses on the experiences of people with ASD and families living with ASD accessing mainstream health and mental health services.

The Royal Children's Hospital (RCH) Clinical Practice Guidelines on managing distress and agitation in ASD and developmental disabilities, cite two studies which show that children and teenagers with ASD and other developmental disabilities are '10 times more likely to be admitted to hospital for medical illnesses and complaints'.<sup>1028</sup> Other research has suggested that children with ASD have higher than expected rates of eczema, severe headaches, migraines, seizures, gastrointestinal problems, asthma, allergies, and ear and respiratory infections.<sup>1029</sup> A report published by UK charities Treating Autism and Autism Treatment Trust stated:

Medical comorbidities are much more prevalent and difficult to recognise in patients with autism than in the general population. The failure to identify such comorbidities is due in part to communication impairments and ambiguous symptomatology, but widespread under-diagnosis is also the result of commonly held beliefs that aberrant behaviours and symptoms are 'just a part of autism'. As a result, these pathologies are often left untreated.<sup>1030</sup>

This chapter relates primarily to the following terms of reference: (b) the availability and adequacy of services provided by the Commonwealth, State and local governments across health, education, disability, housing, sport and employment

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1027 Amaze, submission no. 139; Mindful – Centre for Training and Research in Developmental Health, submission no. 134; Royal Children's Hospital Melbourne, submission no. 143; Associate Professor Jill Sewell, Deputy Director, Centre for Community Child Health, Royal Children's Hospital, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence.

1028 T Lokhandwala, R Khanna and D West-Strum, 'Hospitalization burden among individuals with autism', *Journal of Autism and Developmental Disorders*, vol. 42, 2012, pp. 95-104, and H Leonard, B Petterson, N De Klerk et al., 'Association of sociodemographic characteristics of children with intellectual disability in Western Australia', *Social Science & Medicine*, 2005, vol. 60, pp. 1499-1513 cited in Royal Children's Hospital, 'Clinical Practice Guidelines: Autism and Developmental disability: managing distress and agitation', June 2015, accessed 23 May 2017, <[www.rch.org.au/clinicalguide/guideline\\_index/Autism\\_and\\_developmental\\_disability\\_\\_Management\\_of\\_distress/agitation](http://www.rch.org.au/clinicalguide/guideline_index/Autism_and_developmental_disability__Management_of_distress/agitation)>.

1029 Treating Autism Publications, *Medical comorbidities in autism spectrum disorders: A primer for health care professionals and policy makers*, March 2013, accessed 26 May 2017, <[nationalautismassociation.org/pdf/MedicalComorbiditiesinASD2013.pdf](http://nationalautismassociation.org/pdf/MedicalComorbiditiesinASD2013.pdf)>, p. 3.

1030 Ibid, p. 14.

services; and (d) evidence of the social and economic cost of failing to provide adequate services.

## **8.1. Access to mainstream health services**

The Committee heard from many people with ASD and families living with ASD about the experience of accessing mainstream health services, such as hospital emergency departments, dental services, and mental health facilities. Many individuals with ASD and their families told the Committee that accessing mainstream health services was particularly difficult for people with ASD due to the sensory sensitivities, communication difficulties, a lack of collaboration between services, and a lack of understanding of ASD among health professionals.

### **8.1.1. Hospital emergency and inpatient services**

The Committee heard that hospital emergency departments can be especially challenging for children and adults with ASD due to the often-chaotic nature of the hospital emergency environment. For people with ASD who have sensory sensitivities, the hospital emergency environment can overwhelm and distress an individual with ASD and heighten anxiety due to bright lights, different smells, loud noises, a crowded environment and long waiting times. The Committee heard that many emergency room doctors and nurses did not understand the sensitivities and communication difficulties associated with ASD.

The Office of the Health Services Commissioner (OHSC) expressed concern in their submission that people with ASD were not taken seriously when presenting to health service providers and hospitals:

The OHSC has received complaints about misdiagnosis or incorrect treatment of consumers with ASD. Adults with ASD have complained about not being taken seriously when presenting to health service providers. A number of consumers with ASD have presented at hospitals and were not properly treated for serious conditions, such as compaction of the bowel, ruptured bowel and testicular torsion.<sup>1031</sup>

One submitter to the Inquiry stated in their submission:

Having to present to emergency hospital services can be more stressful, trigger anxiety, frustration etc. Mental health and medical professionals have been unhelpful in their attitudes with a tendency to blame the patient and be generally unsympathetic.<sup>1032</sup>

While Ms Jane McLean, the mother of a son with ASD, praised the RCH where her son recently had surgery for toe-walking, she told the Committee at a public hearing in

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<sup>1031</sup> Office of the Health Services Commissioner, submission no. 116, p. 2.

<sup>1032</sup> Name withheld, submission no. 118, p. 2.

Swan Hill that there was a lack of understanding about her son's ability to communicate:

It was an amazing service, but I guess there was not a lot of understanding in terms of his autism and his speech. It seemed to take them by surprise, I guess, even though it was kind of obvious... they would be asking, 'How is the pain?', and they would not be able to understand what he said, they would sort of be frustrated and then [he] would be frustrated.<sup>1033</sup>

In her submission, Ms Elisabeth Appelgren-McIntyre, the mother of two adult sons with ASD, spoke of the challenges of the hospital environment with constant change, turnover of staff and a lack of continuity of care:

Another issue which affects autistic people negatively is the frequent change of staff in these settings, particularly if a casual staff member turns up who has never worked with a client previously. There is never a proper handover, as in hospitals and age care, because neither the agency the casual worker is employed by, nor the care facility is prepared to pay for an extra 10/15 minutes that it would take to hand over information!<sup>1034</sup>

At a public hearing in Melbourne, Ms Dianna Lane told the Committee about the difficulties her 17-year-old daughter faces with new situations and procedures like blood tests:

We do have to get a blood test for her and I did ring up Amaze because to even get her into a place to actually get a blood test – we have been waiting two months to try and work her up to it. It is just really difficult. New situations really throw her and us in the family as well.<sup>1035</sup>

Some families who had experienced health services prior to the diagnosis of their children reported frustration at signs of ASD not being recognised and their children being misdiagnosed. One person who submitted to the Inquiry wrote about their 11-year-old son's experience at hospital:

In 2013, prior to my son receiving a diagnosis of ASD, my eldest son, 11, came under the care of Austin Hospital CAMHS as a result of some very complex and challenging behavioural and emotional issues. Both ambulance and police had been involved in dealing with my son's highly escalated state (involving significant property damage, threatening behaviour towards myself and his 6 year old autistic brother and my elderly mother, now deceased). Despite my view that there was an underlying condition contributing to these behaviours of concern, the health professionals involved in assessment insisted that these behaviours of concern were caused solely by 'parent child relational issues' and other contributing factors due to relocation, divorce and ongoing conflict between parents. While I received

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1033 Ms Jane McLean, Family and Community Development public hearing – Swan Hill, 14 February 2017, transcript of evidence, p. 3.

1034 Ms Elisabeth Appelgren-McIntyre, submission no. 95, p. 6.

1035 Ms Dianna Lane, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 3.

emotional and behavior management support, I knew there was something more going on with my son but they were adamant and they were the ‘experts.’<sup>1036</sup>

In their submission, Austin CAMHS drew attention to the challenge for medical staff in addressing anxiety and distress which may arise as a result of the hospital outpatient environment:

Doctors in busy outpatient departments generally need to make special arrangements for clients using public hospital outpatient clinics in order to avoid increased anxiety and the possibility of aggression and distress arising from waiting in large crowds. The likelihood of this occurring is dependent on both the facilities available and awareness of need by medical staff.<sup>1037</sup>

At a public hearing in Melbourne, the Committee heard from Victoria’s Chief Psychiatrist Dr Neil Coventry who stated that he was ‘particularly concerned’ about his hospital colleagues in emergency departments:

Usually an emergency department is very busy and a very different sort of role, and sometimes people with autism do not get treated with the right sort of care and respect... Sometimes people will be picking up a patient with an intellectual disorder, but they do not understand the autism component of that, which might need very different treatment, and they are just responding to the behaviour...<sup>1038</sup>

### **Transitioning to adult health services**

Many parents spoke to the Committee about their concerns as their child aged and became ineligible for paediatric care. Ms Lane spoke to the Committee at a public hearing in Melbourne about her daughter’s transition to adulthood and her daughter’s fears about transitioning to adult health services:

She leaves the paediatric [ward] and moves [to an adult ward], which is also very frightening as well for her. It is the safety aspect. If she does have to go to hospital for any reason and she is in there with all adults, it is just mind-boggling.<sup>1039</sup>

At a public hearing in Geelong, Ms Sarah Hayden told the Committee that her 19-year-old daughter was frequently misunderstood by medical staff:

[M]y daughter has a lot of phobias around medical staff, ambulances, needles, hospitals – very, very severe to the point where she would have to be held down. That was very misunderstood, because they looked at her. She is a beautiful-looking, normal-looking 19-year-old girl, and the hospital staff I found were very unable to accept the fact that this was somebody who looked normal, as one of the nurses said to me, and that she was coping like a toddler or a brat or something else that I heard many of the staff talking about and addressing. I was

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1036 Name withheld, submission no. 145, p. 1.

1037 Austin Child and Adolescent Mental Health Service, submission no. 113, p. 3.

1038 Dr Neil Coventry, Chief Psychiatrist, Department of Health and Human Services, Family and Community Development public hearing – Melbourne, 7 November 2016, transcript of evidence, p. 17.

1039 Ms Dianna Lane, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 3.



not allowed to stay with her during procedures or overnight, they told me. I said if that was the case, I would have to take her home, because she would not be able to stay in there by herself; it just was not a possibility. So suddenly she was being treated as an adult and not as somebody who, even though she has a high IQ — she has high-functioning autism — she in a lot of ways has the mentality of somebody probably a third of her age.<sup>1040</sup>

Ms Hayden described a hospital experience for her daughter in which she was treated like an adult:

She was kicked in the pelvis, so a lot of her examinations were done in the lower pelvis. They would ask me to leave the room because she was an adult, and she would be sitting there holding my hands terrified, or my husband, and the doctors would say, 'It's not appropriate. You're an adult. You're okay'. I ended up losing it at the staff. I found out that none of them knew that she had autism, so despite the fact I had explained it to them when they came in, they knew the accident she had had, they knew the fact that she had internal bleeding, she had this, she had that, they had no idea she had autism.

I thought about what we could do to help people with autism. Is there something we can put above the bed to explain? I ended up speaking to one of the nurses and saying to her, 'Are you aware that my daughter has autism?'. She just looked at me and said, 'No. Is that why she is acting like this?'. I said, 'Yes. It is the first thing I said when she hopped in the ambulance'.<sup>1041</sup>

Ms Hayden's daughter has food phobias, which the hospital did not cater for so her daughter went without food for three days. She described what the experience was like for her daughter:

In her words, she said to me that she had felt belittled. She said that she felt that she was misunderstood, she was ridiculed. She said she was treated like a bratty teenager and was made to feel like it was unacceptable for her to want an adult in the room with her at all times. ... She said to me after we got home from hospital last week, 'The hardest thing about this, Mum, was that everyone expected me to be like an adult', whereas at the children's hospital, even when she was 18, they still accepted that she was a child because she was allowed to be in a children's ward. For an adult with autism to have to be in an adult ward and act like an adult, and for everyone around her to expect her to act like an adult was really traumatic for her. She just went into meltdown mode where she did not want to talk, and I would start talking for her. I actually had some doctors saying, 'Stop. We're asking her'. They could not understand that she could not even speak anymore, she was so petrified. Again when I questioned the doctors, 'Are you aware she has ASD?', they said, 'No, we did not know'. They had not read the file on coming in. Anyway, that was hospital.<sup>1042</sup>

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1040 Ms Sarah Hayden, Family and Community Development public hearing – Geelong, 19 September 2016, transcript of evidence, p. 2.

1041 Ibid.

1042 Ibid, pp. 2, 3.

### 8.1.2. Dental services

The Committee heard that many children and adults with ASD found accessing dental services challenging, particularly those that struggled with sensory integration.<sup>1043</sup> In her submission, Ms Deborah Ditchburn, the mother of a nine-year-old son with ASD, wrote of her son's experience with emergency dental surgery:

I recently had an experience in hospital with my son when he needed emergency dental surgery. This was quite traumatic for my sensory sensitive child. The nurses, although wonderful and very caring, all agreed that this environment doesn't completely cater for these patients. Following the surgery, I required the services of a paediatric special needs dentist. The only one I was able to find was attached to the Royal Dental Hospital, with a 12 month wait list.<sup>1044</sup>

The Committee heard that it is not uncommon for some people with ASD to need a general anaesthetic or sedation for dental treatment. Ms Carmel Murphy spoke about her daughter with ASD needing to have a general anaesthetic at Bairnsdale hospital to have her teeth checked every year. The general anaesthetic is administered by a visiting Melbourne anaesthetist who specialises in children with special needs.<sup>1045</sup>

At a public hearing in Geelong, Ms Stacey Smith spoke to the Committee about the difficulties interacting with healthcare professionals, such as dentists:

[I]t is the same with healthcare professionals across the board, whether it is a dentist, and especially for mothers, midwives, hospitals, babies, GPs. They do not understand. They do not know how to help you. I am looking for a new dentist because every time I take my children to the dentist I have got to go through what they have and what their issues are and why they will not speak back when they are asked questions. You say 'autism' and then they have a whole opinion about autism, and all of a sudden I am defending it, 'No, it is not overdiagnosed. No, they don't give out diagnoses easily'. I get so frustrated that I try and shut it down by saying, 'Well, I'm autistic too', and then they question that.<sup>1046</sup>

Ms Smith told the Committee that a dentist 'has to have an understanding of sensory issues' impacting people with ASD. She spoke about her experience of a dentist not understanding the presentation of ASD in adults and how hurtful it was to be mistaken for a drug user:

[Dentists] cannot just focus on children, because these children are going to grow up. They internalise it more, but it is just such a minefield. I have had a really bad experience as an adult at a dentist. I hate going. I was very nervous. I was stimming a lot, so I probably was not giving eye contact and I was moving like this. He asked if I was a drug taker or drug user, and I got so upset. I was bawling my eyes out. I could not understand why, and now I look back and I know I must have been not looking where I should have been looking. I must have been moving a lot. I was

1043 Victorian Disability Advisory Council, submission no. 146, p. 9.

1044 Ms Deborah Ditchburn, submission no. 21, p. 2.

1045 Ms Carmel Murphy, submission no. 20, p. 1.

1046 Ms Stacey Smith, Family and Community Development public hearing – Geelong, 19 September 2016, transcript of evidence, p. 3.

very nervous, so immediately they thought, 'You're a drug user', and kept on asking me all these questions to that effect. It was like, 'I'm just here; I don't want to be here. I want to get treated'.<sup>1047</sup>

At a public hearing in Melbourne, Mr Christopher Reid noted that there was a need for more sensory-friendly service providers:

It would also be helpful if children's sensory needs were supported more widely. Melbourne has only two special-needs dental surgeries, and to my knowledge no special-needs hairdressing salons. Perhaps there could be incentives for dentists and hairdressers to retrain and offer these services, or an accreditation process for hairdressers that cater specifically for special needs children.<sup>1048</sup>

The Dental Clinic at the RCH is offered to children and adolescents with chronic medical or dental problems 'which may prevent them obtaining dental care elsewhere'.<sup>1049</sup> Children with 'severe or chronic developmental conditions and/or a behavioural disability for whom there are barriers to accessing routine community dental care services' are eligible for the RCH Dental Clinic. This includes children with global developmental delay, severe intellectual disability and ASD, including ADHD and OCD.<sup>1050</sup> Any health care practitioner or allied health care practitioner can refer patients.<sup>1051</sup>

At a public hearing in Melbourne, Ms Dianna Lane told the Committee about her daughter's experience accessing the RCH Dental Clinic:

The Royal Children's Hospital is fantastic. They completely understand what you are going through — we have to access the dental unit there. We can now get her in and sit her in the chair for about 5 minutes before she jumps up and has to run out. But they are wonderful. You know they will have little things to comfort her and calm her down.<sup>1052</sup>

The Committee is concerned that many children and adults with ASD have had difficult experiences accessing dental services due to sensory sensitivities and the lack of awareness of ASD among dental clinicians. The Committee believes that while the RCH Dental Clinic is providing an excellent service, there is a need for more sensory-friendly service providers and that general dental clinics would benefit from an understanding and awareness of the sensory needs of both children and adults with ASD. Accordingly, the Committee recommends that:

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1047 Ibid.

1048 Mr Christopher Reid, Family and Community Development Committee public hearing – Melbourne, 12 September 2016, transcript of evidence, p. 3.

1049 Royal Children's Hospital, 'About the Department of Dentistry', accessed 21 May 2017, <[www.rch.org.au/dentistry](http://www.rch.org.au/dentistry)>.

1050 Royal Children's Hospital, 'Dentistry: Eligibility criteria', accessed 21 May 2017, <[www.rch.org.au/dentistry/about\\_us/Eligibility\\_criteria](http://www.rch.org.au/dentistry/about_us/Eligibility_criteria)>.

1051 Royal Children's Hospital, 'Dentistry: Referral procedure', accessed 21 May 2017, <[www.rch.org.au/dentistry/about\\_us/Eligibility\\_criteria](http://www.rch.org.au/dentistry/about_us/Eligibility_criteria)>.

1052 Ms Dianna Lane, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 4.

**RECOMMENDATION 8.1**

**The Victorian Government in conjunction with the Australian Dental Association – Victorian Branch develop education and training options to dental clinicians in understanding ASD and the way in which ASD presents in their clients.**

**8.2. Mental health**

ASD frequently co-occurs with mental illnesses, particularly anxiety and depression. A recent report from the Australian Advisory Board on Autism Spectrum Disorders and funded by FaHCSIA found that people with ASD experience ‘strikingly high rates of lifetime mental illness ... in the 50-70% range’.<sup>1053</sup>

As discussed in Chapter Four, for many people with ASD, the school years are characterised by bullying, social isolation, and the failure of schools to meet learning support needs.<sup>1054</sup> In adulthood, people with ASD may experience increased social isolation, unemployment and mental health issues.<sup>1055</sup> The report stated that there is a lack of knowledge and a lack of sector collaboration which has contributed to health services ‘not taking an appropriate level of responsibility for the identification, assessment, intervention and care of the mental health needs of people with an ASD’.<sup>1056</sup> The report states that:

These factors also explain to some extent why services often mistakenly view mental health concerns as part of the person’s ASD, often resulting in a failure to even recognise mental illness, let alone treat mental health issues.<sup>1057</sup>

The report made several recommendations, including the following recommendation around improved recognition and treatment of co-occurring mental health conditions:

Because people with an ASD have a significantly increased risk for co-morbid mental health conditions, we call for improved recognition and treatment of these by services with specialist ASD and mental health knowledge and skills.<sup>1058</sup>

The report also made the following recommendation around mental health surveillance:

We call for the ongoing surveillance of the mental health of children and young people, commencing at the age of initial diagnosis of an ASD, in order to identify

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1053 Australian Advisory Board on Autism Spectrum Disorders, *The interface between Autism Spectrum Disorders and Mental Health: The ways forward*, discussion paper, December 2012, accessed 23 May 2017, <[www.autismadvisoryboard.org.au/uploads/file/pdfs/The%20Interface%20between%20ASD%20and%20Mental%20Health%20AAB.pdf](http://www.autismadvisoryboard.org.au/uploads/file/pdfs/The%20Interface%20between%20ASD%20and%20Mental%20Health%20AAB.pdf)>.

1054 Ibid, p. 3.

1055 Ibid.

1056 Ibid.

1057 Ibid.

1058 Ibid, p. 4.

and treat as early as possible mental health issues such as anxiety and depression.<sup>1059</sup>

Autism Spectrum Australia's (Aspect) *We Belong* survey, which is the first large scale study of adults with ASD in Australia, found that 78 per cent of adults with ASD who responded to the survey experienced frequent worry or stress and 71 per cent experienced a mental health condition.<sup>1060</sup> The report also found that people with ASD living in rural and regional areas were more likely to report experiencing frequent worry or stress (87 per cent) compared with those living in urban areas (76 per cent).<sup>1061</sup> Furthermore, a higher proportion of females with ASD (83 per cent) reported having a mental health condition compared with males with ASD (67 per cent).<sup>1062</sup> Over 40 per cent of the people with ASD who experienced frequent worry or stress, communication difficulties, and mental health conditions had unmet support needs and indicated that they needed more support to help them manage these health and wellbeing issues.<sup>1063</sup>

The Committee heard that some people with ASD were anxious about seeking treatment for mental health conditions. At a public hearing in Bendigo, Ms Chloe Fitton expressed concern about being 'shuffled around the mental health system... because nobody knows how to deal with us':

I cannot really feel safe, because if I have to go back and get in contact with the John Bomford Centre because my mental health is worsening, I do not know what is going to happen to me, and I know that I am not going to have a great lot of say in that. I know that my medical records still have my incorrect diagnoses on them, which directly affects my treatment. Even if I go up to the ER, one of the first things that they will see on my file is the incorrect diagnoses. The stigma against mental health anyway is a disgusting thing that directly affects the way I get treated, so I need to be able to go to places and feel safe when I need help.<sup>1064</sup>

The Committee heard that difficulties in communication often presented a barrier to accessing health and mental health assessment, treatment and services. At a public hearing in Melbourne, Ms Florence McIver told the Committee about the difficulty in diagnosing a mental illness in her son with ASD who is 'almost non-verbal':

In the past two years our son has regressed cognitively and socially, and we do not know why. We have been to countless doctors and professionals, and they do not know. We think it is mental illness that seems to have been added to the mix, and we are told it is not unusual in young adults with ASD as they come to realise that life will be very different. As very little is known about the brain and where ASD comes from and as literally no two autistic children are the same, knowledgeable

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1059 Ibid.

1060 Autism Spectrum Australia (Aspect), *We Belong: The experiences, aspirations and needs of adults with Asperger's disorder and high functioning autism*, April 2013, accessed 23 May 2017, <[www.autismspectrum.org.au/sites/default/files/Autism\\_Spectrum\\_WE\\_BELONG\\_Research\\_Report-FINAL\\_LR\\_R.pdf](http://www.autismspectrum.org.au/sites/default/files/Autism_Spectrum_WE_BELONG_Research_Report-FINAL_LR_R.pdf)>, p. 15.

1061 Ibid, p. 16.

1062 Ibid.

1063 Ibid, p. 17.

1064 Ms Chloe Fitton, Family and Community Development public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 5.

mental health support is hard to find. Our son is almost non-verbal, which makes it even trickier to diagnose anything.<sup>1065</sup>

Dr Coventry told the Committee that difficulties around verbal communication added to the complexity of managing patients with ASD and co-occurring mental illnesses:

[U]nfortunately there is quite a high comorbidity or coexistence of psychiatric illness and autism. It means that some autistic young people and adults end up in our public mental health services. Particularly because of their difficulties around verbal communication often their distress is communicated by challenging behaviours, and it is challenging for everyone to understand how best to try and manage them.<sup>1066</sup>

The issue of diagnostic overshadowing is also a challenge for mental health practitioners and it can be difficult for practitioners to distinguish symptoms of mental ill health from ASD.<sup>1067</sup> As stated in an article in the Royal Australian College of General Practitioners' (RACGP) journal *Australian Family Practitioner*:

Diagnostic overshadowing, limitations of communication skills and the heterogeneous nature of this patient population can make practice in this area more challenging, and can contribute to poorer outcomes, including overprescribing of psychotropic medications.<sup>1068</sup>

Importantly, in their submission, Austin CAMHS emphasised the need to accommodate ASD before the mental health needs can be addressed:

The needs of a person with ASD and significant intellectual disability experiencing mental illness, distress and aggression may be difficult to accommodate on a ward where the population, presentations and needs may be very different. In the writer's view, the primary diagnosis of ASD/ Intellectual Disability needs to be accommodated before the mental health needs can be addressed and this may best occur in a specialised facility with disability trained staff who have additional training in mental health. No such facility exists in Melbourne currently.<sup>1069</sup>

Ms Chloe Fitton told the Committee at a public hearing in Bendigo about being misdiagnosed with bipolar disorder and being placed on a range of different medications:

When getting help for mental health issues like anxiety, depression or even more severe issues, non-typically presenting Autistic people are significantly more likely to be diagnosed with things like OCD, bipolar disorder or personality disorders, especially those from cluster B, if you are a woman, and to be shunted around

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1065 Ms Florence McIver, Family and Community Development Committee public hearing – Melbourne, 12 September 2016, transcript of evidence, p. 3.

1066 Dr Neil Coventry, Chief Psychiatrist, Department of Health and Human Services, Family and Community Development public hearing – Melbourne, 7 November 2016, transcript of evidence, pp. 6-7.

1067 K Foley and J Troller, 'Management of mental ill health in people with autism spectrum disorder', *Australian Family Practitioner*, vol. 44, no. 11, November 2015, pp. 784-790.

1068 Ibid.

1069 Austin Child and Adolescent Mental Health Service, submission no. 113, p. 3.

different parts of the mental health system... Mental health services are incredibly hesitant to diagnose adults, especially women, with Autism. My journey to getting diagnosed started with me being kicked out of home while I was in ... the Youth Prevention and Recovery Care centre in Bendigo. They also did not have any idea what to do with me. I was not diagnosed then. They diagnosed me with bipolar disorder, which I do not have. They had no idea how to help me, because I think differently. I behave differently. I do not make sense to them, which is okay; they do not know. So since getting kicked out of home I have been shunted around both public and private sector mental health facilities, had no say in my treatment and been put on all of these different kinds of drugs that have a significant effect on both my physical and mental health.<sup>1070</sup>

### **Child and adolescent mental health services**

As discussed in Chapter Three, the Child and Adolescent Mental Health Services (CAMHS) provide comprehensive services for children and adolescents up to the age of 18 years experiencing mental health problems. The Child and Youth Mental Health Services (CYMHS) provides services for children and youth up to the age of 25.

Both CAMHS and CYMHS are government-funded to conduct multidisciplinary assessments and diagnosis of ASD and have assessment teams in metropolitan and regional areas. Child and mental health services provide a range of mental health services including crisis assessment and treatment and an intensive mobile youth outreach support service, and inpatient services.<sup>1071</sup>

The Committee heard that CAMHS are over-stretched and have significant waiting lists with patients prioritised by urgency.<sup>1072</sup> Consequently, the majority of the CAMHS service is devoted to supporting people experiencing acute mental health crises, rather than ASD assessments.<sup>1073</sup> The combined submission of clinicians and parents associated with the Autism Spectrum Disorder Assessment Program (ASDAP) within Austin CAMHS noted that: 'There is a gap in access for families seeking diagnosis in older children without mental health difficulties'.<sup>1074</sup>

In their submission to the Committee, the Victorian branch of the Royal Australian and New Zealand College of Psychiatrists (RANZCP) noted that the training of the CAMHS workforce 'needs to enable clinicians to work with the levels of complexity often present in children with severe ASD and comorbidities'.<sup>1075</sup> They stated that it is

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1070 Ms Chloe Fitton, Family and Community Development public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 3.

1071 Department of Health and Human Services, 'Child and adolescent mental health services', accessed 26 May 2017, <[www2.health.vic.gov.au/mental-health/mental-health-services/services-by-population-group/services-for-children-and-adolescents/child-and-adolescent-mental-health-services](http://www2.health.vic.gov.au/mental-health/mental-health-services/services-by-population-group/services-for-children-and-adolescents/child-and-adolescent-mental-health-services)>.

1072 Ms Frances Saunders, Statewide Autism Spectrum Disorder Coordinator, Mindful, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 6.

1073 K Bull and S Radovini, *A guide to identification, diagnosis and treatment of autism spectrum disorder in Victorian mental health services*, Mindful Centre for Training and Research in Developmental Health, Melbourne, 2013, p. 57.

1074 Austin Child and Adolescent Mental Health Service, submission no. 113, p. 2.

1075 Royal Australian and New Zealand College of Psychiatrists (RANZCP) Victorian Branch Committee, submission no. 144, p. 5.



important that CAMHS are resourced ‘at a level that allows for genuine cross-sector collaboration’ so that CAMHS have the capacity to share information with multiple services, and ‘the time to invest in case coordination, consultation and liaison’.<sup>1076</sup> They stated:

It is essential that children with severe ASD and co-morbidities are able to access child and adolescent mental health services (CAMHS) as required. This necessitates the presence of a highly trained workforce, including psychiatrists with advanced training in child and adolescent mental health. Currently there are shortages and maldistribution in some psychiatry trainee positions, meaning that trainees will encounter difficulty securing the positions they require to complete their rotations. This is particularly the case for child and adolescent psychiatry where previously advanced trainee positions are now largely being taken up by mandatory child and adolescent psychiatry rotations. This issue has significant implications for the future of the child and adolescent psychiatry workforce in Victoria.<sup>1077</sup>

### Adult mental health services

The Committee heard that support for adults with ASD and mental illness was ‘very patchy’.<sup>1078</sup> Furthermore, there is a lack of research on adults with ASD who also have co-occurring mental illnesses.<sup>1079</sup> This is consistent with services for adults with ASD more generally. As noted in Chapter Five, there are no publicly funded assessment and diagnostic services for adults and no funded targeted intervention therapies for adults. There is also a paucity of specialists who understand ASD in adults.

In their submission to the Committee, the Victorian branch of the Royal Australian and New Zealand College of Psychiatrists (RANZCP) stated that it is essential that public mental health services are able to respond to adults with ASD as co-occurring mental illness and behavioural and emotional disturbances are present in 20-40 per cent of adults with ASD:

[G]eneralist public mental health services do not always have the expertise available to assess and identify the complicating presence of ASD in adults with mental illness, or alternatively the presence of mental illness in adults with ASD.<sup>1080</sup>

In their submission to the Inquiry, Professor Bruce Tonge and Dr Avril V Brereton from Monash University’s Centre for Developmental Psychiatry and Psychology also stated that there is a lack of expertise in public mental health services in assessing and

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1076 Ibid.

1077 Ibid.

1078 Dr Sandra Radovini, Director of Mindful, Centre for Training and Research in Developmental Health, Department of Psychiatry, University of Melbourne, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 8.

1079 K Foley and J Troller, ‘Management of mental ill health in people with autism spectrum disorder’, *Australian Family Practitioner*, vol. 44, no. 11, November 2015, pp. 784-790.

1080 Royal Australian and New Zealand College of Psychiatrists (RANZCP) Victorian Branch Committee, submission no. 144, p. 5. See also: Professor Bruce Tonge and Dr Avril V Brereton, submission no. 48, p. 1.

identifying the presence of mental illness in adults with an ASD, which is concerning given the high prevalence of co-occurring mental illness in people with ASD.<sup>1081</sup>

The Committee heard that there were gaps in understanding ASD in adults, and that adult inpatient services did not see many people with ASD, unlike child and adolescent mental health services, and thus they were not experienced in treating adults with ASD appropriately. To address this, Dr Coventry stated that there were efforts to encourage consultations across sectors:

In many services we are encouraging the child and adolescent staff to provide some in-region consultation to their mental health adult colleagues to help them manage these patients better.<sup>1082</sup>

### **8.3. Supporting people with ASD in accessing mainstream health and mental health services**

The Committee heard of several strategies and improvements that could enable mainstream health and mental health services to be more accessible and inclusive for children and adults with ASD. These included creating quiet rooms to address sensory needs, providing support for transitions such as through social stories, and enhancing the awareness and knowledge of ASD among mainstream health and mental health staff.<sup>1083</sup>

#### **8.3.1. Creating quiet rooms and addressing sensory needs**

In their combined submission, Distinctive Options, The Lab Network and Smart Communities recommended that hospitals consider the development of specific treatment areas, such as autism sensitive wards, to accommodate the needs of individuals with ASD.<sup>1084</sup> Many healthcare providers recognised the need for a calm, sensory sensitive environment for people with ASD.<sup>1085</sup> This was often a challenge with existing building infrastructure.<sup>1086</sup>

In their supplementary submission, the Royal Children's Hospital noted that 'by its very nature, the RCH is a busy hospital with a highly stimulating environment with limited low stimulus and sensory appropriate spaces' and that challenging behaviours 'are often exacerbated in the foreign and overwhelming hospital

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1081 Professor Bruce Tonge and Dr Avril V Brereton, submission no. 48, p. 1.

1082 Dr Neil Coventry, Chief Psychiatrist, Department of Health and Human Services, Family and Community Development public hearing – Melbourne, 7 November 2016, transcript of evidence, p. 17.

1083 Royal Children's Hospital, submission no. 150; Distinctive Options, The Lab Network and Smart Communities, submission no. 77.

1084 Distinctive Options, The Lab Network and Smart Communities, submission no. 77, p. 7.

1085 Royal Children's Hospital, submission no. 150, p. 4; Ms Liz Morkham, ASD coordinator, Austin Child and Adolescent Mental Health Service, Mindful, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 8.

1086 Ms Leonie Baker, Chief Speech Pathologist, Swan Hill District Health, Family and Community Development public hearing – Swan Hill, 14 February 2017, transcript of evidence, p. 5.

environment'.<sup>1087</sup> However, in relation to addressing challenging behaviours, the RCH outlined some of the steps they had taken, including the following:

- providing 'a containing environment' by closing beds to 'facilitate a safe and quieter environment';
- ensuring the child or young person is safely cared for by two nursing staff at all times;
- conducting daily or twice-daily multidisciplinary meetings to ensure that all aspects of care and key behavioural management strategies are identified and incorporated into a comprehensive care management plan; and
- providing sensory-specific treatment and where possible routine activities promoting consistency with all aspects of care delivery.<sup>1088</sup>

Currently, planning and design teams of public healthcare facilities need to ensure that health care facilities are suitable for people with a wide range of disabilities. These requirements are contained in the Commonwealth *Disability Discrimination Act 1992* (section 23) and in the *Australasian Health Facilities Guidelines* (AusHFG).<sup>1089</sup> The Australasian Health Infrastructure Alliance (AHIA), which is the custodian of the AusHFG, provides information in the form of 'Health Planning Units (HPUs)' to support planners and project managers in the design of health facilities.<sup>1090</sup> HPUs have been developed to assist in the planning and design of a range of hospital spaces, including hospital reception areas, emergency departments, mental health units, and Child and Adolescent Mental Health Units. These HPUs set out environmental considerations, such as acoustics, lighting, and interior décor, and include guidance on natural lighting, sensory/quiet rooms, the use of sound-absorbing materials, sensory modulation therapy rooms, the separation of quiet areas from noisy areas, and the avoidance of colour and pattern extremes in décor.<sup>1091</sup>

The new Bendigo Hospital has an emergency department that features 'a discreet entry for behaviourally disturbed patients', family rooms that offer a private and quiet space for families, and a tranquil garden space.<sup>1092</sup> A research project conducted by RMIT and funded by Exemplar Health is currently studying whether the new hospital

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1087 Royal Children's Hospital, submission no. 150, p. 3.

1088 Royal Children's Hospital, submission no. 150, pp. 3-4.

1089 Australasian Health Infrastructure Alliance (AHIA), *Australasian Health Facility Guidelines*, North Sydney, AHIA, 2015.

1090 Australasian Health Infrastructure Alliance (AHIA), 'Health planning units', accessed 31 May 2017, <[healthfacilityguidelines.com.au/health-planning-units](http://healthfacilityguidelines.com.au/health-planning-units)>.

1091 Ibid.

1092 Bendigo Hospital Project, 'Preserving our past, building our future', accessed 30 May 2017, <[bendigohospitalproject.org.au/wp-content/uploads/2013/12/New\\_Bendigo\\_Hospital\\_Newsletter\\_March\\_2016.pdf](http://bendigohospitalproject.org.au/wp-content/uploads/2013/12/New_Bendigo_Hospital_Newsletter_March_2016.pdf)>; Bendigo Health, 'New Bendigo Hospital', accessed 30 May 2017, <[www.bendigohealth.org.au](http://www.bendigohealth.org.au)>.

design improves patient care, reduces aggressive behaviour and enables patients to feel in control.<sup>1093</sup>

In an article for the RACGP journal *Australian Family Practitioner*, authors Kitty-Rose Foley and Julian Troller, who are both associated with the Autism CRC, state that sensory sensitivities may complicate assessment and management of mental disorders:

Sensory processing differences are now included within the diagnostic criteria for ASD. Heightened or lowered tolerance to sound, vision, touch, movement, taste and smell can be experienced by individuals with ASD. Inability to tolerate sensory input can have an impact on the adult's ability to participate in the community, and have significant implications for their mental health (eg as a driver of anxiety and avoidance symptoms). Referral to an occupational therapist for a sensory assessment and therapy may be useful. However, practitioners should be aware that evidence for the effectiveness of sensory interventions is limited at this time. In view of issues with sensory tolerance, adaptations to consultation rooms in general practice may improve the consultation experience for adults with ASD. These include avoiding fluorescent lighting, dimming the lights, reducing visual distractions, minimising auditory distractions including those from machines and loud ticking clocks, providing a comfortable chair, and fidget, tactile and/or weighted items that the person may hold or touch to aid in self-regulation.<sup>1094</sup>

In addition to considering the environment of the waiting room and offices, the article advised GPs to allow additional time for consultations and adjust their communication style when attending to a patient with ASD.<sup>1095</sup>

There is a range of health and mental health resources for people with ASD and medical professionals on the Autism CRC website, including information on how medical professionals should communicate with people with ASD, as well as visual boards to convey medical procedures and instructions.<sup>1096</sup> Guidance for health professionals include:

- showing empathy and an understanding of the sensory, communication and processing differences;
- providing visual information;
- giving the individual time to process verbal information and to respond;
- providing a quiet environment; and

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1093 S Corsetti, 'Bendigo Health aims to prove hospital patients benefit from design', *ABC News* online, 15 August 2016, <[www.abc.net.au/news/2016-08-11/bendigo-hospital-design-aims-to-help-patient-recovery/7717830](http://www.abc.net.au/news/2016-08-11/bendigo-hospital-design-aims-to-help-patient-recovery/7717830)>. See also: Bendigo Hospital Project, 'Exemplar Health funds RMIT research into hospital design', accessed 30 May 2017, <[bendigohospitalproject.org.au/exemplar-health-funds-rmit-research-into-hospital-design](http://bendigohospitalproject.org.au/exemplar-health-funds-rmit-research-into-hospital-design)>.

1094 Footnotes in original omitted. K Foley and J Troller, 'Management of mental ill health in people with autism spectrum disorder', *Australian Family Practitioner*, vol. 44, no. 11, November 2015, pp. 784-790, p. 788.

1095 K Foley and J Troller, 'Management of mental ill health in people with autism spectrum disorder', *Australian Family Practitioner*, vol. 44, no. 11, November 2015, pp. 784-790, p. 789.

1096 Autism CRC, 'Health hub', accessed 26 May 2017, <[www.autismcrc.com.au/health-hub](http://www.autismcrc.com.au/health-hub)>.

- understanding the communication preferences and needs of the individual (asking: how can I convey this information differently?).<sup>1097</sup>

The Committee heard that people with ASD benefit from a calm environment. The Committee is of the view that the design of new hospitals and healthcare facilities should have provision in their budget for quiet spaces. Existing hospitals and healthcare facilities need to modify their environments to accommodate the sensory needs of people with ASD. The Committee is also of the view that more broadly public health and mental health services need to accommodate the needs of people with ASD who present as their patients. Accordingly, the Committee recommends:

### **RECOMMENDATION 8.2**

**In the updated State Autism Plan, the Victorian Government develop a strategy for public health and mental health services to accommodate the needs of people with ASD, including the roll out of autism specialists in the public health system.**

- **That people with ASD are identified on presentation to health services and that this information is recorded.**

### **RECOMMENDATION 8.3**

**The Victorian Government ensure all new and existing public hospitals and healthcare facilities have provision for dedicated quiet spaces for people with ASD in emergency departments and other inpatient and outpatient areas.**

## **8.3.2. Enhanced awareness/training of ASD amongst mainstream health professionals including hospital staff**

At a public hearing in Melbourne, Ms France Saunders stated that mental health community support services 'feel reluctant to accept referral of clients with ASD because they do not feel they have a sufficient level of training'.<sup>1098</sup>

This was also the case in hospital settings. Ms Saunders told the Committee:

[I]n hospitals it is a huge problem when young people present to accident and emergency and nobody knows that they are on the spectrum, or people do know they are on the spectrum and they do not know how to respond.<sup>1099</sup>

Mallee Family Care noted in their submission to the Inquiry that there was a lack of understanding from nurses about how to deal with challenging behaviours when they

1097 Autism CRC, 'What do health professionals need to better understand autism?', accessed 29 May 2017, <[www.autismcrc.com.au/sites/default/files/Health%20Professionals%20understanding%20autism%20-%20for%20Health%20Professionals.pdf](http://www.autismcrc.com.au/sites/default/files/Health%20Professionals%20understanding%20autism%20-%20for%20Health%20Professionals.pdf)>.

1098 Ms Frances Saunders, Statewide Autism Spectrum Disorder Coordinator, Mindful, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 6.

1099 Ibid, p. 7.

present at the hospital.<sup>1100</sup> In their combined submission, Distinctive Options, The Lab Network and Smart Communities recommended that health education courses for medicine, nursing and allied health provide specific and specialist training in how to support people with ASD when attending hospitals for treatments.<sup>1101</sup>

In their submission, Lancaster Consulting Australia, a specialist consulting service for individuals with complex presentations, including ASD, stated:

If a person on the spectrum is in need of hospitalisation, staff often do not have the skills or knowledge to support their admission, often relying on family or disability support staff to assist whilst they are hospitalised. In a number of situations, there is increased use of restrictive interventions, such as chemical, physical or mechanical restraint used whilst that person is admitted. For example, it is not unusual for the waiting list to access DHHS's internal specialist behavioural teams to be six months or longer. When support from specialist behavioural teams is provided, it has often failed to address the gaps in staff knowledge and practice, in part due to the relatively brief interventions offered without the benefit of staff training and follow-up clinical support.<sup>1102</sup>

Dr Coventry, at a public hearing in Melbourne, explained to the Committee that hospitals have consultation liaison services and psychiatric staff who work in emergency departments:

In just about every area mental health service that has an emergency department there would be psychiatric trained nursing staff and staff trained in other mental health conditions that are actually based in the emergency department, and a number of larger area mental health services would have psychiatrist-led consultation liaison teams who also work in the medical and surgical wards.<sup>1103</sup>

While these psychiatric trained staff are not available 24/7, they do provide education and training to other staff.<sup>1104</sup> Dr Coventry explained:

I would say in the department, since I have been Chief Psychiatrist working with the Chief Mental Health nurse – one of my colleagues in my team – we have had very good connections with emergency departments who are very concerned not just about mental health patients but all patients who come into their emergency departments with any sort of disability to make sure they get treated appropriately. So we are doing quite a lot of training specifically focusing on the pointy end at emergency departments and that first assessment where it may not be a mental health condition.<sup>1105</sup>

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1100 Mallee Family Care, submission no. 130, p. 2.

1101 Distinctive Options, The Lab Network and Smart Communities, submission no. 77, p. 7.

1102 Lancaster Consulting Australia, submission no. 88, p. 5.

1103 Dr Neil Coventry, Chief Psychiatrist, Department of Health and Human Services, Family and Community Development public hearing – Melbourne, 7 November 2016, transcript of evidence, p. 17.

1104 Ibid.

1105 Ibid.

At a public hearing in Melbourne, Ms Saunders told the Committee that training of emergency departments was occurring:

So what has happened in our hospital is that they have got the ASD people who know about ASD together to write some policy around that, to write some guidelines about how these young people should be managed. I know in our adolescent mental health unit they have undertaken some of the training that we have offered at Mindful, so utilising that kind of expertise to skill up their nursing staff.<sup>1106</sup>

Ms Saunders told the Committee that in the past there have been consultations of emergency departments aimed at supporting young people with ASD:

In terms of looking at accident and emergency and looking at even the spaces within our mental health units, we have in the past asked the previous coordinator of Aspect Positive Behaviour Support, Heather Kirkhope, to come in and consult with our unit staff and walk down and have a look at accident and emergency and provide some consultation and support around what can be different, how can we approach these young people in more sensitive ways. That is just a beginning, and that process was just a beginning. I do not think it has followed through in any concerted way. But I think that is where, if you have agencies and organisations connected and networking, we can utilise the skills of other groups, say, for instance, Aspect, to skill up [accident and emergency] and emergency at RCH.<sup>1107</sup>

On their website, the Royal Children's Hospital provides detailed Clinical Practice Guidelines to manage distress and agitation for young people in hospital settings who may require medical or surgical care.<sup>1108</sup> The RCH Guidelines emphasise the need for 'a high quality preadmission or at admission assessment' and encourages medical practitioners to find out about a patient's routines, interests, sensory sensitivities, disruptive behaviours and calming strategies. The Guidelines include questions for parents and carers from the Autism Intervention Centre at the Rady Hospital in San Diego which are aimed to utilise the knowledge of parents and carers in knowing how best to comfort the child and prepare the child for a procedure.<sup>1109</sup> The RCH Clinical Practice Guidelines state:

Routines enable young people with developmental disabilities to manage their internal states of distress. They can experience significant distress upon changes to these routines. This may lead to the young person being seen as uncooperative or difficult. They might, for instance, become very anxious and disruptive when plans are changed or if they are required to wait for procedures.

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1106 Ms Frances Saunders, Statewide Autism Spectrum Disorder Coordinator, Mindful, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 7.

1107 Ibid.

1108 Royal Children's Hospital, 'Clinical Practice Guidelines: Autism and Developmental disability: managing distress and agitation', June 2015, accessed 23 May 2017, <[www.rch.org.au/clinicalguide/guideline\\_index/Autism\\_and\\_developmental\\_disability\\_\\_Management\\_of\\_distress/agitation](http://www.rch.org.au/clinicalguide/guideline_index/Autism_and_developmental_disability__Management_of_distress/agitation)>.

1109 Ibid.



Some children will develop intense interests, which they prefer to engage with most of the time and can become distressed if interrupted. Ascertain what the young person does during leisure periods, what they enjoy doing and accommodate what is possible within an acute ward setting.<sup>1110</sup>

The Guidelines encourage inpatient care aimed at preventing or minimising agitation and aggression by:

- maintaining a low stimulus environment;
- planning medical or surgical procedures ahead of time;
- avoiding unnecessary examinations and interventions;
- minimising delays and waiting times; and
- allowing food from home where possible.<sup>1111</sup>

The Guidelines also suggest explaining procedures, including with pictures, allowing the patient to examine any instruments to be used and modelling parts of the procedure on the patient's trusted adult or doctor/nurse. Practitioners can also consult the RCH's Education Play Therapy team for ways to promote effective coping through a range of methods, such as medical play, cognitive distraction, and developmental play opportunities.<sup>1112</sup>

The Guidelines also recommend minimising the number of staff attending the room during ward rounds, limiting the number of professionals the young person needs to interact with and allowing items in the ward that support the patient's sensory processing (for example, lighting and comfort toys). The Guidelines also direct practitioners to additional resources such as a website that has online story books on getting blood drawn and visiting a doctor's office.<sup>1113</sup>

During its study tour, the Committee heard from Autism Speaks in New York about the Autism Treatment Network (ATN). The ATN receives funding from the U.S. government under the *Combating Autism Act* to serve as the Autism Intervention Research Network on Physical Health.<sup>1114</sup> The ATN network is comprised of 13 leading children's hospitals in the U.S. and academic teams.<sup>1115</sup> The goal of the ATN is to provide expert care to children with autism across the U.S. The ATN also run a medical registry of over 7,000 people with autism, aged from 2-17 for a longitudinal study that examines medical issues of people with ASD. Recent research studies coming out of the registry include the following medical issues: metabolic, genetic

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1110 Ibid.

1111 Ibid.

1112 Royal Children's Hospital, 'About Education Play Therapy', accessed 23 May 2017, <[www.rch.org.au/ept](http://www.rch.org.au/ept)>.

1113 Help Autism Society Now, 'Blood draw book', accessed 23 May 2017, <[www.helpautismnow.com/blood\\_draw.html](http://www.helpautismnow.com/blood_draw.html)>.

1114 National Autism Network, 'Autism Treatment Network', accessed 29 May 2017, <[nationalautismnetwork.com/research/research-programs/autism-treatment-network.html](http://nationalautismnetwork.com/research/research-programs/autism-treatment-network.html)>.

1115 Ibid.

and gastrointestinal concerns; obesity; psychiatric comorbidity and sleep disturbances; and neurological problems, metabolic disorders.<sup>1116</sup>

The work of the ATN also involves developing professional treatment guidelines as well as ATN tool kits for families, such as a dental guide tool kit, a blood draw tool kit, and a vision/eye exam social narrative.<sup>1117</sup> Other research institutions are also conducting work in these fields.

### 8.3.3. Helping people with ASD through transitions

Social stories, which are short descriptions describing what a person is likely to expect in a particular situation have been successful with people with ASD and have been increasingly used in a variety of contexts. The importance of constructing social stories to guide people with ASD through change and transitions was discussed by several witnesses.

Mr Murray Dawson-Smith, the Chief Executive Officer of Distinctive Options, told the Committee at a public hearing in Bendigo that the lack of communication was often what causes distress and creating a proper transition process for people with ASD did not need to be complicated.<sup>1118</sup> He described what that might look like, in the case of a visit to the hospital to prepare a person with ASD for what they are likely to see, but noted that this story can fall down where people in the hospital do not understand the transitional process that is going on:

[T]he reality for most people on the autism spectrum is that you can introduce change as long as it is a natural part of your practices, if you like, and where it is not, then there is an obligation, in my view, to create a proper transition process. So for example, if I am working with somebody and they have to go to hospital, then I would automatically say, 'I now need to create a whole social story around this and around what you are going to see and what you are going to expect to see', before they go to hospital. I also then expect that when I get to the hospital the people in the hospital will also understand the transitional process that is going on, and that is where it often falls down.

I can clearly create a social story for an individual and say, 'My name is Jack. I am not well. I am going to the hospital', and I can create photos and all those other things, and we can drive past the hospital a couple of times before, we can actually do a visit to the hospital. If I take those processes in, generally speaking I have a fair chance of success. The problem is then once they are in hospital and they are being supported by nursing and medical staff and allied health staff, are they as equipped and as skilled in terms of creating the support system for those people? Again, with due respect to the hospital system — and I appreciate they do not see

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1116 Autism Speaks, 'ATN information for researchers', accessed 29 May 2017, <[www.autismspeaks.org/science/resources-programs/autism-treatment-network/atn-information-physicians-and-researchers](http://www.autismspeaks.org/science/resources-programs/autism-treatment-network/atn-information-physicians-and-researchers)>.

1117 National Autism Network, 'Autism tool kits', accessed 29 May 2017, <[nationalautismnetwork.com/resources/general\\_resources/autism-toolkits.html](http://nationalautismnetwork.com/resources/general_resources/autism-toolkits.html)>.

1118 Mr Murray Dawson-Smith, Chief Executive Officer, Distinctive Options, Family and Community Development public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 7.

that many autistic people, necessarily, coming through — I do not think that is necessarily the case.

So I put them in a standard ward with all of the noises and crashes and bashes that go on with a standard ward. Having been in hospital myself, I do not like those noises. I get woken up at 7 o'clock in the morning. I do not know why I am woken up at 7 o'clock in the morning. I am capable of saying, 'Hang on a minute, why are you waking me up?', but someone on the spectrum simply says, 'What is happening that I am being woken up here?', because no-one has bothered to create a social story for them that says, 'You get woken up at 7 o'clock in the morning'. Now I know that, and I have no anxiety because I know that is what is going to happen.<sup>1119</sup>

In their submission, the Royal Children's Hospital stated:

Children and young people with autism and their families require the same sort of support that is needed for all children with other disabilities. This means adapting the environment to meet the needs of the child, not the other way round; a real but necessary challenge for schools and the community.<sup>1120</sup>

#### **8.3.4. Coordination and integration of health and mental health services for people with ASD**

The Committee heard from many people with ASD and families living with ASD about poor coordination and collaboration between different services. For people with ASD and a co-occurring mental health condition, a lack of knowledge of ASD by health professionals and an absence of sector collaboration within mental health services was detrimental to their health and wellbeing.<sup>1121</sup>

The Australian Advisory Board on Autism Spectrum Disorders report called on health and disability sectors to 'work together to design a service system that is knowledgeable about ASD and co-occurring mental health issues'.<sup>1122</sup> The report stated:

The prevalence and range of co-morbid psychiatric disorders in people with an ASD means that collaboration across all levels and sectors from national policy consensus to professional knowledge sharing, diagnosis and intervention is

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1119 Ibid.

1120 Royal Children's Hospital, submission no. 143, p. 2.

1121 Professor Bruce Tonge and Dr Avril V Brereton, submission no. 48, p. 1; Australian Advisory Board on Autism Spectrum Disorders, *The interface between Autism Spectrum Disorders and Mental Health: The ways forward*, discussion paper, December 2012, accessed 23 May 2017, <[www.autismadvisoryboard.org.au/uploads/file/pdfs/The%20Interface%20between%20ASD%20and%20Mental%20Health%20AAB.pdf](http://www.autismadvisoryboard.org.au/uploads/file/pdfs/The%20Interface%20between%20ASD%20and%20Mental%20Health%20AAB.pdf)>, p. 16; Dr Sandra Radovini, Director of Mindful, Centre for Training and Research in Developmental Health, Department of Psychiatry, University of Melbourne, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 8.

1122 Australian Advisory Board on Autism Spectrum Disorders, *The interface between Autism Spectrum Disorders and Mental Health: The ways forward*, discussion paper, December 2012, accessed 23 May 2017, <[www.autismadvisoryboard.org.au/uploads/file/pdfs/The%20Interface%20between%20ASD%20and%20Mental%20Health%20AAB.pdf](http://www.autismadvisoryboard.org.au/uploads/file/pdfs/The%20Interface%20between%20ASD%20and%20Mental%20Health%20AAB.pdf)>.

essential for this target group of people with mental health needs... When services lack the understanding and professional expertise required to recognise mental health issues in people with ASD, the first priority is to address this knowledge gap.

Collaboration and co-ordination between the sectors responsible for the well-being of people with an ASD will be more effective, if their understanding of co-morbid mental health issues is improved.<sup>1123</sup>

Many stakeholders identified a 'silo' approach to ASD and mental health services, whereby some practitioners were not comfortable treating a person with ASD's mental health issues. Dr Sandra Radovini, Director of Mindful, Centre for Training and Research in Developmental Health, illustrated this when she told the Committee at a public hearing in Melbourne that adults with ASD often do not get a very positive response when accessing mental health services:

I would have to say that [support for adults] would be very patchy rather than there being a clearly understood need, and this would be broader than just people with ASD. It would include people with more broadly intellectual disability that our adult mental health services again have distanced themselves from, often saying that they do not have the expertise in being able to look after people with ASD or people with intellectual disability. In some ways that is a historical split. I have been around a long time, so when I started my training those two things were more closely aligned, but philosophically they have drifted apart in terms of disability and mental health, and the fallout from that has been that when adults with an intellectual disability, adults with ASD, do need mental health services, often they do not get a very positive response. People are saying, 'It's the ASD', or, 'It's the intellectual disability', and not recognising that there are two things going on. Yes, there is that, but there is also mental health issues arising. In fact the literature would suggest that people with an intellectual disability, for a range of reasons, have an even higher risk of developing a mental health comorbidity along the way.<sup>1124</sup>

Many stakeholders identified a lack of collaboration across other departments and sectors as well, such as education, employment and housing.<sup>1125</sup> In their submission to the Inquiry, Professor Tonge and Dr Brereton stated:

The compartmentalisation of government services into health, disability, employment and housing often means that services are fragmented or unavailable to adults with an ASD who have complex mental health, disability, employment and housing needs.<sup>1126</sup>

The Committee believes that the coordination and collaboration between allied health services needs to be improved. In Chapter Two of this report, the Committee

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1123 Ibid, p. 16.

1124 Dr Sandra Radovini, Director of Mindful, Centre for Training and Research in Developmental Health, Department of Psychiatry, University of Melbourne, Family and Community Development public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 8.

1125 Royal Australian and New Zealand College of Psychiatrists (RANZCP) Victorian Branch Committee, submission no. 144, p. 5.

1126 Professor Bruce Tonge and Dr Avril V Brereton, submission no. 48, p. 2.

recommended the integration and coordination of government-funded services for people with ASD.

### 8.3.5. Restrictive interventions

Children and adults with ASD are more likely to behave in challenging ways due to experiencing difficulties with communication and having trouble understanding what is happening around them, as well as higher levels of anxiety and frustration.<sup>1127</sup> Behaviours may include aggression, tantrums, and self-injury.<sup>1128</sup> In their submission to the Inquiry, the Office of the Health Services Commissioner (OHSC) expressed concern over the safety of people with ASD in hospitals:

We have also received complaints describing safety issues for consumers with ASD who had behavioural problems in hospitals. In one instance, a consumer with ASD jumped over a balustrade in a hospital and suffered significant brain injury. In another instance, a psychiatric ward suggested discharging a child with ASD because it could not guarantee the child's safety.<sup>1129</sup>

Various triggers for challenging behaviours are changes in routines, transitions, sensory sensitivities and sensory overload, tiredness, unrealistic expectations, and discomfort.<sup>1130</sup> Challenging behaviours may also be triggered by a 'new onset or exacerbations of mental disorders, altered sensory processing, pain, physical health comorbidities (eg gastrointestinal disorders), and environmental factors'.<sup>1131</sup> Challenging behaviours are more likely to occur in those with an intellectual disability.<sup>1132</sup>

In their supplementary submission, the Royal Children's Hospital stated:

Children and young people with ASD present to the Emergency Department (ED) with physical problems that require acute medical intervention. The ED is a busy and highly stimulating environment and this often leads to an escalation of aggressive, destructive or impulsive behaviours for children and young people with ASD. Every effort is taken to minimise waiting times and other environmental stressors when the ASD diagnosis is known to clinical staff.

However, at times, clinical staff are unaware of the consumer's background until behaviours rapidly escalate to a degree where the safety of the child or young person, parents, other consumers or staff is at risk. De-escalation of the child or

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1127 Raising Children Network, 'Managing challenging behaviours in children with autism spectrum disorder', accessed 29 May 2017, <raisingchildren.net.au/articles/autism\_spectrum\_disorder\_managing\_behaviour.html>; K Foley and J Troller, 'Management of mental ill health in people with autism spectrum disorder', *Australian Family Practitioner*, vol. 44, no. 11, November 2015, pp. 784-790, p. 788.

1128 K Foley and J Troller, 'Management of mental ill health in people with autism spectrum disorder', *Australian Family Practitioner*, vol. 44, no. 11, November 2015, pp. 784-790, p. 788.

1129 Office of the Health Services Commissioner, submission no. 116, p. 2.

1130 Raising Children Network, 'Managing challenging behaviours in children with autism spectrum disorder', accessed 29 May 2017, <raisingchildren.net.au/articles/autism\_spectrum\_disorder\_managing\_behaviour.html>.

1131 K Foley and J Troller, 'Management of mental ill health in people with autism spectrum disorder', *Australian Family Practitioner*, vol. 44, no. 11, November 2015, pp. 784-790, p. 788.

1132 Ibid.

young person's anxiety or agitation in this environment can be difficult. There have been occasions when restrictive interventions, either physical or chemical restraint, have been implemented as a last resort means of providing safety and containment for the child or young person.<sup>1133</sup>

The Royal Children's Hospital reported on 'a number of complex cases where young people with ASD experience behavioural changes during developmental milestones, such as progressing through puberty'.<sup>1134</sup> Their submission stated:

In these cases, these developmental stages have exacerbated aggressive, threatening and impulsive behaviours. At times, this has presented an extreme safety risk to the child or young person and their family, other consumers, staff and members of the public visiting the RCH. Situations like this require urgent management and a resource-intensive response.<sup>1135</sup>

The RCH noted that over the last five years there have been increasing numbers of emergency department presentations of families of children and young people with ASD 'who have reached a crisis point in the home environment':

There have been circumstances when families have stated to staff that they are unable to return home with the child or young person as the risk of violence and aggression is too high. Sometimes, these families have had limited medical engagement before their attendance at the RCH and, frequently, staff identify that these families have had limited involvement with support services in the community. The RCH holds the view that early intervention, disability support and educational services in the community would assist families to avoid reaching the crisis point that brings them into hospital.<sup>1136</sup>

Restrictive interventions include seclusion and bodily restraint of a person. Part 6 of the *Mental Health Act 2014* sets out restrictive interventions, and the circumstances in which a restrictive intervention can be used. Importantly, the *Mental Health Act 2014* states that 'a restrictive intervention can only be used on a person receiving mental health services in a designated mental health service after all reasonable and less restrictive options have been tried or considered and have been found to be unsuitable'.<sup>1137</sup> It is also an objective of the Act to provide for persons to receive assessment and treatment 'in the least restrictive way possible with the least possible restrictions on human rights and human dignity'.<sup>1138</sup>

Dr Coventry explained at a public hearing in Melbourne the role of the Chief Psychiatrist in reviewing restrictive interventions:

In Victoria we have had a very successful project across all mental health services and also including emergency departments to try and reduce what we call

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1133 Royal Children's Hospital, submission no. 150, pp. 2-3.

1134 Ibid, p. 3.

1135 Ibid.

1136 Ibid.

1137 *Mental Health Act 2014*, section 105.

1138 *Mental Health Act 2014*, section 10(b). See also 'The mental health principles' in section 11(1)(a).

restrictive practices. This means seclusion, where someone is in an isolation room, or bodily restraint, either using the old-fashioned bodily restraint mechanisms we used to call shackles – we do not call them that anymore – or physically holding. In some cases people with diagnoses like autism get subjected to these practices. We have now got very strict criteria about how they can be used under the Mental Health Act. They can only be authorised in particular, specific situations. They have to be authorised by a psychiatrist. They have to be regularly reviewed, and there are a number of hoops people have to jump through in terms of documentation and review. My job in the department is to audit all of this on a monthly basis. I can go to investigate if I have got particular concerns about any individual patient.

With respect to autism we hope to train staff to look at what the meaning of the challenging behaviour might be and to try and do a more sophisticated analysis of that before jumping into using these restrictive practices, which can be for people with autism quite detrimental and very frightening and traumatic. They really need to be a last resort, so we are training all of our staff to diminish, and if possible totally diminish, the use of these practices but particularly to think about people with autism and intellectual difficulty disorders who may be subject to these sorts of practices.<sup>1139</sup>

Several witnesses expressed concern over the use of restrictive interventions.<sup>1140</sup> In their submission, the Office of the Public Advocate argued that there are ‘significant service gaps for people with ASD who have complex needs and exhibit behaviours of concern’.<sup>1141</sup> They noted that decisions with regard to restrictive practices are ‘often’ made without appropriate statutory oversight:

When the person with ASD needs services and support from mainstream community facilities these difficulties are often exacerbated. A lack of understanding of how to support people with ASD with complex needs in mainstream services can result in the person with ASD being subject to restrictive practices because of fears for the safety of staff, bystanders and/or the person with ASD. Often these decisions are made without appropriate statutory oversight.<sup>1142</sup>

The Office of the Public Advocate also expressed concern over the use of restrictive interventions:

The use of physical and chemical restraints occurs in a variety of settings, including but not limited to, hospitals, schools and residential settings. OPA has serious concerns about the inappropriate use of restrictive interventions including mechanical and physical restraint, seclusion and chemical restraint on people with cognitive impairments and mental illness.<sup>1143</sup>

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1139 Dr Neil Coventry, Chief Psychiatrist, Department of Health and Human Services, Family and Community Development public hearing – Melbourne, 7 November 2016, transcript of evidence, p. 7.

1140 Ms Julie Phillips, submission no. 70; Ms Karen Burgess, submission no. 58; Office of the Public Advocate, submission no. 89; Ms Anne Mallia, submission no. 135.

1141 Office of the Public Advocate, submission no. 89, p. 11.

1142 Ibid.

1143 Ibid.



Mr Dawson-Smith told the Committee at a public hearing in Bendigo about a woman with ASD who had been ‘enormously traumatised’ by the experience of being restrained by the hospital.<sup>1144</sup> Mr Dawson-Smith said:

So here is a person who has been enormously traumatised by that experience when there was absolutely no need for it. To me then why not have a quiet ward somewhere that only has one or two people in it, has subdued lighting and does not have the sound that intrudes? I am not sure that that is a massive thing when you are building, remodelling or renewing a hospital site.<sup>1145</sup>

The experience of the woman referred to by Mr Dawson-Smith at a public hearing, was further elaborated on in the combined submission of Distinctive Options, The Lab Network and Smart Communities in which they noted:

There are a number of lessons that can be taken from this experience and to learn from in this story, including clear failures by the support staff in the disability service in that they failed to transition and inform the individual with regards the processes they would experience in attending Hospital. There was also a critical failure by the health system to understand autism and the impact the restraint would have on the patient and a further failure by the health system to ensure this individual had the level of support in hospital that may have made the hospital stay less traumatic and reduced the need for any form of restraint.<sup>1146</sup>

The Royal Children’s Hospital states that physical restraint is only used for safety and/or treatment:

As physical restraint and sedation deprives the patient of autonomy, it should only be contemplated as a last resort... When physical restraint is required a coordinated team approach is essential, with roles clearly defined and swift action taken... RCH staff members should never attempt to restrain the patient without the Code Grey response team resource on hand.<sup>1147</sup>

The Committee understands that there are legislative safeguards in place that make restrictive practices a matter of ‘last resort’. The Committee is concerned that people with ASD have been the subject of restrictive practices and that this has seriously negative effects on them. Hospital staff need to be sufficiently trained to recognise the characteristics of ASD presentations, including behaviours of concern.

The Committee is concerned by the lack of experience, knowledge and awareness of ASD among health and mental health professionals. The Committee recognises that some institutions such as the Royal Children’s Hospital do provide guidelines to staff on managing and engaging with children and adolescents with ASD and their needs. However, the Committee heard throughout the Inquiry that staff in mainstream public

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1144 Mr Murray Dawson-Smith, Chief Executive Officer, Distinctive Options, Family and Community Development public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 8.

1145 Ibid.

1146 Distinctive Options, The Lab Network and Smart Communities, submission no. 77, p. 16.

1147 Royal Children’s Hospital, ‘Emergency restraint and sedation – code grey’, May 2013, accessed 23 May 2017, <[www.rch.org.au/clinicalguide/guideline\\_index/Emergency\\_Restraint\\_and\\_Sedation\\_Code\\_Grey](http://www.rch.org.au/clinicalguide/guideline_index/Emergency_Restraint_and_Sedation_Code_Grey)>.

hospitals and healthcare facilities are in general uninformed of autism and how it presents in people with ASD.

The Committee believes that health professionals in public hospitals and healthcare facilities need to be trained in recognising and understanding ASD. Public health professionals need to have the knowledge and skills to be able to manage communication difficulties, sensory sensitivities and behavioural concerns, and have the ability to manage these concerns without resorting to restrictive practices. Accordingly, the Committee recommends that:

#### **RECOMMENDATION 8.4**

**The updated State Autism Plan make provision for training and professional development of public hospital staff and public mental health clinicians in the awareness and understanding of ASD presentations.**

The evidence received by the Committee indicates that there is a lack of mental health services specifically for people with ASD and that this gap in services needs to be addressed. Accordingly, it recommends that:

#### **RECOMMENDATION 8.5**

**The Victorian Government increase funding to public mental health services and community health services so they have the capacity to provide services for people with ASD with a co-occurring mental health condition.**

# Chapter 9

## Services for People with ASD in Rural and Regional Victoria

### AT A GLANCE

#### Background

The Committee heard that paediatricians, child psychiatrists, child psychologists, speech therapists and allied health workers were in short supply in rural and regional areas, making access to diagnosis and early intervention difficult with long waiting periods. While the experiences of families and individuals living with ASD in the metropolitan region have been outlined in the previous chapters, during the Inquiry, the Committee found that the paucity of appropriate and available ASD services and the lack of inclusive school options was particularly acute for families and individuals located in rural and regional areas.

#### Chapter overview

This chapter focuses on rural and regional experiences of accessing services for children, youths and adults with ASD. It begins by describing the shortages in ASD services particularly in the area of diagnostic services and therapies in rural and regional areas. The chapter follows on to consider some promising initiatives developed by rural and regional community health services to respond to local gaps in ASD services. In addition, the Committee heard about the desperate need for inclusive school options and programs for children and youths with ASD living in rural and regional areas. While the NDIS will bring much change to service delivery in rural and regional areas, the Committee heard of the need to retain existing services that work. This chapter addresses the following terms of reference:

- b) the availability and adequacy of services provided by the Commonwealth, State and local governments across health, education, disability, housing, sport and employment services;
- c) the adequacy of services to be provided under the National Disability Insurance Scheme (NDIS); and
- d) evidence of the social and economic cost of failing to provide adequate services.

Throughout the Inquiry, the Committee heard from a wide range of stakeholders including service providers as well as individuals with ASD and their families in rural and regional Victoria. About a third of the written submissions received were from stakeholders located in rural and regional Victoria. The Committee also travelled to Geelong, Bendigo, Shepparton, Morwell and Swan Hill to hold public hearings and gather evidence about the availability and adequacy of services in rural and regional Victoria. The Committee found that the challenges faced by families and individuals living with ASD are multiplied and heightened in a rural and regional location where there is a shortage of ASD services and extensive travel to Melbourne or another regional centre is required to access services. At the time of the Inquiry, rural and regional stakeholders also expressed a significant level of concern about the NDIS and its impact on families and individuals with ASD and local service providers.

The Committee frequently heard that rural and regional communities experienced a shortage of ASD services from timely diagnosis and inclusive school options to services and support for adults. The Committee also received evidence of several positive initiatives, which local service providers and community groups have developed to support families and individuals living with ASD. The Committee heard that rural and regional service providers were often 'ground-breakers'.<sup>1148</sup> At a public hearing in Melbourne, the State-wide Director of ASD Training at the Mindful Centre for Training and Research in Developmental Health, Ms Frances Saunders, pointed out that close knowledge of their communities and the lack of policy barriers have enabled rural and regional organisations to develop innovative responses to local needs.<sup>1149</sup>

This chapter addresses the following terms of reference:

b) the availability and adequacy of services provided by the Commonwealth, State and local governments across health, education, disability, housing, sport and employment services; c) the adequacy of services to be provided under the National Disability Insurance Scheme (NDIS); and d) evidence of the social and economic cost of failing to provide adequate services.

## **9.1. Shortage of ASD health and disability services in rural and regional areas**

Almost all of the submissions from ASD service providers indicated that rural and regional communities were more likely to experience 'multiple levels of vulnerability'.<sup>1150</sup> Rural and regional families were also more likely to have low-to-moderate income levels.<sup>1151</sup> In a submission from the Gippsland region, the Committee heard that natural and manmade disasters have also had a negative

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1148 Ms Frances Saunders, State-wide Autism Spectrum Disorder Coordinator, Mindful, Family and Community Development Committee public hearing - Melbourne, 29 August 2016, transcript of evidence.

1149 Ibid, p. 5.

1150 Mr David Tennant, Chief Executive Officer, FamilyCare, Family and Community Development Committee public hearing - Shepparton, 15 November 2016, transcript of evidence, p. 2.

1151 Latrobe Community Health Service, submission no. 34, p. 1. See also, Sunraysia Community Health Service, submission no. 112, p. 2.

effect on families and services in the region.<sup>1152</sup> In addition, the Committee received evidence that Aboriginal and Torres Strait Islander people with ASD and their families in rural and regional areas required more information and support in order to access services.<sup>1153</sup> While this chapter does not detail the existing socio-economic disadvantages that rural and regional families face, the shortage of ASD services in rural and regional Victoria has likely compounded existing hardship.

During the Inquiry, the Committee frequently heard of lengthy wait times for diagnosis and a shortage of specialist health workers such as, paediatricians, child psychiatrists, psychologists, speech pathologists and allied health practitioners who are critical to the diagnosis process and treatment of children and adults with ASD. The Committee also heard that rural and regional workers across the health, disability and education sectors were disadvantaged as relevant training occurred in Melbourne. At a public hearing in Melbourne, the State-wide Director of ASD Training at the Mindful Centre, Ms Saunders stated:

There is very limited access to privately or publicly funded services for ongoing care and treatment. There are very few paediatricians and child and adolescent psychiatrists in regional Victoria – I am sure that you are very well aware of this – and there is less access to support services. My regional ASD coordinators will say, look, a lot of the training is city-centric. Yes, some of these programs do come out to regional areas, but they are not as available as they are in Melbourne.<sup>1154</sup>

According to a national study investigating whether Australia was meeting best-practice standards for diagnosis, which was published by the Autism Cooperative Research Centre (Autism CRC), families in rural and regional areas seeking diagnosis:

[E]xperience wait list periods that are twice as long as families living in the major cities of Australia, unless they travel to metropolitan clinics.<sup>1155</sup>

### 9.1.1. Long wait times for diagnostic services

The Committee received ample evidence from its rural and regional stakeholders that the shortage of specialist health workers, particularly of experienced paediatricians and speech pathologists, contributed to delayed diagnosis and access to funded therapy for families. At a public hearing in Swan Hill, in Victoria's Mallee region, Chief Speech Pathologist at Swan Hill District Health Ms Leonie Baker stated:

Currently in Swan Hill we do not have any multidisciplinary assessment services available, and we have no local paediatrician. A visiting private paediatrician

1152 Latrobe Community Health Service, submission no. 34, p. 1.

1153 Mr Shilo Wilson, Manager, Respite and Support, Interchange Gippsland, Family and Community Development Committee public hearing – Morwell, transcript of evidence, p. 6.

1154 Ms Frances Saunders, State-wide Autism Spectrum Disorder Coordinator, Mindful, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, pp. 4-5.

1155 L Taylor, P Brown, V Eapen, S Midford, J Paynter, L Quarmby, T Smith, M Maybery, K Williams and A Whitehouse, *Autism Spectrum Disorder diagnosis in Australia: Are we meeting best practice standards?* Autism CRC, Indooroopilly, 2016, p. 22.

attends once a month, and there is no child psychologist based in Swan Hill who can see children under school age.<sup>1156</sup>

In their submission to the Inquiry, Latrobe Community Health Service in the Gippsland region described the lack of pathways towards diagnosis and therapy:

It is also our experience that there is an undersupply of skilled health professionals for early intervention services. Families are often assessed at multiple points by multiple health professionals but at times receive little actual intervention.<sup>1157</sup>

A shortage of specialist health workers in the public sector contributed to lengthy wait times in other parts of the state. In their submission to the Inquiry, representatives of the Mindful Centre highlighted Shepparton and Seymour as places where their Child and Youth Mental Health Services (CYMHS) regional coordinators have reported a wait time of two years for diagnosis.<sup>1158</sup> Furthermore, while private services existed in the major regional centre of Bendigo, they were costly and the Committee received evidence that the wait time for the public multidisciplinary diagnostic service in Bendigo was approximately nine months.<sup>1159</sup>

The Committee also heard that the challenges, which families face in rural and regional areas have been compounded by the fact that lead diagnosticians may not have the experience and expertise to accurately assess and diagnose ASD. At a public hearing in Melbourne, Professor Bruce Tonge of the Monash Centre for Developmental Psychiatry and Psychology stated:

Mind you, one of the biggest demands on paediatricians in country practice is for behavioural paediatrics – that is, dealing with kids that have got emotional behavioural difficulties, and most of those will have autism. So they are another workforce.<sup>1160</sup>

The Committee heard from parents who described seeing a paediatrician multiple times with the same issues before they were given a referral to a comprehensive assessment. For many parents this has been complicated and stressful, particularly if there is only one paediatrician servicing the community.<sup>1161</sup> At a public hearing in Swan Hill, Ms Rachel Blandthorn spoke about the long and arduous process before her son Angus received a comprehensive and reliable diagnosis:

When he was four I took him to a paediatrician because I had no clue what I was dealing with. He was a difficult child, but he could talk; he could do everything that his brother was doing. So after a 30-minute appointment I was advised that there was definitely no autism but there could be perhaps a little bit of ADHD, which they would look at later on when he was around five. I just continued on... But then I

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1156 Ms Leonie Baker, Chief Speech Pathologist, Swan Hill District Health, Family and Community Development Committee public hearing – Swan Hill, 14 February 2016, p. 3.

1157 Latrobe Community Health Service, submission no. 34, p. 3.

1158 Mindful – Centre for Training and Research in Developmental Health, submission no. 134, p. 6.

1159 Department of Health and Human Services, (DHHS Vic), correspondence, dated 10 May 2017.

1160 Emeritus Professor Bruce Tonge, Monash University Centre for Developmental Psychiatry and Psychology, Family and Community Development public hearing - Melbourne, 6 March 2017, transcript of evidence, pp. 15-16.

1161 Mallee Family Care, submission no. 130, p. 1.

went to a maternal and child health nurse, and she noticed he was having staring episodes. I had not noticed them particularly, but when she pointed it out I did actually notice that he was focusing on things. But she actually thought it was a bit of epilepsy or something like that.

We then went back to the paediatrician, and we got referred for an EEG and things like that, and everything came back fine. In the middle of that, when the paediatrician said there was definitely no autism, he then referred Angus over to the speech pathologist. Now once again with the speech pathologist at the hospital he had like a half-hour appointment, and in my opinion the right questions were not asked about Angus's behaviour, because he went in there and he was just doing what he does — running around, checking everything out, hard to contain and did not talk a great deal.<sup>1162</sup>

Ms Blandthorn 'continued on' until kindergarten teachers noticed her son's symptoms and she decided to take her son to Melbourne to see a paediatrician at the Royal Children's Hospital where she was referred to a speech pathologist and a psychologist as part of a multidisciplinary assessment that confirmed ASD. It took 13 months from her initial visit to the paediatrician in Swan Hill to gain a reliable diagnosis for her son and multiple trips to Melbourne to receive the diagnosis.<sup>1163</sup>

### 9.1.2. Shortage of therapists and therapy options

Once families received a diagnosis, the Committee frequently heard that they found themselves faced with a lack of therapists and therapy options and needed to shoulder significant costs to access therapy elsewhere. At the hearing in Swan Hill, Mr Brenten and Ms Janelle Hogan described how a lack of therapists in Swan Hill drove them to seek therapy in Melbourne for their son Cade. They stated:

Once he did have his assessment — that all came back 'Yes, he is autistic' — there is this \$6000 funding to utilise, but there were no providers in Swan Hill. Everything we had to do, we had to go to Melbourne of course. When you have got three other kids that is pretty tough. We got into the Listen and Learn Centre, which used Tomatis therapy, but they also had OTs, they had speechies, they had psychologists — — ...

We eventually got into that, and it was a two-week stint. So I would go down with Cade for two weeks while Brenten stayed home with the other three kids. Yes, we got funding through that to support that, but it did not include accommodation and it did not include travel. There were so many thousands of dollars that we spent doing that. I would go and do that from Monday to Friday, come home on the weekend and then go back Monday to Friday. We did that on and off for two years, which helped him dramatically.<sup>1164</sup>

1162 Ms Rachel Blandthorn, Family and Community Development Committee public hearing - Swan Hill, 14 February 2017, transcript of evidence, p. 2.

1163 Ibid, pp. 2-3.

1164 Mr Brenten and Ms Janelle Hogan, Family and Community Development Committee public hearing - Swan Hill, 14 February 2017, transcript of evidence, pp. 2-3.



The Listen and Learn Centre in Melbourne, which the Hogans accessed with their son, is a provider of assessment and therapeutic services to children and young adults experiencing emotional, behavioural, speech, cognitive and learning difficulties or disorders.<sup>1165</sup>

At the hearing in Swan Hill, Ms Blandthorn described the lack of child psychologists in the area and the need to travel two hours for her son Angus to see a child psychologist on a regular basis. She also highlighted the need for Medicare to take into account the particular therapy needs of children with ASD. She stated:

The one on the list was in Mildura, which serviced the whole region, and she worked two days a week, so it was impossible to get into her. I was lucky enough that through those phone calls I got hold of another psychologist in Mildura who actually provided services under the mental health services in rural and remote areas program. Angus was eligible for that funding, so we then started going to Mildura fortnightly for appointments, which we still continue to do. The government has since withdrawn that model of funding, and it has now been replaced with psychological therapy services. Now under that funding appointments are limited to 12 sessions a calendar year, so that is effectively half of what Angus had previously been able to access. Now it is the days off work, the days off school, the travel and the cost of the appointment. We are looking at \$800 a day to go to a psychologist appointment. He needs to go, so we continue to do that, and we will figure it out, but that was a big hit when it went from unlimited — you know, what you require — to 12.<sup>1166</sup>

The Committee also heard that specialist therapies including ABA are unavailable in rural and regional areas. Some families who gave evidence at the hearings were unfamiliar with ABA as a therapy.<sup>1167</sup> Mr Ben Snow is a parent of a son with ASD and a daughter who is beginning to display signs of ASD. At a public hearing in Shepparton, Mr Snow told the Committee that there is no access to ABA in Shepparton:

The people in Shepparton, even [local paediatrician] Peter Eastaugh, really had not come across ABA or even knew what it was. Over in America it is a known program; it is an evidence-based program. It is sad that the knowledge of that has not even reached Shepparton let alone the access to services for it.<sup>1168</sup>

While Mr Snow appreciated the guidance that he and his family received from their local paediatrician, Mr Snow stated that he and his wife saw their only option was to access ABA in Melbourne. During the hearing in Shepparton, Mr Snow described needing to finance a second home in Melbourne for his wife and his children to

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1165 Listen and Learn Centre, 'Homepage', accessed 10 May 2017, <[www.listenandlearn.com.au](http://www.listenandlearn.com.au)>.

1166 Ms Rachel Blandthorn, Family and Community Development Committee public hearing - Swan Hill, 14 February 2017, transcript of evidence, p. 3.

1167 See for example, Ms Carmel Murphy, Family and Community Development Committee public hearing - Morwell, 5 December 2015, transcript of evidence, p. 7.

1168 Mr Ben Snow, Family and Community Development Committee public hearing - Shepparton, 15 November 2016, transcript of evidence, p. 3.

access ABA therapy at a substantial cost, which he could only afford by remaining in Shepparton for his work.<sup>1169</sup>

### **9.1.3. Lack of services and support for adults with ASD in rural and regional areas**

As discussed in Chapter Five, the Committee received much evidence illustrating the lack of services for adults with ASD across the state. The joint submission from Echuca Regional Health and Kyabram Health Service captured the lack of services and support for adults with ASD in rural and regional areas:

In addition to limited health services for those with a diagnosis of ASD, housing, education, travel, general community services and employment services are also lacking. Locally there are few supported accommodation facilities, with no specialised ASD supported accommodation. Young adults with a diagnosis of ASD are particularly disadvantaged, as they are often housed with the elderly either in aged care facilities or supported accommodation. Local supported accommodation facilities are not necessarily set up to engage those with a diagnosis of ASD to their fullest potential, and education of staff is sometimes lacking in regards to a diagnosis of ASD. Furthermore respite care for all age groups is extremely difficult to obtain in the local area, further burdening the families affected by a diagnosis of ASD.<sup>1170</sup>

Murray Human Services supports approximately 200 clients with a range of disabilities including clients with ASD who live in Swan Hill, Echuca and the surrounding areas. During the hearing in Swan Hill, the CEO of Murray Human Services Mr Scott Alexander spoke about the shortage of disability support staff in the area and that service providers in rural and regional areas often could not access specialised training in ASD. Mr Alexander stated:

We definitely need autism training, and we have not yet adequately sourced or worked out a way to provide that in a cost-effective and efficient way which has effective outcomes for our staff.<sup>1171</sup>

Mr Alexander stated that specialised training has been available in Melbourne and Bendigo. However, Murray Human Services only have a limited capacity to send staff to the training, due to the cost of travel and accommodation.

## **9.2. Addressing the shortage of ASD health and disability services in rural and regional communities**

During the Inquiry, the Committee received evidence that several community health services had developed initiatives to address shortages in diagnostic and therapeutic

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<sup>1169</sup> Ibid, pp. 2-3.

<sup>1170</sup> Echuca Regional Health and Kyabram Health Services, submission no. 33, pp. 2-3.

<sup>1171</sup> Mr Scott Alexander, Chief Executive Officer, Murray Human Services, Family and Community Development Committee public hearing – Swan Hill, 14 February 2017, transcript of evidence, p. 5.

services for children with ASD in their region, often by accessing additional training and collaborating with other local health providers.<sup>1172</sup>

### 9.2.1. The role of community health services

At a public hearing in Morwell, the Committee heard from the Manager of the Disability and Carer Program at Latrobe Community Health Service Ms Denise Bromiley. Ms Bromiley described Latrobe Community Health Services' development of a paediatric allied health service in the Gippsland region, which commenced in 2013. The service addressed the needs of children without a diagnosis in the Gippsland region and it took into account the hardships that many families in the region faced in obtaining services and support. Ms Bromiley stated:

The paediatric project provided early intervention allied health programs for children with mild to moderate delay and who didn't meet the guidelines for the Early Childhood Intervention Service. So this includes those who already had a definitive diagnosis of autism. So the landscape for families with children with difficulties remains complex to navigate and early criteria to the various services, at times, has been very difficult. Linkages to the right service at the right time are further compromised when barriers of poor health and low socio-economic status and financial hardship are co-existing.<sup>1173</sup>

In their submission, Latrobe Community Health Service noted the need for greater flexibility in service provision for children and families living with ASD and or other disorders in rural and regional areas:

Our experience suggests that whilst we would like to see an increase in services for children with a diagnosis, consideration needs to be given to those children who either have not yet been diagnosed and those who do not meet the criteria of funded services. In particular in a rural area if the only service available has eligibility criteria that relies on a definitive diagnoses then there is nowhere else families can go to get help.<sup>1174</sup>

In order to address the lack of accessible diagnostic services in a remote area of the state, the Committee heard that the Gippsland Lakes Community Health service had applied for a grant from the federal Primary Health Network to have their own therapists trained to administer the Autism Diagnostic Observation Schedule (ADOS).<sup>1175</sup> The ADOS is one of the primary observation and interview schedules used

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1172 See as example, Latrobe Community Health Service, submission no. 34.

1173 Ms Denise Bromiley, Manager Disability and Care Program, Latrobe Community Health Service, Family and Community Development Committee public hearing – Morwell, 5 December 2016, transcript of evidence, pp. 2-3.

1174 Latrobe Community Health Service, submission no. 34, p. 2.

1175 Ms Angela Ellis, Executive Manager of Community Health Services, Gippsland Lakes Community Health, Family and Community Development Committee public hearing – Morwell, 5 December 2016, transcript of evidence, p. 3. Primary Health Networks, 'About us', accessed 10 May 2017, <[www.health.gov.au/internet/main/publishing.nsf/Content/PHN-Background](http://www.health.gov.au/internet/main/publishing.nsf/Content/PHN-Background)>. The Federal Government established Primary Health Networks (PHNs) in each state in 2015, in order to increase the efficiency and effectiveness of medical services for patients, particularly those at risk of poor health outcomes, and to improve coordination of care for patients. In Victoria, there are six PHNs of which three (Murray, Gippsland and Western Victoria) cover the rural and regional parts of the state.

to assess children and youths for autism. At the hearing in Morwell, Executive Manager of Community Health Services Ms Angela Ellis explained to the Committee that:

We actually had noted that the ADOS... is not available further east than Traralgon and actually applied to the Primary Health Care Network to allow us to begin that service. So we now have staff who are trained to deliver that. We are still completing the training, which will happen by the end of December. We already have a wait list. We have informed the paediatricians locally that this is going to be available and all of the paediatricians have already started to say, "Well, here's my list. Let's go." It hasn't even started yet and we have a wait list. So there is definitely a need for that.<sup>1176</sup>

In addition, the Committee heard that combining various funding sources has enabled Gippsland Lakes Community Health to operate flexibly for its clients and to pay for full time allied health practitioners to increase access to allied health practitioners in their area. At the Morwell hearing, Ms Ellis further explained:

I suppose the uniqueness of the allied health service that we deliver is that we are now quite an established public/private service. So we have gone down the lines of combining all our varied funding sources. We are FaHCSIA registered. We provide services under Medicare, case management, private health insurance. We have the public funding of community health and HACC and CHSP. We also use client fees and successful submissions to be creative in how we deliver our services. Obviously we are fairly small in the big picture but that does allow us all that varied funding to basically recruit full time positions, one of our major challenges in rural and remote.<sup>1177</sup>

In order to address the demand for allied health services in their region, Ms Ellis also spoke of Gippsland Lakes Community Health's employment of allied health assistants to support their allied health practitioners:

We've also gone down the line, and probably have for quite a few years now, of having a large team of support workers. We call it the Allied Health Assistance. Very much developed under the supervision and delegation framework and qualified AHPs developed competency packages to support the speech pathologists, occupational therapists and physiotherapists. So we do a lot of one to one intervention using the health professionals and we do a lot of group activities with the AHAs, particularly around language and we incorporate the families and educators.<sup>1178</sup>

According to the Victorian Department of Health and Human Services, Allied Health Assistants (AHAs) work within 'a certain scope of practice' under the supervision of

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1176 Ms Angela Ellis, Executive Manager of Community Health Services, Gippsland Lakes Community Health, Family and Community Development Committee public hearing – Morwell, 5 December 2016, transcript of evidence, p. 3.

1177 Ibid, p. 2.

1178 Ibid, p. 4.

allied health practitioners.<sup>1179</sup> The Committee heard that such workforce initiatives have been a way to manage limited resources in rural and regional communities.

The Committee also heard of key rural and regional health services that have collaborated with other local health services to create the multidisciplinary teams necessary for ASD diagnosis in their region. In their submission, Sunraysia Community Health Service (SCHS) described their partnership with the Mildura Base Hospital (MBH) to provide a singular pathway for autism assessment and diagnosis in the area:

[T]he Murray Primary Health Network is providing short term funding to MBH (1.7.15-30.6.16) which has allowed MBH and SCHS to work together and provide the multidisciplinary assessment in a joined up, timely and cost effective manner. This has meant there has been one pathway for publicly funded Autism assessments in the Northern Mallee over the last 12 months.<sup>1180</sup>

According to Sunraysia Community Health Service's submission, another positive outcome of the partnership has been the creation of the coordinator role for the Autism Spectrum Support and Evaluation Team (ASSET) at Mildura Base Hospital. The ASSET coordinator has helped families navigate the assessment process and post-diagnosis options for therapy. However, the Committee heard that families in Mildura still faced barriers in accessing timely and appropriate services given the varying availability of different therapists and complex funding streams for therapies.<sup>1181</sup>

The Committee also heard that in some rural and regional communities, partnerships have had to occur between community health services and the Department of Education because of a shortage of department-employed therapists in schools. In their joint submission, Echuca Regional Health and Kyabram Regional Health Service stated:

When children are enrolled in school it is the responsibility of the Department of Education to provide services. The service provided by Department of Education is stretched and quite limited. Echuca Regional Health are also contracted to provide an Allied Health Team (Speech Therapist, Physiotherapist and Occupational Therapist) to the Echuca Specialist School.<sup>1182</sup>

Their joint submission included insights into the needs of children with ASD in the local specialist and mainstream schools, indicating that such partnerships can broaden local health workers' knowledge into the needs of children with ASD in their community.<sup>1183</sup>

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1179 Department of Health - Victoria, 'Allied Health Assistants Workforce', accessed 10 May 2017, <[www2.health.vic.gov.au/health-workforce/allied-health-workforce/victorian-assistant-workforce-model](http://www2.health.vic.gov.au/health-workforce/allied-health-workforce/victorian-assistant-workforce-model)>.

1180 Sunraysia Community Health Service, submission no. 112, p. 4.

1181 Ibid, p. 5. See also, Ms Donna Milne, Submission no. 91, p. 1; Mallee Family Care, submission no. 130, p. 1.

1182 Echuca Regional Health and Kyabram Health, submission no. 33, pp. 1-2.

1183 Ibid, p. 3.

## A regional cooperative network

Similarly, the Committee heard that cooperative networks between rural and regional disability service providers had enabled better management of scarce resources and planning for services. According to Mr David Tennant, CEO of FamilyCare (a disability service provider to children and families in Shepparton):

We have, however, built an emerging cooperative network with a series of other community service providers locally. It is called Shepparton Community Share. We received a small amount of funding from the Helen Macpherson Smith Trust that gave us an authorising environment to try that and, if it did not work, to fail, without having too many adverse consequences. But we have included one of the main adult disability service providers, ConnectGV, in that network, and as we get better at learning how to communicate with each other as a network and more as a community, then we are finding ways that we can swap information and perhaps help some of those transition points.<sup>1184</sup>

Mr Tennant further explained:

It helps us as providers recognise that there are some things that each of us do that cost us a lot of money but that if we were clever and perhaps cooperated more, we might do once and share between us. But it also allows us to form a view about our community based on the interactions we have with our different client segments and then join those forces together. We have recently put in submissions to that Productivity Commission review that I referred to earlier, and that would not have happened if we had not have had that network.<sup>1185</sup>

During the Inquiry, the Committee heard of a range of locally led responses to gaps in health and disability services and the lack of ASD services in rural and regional communities. The Committee recognises the need for a more systematic approach to connecting key health, disability and education workers on the issue of ASD services in rural and regional communities. The Committee also recognised the need to examine the capacity of community health services to deliver services that fill the need for accessible, affordable and timely ASD diagnosis, as well as therapies.

Accordingly, the Committee recommends that:

### **RECOMMENDATION 9.1**

**The Victorian Government through the Department of Health and Human Services support a state-wide ASD diagnostic service that expands ASD diagnostic services across the state and builds on existing rural and regional community health initiatives to enable a consistent model of care to be extended to rural and regional areas.**

As outlined in Chapter Three, there is a shortage of regional ASD coordinators.

<sup>1184</sup> Mr David Tennant, Chief Executive Officer, FamilyCare, Family and Community Development Committee public hearing - Shepparton, 15 November 2016, transcript of evidence, p. 9.

<sup>1185</sup> Ibid.

## RECOMMENDATION 9.2

The Victorian Government support the establishment of a rural and regional autism health and disability service network to connect with ASD state-wide coordinators and regional coordinators.

### Regional autism centres: hub and spoke model of training and service delivery

In healthcare, the hub and spoke model describes a partnership between a lead agency (hub) and other agencies (spokes) committed to delivering a service and/or training to staff in spoke locations where there is a shortage of specialist health services. In Victoria, a recent successful hub and spoke model provided a cardiac rehabilitation program to rural and remotely located clients in the Wimmera region. The Wimmera Health Care Group (the hub) provided supervision and training via telehealth to Rural Northwest Health Warracknabeal and West Wimmera Health Service Nhill, (the spoke agencies) and their clients.<sup>1186</sup>

In their submission to the Inquiry, the Royal Children's Hospital advocated for the development of a hub and spoke model that connects community health services in the regions to ASD expertise in Melbourne:

Rather than creating autism specific services, we propose a state-wide system for neurodevelopmental problems that supports regional hubs. Such a service could build on existing similar services and be embedded in the existing infrastructure, such as early childhood intervention, disability and hospital and community health services. An existing successful example of a state-wide service with similar goals and workforce is the Victorian Paediatric Rehabilitation Service, which provides services for children with brain and spinal injury, and also children with physical neurodisability... A similar hub and spoke model with specialist community paediatricians and allied health practitioners collaborating with community based health, disability and education professionals could be developed for the wider range of significant neurodevelopmental problems, of which autism is a prime example.<sup>1187</sup>

Deputy Director of the Centre for Community Child Health at the Royal Children's Hospital, Associate Professor Sewell further explained the proposed model and its potential effects, during a public hearing in Melbourne:

But it is actually providing the workforce that is there – your childcare centres, your kindergartens, your schoolteachers – with some overall understanding about children with neurodevelopmental disabilities, including autism, what they can do in their ordinary, everyday setting to improve the chances for that child... but also then have access to a planned process of next stage and next-stage help. That, I think, can be really helped by – we commented in our report on the rehabilitation model, where you got a sort of statewide model where there is a responsibility for

1186 Department of Health and Human Services - Victoria, 'Wimmera: the hub for clinical prize project', accessed 10 May 2017, <[www.health.vic.gov.au/healthvictoria/sep16/clinical.htm](http://www.health.vic.gov.au/healthvictoria/sep16/clinical.htm)>.

1187 Royal Children's Hospital, submission no. 143, p. 12.



the major centres to be providing workforce support and education and training as well as outreach-type clinical services into the broader reaches of Victoria.<sup>1188</sup>

The Victorian Paediatric Rehabilitation Service (VPRS) vision is to ensure that children requiring rehabilitative medical and healthcare are able to access the level of service they need, when they need it, in the most appropriate location, no matter where they and their families live. Children requiring rehabilitation or their families can contact the service at a number of different sites. A consistent model of care underpins the VPRS. There is a regional coordinator in each metropolitan area and each regional area.<sup>1189</sup> Currently, Mindful operates a state-wide coordination service, based on the hub and spoke model that connects to regional coordinators who oversee ASD diagnostic services for the regional CAMHS/ CYMHS.<sup>1190</sup> The Committee heard that there is the need to develop a more extensive hub and spoke model that connects ASD expertise in Melbourne to the state's rural and regional workers.

The Committee believes that the hub and spoke model provides advantages for the delivery of services for people with ASD and their families in regional Victoria. The Committee believes that this model needs to be founded on a network of regional centres, that can provide a range of services for people with autism, including diagnosis, therapy services, and information, and create the outreach programs for more remote parts of the state. The regional centres will exist as new centres, and can, where appropriate, be co-located with regional health and community services. Accordingly, the Committee recommends that:

### **RECOMMENDATION 9.3**

**The Victorian Government support the establishment of centres for autism excellence in regional Victoria. The centres will provide specialist services for people with autism, including multidisciplinary diagnostic assessments, early intervention and therapy services, and provide information, resources and referral services.**

- **The centres will act as the hubs for a 'hub and spoke' model of training and service delivery for rural and regional communities, and where appropriate be co-located with regional health services.**

## **9.2.2. Other strategies to increase access to ASD training and services**

During the Inquiry, the Committee heard support for the use of various other strategies to provide ASD services and training to professional health workers in rural and regional areas. These included the development of a 'hub and spoke model' for training and service delivery; greater use of telehealth; and fly in fly out specialists to remote areas of the state. The Committee also heard support for the allied health

<sup>1188</sup> Associate Professor Jill Sewell, Deputy Director, Centre for Community Child Health, Royal Children's Hospital, Family and Community Development Committee public hearing - Melbourne, 29 August 2016, transcript of evidence, p. 6.

<sup>1189</sup> Victorian Paediatric Rehabilitation Service (VPRS), 'VPRS: model of care', accessed 10 May 2017, <[www.vprs.org.au/wp-content/uploads/2016/01/VPRS\\_Model-of-care-final-sep-07.pdf](http://www.vprs.org.au/wp-content/uploads/2016/01/VPRS_Model-of-care-final-sep-07.pdf)>.

<sup>1190</sup> Mindful - Centre for Training and Research in Developmental Health, submission no. 134, p. 3.

and special education courses offered by universities based in rural and regional Victoria.

### **Telehealth**

The Committee heard support for greater use of telehealth and other technology to provide mentoring and training to allied health practitioners and to provide allied health services to rural and regional clients.<sup>1191</sup> In their submission to the Inquiry, the national peak body for speech pathologists, Speech Pathology Australia, described one way of supporting greater access to and use of telehealth:

At present, most private health insurers and Medicare only provide a rebate for services provided individually and face-to-face. Members report wishing to provide group therapy or telepractice sessions, both of which have a strong evidence base and have been found to be just as effective as other more traditional methods of service delivery. Providing access to rebates particularly for telepractice would be one step towards providing increased access to services for Victorian's living in rural locations.<sup>1192</sup>

However, the Committee also heard that telehealth sessions could not replace the assessment and diagnosis process, which requires close observation of a person's communication and behaviour.<sup>1193</sup> The Committee also heard that telehealth is just one means of communicating over long distances and online training and other technology can also be considered.<sup>1194</sup>

The Committee has heard that health professionals in rural and regional areas require training and mentoring opportunities and that this can be highly beneficial for developing ASD knowledge among health professionals and encouraging retention of staff in rural and regional areas. The Committee has identified that greater usage of telehealth and other technologies, as well as the development of a hub and spoke model of training provision can connect experienced health professionals in Melbourne and in regional centres with rural and remote health professionals. Accordingly, the Committee recommends:

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1191 Latrobe Community Health Service, submission no. 34, p. 3. Ms Leonie Baker, Chief Speech Pathologist, Swan Hill District Health, Family and Community Development Committee public hearing - Swan Hill, 14 February 2017, transcript of evidence, p. 8.

1192 Speech Pathology Australia, submission no. 136, p. 13.

1193 Ms Leonie Baker, Chief Speech Pathologist, Swan Hill District Health, Family and Community Development Committee public hearing - Swan Hill, 14 February 2017, transcript of evidence, p. 8.

1194 Associate Professor Jill Sewell, Deputy Director, Centre for Community Child Health, Royal Children's Hospital, Family and Community Development Committee public hearing - Melbourne, 29 August 2016, transcript of evidence, p. 6.

## RECOMMENDATION 9.4

The updated State Autism Plan ensure affordable and ongoing training and mentoring opportunities for health professionals in identifying developmental delays, and diagnosing and treating children and adults with ASD.

- Training be extended to health practitioners in rural and regional locations through the greater use of technologies such as telehealth.
- The Plan explore alternative ideas and opportunities to ensure services are striving for inclusiveness.

### Fly in fly out specialists

The Committee received some evidence that local health care providers have employed fly in fly out specialists effectively to provide assessment and diagnostic services in remote areas. Located in the north-west corner of the state, Mildura is a 6.5 hour drive to Melbourne and a 4.5 hour drive to Adelaide. In their submission to the Inquiry, early intervention services and disability service provider, Mallee Family Care stated that the area had previously seen ‘a surge of people diagnosed with ASD’.<sup>1195</sup> Medicare Local had organised a fly in fly out specialists service that provided ASD assessment for local families. The service ceased as assessment and diagnosis went to the CYMHS team at the Mildura Base Hospital.<sup>1196</sup> In their submission, Mallee Family Care noted that there were limitations to this service. There needed to be better local coordination to ensure that families could access therapies post-diagnosis.<sup>1197</sup>

### Rural and regional universities

One of the most concerning issues highlighted by rural and regional stakeholders has been the overall shortage of professional workers in health care, disability services and education in rural and regional areas. In addition to measures aimed at delivering greater support and training to health workers in rural and regional areas, the Committee also heard support for the availability of tertiary courses in allied health and special education in rural and regional universities.

At a hearing in Bendigo, former CEO of Amaze and the CEO of Distinctive Options, Mr Murray Dawson-Smith considered that there needed to be, ‘a system where people are leaving to get qualifications and then returning home or to their regional centres’.<sup>1198</sup> During the hearing in Swan Hill, the Committee heard from the Chief Speech Pathologist of the Swan Hill District Health service, Ms Baker who observed that the retention of allied health practitioners in Swan Hill has improved because of the availability of tertiary-level courses offered at Latrobe University in Bendigo.<sup>1199</sup>

<sup>1195</sup> Mallee Family Care, submission no. 130, p. 1.

<sup>1196</sup> Ibid. See also, Ms Donna Milne, submission no. 91, p. 1.

<sup>1197</sup> Mallee Family Care, submission no. 130, p. 1; Sunraysia Community Health Service, submission no. 112, p. 3.

<sup>1198</sup> Mr Murray Dawson-Smith, Chief Executive Officer, Distinctive Options, Family and Community Development Committee – Bendigo, 17 October 2016, transcript of evidence, pp. 5-6.

<sup>1199</sup> Ms Leonie Baker, Chief Speech Pathologist, Swan Hill District Health, Family and Community Development Committee public hearing - Swan Hill, 14 February 2017, transcript of evidence, p. 7.

Representatives of the Bendigo Autistic Advocacy and Support Service also highlighted the importance of the availability of the special education course offered at La Trobe University in Bendigo for all educators particularly those located in the Bendigo region.<sup>1200</sup>

### **Scholarships for Aboriginal and Torres Strait Islander students in allied health**

The Committee also heard of the need for more Aboriginal and Torres Strait Islander graduates trained in the professions that diagnose and support people with ASD. At the Bendigo hearing, Ms Rebecca Kelly of the Bendigo Autistic Advocacy and Support Services (BAASS) stated:

Another issue that is rarely spoken about is the fact that most rural and regional areas have no Aboriginal therapist qualified in the fields of speech therapy, activation therapy or psychology. This is concerning because a majority of Aboriginal families who have autistic children want to raise their children strong in culture.<sup>1201</sup>

BAASS supported the creation of a scholarship for Aboriginal students in regional and rural areas to train in an allied health profession, social work, psychology and education, which will ensure that a network of Aboriginal professionals 'will build up in these areas to accommodate the cultural needs of Aboriginal autistic families living in the area'.<sup>1202</sup>

Shortages of diagnostic and therapeutic services in rural and regional areas impacted all families but the impact is potentially even more acute for Aboriginal families. At the hearing in Swan Hill, Chief Speech Pathologist of Swan Hill District Health, Ms Baker stated:

We have a clinic at Mallee District Aboriginal Services once a week on a Wednesday morning, and probably over 50 per cent of the clients I see there would have ASD or a possible ASD diagnosis. I am only probably seeing about four clients a week there, though.<sup>1203</sup>

As discussed in Chapter One, there is a need for prevalence data and further training and understanding across the health sector on the needs of Aboriginal and Torres Strait Islander children and adults with ASD and their families. The Committee recognised the proactive efforts of the rural and regional health and disability service providers who have worked closely with local Aboriginal health and community

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1200 Ms Rebecca Kelly, Co-convenor, Bendigo Autistic Advocacy and Support Service, Family and Community Development Committee public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 12.

1201 Ibid, p. 7. See also, Mr Shilo Wilson, Manager, Respite and Support Services, Interchange Gippsland, Family and Community Development Committee public hearing – Morwell, 5 December 2016, transcript of evidence, p. 6.

1202 Ms Rebecca Kelly, Co-convenor, Bendigo Autistic Advocacy and Support Service, Family and Community Development Committee public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 8.

1203 Ms Leonie Baker, Chief Speech Pathologist, Swan Hill District Health, Family and Community Development Committee public hearing - Swan Hill, 14 February 2017, transcript of evidence, p. 9.

services to provide services to Aboriginal families. The Committee also recognised potential benefits in providing scholarships for Aboriginal and Torres Strait Islander students to train in the areas of allied health in regional universities.

La Trobe University has campuses in rural and regional areas including Bendigo, Albury-Wodonga, Mildura and Shepparton.<sup>1204</sup> La Trobe offers relevant courses in allied health, education and special education, psychology and social work at undergraduate and postgraduate levels.<sup>1205</sup> The Committee has heard of the importance of La Trobe University's courses such as the Master of Special Education offered at the Bendigo campus and the Master in Speech Pathology offered in Bendigo (and Melbourne) to promote graduates from rural and regional areas to practice in rural and regional communities.<sup>1206</sup>

Accordingly, the Committee recommends that:

#### **RECOMMENDATION 9.5**

**The Victorian Government collaborate with relevant tertiary campuses in rural and regional areas to develop strategies for the retention of graduate students in allied health, psychology, speech pathology, social work and education in rural and regional communities, and to maintain and grow relevant courses in rural and regional campuses.**

#### **RECOMMENDATION 9.6**

**The Victorian Government fund scholarships to Aboriginal and Torres Strait Islander students in the areas of allied health, psychology, speech pathology, social work and education – and to provide support to Aboriginal and Torres Strait Islander students to learn their profession in rural and regional communities.**

### **9.3. Schooling options in rural and regional Victoria**

During the Inquiry, the Committee received evidence of the lack of appropriate school options for students with ASD in rural and regional communities. There were exceptions and the Committee heard about model schools that have developed in response to the lack of appropriate schooling options for children and youths with ASD and other special needs. The Committee frequently heard that rural and regional

1204 La Trobe University, 'Campuses', accessed 19 May 2017, <[www.latrobe.edu.au/campuses](http://www.latrobe.edu.au/campuses)>.

1205 La Trobe University, 'Courses', accessed 19 May 2017, <[www.latrobe.edu.au/courses/study-health-sciences](http://www.latrobe.edu.au/courses/study-health-sciences)>.

1206 La Trobe University, 'Master of Special Education', accessed 19 May 2017, <[www.latrobe.edu.au/courses/education-career-development/postgraduate](http://www.latrobe.edu.au/courses/education-career-development/postgraduate)>; Ms Rebecca Kelly, Co-convenor, Bendigo Autistic Advocacy Support Service, Family and Community Development Committee public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 12. See also: La Trobe University, 'Master of Speech Pathology', accessed 19 May 2017, <[www.latrobe.edu.au/courses/speech-pathology/postgraduate](http://www.latrobe.edu.au/courses/speech-pathology/postgraduate)>; Ms Leonie Baker, Chief Speech Pathologist, Swan Hill District Health, Family and Community Development Committee public hearing - Swan Hill, 14 February 2017, transcript of evidence, p. 7.

families experienced significant stress when their children struggled at school and teachers had limited training to support children with ASD. Families that had been able to send their children to appropriate schooling options considered themselves 'lucky'.<sup>1207</sup>

A recurrent issue in the Inquiry has been the lack of support for students with ASD who do not qualify for funded support from the Department of Education and Training. In some metropolitan areas there are better options, however, as the parent group, the South Gippsland Autism Action Group stated in their submission, there are very limited options in rural and regional areas. In their submission, they stated:

Some parents are currently in desperate situations with their children and have nowhere else to turn for support as current schooling arrangements stand. Those families who are able have even moved intra and inter-state to seek the support they desperately need. This is not an option for everyone, nor should it have to be.<sup>1208</sup>

Aside from a lack of appropriate schooling options for students who do not qualify for a specialist school setting, at the hearing in Morwell, the Committee heard of the lack of accommodations in mainstream schools for children with ASD. At a public hearing in Morwell, Ms Natalie Owens of the South Gippsland Autism Action Group described the situation for her 10-year-old son at school:

I have a son, Caelan, who is struggling in school. He is increasingly becoming unable to cope at all. He lashes out and hurts others, swears, and throws things, because he is at such a loss. He needs constant breaks and spends a lot of time in his "calm down spot", which is placed under a teacher's desk because they are unable to provide him a sensory room or calming area. It has been a constant fight with the school on how to deal with this behaviour. Past reactions have been expulsions, behaviour contracts and punishments.<sup>1209</sup>

Repeatedly, the Committee heard that students with ASD who do not qualify for a specialist school setting or funded support were left in mainstream schools with scant support, which built stress and pressure on children, families and teaching staff in rural and regional areas.<sup>1210</sup>

At the hearing in Morwell, parents of children with ASD, Ms Tona O'Conner, Ms Natalie Owens and Ms Michelle Hackett of the South Gippsland Autism Action Group told the Committee that there was a need for an autism-specific school in their area, one that would be modelled on EdSpace. EdSpace is an independent school for

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1207 Mr Brenten Hogan, Family and Community Development Committee public hearing - Swan Hill, 14 February 2017, transcript of evidence, p. 3; Ms Trudy Gribben, Family and Community Development Committee public hearing - Shepparton, 15 November 2016, transcript of evidence, p. 8.

1208 South Gippsland Autism Action Group, submission no. 93, p. 3.

1209 Ms Natalie Owens, South Gippsland Autism Action Group, Family and Community Development Committee public hearing - Morwell, 5 December 2016, transcript of evidence, p. 2.

1210 For example, see, South Gippsland Autism Action Group, submission no. 93; Ms Susanna and Mr Martin Flanagan, submission no. 97, pp. 10-12 and Ms Shannon Leahy, submission no. 82, p. 1.



students with special needs who have been unable to succeed in other settings, located in the northeast of the state in Benalla.<sup>1211</sup>

### 9.3.1. Independent school models – EdSpace and Mansfield Autism Statewide Services (MASS)

Throughout the Inquiry, the Committee encountered a range of community-generated solutions to the needs of people with ASD. EdSpace was one such response. A group of families founded EdSpace Education and Training Centre, an independent school in the rural city of Benalla. During the Inquiry, the Committee visited EdSpace. EdSpace is an independent therapeutic school for children aged 11 to 18 who have emotional, medical, or developmental disorders, including ASD, which have affected their ability to succeed in previous schools. The school offers a wraparound approach to service provision and students are supported by a multidisciplinary team of health and education professionals. EdSpace is a registered provider of the Victorian Certificate of Applied Learning (VCAL). EdSpace currently provides Vocational Education Training (VET) courses in animal studies, business and retail. The school offers additional planning and support when students transition to further training and employment.<sup>1212</sup>

In classrooms, EdSpace offers a structured learning environment with an emphasis on the appropriate use of information technology. Teachers at EdSpace develop individual learning plans for the students. The teachers also modify mainstream subjects to include an emphasis on human relations and social skills. Students' mental health and social development are supported by two visiting speech pathologists each week and the Principal, who is a qualified teacher and a triple certificate nurse with a qualification in Child and Adolescent Health. EdSpace has existing links with local employment and TAFE agencies that are able to help with transition. In 2012, EdSpace invited a trainer from the Centre for Service and Therapy Dogs into the school.<sup>1213</sup> The Committee saw, first-hand, the benefits of this program, and heard how it had improved students' confidence and self-esteem. The Committee was impressed by EdSpace and the work being undertaken there.

The Committee also received evidence about the importance of the programs operated by the Mansfield Autism Statewide Services (MASS) – a leader in support services for rural and regional individuals and families living with autism. The Committee visited and met with staff at MASS, which is a private service established in 1968. MASS began as family camps, which offered parents of children with ASD the opportunity to come together and learn more about their children's needs in a relaxed setting. MASS aims to prepare children to integrate into schools, home and the community through a coordinated, wraparound approach to service provision. Their (fee-based) services include a school and therapeutic residential placement. Students at the Mansfield Campus (ages 6–16) are admitted for one term (9 weeks)

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1211 South Gippsland Autism Action Group, submission no. 93, p. 5. See also, Ms Natalie Owens, South Gippsland Autism Action Group, Family and Community Development Committee public hearing – Morwell, 5 December 2016, transcript of evidence, p. 5.

1212 See also, EdSpace: education and training centre, 'About Us', accessed 7 May 2017, <[www.edspace.org.au/how-edspace-runs](http://www.edspace.org.au/how-edspace-runs)>.

1213 Dogs Life, 'Dogs help fight Autism', accessed 6 June 2017, <[www.dogslife.com.au/dog-news/life-with-dogs/dogs-help-fight-autism](http://www.dogslife.com.au/dog-news/life-with-dogs/dogs-help-fight-autism)>.



to the campus and residential facility. The program is individually tailored and no one therapeutic model is used. The program assists students with ASD to gain sufficient skills to be able to integrate (or re-integrate) into a mainstream school. Speech pathologists and occupational therapists visit the campus. The numbers for the program are capped, and the staff to student ratio is high.<sup>1214</sup>

MASS runs a number of other services both locally and more broadly in regional Victoria. The Mansfield Autism Practitioners (MAPs) is an outreach service of teachers and other professionals, who travel out to families and schools across the state, providing advice and advocacy both in family homes and at schools. MASS also offers family camps, short-term respite during school holidays and on weekends for children and youths and provides a range of activities for children, which include: bush walking, picnics, swimming and visiting local attractions. MASS also runs an adult day program for adults with ASD and an equine therapy program.<sup>1215</sup> Up until a few years ago, MASS provided services to people in rural and regional areas only, but has now changed to also offer its services to people from across the state, including metropolitan Melbourne.<sup>1216</sup>

At a public hearing in Melbourne, the Committee heard from parent, Mr Shane Pendergast about how his son had benefited from the MASS program:

We live in Bairnsdale, and we have obviously used Mansfield quite a bit. Our young bloke attended Mansfield and has also attended the camps which we found. Mansfield was great. He spent eight weeks over there. Obviously he was working on his life skills and working on his behaviour. They were fantastic. Certainly it was a life-changing experience for him and also us.<sup>1217</sup>

MASS also runs the Dookie Campus, which is a small secondary school with a maximum enrolment of twelve local students (ages 11–18), with two full-time staff.<sup>1218</sup> The Committee visited the campus at Dookie, meeting staff and students, and was highly impressed with the work of the school. At a public hearing held in Shepparton, the Committee heard from Ms De'arne Treacy, mother of a 14-year-old girl with ASD, who attends the Dookie Campus. Ms Treacy praised the school and its activities:

So the ratio is fantastic. The activities are just amazing. They do yoga and art and swimming in the summer when it is hot enough, and walking every day. They cook – they are very diet conscious. There is a bit of reading and writing in there, believe it or not – they have time for that. But my daughter obviously has a learning disability as well, so she is able to get one-on-one time with her reading and writing

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1214 Mansfield Autism Statewide Services, 'Services', accessed 7 May 2017, <[www.autismmansfield.org.au/index.asp?pagename=services](http://www.autismmansfield.org.au/index.asp?pagename=services)>.

1215 Ibid.

1216 Approximately 20 per cent of enrolments at MASS are currently students from metropolitan areas. For example, 'all Victorian clients with a diagnosis of Autism are eligible to apply to attend our short term... Therapeutic Residential Placement' see: Ibid.

1217 Mr Shane Pendergast, Family and Community Development Committee public hearing – Melbourne, 6 March 2017, transcript of evidence, p. 2.

1218 See also, Mansfield Autism Statewide Services, 'Services', accessed 7 May 2017, <[www.autismmansfield.org.au/index.asp?pagename=services](http://www.autismmansfield.org.au/index.asp?pagename=services)>.

and arithmetic – self-esteem comes into play again, so that is really important. Yoga, art, singing – I think one term they might do a bit of dancing?<sup>1219</sup>

However, the Committee also heard that the cost of education at MASS's Dookie Campus was out of reach for most families in rural and regional areas.<sup>1220</sup> The cost is \$10,000 - \$12,000 per annum. In addition, the Dookie Campus only admits twelve students.<sup>1221</sup> Further, while the Committee heard that the MAPs travelling teacher service has been very successful in assisting children with ASD and their families, there was a long wait list for the service. At the hearing in Shepparton, Ms Trudy Gribben, whose son Robert has ASD, stated:

We actually went to Mansfield – we had a travelling teacher – but it took us four years to get a travelling teacher to come to us, and I was on to them from prep, grade 1. It took us four years for one person to come to us one or two days a term from Mansfield. They came into our house, which was great. The first travelling teacher, we did not get along with; I do not think she actually really got Robert or got us. The second one was fantastic. She stayed and she actually put strategies in place... We eventually got into Mansfield for one term, and that did change our lives – totally and utterly changed our lives. It totally changed Robert's life.<sup>1222</sup>

The Committee heard that MASS's educational services were hugely successful for children and parents with ASD – and that in fact these services had been 'life changing' for children and their families in rural and regional Victoria.<sup>1223</sup> In order to access MASS's services, the Committee heard that some families like the Pendergast family from Bairnsdale had travelled extensively to reach MASS's residential school in Mansfield.<sup>1224</sup> At the hearing in Shepparton, Ms Treacy told the Committee 'there need to be more Dookies'.<sup>1225</sup>

### 9.3.2. Specialist school models

The Committee also heard of specialist schools in rural and regional locations with an 'excellent reputation' for students with ASD and intellectual disabilities, but these schools were rare. During the hearing in Swan Hill, several parents spoke positively

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1219 Ms De'arne Treacy, Family and Community Development Committee public hearing - Shepparton, 15 November 2016, transcript of evidence, p. 3.

1220 Ms Shannon Leahy, submission no. 82, p. 1.

1221 Mansfield Autism Statewide Services, 'Services', accessed 7 May 2017, <[www.autismmansfield.org.au/index.asp?pagename=services#DSS](http://www.autismmansfield.org.au/index.asp?pagename=services#DSS)>. See also: Ms De'arne Treacy, submission no. 76, p. 1; Ms Shannon Leahy, submission no. 82, p. 1.

1222 Ms Trudy Gribben, Family and Community Development Committee public hearing - Shepparton, 15 November 2016, transcript of evidence, p. 5.

1223 Mr Shane Pendergast, Family and Community Development Committee public hearing – Melbourne, 6 March 2017, transcript of evidence, p. 2.

1224 Ibid. See also, Ms Trudy Gribben, Family and Community Development Committee public hearing – Shepparton, 15 November 2016, transcript of evidence, p. 7.

1225 Ms De'arne Treacy, Family and Community Development Committee public hearing - Shepparton, 15 November 2016, transcript of evidence, p. 7.

about the program and school community at the Swan Hill Specialist School. The Committee again heard that parents felt very 'lucky' to have found such schools.<sup>1226</sup>

Ms Ann Mafi is a parent of a school-aged son with ASD. At the Swan Hill hearing, Ms Mafi described her journey from New South Wales to Victoria with her son and how her decision to settle in Swan Hill hinged on having found a good school for her son:

My son and I then travelled on holidays to Nyah West, not far from Swan Hill, to visit family in 2013. I hit a kangaroo, as you do, and found employment while waiting for my car to be fixed and decided to stay after hearing about the Swan Hill Specialist School. I approached the school and had discussions about the enrolment process, what it involved, and decided that we would do this process... to finally hear that he was going to be accepted in the school brought me to tears. Finally I could rest for a while, knowing that my son and I could settle and that my son's educational and emotional wellbeing was going to be okay – for now.<sup>1227</sup>

The Swan Hill Specialist School has small class sizes and a program that helps manage the critical transition years. Its program includes an early years unit (prep to grade 5), middle years (years 6-9) and senior years unit (VCAL or Years 10-12). The school offers speech and occupational therapy and it has implemented school-wide Positive Behaviour Support to promote socially responsible behaviour. The school curriculum also includes subjects that develop, visual literacy and social emotional development for students. Other subjects of potential interest to students with ASD at the school include: bike education, the music program, art therapy and a sensory room.<sup>1228</sup>

In rural and regional settings, local schools and the 'school community' are likely to gain heightened significance for families whose children have special needs. The Committee also heard of other standalone specialist schools that had been successful by working with parents of children with special needs including ASD. At a public hearing in Morwell, Ms Carmel Murphy, a parent of a daughter with Down Syndrome and ASD, praised the local primary school's support for children with special needs. However she stated:

It wasn't easy to begin with. They weren't as accepting but because we worked so closely, all of us together, to put programs in place – the speech therapists, myself, the teachers – it was a battle to start with but they came on board and now we have set programs up for other children and it is working really well.<sup>1229</sup>

Repeatedly, the Committee heard of the need for inclusive school options and programs to be made available to rural and regional students with ASD and their families. Exemplary models exist in rural and regional communities, but they are few

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1226 Mr Brenten Hogan, Family and Community Development Committee public hearing - Swan Hill, 14 February 2017, transcript of evidence, p. 3.

1227 Ms Ann Mafi, Family and Community Development Committee public hearing - Swan Hill, 14 February 2017, transcript of evidence, pp. 2-3.

1228 Swan Hill Specialist School, 'Our Structure', accessed 7 May 2017, <[www.swanhillspec.vic.edu.au/shss\\_structure.pdf](http://www.swanhillspec.vic.edu.au/shss_structure.pdf)>.

1229 Ms Carmel Murphy, Family and Community Development Committee public hearing - Morwell, 5 December 2016, transcript of evidence, p. 5.

and far between and they are in high demand. Therefore, the Committee recommends:

#### **RECOMMENDATION 9.7**

The Victorian Government enable the Department of Education and Training to draw upon models of outreach success, both in the public and private school systems, to expand inclusive education and choice for students with ASD in rural and regional Victoria.

#### **RECOMMENDATION 9.8**

The Victorian Government fund the expansion of the “Mansfield Autism Statewide Services model” including the travelling teacher program, across regional Victoria.

#### **RECOMMENDATION 9.9**

The Victorian Government fund and expand the “Dookie model” of education for students with ASD to provide specialist autism classes with high staff to student ratios in regional secondary colleges.

## **9.4. NDIS in rural and regional areas**

The key issues about the NDIS and ASD services have been covered in Chapter Six. Of concern for many rural and regional stakeholders has been the disjuncture between the NDIS model, which is premised on providing its participants with choice and control, and the paucity of services in rural and regional areas.

The Committee heard that while disability service providers in rural and regional areas were hopeful that their clients will eventually receive better support, they nonetheless emphasised the potential for ‘market failure’ in rural and regional areas where the needs of participants outstripped the few services available.<sup>1230</sup> At the Shepparton hearing, the CEO of FamilyCare, Mr Tennant stated:

Like the overwhelming majority of service providers around Australia, FamilyCare is very welcoming of the rollout of a national disability insurance scheme and the fact that it recognises access to resources as a right for people with disabilities. There are, however, limitations to market-based responses generally and those limitations are more likely to play out in rural and regional communities.<sup>1231</sup>

At the hearing, Mr Tennant expressed relief that the transition to the NDIS will not occur in Shepparton until 2019, which gave local service providers time to observe the NDIS in other parts of Victoria and prepare for the transition.

1230 Ms Denise Bromiley, Manager Disability and Carer Program, Latrobe Community Health Service, Family and Community Development Committee public hearing - Morwell, 5 December 2016, transcript of evidence, p. 4.

1231 Mr David Tennant, Chief Executive Officer, FamilyCare, Family and Community Development Committee public hearing - Shepparton, 15 November 2016, transcript of evidence, p. 3.

Service providers located where the NDIS has had an earlier transition date have expressed a feeling of not being ready for the transition. During the Morwell hearing, Ms Bromiley, Manager of the Disability and Carer Program at Latrobe Community Health Service described her concern about the lack of services for participants and whether the NDIS will cover travel costs for rural and regional participants :

I think even though we're seeing some service providers and some other therapists move into the inner Gippsland region it is still pretty slow given we are looking at a roll out date of 1 October. So 10 months away... I think the market will take time to pick up the gap and I think in the interim time I would see that families are not going to be a whole lot better off to start with. I think even if they've had a plan done and those plans include access to supports, the actual physical ability to access those supports is still going to be challenged until the market picks that up and I don't see the market doing that, being ready to go, as soon as the roll out comes out.<sup>1232</sup>

At a public hearing in Geelong, the Committee heard that the NDIA is monitoring demand and supply in rural and regional areas. Deputy Chief Executive Officer, stakeholder relations and organisational capability Ms Louise Glanville stated:

We think in some areas it will mean perhaps some enhanced intervention by the agency in order to stimulate the sort of supply we would wish to see. We have learned from the Barkly region, for example, in the Northern Territory that we need to work very carefully and very locally, often with communities there, to actually generate different ways of supply occurring in those sorts of communities. This is why we monitor what is happening in the markets. We look at what is occurring, we try and see when is it our role to intervene and when is it the role of states or territories or indeed the commonwealth to look at this as well.<sup>1233</sup>

Ms Glanville noted that the process of building up supply would take time.

While the Committee supports the NDIA's monitoring of rural and regional participants and available services, the Committee heard of the need to ensure that established health and disability service providers, which are providing, in some cases innovative services do not lose their ability to provide their services. At the hearing in Morwell, Executive Manager of Community Health Services at Gippsland Lakes Community Health, Ms Ellis, expressed concern about the potential loss of staff like Ms Lyn Nicol, Speech Pathologist at Gippsland Lakes Community Health under the NDIS. Ms Ellis stated:

We don't roll out until 1 January '19. So the clients and the practitioners and the managers don't fully understand it to be honest. We have just started going to our meetings and information session and starting to develop funding models but from a manager's perspective it is a big transition to go from block funding onto NDIS. I'm nervous, I'll be honest. I'm really nervous that we haven't got the systems in

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1232 Ms Denise Bromiley, Manager Disability and Carer Program, Latrobe Community Health Service, Family and Community Development Committee public hearing - Morwell, 5 December 2016, transcript of evidence, p. 4.

1233 Ms Louise Glanville, Deputy Chief Executive Officer, Stakeholder Relations and Organisational Capability, National Disability Insurance Agency, Family and Community Development Committee public hearing - Geelong, 19 September 2016, transcript of evidence, pp. 9-10.

place and the bulk number of people to guarantee that income that will keep people like Lyn fully employed.<sup>1234</sup>

In addition, the Committee heard that one of the lessons from the Barwon trial has been that more services does not necessarily equate to better services. At the hearing in Geelong, Acting Coordinator of Care Services, Aged and Disability Services, Mr Geoff Barber, described how the City of Greater Geelong, had to pull out of disability support services because it could not meet the 'unit-costs' for services set by the NDIA.<sup>1235</sup> According to Mr Barber, while there has been an increase in service providers in the Barwon region, the long term effects of a competitive market of service provision may not be beneficial to participants:

But in the long term possibly I would think there are going to be some ongoing issues because providers are not going to have the staff retention that we have had, given the kind of wage that they have got.<sup>1236</sup>

During the Geelong hearing, Mr Barber further advised:

People with disabilities, but particularly people with autism, have difficulty with change. It is one thing to say that there will be lots of different players in the market, but they do not want lots of different players; they just want someone that is secure.<sup>1237</sup>

While the Committee heard of a need for more services including therapy options in rural and regional areas for individuals and families living with ASD, the Committee received evidence of the importance of some of the established health and community service providers in rural and regional areas.

In addition, the Committee heard of the need for greater support to be extended to rural and regional families given the multiple disadvantages they face. As Ms Karen Goodger, Practice Manager, Disability Support Services of FamilyCare explained during the Shepparton hearing:

[A] lot of our families are also child and family services families so they are experiencing family crisis and a range of other issues that the NDIS, in all that transitioning and that change, will be another confusing area for them, so we will try and help them as much as we can.<sup>1238</sup>

Despite the level of concern and confusion among service providers and families living in rural and regional areas, the majority of the Inquiry's stakeholders expressed

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1234 Ms Angela Ellis, Executive Manager of Community Health Services, Gippsland Lakes Community Health, Family and Community Development Committee public hearing – Morwell, 5 December 2016, transcript of evidence, p. 5.

1235 Mr Geoff Barber, Acting Coordinator, Care Services, Aged and Disability, Greater Geelong City Council, Family and Community Development Committee public hearing - Geelong, 19 September 2016, transcript of evidence, pp. 2-3.

1236 Ibid, p. 5.

1237 Ibid, p. 5.

1238 Ms Karen Goodger, Practice Manager, Disability Support Services, FamilyCare, Family and Community Development Committee public hearing - Shepparton, 15 November 2016, transcript of evidence, p. 4.

hope for the NDIS. At the hearing in Bendigo, Ms Shantelle Grant, parent of a daughter with ASD, from the Macedon Ranges Autism Network stated:

We hope that the introduction of the NDIS will enable families to access services more readily within our local communities. We also hope that these services are adequately trained and offer evidence-based outcomes and supports. Our greatest concern with the NDIS is that there will not be enough service providers in our region to meet the anticipated needs.<sup>1239</sup>

The Committee heard of the need to support rural and regional families to navigate the transition to the NDIS and to ensure that services are adequate and available in rural and regional areas following the transition. The Committee heard that more consultation and engagement with local families and service providers is required. At the Morwell hearing, Ms Nicol, speech pathologist of Gippsland Lakes Community Health highlighted the work of the East Gippsland Children with Additional Needs Working Group in preparation for the NDIS:

I think also as a general regional thing as well, Children With Additional Needs Working Group is very conscious of mapping exactly what is available in the area across all the services, respite, those sorts of things, finding out what exactly it is that parents need ... they're certainly looking at the NDIS and how the mapping of that rolls over into an NDIS.<sup>1240</sup>

The Committee encourages the NDIA to ensure that services are appropriate and available by working with local rural and regional communities to understand local needs more closely.

Accordingly, the Committee recommends that:

#### **RECOMMENDATION 9.10**

**The Victorian Government use its position on the COAG Disability Reform Council to ensure that the NDIA addresses potential market failures in the NDIS in rural and regional communities so that services in rural and regional communities are not diminished, particularly established services that have been found to be effective and reliable for people with ASD and their families.**

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1239 Ms Shantelle Grant, Macedon Ranges Autism Network, Family and Community Development Committee public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 3.

1240 Ms Lyn Nicol, Speech Pathologist, Gippsland Lakes Community Health, Family and Community Development Committee public hearing – Morwell, 5 December 2016, transcript of evidence, p. 7.



# Chapter 10

## Social Inclusion, Community Participation and Sport

### AT A GLANCE

#### Background

The Committee heard that people with ASD and their families have frequently been isolated, marginalised and have felt excluded. This has stemmed from the core challenges that people with ASD face in terms of communication, socialisation and their sensory issues – as well as the institutional challenges of including people with ASD across all settings. The Committee has found that the social costs of failing to include people with ASD in the community has contributed to a loss of health and wellbeing for people with ASD and their families.

#### Chapter overview

This chapter begins by discussing the key barriers to social inclusion, community participation and access to sports and recreational activities for people with ASD. The Committee heard that the lack of awareness of ASD in the community has left not only individuals but also their family members more socially isolated. The chapter discusses some of the leading initiatives that have emerged in the community to facilitate access for people with ASD to community-based activities and programs and the importance of raising awareness among public transport officers and police. The chapter concludes by discussing the role of self-advocates in defining social inclusion and community participation for people with ASD. This chapter addresses the following terms of reference:

- b) the availability and adequacy of services provided by the Commonwealth, State and local governments across health, education, disability, housing, sport and employment services;
- c) the adequacy of services to be provided under the National Disability Insurance Scheme (NDIS); and
- d) evidence of the social and economic cost of failing to provide adequate services.

During the Inquiry, the Committee heard that people with ASD and their families have frequently been isolated, marginalised and excluded from the community. An earlier Parliamentary Inquiry conducted by this Committee into the social inclusion of Victorians with disability found Victorians with disability were less likely to have their social and community participation needs met. In addition, Victorians with disability were less likely to access sports activities in the community despite the health benefits.<sup>1241</sup> While recommendations for key service areas including diagnosis and early intervention, education and employment, health and mental health have been outlined in earlier chapters, this chapter considers the fundamental need for people with ASD to have the opportunity to participate in the community and contribute to the development of the community.

The current State Disability Plan (2017) has outlined an extensive range of actions to facilitate the inclusion of people with disability in Victoria. The Committee believes that the recommendations in this Inquiry will further inform the State Government about the specific needs and strengths of people with ASD. Given the complexity and diversity of ASD, there is some evidence to suggest that designing spaces and buildings, as well as creating programs and activities, that are inclusive of people with ASD can potentially lead to gains for people experiencing a wide range of disabilities and benefit everyone.<sup>1242</sup> This chapter addresses the following terms of reference:

b) the availability and adequacy of services provided by the Commonwealth, State and local governments across health, education, disability, housing, sport and employment services; c) the adequacy of services to be provided under the National Disability Insurance Scheme (NDIS); and d) evidence of the social and economic cost of failing to provide adequate services.

## **10.1. Barriers to social inclusion, community participation and sport**

People with ASD experience internal and external barriers that prevent their participation in the community. Parents have stated that poor motor skills and coordination, lack of understanding of social and sporting rules, high anxiety, challenging behaviours and sensory issues have contributed to the exclusion of people with ASD. The general lack of awareness of ASD in the community about how to help people with ASD, as well as the limited activities and programs on offer, have

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1241 Family and Community Development Committee, (FCDC), *Inquiry into the Social Inclusion of Victorians with Disability*, Parliament of Victoria, 2014.

1242 Professor Nicole Rinehart, Deakin Child Study Centre, Family and Community Development Committee public hearing - Melbourne, 6 March 2017, transcript of evidence, p. 2. See also, Amaze submission, 'Building Autism Friendly Environments', Senate Community Affairs References Committee, *Inquiry into the Delivery of Outcomes under the National Disability Strategy 2010-20, to build inclusive and accessible communities*, 29 April 2017, p. 7, accessed 29 May 2017, <[www.amaze.org.au/2017/05/building-autism-friendly-environments-amaze-submission](http://www.amaze.org.au/2017/05/building-autism-friendly-environments-amaze-submission)>. See also, S Shell, 'Why Buildings for Autistic People are Better for Everyone, Forte Building Science, (2016), cited in Amaze Submission, 'Building Autism Friendly Environments', p. 6.

further prevented people with ASD from taking part in community events, sports and recreational activities.<sup>1243</sup>

During a public hearing in Morwell, Ms Tona O'Connor of the South Gippsland Autism Action Group spoke about her son's challenging behaviours and the lack of appropriate support at school. Ms O'Connor also described the very limited range of extracurricular activities that her son takes part in:

We don't do anything apart from disability services. My son can't play sport. He doesn't go to birthday parties, play dates. He is purely at home, at school or we do have once a month he goes for a... small social group date with Scope for five hours but he has to have one-on-one and that is even a nightmare. They struggle to manage even that. With four children and three support workers and that is even difficult. We don't really go out to social things.<sup>1244</sup>

At a public hearing in Melbourne, Ms Dianna Lane, a parent of a daughter with ASD, described how the recreational program offered by her local council has been beneficial but also highly problematic because activity organisers have frequently taken participants on outings. Ms Lane's 19-year-old daughter Chloe has ASD, an intellectual disability, ADHD and a sensory disorder and she requires a structured and routine environment. Ms Lane understood that other participants with disability enjoyed the outings but she hoped that there could be more done for youths like her daughter. Ms Lane and her husband have been the primary carers of their daughter and in their experience:

For Chloe the activities have to be centre-based because to take her out into the community and into the environment takes a lot. We have to prep her up with a social story, we have got to go and then maybe we will have to leave straightaway.<sup>1245</sup>

According to Ms Lane, the lack of appropriate programs and the limited awareness of the needs of people with ASD has further reduced the social and recreational options for her daughter Chloe in the community:

All Chloe does is attend South Kingsville Community Centre one Saturday a month and that's if they stay at the centre.<sup>1246</sup>

In her submission, Ms Deborah Ditchburn, a parent of a 9-year-old son with ASD, also highlighted the lack of respite and recreational services offered by local agencies and by her local council. Ms Ditchburn had been looking for 'a small group that can offer activities once a month on a weekend' so that her son can form social connections

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1243 See for example: Ms Tona O'Connor, Family and Community Development Committee public hearing – Morwell, 5 December 2016, transcript of evidence, p. 11 and Ms Deborah Ditchburn, submission no. 21, p. 2.

1244 Ms Tona O'Connor, Family and Community Development Committee public hearing – Morwell, 5 December 2016, transcript of evidence, p. 11.

1245 Ms Dianna Lane, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 2.

1246 Ms Dianna Lane, submission no. 11, p. 1.

independently, and she can spend some time with her younger son. Ms Ditchburn's enquiries to relevant local agencies and the council met with the following response:

I was told that due to funding restrictions, most services are now geographically zoned and there is very little offered in my area. My local Council service has a waitlist of up to 3 years.<sup>1247</sup>

Ms Ditchburn also highlighted a 'gap in the availability of suitable school holiday programs' and explained that many community-based recreational programs were short-lived and had a turnover of staff, which presented significant challenges for children with ASD:

[M]ost children with autism don't transition well to new environments and unfamiliar people and routines. In the case of my son, it would take almost the whole holiday period for him to adjust to the program and there would be considerable emotional consequences along the way. He would just get to the point of managing the environment when it would end and the point would be [moot].<sup>1248</sup>

People with ASD also experience difficulties accessing mainstream sports programs in the community. At a public hearing in Swan Hill, Mr Brenten and Ms Janelle Hogan told the Committee that they attended the football weekly and their children play football, except their son Cade who has ASD. According to Mr and Ms Hogan, Cade attends Saturday football with his family as he 'likes being around people' but 'probably to kick, handball and run' is just difficult; Mr and Ms Hogan were hopeful that their son's physiotherapist can assist him to improve his ability to participate and his motor skills.<sup>1249</sup>

At a public hearing in Shepparton, Ms Carole Trotter who has a middle-aged son with ASD and a granddaughter with ASD told the Committee that her son has poor 'brain-body coordination', which has prevented his participation in sports programs.<sup>1250</sup> However, Ms Trotter stated that 'it would have helped' her son to have had the opportunity to participate in community-based sports and recreational activities, further:

He was a member of a venture club here in Shepparton at one stage. There were two older guys that looked after him. They accepted him for what he was. But any other groups, no.<sup>1251</sup>

At the hearing in Morwell, Ms Michelle Hackett of South Gippsland Autism Action Group who has three children, including a son with ASD and a daughter with Down syndrome, described her son's highly challenging behaviours, which manifest when he feels stressed. Recognising the benefits of sports and recreation and having few

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1247 Ms Deborah Ditchburn, submission no. 21, p. 2.

1248 Ms Deborah Ditchburn, submission no. 21, pp. 2-3.

1249 Mr Brenten and Ms Janelle Hogan, Family and Community Development Committee public hearing – Swan Hill, 14 February 2017, transcript of evidence, p. 5.

1250 Ms Carole Trotter, Family and Community Development Committee public hearing – Shepparton, 15 November 2016, transcript of evidence, p. 8.

1251 Ibid.

options for support in their community, Ms Hackett described the significant sacrifices that she and her husband have made to ensure their children participate:

James does swimming, Little Athletics and soccer. We just make him. We just make him. He hates it. We split up. So I go with the littlest with Down syndrome and he goes with the other two and you have to have an eye on him and an eye on Sam. So we are just basically separate all the time. That's our daily life anyway on weekends. But we make him. We make him do swimming one-and-a-half hours per session twice a week, Little Athletics.<sup>1252</sup>

Despite his behaviours of concern, Ms Hackett described her son's desire to be social and to have friends:

The other thing is he does like being social and he just doesn't understand and he can get very angry and he does have play dates but it is all on his terms and his level and we just have to be there all the time watching him.<sup>1253</sup>

Parents have also often emphasised that their children have the potential to engage in community-based activities, in the right environment and given the right support. At the Morwell hearing, Ms Hackett told the Committee:

James is a great kid when he is calm and full of interesting facts and questions. He loves to be doing things and makes us laugh.<sup>1254</sup>

Ms O'Connor also emphasised that 'when Leo [her son] is not under stress he is a beautiful boy'.<sup>1255</sup> Ms Lane has helped her daughter Chloe access extra-curricular activities and in her submission, she described the success of earlier recreational programs for her daughter:

When she was younger, Chloe really enjoyed attending the local school holiday programs and she was supported with a helper and although she was older than the other able children, developmentally she is like a 7 yo and loved to play at the centre with all the other children...Chloe loves centre based activities as she knows what she will be doing... She is also very social and loves being around people and likes routines and rituals.<sup>1256</sup>

According to the CEO of Amaze, Ms Fiona Sharkie, people with ASD frequently experience discrimination, and stigma in the community. In her experience, one of the most stressful experiences for parents has been to go out and experience 'what they call the "tut-tut"' from people around them who think it is their bad parenting

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1252 Ms Michelle Hackett, Family and Community Development Committee public hearing – Morwell, 5 December 2016, transcript of evidence, p. 11.

1253 Ibid.

1254 Ibid, p. 4.

1255 Ms Tona O'Connor, Family and Community Development Committee public hearing – Morwell, 5 December 2016, transcript of evidence, p. 4.

1256 Ms Dianna Lane, submission no. 11, p. 1.

when their child (or adult) has a meltdown.<sup>1257</sup> Yet Ms Sharkie described the positive effects when people in the community understand ASD:

We do hear good stories of families that say, ‘My child was overwhelmed in a retail shop. The shopkeeper was looking at me disapprovingly. I said my child had autism, and suddenly they went, “Oh fine. What can I do?” So it is about really having to say this is what it looks like, this is how you can help and this is how you can be supportive, and saying tut-tut and looking down at people and casting that stigma and judgement is not helpful at all.’<sup>1258</sup>

The Committee heard that social connectedness is important for people with ASD and their families.

People with ASD want to find others who understand them and to access the events and activities that support their identity and appeal to their interests. For people with ASD, there have been environmental barriers preventing their participation in the community. At a public hearing in Geelong, Ms Stacey Smith, an adult with ASD, described the need to raise awareness of ASD across all settings,

So, yes, children, but also adults, please. We need help, we need understanding. You do not grow out of autism. Things are just as hard. Like the lighting in this room is horrible. I wish I had a hat. If I was in here all day, that would have an effect on me. These things do not get spoken about...<sup>1259</sup>

By meeting people with ASD and listening to their needs, the Committee learnt about the difficulties people with ASD have faced in the community. The Committee heard that it is vital to make accommodations across the board to facilitate access and inclusion in the community of people with ASD, which can support the health and wellbeing of people with ASD and their families.

The Committee believes the Victorian Government has a role to play in educating and informing the community of ASD and to collaborate with people who have ASD to build an all-inclusive community.

Accordingly, the Committee recommends that:

### **RECOMMENDATION 10.1**

**In the updated State Autism Plan, the Victorian Government make provision for a broad and extensive public education campaign to raise awareness about ASD and the inclusion of people with ASD, their families and carers in the community.**

<sup>1257</sup> Ms Fiona Sharkie, Chief Executive Officer, Amaze, Family and Community Development Committee – Melbourne, 29 August 2016, transcript of evidence, p. 11.

<sup>1258</sup> Ibid.

<sup>1259</sup> Ms Stacey Smith, Family and Community Development Committee – Geelong, 19 September 2016, transcript of evidence, p. 3.

## 10.2. Building community and institutional awareness of ASD

During a public hearing in Melbourne, the CEO of Amaze, Ms Fiona Sharkie, described the need to build community and institutional awareness of ASD and to develop access solutions for people with ASD:

Whilst we have made considerable gains in recent decades for people with physical disability – you do not go into a building now without having ramps, you do not go into a lift without it having Braille on the lift buttons – we need to now consider what are those equivalent ramps and rails for people with non-physical disability and autistic people.<sup>1260</sup>

The Committee heard of several initiatives that have been developed by local councils, organisations and individuals to include people with ASD in community events, local sports and recreation activities and in cultural institutions. However, the Committee heard that these initiatives remain few and far between in the community. There is a need to raise ASD-awareness and the capacity of the entire community to include people with ASD and not just in isolated settings.

### Local government: libraries, pools and community events

In their submission, Darebin City Council referred to initiatives undertaken to enhance access for people with ASD in their community facilities. Darebin Council has created a ‘sensory story time’ initiative in their public libraries and library staff have been supportive of people with ASD by taking photos of the various steps involved in borrowing a book to assist people with ASD.<sup>1261</sup> In addition, Darebin Council have incorporated ‘quiet time’ into their Children’s Day Festival. In their submission, they stated that they have undertaken these initiatives due to the example set by the neighbouring City of Banyule:

There [is] an increased awareness across council of the need to adapt community events to cater to the needs of people with ASD, and this has been evidenced by the ‘sensory story time’ initiative of Darebin libraries, and measures at local festivals to improve accessibility. The upcoming Children’s Day Festival incorporates a space for quiet time in recognition of the overwhelming nature of these festivals for some children with ASD, and Darebin City Council note the example set by City of Banyule in the recent ‘Arty Farty Sensory Friendly Festival’ initiative.<sup>1262</sup>

Banyule City Council won first place for their autism-friendly initiative in the 2017 Municipal Association Victoria (MAV) National Local Government Innovation Awards.<sup>1263</sup> According to Banyule Council, they were ‘inspired by work happening globally’ to support the attendance of children with ASD at sport and culture events.

<sup>1260</sup> Ms Fiona Sharkie, Chief Executive Officer, Amaze, Family and Community Development Committee – Melbourne, 29 August 2016, transcript of evidence, p. 3.

<sup>1261</sup> Darebin City Council, submission no. 99, p. 5.

<sup>1262</sup> Ibid.

<sup>1263</sup> Banyule City Council, ‘News and Public Notices - Sensory Friendly Festivals Win Gold Award, 28 March 2017’, accessed 25 May 2017, <[www.banyule.vic.gov.au/Council/News-and-Public-Notices/Award-Wins](http://www.banyule.vic.gov.au/Council/News-and-Public-Notices/Award-Wins)>.



Banyule Council consulted with ASD organisations to develop the festival. All festival volunteers, stall holders and performers also undertook autism awareness training and there were resources at the festival to ‘ensure the fun and safety’ of attendees.<sup>1264</sup>

In a submission to the Inquiry, Hobsons Bay City Council described supporting a number of community-based initiatives for people with ASD including the Laverton Swim and Fitness Centre, which delivers specific classes for children with ASD. They have also partnered with the Western Autistic School, located within the municipality, to deliver programs.<sup>1265</sup>

The Committee has been impressed by these leading examples. But it has also heard of the need for much more to be done to assist people with ASD to access the sports and recreation facilities and events offered in the community. According to Hobsons Bay’s Disability Advisory Committee, there has been a lack of recreational activities available for children with ASD over 13 years of age in their municipality. Hobsons Bay also highlighted the fact that recreational activities for people with ASD often need to be ‘tailored to meet their needs’ and there are few after-school and school holiday programs on offer in their area, due to funding limitations.<sup>1266</sup>

Hobsons Bay City Council also highlighted the need for resource and design guidelines to include the access needs of people with ASD:

Resources, design guidelines and standards need to be developed to support local and state governments as well as private developers to ensure infrastructure can also cater for the needs of young people with autism spectrum disorder.<sup>1267</sup>

Local governments hold responsibilities for planning, developing and engaging the local community. The Committee believes more can be done to raise the capacity of all local governments to plan and build accessible spaces, facilities and activities so that people with ASD can access all of the amenities and events that are offered in their local government area. Accordingly, the Committee recommends that:

## **RECOMMENDATION 10.2**

**The Victorian Government partner with local governments to provide more sporting and recreation opportunities for people with ASD through each LGA local Disability Action Plan.**

### **Northland Shopping Centre**

During the Inquiry, the Committee also heard of the benefits of including a quiet room in shopping centres for people with ASD. In 2014, Northland Shopping Centre opened

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1264 Municipal Association of Victoria (MAV), ‘Banyule City Council Wins Innovation Award’, accessed 25 May 2017, <[www.mav.asn.au/news/Pages/banyule-city-council-wins-innovation-award-%2822-Mar%29.aspx](http://www.mav.asn.au/news/Pages/banyule-city-council-wins-innovation-award-%2822-Mar%29.aspx)>.

1265 Hobsons Bay City Council, submission no. 80, p. 3.

1266 Ibid, p. 4.

1267 Ibid, p. 5.

a quiet room for people with ASD.<sup>1268</sup> Northland had partnered in this initiative with Amaze. According to Amaze, the purpose-built room has provided a comforting space with minimal sensory input, which has been well attended by people with ASD since opening. According to Amaze, Northland's quiet room is the first in Australia and possibly the first ever purpose-built quiet room inside a shopping centre for people with ASD worldwide.<sup>1269</sup>

### **Autism Friendly Museum experience**

The Committee was pleased to hear about the Autism Friendly Museum initiative undertaken by Museum Victoria. In their submission, Museum Victoria described their autism-friendly initiative, which developed during 2014 and represented a partnership between Museum Victoria, the Department of Education and Training, and Amaze. At the heart of the Autism Friendly Museum experience has been the following strategies:

- Raising awareness within Museum Victoria front of house staff on autism, and support of those staff to be confident to welcome and engage visitors with autism
- Published online resources on the museum's website in the form of social stories, and maps of low and high sensory spaces
- Extensive communication internally and externally about the project and the resulting web resources, to ensure awareness and community use
- Ongoing evaluation and updating of the social stories and maps with key audience groups and stakeholders.<sup>1270</sup>

In their submission, Museum Victoria informed the Committee that in the first six months of availability 7,000 people have downloaded their social stories and sensory maps. The social stories have been published in Microsoft Word format which have enabled parents to tailor the social stories to their unique experience. The social stories have prepared children with ASD for their trip to the Melbourne Museum by describing what they can expect. The social stories include descriptions about the Museum and photographs of the Museum and its key exhibitions. They also contain information on where parents and children with ASD can get support inside the Museum and expectations towards children's behaviour inside the galleries. The sensory map has also highlighted 'high' and 'low' sensory spaces inside the Museum, giving parents and their children forewarning and a guide to the location of low sensory areas inside the Museum for when quiet time is required.<sup>1271</sup>

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1268 Ms Fiona Sharkie, Chief Executive Officer, Amaze, Family and Community Development Committee – Melbourne, 29 August 2016, transcript of evidence, p. 3.

1269 Ibid. See also, Amaze submission, 'Building Autism Friendly Environments', Senate Community Affairs References Committee, *Inquiry into the Delivery of Outcomes under the National Disability Strategy 2010-20, to build inclusive and accessible communities*, 29 April 2017, pp. 11, 28, accessed 29 May 2017, <[www.amaze.org.au/2017/05/building-autism-friendly-environments-amaze-submission](http://www.amaze.org.au/2017/05/building-autism-friendly-environments-amaze-submission)>.

1270 Museum Victoria, submission no. 115, pp. 1-2.

1271 Museum Victoria, 'The Autism Friendly Museum', accessed 28 May 2017, <[museumvictoria.com.au/melbournemuseum/visiting/access/the-autism-friendly-museum](http://museumvictoria.com.au/melbournemuseum/visiting/access/the-autism-friendly-museum)>.

Museum Victoria has received positive feedback from many parents about the initiative. According to their submission, the Autism Friendly Museum initiative won the Victorian Museums Award in 2015 and the initiative is now 'being used as a model by other museums'.<sup>1272</sup> The Committee has been impressed with the few isolated and important initiatives to engage and include people with ASD in the community such as the Autism Friendly Museum initiative. The Committee heard of the need to consult with people who have ASD in the design and evaluation of programs. The Committee also heard about the importance of being aware of the environmental barriers faced by people with ASD and their need for structure, familiarity and routine. The Committee believes that any updated State Autism Plan could draw on these existing examples in the community to revise the original wide-reaching awareness and inclusion strategy for people with ASD. Accordingly, the Committee recommends that:

### **RECOMMENDATION 10.3**

**The Victorian Government fund Creative Victoria to develop an autism inclusion strategy for all publicly funded arts and cultural institutions and events in order to facilitate visitation and participation for people with ASD and their families.**

### **RECOMMENDATION 10.4**

**The Victorian Government in the updated State Autism Plan develop a strategy for the social inclusion of people with ASD across all government departments responsible for community, cultural and sporting events.**

### **Awareness and training for public transport officers and police (including protective services officers and custody officers)**

In addition to the general lack of appropriate activities and programs for people with ASD, the Committee was disappointed to hear of the lack of ASD-awareness and training among public transport officers. At a public hearing in Geelong, Ms Sarah Hayden, a parent of a 19-year-old daughter with ASD, told the Committee that she had encouraged her daughter to become 'a bit more independent' by allowing her to catch the train from Geelong to Melbourne. However, a recent confrontation with public transport officers left her daughter in great distress:

Recently she travelled with her ticket, but she forgot to have her healthcare card with her. When the officers came up, they said, 'Ticket'. She handed the ticket, and they said, 'On what grounds do you have this?'. She said, 'My mum bought it for me'. She could not understanding the literal wording.

Basically they took her off the train, took her into a room and told her that she could go to gaol. By this stage she was having a full-blown meltdown. They would not allow her to call anybody, so I had to drive hours to pick her, basically in a foetal position having a full meltdown... They pulled her off the train. She had a literal misunderstanding of, 'I don't understand what you are asking'. They said,

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<sup>1272</sup> Museum Victoria, submission no. 115, p. 2.

'On what grounds do you have this ticket?'. She said, 'My mum bought it for me'. 'Don't be a smart-arse', they said to her.<sup>1273</sup>

Ms Hayden contacted the police following the incident and she was informed that 'it is not an uncommon thing to get a phone call from a parent of a special needs child who... looks normal'.<sup>1274</sup> People with ASD may not have any visible disabilities and the Committee heard of how a lack of awareness and understanding of ASD among public transport officers and in the community at large can deter people with ASD from leaving their homes.<sup>1275</sup>

As demonstrated by the evidence given by Ms Hayden described above, interactions between people with ASD and public officials can be fraught with misunderstanding and unnecessary negative consequences.<sup>1276</sup> Given that ASD is a complex condition and it can be 'invisible', the Committee believes that there is a need to raise capability among frontline officers including public transport officers, and the police (including protective services officers and custody officers) to identify people with ASD and to provide support to facilitate their communication needs when there has been a suspected offence.

In the U.S. the Committee met with representatives of the Arc, a peak advocacy organisation for people with intellectual and developmental disabilities.

The Arc's Pathways to Justice Model has within it a key strategy that promotes procedural justice for people with an intellectual or developmental disability to train police officers to 'slow down' in their interactions with people who have an intellectual or developmental disability. This provides officers with 'an opportunity to build rapport with the individual' and to ask questions, assess the situation and formulate a plan for de-escalating the incident rather than using force.<sup>1277</sup> The ARC's

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1273 Ms Sarah Hayden, Family and Community Development Committee – Geelong, 19 September 2016, transcript of evidence, p. 3.

1274 Ibid. See also, 'Box 7.1: Case Study – disability, diversity and public transport' in Family and Community Development Committee, (FCDC), 'Chapter Seven: Accessible and Enabling Environments', *Parliamentary Inquiry into the Social Inclusion of Victorians with Disability*, Parliament of Victoria, 2014, p. 5.

1275 Ms Sarah Hayden, Family and Community Development Committee – Geelong, 19 September 2016, transcript of evidence, p. 3. See also, 'Box 7.1: Case Study – disability, diversity and public transport' in Family and Community Development Committee, (FCDC), 'Chapter Seven: Accessible and Enabling Environments', *Parliamentary Inquiry into the Social Inclusion of Victorians with Disability*, Parliament of Victoria, 2014, p. 5 and p. 18.

1276 Ms Sarah Hayden, Family and Community Development Committee – Geelong, 19 September 2016, transcript of evidence, p. 3; Mr Stan Pappos, Senior Manager, High Risk and Support Services, Australian Community Support Organisation (ACSO), Family and Community Development public hearing – Melbourne, 21 November 2016, transcript of evidence, p. 2. Mr Rob and Ms Loretta Krelle, Family and Community Development public hearing – Melbourne, 21 November 2016, transcript of evidence.

1277 M Bradley, L A Davis, W Johnson, 'Supporting Procedural Justice for People with Intellectual Disabilities': an evidence-based law enforcement practice that works', *IMPACT Feature Issue: The Justice System and People with Intellectual, Developmental, and Other Disabilities*. Vol. 30, (1), Minneapolis: University of Minnesota, Institute of Community Integration (in publication), p. 10.

National Centre on Criminal Justice and Disability provides a resource list on police training and examples of police training throughout the U.S.<sup>1278</sup>

Similarly, in the U.S., the Committee visited the advocacy organisation the Autism Society. Representatives of the Autism Society illustrated how parents/caregivers and people with ASD could promote their own safety in the community. The Autism Society's 'Safe and Sound' initiative commenced in 2005, and it has produced and provided resources on general safety, emergency preparedness and prevention for people with ASD.<sup>1279</sup> As part of the initiative, the Autism Society has also produced a standard set of guidelines and helpful hints for interacting with people who have autism for 'first responders' including law enforcers and emergency medical personnel. The helpful hints along with a set of characteristics of a person with ASD also feature on a 'wallet card' produced by the Autism Society for people with ASD.<sup>1280</sup>

In their earlier Inquiry into Abuse in Disability Services, the Committee expressed their support for the goals outlined in the Victoria Police Accessibility Action Plan (2014 -17), which aims to ensure that people with disability are supported in the community in their interactions with the police.<sup>1281</sup> The Committee remains supportive of the Victoria Police Accessibility Action Plan and the plan's articulation of a set of actions and goals to ensure accessible and equitable policing services for people with disability. The Committee also supports an expansion of the Independent Third Person program as recommended in the Inquiry into Abuse in Disability Services. Given their insights into the ASD experience, the Committee believes that more needs to occur to ensure people with ASD are fairly treated when they interface with public transport and policing agencies in the community. Accordingly, the Committee recommends that:

#### **RECOMMENDATION 10.5**

**In the updated State Autism Plan provision be made for the education and training of frontline public transport officers to understand and recognise ASD and to engage with people with ASD.**

#### **RECOMMENDATION 10.6**

**The Victorian Government ensure the goals set out in the Victoria Police Accessibility Action Plan include an understanding of ASD including the diversity of presentation of people with ASD.**

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1278 The Arc for People with Intellectual and Developmental Disabilities, 'Law Enforcements, First Responders and Corrections', accessed 31 May 2017, <[www.thearc.org/NCCJD/resources/by-audience/law-enforcement](http://www.thearc.org/NCCJD/resources/by-audience/law-enforcement)>.

1279 Autism Society, 'Safe and Sound', accessed 25 May 2017, <[www.autism-society.org/living-with-autism/how-the-autism-society-can-help/safe-and-sound](http://www.autism-society.org/living-with-autism/how-the-autism-society-can-help/safe-and-sound)>.

1280 Autism Society, 'Tips for First Responders', accessed 31 May 2017, <[www.autism-society.org/living-with-autism/how-the-autism-society-can-help/safe-and-sound/tips-for-first-responders](http://www.autism-society.org/living-with-autism/how-the-autism-society-can-help/safe-and-sound/tips-for-first-responders)>.

1281 Family and Community Development Committee, (FCDC), *Inquiry into Abuse in Disability Services*, Parliament of Victoria, 2015, p. 78.

### 10.3. The benefits of sport for people with ASD

During a hearing in Melbourne the Committee also heard from Professor Nicole Rinehart, psychologist and researcher at the Deakin Child Study Centre. Professor Rinehart has had 20 years of experience studying the motor functioning and development of children with developmental disorders. According to Professor Rinehart:

Essentially the evidence is mixed, but on balance children with autism spectrum disorders are having less opportunity for physical activity, so that is taken from a whole lot of studies from around the world.<sup>1282</sup>

Professor Rinehart further stated:

[F]rom my work as a clinical psychologist where I have worked with children for the last 20 years who have autism. I was starting to notice a pattern – that the groups of children with autism who are participating in organised sports and had those opportunities from a young age and were well supported seemed anecdotally from a clinical perspective to do better than children who did not receive those benefits.<sup>1283</sup>

Physical activity has health benefits and can reduce the risk of diseases such as diabetes and cardiovascular disease. Statistics in the U.S. have indicated a higher prevalence of overweight children with ASD and the vital importance of physical activity and participation in sport for children and youths with ASD.<sup>1284</sup> In addition to the health benefits, the Committee heard that participation in team sports has helped children with ASD to build confidence and expand their range of interests.<sup>1285</sup>

During a hearing in Melbourne, Ms Julie Langdon, CEO of Extended Families, gave evidence about the benefits of team sports for youths with ASD. Extended Families is a not-for-profit organisation supporting children and young people aged 0-30 and their families by providing respite services, support and volunteers. Their volunteers are matched with families to build friendships for young people with disability. During the hearing, Ms Langdon reported on a previous pilot program titled 'Sporting Mates', which they ran in 2010 and assisted youths with ASD and other conditions. Ms Langdon spoke about Adam, a young man with ASD that Extended Families had supported since he was 13 years of age. Adam was matched up with a volunteer called Jake under the Sporting Mates program and flourished as a result.<sup>1286</sup>

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1282 Professor Nicole Rinehart, Deakin Child Study Centre, Family and Community Development Committee public hearing - Melbourne, 6 March 2017, transcript of evidence, p. 7.

1283 Ibid, p. 2.

1284 G Dawson and M Rosanoff, 'Sports, Exercise, and the Benefits of Physical Activity for Individuals with Autism', Autism Speaks, New York City, U.S., 19 February 2009, accessed at: <[www.autismspeaks.org/science/science-news/sports-exercise-and-benefits-physical-activity-individuals-autism](http://www.autismspeaks.org/science/science-news/sports-exercise-and-benefits-physical-activity-individuals-autism)>.

1285 Ibid.

1286 Ms Julie Langdon, Chief Executive Officer, Extended Families Australia, Family and Community Development Committee public hearing - Melbourne, 21 November 2016, transcript of evidence, p. 3.



The Committee received evidence about community-led programs directed at children and youths with ASD.<sup>1287</sup> In Bendigo, the Bendigo Autistic Advocacy Support Service (BAASS) has secured funding for a sensory gymnastics program at their local gymnasium for 40 children with ASD across the region on a term-by-term basis.<sup>1288</sup>

While the Committee has been impressed with the programs that have been developed from the ground-up, the Committee also heard of the fundamental need to 'scale up' sporting opportunities for children and youths with ASD so sport is widely available and accessible to children with ASD across the state.<sup>1289</sup>

### **The ALLPlay Sports Program**

The Committee was encouraged to hear of a new initiative to help children with ASD participate in the regular Auskick football sessions that are offered across Victoria and throughout Australia to all children. The Committee heard that the ALLPlay Sports Program represented a collaboration involving the Deakin Child Study Centre in Melbourne and the Australian Football League (AFL) with support from the Moose Foundation and other supporters. The program's aim has been to create an inclusive culture for children with ASD by offering children with ASD and children with disabilities access to a supported program in order to attend the Auskick football sessions. Professor Rinehart of the Deakin Child Study Centre conceived of the ALLPlay program and she continues to lead the program.<sup>1290</sup> While the program's broader aim is to be inclusive of all disabilities, the Committee heard that its initial focus has been on children with ASD. According to Professor Rinehart this has been because:

[I]f we look at all of the groups of children with disability, the one in five children who will have some sort of developmental challenge in their lives — children with autism, we argue — have the most significant difficulties that affect social functioning, psychiatric, mental health, motor functioning, family functioning and broader. We have a saying in our group then that if we get our program right for children for autism, then we will be able to reach all of the children.<sup>1291</sup>

The program also represented a rare partnership between researchers and industry. During the hearing, Professor Rinehart expressed the hope that sport will eventually

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1287 Ms Susanna Flanagan, Co-convenor, Bendigo Autistic Advocacy Support Service, Family and Community Development Committee public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 2. Girton Grammar School has an inclusive sports program for youths with ASD, see: – 'A Sporting Chance', *Bendigo Weekly*, Bendigo, Vic., 21 April 2017.

1288 Ms Susanna Flanagan, Co-convenor, Bendigo Autistic Advocacy Support Service, Family and Community Development Committee public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 2.

1289 Professor Nicole Rinehart, Deakin Child Study Centre, Family and Community Development Committee public hearing - Melbourne, 6 March 2017, transcript of evidence, p. 3.

1290 Ibid, pp. 2-3. See also, Deakin University, 'Media Release, I play, you play, we AllPlay', accessed 29 May 2017, <[www.deakin.edu.au/about-deakin/media-releases/i-play-you-play-we-allplay-deakin-kicks-goal-s-for-kids-with-disability](http://www.deakin.edu.au/about-deakin/media-releases/i-play-you-play-we-allplay-deakin-kicks-goal-s-for-kids-with-disability)>.

1291 Professor Nicole Rinehart, Deakin Child Study Centre, Family and Community Development Committee public hearing - Melbourne, 6 March 2017, transcript of evidence, p. 2.



be prescribed to children with ASD by GPs and paediatricians based on the ALLPlay Sport Program's research outcomes.<sup>1292</sup>

According to Professor Rinehart, ALLPlay consists of four key research and activity components:

- A pre-learn day. During the pre-learn day, children with ASD who have participated in the Deakin Child Study Centre's research are offered an experience of Auskick in a safe, autism-friendly environment.
- A buddy program. ALLPlay will buddy a child with autism with an older 'able' child as a way of promoting ASD-inclusion in Auskick and greater awareness of ASD in the mainstream community.
- ALLPlay will also include pre and post program research. Professor Rinehart informed the Committee of the importance of studying a group of children with autism before and after they participate in Auskick compared to a group of children who are not participating in organised sports and factoring variables such as motor development, social and family functioning and parental mental health to understand and consider what the benefits are, following participation in the program.<sup>1293</sup>

During a public hearing in Melbourne, the Committee heard about the ALLPlay ASD awareness training being provided to Auskick's volunteer coaches who number in the tens of thousands across Australia. Currently training is delivered via the ALLPlay program website and app, which provides online resources including social scripts, information sheets and a series of brief animations that convey key points for coaches and parents to consider when training and supporting children with ASD during their sessions.<sup>1294</sup> At the hearing, Associate Professor David Austin, also of the Deakin Child Study Centre, stated that their eventual goal is to create 'an accredited course', which will 'establish best practice' in the sporting industry for children with ASD and other disabilities.<sup>1295</sup>

At the hearing, the Committee heard that ALLPlay builds on a disability-access program that has already been in place with Auskick. According to Mr Logan Whittaker, Inclusion (All Abilities) Manager AFL, the existing program has provided different tiered avenues to participate in Auskick. They include a disability access program that is delivered in the special schools and a 'side-by-side' program, which provides more support for children with disabilities to play and occurs on the same oval as a 'mainstream' program.<sup>1296</sup> According to Mr Whittaker, the models have

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1292 Ibid, p. 4.

1293 Ibid.

1294 See for example, ALLPlay, 'Change the activity, not the child', accessed 29 May 2017, <[www.allplay.org.au/coaches/tips/703135/Change-the-activity-not-the-child](http://www.allplay.org.au/coaches/tips/703135/Change-the-activity-not-the-child)>.

1295 Associate Professor David Austin, Deakin Child Study Centre, Family and Community Development Committee public hearing – Melbourne, 6 March 2017, transcript of evidence, p. 6.

1296 Mr Logan Whittaker, Inclusion (All Abilities) Manager, Australian Football League (AFL), Family and Community Development Committee public hearing – Melbourne, 6 March 2017, transcript of evidence, pp. 6-7. See also, Australian Football League (AFL) Victoria, 'Access All Abilities Auskick', accessed 29 May 2017, <[aflvic.com.au/auskick/access-abilities-auskick/](http://aflvic.com.au/auskick/access-abilities-auskick/)>.

provided parents with choice, and it has engaged children with the goal of working towards the next level. In the Auskick program at the special school:

We set them up in those really comfortable environments. We upskill them in football, with the hope to then move them through into a side-by-side model, where they can start to slowly, step by step, integrate into the community. What we hope to see in a couple of years time is a child that starts out over here and works their way up into the grade 3 group, and all of a sudden, through the support we have been able to provide in a football environment with ALLPlay behind it, they are now able to participate in grade 3 with all the other kids.<sup>1297</sup>

The Committee supports the actions outlined in the State Disability Plan (2017) to provide funding to organisations through the current Access All Abilities program and to further assist families and individuals living with disability to find out about relevant and available sports and recreational programs in the community.<sup>1298</sup> However, the Committee believes that more needs to be done to include people with ASD in community sports and recreation. This is particularly important given the higher risks of inactivity and isolation for people with ASD. The Committee views ALLPlay as an initiative that represents much needed focus on the needs of people with ASD, and the Committee supports partnerships between researchers and industry to deliver programs for people with ASD.

Currently, there are a few isolated and often temporarily funded community initiatives to engage and support people with ASD to participate in sports and recreation, for example Sporting Mates run by Extended Families Australia and Darebin City Council's pre-sports for children initiative.<sup>1299</sup>

The Committee believes that the successful Access All Abilities program can be expanded to provide more sporting and recreation opportunities for children with ASD. The Committee also believes that the State Government can support local governments in providing sport and recreation opportunities for children with ASD in their communities. Accordingly, the Committee recommends that:

#### **RECOMMENDATION 10.7**

**The Victorian Government fund the expansion of the Access All Abilities program to provide more sporting and recreation opportunities for children with ASD in their communities.**

#### **RECOMMENDATION 10.8**

**The Victorian Government fund autism specialists to liaise with local governments in the delivery of sport and recreation activities across the state for people with ASD.**

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1297 Mr Logan Whittaker, Inclusion (All Abilities) Manager, AFL, Family and Community Development Committee public hearing – Melbourne, 6 March 2017, transcript of evidence, p. 7.

1298 Victorian Government, *Absolutely Everyone: state disability plan 2017 - 2020*, Melbourne, 2017, p. 11.

1299 Ms Julie Langdon, Chief Executive Officer, Extended Families Australia, Family and Community Development Committee public hearing – Melbourne, 21 November 2016, transcript of evidence, p. 3; Darebin City Council, submission no. 99, pp. 3-4.

The Committee also supports greater cooperation between federal, state and local governments to ensure that programs and existing community facilities will be maximised for their potential to deliver sports and recreation to people with ASD. As highlighted earlier in the chapter, there remains a vital role to play for local governments in this area.

The Committee is of the view that there is the potential for the State Government and the Federal Government through the NDIS Information, Linkages and Capacity Building (ILC) component (as discussed in Chapter Six) to support wide-reaching ASD-inclusive sport and recreational programs for people with ASD.

Accordingly, the Committee recommends:

#### **RECOMMENDATION 10.9**

**The Victorian Government use its position on the COAG Disability Reform Council to encourage the NDIS Information, Linkages and Capacity Building (ILC) component be expanded to support sporting programs for people with ASD.**

### **10.4. Autistic networks, programs and social activities: redefining inclusion**

While the Committee has consistently heard of the need for the mainstream community to do more to facilitate the inclusion of people with ASD, the Committee also recognises that people with ASD hold their own views on how they can best be included in the community. Throughout the Inquiry, adults and some adolescents with ASD have spoken to the Committee about their strengths and how they have been empowered to advocate on their own behalf, as well as to act to define social inclusion and community participation on their own terms.

During a public hearing in Melbourne, the Committee heard from the I CAN Network, which has provided training and mentoring opportunities to adolescents and youths with ASD in Melbourne and in some regional areas of Victoria.

#### **The I CAN Network**

The I CAN Network described itself as the ‘first social enterprise founded by people with Autism’ in Australia.<sup>1300</sup> The organisation has mandated that a minimum of 50 per cent of the organisation including its Board, management team and volunteers have to be on the autism spectrum. The I CAN network aims to change community perceptions about ASD from a ‘deficit approach’ to a ‘strengths-based approach’ – by focusing on the strengths of people with ASD and their contributions to society.<sup>1301</sup>

Beginning from the premise that many people with ASD have been raised to have low expectations of their capabilities, the I CAN Network delivers a peer mentoring program that builds awareness, self-confidence and social connections for young people with ASD. The I CAN Network also operates youth leadership camps to train

<sup>1300</sup> I CAN Network, submission no. 127, p. 1.

<sup>1301</sup> Ibid.

young people with ASD to become mentors, and the network runs a speaking program and training program for schools, businesses and other organisations.<sup>1302</sup>

During the hearing in Melbourne the Committee heard how the I CAN Network represents a 'rethinking' of ASD by reframing ASD as a positive part of a person's identity. According to the founder and Chief Enabling Officer of the I CAN Network, Mr Chris Varney:

Very much the thrust with the I CAN Network is that we are unbelievably positive about the benefits of being on the autism spectrum. That is our product. We get out there, we train people on how to benefit from embracing autism...<sup>1303</sup>

Mr Varney also spoke about I CAN's camps, which have encouraged youths with ASD to embrace their differences and to develop a positive sense of being 'autistic':

As a measure to accelerate the development of mentors, we also run I CAN camps for both teenagers and young adults. These occur on a quarterly basis. They have now got a regional iteration as well. These are hilarious experiences. The first I CAN camp was ... not run by professors, researchers, service providers or advocates; it was run by autistics. It was a huge experience. But now they are quite an operation. We run these, and to give you a sense, you get about 70 people who say, 'I want to come on the camp', but we only take 40 autistic teenagers and then a team of 20. It is an extraordinary weekend. The picture up there is of their dress-to-obsess night, where they dress up in their favourite obsession, so you can imagine you get like seven Doctor Whos or the whole *Star Wars* cast there on one night. It is a wonderful sense of belonging that they have when they are there. You can see that 86 per cent of teens and 94 per cent of young adults enjoy the camp experience.<sup>1304</sup>

During the hearing, the Committee also heard of the myriad benefits of participation in I CAN's network for their participants. Marymede Catholic College student and I CAN mentor, Ms Jenna Gephart informed the Committee that the friends she has made from the I CAN Network have been some of her 'strongest friendships' and that despite her 'shyness', she has found a sense of belonging with the I CAN Network.<sup>1305</sup>

Brauer College student and mentor Mr Bryce Pace also spoke during the hearing about his personal transformation. Mr Pace described how he overcame his experience in primary school where he was 'just their kid with the disability label' to making a recent 'big leap' in confidence by being elected to the state's student representative council following his experience with I CAN. Mr Pace further informed the Committee that it has only been this year that he has 'started telling people' of his diagnosis, illustrating how he has overcome the need to hide his diagnosis to now

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1302 Ibid, pp. 1, 4.

1303 Mr Chris Varney, Chief Enabling Officer and Founder, I CAN Network, Family and Community Development Committee public hearing – Melbourne, 12 September 2016, transcript of evidence, p. 2.

1304 Ibid, p. 4.

1305 Ms Jenna Gephart, Marymead Catholic College student, Family and Community Development Committee public hearing – Melbourne, 12 September 2016, transcript of evidence, p. 4.

feeling confident and empowered to share this part of his identity with others.<sup>1306</sup> At the hearing, Mr Pace concluded his presentation by stating:

I love this program, as it has given me an opportunity to allow all of my autism traits to come out to play. I have gotten to talk to students who before the program I probably would not have talked to or even known existed. This program has also given my confidence a boost...

I would like to finish by saying the one thing that has gotten me this far is my belief in myself and how my autism and my voice can be of benefit to those who still struggle with their own diagnosis.<sup>1307</sup>

The Committee also heard of several newly formed social and recreational initiatives for children and youths with ASD that are premised on embracing and celebrating ASD traits. The Committee heard that the opportunity to be engaged in specialised areas of interest with likeminded people have been another way that people with ASD can be engaged and begin to be included and participate in the community.<sup>1308</sup>

During the Inquiry, the Committee was also introduced to NAO, a robot who has been helping children and youths with ASD to stay engaged with another 'being' for lengthy periods of time, and to rehearse and develop social skills.<sup>1309</sup>

### **NAO: the robot companion**

Given many people with ASD have a special interest in technology, the Committee heard of a robot that can assist children and youths with ASD. During a public hearing in Melbourne, the Committee witnessed the potential of robot NAO to help children and adolescents engage with the social world and in other therapeutic activities. Mr Hugh Kingsley and Mr Sam Kingsley of the Brainary, a company that is based in Geelong and specialises in education support and resources, introduced NAO to the Committee at the hearing.<sup>1310</sup>

NAO is a 'humanoid robot' that is 58 centimetres in height and invented by Alderbaran Robotics, 'to create and deliver content' for children with ASD.<sup>1311</sup> NAO was designed to be a 'companion robot' and according to the Brainary's website, NAO 'has the benefit of being a non-threatening, non-judgemental, entity' who 'can be programmed to breakdown social interactions into manageable pieces'.<sup>1312</sup> NAO has

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1306 Mr Bryce Pace, Brauer College student, Family and Community Development Committee public hearing – Melbourne, 12 September 2016, transcript of evidence, p. 6.

1307 Ibid, p. 5.

1308 See for example, Ms Jules Haddock, Family and Community Development Committee public hearing – Geelong, 19 September 2016, transcript of evidence, p. 4.

1309 Mr Sam Kingsley, NAO Robot Operator, the Brainary, Family and Community Development Committee public hearing – Melbourne, 6 March 2017, transcript of evidence, p. 3.

1310 Ibid.

1311 Softbank Robotics, 'Who is NAO', accessed 22 May 2017, <[www.ald.softbankrobotics.com/en/cool-robots/nao](http://www.ald.softbankrobotics.com/en/cool-robots/nao)>.

1312 The Brainary, 'Autism Solutions for kids: ASK NAO', accessed 22 May 2017. <[www.brainaryinteractive.com/autism-solutions-for-kids-ask-nao](http://www.brainaryinteractive.com/autism-solutions-for-kids-ask-nao)>.

acted as a companion to children and adolescents in a range of service settings including schools, libraries, hospitals and disability service settings.<sup>1313</sup>

During the same public hearing in Melbourne, the Committee learned that a child with ASD can engage directly with NAO and ask NAO questions, which NAO is able to respond to; children can also play games with NAO and direct NAO to dance. The software that guides NAO's actions is adaptable to individual needs. The Committee witnessed how NAO blinked and his eye colour changed as he recognised human faces and as he was processing information. According to Mr Sam Kingsley, robot operator from the Brainary, NAO has been introduced in schools successfully:

The engagement factor behind NAO is wonderful. Speaking from my experience in schools and taking NAO into those schools, students really engage with it. The really interesting thing is they start to project human characteristics and human identities onto the robot.<sup>1314</sup>

NAO has also been introduced in rehabilitative settings. At the hearing, Mr Hugh Kingsley, Educationalist from the Brainary, spoke about the success of NAO at the Royal Children's Hospital where NAO has successfully engaged young patients with Acquired Brain Injury to undertake rehabilitation activities. According to Mr Kingsley, NAO's interactions with young patients were:

[I]nitially this is simply about the children needing to do their rehab but for various reasons they do not want to do it. Would this robot inspire them to do it? Yes, it does. Anecdotally we hear stories. The robot might say, 'We're going to do 10 arm-ups', or whatever they are, and some of the children are saying, 'Well, I can do more than that'. No-one expected that – well, it is logical.<sup>1315</sup>

Mr Kingsley also spoke about the potential of NAO for assisting children with ASD:

We also have the Ask NAO software and games, where you would show a child an emotion card. That is where you would have the child – facilitate it with them – and NAO would say from these cards, 'show me excitement' or 'fear' or 'fright' and so forth. The child will pick one and show the robot, and the robot would be able to recognise it and say, 'That's interesting, but it's not what I'm looking for. Can you try again?', until the child gets the right one. The robot will play this game continuously to the same standard, non-discriminatory and so on. That is one of the ways it works.<sup>1316</sup>

In 2015, the Children's Autism Foundation in New Zealand hosted NAO for a week and NAO spent time with children at a special school and at a disability resource centre. According to the General Manager of the NZ Children's Autism Foundation, Ms Teresa Moore, parents and teachers witnessed children and youths with ASD

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1313 Mr Hugh Kingsley and Mr Sam Kingsley, the Brainary, Family and Community Development Committee public hearing – Melbourne, 6 March 2017, transcript of evidence.

1314 Mr Sam Kingsley, NAO Robot Operator, the Brainary, Family and Community Development Committee public hearing – Melbourne, 6 March 2017, transcript of evidence, p. 3.

1315 Mr Hugh Kingsley, Educationalist, the Brainary, Family and Community Development Committee public hearing – Melbourne, 6 March 2017, transcript of evidence, p. 5.

1316 Ibid, p. 4.



engage for the entire session of an hour and fifteen minutes with NAO. Ms Moore was positive about the potential of using NAO to support their teaching of social skills to children and youths with ASD and high support needs at the special school and centre.<sup>1317</sup>

The Committee heard that robot NAO and the ASK NAO software has been expensive for organisations to purchase. The technology is also not at a stage where it can be mass distributed. Nonetheless, the Committee witnessed the potential of NAO for children and youths with ASD, not least because of the patience a robot can bring to teaching social skills but also the enjoyment that children and youths with ASD can experience as they interact with NAO.<sup>1318</sup>

### The Lab

Several stakeholders to the Inquiry spoke about the Lab.<sup>1319</sup> The Lab is a network of technology clubs for children and adolescents (aged 10–16) with autism with low support needs. The Lab provides mentoring by professionals in areas such as programming, 3D, digital design and gaming; the sessions are unstructured and each participant is paired with a tutor.<sup>1320</sup> At a public hearing in Geelong, Ms Jules Haddock, parent of a son with ASD who ‘loves computers’, described her son’s joy when attending the Lab. Ms Haddock has observed additional benefits for her son:

But the day he walked in he was at home, and the conversations were starting, the chatter going on amongst the kids, and the mentors are just brilliant because they do not just silo the kids behind computers. Occasionally they stop them and work on some social interaction with the kids, but they are really powerful. As a consequence he has actually developed friendships through that. Some of them remain sort of cyber-based, but without fail every Monday he is standing at the door with his laptop under his arm ready to bolt out the door because it is a safe place for him to be.<sup>1321</sup>

Ms Haddock further explained that her son ‘will never talk to other kids in foreign environments’ however ‘if he spots someone... from the Laboratory’ she stated to the Committee that ‘it is me going ‘Come on, hurry up’.<sup>1322</sup> While programs such as the Lab evidently provide a safe and accepting space for children and adolescents with

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1317 Emily Ford, ‘Humanoid Robot Helps Autistic Children’, *North Shore Times*, Auckland, New Zealand, 22 September 2015, accessed 26 May 2017, <[www.stuff.co.nz/auckland/local-news/north-shore-times/72253352/humanoid-robot-helps-autistic-children](http://www.stuff.co.nz/auckland/local-news/north-shore-times/72253352/humanoid-robot-helps-autistic-children)>.

1318 Mr Hugh Kingsley, Educationalist, the Brainary, Family and Community Development Committee public hearing – Melbourne, 6 March 2017, transcript of evidence, p. 6.

1319 See: Ms Jules Haddock, Family and Community Development Committee public hearing – Geelong. Ms Susanna Flanagan, Co-convenor, Bendigo Autistic Advocacy and Support Service, Family and Community Development Committee public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 2.

1320 The Lab, ‘About the Lab’, accessed 22 May 2017, <[thelab.org.au/](http://thelab.org.au/)>.

1321 Ms Jules Haddock, Family and Community Development Committee public hearing – Geelong, 19 September 2016, transcript of evidence, p. 4.

1322 Ibid.



ASD, the Committee heard it has been an effective way to help children and youths with ASD to connect with others.<sup>1323</sup>

### **Lego clubs**

The Committee also heard about the appeal of lego groups.<sup>1324</sup> Mr James Tucker has a son with ASD. At a hearing in Melbourne, Mr Tucker described the way his son has benefited from the lego club organised by Inside the Brick. Inside the Brick is a social enterprise based in Melbourne that has been running its own lego club and helping other groups in Victoria create their own lego clubs.<sup>1325</sup> Mr Tucker stated:

[M]y son goes to a group called Inside the Brick. It is a Lego club... My son absolutely loves it. There is no judgement; he just plays. He really gets on and it is a safe environment where he can de-stress, let his tape run down, quieten down, calm down – and everybody is like him. I have to say there is only one girl there – and she runs the place. She is fantastic. She is so smart.<sup>1326</sup>

### **Studio G (Brisbane)**

In Brisbane, the Committee visited Autism Queensland's Studio G Creative Programs, a post-secondary-school transitional learning program that offers youths with ASD aged 16–25 a program to participate in art, music and digital technology classes. Studio G uses facilities at the State Library of Queensland's arts technology, science and enterprise centre in the thriving arts, science and cultural precinct of Brisbane. Studio G programs are fee-based and provide regularity with two afternoons per week set aside for classes and the intention is for their students to move on to further education or employment. All students have access to skilled mentors who have been employed from universities and TAFES.<sup>1327</sup> Studio G has been popular with youths with ASD by building on their existing interests and skills to engage them in a regular study and work setting and to help them make the transition to work or further education.<sup>1328</sup>

The Committee heard that the hallmark symptoms of ASD, which include difficulties in communication, reading social cues and relating to others, repetitive behaviours and sensory issues have undermined the very basis of a person's ability to interact

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1323 Ibid. See also, Ms Susanna Flanagan, Co-convenor, Bendigo Autistic Advocacy and Support Service, Family and Community Development Committee public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 2.

1324 Ms Lisa Hamling, Facilitator, The Treehouse, Family and Community Development Committee public hearing – Geelong, 19 September 2016, transcript of evidence, p. 2; Ms Shantelle Grant, Macedon Ranges Autism Network, Family and Community Development Committee public hearing – Bendigo, 17 October 2016, transcript of evidence, p. 2.

1325 Into the Brick, 'About us', accessed 29 May 2017, <[www.insidethebrick.com/about-studio](http://www.insidethebrick.com/about-studio)>.

1326 Mr James Tucker, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 5.

1327 Autism Queensland, 'Studio G', accessed 22 May 2017, <[autismqld.com.au/page/studio-g](http://autismqld.com.au/page/studio-g)>.

1328 Michael Whelan, 'Art Changing the World: one person at a time', post, 18 June 2015, Arts Queensland website, accessed 1 June 2017, <[www.arts.qld.gov.au/aq-blog/employment-and-training/5041-art-changing-the-world-one-person-at-a-time](http://www.arts.qld.gov.au/aq-blog/employment-and-training/5041-art-changing-the-world-one-person-at-a-time)>. See also, Olivia Muir, 'Good News from the Edge', blogpost, 5 May 2016, State Library of Queensland - The Edge website, accessed 1 June 2017, <[edgeqld.org.au/technology-2/good-news-from-the-edge](http://edgeqld.org.au/technology-2/good-news-from-the-edge)>.

with the world. However, repeatedly the Committee heard that this has not meant that some people with ASD do not need or want to experience social connection and belonging in the community. Instead, the Committee heard that people with ASD need more support and understanding from the mainstream community. For some individuals with ASD and their caregivers, this will mean extending and improving disability support services for people with ASD. For others it will mean focusing not on disability but on ways to facilitate people with ASD to express their talents to their utmost potential, and to have their voices heard.<sup>1329</sup>

### Self-advocates

The advent of the NDIS promises an individualised approach to supporting people with disabilities in the community, however this does not negate the role that state and local governments have in creating and coordinating efforts to include people with ASD across all settings and to work with people who have ASD as partners in developing a more ASD-friendly world. The Committee heard of many ways in which people with ASD can be supported and included, and it found the most promising initiatives have been those that have responded to needs, as well as drawing on the strengths and aspirations of people with ASD.<sup>1330</sup>

At a Melbourne hearing, the CEO of Amaze Ms Sharkie stated that there is a great need to improve the community's understanding of ASD and its capacity to support autistic people.<sup>1331</sup> The Committee firmly believes that the development of any State Government policies, programs and services that touch the lives of people with ASD should include the views of people with ASD including autistic self-advocates.

Facilitating the inclusion of self-advocates in public policy development also reflects a trend developing in other countries. In the U.S., the Committee met with representatives of the peak self-advocacy body, the Autistic Self Advocacy Network (ASAN). ASAN has chapters throughout the U.S. and affiliated organisations in Canada, the UK, Australia and Israel.<sup>1332</sup> ASAN actively advocates for people with autism and people with disability and continues to run leadership programs for college students with ASD to improve the lives of people with ASD and disability in their colleges and states.<sup>1333</sup> ASAN's leadership team includes people who have been appointed to government advisory positions and committees; ASAN's co-founder was appointed to the National Council on Disability during the Obama Administration.<sup>1334</sup>

According to the Chief Enabling Officer of I CAN, Mr Chris Varney, the I CAN Network's program is also premised on flexibility and the desire to 'push' themselves – but 'not to breaking point', which has been evident in the way that their young mentors have

1329 See for example, I CAN Network, submission no. 127.

1330 Name withheld, submission no. 138B, (supplementary submission). See also, I CAN Network, submission no. 127.

1331 Ms Fiona Sharkie, Chief Executive Officer, Amaze, Family and Community Development Committee public hearing – Melbourne, 29 August 2016, transcript of evidence, p. 3.

1332 Autistic Self Advocacy Network, 'Chapters', accessed 29 May 2017, <autisticadvocacy.org/chapters>.

1333 Autistic Self Advocacy Network, 'About us', accessed 29 May 2017, <autisticadvocacy.org/about-asan>.

1334 See, Autistic Self Advocacy Network, 'Leadership', accessed 29 May 2017, <autisticadvocacy.org/about-asan/leadership>.

pushed themselves to engage with others as proud autistic people.<sup>1335</sup> Accordingly, the Committee recommends that:

#### **RECOMMENDATION 10.10**

**The Victorian Government fund the expansion of the coordinator positions of the I CAN network across the state to ensure the roll out of support and mentoring programs in primary and secondary schools; facilitate coordination of support camps; and training opportunities for mentors.**

The Committee recognises the potential of autistic self-advocates to contribute to the development of public policy in relation to some people with ASD, and in advocating on behalf of some people with ASD in a range of community settings. The Committee advises the Victorian Government to make every effort to include people with ASD who are self-advocates in strategies to build inclusion for people with ASD. Accordingly, the Committee recommends that:

#### **RECOMMENDATION 10.11**

**The Victorian Government in the updated State Autism Plan develop strategies to build inclusion in the community for people with ASD in consultation with both people with ASD who are self-advocates and with ASD advocacy groups.**

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<sup>1335</sup> Mr Chris Varney, Chief Enabling Officer and Founder, I CAN Network, Family and Community Development Committee public hearing – Melbourne, 12 September 2016, p. 11.

# Appendix 1

## List of submissions

<b>Submission No.</b>	<b>Name of Submitter</b>
1	Mrs Andrea Bolton
2	Confidential
3	Miss Hayley Reed
4	Ms Soula Dritsas
5	Confidential
6	Mrs Jules Haddock
7	Mr Ray Roney
8	Confidential
9	Mr James Tucker
10	Confidential
11	Ms Dianna Lane
12	Ms Rosemary Doherty
13	Confidential
14	Ms Janeane Baker
15	Ms Avigale Bischard
16	Mrs Rebecca Spiteri
17	Confidential
18	Name withheld
19	Mr Graeme Drysdale
20	Mrs Carmel Murphy
21	Ms Deborah Ditchburn
22	Confidential
23	Interchange Gippsland
24	Confidential
25	Mr Brem Chandru
26	Confidential
27	Dr Deborah Morawetz
28	Melton City Council
29	Lifestyle in Supported Accommodation (LISA) Inc
30	Northern School for Autism
31	Confidential
32	Ms Sandra Cohen
33	Echuca Regional Health and Kyabram District Health Service

<b>Submission No.</b>	<b>Name of Submitter</b>
34	Latrobe Community Health Service
35	Illoura Early Childhood Intervention Services Inc
36	Scope
37	Merri Health
38	Ms Cathy Talia-Parker
39	Gippsland Lakes Community Health
40	Confidential
41	Mrs Shelley Fleming
42	Ms Penny Callaghan
43	Health and Community Services Union (HACSU)
44	City of Greater Geelong
45	Living with Autism Spectrum Resource Support Group
46	Mrs Ann O'Sullivan
47	Australian Institute of Health and Welfare
48	Professor Bruce Tonge and Dr Avril V Brereton
49	Ms Joan Esser
50	Ms Susan Pearce
51	ABA Parent Support Network
52	Lizard Centre
53	Ms Maree Maxfield
54	Communication Rights Australia
55	Ms Carole Trotter
56	Mr Ryan Kennedy
57	Mr Steve Ager
58	Ms Karen Burgess
58A	Ms Karen Burgess - supplementary submission
59	Ms Jo Backway
60	Autism Behavioural Intervention Association
61	Confidential
62	Confidential
63	Mrs Michele Maes
64	Specialisterne Australia
65	FamilyCare
66	Mr Christopher Reid
67	Ms Helen Farrell
68	Ms Trish Edgar
69	Confidential
70	Ms Julie Phillips
71	Autism Family Support Association

<b>Submission No.</b>	<b>Name of Submitter</b>
72	Department of Social Services
73	City of Greater Dandenong
74	Murray Human Services Inc
75	Confidential
76	Ms De'arne Treacy
77	Distinctive Options, The Lab Network and Smart Communities
78	Ms Deborah Ross-Soden
79	Mr Phil Gluyas
80	Hobsons Bay City Council
81	cohealth
82	Ms Shannon Leahy
83	Ms Sally Smith
84	Disability Discrimination Legal Service
85	Extended Families Australia
86	Disability Advocacy Victoria
87	Gateways Support Services
88	Lancaster Consulting Australia
89	Office of the Public Advocate
90	Moomba Park Autism Inclusion Parents
91	Ms Donna Milne
92	Connect and Relate for Autism
93	South Gippsland Autism Action Group
94	Ms Genevieve Tucker
95	Ms Elisabeth Appelgren-McIntyre
96	Dr Anna Middleton
97	Ms Susanna Flanagan and Mr Martin Flanagan
98	Confidential
99	Darebin City Council
100	Autism Spectrum Australia (Aspect)
101	Name withheld
102	Confidential
103	Mr Ben Snow
104	Association for Children with a Disability
105	Confidential
106	Disability Services Commissioner
107	Confidential
108	Name withheld
109	Ms Meaghan O'Brien
110	Creating Connections Australia

<b>Submission No.</b>	<b>Name of Submitter</b>
111	Key Word Sign Australia – Victoria
112	Sunraysia Community Health Services
113	Austin Child and Adolescent Mental Health Service
114	Occupational Therapy Australia
115	Museum Victoria
116	Office of the Health Services Commissioner
117	Yellow Ladybugs
118	Name withheld
119	Name withheld
120	Ms Judith Horne
121	Mr Scott Heath
122	Ms Rebeckah Owens
123	Irabina Autism Services
124	Ms Sara Cartwright
125	Mr Angus Mackellar
126	Learning for Life Autism Centre
127	I CAN Network
128	Ms Narelle McCaffrey
129	Mr William Fidler
130	Mallee Family Care
131	The Autism Teaching Institute
132	Broad Insight Group, Dianella Community Health
133	National Disability Services Victoria
134	Mindful - Centre for Training and Research in Developmental Health
135	Ms Anne Mallia
136	Speech Pathology Australia
137	Victorian Advocacy League for Individuals with Disability Inc (VALID) and the Behaviours of Concern Peer Action Group
138	Name withheld
138A	Name withheld - supplementary submission
138B	Name withheld - supplementary submission
139	Amaze
140	Commission for Children and Young People
141	Aspergers Victoria
142	Autism Partnership
143	Royal Children's Hospital Melbourne
144	Royal Australian & New Zealand College of Psychiatrists (RANZCP) Victorian Branch Committee
145	Name withheld



<b>Submission No.</b>	<b>Name of Submitter</b>
146	Victorian Disability Advisory Council
147	Confidential
148	Anne McDonald Centre
149	Office of the Public Advocate
150	Royal Children's Hospital Melbourne
151	Autism Spectrum Australia (Aspect)
152	Swan Hill District Health
153	Dr Anthony Engwirda
154	Compumedics Limited



## Appendix 2

### Public hearings

The Committee held the following Public Hearings:

Date	Venue
29 August 2016	Melbourne
12 September 2016	Melbourne
19 September 2016	Geelong
10 October 2016	Melbourne
17 October 2016	Bendigo
7 November 2016	Melbourne
15 November 2016	Shepparton
21 November 2016	Melbourne
5 December 2016	Morwell
14 February 2017	Swan Hill
6 March 2017	Melbourne

### 29 August 2016, Melbourne

Organisation	Name	Position
Amaze	Ms Fiona Sharkie	Chief Executive Officer
	Mr Braedan Hogan	Policy and Advocacy Manager
Mindful - Centre for Training and Research in Developmental Health	Dr Sandra Radovini	Director, Mindful, Department of Psychiatry, The University of Melbourne
	Ms Frances Saunders	Statewide Autism Spectrum Disorder Coordinator
	Ms Liz Morkham	Autism Spectrum Disorder Coordinator, Austin Child and Mental Health Service
Olga Tennison Autism Research Centre, La Trobe University	Professor Cheryl Dissanayake	Founder and Director
Royal Children's Hospital Melbourne	Associate Professor Jill Sewell	Deputy Director, Centre for Community Child Health
	Ms Charmaine Bernie	Senior Occupational Therapist
Individual	Ms Narelle McCaffrey	
Individual	Mr James Tucker	
Individual	Ms Susan Pearce	
Individual	Ms Dianna Lane	

Organisation	Name	Position
Yellow Ladybugs	Ms Katie Koullas	Founder

## 12 September 2016, Melbourne

Organisation	Name	Position
Aspergers Victoria	Ms Tamsin Jowett	President
	Ms Bronwyn Carter	Volunteer Consultant to the Board
Individuals	Ms Cathy Talia-Parker	
	Mr Liam Parker	
Autism Family Support Association	Ms Catrina Mulderry	President
	Mr Michael Tucker	Vice President
	Ms Tracey Hayes	Committee Member
	Mr Phil Lipshut	Committee Member
I CAN Network	Mr Chris Varney	Chief Enabling Officer & Founder
	Ms Gabrielle Breheny	Chair
	Mr Will Rosewarne	Stakeholders Director
	Ms Jenna Gephart	Marymede Catholic College
Speech Pathology Australia	Mr Bryce Pace	Brauer College
	Ms Christine Lyons	Acting Chief Executive Officer
Autism Behavioural Intervention Association (ABIA)	Ms Robyn Stephen	Acting President
	Ms Susan Pavey	General Manager
Individuals	Dr Amanda Sampson	
	Ms Rosemary Doherty	
Individuals	Mr Chris Doherty	
	Ms Florence McIver	
Individual	Mr Mike McIver	
	Mr Ryan Kennedy	
Individual	Mr Christopher Reid	

## 19 September 2016, Geelong

Organisation	Name	Position
National Disability Insurance Agency	Ms Louise Glanville	Deputy Chief Executive Officer, Stakeholder Relations and Organisational Capability
	Ms Chris Faulkner	Regional Manager, Victoria West
	Mr Peter De Natris	Strategic Adviser

Organisation	Name	Position
City of Greater Geelong	Mr Geoff Barber	Acting Coordinator, Care Services, Aged and Disability
Individual	Ms Jules Haddock	
Treehouse	Ms Lisa Hamling	Facilitator
	Ms Michelle Anderson	Facilitator, Pink Musketeers
Individual	Mr Stephen Williams	
Individual	Mr Gordon Portway	
Individual	Ms Leah Thomson	
Individual	Ms Sarah Hayden	
Individual	Ms Deirdre Wirth	
Individual	Ms Nicole Stephenson	
Individual	Ms Stacey Smith	

## 10 October 2016, Melbourne

Organisation	Name	Position
ABA Parent Support Network	Ms Sarah Wilson	Convenor
Specialisterne Australia	Mr John Craven	Chair
	Mr Jason White	Employment Services Manager
Individual	Dr Anna Middleton	
Individual	Ms Susan Rees	
Individual	Mr Steve Ager	
Individuals	Mr Dom Williams	
	Mr Stephen Williams	
Individual	Ms Karen Burgess	
Department of Education and Training	Ms Katy Haire	Acting Secretary
	Dr David Howes	Assistant Deputy Secretary, Early Childhood and School Education Group
	Mr Alan Wilson	Acting Director, Inclusion, Access and Participation, Wellbeing, Health and Engagement Division

## 17 October 2016, Bendigo

Organisation	Name	Position
Distinctive Options	Mr Murray Dawson-Smith	Chief Executive Officer
Individuals	Ms Susanna Flanagan	

Organisation	Name	Position
	Mr Martin Flanagan	
Bendigo Autistic Advocacy and Support Service	Ms Rebecca Kelly	
	Ms Susanna Flanagan	
Individual	Ms Chloe Fitton	
Macedon Ranges Autism Network	Ms Shantelle Grant	

## 7 November 2016, Melbourne

Organisation	Name	Position
Department of Health and Human Services	Ms Amanda Cattermole	Deputy Secretary, Community Services Programs and Design Division
	Mr James Maclsaac	Acting NDIS Project Director
	Dr Neil Coventry	Chief Psychiatrist
Kalianna School	Mr Peter Bush	Principal
	Ms Britt Holmberg	Autism Connect and Inclusion Coordinator

## 15 November 2016, Shepparton

Organisation	Name	Position
FamilyCare	Mr David Tennant	Chief Executive Officer
	Ms Karen Goodger	Practice Manager, Disability Support Services
Individual	Mr Ben Snow	
Individuals	Ms Meaghan O'Brien	
	Ms Michaela O'Brien	
Individual	Ms Sally Smith	
Individuals	Ms De'arne Treacy	
	Ms Trudy Gribben	
Individual	Ms Carole Trotter	

## 21 November 2016, Melbourne

Organisation	Name	Position
Autism Teaching Institute	Ms Mary Thomson	Principal, Western Autistic School, and Chief Executive Officer, Autism Teaching Institute

Organisation	Name	Position
Extended Families Australia	Ms Julie Langdon	Chief Executive Officer
	Ms Nga Do	Family and Volunteer Match and Program Coordinator
Individuals	Ms Sheryl O'Connor	
	Ms Katherine Barling	
Australian Community Support Organisation (ACSO)	Mr Stan Pappos	Senior Manager, High Risk and Support Services
Individual	Ms Lisa Carr	
Individuals	Ms Loretta Krelle	
	Mr Rob Krelle	
Baltara Special School	Ms Nancy Sidoti	Principal

## 5 December 2016, Morwell

Organisation	Name	Position
Latrobe Community Health Service	Ms Denise Bromiley	Manager Disability and Carer Program
Interchange Gippsland	Mr Shilo Wilson	Manager Respite and Support
South Gippsland Autism Action Group	Ms Tona O'Connor	
	Ms Michelle Hackett	
	Ms Natalie Owens	
Individual	Ms Carmel Murphy	
Gippsland Lakes Community Health	Ms Angela Ellis	Executive Manager Community Health Services
	Ms Lyn Nicol	Speech Pathologist

## 14 February 2017, Swan Hill

Organisation	Name	Position
Swan Hill District Health Service	Ms Leonie Baker	Chief Speech Pathologist
	Ms Marisa Barbarioli	Acting Chief Occupational Therapist
Individual	Ms Rachel Blandthorn	
Individuals	Mr Brenten Hogan	
	Ms Janelle Hogan	
Individual	Ms Jane McLean	
Individuals	Ms Amanda Neil	
	Mr Daryl Neil	
Individual	Ms Ann Mafi	



Organisation	Name	Position
Murray Human Services	Mr Scott Alexander	Chief Executive Officer
	Ms Nicole Doolan	Services Manager
Creating Connections Australia	Ms Sherri Cincotta	Director and Program Facilitator
	Ms Elissa Plumridge	Director and Program Facilitator
Echuca Regional Health and Kyabram District Health Services	Mrs Leah Williams	Occupational Therapist, Echuca Regional Health
	Ms Denise Liddell	Manager of Campaspe Early Childhood Intervention Service, Kyabram District Health Services
Swan Hill Specialist School	Mr Graeme Scoberg	Former Principal
Individual	Mr Scott Morrison	

## 6 March 2017, Melbourne

Organisation	Name	Position
Occupational Therapy Australia	Ms Kim Mestroni	Victorian Division Manager, Occupational Therapy Australia
	Ms Lisa Vale	Paediatric Occupational Therapist and Clinical Services Manager, Splash Occupational Therapy
	Ms Johanna Rouse	Senior Occupational Therapist and Autism Spectrum Disorders Coordinator, Orygen Youth Health
Deakin University Child Study Centre	Professor Nicole Rinehart	Director, Deakin Child Study Centre, Deakin University
	Associate Professor David Austin	
Individual	Mr Logan Whittaker	Inclusion (All Abilities) Manager, AFL
Individual	Mr Shane Pendergast	
The Brainary	Mr Hugh Kingsley	Educationalist
	Mr Sam Kinglsey	NAO Robot Operator
	NAO	Robot
Monash University Centre for Developmental Psychiatry and Psychology	Emeritus Professor Bruce Tonge	
	Dr Avril Brereton	

# Appendix 3

## Briefings and site visits

### Briefings

Date	Organisation	Name
6 June 2016	Centre for Developmental Disability Health Victoria (CDDHV)	Dr Jane Tracey, Director
		Dr Jean Graham, Director of Mental Health Services
20 June 2016	Amaze	Ms Fiona Sharkie, CEO
		Mr Braedan Hogan, Policy Manager

### Site visits

Date	Site
19 September 2016	Gateways Support Services, Geelong
	Whittington Primary School, Geelong
17 October 2016	Kalianna School, Bendigo
	Bendigo Special Development School, Bendigo
24 October 2016	Olga Tennison Autism Research Centre, La Trobe University, Bundoora
	Moomba Park Primary School, Fawkner
	Northern School for Autism (Reservoir Campus), Reservoir
14 November 2016	Mansfield Autism Statewide Services (MASS), Mansfield
	EdSpace Education and Training Centre, Benalla
15 November 2016	Dookie Secondary College – Mansfield Autism Statewide Services (MASS), Dookie
29 November 2016	Cooperative Research Centre for Living with Autism (Autism CRC), Brisbane
	Secret Agent Society Social Skills and Emotional Regulation Training Program, Brisbane
	Autism Queensland Studio G Program, Brisbane
	Autism Hub, Brisbane



# Appendix 4

## Overseas study tour meetings

<b>Date</b>	<b>Organisation</b>	<b>Location</b>
30 March 2017	State Senator Richard Pan, Chairman Select Committee on Children with Special Needs	Sacramento, CA, USA
	UCP (United Cerebral Palsy) Autism Center for Excellence (ACE)	Sacramento, CA, USA
	UC Davis MIND Institute	Sacramento, CA, USA
31 March 2017	Applied Behaviour Consultants (ABC) School	Sacramento, CA, USA
	Sacramento Autistic Spectrum and Special Need Alliance	Sacramento, CA, USA
3 April 2017	The Arc	Washington DC, USA
	Autistic Self-Advocacy Network (ASAN)	Washington DC, USA
	Office of Autism Research Coordination	Washington DC, USA
	Autism Society	Bethesda, MD, USA
4 April 2017	School District of Philadelphia	Philadelphia, PA, USA
	Autism Cares Foundation	Philadelphia, PA, USA
	Kinney Center for Autism Education and Support	Philadelphia, PA, USA
	The Center for Autism Research (CAR) at the Children's Hospital of Philadelphia	Philadelphia, PA, USA
5 April 2017	ASD Nest Support Project	New York, NY, USA
	Imagine Academy	New York, NY, USA
	Autism Speaks	New York, NY, USA
	AHRC NYC	New York, NY, USA
6 April 2017	Autism Community Theatre	New York, NY, USA
	Quality Service for the Autism Community (QSAC)	New York, NY, USA
	New York Collaborates for Autism (NYCA)	New York, NY, USA
7 April 2017	Yale Developmental Disabilities Clinic	New Haven, CT, USA
	Child Study Centre, Yale University School of Medicine	New Haven, CT, USA
	Chapel Haven Inc	New Haven, CT, USA
	Center of Excellence on Autism Spectrum Disorders	New Haven, CT, USA
10 April 2017	The National Board of Social Services	Copenhagen, Denmark
	Specialomrade Autisme	Copenhagen, Denmark
	Centre for Autisme	Copenhagen, Denmark
	Specialisterne Foundation	Copenhagen, Denmark
11 April 2017	Norwegian Directorate for Children, Youth and Family Affairs	Oslo, Norway
	Department of Special Needs Education	Oslo, Norway

<b>Date</b>	<b>Organisation</b>	<b>Location</b>
	Statped	Oslo, Norway
12 April 2017	Early Autism Sweden (EASE)	Stockholm, Sweden
	Autism – och Asbergerförbundet	Stockholm, Sweden
13 April 2017	The Swedish Agency for Participation	Stockholm, Sweden

# Appendix 5

## Diagnostic and Statistical Manual 5 (DSM-5)

Extract from the Diagnostic and Statistical Manual of Mental Disorders  
FIFTH EDITION | DSM-5®

Edited by American Psychiatric Association, 2013 (Arlington, VA: American Psychiatric Association)

### Autism Spectrum Disorder

#### Diagnostic Criteria

299.00 (F84.0)

1. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by all of the following, currently or by history (examples are illustrative, not exhaustive; see text):
  1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
  2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
  3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

Specify current severity:  
**Severity is based on social communication impairments and restricted, repetitive patterns of behavior (see Table).**
2. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):
  1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
  2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).
  3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
  4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Specify current severity:

**Severity is based on social communication impairments and restricted, repetitive patterns of behavior** (see Table).

3. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).
4. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.
5. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

**Note:** Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger’s disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

Specify if:

- With or without accompanying intellectual impairment
- With or without accompanying language impairment
- Associated with a known medical or genetic condition or environmental factor (Coding note: Use additional code to identify the associated medical or genetic condition.)
- Associated with another neurodevelopmental, mental, or behavioral disorder (Coding note: Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioral disorder[s].)
- With catatonia (refer to the criteria for catatonia associated with another mental disorder, pp. 119–120, for definition) (Coding note: Use additional code 293.89 [F06.1] catatonia associated with autism spectrum disorder to indicate the presence of the comorbid catatonia.)

**Specifiers Severity levels for intellectual disability (intellectual developmental disorder)**

Severity level	Conceptual domain	Social domain	Practical domain
<b>Mild</b>	For preschool children, there may be no obvious conceptual differences. For school-age children and adults, there are difficulties in learning academic skills involving reading, writing, arithmetic, time, or money, with support needed in one or more areas to meet age-related expectations. In adults, abstract thinking, executive function (i.e., planning, strategizing, priority setting, and cognitive flexibility), and short-term memory, as well as	Compared with typically developing age-mates, the individual is immature in social interactions. For example, there may be difficulty in accurately perceiving peers’ social cues. Communication, conversation, and language are more concrete or immature than expected for age. There may be difficulties regulating emotion and behavior in age-appropriate fashion; these difficulties are noticed by peers in social situations. There is limited	The individual may function age-appropriately in personal care. Individuals need some support with complex daily living tasks in comparison to peers. In adulthood, supports typically involve grocery shopping, transportation, home and child-care organizing, nutritious food preparation, and banking and money management. Recreational skills resemble those of age-mates, although judgment related to well-being and organization around recreation requires support. In adulthood, competitive



	functional use of academic skills (e.g., reading, money management), are impaired. There is a somewhat concrete approach to problems and solutions compared with age-mates.	understanding of risk in social situations; social judgment is immature for age, and the person is at risk of being manipulated by others (gullibility).	employment is often seen in jobs that do not emphasize conceptual skills. Individuals generally need support to make health care decisions and legal decisions, and to learn to perform a skilled vocation competently. Support is typically needed to raise a family.
<b>Moderate</b>	All through development, the individual's conceptual skills lag markedly behind those of peers. For preschoolers, language and pre-academic skills develop slowly. For school-age children, progress in reading, writing, mathematics, and understanding of time and money occurs slowly across the school years and is markedly limited compared with that of peers. For adults, academic skill development is typically at an elementary level, and support is required for all use of academic skills in work and personal life. Ongoing assistance on a daily basis is needed to complete conceptual tasks of day-to-day life, and others may take over these responsibilities fully for the individual.	The individual shows marked differences from peers in social and communicative behavior across development. Spoken language is typically a primary tool for social communication but is much less complex than that of peers. Capacity for relationships is evident in ties to family and friends, and the individual may have successful friendships across life and sometimes romantic relations in adulthood. However, individuals may not perceive or interpret social cues accurately. Social judgment and decision-making abilities are limited, and caretakers must assist the person with life decisions. Friendships with typically developing peers are often affected by communication or social limitations. Significant social and communicative support is needed in work settings for success.	The individual can care for personal needs involving eating, dressing, elimination, and hygiene as an adult, although an extended period of teaching and time is needed for the individual to become independent in these areas, and reminders may be needed. Similarly, participation in all household tasks can be achieved by adulthood, although an extended period of teaching is needed, and ongoing supports will typically occur for adult-level performance. Independent employment in jobs that require limited conceptual and communication skills can be achieved, but considerable support from co-workers, supervisors, and others is needed to manage social expectations, job complexities, and ancillary responsibilities such as scheduling, transportation, health benefits, and money management. A variety of recreational skills can be developed. These typically require additional supports and learning opportunities over an extended period of time. Maladaptive behavior is present in a significant minority and causes social problems.
<b>Severe</b>	Attainment of conceptual skills is limited. The individual generally has little understanding of written language or of concepts involving numbers, quantity, time, and money. Caretakers provide extensive supports	Spoken language is quite limited in terms of vocabulary and grammar. Speech may be single words or phrases and may be supplemented through augmentative means. Speech and communication are focused on the here and	The individual requires support for all activities of daily living, including meals, dressing, bathing, and elimination. The individual requires supervision at all times. The individual cannot make responsible decisions regarding well-being of self or others. In adulthood,

	for problem solving throughout life.	now within everyday events. Language is used for social communication more than for explication. Individuals understand simple speech and gestural communication. Relationships with family members and familiar others are a source of pleasure and help.	participation in tasks at home, recreation, and work requires ongoing support and assistance. Skill acquisition in all domains involves long-term teaching and ongoing support. Maladaptive behavior, including self-injury, is present in a significant minority.
<b>Profound</b>	Conceptual skills generally involve the physical world rather than symbolic processes. The individual may use objects in goal-directed fashion for self-care, work, and recreation. Certain visuospatial skills, such as matching and sorting based on physical characteristics, may be acquired. However, co-occurring motor and sensory impairments may prevent functional use of objects.	The individual has very limited understanding of symbolic communication in speech or gesture. He or she may understand some simple instructions or gestures. The individual expresses his or her own desires and emotions largely through nonverbal, nonsymbolic communication. The individual enjoys relationships with well-known family members, caretakers, and familiar others, and initiates and responds to social interactions through gestural and emotional cues. Co-occurring sensory and physical impairments may prevent many social activities.	The individual is dependent on others for all aspects of daily physical care, health, and safety, although he or she may be able to participate in some of these activities as well. Individuals without severe physical impairments may assist with some daily work tasks at home, like carrying dishes to the table. Simple actions with objects may be the basis of participation in some vocational activities with high levels of ongoing support. Recreational activities may involve, for example, enjoyment in listening to music, watching movies, going out for walks, or participating in water activities, all with the support of others. Co-occurring physical and sensory impairments are frequent barriers to participation (beyond watching) in home, recreational, and vocational activities. Maladaptive behavior is present in a significant minority.

**Autism Spectrum Disorder Severity levels for autism spectrum disorder**

<b>Severity level</b>	<b>Social communication</b>	<b>Restricted, repetitive behaviors</b>
<b>Level 3 “Requiring very substantial support”</b>	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches.	Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.

<p><b>Level 2</b>  <b>“Requiring substantial support”</b></p>	<p>Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and who has markedly odd nonverbal communication.</p>	<p>Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.</p>
<p><b>Level 1</b>  <b>“Requiring support”</b></p>	<p>Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to-and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.</p>	<p>Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.</p>

**Recording Procedures**

For autism spectrum disorder that is associated with a known medical or genetic condition or environmental factor, or with another neurodevelopmental, mental, or behavioral disorder, record autism spectrum disorder associated with (name of condition, disorder, or factor) (e.g., autism spectrum disorder associated with Rett syndrome). Severity should be recorded as level of support needed for each of the two psychopathological domains in Table (e.g., “requiring very substantial support for deficits in social communication and requiring substantial support for restricted, repetitive behaviors”). Specification of “with accompanying intellectual impairment” or “without accompanying intellectual impairment” should be recorded next. Language impairment specification should be recorded thereafter. If there is accompanying language impairment, the current level of verbal functioning should be recorded (e.g., “with accompanying language impairment—no intelligible speech” or “with accompanying language impairment—phrase speech”). If catatonia is present, record separately “catatonia associated with autism spectrum disorder.”

**Specifiers**

The severity specifiers (see Table) may be used to describe succinctly the current symptomatology (which might fall below level 1), with the recognition that severity may vary by context and fluctuate over time. Severity of social communication difficulties and restricted, repetitive behaviors should be separately rated. The descriptive severity categories should not be used to determine eligibility for and provision of services; these can only be developed at an individual level and through discussion of personal priorities and targets.

Regarding the specifier “with or without accompanying intellectual impairment,” understanding the (often uneven) intellectual profile of a child or adult with autism spectrum disorder is necessary for interpreting diagnostic features. Separate estimates of verbal and nonverbal skill are necessary (e.g., using untimed nonverbal tests to assess potential strengths in individuals with limited language).

To use the specifier “with or without accompanying language impairment,” the current level of verbal functioning should be assessed and described. Examples of the specific descriptions for “with accompanying language impairment” might include no intelligible speech (nonverbal), single words only, or phrase speech. Language level in individuals “without accompanying language impairment” might be further described by speaks in full sentences or has fluent speech. Since receptive language may lag behind expressive language development in autism spectrum disorder, receptive and expressive language skills should be considered separately.

The specifier “associated with a known medical or genetic condition or environmental factor” should be used when the individual has a known genetic disorder (e.g., Rett syndrome, fragile X syndrome, Down syndrome), a medical disorder (e.g., epilepsy), or a history of environmental exposure (e.g., valproate, fetal alcohol syndrome, very low birth weight).

Additional neurodevelopmental, mental or behavioral conditions should also be noted (e.g., attention-deficit/hyperactivity disorder; developmental coordination disorder; disruptive behavior, impulse-control, or conduct disorders; anxiety, depressive, or bipolar disorders; tics or Tourette's disorder; self-injury; feeding, elimination, or sleep disorders).

### Diagnostic features

The essential features of autism spectrum disorder are persistent impairment in reciprocal social communication and social interaction (Criterion A), and restricted, repetitive patterns of behavior, interests, or activities (Criterion B). These symptoms are present from early childhood and limit or impair everyday functioning (Criteria C and D). The stage at which functional impairment becomes obvious will vary according to characteristics of the individual and his or her environment. Core diagnostic features are evident in the developmental period, but intervention, compensation, and current supports may mask difficulties in at least some contexts. Manifestations of the disorder also vary greatly depending on the severity of the autistic condition, developmental level, and chronological age; hence, the term spectrum. Autism spectrum disorder encompasses disorders previously referred to as early infantile autism, childhood autism, Kanner's autism, high-functioning autism, atypical autism, pervasive developmental disorder not otherwise specified, childhood disintegrative disorder, and Asperger's disorder.

The impairments in communication and social interaction specified in Criterion A are pervasive and sustained. Diagnoses are most valid and reliable when based on multiple sources of information, including clinician's observations, caregiver history, and, when possible, self-report. Verbal and nonverbal deficits in social communication have varying manifestations, depending on the individual's age, intellectual level, and language ability, as well as other factors such as treatment history and current support. Many individuals have language deficits, ranging from complete lack of speech through language delays, poor comprehension of speech, echoed speech, or stilted and overly literal language. Even when formal language skills (e.g., vocabulary, grammar) are intact, the use of language for reciprocal social communication is impaired in autism spectrum disorder.

Deficits in social-emotional reciprocity (i.e., the ability to engage with others and share thoughts and feelings) are clearly evident in young children with the disorder, who may show little or no initiation of social interaction and no sharing of emotions, along with reduced or absent imitation of others' behavior. What language exists is often one-sided, lacking in social reciprocity, and used to request or label rather than to comment, share feelings, or converse. In adults without intellectual disabilities or language delays, deficits in social-emotional reciprocity may be most apparent in difficulties processing and responding to complex social cues (e.g., when and how to join a conversation, what not to say). Adults who have developed compensation strategies for some social challenges still struggle in novel or unsupported situations and suffer from the effort and anxiety of consciously calculating what is socially intuitive for most individuals.

Deficits in nonverbal communicative behaviors used for social interaction are manifested by absent, reduced, or atypical use of eye contact (relative to cultural norms), gestures, facial expressions, body orientation, or speech intonation. An early feature of autism spectrum disorder is impaired joint attention as manifested by a lack of pointing, showing, or bringing objects to share interest with others, or failure to follow someone's pointing or eye gaze. Individuals may learn a few functional gestures, but their repertoire is smaller than that of others, and they often fail to use expressive gestures spontaneously in communication. Among adults with fluent language, the difficulty in coordinating nonverbal communication with speech may give the impression of odd, wooden, or exaggerated "body language" during interactions. Impairment may be relatively subtle within individual modes (e.g., someone may have relatively good eye contact when speaking) but noticeable in poor integration of eye contact, gesture, body posture, prosody, and facial expression for social communication.

Deficits in developing, maintaining, and understanding relationships should be judged against norms for age, gender, and culture. There may be absent, reduced, or atypical social interest, manifested by rejection of others, passivity, or inappropriate approaches that seem aggressive or disruptive. These difficulties are particularly evident in young children, in whom there is often a lack of shared social play and imagination (e.g., age-appropriate flexible pretend play) and, later, insistence on playing by very fixed rules. Older individuals may struggle to understand what behavior is considered appropriate in one situation but not another (e.g., casual behavior during a job interview), or the different ways that language may be used to communicate (e.g., irony, white lies). There may be an apparent preference for solitary activities or for interacting with much younger or older people. Frequently, there is a desire to establish friendships without a complete or realistic idea of what friendship entails (e.g., one-sided friendships or friendships based solely on shared special interests). Relationships with siblings, co-workers, and caregivers are also important to consider (in terms of reciprocity).

Autism spectrum disorder is also defined by restricted, repetitive patterns of behavior, interests, or activities (as specified in Criterion B), which show a range of manifestations according to age and ability, intervention, and current supports. Stereotyped or repetitive behaviors include simple motor stereotypies (e.g., hand flapping, finger flicking), repetitive use of objects (e.g., spinning coins, lining up toys), and repetitive speech (e.g., echolalia, the delayed or immediate parroting of heard words; use of “you” when referring to self; stereotyped use of words, phrases, or prosodic patterns). Excessive adherence to routines and restricted patterns of behavior may be manifest in resistance to change (e.g., distress at apparently small changes, such as in packaging of a favorite food; insistence on adherence to rules; rigidity of thinking) or ritualized patterns of verbal or nonverbal behavior (e.g., repetitive questioning, pacing a perimeter). Highly restricted, fixated interests in autism spectrum disorder tend to be abnormal in intensity or focus (e.g., a toddler strongly attached to a pan; a child preoccupied with vacuum cleaners; an adult spending hours writing out timetables). Some fascinations and routines may relate to apparent hyper- or hyporeactivity to sensory input, manifested through extreme responses to specific sounds or textures, excessive smelling or touching of objects, fascination with lights or spinning objects, and sometimes apparent indifference to pain, heat, or cold. Extreme reaction to or rituals involving taste, smell, texture, or appearance of food or excessive food restrictions are common and may be a presenting feature of autism spectrum disorder.

Many adults with autism spectrum disorder without intellectual or language disabilities learn to suppress repetitive behavior in public. Special interests may be a source of pleasure and motivation and provide avenues for education and employment later in life. Diagnostic criteria may be met when restricted, repetitive patterns of behavior, interests, or activities were clearly present during childhood or at some time in the past, even if symptoms are no longer present.

Criterion D requires that the features must cause clinically significant impairment in social, occupational, or other important areas of current functioning. Criterion E specifies that the social communication deficits, although sometimes accompanied by intellectual disability (intellectual developmental disorder), are not in line with the individual’s developmental level; impairments exceed difficulties expected on the basis of developmental level.

Standardized behavioral diagnostic instruments with good psychometric properties, including caregiver interviews, questionnaires and clinician observation measures, are available and can improve reliability of diagnosis over time and across clinicians.

#### **Associated Features Supporting Diagnosis**

Many individuals with autism spectrum disorder also have intellectual impairment and/or language impairment (e.g., slow to talk, language comprehension behind production). Even those with average or high intelligence have an uneven profile of abilities. The gap between intellectual and adaptive functional skills is often large. Motor deficits are often present, including odd gait, clumsiness, and other abnormal motor signs (e.g., walking on tiptoes). Self-injury (e.g., head banging, biting the wrist) may occur, and disruptive/challenging behaviors are more common in children and adolescents with autism spectrum disorder than other disorders, including intellectual disability. Adolescents and adults with autism spectrum disorder are prone to anxiety and depression (Simonoff et al. 2008 ). Some individuals develop catatonic-like motor behavior (slowing and “freezing” mid-action), but these are typically not of the magnitude of a catatonic episode. However, it is possible for individuals with autism spectrum disorder to experience a marked deterioration in motor symptoms and display a full catatonic episode with symptoms such as mutism, posturing, grimacing and waxy flexibility. The risk period for comorbid catatonia appears to be greatest in the adolescent years.

#### **Prevalence**

In recent years, reported frequencies for autism spectrum disorder across U.S. and non-U.S. countries have approached 1% of the population, with similar estimates in child and adult samples (Brugha et al. 2011 ). It remains unclear whether higher rates reflect an expansion of the diagnostic criteria of DSM-IV to include subthreshold cases, increased awareness, differences in study methodology, or a true increase in the frequency of autism spectrum disorder.

#### **Development and Course**

The age and pattern of onset also should be noted for autism spectrum disorder. Symptoms are typically recognized during the second year of life (12–24 months of age) but may be seen earlier than 12 months if developmental delays are severe, or noted later than 24 months if symptoms are more subtle. The pattern of onset description might include information about early developmental delays or any losses of social or language skills. In cases where skills have been lost, parents or caregivers may give a history of a gradual or relatively rapid deterioration in social behaviors or language skills. Typically, this

would occur between 12 and 24 months of age and is distinguished from the rare instances of developmental regression occurring after at least 2 years of normal development (previously described as childhood disintegrative disorder).

The behavioral features of autism spectrum disorder first become evident in early childhood, with some cases presenting a lack of interest in social interaction in the first year of life. Some children with autism spectrum disorder experience developmental plateaus or regression, with a gradual or relatively rapid deterioration in social behaviors or use of language, often during the first 2 years of life. Such losses are rare in other disorders and may be a useful “red flag” for autism spectrum disorder ( Baird et al. 2008 ). Much more unusual and warranting more extensive medical investigation are losses of skills beyond social communication (e.g., loss of self-care, toileting, motor skills) or those occurring after the second birthday (see also Rett syndrome in the section “Differential Diagnosis” for this disorder).

First symptoms of autism spectrum disorder frequently involve delayed language development, often accompanied by lack of social interest or unusual social interactions (e.g., pulling individuals by the hand without any attempt to look at them), odd play patterns (e.g., carrying toys around but never playing with them), and unusual communication patterns (e.g., knowing the alphabet but not responding to own name). Deafness may be suspected but is typically ruled out. During the second year, odd and repetitive behaviors and the absence of typical play become more apparent. Since many typically developing young children have strong preferences and enjoy repetition (e.g., eating the same foods, watching the same video multiple times), distinguishing restricted and repetitive behaviors that are diagnostic of autism spectrum disorder can be difficult in preschoolers. The clinical distinction is based on the type, frequency, and intensity of the behavior (e.g., a child who daily lines up objects for hours and is very distressed if any item is moved).

Autism spectrum disorder is not a degenerative disorder, and it is typical for learning and compensation to continue throughout life. Symptoms are often most marked in early childhood and early school years, with developmental gains typical in later childhood in at least some areas (e.g., increased interest in social interaction). A small proportion of individuals deteriorate behaviorally during adolescence, whereas most others improve. Only a minority of individuals with autism spectrum disorder live and work independently in adulthood; those who do tend to have superior language and intellectual abilities and are able to find a niche that matches their special interests and skills. In general, individuals with lower levels of impairment may be better able to function independently. However, even these individuals may remain socially naive and vulnerable, have difficulties organizing practical demands without aid, and are prone to anxiety and depression. Many adults report using compensation strategies and coping mechanisms to mask their difficulties in public but suffer from the stress and effort of maintaining a socially acceptable facade. Scarcely anything is known about old age in autism spectrum disorder ( Happé and Charlton 2012 ).

Some individuals come for first diagnosis in adulthood, perhaps prompted by the diagnosis of autism in a child in the family or a breakdown of relations at work or home. Obtaining detailed developmental history in such cases may be difficult, and it is important to consider self-reported difficulties. Where clinical observation suggests criteria are currently met, autism spectrum disorder may be diagnosed, provided there is no evidence of good social and communication skills in childhood. For example, the report (by parents or another relative) that the individual had ordinary and sustained reciprocal friendships and good nonverbal communication skills throughout childhood would rule out a diagnosis of autism spectrum disorder; however, the absence of developmental information in itself should not do so.

Manifestations of the social and communication impairments and restricted/repetitive behaviors that define autism spectrum disorder are clear in the developmental period. In later life, intervention or compensation, as well as current supports, may mask these difficulties in at least some contexts. However, symptoms remain sufficient to cause current impairment in social, occupational, or other important areas of functioning.

### **Risk and Prognostic Factors**

The best established prognostic factors for individual outcome within autism spectrum disorder are presence or absence of associated intellectual disability and language impairment (e.g., functional language by age 5 years is a good prognostic sign) and additional mental health problems. Epilepsy, as a comorbid diagnosis, is associated with greater intellectual disability and lower verbal ability( Bolton et al. 2011 ).

### **Environmental**

A variety of nonspecific risk factors, such as advanced parental age, low birth weight, or fetal exposure to valproate, may contribute to risk of autism spectrum disorder.



### Genetic and physiological

Heritability estimates for autism spectrum disorder have ranged from 37% to higher than 90%, based on twin concordance rates( Geschwind 2011 ). Currently, as many as 15% of cases of autism spectrum disorder appear to be associated with a known genetic mutation, with different de novo copy number variants or de novo mutations in specific genes associated with the disorder in different families. However, even when an autism spectrum disorder is associated with a known genetic mutation, it does not appear to be fully penetrant. Risk for the remainder of cases appears to be polygenic, with perhaps hundreds of genetic loci making relatively small contributions.

### Culture-Related Diagnostic Issues

Cultural differences will exist in norms for social interaction, nonverbal communication, and relationships, but individuals with autism spectrum disorder are markedly impaired against the norms for their cultural context. Cultural and socioeconomic factors may affect age at recognition or diagnosis; for example, in the United States, late or underdiagnosis of autism spectrum disorder among African American children may occur( Mandell et al. 2009 ).

### Gender-Related Diagnostic Issues

Autism spectrum disorder is diagnosed four times more often in males than in females. In clinic samples, females tend to be more likely to show accompanying intellectual disability( Mandy et al. 2012 ), suggesting that girls without accompanying intellectual impairments or language delays may go unrecognized, perhaps because of subtler manifestation of social and communication difficulties( Rivet and Matson 2011 ).

### Functional Consequences of Autism Spectrum Disorder

In young children with autism spectrum disorder, lack of social and communication abilities may hamper learning, especially learning through social interaction or in settings with peers. In the home, insistence on routines and aversion to change, as well as sensory sensitivities, may interfere with eating and sleeping and make routine care (e.g., haircuts, dental work) extremely difficult. Adaptive skills are typically below measured IQ. Extreme difficulties in planning, organization, and coping with change negatively impact academic achievement, even for students with above-average intelligence. During adulthood, these individuals may have difficulties establishing independence because of continued rigidity and difficulty with novelty.

Many individuals with autism spectrum disorder, even without intellectual disability, have poor adult psychosocial functioning as indexed by measures such as independent living and gainful employment( Howlin et al. 2004 ). Functional consequences in old age are unknown, but social isolation and communication problems (e.g., reduced help-seeking) are likely to have consequences for health in older adulthood.

### Differential diagnosis

#### *Rett syndrome*

Disruption of social interaction may be observed during the regressive phase of Rett syndrome (typically between 1–4 years of age); thus, a substantial proportion of affected young girls may have a presentation that meets diagnostic criteria for autism spectrum disorder. However, after this period, most individuals with Rett syndrome improve their social communication skills, and autistic features are no longer a major area of concern. Consequently, autism spectrum disorder should be considered only when all diagnostic criteria are met.

#### *Selective mutism*

In selective mutism, early development is not typically disturbed. The affected child usually exhibits appropriate communication skills in certain contexts and settings. Even in settings where the child is mute, social reciprocity is not impaired, nor are restricted or repetitive patterns of behavior present.

#### *Language disorders and social (pragmatic) communication disorder*

In some forms of language disorder, there may be problems of communication and some secondary social difficulties. However, specific language disorder is not usually associated with abnormal nonverbal communication, nor with the presence of restricted, repetitive patterns of behavior, interests, or activities.

When an individual shows impairment in social communication and social interactions but does not show restricted and repetitive behavior or interests, criteria for social (pragmatic) communication



disorder, instead of autism spectrum disorder, may be met. The diagnosis of autism spectrum disorder supersedes that of social (pragmatic) communication disorder whenever the criteria for autism spectrum disorder are met, and care should be taken to enquire carefully regarding past or current restricted/repetitive behavior.

*Intellectual disability (intellectual developmental disorder) without autism spectrum disorder*

Intellectual disability without autism spectrum disorder may be difficult to differentiate from autism spectrum disorder in very young children. Individuals with intellectual disability who have not developed language or symbolic skills also present a challenge for differential diagnosis, since repetitive behavior often occurs in such individuals as well. A diagnosis of autism spectrum disorder in an individual with intellectual disability is appropriate when social communication and interaction are significantly impaired relative to the developmental level of the individual's nonverbal skills (e.g., fine motor skills, nonverbal problem solving). In contrast, intellectual disability is the appropriate diagnosis when there is no apparent discrepancy between the level of social-communicative skills and other intellectual skills.

*Stereotypic movement disorder*

Motor stereotypies are among the diagnostic characteristics of autism spectrum disorder, so an additional diagnosis of stereotypic movement disorder is not given when such repetitive behaviors are better explained by the presence of autism spectrum disorder. However, when stereotypies cause self-injury and become a focus of treatment, both diagnoses may be appropriate.

*Attention-deficit/hyperactivity disorder*

Abnormalities of attention (overly focused or easily distracted) are common in individuals with autism spectrum disorder, as is hyperactivity. A diagnosis of attention-deficit/hyperactivity disorder (ADHD) should be considered when attentional difficulties or hyperactivity exceeds that typically seen in individuals of comparable mental age.

*Schizophrenia*

Schizophrenia with childhood onset usually develops after a period of normal, or near normal, development. A prodromal state has been described in which social impairment and atypical interests and beliefs occur, which could be confused with the social deficits seen in autism spectrum disorder. Hallucinations and delusions, which are defining features of schizophrenia, are not features of autism spectrum disorder. However, clinicians must take into account the potential for individuals with autism spectrum disorder to be concrete in their interpretation of questions regarding the key features of schizophrenia (e.g., "Do you hear voices when no one is there?" "Yes [on the radio]").

*Comorbidity*

Autism spectrum disorder is frequently associated with intellectual impairment and structural language disorder (i.e., an inability to comprehend and construct sentences with proper grammar), which should be noted under the relevant specifiers when applicable. Many individuals with autism spectrum disorder have psychiatric symptoms that do not form part of the diagnostic criteria for the disorder (about 70% of individuals with autism spectrum disorder may have one comorbid mental disorder, and 40% may have two or more comorbid mental disorders)( Simonoff et al. 2008 ). When criteria for both ADHD and autism spectrum disorder are met, both diagnoses should be given. This same principle applies to concurrent diagnoses of autism spectrum disorder and developmental coordination disorder, anxiety disorders, depressive disorders, and other comorbid diagnoses. Among individuals who are nonverbal or have language deficits, observable signs such as changes in sleep or eating and increases in challenging behavior should trigger an evaluation for anxiety or depression. Specific learning difficulties (literacy and numeracy) are common, as is developmental coordination disorder ( Baird et al. 2011 ). Medical conditions commonly associated with autism spectrum disorder should be noted under the "associated with a known medical or genetic condition or environmental factor" specifier. Such medical conditions include epilepsy, sleep problems, and constipation. Avoidant/restrictive food intake disorder is a fairly frequent presenting feature of autism spectrum disorder, and extreme and narrow food preferences may persist.

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# Appendix 6

## Submission guide



PARLIAMENT OF VICTORIA  
Family and Community Development Committee

### INQUIRY INTO SERVICES FOR PEOPLE WITH AUTISM SPECTRUM DISORDER

#### GUIDE TO SUBMISSIONS & PUBLIC HEARINGS

#### 1. OVERVIEW

The Family and Community Development Committee has been asked by the Victorian Parliament to inquire into services for people with autism spectrum disorder.

This Guide is intended to assist organisations and individuals who want to make a written submission to the Committee.

Submissions close on **FRIDAY 22 APRIL 2016**.

The Committee will hold public hearings in 2016. Public hearings provide an opportunity for the Committee to meet members of the public – including individuals and organisations that have made submissions – and discuss key issues. If you would like to talk to the Committee at a public hearing please indicate this in your submission. Once the locations and times for the public hearings have been confirmed the Committee will publicise these on its website.

#### 2. THE INQUIRY – TERMS OF REFERENCE

The Family and Community Development Committee has been asked to inquire into, consider and report, on services for people with autism spectrum disorder in Victoria, including but not limited to –

- a) the prevalence of autism spectrum disorder in Victoria;
- b) the availability and adequacy of services provided by the Commonwealth, State and local governments across health, education, disability, housing, sport and employment services;

- c) the adequacy of services to be provided under the National Disability Insurance Scheme (NDIS);
- d) evidence of the social and economic cost of failing to provide adequate services; and,
- e) the projected demand for services in Victoria.

#### 3. MAKING A SUBMISSION

All interested parties can make submissions to the Inquiry. The Family and Community Development Committee is seeking submissions from both individuals and organisations relating to the terms of reference for the Inquiry.

There is no single way for any person or organisation to approach a submission. The Committee understands that people will want to approach their submissions differently.

Your submission can take the form of a letter, an email or a longer document. Submissions can be provided in either hard copy or by email to the Committee Secretariat.

Your submission must relate to at least one of the terms of reference.

Please include your contact details in your submission, including an address and phone number.

Electronic submissions should be sent via:

- The eSubmission form on the Committee's website:  
<http://www.parliament.vic.gov.au/fcdc>
- Or by email to:  
[fcdc@parliament.vic.gov.au](mailto:fcdc@parliament.vic.gov.au)

Hard copy submissions should be sent to:

Family and Community Development  
Committee  
Parliament House  
Spring Street  
EAST MELBOURNE VIC 3002

#### 4. CONFIDENTIALITY

All submissions are treated as public, unless otherwise requested. The Committee can receive written submissions on a confidential basis or can withhold names where this is requested and agreed to by the Committee. Please indicate if you want your submission treated as confidential or your name withheld and provide a brief explanation.

#### 5. PARLIAMENTARY PRIVILEGE

A submission to a Committee becomes a Committee document once the Committee formally decides to accept it as a submission. A Committee may decide not to accept a submission as evidence if it is not relevant to the Terms of Reference, or is offensive.

Once the Committee has authorised the release of a submission, any subsequent publication of it by the Committee is protected by parliamentary privilege. This means that what you say in your submission cannot be used in court against you.

Parliamentary privilege only extends to submissions that are published by the Committee. If a submission is published in another form or for another purpose, that publication will not be protected by parliamentary privilege. This means that you should not reproduce the submission in another format or context. You can, however, refer others to your submission on the Committee's website, or advise them to contact the Committee directly.

It is against parliamentary rules for anyone to try to stop you from making a submission by threats or intimidation. It is also a breach of these rules for anyone to harass you or discriminate against you because you have made a submission, and Parliament can take action against this behaviour.

#### 6. PUBLIC HEARINGS

The Committee will be holding public hearings in Melbourne and throughout regional Victoria. Public hearings are an opportunity for the Committee to meet with individuals and organisations to discuss the Inquiry's key issues.

The Committee decides who will be invited to give evidence at a public hearing. Generally, the Committee will invite individuals and representatives of organisations that have made submissions.

If you do not wish to make a submission but still want to talk to the Committee at a public hearing, please contact the Committee to request this.

In general, all submissions and transcripts of evidence given at public hearings are public documents. This means that the evidence may be published on the Committee's website and quoted in the Committee's report to the Parliament. However, in special circumstances, the Committee may decide to hear evidence in private (in camera). If you wish to present all or part of your evidence confidentially, you must ask the Committee in advance.

More information about public hearings is available on the Parliament's website:

<http://www.parliament.vic.gov.au/committees/get-involved/giving-evidence>

#### 7. SCOPE OF INQUIRY

The Inquiry into services provided for people with autism spectrum disorder is a major inquiry, with a broad frame of reference. The Committee is particularly interested to hear from people with autism spectrum disorder and their families and carers, concerning their experiences of the sector.

The Inquiry will examine the federal, state and local levels of government service provision, in the areas of health, education, housing, employment, sport and disability services. The Committee will investigate the prevalence of autism in Victoria, the adequacy of services that will be provided under the NDIS, the costs of failing to provide adequate services in both social and economic terms, and projected levels of demand.

The Committee wishes to hear from all stakeholders who have an interest in this Inquiry. These include:

- People with autism spectrum disorder
- The carers and families of people with autism
- Organisations, departments and agencies that provide services to people with autism
- Groups and individuals who advocate on behalf of people with autism
- Local councils and government bodies
- Peak bodies and representative groups
- Academics and experts in autism spectrum disorder
- Employers of people with autism

The Committee will report its findings to the Parliament and make recommendations to the State Government.

## 8. SOME KEY QUESTIONS TO CONSIDER

The questions that follow provide a further guide to the Inquiry's investigations. They are designed to help you think about issues for your submission. However, please note, that you are not required to answer any of these questions in order to make a submission. So long as your submission relates to at least one of the terms of reference the Committee will receive your submission.

### Accessing services and quality of service

What is the experience of people with autism spectrum disorder (ASD), their families and carers in accessing services, information, advice and support?

What is the quality of these services, the standard of advice and the reliability of information given on ASD, and the support provided?

### Health services

Does the health system provide adequate access, information and support to people with ASD and their families in Victoria? What is the accessibility and availability of quality

assessments and diagnoses of people presenting with ASD?

### Services in rural and regional Victoria

Are there particular issues with service access and quality of service in rural and regional areas of Victoria? What is the accessibility and availability of services that are age appropriate?

### Integration across governments and services

How well are services across the different levels of government integrated? Is there collaboration and appropriate linking up between service providers, particularly in relation to transitions from one area of the sector to another?

### Disability service providers

Does the disability service sector provide sufficient and quality tailored services to people with ASD? What is the level of unmet demand for these services? How well do these services perform in meeting the expectations of their clients?

### Education and housing

What is the accessibility to, and quality of the education services provided to people with autism? How inclusive is the education sector, at all levels, to people with ASD? What are the resource limitations?

Are the accommodation needs of people with ASD being met? What models of housing represent best practice, and how developed is the sector in providing sufficient and appropriate housing options?

### Workforce issues

How well equipped is the workforce across the sector in providing informed, compassionate, and professional service to people with ASD? What are the training needs and qualifications necessary to ensure a skilled workforce?



### Impact of NDIS

What will be the impact of the roll-out of the NDIS on services, and choice of service, for people with ASD and their families? Are there likely to be gaps in service emerging as a result? How will the different levels of government service provision be changed or impacted?

### Research into ASD and its prevalence

How well developed is research into ASD in Victoria? What are the current limitations to knowledge, and the dissemination of knowledge, in this area, and how can this be addressed? Is there an accurate picture available on the prevalence of ASD?

### Community participation

What programs exist to facilitate the participation of people with ASD in the community and in employment? How available, accessible and successful are employment services for people with ASD?

How inclusive are the state's sports programs of people with ASD? What are the opportunities for participation in sport and recreation?

## 9. EASY READ GUIDE

The Committee is developing an Easy Read Guide to assist stakeholders to the Inquiry. Please contact the Committee Secretariat for further information and to obtain a copy.

## 10. NATIONAL RELAY SERVICE

If you are deaf, or have a hearing or speech impairment, contact us through the National Relay Service. You will need to provide them with our number, 03 8682 2843. For more information, visit [www.relayservice.com.au](http://www.relayservice.com.au)

## 11. FURTHER INFORMATION

If you have any questions please contact the Committee Secretariat on:

- Email: [fcdc@parliament.vic.gov.au](mailto:fcdc@parliament.vic.gov.au)
- Phone: 8682 2843
- Website: <http://www.parliament.vic.gov.au/fcdc>



# Appendix 7

## Easy Read guide



PARLIAMENT OF VICTORIA  
Family and Community Development Committee



### The Parliamentary Inquiry into Autism spectrum disorder services in Victoria

#### An Easy Read guide

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#### How to use this document



This information is written in an easy to read way.  
We use pictures to explain some ideas.



This document has been written by the  
Parliament of Victoria's Family and Community  
Development Committee, or the Committee.  
When you see the word 'we', it means  
the Committee.



You can ask for help to read this document.  
A friend, family member or support person may  
be able to help you.

## What we want to do



The Parliament of Victoria's Family and Community Development Committee is starting an Inquiry.



An Inquiry is when the government looks into a problem or issue.



This Inquiry is about services in Victoria for people with autism spectrum disorder.



Autism spectrum disorder (ASD) is a type of disability that affects the way a person:

- thinks
- behaves
- experiences the world.

The services could be from:



- local government



- State government



- Commonwealth government.



- private providers

The services could be for:



- health
- education
- disability
- housing
- sport
- employment – work and jobs.

## What we want to know

We want to know:



- how common ASD is in Victoria



- what services are available for people with an ASD



- how good services for people with ASD are



- if the information people with ASD and their families are given is good enough.



We also want to know how good services will be under the National Disability Insurance Scheme. This is usually called the NDIS.



The NDIS is a new way of providing care and support for people with disability.



In the future, the NDIS will be responsible for making sure that people who use disability services:

- receive good services
- feel safe.

We want to find out what could happen if services aren't good enough, including:



- how this could affect people



- how much this could cost.



We would like to know how much people will need to use services in the future.



When we have found out what we want to know we will write a report.

## Who we want to hear from



We need different people to tell us what they think.

We want to hear from:



- people with ASD, their families and carers



- people who provide services for people with ASD



- people who advocate for people with ASD



- anybody who has an interest in services for people with ASD.

## What we will do next



We will ask people what they think.



We will hold public meetings.



We will hold meetings in:

- Melbourne
- regional Victoria.



To find out about our public meetings you can contact us.



Our contact details are on the next page.



## How can you take part?



You can tell us what you think by writing to us.  
We call this a submission.



We need to have your submission by  
**Friday 22 April 2016.**



You will find information about how to tell  
us what you think at  
<http://www.parliament.vic.gov.au/fcdc/article/2586>



(03) 8682 2843



[fcdc@parliament.vic.gov.au](mailto:fcdc@parliament.vic.gov.au)



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[www.parliament.vic.gov.au/fcdc](http://www.parliament.vic.gov.au/fcdc)



If you are deaf, have a hearing problem or a speech problem and need to talk to us you should contact the National Relay Service.



TTY: 133 677

Speak and Listen: 1300 555 727

Text: 0423 677 767



You will need to give them our phone number:

03 8682 2843



For more information about the National Relay Service visit their website:

[relayservice.gov.au](http://relayservice.gov.au)



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