

TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Bendigo — 17 October 2016

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Witnesses

Ms Rebecca Kelly, and

Ms Susanna Flanagan, Bendigo Autistic Advocacy and Support Service.

The CHAIR — I welcome to our public hearing this afternoon Rebecca Kelly, and I welcome again Susanna Flanagan — Sarah Hansford is an apology — from the Bendigo Autistic Advocacy and Support Service. Thank you very much for attending today. All evidence taken at this hearing 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. Beck, thank you so much for coming along today. It is much appreciated.

Ms KELLY — Thank you for having us.

The CHAIR — Thank you for your very large handout as well.

Ms KELLY — We are comprehensive at BAASS.

The CHAIR — Can I take this opportunity to congratulate you and the advocacy and support group — you have done such an amazing job here in Bendigo to get that service up and running — on all the hard work that has gone on behind the scenes. I invite you now to make a 15-minute contribution.

Ms KELLY — To begin with we would like to acknowledge that the Bendigo Autistic Advocacy and Support Service and the City of Greater Bendigo are on both Dja Dja Wurrung and Taungurung country, whose ancestors and their descendants are the traditional owners of this country. We acknowledge that they have been custodians for many centuries and continue to perform age-old ceremonies of celebration, initiation and renewal. We acknowledge their living culture and their unique role in the life of this region.

Good afternoon. My name is Rebecca Kelly and this is Susanna Flanagan. We are autistic advocates and two of five co-conveners of the Bendigo Autistic Advocacy and Support Service, or BAASS, as we will refer to it in our submission. I am also the parent of two school-aged children, who are autistic. Susanna is the autistic wife of an autistic husband and mother to three incredible autistic children.

Ms FLANAGAN — We would like to thank you all for allowing us to present our submission today to the inquiry into services for autistic children in Victoria. We are a not-for-profit service that is led and driven by autistic adults. We launched BAASS in July 2016 but have been active in the community as advocates and support persons for approximately five years. Our service operates through fundraising and donations. We do not receive any government funding, but we have been very fortunate to have been given a pool of funding from carer support services here in Bendigo.

Our service offers person-to-person advocacy, with human rights being our biggest priority. We offer counselling by qualified counsellors and support for families, children and adults. We welcome local autistic support groups to gather in our building. Programs we currently deliver via BAASS include the Lab Network computer club for autistic children aged between 8 and 17. This club is mentored by autistic adults with a background in computers who are employed by our service to deliver the program. We also run a filmmaking club, which was formed at a school holiday filmmaking workshop that we ran over two weekends at our building, and AsperTeens, which is a support group for autistic teenagers founded and run by myself and my daughter. Sensory gymnastics runs at our local gymnastics club as a funded program for 40 children to attend on a term-by-term basis.

Each person working in our building does so out of a passion for what we do. Our mentors are the only paid staff. We are very proud of what we have accomplished in such a short period of time, and with increased funding we hope to expand even further in developing an employment and apprenticeship program, a school mentor program, workshops, PD sessions for professionals and teachers to learn about autism from a lived experience perspective and a peer support worker program matching the right people to the right organisations.

Keeping in line with the terms of reference, we will be submitting the BAASS perspective on services in not only our Bendigo community but in the broader scope of Victoria. We would like to start with the current state of supports and services within our public and private school sector for autistic children and teenagers, which, in our opinion, is quite dire and, to be blunt, not inclusive of or safe for autistic people. In April 2016 a review of the funding for the program for students with disabilities released its findings and recommendations to the

Victorian state Labor government. This review was aimed at looking at the current funding structure for autistic and dyslexic students in Victorian schools. Twenty-five recommendations were made, with 21 of these accepted and 4 deemed under consideration. It is these four that we wish to focus our attention on this morning. The 11th key finding in the review states:

The year 6–7 review is currently required to reassess eligibility into the PSD and there would not be significant benefits in moving the timing of the review to a year 5–6 or year 7–8 review.

The recommendation is:

Design and implement a new funding model, based on functional needs, that removes the requirement for the year 6–7 review process.

In our personal experience as advocates, parents and autistic adults, this current working structure is inherently flawed. Most autistic children receive their funded support in primary school in grades 1 to 2. This funding does not change until they end grade 6, unless the individual child's needs change. When a new assessment is conducted to determine supports for entering their first year of higher education, the majority of children who have been supported through their primary years do not meet the criteria for supports and some, if not all, funding ceases.

The transition from primary to higher education is hard enough, but to enter into a differently structured education system with different rules and boundaries, higher workloads, an inherent focus on academic skills, a severely dramatic increase in school population, sensory input and output changes and dramatic changes in routines regarding classrooms and new teachers, for an autistic child with little to no support this is starting them with a severe deficit.

Since becoming a local advocate four years ago for our Bendigo autism community, the number of calls from parents and carers who have had children reassessed under the current structure has risen significantly. Autistic children requiring supports that are moving into higher education are being left behind before they have even started. For example, an independent school in Bendigo has a student that is about to transition to year 7. This student has received support in the form of an aide since enrolment in prep. A cognitive assessment was undertaken resulting in a baseline score of 56. The parents have been told already that their child will not receive any supports in year 7, even though the score reflects an intellectual disability. How can this be? This student will start year 7 with absolutely no assistance.

BAASS are working with families to develop educational plans and solutions to take to schools to assist them in providing supports. This includes an autistic perspective on how best to transition a child into higher education through sensory breaks, lunchtime programs based on special interests, information sessions for teachers and support staff, and autistic mentoring programs for autistic children.

Ms KELLY — Key finding 17 of the review was:

The current approach to assessing eligibility for funding through the targeted PSD component is costly, inconsistently understood and applied by schools, and results in inequitable funding outcomes.

The recommendation is:

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.

BAASS understands and supports the argument for needs-based funding. It is also inherently important to understand why the need for functioning labels in regard to autistic people be removed when deciding on this funding. Functioning labels are harmful and perpetuate a stigma around individuals based on a label given to them by non-autistic professionals who have no right to assume ability or inability. The current and past DSM criteria never included the labels of high functioning or low functioning, so why is it that the needs of autistic children in our schools are determined by a functioning label that does not exist in the diagnostic autistic criteria or a cognitive score on a piece of paper?

Under the United Nations Convention on the Rights of Persons with Disabilities, in article 24, titled 'Education', section 2 states that states parties shall ensure:

- (c) reasonable accommodation of the individual's requirements is provided;
- (d) persons with disabilities receive the support required, within the general education system, to facilitate their effective education;
- (e) effective individualised support measures are provided in environments that maximise academic and social development, consistent with the goal of full inclusion.

We at BAASS interpret this as, 'If an autistic child requires support, then give it to them'. Further to this, the *Disability Standards for Education 2005*, part 5.2, 'Participation standards', states:

1. The education provider must take reasonable steps to ensure that the student is able to participate in the courses or programs provided by the educational institution, and use the facilities and services provided by it, on the same basis as a student without a disability, and without experiencing discrimination.
2. The provider must:
 - (a) consult the student, or an associate of the student, about whether the disability affects the student's ability to participate in the courses or programs for which the student is enrolled and use the facilities or services provided by the provider ...

Again, we wish to add that in our opinion the evidence through our experience as autistic individuals, advocates and parents suggests that not enough is being done in our education system to assist autistic children through supports or understanding to achieve the goal of full inclusion and academic success in line with their non-autistic peers. We are seeing a significant increase in severe mental health decline and rates of parents being forced to homeschool secondary to the profound impact that a failing education system has on our autistic children's safety and wellbeing. If the systems were working, there would be no need for an inquiry or countless investigations into schools that are not doing the right thing by their autistic students.

A small sidenote here for informative purposes: the Victorian equal opportunity board and human rights commission receives more discrimination complaints from Bendigo parents and individuals than any other area in Victoria. The use of restraint and seclusion is a go-to method in a lot of Bendigo schools. This also is documented in countless complaints from the Bendigo region. Melbourne disability advocate Julie Phillips, who handles a majority of these complaints, relayed this information to us. Why is that? Is it because the Victorian department of education hides behind regulation 15 of the Education and Training Reform Regulations, titled 'Restraint from Danger'? It reads like this:

A member of the staff of a Government school may take any reasonable action that is immediately required to restrain a student of the school from acts or behaviour dangerous to the member of staff, the student or any other person.

As an advocate when asked to support a child who is a victim of restraint and seclusion, the DET uses regulation 15 in nearly all complaints to explain the reasoning behind its usage. The wording of the regulation is too broad and open-ended, and as a result children are being subjected to prone restraint, martial arts pressure points and being secluded from their peers or being locked into cage-like structures and small non-ventilated rooms for exhibiting behaviours of concern.

We need to work together with schools and teachers to minimise these complaints, as it is not a statistic we as an organisation are proud of or support. It results in long-term trauma, which inevitably either costs the state in lawsuits resulting from the abuse or funded therapy to manage the trauma.

It is integral for the inquiry to recommend autistic mentors and autistic peer workers and counsellors be allocated to all schools, particularly those experiencing difficulty. The current model of Autism Connect programs run through the DET and local schools and Amaze online teaching programs are not giving schools and teachers an adult autistic perspective of what the child is experiencing. Whilst they are effective in some areas, both of these programs are based on blackboard-learned teachings, not autistic experience. Teachers in all school environments require a minimum one-year personal development session facilitated and presented by not only non-autistic professionals but autistic professionals as well. This should be a requirement that is compulsory. BAASS provides this, as does Creating Connections.

Ms FLANAGAN — The final two key findings of the review I have combined, as BAASS feels the response from us would be the same. Key finding 18:

There are a number of benefits from aligning the approach taken to assessing student needs to the approach used under the evolving NDIS. This would assist parents and families to navigate services and supports in and out of school, reduce the administrative burden for families, carers and students, provide a holistic approach to meeting the health and education needs of students with disabilities, and may make the assessment process more efficient.

With the recommendation being:

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.

Key finding 19:

Implementation of a strength-based, functional-needs approach in the process of assessing eligibility and determining funding amounts would improve the capacity of the future disability funding model to meet the needs of students with disabilities.

With the recommendation being:

Develop and implement a strength-based, functional-needs approach to assessing student need, to support the achievement and participation of students with disabilities.

There is a lot that is still unknown regarding the NDIS until full rollout occurs across the state. The one thing that is known is that the NDIS is goal oriented.

Our school education system currently has an independent learning plan structure in place for students with a disability that has the potential and intention to be very focused on goal-oriented skill sets for the student. The problem is that a lot of these plans are poorly written and do not reflect the individual child's needs or goals. Majorities of teaching staff are not consistent with updating their skills on how to effectively write these plans properly. The focus in a lot of these plans is on the emphasis of deficits of the child's current educational performance. Again, a presumption of inability is made based on the child's diagnosis. This includes the mindset of low and high-functioning labels.

For example, two 10-year-old autistic children were attending a special development school. One of the children was non-speaking and, due to motor dyspraxia, was presenting with involuntary movements. The other child was classed as intellectually disabled based on his cognitive score. The children were classed as low functioning. The school's goal for these children for two years consecutively was that they would be able to count to five and know the words to *Baa Baa Black Sheep*. The plan also included the school introducing PECS cards to assist in communication with the non-speaking child, which, by the way, never happened. These are visual cards with words attached to them. There was no functional communication assessment done by the school with a specialist speech pathologist trained in augmentative or facilitated communication, and when the parent expressed that they had tried PECS at home and the child did not respond to them, the school insisted PECS was the only relevant method of communication.

This was a massive failure by the school in a number of ways. The presumption of the teaching staff that these particular children at the age of 10 could not count higher than five is astounding. Because the child is autistic, is non-speaking and has a diagnosis of dyspraxia does not mean they are intellectually disabled. Also, because a child with a low cognitive score falls under the intellectual disability moniker does not mean they are given goals that reflect that of a kindergarten student.

Also, the fact that the school refused to listen to the parent, who identified as autistic, in regard to communication methods for her non-speaking child shows a blatant disregard to the individual child's needs and a detrimental, ignorant and arrogant attitude that teacher knows best. This is also in contradiction of the *Disability Standards for Education 2005*, in particular part 3.5, in which 'the education provider must consult the student, or an associate of the student' about determining an adjustment. Further to this, an associate is defined as per the *Disability Standards for Education*, part 1.4:

associate, in relation to a person, includes:

...

(b) another person who is living with the person on a genuine domestic basis; and

(c) a relative of the person; and

(d) a carer of the person ...

Parents work closely with therapists and are an authority to be consulted and considered in relation to what their child's needs are. The non-speaking child was removed from the school and enrolled in a mainstream educational setting with full aide support. The child's new school takes on board information from the parent, and a functional communicational assessment is now in place with the help of Cathy Basterfield, who is a specialised speech pathologist from Melbourne who works in the field of alternative communication.

The school also conducted an ABLES — Abilities Based Learning and Education Support — assessment. 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.

This particular child has grown academically in an environment that does not treat them as less based on their diagnosis. The new learning plans include more meaningful goals based on the child's strengths, abilities and special interests, and each term the goals are achieved. The parents are linking in with NDIS to provide specialised equipment to assist with communication at school and at home, based on the individual child's needs, and teaching staff are eager to learn all they can about the alternative methods of communication.

Current rollout areas of NDIS are also providing funding for tutors to work with autistic students that are currently not in line with their non-autistic peers in an academic sense. BAASS feels that for situations such as this, and for other autistic students and families who are experiencing difficulties with their individualised learning, by linking schools with the NDIS they will be able to work collaboratively to achieve consistency and reach attainable goals both in and out of school.

We recommend and support changes regarding university training for undergraduate teachers, social workers and psychologists, and we believe medical-based tuition should include a compulsory subject on people with neurological differences that includes components relating to independent learning plans, consistent reporting and sessions presented by autistic adults regarding lived experience and co-occurring conditions.

Ms KELLY — Far too often distressed families and parents who have contacted DHHS contact our service due to intake workers having inadequate training, experience and understanding of the needs, realities and co-occurring considerations of autism and autistic households when reaching out for help and support and due to these workers misguidedly flagging the families as at risk and reporting them to child protection services — CPS. This is not only highly inappropriate but can also have devastating consequences, and it is becoming more and more frequent.

This is also happening in mainstream educational settings. Primary and secondary teaching staff are not provided knowledge in their training that an autistic household has different needs and requires different parenting from a non-autistic household. CPS can be and have been contacted by teachers who do not have an understanding of autism and co-occurring considerations. This often leads to families refusing support and intervention from government agencies due to fear of misunderstanding and of having their children removed from them when all they want and need is some support.

We would also like to see better training and mandatory qualifications in place for educational support staff. For example, in one of the local Bendigo SDS schools an aide was employed to work with autistic and disabled children, whose only work experience was cooking dim sims in a petrol station. This is not acceptable. There needs to be a system in place that requires all educational support staff in all schools to have a minimum TAFE qualification in educational support before being employed. This should include a mandatory placement in a mainstream or SDS school and a component included in the curriculum that includes autism and co-occurring considerations. BAASS is aware that some schools have adopted a policy of employing people with this qualification, but it is not mandatory. This needs to change.

Ms FLANAGAN — Another alarming trend, as briefly mentioned above, is the rise of homeschooling not only in our region but also in Victoria as whole. This schooling option is sometimes by choice, but a majority of the time it is not by choice; there is no other option but to homeschool. This is leaving families at an enormous financial deficit due to the fact that an income is lost with either a sole parent or one parent staying home to

educate the child. Currently the state of Victoria does not offer funding to families that homeschool. This is done at the family's expense and can take a toll.

There is also an increase in complaints being made to CPS by professionals working either in health care, social work or education-directed services in regard to families homeschooling. There is presumption made by these services that autistic children that are not being educated in a classroom are at risk. It seems to be a catch 22 really. Autistic children and their families whose needs and support are not being met by schools a majority of the time have no choice but to homeschool, yet when they do this to prioritise their child's safety and wellbeing and ensure their child is engaged in a meaningful education they are punished for doing so by being investigated by child protection. This not only causes distress and anxiety but also costs the state. The funds for these investigations could be directed into better education and training for staff on how to understand these situations, or funding for a peer support worker to handle these cases.

Ms KELLY — Another important issue that we feel needs to be addressed is the supports available for Aboriginal families with autistic children or individuals who are autistic themselves. There are systemic problems when it comes to cultural awareness within the therapeutic community in relation to the Aboriginal community. To place them all into separate categories for the presentation would take too long. BAASS will make comment on some issues we feel have not been addressed publicly and that we feel are a matter of urgency.

As longstanding allies to the Aboriginal community, and one of our co-conveners identifies as Aboriginal, we are having ongoing discussions with our local Indigenous community about issues they feel are being overlooked. 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.

For example, a local Bendigo parent took her three-year-old child to three different paediatricians because she believed that her child was autistic. The mother does not drink alcohol and does not take drugs, and she was living in a privately owned home and working full time. She was told by three separate doctors that her child was not autistic and on one occasion was told the child just needed a good smack to get his behaviour under control. She gave up until the child was eight, at which time the behaviours became so unmanageable that she was forced to consider relinquishing her child. By this time she had lost her job because she was getting called into her son's primary school so often, and she was unable to work because there was nobody else to watch her son when he failed to attend school.

Finally it was recommended that she approach specialist clinic Time for a Future in Woodend, where he was diagnosed with classic autism, ADHD and sensory processing disorder. There was no funding available to him due to his age, but at least a diagnosis meant that he might receive some supports at school to assist him. It took nearly a year for the Department of Education and Training to fund him for 10 hours a week of aide support, but five vital years were missed because a presumption was made due to the colour of his skin and a mindset about Aboriginal parenting, which needs to change.

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.

In 2014 I, a BAASS co-convenor, did a radio interview with Aboriginal mother and Aboriginal Early Days presenter Jackie French. 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 important for all out-of-home services to be provided with an Indigenous-led service or co-op.

Aboriginal presenters should deliver any Aboriginal Early Days autism information sessions. These should be held within local Aboriginal agencies. Currently Amaze presents an Aboriginal workshop, which is convened by a white Irish woman. This is ineffective and offensive, and it consequently results in limited participants.

Now we come to the recommendations. Recommendation 1 includes the two most crucial recommendations, which are that autistic mentors, autistic peer workers and counsellors be allocated to schools for assistance in the development of individual plans and professional development and that autistic professionals and mentors be included at development and delivery level within all undergraduate studies in health and community services. This must include a compulsory subject on people with neurological differences that incorporates independent learning plans, consistent reporting and sessions presented by autistic adults regarding lived experience and co-occurring conditions for all teaching, social work, psychology and medical-based tuition.

Our other recommendations include: two, that the Victorian state government accept the four current recommendations from the PSD review that are currently under consideration; three, that regulation 15 be completely removed from the Education and Training Reform Act to be replaced by a workable approach that does not involve harm and trauma being caused to the child; four, for all schools to adopt a needs-based funding model in line with the United Nations Convention on the Rights of Persons with Disabilities that has a strong focus on the strengths of the individual child; and five, the years 6 to 7 review process be scrapped and for autistic students funded under the PSD to receive their review from years 7 to 8. This would ensure funded support through the first year of higher education and gain a better perspective on what supports will be required in future years to ensure academic success. DET and schools should engage with autistic mentors assisting in transition and with individualised mentoring programs.

Recommendation 6 is that a system be in place that requires all educational support staff in all schools to have a minimum TAFE qualification in educational support before being employed. This should include a mandatory placement in a mainstream or SDS school and a component included in the curriculum that includes autism and co-occurring considerations.

Recommendation 7 is that teachers in all school environments require mandatory and regular — minimum one per year — personal development sessions facilitated and presented by autistic professionals and any additional non-autistic training. BAASS provides this, as does Creating Connections. Schools and government services should employ adult autistic mentors, peer support workers and autistic counsellors to individual schools and services that are experiencing difficulty, and all statewide autism programs allocated to schools should include an autistic perspective on how to educate an autistic child in the classroom.

Other recommendations include: eight, that every autistic student in every Victorian school should automatically be assessed with ABLES, not just the students whose parents request it; nine, for all state government agencies and departments to remove the use of functioning labels such as high and low functioning, as these labels are harmful to autistics and are not recognised by a majority of the adult autistic community; 10, that a statewide information-sharing model be adopted that allows a collaborative working approach for schools and the NDIS to obtain goals for each child funded for NDIS supports; and 11, for DHHS staff to undertake a compulsory personal development workshop with autistic presenters who will inform and educate them on the importance of understanding an autistic household. We recommend this should be a condition of employment.

Recommendation 12 is that a needs-based funding model be adopted for families who either choose to homeschool or have no choice but to homeschool. This should include a needs-based assessment for each family to ascertain the level of support required for them to educate their child or children in an environment of their choosing without prejudice or fear of being reported to DHHS or child protection services due to a lack of knowledge and understanding of the family's or the child's situation.

Recommendation 13 is that more training and understanding is needed across the healthcare sector in regard to assessment and diagnosis of Aboriginal autistic children, with extended family members and elders recommended to be invited to assessments for cultural and family support, while recommendation 14 is that a cultural identity program delivered by the Aboriginal organisation that is local to the region be rolled out in primary and secondary schools for autistic Aboriginal students as part of their curriculum.

Recommendation 15: BAASS recommends that a scholarship or funded place be made available in tertiary education for an Aboriginal student in regional and rural areas to train in speech therapy, occupational therapy, social work, psychology and education. This will ensure that over time a network of Aboriginal professionals

will build up in these areas to accommodate the cultural needs of Aboriginal autistic families living in the area. Recommendation 16 is that an Aboriginal presenter with not only professional experience but also lived experience deliver any and all autism presentations directed at Aboriginal families as well. State-funded autism organisations should be mindful of the cultural needs of participants and employ Aboriginal presenters for their Early Days workshops.

Ms FLANAGAN — Within these recommendations we would like to briefly touch on the accessibility component of government inquiries as it relates to the needs of the autistic population. BAASS recognises that the processes in submitting statements and presenting at hearings is simply not viable for many, given the barriers inherent in the process. We have sought Australia-wide feedback from the autistic community, parents of autistic children and employees within disability services. We note the limitations of our survey relating primarily to inadequate preparation time.

From our personal experience and drawing from survey responses which were primarily submitted by autistic individuals, our recommendations for improving the accessibility of the government inquiry process for autistic people include but are not limited to: provision of supports to submit to inquiries and to physically attend hearings — for example, support persons, support animals, assistance with children and transport — and having these options publicised and easily available.

The next ones are: providing the option for allocation of more time during hearings for communication differences; provision of a breakdown of submissions into a Q and A format based on a breakdown of the terms of reference of the inquiry; providing adequate time to prepare for presenting at hearings — for example, greater than two weeks; no last-minute time changes where at all possible; help working through a submission at a public hearing by asking specific questions, with provision of these questions before the hearing to enable preparation for responses; flexibility and provision of options for presentation times; employ and involve autistic people in the process; and environment considerations to ensure a calm and sensory-friendly atmosphere.

BAASS wishes to thank the Victorian government for inviting us to give our perspective into the issues faced by autistic individuals.

The CHAIR — Take a deep breath. Thank you very much, Rebecca and Susanna. I have a couple of questions in response to the recommendations that you have put to the committee. Yes, I note some of the concerns in response to our public hearings et cetera, but unfortunately that is sometimes out of our control. But we have, I think, received 148 written submissions to the inquiry, and the majority of those are from people with autism or parents of children with autism, which is really good. We do have quiet rooms available in our public hearings in Melbourne, and we have dim lights. We have a whole lot of good stuff. You mentioned autism mentors and autistic peer workers and counsellors, particularly in schools and in training institutions, to provide an adult autistic perspective. Some of the things we are hearing through this committee are the voices of autistic people who are able to communicate very well, and I am just curious about those people on the spectrum who do not have the ability to communicate their needs, wants and desires, who are being spoken for by others on the spectrum who do have that ability. I just wanted to get your opinion around all of that.

Ms KELLY — My response to that would be that it is not their autism that is actually inhibiting them from speaking; that is a co-occurring condition that is usually a form of dyspraxia when it comes to speaking. But if you actually look under the criteria of the diagnosis for autism under the DSM, it pretty much states that there are social and communication barriers; there is absolutely no mention of speech. These are things that I guess have just been lumped along with autism — what autism is — when the reality of it is that autism and these co-occurring conditions are kind of separate.

We get into conversations quite a bit in some of our online advocacy with parents who try to say, ‘Well, you are not like our children; you are highly verbal’, and it is like, ‘Well, hang on a minute. No, we are both autistic. We both might not have the same co-occurring considerations, but we have the same form of autism’. What I usually say to that too is, if there are parents out there who have a problem with someone who is highly verbal advocating for a non-speaking child, we at BAASS actually have connections in the community with parents who are advocates as well who have children like that. So I guess my answer to that would be to engage with those parents who have that lived experience, which I actually have done in the past, to work with that particular family. As I said, matching the right people to the right schools is important.

The CHAIR — So when it comes to comorbidities, and clearly people on the spectrum often have those comorbidities — in fact, quite a few — in being a mentor or a counsellor or supporting someone with autism, how do you separate out the autism from those comorbidities? Do you know what I am trying to say?

Ms FLANAGAN — I think one of things that comes to mind for me is that we do not speak for these people; we speak with them. There are numerous autistic and non-speaking adults out there blogging about this exact thing, and they say the same thing, that we are all speaking together. We are not speaking for anyone particular person, I think. But it is changing the way you do things as well, working with people with their own individual needs and strengths rather than a whole blanket approach that mainstream tends to take.

Ms McLEISH — I just want to focus a little bit on teacher's aides. You have been quite damning, I would say, about the qualifications and skills of one person who is working as a teacher's aide — —

Ms KELLY — Not so much damning, it is just through personal experience. There are some absolutely fantastic aides that I have worked with.

Ms McLEISH — What skills and experience do you think are most important for them?

Ms KELLY — TAFE qualifications as a minimum.

Ms McLEISH — What is the skill within that TAFE qualification that you see is most important that they get?

Ms KELLY — We are not just talking about autism here when it comes to educational support. A lot of these aides will go into schools and they could have an autistic client, they could have a client with Down syndrome or they could have a client with an intellectual disability. So I guess when we talk about the curriculum, we talk about the curriculum as a whole when it comes to tertiary education — the university subjects as well as the TAFE qualifications. I believe there needs to be a separate component, like a subject that is directed at neurological difference, those people who think differently to others. Autism is one of those sorts of conditions that I think should actually be focused on, because regardless of whether you go to work in an SDS or whether they go to work in a mainstream school, mainstream in particular, you are going to walk into a classroom where there are at least two children who have a diagnosis and then probably another three that are undiagnosed.

Ms McLEISH — So what are the most important skills? You have said the course. What other skills do you want?

Ms KELLY — Empathy and understanding.

Ms McLEISH — Can I have empathy without doing a TAFE course?

Ms KELLY — Yes, but at the same time the ones that we are seeing going into a lot of these SDS schools in particular, they are not understanding, and in my experience as an advocate I am seeing, I guess, disrespectful language towards the disabled students. When a student is a constant dribbler, for example, you get reports of the aide saying, 'That's disgusting. How can you do that?'

Ms McLEISH — Who chooses the aides? Do the parents have any input into the aides that will be working with their child?

Ms KELLY — No, absolutely none, and I think that needs to change too. I should have put that in. But no, there is no choice. It is pretty much that the department of education puts the call out for a job application, they receive applicants, they go through them and they employ the person. If you actually look at the job applications for educational support staff, it is worded quite broadly, I guess. It states that a TAFE qualification is preferred but not essential.

Ms FLANAGAN — I think a basic understanding of disabilities and the different ways of dealing with people with disabilities and the different considerations to have in mind as well, that would be a good thing too.

Ms McLEISH — So if I have had experience because my brother or sister was disabled, I did not have a TAFE qualification but I was quite empathetic, would that be suitable or not?

Ms KELLY — I think a lived experience is a good thing to have too. We are seeing a lot of parents and we are encouraging a lot of parents to get involved with schools as aides, working with autistic children, especially parents of autistic children and especially here in Bendigo, because we feel that they have that level of understanding when it comes to our kids. If they see behaviours of concern, they get it. We are hoping to encourage autistic adults to get involved in applying as aides as well. That being said, you cannot issue a TAFE qualification for one set of people and not for another. I believe that you have to have a nurse's aide qualification to work in a nursing home, so why are we not looking at the same thing for children who are disabled? Why have we not got a mandatory qualification in place for disabled children?

Ms McLEISH — Do you see that it will change with the NDIS, that parents might be able to choose their own aide, or not?

Ms KELLY — From my understanding, and please do not quote me on this — —

The CHAIR — Sorry, you are on the public record.

Ms KELLY — My understanding of the NDIS is that there is a lot of non-involvement when it comes to schools. I have actually questioned Murray Dawson-Smith about certain things that I am able to write up for plans for families when we are submitting them to DHHS and note that you cannot do that with the school involved. The only thing that I am aware of that I think is actually being funded under the NDIS is tutoring hours, and that is if you word it — —

Ms McLEISH — In a particular way.

Ms KELLY — You word it cleverly when it comes to putting in those applications and ensuring that it is goal based, which it is. That is when I guess you can engage the tutors and the schools together through the NDIS. But I think that if there is that consistent reporting with NDIS and the schools, you can have that consistency across the board when it comes to tutoring and what is going on in the school. But I do not think you will find that aides will be funded under the NDIS. I hope they will be; that would be great.

The CHAIR — We do not know what the criteria are.

Ms KELLY — Yes. That would solve a lot of families problems if that were the case.

Ms COUZENS — I have just got one question; I think you have covered just about everything else I want to know. What do you hope the NDIS will bring for the people of Bendigo?

Ms KELLY — In our building we have a lot of fear happening — fear of the unknown. No matter how much we try to run workshops and information sessions about the NDIS there is still a lot that is not known. The biggest thing that continually comes up in conversations is, 'What will happen if my child doesn't get the support they need? What if they get turned down for the NDIS? What will we do?'. We as a service have pretty much gone, 'We'll just pick up the slack, I guess'. My passion is education, and I am hoping that it does cover the supports in education that are required, especially for those families who have kids who are really struggling and they do not qualify for any kind of support in schools. They are the ones we are seeing falling through the cracks. We want those kids who are falling through the cracks to be picked up by the NDIS to get support. I would like the NDIS to really look at homeschoolers as well and funding some form of support for homeschoolers. We are seeing families having to sell their houses just so they can educate their kids.

Ms COUZENS — We have heard a lot of that.

Ms KELLY — This is through no fault of their own; this is because the system has failed their kids at school. You have got to also remember that the minute a family decides — and we talk about the cost to the state — to remove their child from school and homeschool, either as a sole parent as we stated or as a two-income family, it automatically dramatically brings that income down. Now if it is a sole parent, they have to go on Centrelink to support their kids. They can no longer work, and so they then have to rely on the state government to fund them to homeschool their kids. That is how they pay their bills or whatever. If we have some form of plan in place when it comes to the NDIS that can cover some of those things for homeschoolers, then maybe we can actually see that it is all about goals, not only the goals of the disabled person but also the goals of the family as a whole. We would like to see taxpayers coming back to the fold and boosting the state coffers.

The CHAIR — It is about improving services within the state system as opposed to increasing funding for homeschooling, I think, to make sure the system is actually supportive of all children.

Ms FLANAGAN — That too. On the other side of that, there are also the kids that are already too traumatised to go back into school, so you are going to need some homeschooling support there regardless.

The CHAIR — I have one last question. I think it is really important for the committee to understand and know why you actually started your organisation in the first place, and could you just maybe keep your answer to a minute or two?

Ms KELLY — Oh gosh. A few years ago — I have got to keep it short though —

The CHAIR — I suppose I am trying to steer you in the direction of lack of services in regional areas and along that line.

Ms KELLY — Yes, there is. There is a huge gap. The need was just so huge. We had been trying to get it off the ground with the Bendigo Autism Resource Centre, as it was originally named. Things just were not happening. I got a little bit toey around December. I decided to resign my position from the resource centre and start my own organisation up. I invited in five autistic people to join as co-conveners, and we got together. That was around January, and we officially announced our opening. We linked in with Murray Dawson-Smith, who we share the building with — with Distinctive Options — and we opened in July 2016. So it was a very quick turnaround, but we saw the desperate need to open our doors up and have a physical presence.

Our online presence was just enormous. My phone rings off the hook constantly, and it takes time away from my family. You have got to remember I have two autistic kids that I need to parent as well, and by opening up a building and having set times when people could come in and make appointments to see us, we were able to, I guess, create a sense of safety. It is a safe space for autistic adults and children to come into and feel that they can open up to us, and it is also a space for us where we can provide programs and supports, so when we do go to potential donors and funding bodies we can say, 'Well, we have this physical presence in the town. We've already done this. Now we're looking at doing this'. So we just saw a huge need for it. It was something that had never been done before. We have kind of stepped outside the box a bit, but we are really happy about it. I have to tell you, the proof is in the pudding; since we opened our doors we have been flat out. Now I do not know if that is a good or bad thing, but it shows us we have at least 1000 families in our region who either have a diagnosis themselves or have children diagnosed as autistic.

I also wanted to, I guess, along with our co-conveners, change the mindset of what autism is all about and start empowering that generation of kids that are coming through who are being made to feel ashamed of their diagnosis. We are slowly doing that, so we are really proud of it. We are working very well, believe it or not, with schools and in discussions with the department and regions.

I will actually say, just quickly too — because I heard Murray talk about the special needs component and everything — a discussion was actually had with me and a senior member of the Department of Education and Training about two weeks ago, and she told me that the special needs component was actually being removed from the La Trobe University Bendigo primary and secondary education teaching degree, which really worried me to no end. I actually need to get that clarified, but yes, she was saying that she was going to push very hard to ensure that it stayed in.

Ms McLEISH — For what reason would they be removing it?

Ms KELLY — It just came up in conversation.

The CHAIR — There would be no reason, particularly as the state government is pushing to make it compulsory to have special needs training.

Ms KELLY — I know. That is why we kind of made a big point of it, because it really put the fear of God into us.

The CHAIR — Thank you very much for your presentation, Bec and Susanna.

Ms KELLY — Thank you so much for having us.

The CHAIR — We are very appreciative of your time this afternoon. You have given us an awful lot of information. It is much appreciated and will help us enormously.

Ms FLANAGAN — It is the tip of the iceberg.

Witnesses withdrew.