TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Melbourne — 29 August 2016

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Ms Frances Saunders, statewide autism spectrum disorder coordinator, and

Ms Liz Morkham, autism spectrum disorder coordinator, Austin Child and Adolescent Mental Health Service, Mindful Centre for Training and Research in Developmental Health.

The CHAIR — I welcome to these public hearings Ms Frances Saunders, statewide ASD coordinator, Dr Sandra Radovini, director, and Ms Liz Morkham, Austin CAMHS ASD coordinator from the Mindful Centre for Training and Research in Developmental Health. Thank you for your attendance here this morning.

All evidence at this hearing taken by the committee is protected by parliamentary privilege as provided by the Constitution Act 1975 and is subject to the provisions of the Parliamentary Committees Act 2003 and other relevant legislation. Any comments you make outside the hearing will not be afforded such privilege. It is a contempt of Parliament to provide false evidence. Recording of the proceedings will commence today, and you will be sent a proof copy of the transcript and be able to make factual or grammatical corrections if necessary. I will hand over to you now for your presentation. Thank you again for coming this morning.

Visual presentation

Dr RADOVINI — Thank you very much for the opportunity to present to you. We represent the tertiary mental health service sector and the teaching and training in ASD that has occurred in this area over the last few years. I am going to speak a little bit about the context and then hand over to Fran to continue on.

This is in relation to the Victorian mental health service system. We have metropolitan mental health services and then right across the state. They have the catchment areas and within that the responsibility for children, young people and adults with autism where they intersect with the mental health service system. There are ASD coordinators in each of the Child and Adolescent Mental Health Services (CAMHS) or Child and Youth Mental Health Services (CYMHS) across Victoria, and their responsibilities are as listed there with respect to facilitating ASD assessment and diagnosis, overseeing early intervention and the ongoing care — again, with the crossover with mental health services — trying to facilitate referral pathways to other services and providing leadership within the mental health service system. Really the ASD coordinators are the go-to people within that service with respect to anything related to ASD — any inquiries, any difficulties. Liz is one of those ASD coordinators at the Austin. The other is really to link in with the rest of the service system in a region, whether it be paediatricians, disability services or early intervention.

In addition, we have a statewide coordinator, and that is Frances Saunders. Frances assists the regional ASD coordinators in terms of forming a network which tries to problem-solve, which tries to network, which tries to see that there is consistency around ASD assessments and diagnosis across the state. One of the other key roles for Frances has been to develop a very extensive training calendar to meet the needs of mental health practitioners, whether they be public or private practitioners, across the state. There was a comment in the previous presentation about skilling allied health. That is our role — skilling allied health as well as medical staff.

This is the kind of training that Mindful has developed or is being developed at Mindful to assist the workforce. We see this as a very key thing — that you need a skilled workforce in ASD to be able to do timely assessments and to be able to provide ongoing appropriate care for people with ASD — so there is ongoing training in both assessment and treatment. This has been developed gradually over about the last five years.

We sit at the top of that pyramid or we represent the people who sit at the top of that pyramid with respect to specialist services, but there is obviously a need to link in with everybody else, to be clear about referral pathways in both directions and to think about training as well at all levels of that pyramid. In particular, over the last five years the children and families who come to the specialist services are increasingly those with complex difficulties and with co-occurring mental health problems, families who have complex difficulties and families who also have special needs. We have moved from an idea that every child with autism needed to have an assessment within a mental health service to actually saying, ‘No, we should be looking at those with complex difficulties’. There are other providers in the community who can do assessments where it is more straightforward. Here in particular we are thinking about paediatricians. That brings with it other problems when it comes to who is available in a community. Is there that tier 2 level of providers or not? Some parts of Victoria are better serviced than others. In some areas there are indeed significant shortages within that tier 2 level.

It was mentioned in the previous presentation about the diversity of autism, and we think this is a very important point. 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.

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. We are just listing some of the disorders that we might see in mental health services. 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 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.

Similarly, it was mentioned, again in the previous presentation, that parents need support. In fact parents 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 been quite a bit of research in this area — so we strongly believe that families need to be supported, again throughout the life span.

What leads to good adjustment and wellbeing? This slide is really key. All of these things need to be attended to, and they need to be attended to across the life span. People mentioned previously educational opportunities — absolutely. Appropriate educational opportunities are key, as is support for families and as is appropriate medical care, appropriate psychiatric care, where that is needed. What we find is that these things are not often well integrated, and what you have is really a service system that should be integrated but is not. So families struggle at any one of those points, whether it be education or getting support themselves or getting appropriate mental health care or dealing with disability services. It reflects that we have a fragmented service system and a siloed service system that struggles, sometimes, to talk to each other. It struggles, sometimes, at the level of the particular person and sometimes at the systems level as well.

I think, again, it was mentioned in the previous presentation: how do you get, at a departmental level, that kind of cooperation or troubleshooting or those policies that can sit across and do not actually cut across? We have got some examples of some things where things do not work well later on. Fran is going to talk about some of the big changes that occurred with the autism state plan since 2009. The Autism State Plan was very significant for our sector in being able to see quite a number of changes that we feel led to some improvements, but then we have also had the problem of funding not being continued for many initiatives that were really important.

Ms SAUNDERS — A lot of what we are seeing in Victoria now has come about, as Sandra said, from this state plan — things like a big rollout of preschool parent training for ACT-NOW, which was incredibly significant at the time, training people across various different sectors to deliver that training. At the time there was a very strong network of regional consultation and training networks called ReACT, and these also were strengthened during that state plan period of time, creating a lot of inter-agency collaboration. Case consultant practitioners were funded under DHS to provide consultancy to other agencies. There were waiting list reduction initiatives that had a very big impact at the time. Positive behaviour support was developed as part of this as well to provide education programs for parents of school-age and young adult children. There were a number of different supports put in for education in schools, and one included the regional coaches.

As Sandra mentioned, there was specific training funding given for training CAMHS workers, and it was related to the waiting list initiative. If we need to increase the workforce, then we have got to have a highly skilled workforce. Then we need to train people, and we need to train people in an ongoing way. In any organisation you are going to have staff turnover, attrition, people on maternity leave, so this is how the training calendar began and was established — to provide expert and consistent training across the mental health sector. So at that highest level we had people who were very skilled and who were making that ASD diagnosis in a very considered way and in a way that was gold standard and best practice.

ASD coordinators were appointed in each of those CAMHS mental health regions, and there was recurrent funding attached to that, which meant that those assessment teams have continued in a quality way and the position of the ASD statewide coordinator to facilitate and support the coordinators was established. But over time we have lost most of these things, or they have just decreased. This has been very difficult, I think, across Victoria where people have had access to things and things have changed, and then they have gone. So the

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. So it is a cyclical pattern, particularly within publicly funded services, that you do have that build-up of waiting lists. But also we have better identification where most people now can 'pick on the train' who might be autistic. So there is a much better acknowledgement of who might need assessment services, and I think there is probably an increase for most services. And too, I think, for those of us who work in the tertiary sector in that complex end, the top of the triangle, there is much more thought about young people and children presenting in a complex way — 'Could there be an ASD as part of this presentation?'.

The positive behavioural support workshops for parents of children and young people — this is coming to the end of its funding. It was funded for two years. It was reviewed, and I think they got another two years of funding, but that will soon come to an end as well. Where parents of school-age children and young adults have been getting a lot of support from this training, that will also disappear.

Many of the supports for schools that were implemented under that statewide plan, particularly the regional coaches, have gone, and that was a great support to offer individual schools — training, support, consultation. Also our [Mindful] funding for training and the statewide position has gone, and currently we are in discussion with DHHS about that.

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.

The priorities of the Autism State Plan are still priorities now. One of the biggest ones was this idea that it needed a whole-of-government approach — that it could not be siloed in sectors; that all departments, all sectors, need to work together. I think Amaze have also referred to these priorities in their submission and that the whole idea was to make it easier for families, to strengthen ASD expertise of the workforce, to extend and link key services, particularly in times of transition, to provide appropriate educational opportunities et cetera. So we are still in the same position. I guess the needs of a particular group do not change over time — they are enduring — and so the strategies, the funding strategies and the positions also need to be enduring.

In terms of the ASD coordinators that I meet with regularly across the state of Victoria, they come to Mindful for regular meetings, our concerns are similar across all of Victoria — that the major issues are about equity and access for families to quality services, to good diagnostic assessment and to good treatment services. We are particularly concerned about the lack of integration across government services and the policy barriers that might prevent a client from moving from one sector to another. The training and workforce issues are ongoing and always will be. Our biggest concern — and I guess having been very much a part of the state plan — is the continuity of these past positive initiatives. Many of them have disappeared, which is very disappointing for us as professionals, but also for families.

There are key regional issues, and these are very similar to the broad, statewide issues. Regional country areas have very particular issues, and most specifically, their access to allied health is very poor. If you look at what is regarded as the best practice assessment, in CAMHS or CYMHS you would have a child psychiatrist or a paediatrician working with a psychologist to provide that assessment. Many regional CYMHS do not have that suite of professionals, particularly speech pathologists. Obviously they cannot provide the full service and then have to find ways of collaborating with other services.

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.

There are the ongoing issues in regional areas of attrition, of people moving through, of professionals coming and going. How do we keep them trained and how do we keep the skilled workforce out there in regional areas? Regional areas are often leading the way. They are the ones who are the groundbreakers. They are the ones who are able to work with, 'Well, we are a CAMHS, but actually we're going to work with the local private speech pathologist or a CAMHS, and we're actually going to work with the local community health centre', whereas in Melbourne there are lots of policy barriers that prevent that from actually happening. So regional areas actually lead the way in some of the more creative solutions because of their community concerns about their client group and their connectedness, I guess.

Our recommendations really are our ongoing concerns, similar to what they were when the state plan was being developed, to address workforce shortages and that kind of maldistribution of how do we get the right people in the right place; how do we foster that; how do we mentor them; and how do we keep them there? Consideration of funding new positions — clearly in regional areas there is a high need for that, and certainly in areas of Melbourne, if you look at western metropolitan Melbourne, there is not the same service provision or even distribution of private practitioners that you see in other regions of Melbourne. There is a very real inequity there.

I guess the learnings from the state plan are that funding streams need to be ongoing. These programs just get started, they run for a year and then they disappear. It is a tragic loss of skills and expertise. So that, I think, is one of the big learnings from the state plan — that whatever we start needs to be evidence based, needs to be well planned and thought through and that there needs to be a commitment to those professionals, to building up their skills and working with the ASD community.

The other thing we talked about was the very big issue of removing agency policies in local communities. So where children might be able to access a service there might be a great paediatrician, but in that community health centre there is a policy that the psychologist and the speech pathologist are not allowed to work with children with queried ASD. They have to go somewhere else. So you have got a lovely little team ready to go that is actually prevented by policy.

Parents need adequate support and access to training. Two of the very positive programs for parents were the ACT-NOW — that rolling out of training for parents of preschool children — and currently we are getting very good feedback from parents about their experience of positive behaviour support programs for those older children and adolescents. Of course for any change to work, departmental and interagency coordination and consultation mechanisms need to be set up and need to be established again in the long term so that these things are supported and encouraged and so that they continue.

So what are some examples? Where do children fall through the gaps? These are just a few examples of common presentations we see. This is one where four-and-a-half-year-old Noah presents at the local community health centre. The paediatrician is very experienced. He is a bit of a complex kid but she has got concerns that he does have an autism spectrum disorder, but of course she needs other supporting information and assessments to finalise that conclusion and to be sure of her clinical judgement. She would like to refer to the speech pathologist and the psychologist in her community health centre, but they are unable to see the child because of those policy barriers. Her only choice then, really, because this family cannot afford private assessments and one parent does not speak English, is to refer to the local CAMHS, which has a waiting list of about 12 months.

Noah manages to start school before this assessment occurs, and of course in that transition to school there has been no planning. He comes to school without the teacher's understanding that he might be a child on the ASD spectrum, and of course his behaviour deteriorates — he is running away; he is hurting other children. Staff do not know how to respond to him because they have not got appropriate strategies in place. Then often what happens is the school again refers to CAMHS. So timeliness of assessment is really important, and somehow if we could break down these policy barriers in local communities where people should be able to access assessments, that would really help families like Noah's.

In regional Victoria, this is one example that one of our coordinators gave recently: she saw Tom in a triage role when he was about six. They presented to CAMHS and very clearly this child was on the autism spectrum but had not been diagnosed. Because of CAMHS waiting lists and needing to prioritise who would get a CAMHS assessment, she referred him back to the paediatrician at the time to follow through those diagnostic procedures. Tom is now 12 and he is having enormous difficulties. He has been having a term at Mansfield residential school.

His mother is trying to get some support from disability services for Tom, and she is frustrated. She has rung back her CAMHS coordinator and said, ‘Look, I can’t even get disability support services for him because his first diagnosis was ADHD’. So disability services will not accept the application that he has got autism because they see his primary diagnosis is ADHD, which is not correct; it just happened to be the sequence and the way that things were diagnosed. So then they would like him to have a full assessment. They will not proceed until he gets a full assessment again. Now, for a child like Tom, he is not really eligible for a public service — because of our waiting lists we do not prioritise children who have already got an ASD diagnosis — so the only option is for the family to try and access a multidisciplinary assessment privately, which most families cannot afford. So you can see where families are frustrated and stymied just because our service systems are not working together.

This is very common for CAMHS and CYMHS. 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 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.

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.

Lastly, this is an example from our Orygen mental health service who deal with young adults. Again they struggle to see kids on the spectrum. It is more difficult for them to get through the triage. Alex is a 20-year-old Turkish male. He had been diagnosed with a language disorder and selective mutism in childhood. His functioning had deteriorated during adolescence. He was housebound and isolated, just stuck in his room. Usually these young people are just with their computers and totally occupied by that. He had been referred to youth mental health five times due to risk of self-harm. When eventually he was assessed through the ASD coordinator at Orygen, because they also have an ASD coordinator, he was given the diagnosis and found also to have borderline IQ.

But then again the next point of transition is ‘Mental health issues largely addressed’ and trying to transfer him on to other more adult services. There were no public health services for his speech and language difficulties. 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. There are difficulties with accessing funding packages for disability services in his area, and currently the positive behaviour support workshops are reducing due to their funding stream and there is less support available.

So those are some examples of where we see that these young people have difficulties around transition. There is a lack of pathways between adult and youth and child services, and training, particularly in the adult area, has not been yet established. So that is our formal presentation completed, and we are happy to take questions.

The CHAIR — Thank you very much. I think it is becoming very clear already through our public submissions and just from the two presentations we have heard this morning that there are some themes running through people with ASD across Victoria, and clearly access to adequate services is one of them, as is the cost associated with that.

In terms of rural and regional areas, and some of us members here are from regional areas and we very well understand how difficult that is in our own local electorates, I want to ask you a question around health services more broadly. For someone who might present to an emergency department or have ambulance services attend or someone who has to go in for surgery, there is a real lack of understanding of ASD across our health services, and that has come through in the public submissions we have received — clearly nurses, doctors, surgeons, ambulance people, emergency departments and allied health services. There is a real lack of understanding of ASD. How do you see that we can address that? A coordinated approach and more training is obvious, but how do you do that, because that is such a broad area?

Every person who presents to a health service with ASD is potentially misunderstood or not able to clearly express what their needs are, and then you have parents as well with children with ASD who are just floundering because they cannot get the support for those children that they need. Then they get referred off to a mental health service because that is the only option when, if we had the better understanding or better training of all health professionals — do you see what I am saying?

Ms SAUNDERS — Yes, I agree there is a need for training across all levels and I guess it is different training for different sectors. It also does require different sectors to work together and to utilise the skills of one sector in a different sector. I am also the ASD coordinator at the children's hospital for our CAMHS, and Liz can probably speak to this as well, but in 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. Often these young people can be admitted to our inpatient unit as well — our adolescent inpatient unit in mental health.

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.

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 A and E and emergency at RCH. Liz also has some examples in her hospital where it has been problematic.

Ms MORKHAM — We have had a number of children who have got severe intellectual disability and autism coming into the accident and emergency with aggressive behaviours and needing restraints, which is extremely distressing for families and for the young person, and they are needing to be admitted into a mental health ward at a time when there is only one high-dependency unit where that young person can be separated from the other patients in the unit and observed. They are presenting actually with very different presentations. Most adolescents in a mental health ward are ambulant and not having the same sort of difficulty, so it was very difficult for — this is just one example that was very striking. The mother of that young person needed to stay in the mental health ward with her son in order to help the staff understand what his needs were at a time that was very difficult for the family, because mental health staff are not perhaps trained up in autism to the degree that was needed.

I suppose there are more and more incidents of these very complex presentations. At the Austin there has been a submission to create a particular room in accident and emergency where people struggling particularly with aggression, and that would include young people who have autism spectrum disorders who are really struggling with aggression and anxiety, can be kept away from the open environment of an accident and emergency setting. We also have a small room for mental health clients that can be dimmed. I suppose the difference between the Austin and the children's is that it is adult to child, so a whole of life span service. CAMHS is child and adolescent, and we are needing to then intersect with the adult sectors of the hospital, both in health and mental health. I am not sure how much autism is understood in adult mental health. In fact I think there is very little attention paid to adult mental health. In the adult mental health sector they are seeing more acute suicidality and psychosis, so autism is seen to be a less acute presentation, and so there would be less knowledge about it in that sector.

We are hoping that we can have input into the design of that room so it can be a low sensory room, but I think that would need to come from a health perspective because that is actually the health part of the hospital. It is the medical side of the hospital that the mental health section is inputting to. I suspect that if that was to happen across the board, a number of hospitals do not have mental health departments, and so you would need that to come from a health department.

The CHAIR — I am very pleased that the new Bendigo Hospital has that very facility you are referring to, so it is a big change to the current facility to actually have that space in emergency and also the mental health section separated as well.

Dr RADOVINI — Just to touch on a point that Liz was making with respect to our adult mental health colleagues, one of the things that we had hoped at Mindful is that we would begin to look at training for our adult mental health colleagues, but we have run out of funding.

The CHAIR — Just while you are referring to adults with ASD, clearly there are not good diagnostic services available for people to be diagnosed as adults. Would you agree with that?

Dr RADOVINI — For adults, it would be very poor.

The CHAIR — Once they are diagnosed — it is a late diagnosis — what sort of support is available from that point?

Dr RADOVINI — I would have to say that it 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.

The CHAIR — So the diagnosis of a mental health issue or the diagnosis — —

Dr RADOVINI — Is missed.

The CHAIR — Well, it could actually be the first diagnosis and then the ASD be the second diagnosis — —

Dr RADOVINI — Yes, indeed it can happen that way.

The CHAIR — So basically what you are saying is there really are no support services for adults who are diagnosed with ASD later in life.

Dr RADOVINI — There would not be, no, unless — if they have an intellectual disability, then they slot in, if you like, to disability services. If they do not, then really there is nothing.

The CHAIR — For example, we have received submissions from parents who have been diagnosed later in life along with their children’s diagnosis and never knew that they had ASD until they had their children diagnosed. There really is no support for those parents, apart from following the trajectory of their children’s lives with support services. There is really nothing for an adult at the moment who is diagnosed with ASD, let us say, when you are talking about the spectrum where they are absolutely able to function and have lived pretty much what we would consider a relatively normal life.

Dr RADOVINI — It would be if they found a sympathetic private practitioner. That would be where they might find support, and that would be very ad hoc. There are some people around town who do offer support to adults with ASD, but they are sitting in private practice land.

The CHAIR — Are there any support groups or things like that happening that you know of?

Ms MORKHAM — There are some sort of like local children and adolescent parent groups, so parents will get together and set up support groups.

The CHAIR — For parents with ASD?

Ms MORKHAM — No, so I am talking about just general support.

The CHAIR — I am referring to adults with ASD and perhaps support groups that exist within communities.

Ms MORKHAM — I am not aware of any.

Ms SAUNDERS — I think there are groups. It is not really the group that we deal with, but certainly online groups exist. There are a lot of adults with ASD who are connected. I am sure there are other groups that can speak to what is out there for them. I think it is limited in terms of professional support to those groups, but there are certainly those groups of people getting together and forming their own self-help groups.

Ms McLEISH — I want to drill down a little bit more into the policy barriers, and you gave the example of Noah with the issues. Can you describe what sorts of policies are in place that act as these barriers?

Ms SAUNDERS — Well, they are the ones that we come across when we are trying to help families put together an assessment or when we get referrals and we say to the paediatrician, 'Look, I think this is one that maybe you could do with your local services'. There are barriers within certain community health centres for allied health — that is a very clear one — that if there is a suspicion of ASD, they will not see them and they should go to early intervention. But if you go to early intervention — —

Ms McLEISH — Each community health centre will have its own set of policies, so in one you could — —

Ms SAUNDERS — Again it is not something I can speak to 100 per cent, but in general most of metropolitan Melbourne — not all of them, though — have that policy. Some do have different policies. There is one community health centre that I know of that is doing some ASD assessments, but the actual specifics of the policy I am not across. But certainly I know that there have been approaches to community health centres to try and assist them setting up their own teams, because most of them have very experienced paediatricians, and whether there is a lack of interest or a lack of will or whether they are not seeing it as their — —

Ms McLEISH — So you come in the door and you have to go out to somewhere else rather than deal with it in-house?

Ms SAUNDERS — Yes, absolutely. The other barrier is sometimes within early intervention the paediatrician might need the report from the speech pathologist or the psychologist or the OT working with the child in the early intervention centre, and some EI services have policies around not doing formal assessments. I think if the family directly asks for them, some families can get these assessments that then go to support the paediatrician making a diagnosis, because then they would have input from a psychologist and a speech pathologist, but again for many families there are policy barriers there. So where the paediatrician could work in conjunction with the EI service to collaborate for children who are much more obviously on the spectrum, the diagnosis could be encapsulated within that group, but there are also barriers there. It varies between agencies.

Ms McLEISH — Do you have a feeling why it is there? Is it something that each — —

Ms MORKHAM — My sense is that all the public health sector services are struggling with numbers really, and so services are putting very tight boundaries around the eligibility for their service so that they do not get flooded, I think, would be my sense.

Ms McLEISH — Rather than an historic way: this is the way it is always been?

Ms MORKHAM — No, well, I do not know. In my time things have been different in the past. I mean, I see the same thing with mental health and disability. Whilst someone is eligible, and there is no policy as such that you cannot get disability services if you have ASD, if you are a mental health client with ASD, it is very, very difficult. You usually have to get an advocate involved to get disability services. So whilst it is not a formal policy it seems to be a practice, and I suspect that is about 'That is more your bag; you deal with that', because it is more mental health than it is disability. But mental health cannot provide as much respite, for example, for families, or there is certain access to behavioural support teams that mental health would not supply that disability would, and that would be very helpful for the family's management of the young person.

Ms McLEISH — Just quickly, what training program have you conducted that you think has probably been the stand-out?

Ms SAUNDERS — That is a difficult question to answer because we do two things: we do assessment training and we have started doing more training around intervention. Clearly what we want to happen is for good quality, best practice assessments to occur. So I guess our suite of assessment training is probably the stand-out and for CAMHS, building on the work that Bruce Tonge has done in training CAMHS workers, Monash Health and RCH. CAMHS got together and collaborated to develop a two-day training, which is our introduction to ASD assessment, particularly including complex thinking about mental health — that in assessing ASD you need to take a good developmental history, a good child assessment, collateral information from all the people involved with the child and then thinking about how that is formulated. So is there an ASD there or not and what other diagnoses might also exist for that child? That is our centre point at the beginning of our training and then people go on. We provide a place where they can do ADOS training and other specific assessment training.

I think for the CAMHS workers we use a lot of the experience within CAMHS to provide training about treatment, particularly working with complex clients with mental health issues. A really good example is Beth Angus, the ASD coordinator at Orygen youth health, who put together a lovely training manual about how to adjust mental health interventions for young people with comorbid ASD. She comes and trains people around a manual of ideas and activities to do with young people and how to modify mental health treatment.

Mr FINN — My ears pricked up just a tad when you mentioned the western suburbs and the lack of services throughout the western suburbs. What is the differential between the two sides of town? It seems to me that over a long period of time in the west we have been at a disadvantage. Where would you put that disadvantage?

Ms SAUNDERS — So, yes, the west is disadvantaged. In terms of publicly funded ASD teams the western region of Melbourne seems well resourced, because we have got Melton Health doing ASD assessments, we have got the CAMHS team at the children's hospital — the specialist team — doing ASD assessments and there are some assessments available at Sunshine Hospital through their allied health. So there are more publicly funded ASD assessments, but there is not the breadth of other community health and other sectors — paediatricians, private practitioners — in the west that there are in other parts of Melbourne, and the waiting lists are much longer in the western region of Melbourne so our waiting lists are much higher than the other sectors across Melbourne.

There was a map put together for a different inquiry to the Senate around speech pathology and that is the map that I take to every meeting. It puts together the ADI data. Have you seen that map?

The CHAIR — No, but I would like to.

Mr FINN — I do not know if I have, but I would be very keen to see it, though.

Ms SAUNDERS — So the blue dots are where all the services are and the rest is the west of Melbourne. You are welcome to — —

Mr FINN — Yes.

Ms SAUNDERS — They mapped all the publicly available data about where the services need was and you can see that around one side of metropolitan Melbourne there are lots of services and on the other side of metropolitan Melbourne there are not the same range of services. I guess it is just that factor that there are not the private practitioners where people go for alternative assessments and there is not the population of people that can support those assessments, plus you have the higher CALD, non-English-speaking, issues in that area. I very much like that document because having worked in the western suburbs of Melbourne it is very frustrating when you feel: why are our waiting lists longer and other people's are much shorter? It does provide very hard evidence. There is a different population mix, there is a different socioeconomic mix and there just is not the same range. It is black and white: there are not the same number of services there.

Dr RADOVINI — Our colleagues in the eastern suburbs would indeed be seeing the top end of the triangle of complexity and be able to refer to other private providers for more straightforward assessments. That is one of the things that is not easily able to be done in the western suburbs; there are not those practitioners there and families cannot afford to pay. Even if there were, funding would be an issue.

Mr FINN — Moving on from that, I would be interested to know what the differential is between Melbourne and the regional areas of Victoria, because one thing that I have discovered over the last 18 months or so is that country Victoria is not very well provided for. Families with autism in country Victoria are not very well provided for. I would be interested to know, from your perspective, what that differential is.

Ms SAUNDERS — In terms of assessments, it is very clear. In terms of the availability of diagnostic services, the differential is huge, but it differs from regional areas. There are some regional areas, which I am sure you know, that have very high waiting lists. There is one region that has a waiting list of up to two years.

Mr FINN — Which one is that, could I ask?

Ms SAUNDERS — The Shepparton region has a very high waiting list. Bendigo has a very high waiting list — not that high. There are other regions, such as the Latrobe Valley where the waiting list is not very long. It also depends on the number of staff. In one region I can think of they have a small CAMHS team, and they have sent the whole CAMHS team to do ASD training. But being a small team the demands of crisis assessments mean that people get taken away from being able to provide those more specific assessments that they have been trained in. Their waiting list grows more because the demands on the whole service are huge and there has to be some prioritising of services. So it does differ from region to region.

Mr FINN — What percentage of people with ASD have added mental problems?

Dr RADOVINI — It is pretty high, and it often correlates with the intellectual disability from the point of view that if people have an intellectual disability, they have a vulnerable brain, neurologically speaking, and they are more likely to end up with mental health problems — so that is from a biological perspective. There is also then the environmental and social perspective. If you think about kids with what used to be called Asperger's, with their difficulties socially there is the impact of bullying and the impact of being isolated. So the figures — Bruce Tonge did some of that work — are fairly high, but, I am sorry, right now I cannot put a percentage on it.

Ms SAUNDERS — But certainly in the adolescent years the prevalence of mental ill health is much higher in ASD than it is in the general population.

Mr FINN — Are we talking in the 60 per cent to 70 per cent range or lower? Could we get a ballpark figure?

Prof. Dissanayake (from floor) — I can address that. It is about 40 per cent.

Mr FINN — Thank you, Cheryl. Very good of you.

Ms SAUNDERS — That is why we love our academics.

Mr FINN — Yes, they are good, aren't they.

Ms SAUNDERS — They are good at the figures.

Mr FINN — Just one last question, and it concerns the training of emergency services personnel — police and ambos in particular — in dealing with people with ASD. Obviously in many instances they would be the first on the scene. Are they properly prepared for dealing with people with ASD and people who have the problems that ASD provide?

Ms MORKHAM — I think the short answer would be no.

Mr FINN — Okay. Has there been any attempt to bring them up to speed on that?

Ms MORKHAM — Not that I am aware of, no.

Mr FINN — Okay.

Ms MORKHAM — I know with DHHS they have a risk register of clients who are really struggling — their out-of-home risk register. I am not sure if you are aware of it. It would be helpful, I think, for those families where their children are really struggling, they are having lots of police intervention and admissions to the hospital. School is no longer functioning for them. To be able to have some sort of networked meeting at a service level where cases can be discussed and all the various services can actually collaborate together — —

The CHAIR — Similar to what we are doing with family violence?

Ms MORKHAM — Yes, because I think there are those high-needs families where the services really need to be integrated.

The CHAIR — My understanding is VicPol have a review of their disability service provision and training currently underway.

Ms MORKHAM — Yes. So I would be thinking about those children that do not fall into the disability sector in terms of intellectual disability, because I think there is a gap around that group of young people who have normal intelligence because their families are not necessarily getting disability services. Well, in the past they certainly did not get disability services because they were not eligible because their intellectual needs were different, so they often fell into a gap. Were the NDIS — —

The CHAIR — I am sorry, I am just very mindful of time, and we are well and truly behind schedule. I might throw to Christine for some questions.

Ms COUZENS — Thanks for coming along today. You talked a lot about the training. I am really keen to know what the take-up offer is for training, particularly in the regions and the rural areas?

Ms SAUNDERS — So in terms of the training that we offer at Mindful for CAMHS staff, all our trainings are full. It is very well taken up by the regional CAMHS in particular. So I am always incredibly impressed that it is the regions like Warrnambool and Shepparton and north-east and west Victoria — that they are the people that come to the training. They travel very long distances to do that. So the uptake is very high, and all our courses are full.

Ms COUZENS — And Geelong?

Ms SAUNDERS — Yes. I am noticing from Geelong not only CAMHS but the private practitioners are starting to see Mindful as a place where they can find appropriate training in ASD. That has stood out in recent trainings; they are accessing it quite a lot.

Dr RADOVINI — Our concern at the moment is whether we will be able to have ongoing funding for training. We have had preliminary conversations with the mental health branch, but I am not sure whether they will be able to support that training. We have been able to provide training at no or very low cost, which has been, I think, part of the reasons why we have been so successful.

Ms COUZENS — And the NDIS? Do you see an impact in any way with the introduction or rollout of the NDIS?

Ms SAUNDERS — On which?

Ms COUZENS — On your service, on people with autism?

Ms SAUNDERS — Well, I think at the moment we are unsure about how NDIS is particularly going to impact on CAMHS. I guess for us there is a concern about assessments — where the assessments happen, and is that going to put more pressure on our services? On NDIS, I understand children are not supposed to need assessment to access the services, but then I have heard contradictory things saying, ‘Oh yes, they do need an ASD assessment, and at a specific level which is specified in the DSM’. Anything about the severity levels is at the time of the assessment. It is not enduring, so the severity levels 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. So we do not know at this point in time what the impact is going to be on us.

The CHAIR — Thank you so much for your presentation this morning, Liz, Frances and Sandra; we really appreciate it. Thank you.

Dr RADOVINI — Thank you.

Witnesses withdrew.