

TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Melbourne — 29 August 2016

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Ms Fiona Sharkie, chief executive officer, and

Mr Braedan Hogan, policy and advocacy manager, Amaze.

The CHAIR — Welcome everyone to the first of the public hearings to be held for the Family and Community Development’s inquiry into services for people with autism spectrum disorder. Under the terms of reference for this inquiry, the committee has been tasked with examining service provision for people with ASD in Victoria at local, state and commonwealth government levels. The types of services to be examined include health services, housing, employment, education, and disability services. The committee has also been asked to consider the likely adequacy of services to be provided under the national disability insurance scheme and the prevalence rates of ASD in Victoria.

The committee made a call for submissions late last year, and submissions to the inquiry closed in April this year. The committee has received almost 150 submissions to the inquiry. Many of these are from carers and parents of people with ASD and people with ASD. The committee has also received submissions from peak bodies, health professionals, educators, local councils and disability advocates. The committee wishes to hear from a broad range of stakeholders — as many as possible — for this inquiry.

Unless confidentiality has been requested, all submissions to the inquiry will be published on the committee’s website. The hearings being held for this inquiry will be conducted wherever possible as hearings open to the public, and with the transcripts from these hearings being made available on the committee’s website as soon as possible after the completion of the hearing. The committee intends to hold hearings in Melbourne and in regional Victoria. Please see our website for details of upcoming hearings.

These proceedings today are covered by parliamentary privilege and as such nothing that is said here today can be the subject of any action by any court or to any proceedings for defamation. If you have any special needs today, please see the committee staff, who will assist you. We have made available a separate room as a quiet room if anyone wishes to make use of that today. That room is G5 and is just down the hall from this room. Again please see our staff if you require assistance. Today we will hear from a range of people, including parents and carers and people with ASD. We will also be hearing from peak body Amaze and from health professionals and leading ASD researchers.

I now wish to call our first witnesses. Good morning. I welcome to these public hearings Ms Fiona Sharkie, CEO, and Mr Braedan Hogan, policy manager from Amaze. Thank you for attending here today. 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 would like to invite you to present for around 15 minutes to the committee.

Ms SHARKIE — Thank you, Chair. I would like to begin by acknowledging the land on which we are meeting today, the land of the Wurundjeri people of the Kulin nation, and pay my respect to elders past and present and any Aboriginal people here today. Amaze would also like to thank the committee for inviting us to be part of the hearings, and, as the peak body for people on the autism spectrum and their families in Victoria, we have a 25-year plan to achieve greater social and economic participation for autistic people in this state. In preparing our submission to the inquiry we consulted widely. We had more than 500 members of the Victorian autism community provide input into our submission, and we are very proud to be representing those comments and those people today.

So our main aim for this next 15 minutes is really to provide the committee with what we consider our five priority areas for action to improve the quality of life for autistic people in this state. I am sure, with your wide reading of the 150 submissions, it is no surprise that the gap in life outcomes for autistic people and those without a disability is stark. Some 8 in 10 autistic students do not complete school, which is a pretty harsh indictment given the educational policy of most governments in this country of year-12 completion rates being about 80 to 90 per cent. One in three autistic people are engaged in the workforce compared with 53 per cent of people with a disability generally and 83 per cent of the population. We estimate that employment participation for autistic people is the worst of all people with a disability, and the life expectancy gap for autistic people is 16 years. Clearly these statistics paint a picture of huge, high social and economic costs at both the individual and family and systemic level.

In terms of our five priority areas, priority one we have identified is really improving community attitudes and behaviours. We know autistic people and their families face discrimination and stigma every day, either directly, indirectly or structurally. Whilst we have made considerable gains in recent decades for people with physical disability — you do not go into a building now without having ramps, you do not go into a lift without it having Braille on the lift buttons — we need to now consider what are those equivalent ramps and rails for people with non-physical disability and autistic people.

We recently, just in July, commissioned some research through Essential Research where we surveyed 1000 Australians and found that more than half of those people surveyed had a personal connection with autism — 5 per cent of them said they were on the spectrum themselves, but 14 per cent either went to school with somebody on the spectrum or 16 per cent had worked with somebody on the spectrum. So it is no surprise that there was an enormously high level of support of the need to improve community understanding and its capacity to support autistic people. Almost three-quarters of those surveyed agreed that autism and associated behaviours are still very misunderstood, and that schools, workplaces and the wider community need to gain a better understanding. Yet only 29 per cent agreed that they personally had a good understanding of how to support people with autism. So we have a big job to do at Amaze and all of us present here today.

We have already worked with a number of organisations to build their skills in creating autism-friendly environments. Museums Victoria has completed its ASD-friendly work, and it is an absolute delight to me that there has been 7000 downloads in six months of the sensory-friendly map of that museum. Village and Hoyts cinemas have been showing sensory-friendly movies for children and are now considering extending their sensory-friendly movies to adult movies, which is great. Northland shopping centre, to our knowledge, has the world's first quiet room in a retail shopping centre, and 300 people are registered to use that room. Local councils and Parks Victoria have just completed some work in sensory-friendly playgrounds, and the nurses and midwives federation.

So there is movement afoot, and, with half of our population having a personal connection with autism, there is a huge opportunity to harness that personal connection and ambition to improve in a number of public domains, whether it be public transport, health, public buildings and things, but we need to now do more. It is great to hear that you have a quiet room here today. We know, for instance, that there are eight breastfeeding rooms in any shopping centre but no quiet rooms. So could a building — every building — have a quiet room? We could all use a quiet room, I think, from time to time but particularly people on the spectrum. So I am handing that to my colleague Braedan for our next priority area.

Mr HOGAN — Our second priority area is improving access to assessment and diagnosis. It goes without saying that the earlier a diagnosis can be provided for somebody on the autism spectrum the sooner the appropriate supports can be put in place to improve their quality of life and improve their participation and also contribution to the broader community. That goes for not only autistic people but also their families and carers. This is true at any age. The Olga Tennison Autism Research Centre, which I know are speaking later today, recently reported that 1 per cent of children in Victoria are on the autism spectrum, yet Australia-wide we have no accurate or up-to-date population-based prevalence data. We currently have some, which are based on ages, but no population-based prevalence data.

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

However, access to diagnosis currently imposes a number of issues in Victoria, including the inadequate knowledge and understanding of and no uniform approach for health professionals to diagnose and identify the early signs of autism. There is currently a lack of understanding of autism in its presentation in front of the primary healthcare professionals, such as GPs and community health nurses, whilst there is also no nationally consistent diagnostic standards across Australia.

There also seems to be a reluctance of paediatricians and paediatric psychiatrists to diagnose autism under the age of three. Present research is showing now we can actually diagnose from about 12 months, yet there is a hesitance within the public health system, preferring an option of ‘wait and see’ if this does develop into autism, where we see lost time. Other issues are long waiting lists for accessing diagnosis through the public health care system — up to two years in some cases; poor access to diagnosis in regional areas — these waiting lists are often exacerbated in regional areas; and then the cost of diagnosis through private diagnosticians due to the public system being inadequate. We have reports of costs of \$2750 for a diagnosis, yet recent research by the Autism cooperative research centre puts the mean cost to about \$580 per diagnosis. And also through the diagnostic process there is a lack of clear and concise information available to support the family as they investigate and navigate their way through this process.

So what we see as needed is a comprehensive and resourced access to diagnosis strategy, which includes affordable and timely access to diagnosis, irrespective of locality, financial status and age; independently funded information and support services to assist individuals and families gain an assessment at a number of referral points, including early childhood facilities, schools, GPs et cetera; and nationally consistent diagnosis standards.

Ms SHARKIE — Our third priority area we have called ‘education for all’, where ‘all’ means ‘all’. I am quoting the Deputy Premier, James Merlino, on all means all, and we intend to hold him to that. As we mentioned earlier, it is completely unacceptable that 8 out of 10 autistic students do not finish school, and we know why that is, autistic students are more likely to be suspended or excluded and to be the targets of bullying. They will suffer depression and anxiety during school. But the data we have found on the underperformance academically relative to other students is interesting. Prof. Jacqui Roberts, an academic in Queensland, found that 54 per cent of students with autism who do not have an intellectual disability were rated by their teachers as underperforming relative to 8 per cent of typically developing peers. So that means that these students have the capacity to perform, but are not given the right environment or the right teaching approach in order for them to achieve their potential.

We also saw from ABS data that 95 per cent of autistic students experienced educational restrictions, and 86 per cent reported having difficulty at school, and mostly that is to do with autism, about fitting in socially — social communication and interaction. In our own consultation, 15 per cent of respondents told us that their children are either partially attending school or not attending school at all, and, not surprising, homeschool rates are increasing for autistic children, which presents a double economic disadvantage, both to that child and their future earning capacity and the parents being out of the workforce.

So what needs to happen? We are very encouraged that the government has a special needs education plan. We were an active participant in the review of the program for students with disability and saw the 25 recommendations that were made, and it is critical that the government accepts the final 4 recommendations that are yet to be adopted.

What needs to happen in education is in three areas. Very clearly, we need to build the workforce capacity for teaching autistic students in all schools — mainstream schools, specialist schools, across the domains. Principals, teachers from the top down — all school staff — need professional development, and not just didactic, one-way through online learning that is currently available, but actually in situ, where teachers are shown how to teach autistic students. We need to create autism-friendly built environments in schools, both in and out of the classroom. We also need to review the funding to support autistic students. In 2015, \$659 million was spent on the program for students with disability. We do not believe that funding is well spent. It is outmoded and outdated, and it needs a complete overhaul to create a strengths-based and functional needs-based model. So that money could be better spent, and there are ways to do that.

It is critical that the education department develop a formal relationship with the NDIA to maximise the alignment. We can see trouble coming down the road when autistic students will be given supports, therapeutic supports, that will or will not be allowed into the classroom, and unless the schools adjust to support autistic students, it is very likely that the investment by the NDIS into autistic students will not be maximised, because the NDIA will get the students to the school gate, but once they get into the school there needs to be that support carried through, and we are not seeing a great deal of cooperation at that level to date.

Thirdly, what our community told us very loud and clear through the PSD review was: accountability, accountability, accountability. How are we checking the progress and achievement of autistic students who are

receiving disability funding and reporting on their educational outcomes? For students with disability we know the data is collected, but we never see it reported. We do not see any transparency around there, and it is absolutely critical at the student level, at the school level, at the region level and at the state level. So the call for accountability was very strong.

Mr HOGAN — Our fourth priority area is employment and pathways to employment, such as volunteering. For people on the autism spectrum, they experience poorer outcomes in relation to workforce participation. Approximately one-third of autistic people are employed, which is much worse than other people with disabilities, which currently sits at about 50 per cent. This also has a broader impact, from a statewide, economic perspective as well. Within our submission and our survey, 20 per cent of respondents have been able to find employment, yet 94 of those respondents reported that they had not received enough support in helping them find a job. We also asked if people would like to be offered volunteering opportunities as a way to build their skills and experience; 69 per cent indicated they would. There are prevalent attitudinal barriers, which act as a barrier for people on the autism spectrum gaining employment.

We often hear common myths and misbeliefs often cited by employers as to why they do not want to employ people on the autism spectrum. These include assumptions that autistic people will be less capable employees than others; perceptions that they will be burdensome or costly to provide any required assistance, modifications or adjustments in the workplace; and beliefs that they do not have the capacity, experience or skills to employ autistic people. There is also an inherent power imbalance once autistic people are employed between them and their employers to ask for flexibility and adjustments within their workplaces once they have achieved a role.

Our recommendations within our submission reflect earlier comments about the need to upskill the broader community to understand how to better support autistic people in employment. This includes capacity and skill-building for employers on how to best support employees on the autism spectrum, including the development of accessible resources to support the training; development and provision of accessible information regarding rights, responsibilities and services and supports for employers of autistic people, such as reasonable adjustment programs, which are provided by the state and federal governments. Leadership from the Victorian government itself, shown by hiring people on the autism spectrum, and developing policies to support diversity in the workplace; and the Victorian government can also facilitate and incentivise additional volunteering opportunities specifically for people on the autism spectrum as pathways to employment.

Our fifth priority is achieving the aspirations of the national disability insurance scheme. We acknowledge the NDIS is the largest single piece of social policy reform since Medicare, which has the potential to change the lives of the majority of autistic people within Victoria and Australia more broadly. When we asked the autism community about their feelings about the national disability insurance scheme, 95 per cent responded that they had heard about the NDIS, whilst only 13 per cent said they had received enough information about the NDIS, and 14 per cent felt they were prepared to enter the NDIS. There is a clear gap within the community about what information is out there and what the NDIS is about, which currently causes an environment of fear as well with inherent changes which will be occurring.

Currently within the NDIS, autism is the largest single primary diagnostic group of any group of participants with plans, representing 31 per cent of participants nationally. When we look at the cohort-based trial sites in South Australia and the Nepean Blue Mountains, which are focusing on zero to seven years, this is increased — up to 50 per cent of participant plans.

We welcome the child-specific response that the NDIS has developed through the ‘early childhood early intervention’ gateway, so that children and their families will have lower entrance requirements to receive information and support to gain access to the NDIS prior to necessarily having a formal diagnosis, so when signs of developmental delay or global developmental delay are shown. Critical to these being successful is that these services have the expertise and experience in identifying global developmental delay and developmental delay and the early signs of autism to quickly identify those children who are very clearly autistic and can be referred to an NDIS plan without delay and have autism-specific responses put in place. Amaze recognises that not all children from the early childhood early intervention gateway will need to enter the NDIS, but the trial data proves that the greater proportion will, and it is essential that these children receive the appropriate level of support at the earliest possible stage of their journey.

What is needed is a number of issues. On NDIS readiness, as I said earlier, a very significant proportion of the Victorian autism community do not have enough information about the NDIS, so we are wanting the development and distribution of accurate, detailed and accessible information on the NDIS, specifically in relation to autism, given it is such a high proportion of participants, with specific materials provided for culturally and linguistic diverse communities but also Aboriginal communities, along with pre-planning support to include access to participants who have already gone through the NDIS to provide those peer-to-peer stories and support. The workforce is also a massive consideration when we are talking about doubling the amount of funding available for disability services but also having a level of autism-specific expertise. We are asking for the NDIS and its partners — so the local area coordinators and also the early childhood early intervention partners — having an adequate expertise and experience in autism, including identification of the early signs, when diagnosis should be made, evidence-based therapeutic and clinical autism interventions as well.

With the increasing workforce there is already currently a shortfall in skilled allied health professionals with autism-specific expertise, so there needs to be a significant increase in these and a response from government to stimulate the production and availability of adequate allied health professionals. This is again exacerbated in regional and remote areas around Victoria. Also the development and open accessibility of autism-specific training and capacity building to registered providers of supports is needed, so that they have an autism-specific understanding.

We also see that potentially in regional Victoria there will be some issues about providing adequate services in a market-based system. Therefore we are asking the Victorian government and the National Disability Insurance Agency to investigate alternative funding models to stimulate and support these services in regional Victoria, and also potentially innovative service delivery models, such as the use of telehealth, for example. Quality and safeguards are also very, very important, and we are asking that all staff delivering disability services be required to undergo initial and ongoing training relating to the prevention of abuse, neglect and violence towards people with a disability.

The NDIS itself will only see and maximise its potential if it works well and in alignment with the other service systems, such as education, health, employment et cetera. So we are asking that the Victorian government work with the NDIA to define the interface between the NDIS and these other service systems, including health, mental health, early childhood, school education, higher education, employment, justice and aged care, and to optimise and reach the maximum potential of the NDIS. That is a critical element for autistic people who will receive NDIS funding and those who will not.

Ms SHARKIE — So they are our five recommendations, and once again we thank the committee for having us present this morning. Our submission contains 60 recommendations that are derived from analysis and synthesis of current and emerging evidence; in fact we asked for an extension, I think, of five days because a piece of evidence came through that week. So we think it is pretty contemporary but most importantly it involved extensive consultation with our community.

I guess we would just leave you with this: the work of this inquiry is really important to us, and I think we should all be encouraged that more than 50 per cent of the population have a connection with autism. That is a significant force that we can draw upon really to drive our collective agenda forward and make the world a better place for autistic people. We wish you well in your deliberations.

The CHAIR — Thank you very much, Fiona, and thank you, Braedan. Yes, we were very pleased to receive your submission. The 60 recommendations within that were very comprehensive and, as you would be aware, this inquiry is quite extensive and covers quite a large range of areas. I think that for me in particular, as the government ambassador for the special needs plan, my particular interest is in education, and I would like to perhaps ask if you could elaborate on some of the areas around education. You mentioned the challenges facing students with ASD in the education system. I wonder if you could perhaps detail those.

Ms SHARKIE — Yes, thank you, Chair. We had a speaker at our conference two years ago who said she had met teachers who say, you know, ‘I’ve been teaching for 30 years and I know how to do it’. And her comment was: ‘Yes, you’ve been teaching the same way for 30 years and it requires something different’. And we know that every child or every student on the autism spectrum will be different, and so, if you are a teacher that did well with an autistic child last year, it does not mean you will do the same thing this year. So it is very specific, and individual responses are required.

Really the five areas in which we see the school system really working is understanding — that principals and teachers understand the legislation, about the disability standards for education, which is under the Disability Discrimination Act federally — that every student in the country has the right to go to school. We talked before about children who are just not even going to school or only going for a couple of hours of the day because the principal or the teachers has determined that. That is actually not within the realm of the law. So, one, I think that is important. Secondly, it is very clear — and again we have consulted with the Australian Education Union — that teachers and principals do their job because they want to teach students. We have ultimate belief and faith that those educators want the best for students, but they are not equipped to know how to teach autistic children, by and large. There are pockets of good practice that occur, but there really needs to be extensive training. Again with the PSD review, there is mention of that — that there will be training for principals — the leadership level; everything starts at the top — and training for teachers, but we do not want to see that as the current online training tool that is offered to teachers, which is again one way. Teaching autistic students does require some really, as I said, in-school classroom support to help teachers understand that and embed it in the wider school system.

So it is the laws, it is training for teachers, it is the parent, teacher and student collaboration and communication. Where we see really good practice is when parents feel that they can come in regularly and consult with teachers. Parents know their children really well and they are a fantastic resource for teachers to be able to better support. Again, where that works well it works really effectively.

The final one is again about accountability and teaching teachers how best to support. Any student with a disability is entitled to have an individual learning plan, but we are finding that teachers do not really know how to write an individual learning plan that is meaningful and one where you can see progress. Bernie is nodding in furious agreement here. So they need help in even developing those plans and then we can look to see what the progress is. So again it comes to teacher training, but also that accountability. How do we measure if that \$659 million is being well spent and being converted into actual learning outcomes for students? Again we see fantastic practice. I am saying that this is not just at mainstream schools; this is at special schools as well. Often special schools are set up for children with intellectual disability rather than having knowledge of autism, so they also need knowledge of autism.

I have been spending time this year visiting the Northern School for Autism, where I see fantastic practice happening there. Every child there has an individual learning plan and every child there is learning. It is fantastic. They are not just being minded.

The CHAIR — So given that range of concerns that you have, particularly in relation to specialist schools for children with ASD, do you have a view on the benefit of creating specialist schools specifically for students with ASD, and do you think that autism inclusion schools such as Moomba Park Primary School are a useful model?

Ms SHARKIE — I think they are all good models. I think Amaze first and foremost would support inclusion in mainstream schools as being the no. 1 priority. The international evidence attests that this can work but only if the schools are equipped to deal with it. That is the caveat. It should be mainstream. There will be a need for a smaller proportion of autistic students to be in a special school environment, but our main priority — —

I do not know, Braeden, whether you would like to add further on that?

Mr HOGAN — I think that overwhelmingly the international evidence shows that mainstream education is most beneficial if done appropriately, not only for the students with disabilities but also for the other students. When we talk about changing cultural and societal views of autism and disability more broadly — if we do see classrooms that reflect our community, then we do not necessarily inherently enshrine those stigmas as people grow up. Yet I do think that methodologies such as reverse integration from special schools and mixed enrolments into mainstream schools as a child integrates in reverse to a mainstream education environment does work very well. But I think that, as Fiona said, there is that caveat that schools have the appropriate capacity, that they have an inclusive culture and they foster that. They can have high expectations for students on the autism spectrum, but they should also have the funding and the resources to support them appropriately.

The CHAIR — Do you think incorporating student-teacher training into the autism specialist schools, or even into mainstream schools, would be a good way for training teachers to learn about children with ASD as a learning model, so, for example, a university collaborating with specialist schools or mainstream schools?

Ms SHARKIE — Yes, I guess there are two sides to that. There are teachers in training who are going to go through the university system, and currently in Victoria there is no requirement to have any special needs education training. There are debates from academics on both sides of that about whether you should or should not, but I think the parent community would certainly say they need to know more about ASD. But teachers in training are obviously a very small proportion of the vast amount of teachers who are currently teaching in schools now. I guess we have a slight concern about a proposal where specialist schools might train mainstream schools. The concern we have about that is the potential of using a segregated specialist school approach when we want to build an inclusive approach and whether they are the best people to do that. There can be certainly learnings about how to support students with autism, but I think it needs a broader inclusion-based focus rather than a specialist school one.

Ms McLEISH — Thank you for coming in and for having us out there as well. I have just got a couple of questions with regard to your relationship with the medical profession and how closely you work with, for example, the Royal Children's Hospital or the college of general practitioners, because a number of issues that you have raised are about getting this diagnosis up-front and perhaps some of the GPs, for example, are not fully versed on ASD.

Ms SHARKIE — In terms of how we would serve to upskill?

Ms McLEISH — No, how are you working with them now?

Ms SHARKIE — As Amaze is the Victorian provider for the Helping Children with Autism package, we are taking about 2300 newly diagnosed families each year that we support. They come in to us and they have had a diagnosis. The experiences that they have had really range between the knowledge that their GP might have to even the knowledge that their paediatrician really has about ASD. From that vast number of families — and again anecdotally — we would say that the information is not consistent out there, and that is why one of our recommendations is that there does need to be nationally consistent standards for how you assess.

Ms McLEISH — Okay, my question is more around: what are you doing to interact and engage with the college of general practitioners — —

Ms SHARKIE — We are not currently working with the college of general practitioners.

Ms McLEISH — Not them specifically.

Mr HOGAN — In 2008, when the Helping Children with Autism package was developed federally, there was an element of that package to actually develop and increase the understanding of autism through an on-line training module, which was owned by the AMA and the RACGP as well — to increase the capacity of the medical professionals, particularly primary health care professionals, so general practitioners, and increase their understanding and knowledge of autism. I guess with anything within the medical profession it does require a prolonged, sustained approach, and these things do take a long time. I guess from the general practitioner's perspective there are 100 things coming in the door that they need to be across. Because we are a state body and the AMA and the general college are federal bodies, we are not currently doing anything with them.

Ms SHARKIE — I guess the wider thing, Cindy, on that is that with the NDIS early childhood early intervention gateway anyone can refer into that. So you can self-refer in, you can be a teacher that refers in, a maternal and health child nurse that refers in, or whatever. So you are going to get a much broader referral system coming in and that is why it is so critical that the people who work in those gateway areas really know what they are looking for, because our concern is that children are going to turn up there who are clearly autistic and have not been identified as such and may waste one, two or three years without getting an early enough intervention straightaway.

Mr HOGAN — I think also, and I am sure OTARC will talk about this later, that their developmental surveillance approach through the maternal and health child network on capacity has shown wonderful and extreme results.

Ms McLEISH — What is the uptake from the maternal and child health nurses?

Mr HOGAN — Well, I think it is subject to funding, and I am not 100 per cent across it.

Ms McLEISH — How many people are accessing it from maternal and child health?

Ms SHARKIE — You mean the training itself?

Ms McLEISH — Yes.

Ms SHARKIE — Again, I would hope we will be able to comment, but my understanding is that they trained 200 to 300 maternal and child healthcare nurses some years ago. I do not believe there is current work happening in that area. But the 1 per cent prevalence figure of autistic children in Victoria is higher than other states. Victoria has the highest prevalence from that OTARC study, and we believe that the maternal and child health training has probably something to do with that — that they are really identifying earlier and referring through.

Ms McLEISH — On that, can I get a comment — this is from one of the submissions that we are hearing from a bit later, which states that:

It is possible that funding arrangements that require a diagnosis for entry to services have contributed to an increase in diagnosis of autism.

What do you think of that?

Mr HOGAN — I think that obviously inherently where there is any funding available there will be an attraction towards that. Those claims have been made for a number of years, especially since the Helping Children with Autism packages have been around, since about 2008. I do know personally that the federal government did investigate a number of those claims. They were found to be unfounded — they were not necessarily accurate. Also the Autism CRC in their recent report on diagnostic practices, which considered and spoke to diagnosticians about this specifically, found that there was a small level of diagnosis where it necessarily had not been to access funding, but it was not in any way prevalent. I do not have the statistics in front of me that the CRC's paper actually quoted, but it is available there and it is evidence based as well.

Ms COUZENS — Thank you for coming along today and for your comprehensive submission. I know we have got limited time, so I have got a couple of quick questions. You talked about engaging employers. How would you actually do that? Have you got any ideas on how you would actually engage employers, apart from the general overall campaign — whether there are some ideas around how you would actually engage them?

Ms SHARKIE — Good question. We have been talking about the need for helping employers. Employers are not necessarily in the business of employing people with disability or anything — they are in the business of banking or they are in the business of museums — but we were saying earlier that they have graduate programs and they have all kinds of programs. I would be prepared to say that I think most employers would like to make a contribution in this area and hire people with disability. What they say is: we need to know who they are, how can we have a ready source of supply and what do we need to do to be able to have them come in.

One of the things that concerns us constantly is the notion of equity versus equality, where employers will say, 'I'm going to have you come in and work for me, but I'm not going to treat you different to anybody else'. And we say: 'Well, you have to treat them different to everybody else because they are not like everybody else and will need adjustment'. So I think it is training on both sides. I think practically speaking it is about: how do we start to identify organisations that we can showcase? There are a number of organisations now, such as Specialisterne here in Victoria, that are working with the commonwealth government. There is a food chain, Fonda, that is working with some autistic young people about entering employment. So I think it is about showcasing those, but the training has to go in. It is not a case of just saying, 'I'm going to give somebody a job'; it is about the support that is built around them, and that needs to happen.

Also with the Disability Employment Services, by and large we get very poor feedback about them — very, very poor feedback. We do not think they are equipped in understanding what autistic means. So even the employment services do not really understand. We are now working with more specialist employment services like EPIC, which has just come into Victoria, that are actually really focused on getting autistic people jobs. But

the Disability Employment Services often will focus on acquired disability. It might be a workforce injury that is rehabilitating people. It is very different to working with people who have a lifelong disability. So there is a lot of work to be done in, again, community attitudes around that but training and skilling up those organisations.

We do a lot. I will quote a woman who was being supported into employment, who said to her support organisation, ‘You know, you guys are the ones with all the skills. Why do we have to do it all? Why aren’t you doing something?’, and I thought it was a really well made point. It was saying: ‘What do you need to do to skill up? You are putting all the focus on me having to perform here, but what about you?’, and I think that really needs to happen.

Ms COUZENS — The other point I want to make is that a lot of the feedback I have had from my electorate from parents with children with autism is that there is inconsistency with schools, which seems to be a big problem, and I am sure that is not just in my electorate.

Ms SHARKIE — No.

Ms COUZENS — But one of the things they have said there is a very clear lack of support in is the change from kinder to primary school to secondary school and in some cases, if they get to it, tertiary education — that lack of support and, I suppose, the walking through that progress. In fact there are some schools that have actively worked against the parents and the child in providing that support. I just want your views on that and how we might address it, because I would suggest that is very support intensive.

Ms SHARKIE — I guess it is and it is not. That is called ‘transitions’, which are very difficult for people on the spectrum — transitions into work or any transitions at all. Going from child care to kinder, from kinder to school, from school classroom to classroom, from room to room and everything — they are all transitions that really need focus. Most children will have some kind of introduction to the next school that they are going to, but it needs to start much earlier with children on the spectrum and go for much longer in those — the introduction into the next classroom, to carrying that through. It really is difficult. I know with typically developing children it is a bit of a fraught experience as well, but support is absolutely imperative for transitions. That is what people on the spectrum will tell us themselves: ‘Transitions are really hard for me’.

We really believe — and it might be Pollyanna or Cinderella — it really is about attitudes, because where we see it works well is a leader in the school saying, ‘We are going to do this’ — and thinking about it and engaging the parents and staying there for the distance and seeing them move into secondary school. But it needs to start in grade 5, not in the last term of grade 6.

Ms COUZENS — But you need the expertise within the school, though, for that to happen, do you not?

Ms SHARKIE — Yes, but again it goes to that training, and it is just about formalising programs to do that.

Mr HOGAN — And the receiving school as well. We are making headway in primary schools, but secondary schools is a whole other kettle of fish. Obviously, if you imagine, primary school is a lot more rigid, going into a lot more, kind of, having to find classrooms than secondary schools, but I think the other — —

Ms COUZENS — My experience with secondary schools is that what they are saying is the money is attached to the school, the support funds, so where a young person at secondary school is going to do maybe a VET course at the TAFE, that support is not following them —

Ms SHARKIE — It does not extend there, yes.

Ms COUZENS — which has created some huge problems.

Ms SHARKIE — Yes.

Mr HOGAN — Yes, and I think it goes to your previous question about work as well, transition to work. There are pockets of good practice — they do it very well in New South Wales — but it really does need to start in year 8, year 9, and then follow them through, talking about what post-school options are so they transition smoothly into that employment option and what they want to do whilst getting qualifications, but what is appropriate for them. Unfortunately we do not see much of that in Victoria.

Ms COUZENS — Thank you. I have a few more, but I have to — —

The CHAIR — We could sit here all day and ask you a lot of questions.

Mr FINN — My apologies for being late a little earlier. Yes, we could be asking questions all day, without doubt. There is one thing that has constantly confronted me as I have gone around the state over the last 18 months — and that is, parents who say to me, ‘Every morning I have to get up knowing that I have to fight for everything that my child will get today, and I have to do that every day, every week, every month’. Now you may have answered this question with the word ‘attitudes’, but where do we start to change the way people with autism are treated, and particularly their parents and the families of those with autism. Where do we start to change that?

Ms SHARKIE — One of Amaze’s priority goals in our strategic plan is around changing attitudes and behaviours and measuring that. We will be conducting some research this year around that, around community attitudes. We have seen some very good work in the UK that has just been done, released on World Autism Awareness Day, where there was a study conducted of community attitudes, the wider community attitudes, and their knowledge of autism — how autism presents, what it looks like on the street and if you saw somebody with autism, would you know what to do — backed up and bookended by a study of autistic people, their families and their medical professionals, saying what they saw the differences were.

What people with autism and their families said is the worst thing that they can have is what they call the ‘tut-tut’ in the environment — you know, ‘Bad parenting. There’s a kid, you know. They’re bad parents’. That is the worst thing that they could do. So that is again about telling people that is the worst thing and telling people what to do when they see someone who is overwhelmed or distressed that has autism and how to support them. It goes to again how do we skill up the wider community to do that, and we are doing that in these places.

We do hear good stories of families that say, ‘My child was overwhelmed in a retail shop. The shopkeeper was looking at me disapprovingly. I said my child had autism, and suddenly they went, “Oh fine. What can I do?”’. So it is about really having to say this is what it looks like, this is how you can help and this is how you can be supportive, and saying tut-tut and looking down at people and casting that stigma and judgement is not helpful at all.

I think the other thing we want to do is work on the media, because reporting of autism has gone like that. You cannot record that, but it has had an exponential rise over the last 10 years. But as more reporting has happened, we have seen a greater proportion of negative stories. We have to reverse that, so we have to start turning that around. You know, how many stories do we see about a boy in a cage or that an autistic person has been involved in some terrible crime or something, which, by and large, is usually not true? So we really want work on the media as well. We are talking about developing a media kit for using the correct language about people with autism. Autistic people do not suffer autism. It makes it sound like a disease. It is not. All that negative language is something that we have to work with.

Mr FINN — That steps into another area that is quite a big one actually. I made a mistake, I think, some time back of suggesting that there should be a cure for autism and that we could find a cure for autism, and a section of the autistic community arced up on that immediately and said, ‘We are proud of being autistic. Why would we want a cure?’. We have got people on that end of the spectrum who are very proud and regard it as very much part of their personality and who they are, and you have got people down the other end of the spectrum who are suffering literally. Families are suffering every day as a result of autism. How do we bridge the gap here? I have been wrestling with this for quite some time. I do not think I am any closer to an answer than when I started. How do we bridge the gap between both ends and of course the even larger group in the middle?

Ms SHARKIE — I wish I could give you the answer today, Bernie, but I do not think I can. The comment I can make is that certainly the community is divided, I think, as you describe, but autistic people, certainly our community, are very strong in that we do not need a cure. We have autistic members of our community saying, ‘Don’t eugenics me out’. I understand scientifically there will not ever be an antenatal test, as with Down syndrome or whatever, to determine it.

Really, Amaze operates from a strength based position, and that is why we are talking about neurodiversity. At our conference this week we have the leader of neurodiversity thought at the moment, Steve Silberman. He will

be here tomorrow and speaking on Thursday about how these people are different and have their right to be in the world but also that they can contribute a lot and we are all different. We really support neurodiversity.

I think what we do see, as you describe, on the parent side is that a lot of parents have a very, very difficult time — there is no doubt about it — and they wished for something different. That is why we hope with the national disability insurance scheme that those families are going to get the support that they need to give early intervention to their children to help them manage their autism. But they are going to have autism all their lives, and we have to say, ‘We live in a world where 50 per cent of people have a personal connection with people with autism, so we had better get better at it’.

Mr FINN — In that area of early intervention it is a very difficult one because, as you are well aware — unless things have changed in the last little while, which they possibly have — world’s best practice is demanding 20 hours a week of early intervention. In Victoria, if a child publicly funded gets 2 or 3 hours a week, they should do a lap of honour. Do you see that changing with the NDIS? Do you see more public funding coming for the early intervention programs? Or do we have to look somewhere else for that?

Mr HOGAN — Before I get into that specifically, I think the really important thing to note, I guess, as you were saying, Bernie, is that families and people on the autism spectrum have had to scrap and fight for every little bit of funding they can possibly get. As you said, at 2 to 3 hours, they would be jumping for joy. I think that is inherent in a historical, ration-based disability funding model.

Looking at the history of disability 20, 30, 40 years ago, the majority of these people were in institutions. We saw the disability rights movement in the 1980s. We are kind of just now grappling with the inherent issues about what the failures of that system, which was structurally created in the 1990s, and now we are seeing an entitlement-based system, which is the basis of the NDIS. So we will actually empower consumers who are people with a disability to be able to say, ‘I want this’, and what they get provided is not based on how bad they can make their story but is actually on what they want to do and the supports that are put around them to go and achieve what they want to go and do. We will have to see how that plays out, and again the devil is in the detail. It is not going to be better; it will not be right, to start with. But again when you throw an insurance-based perspective on a model like this, it should say, ‘Let’s invest early so we increase their trajectory over their lifetime’. That also decreases costs across a lifetime as well.

I completely agree with you that world’s best practice does state 20 hours per week. There was a third report that was done in Australia at the end of this year, the Prior Roberts report, which underpinned the Helping Children with Autism program that was done in 2008, and again in 2011 we saw another one commissioned by the NDIS to support their approach. I think what it goes down to is the skills and abilities and the capacity within the national disability insurance scheme and its partners to identify autism but also put in the appropriate supports that are needed for that person. So if that is 20 hours a week of therapies — as long as it is evidence based, I should also caveat — that is what they need. If it is not that, then it is something different, but they should have the ability and the skills to be able to identify what that child needs at that point, if we are talking about early interventions, and put them in place. There also needs to be an element of choice and control. It is a very contentious field, about what therapy works, what therapy does not work. Amaze is therapy agnostic. We very much point to the evidence and those reports which are —

Mr FINN — Will it be a case, maybe, of depending on the child as to whether it works or not?

Mr HOGAN — Exactly, it is.

Ms SHARKIE — And the family.

Mr FINN — And the family, yes.

Mr HOGAN — And the family, and I think that is the inherent difficulty with public policy in this space — that every person on the autism spectrum is different, so it is very difficult to say, ‘This therapy works for everyone’, ‘This therapy doesn’t work for anyone’. It really is a horses for courses. It needs to be a lot more detailed. The group is not homogenous, so they need an individual approach, but that is why they also need the capacity and the expertise among the people who are making the judgements about what they are entitled to and have the skills and experience relevant to be able to identify that clearly.

Mr FINN — I am glad you made that point — that we are not talking about a homogenous group.

Ms SHARKIE — No, and Bernie, I think very simply it is the NDIS that needs to foot that bill. That is what it is there for, and it is very important that the commonwealth government hold on to its commitment to funding the NDIS.

Mr FINN — I know that we are way over time, but I have just got one last question. We need a revolution in the education area — there are no two ways about that — and that may or may not start at a building around the corner, which is not exactly renowned for its friendliness towards children with autism over a long period of time, as those of us who have gone into battle with them will attest. How do we change the view, the mindset — call it what you will — of the bureaucracy that is used to doing it this way and has done it this way for 147 years and does not want to change? How do we change that view of the people at the top of the tree?

Ms SHARKIE — Leadership. It has got to start at the — —

The CHAIR — Parliamentary inquiries help.

Mr FINN — They do. I am hopeful; I am very hopeful, yes.

Ms SHARKIE — Again, we are very encouraged by James Merlino and his comments, but we know it needs resourcing as well. A lot of this is attitude. We have worked, as I said, with people like the museums and things, so Northland is low-cost stuff, but it does need investment in school. I mean it is an absolute indictment that 8 out of 10 autistic students do not complete schools in an educational policy environment — say, Maree, where 9 out of 10 kids are finishing school. I mean, it is just not acceptable. Something has to happen, and it has got to be from the top.

Mr HOGAN — I think we need to acknowledge that cultural change like this will not happen overnight, and there needs to be sustained political leadership across all sides to make this happen. It needs to be consistent.

The CHAIR — I am mindful of time, but there are practical measures that could be implemented, and some of our public submissions have referred to the need for children or students who have ASD being able to stay at school much past the 18-year cut-off that we currently have because of the delayed development. And there was a suggestion in one of our public submissions around a continuation of that secondary or primary education right through to the age of 30 — or beyond if necessary — and formulating some type of education setting, whether that be within the current secondary schools or the specialist schools, where students who have ASD are enabled to stay beyond that 18-year cut-off. Do you think that that is something that would work, that that is a possibility?

Ms SHARKIE — I do not know the evidence on that, so I would not make a comment. But one of the things that we do know, and again we saw this at Northern School for Autism, which is a specialist school for autism, is that in visiting them recently they find that often their graduates that leave their school go on to TAFE for six, seven, eight years and just cycle through TAFE course after TAFE course after TAFE course. And Northern have taken the approach that if somebody wants to go to TAFE, they only go two days a week and the other two days a week they are doing work experience in their field. So just picking up on that about staying at school, certainly that adjustment needs to be made to the curriculum about being a modified curriculum. A lot of parents told us also that in a mainstream school their child's curriculum was being modified, but they did not realise that meant they were not going to get their qualification.

Ms SHARKIE — The communication around that. So I think certainly it is an interesting idea. I do not know the evidence, so I cannot comment about whether that is a good model, but I think we should be looking at — it is part of those transitions — not seeing autistic kids just cycling through TAFE on and on and on and on. They want to be going out and making a contribution, and these are all the sorts of things. There are a number of factors.

Mr HOGAN — Again I do not know the evidence, but I think there is a lot to be said for building the capacity of people on the autism spectrum to be able to live independently inherently within social and community structures as well, so how that affects them when they go past 18 as well. There is obviously a combined level of support which may necessarily sit outside of a family unit as well if a student stays in school

beyond that, so there might be some broader kind of implications in potentially how that looks. But again I have not seen any evidence or research in that area.

Ms SHARKIE — And certainly that 18-year remark is that their intellectual capacity drops off very rapidly after they leave school if they are not into something else, so again those transitions are critical.

Mr HOGAN — And it is about having appropriate options as well after — employment options.

The CHAIR — We are out of time, but thank you so much for your presentation, Fiona and Braedan. We really appreciate your time this morning, so thank you again.

Ms SHARKIE — And yours. Thank you.

Witnesses withdrew.