

TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Melbourne — 12 September 2016

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Witnesses

Ms Catrina Mulderry, president,

Mr Michael Tucker, vice-president,

Ms Tracey Hayes, committee member, and

Mr Phil Lipshut, committee member, Autism Family Support Association.

The CHAIR — I welcome to our public hearing this morning Ms Catrina Mulderry, president, Mr Michael Tucker, vice-president, Ms Tracey Hayes, committee member, and Mr Phil Lipshut, committee member, of the Autism Family Support Association. Thank you very much for coming along this morning. All evidence at this hearing taken by the committee is protected by parliamentary privilege as provided by the Constitution Act 1975 and is subject to 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. A recording of proceedings will commence today, and you will be sent a copy of the transcription and you will be able to make factual and grammatical corrections if necessary.

Once again, thank you very much for attending today. I will hand over to you now for a 15-minute presentation.

Mr TUCKER — I am Michael Tucker; I am going to be the spokesperson. We have not gone high-tech today, so hopefully I am going to modulate the voice occasionally to make it interesting. The Autism Family Support Association assists and supports individuals with an autism spectrum disorder by providing emotional and practical support for parents, carers and families. AFSA is an incorporated, statewide, voluntary parent-based support group. Through parent-to-parent support our aim is to improve the outcomes and quality of life for individuals with ASD and their families and carers. By supporting families and carers better we can help those with ASD live more fulfilling lives. AFSA has contributed to a number of reference and advisory groups on disability-related issues over recent years. We have been in existence for 30 years. AFSA is a registered charity. Like Aspergers, committee members provide their time and expertise on an honorary basis. We are all parents. I have got a 31-year-old son with autism.

Ms MULDERY — I have a 16-year-old daughter who has been diagnosed on the spectrum.

Ms HAYES — I have identical twins who are on the spectrum.

Ms McLEISH — Age?

Ms MULDERY — Thirteen.

Mr LIPSHUT — I have got a son, 28, who has got autism; he has no speech.

Mr TUCKER — In our submission we represent, we hope, the voice of parents, carers and families on behalf of or together with their loved ones with ASD. We like to say we represent the lived experience of those who love and care for those with ASD. Like everyone else that has got an interest in this committee, we would like to see a comprehensive, effective, appropriate and sufficient system of support and services for those with ASD. And such a system needs to be tailored to the different needs and abilities of people within the ASD population. Many parents and carers are tired and burnt out, and they need more support. This is especially true for those caring for adults with ASD. AFSA believes much more needs to be done to support those family members and carers who look after those with ASD. We think parents and carers must be appropriately consulted with and be allowed input into policy development and implementation of programs.

Unfortunately evidence would suggest that people who are being relinquished due to a lack of support and families who are being overwhelmed and unable to continue to cope in their caring role includes significant numbers of individuals with ASD. Sadly, also it is worth noting that there have been a number of unfortunate examples of individuals with ASD dying through misadventure. Others with ASD are subject to restraint and violence. This is often despite heroic efforts and struggles by parents and carers to keep their children safe. We would like to acknowledge the role that emergency services, disability support workers and school staff play in addition to families and parents in keeping safe those with ASD who abscond.

Sadly, there remain many reports of abuse of the disabled, including those with ASD, in supported accommodation, schools and various other areas of disability services and the community. This very committee of the Victorian Parliament has recently reported on abuse in the disability sector. The Senate committee into the abuse of people with disabilities in its executive summary of November 2015 said:

Throughout this inquiry, the evidence presented from people with disability, their families and advocates, showed that a root cause of violence, abuse and neglect of people with disability begins with the devaluing of people with disability. This devaluing permeates the attitudes of individual disability workers, service delivery organisations and most disturbingly, government systems designed to protect the rights of individuals.

...

Under the guise of ‘therapeutic treatment’, people with disability can be subjected to forcible actions that could be considered assault in any other context.

AFSA wants to see some of these bad stories on neglect and abuse of those with disabilities, including those with ASD, turned around. That involves comprehensive action involving all of the stakeholders working together across all parts of the system for the benefit of those with ASD. AFSA played a key role in the development of the autism state plan, and we respectfully suggest the inquiry should draw on the work done in that plan to assess whether the autism state plan and the subsequent disability state plan have in fact been implemented.

Turning now to AFSA’s recommendations, AFSA has put forward 15 recommendations for the committee’s consideration and made some comments on the NDIS. Coming here today we would like to say there are three key messages from our recommendations we would particularly like to highlight. The first key message is that more needs to be done to improve the quality and skill of those working with people with ASD. This would assist in ensuring amongst other things that the right behaviour management strategies are used to deal with challenging behaviours. Work in the disability sector needs to be valued. We need to attract and retain skilled and motivated staff. Children and adults with ASD, due to their complex needs and challenges, are at greater risk of receiving inappropriate support, and again sadly this can lead to abuse and neglect.

High levels of staff turnover results in inconsistent levels of care and support. Consistency is so vitally necessary for ASD people, who struggle with change, anxiety and difficulties communicating or conveying their needs or frustrations. The never-ending requirement to explain the particular needs of a person with ASD due to constantly changing staff creates issues for all stakeholders — remaining staff, parents/carers and the ASD person him or herself. This increases the stress and workload of all concerned. We need a training regime that educates and continues to build a workforce that can adequately support people with ASD. Staff supporting people with disabilities require appropriate skills, qualifications and training, and a level of financial remuneration commensurate with those qualifications. It obviously should be the case for those working with people with ASD.

In this context of the need for qualified staff, we would like to comment on restrictive practices like restraint and seclusion. Recent well-publicised cases in Victoria and other states highlight the need for better policies and practices to address complex and challenging behaviours. Restraint or seclusion should not be a first resort to deal with the challenging behaviours of a person with ASD. Not only is this practice a denial of a person’s human rights; it can cause serious injuries or even death.

Evidence shows that restraint or seclusion does not reduce or stop the incidence of the unwanted behaviour. Understanding the ‘what’ and ‘why’ of challenging behaviours of concern is a complex issue that requires appropriate, consistent and intense therapeutic intervention. Experts in the field of behaviour management should be consulted and provide evidence-based support plans developed from a comprehensive, functional behaviour analysis.

The second key message we would like to give to the committee today is that we really believe that it is important that all people with ASD must be given every possible support and opportunity to communicate and to be understood. By doing this, we believe that it will also help to address some of the symptoms of frustration that many people with ASD experience in education, in community housing settings and in the wider community. Individuals with ASD vary in their communication skills. Some may never develop language, others might acquire simple language, whilst others will develop fluent and effective language. Some individuals with ASD may not develop speech but will be able to communicate through alternative assisted communication methods, such as signing, picture exchange systems, printed word or communication devices. I have seen it with my own son recently, and my wife, working with apps. There is just so much around now that is helping improve the ability of people with ASD to communicate.

Some people require really intensive assistance to communicate. Due to a lack of functional speech or assisted communication, many people with ASD develop inappropriate and difficult behaviours as their means of communication. These people are often then labelled as being difficult and/or dangerous. We suggest that all people with a language deficit should have a communication assessment by a speech therapist with specific knowledge of ASD, and there should then be the development of an individual communication plan. We just need to do better in supporting the communication of those with ASD.

The third key message we would like to share with the committee relates to education, particularly school education. Education and supporting learning for those with ASD needs to be lifelong. AFSA has a 12-point plan. Everyone has plans; well we have got a 12-point plan that we believe would improve in particular the education of those with ASD in schools. AFSA believes: one, students with ASD must be given the necessary supports to access the curriculum on the same basis as other students; two, students with a language deficit should have a communication assessment by a speech therapist with specific knowledge of ASD and the subsequent development of an individual communication plan; three, a social skills program should be offered to all students with ASD; four, there must be qualified and skilled staff to work with students with ASD; five, there must be the removal of restrictive practices and the use of evidence-based positive behaviour management strategies and safeguards; six, there must be an improvement of transition arrangements within schools and between services at critical age milestones; seven, we need the development of more responsive and accessible complaint systems, with the establishment of an independent schools commissioner; eight, there should be accountability for the expenditure of program for students with disabilities, or PSD, money; nine, there must be the removal of the use of suspension and exclusion as a means of responding to behaviour-related issues; ten, individual learning plans must be of a satisfactory standard with — I have forgotten what the acronym stands for, but — SMART goals and measurable outcomes.

Mr EDBROOKE — Specific, measurable, achievable, relevant and time framed

Mr TUCKER — Thank you. Eleven; PSD guidelines, including for student support group meetings, need to be mandated; and finally, twelve, we need to make schools and other educational institutions, like TAFE providers and universities, more inclusive and ASD-friendly.

We would briefly like to draw the committee's attention to some other parts of our submission. We think there must be greater integration and coordination of services across both public and private sectors. It also must be made easier to access services. To that end, AFSA has made what we think are some practical suggestions around setting up an ASD one-stop shop to complement existing service providers. A well-funded and resourced one-stop shop could include providing assistance with regular medical reviews and financial assistance and guidance.

The human rights of people with disabilities, including those with ASD, need to be respected and understood. Training in the rights of people with disability should be mandatory within all areas of the disability sector. Failure to abide by these rights by any support worker, therapist, teacher or professional should require mandatory reporting, appropriate and timely action and an independent complaints system that actually works for the person with ASD.

We also need a more responsive and accessible complaints system. We need robust systems that allow for timely and thorough investigations concerning the wellbeing of people with ASD. These systems need to be comprehensive, with the right powers and resources and the ability to investigate in both publicly and privately controlled services. Any recommended outcomes from such processes must be able to be implemented quickly. The Department of Health and Human Services has an incident reporting system, but this does not cover poor service delivery. There is anecdotal evidence that families are unwilling to complain about problems with services for fear of their family member with ASD being disadvantaged. It takes a strong, well-supported family to pursue avenues of complaint, including the legal system, in the face of crowds of bureaucrats, interminable meetings and hearings and pages of regulations, policy and procedures.

In regard to advocacy services, we consider that individual advocacy services are essential to support people with ASD and their families and carers. Such services should be accessible across Victoria, adequately funded and overseen by the government. There need to be adequately funded advocacy services which are readily accessible, with clear guidelines and adherence to a mandatory code of conduct for provision of advocacy services. Sadly there are many residents with ASD in supported accommodation facilities who no longer have active family involvement to ensure their continued quality of care, support and wellbeing. These residents with ASD are extremely vulnerable to abuse and neglect, and it is imperative that well-resourced advocacy services are provided as an independent safeguard for this group of individuals to ensure their wellbeing and proper care. As the population of those with ASD and their families get older, individual advocacy in related support services will be critical to the system.

We respectfully suggest there needs to be greater accountability across the system to ensure, for example, that transitions from one setting to another are done in the most cost-effective way while meeting the needs of a

person with ASD and their family. Action also needs to be taken to implement the recommendations of a number of reports, state and federal, that have been handed down in recent times. The growing number of adults with ASD presents major challenges for the whole system. Some areas of concern are, firstly, health. It is extremely common for people with ASD to present with a range of comorbidities, which further impact on their functioning, management and progress. My son, for example, has epilepsy. Some examples of comorbid conditions include intellectual disability or cognitive impairment, mood disorders, sleep disorders, depression, anxiety, epilepsy, attention deficit disorder and obsessive compulsive disorder. Individuals with ASD need integrated support across the whole health and disability sector.

In regard to employment, it was mentioned I think by friends from Aspergers Victoria that statistics show a low workforce participation by people with ASD, and often when they are employed it is frequently in low-skilled work. Government-funded generic disability employment services generally have a limited understanding of ASD. The only ASD-specific employment service in Victoria was forced to close when it lost its funding from the Australian government.

In regard to the legal system, there must be support, management and guidance for those with ASD and their families caught up in juvenile, criminal, family — including domestic violence — and civil legal proceedings. This is a somewhat hidden and rarely referred to impact of ASD on the individuals and their families and carers. People with ASD have the same rights to social inclusion and benefits as all other citizens, but unfortunately they remain some of the most vulnerable in our community. As adults they have the right to live independent full lives of their own choosing with the appropriate supports. We think it is time to eliminate the attitude that it is the responsibility of the parents of the person with ASD to remain their carer for life.

As a community it is imperative that education is provided to change attitudes towards those on the autism spectrum, with improved understanding of their unique needs and challenges. We need to promote acceptance that all people with ASD, regardless of their level of ability, deserve and have a contribution to make to society. People with ASD should have an expectation to live a good life the same as any person would expect.

In conclusion, Chair, we would just like to make a couple of comments in relation to the NDIS. We think that the critical issue around NDIS will be the eligibility of individuals with ASD to be part of the NDIS. We say that those with ASD who need support under the NDIS should get that support. We say there should also be a no-disadvantage or grandfather clause for people currently in receipt of support or benefits, however adequate or otherwise they currently are, to ensure they do not get less than they are currently receiving. NDIA and government should clarify as soon as possible the impact of NDIS on existing service providers. We think roles and responsibilities of Victorian government state departments need to be clarified as the NDIS is introduced.

The announcement by the Victorian state government in December 2015 about the potential outsourcing of existing service provision that may affect the management and staffing of the Department of Health and Human Services accommodation creates uncertainty. We respectfully suggest that if it has not done so already, the committee should ask the Department of Health and Human Services to outline its plan for transition to the full operation of the NDIS. This would be to ensure no gaps remain in the provision of its services for all those with disabilities, including those with ASD.

Finally, transport to and from services that is tailored to the individual needs of a person with ASD is often a critical component of wellbeing for clients and parents, carers and family. Unaccompanied taxi travel can work for some with ASD, but it is not safe for others. Affordable and appropriate transport options need to be provided for people with ASD.

Chair, we commend our submission to the committee and thank you for the time and opportunity. Obviously we are happy to take questions. We think some of us have got some expertise in certain areas, so we will try and share them around, depending upon the nature of the questions. Thank you, Chair.

The CHAIR — Thank you very much, Michael. It is much appreciated. Thank you also for your submission. Michael, you mentioned education and you had a number of suggestions which actually were not included in — —

Mr TUCKER — They were not in our — —

The CHAIR — Are you able to provide them to the committee?

Mr TUCKER — Certainly. I have got a spare copy of them that I can pass to Kelly.

The CHAIR — Thank you. That would be much appreciated. I am also pleased to acknowledge that you have recalled the previous inquiry that this committee did and tabled our report on abuse in disability services earlier this year. I am pleased that we actually addressed many of the concerns that you raised in your comments today, including mandatory reporting and a few other issues. The government has until November to respond to our recommendations.

I would just like to ask a question, if I may, around recommendation 10, which TRAs your one-stop shop proposal. I guess what I wanted to know was: what does that actually encompass?

Mr TUCKER — What does it look like?

The CHAIR — How big does it have to be? You can have a one-stop shop, but it needs to be accessible for people not just in metropolitan Melbourne but right across Victoria, so how do you do that? Do you have a number of one-stop shops? What is your idea around that?

Mr TUCKER — Maybe I will have a first go, and maybe Phil might be able to help. It is not fully fleshed out, but I do not understand exactly what Amaze, the peak body, is currently funded for. I think your committee has already seen Amaze. It is funded for various things, but it is not funded for others. For example, if you just go to the old-fashioned *White Pages*, there used to be a couple of phone numbers there and it used to be a privately run service that said, 'We can help you if you've got problems with ASD'. Apparently, and I did a bit of research on this, they are out of New South Wales. They are a private group.

If I can just give one quick little story, my then 84-year-old father, who is still alive, had a bad fall last October and broke his arm. He was taken to the Austin Hospital and had the arm set. Within 24 hours we had a social worker contact us. She came and visited. She put arrangements in place to have care in the home for three days a week for a number of hours. She arranged two physiotherapy visits, which subsequently happened, and there was regular follow-up from the social worker with our family just to make sure that my father was okay. As he recovered we gradually put in place other arrangements. As I understood it, in a sense it was a great model, but it was partly to try and ensure my dad did not have to go back into hospital, so it obviously had that sort of cost-benefit thinking in mind.

I think our ASD shop model is undeveloped, but what we think is there are gaps in services. When the crisis occurs, who exactly do you contact? With my family, we have got various private agencies if there were an emergency you could contact, but we think it will probably involve government showing some leadership and probably the department looking at models that might work that are cost effective. None of us want money wasted; we want cost-effective models that are going to see support provided. Did you want to add anything, Phil?

Mr LIPSHUT — Listening to the previous woman that spoke, she explained when her son was diagnosed the lack of direction. When children start presenting problems, there is a diagnosis, and then once they are diagnosed, service options, funding options — all of those things, or some of them — are provided by Amaze, formerly Autism Victoria, but I do not think it is a complete one-stop shop. As we know, disability services is a maze, and parents have to find their own way through the maze, and any assistance that they could get would be appreciated because it is usually at stressful times.

Mr TUCKER — So it is an undeveloped concept. We have not whiteboarded it all out, but I think the model seems to work in many other environments, and I am sure the committee is aware of the models. An aged sector model is one example, where in a sense you have got people ready to move in when the crisis hits, you have got the contact people. In that case it was out of the Austin Hospital. It was just that idea. I do not think we want to be prescriptive. There are various models. There is ABIA, and there are various other bodies. I do not think any of us want to be prescriptive that it has to be the one path to be followed, but it is just about better understanding at those critical times — milestones, life events, school, transition from school to other settings — that there is some support and assistance there for families and the person with ASD.

I think it would be fair to say — and I am happy to be corrected by Catrina — that in many cases I suppose as parents of people with ASD we feel often we are the spokesperson. The person with ASD may have limited ability in our experience to advocate on their own behalf.

Ms MULDERY — Our experience with families is that most families feel quite isolated, and they are looking for support. It is exactly as others have said: it is a maze, and you do not really understand where to go for support and where the best thing to do at this time would be. That was the concept behind our thinking on the one-stop shop basically.

The CHAIR — Okay, thank you.

Mr LIPSHUT — I think it is probably unfortunate that Amaze is no longer called Autism Victoria, because it would be clearer as to what its role is.

Ms McLEISH — I want to drill down a little bit on the restrictive practices that you have mentioned several times during your submission. Can you give me an example of where you have seen the restrictive practices used, and then the model that you suggest or the ways of handling it? What should have been done instead?

Ms MULDERY — I will hand over to our colleague Tracey Hayes, who has lived experience of this.

Ms HAYES — I actually have some photos here of my boys. They went to a special development school, and that is where this occurred. They started there, they did early intervention and then they went into the primary school part. Once they hit the primary school part, you have one teacher and one assistant with up to 10 or 11 children. My boys — I have one with little speech and one with no speech. The communication that was given for my boys to be able to communicate was around PECS, but it was not followed through continuously over the years.

Ms McLEISH — Around?

Ms HAYES — Around PECS — picture exchange communication system — which is your little pictures with words. It is very complex, and they should have been given a communication plan. Looking back, my boys were not given a communication plan — I did not know what a communication plan was back then — to work in with their IEP. So my boys' behaviours got quite complex, and the restraints continued over the years at the school, as you can see in those photos. I have actually got hundreds of photos of my boys in restraints.

It became so bad that my boys were displaying extremely huge amounts of anxiety, so I went to human rights and put in a complaint to the education department. They were going to meet, then they withdrew, then they were going to meet again and then they withdrew. Then I went to two ministers. When I went to two ministers, they took it to Gill Callister. Gill Callister asked for an independent inquiry. Sadly it was not an independent inquiry; it was actually done by Ian Claridge, who is a retired principal at a special school. He did an investigative report, which I have with me, and in that investigative report it was said that it was partially substantiated, I guess because I had the photos, but it was based around — sorry, I have gone blank here —

Ms MULDERY — Tracey, therapeutic.

Ms HAYES — Therapeutic. It was therapeutic. There was nothing therapeutic about it. My boys do not need restraints; they needed communication to be able to communicate with what was going on. I actually withdrew the boys from the school. I was very distressed, and so was my family. We were suffering immensely. I did not know what to do. I went to different people, from Amaze to different advocacies. I ended up finding Communication Rights Australia, who were my saviour, and another advocate, who was Julie Phillips, who supported me and my family in transitioning into a mainstream school, which was very difficult, as I thought it was going to be. I had been to many different schools, but everybody had shut me out. Then they went to a mainstream school.

They are in a mainstream school now. They are in grade 6. I have been supported. There have been a lot of hurdles along the way. The principal has been fantastic. We have had a few hurdles, as I said, with the boys, but we got Communication Rights as my advocate supporting the boys to be able to use communication using an AAC. Now my boys are actually learning to read and write and participate in their school life, which they were not doing at a special school.

Ms McLEISH — So, if I am not mistaken, you are saying if a communication plan had have been set up in the very first instance, there would never have been any need to use restrictive practices.

Ms HAYES — I believe that if they had actually had a communication plan, that would have been a huge, big hurdle in my children's lives to reduce the behaviours but also in understanding human rights. We ended up getting, at the school they are at now, a functional behaviour analysis. We got the experts in outside of the department. That was only through the advocacy.

Ms McLEISH — I am thinking quite broadly, not just your one instance. If restrictive practices are used, obviously you would think that it is to restrict somebody's behaviour at that point in time. When they are choosing to do that, what should they do instead?

Ms MULDERY — I think we say that restrictive practices do not actually solve the problem and that in fact they make things worse, which seems to be the story that Tracey is saying. If behaviours of concern are present, we should not blame the individual with ASD; we need to understand what is driving that behaviour, because behaviour is a form of communication. That sometimes entails getting in somebody with that expertise to do a functional behaviour assessment to actually then understand what is driving that behaviour, because we cannot address behaviours if we do not actually know. As in Tracey's case, some of the individuals with ASD have little or no speech, so — —

Ms McLEISH — Is there a workforce capability issue?

Ms MULDERY — It is in that if we are talking about schools, teachers are trained to teach; they are not trained to understand sometimes what is driving some behaviours when there is no speech present. Sometimes you are guessing. The point that Tracey makes I think is very important in that behaviours cannot be looked at in isolation, and that is why communication forms one of the points that we are raising in our education plan, especially for those with little or no speech. That has really got to be addressed, and it does not appear to figure largely in the scheme of things.

And whether or not we heard from Aspergers Victoria, there are also children on the spectrum who have language, but then they have pragmatic problems as well with their language — pragmatic issues — which then drive social issues as well.

Mr FINN — I, like you, have been very concerned about the restraint issue, and I imagine this question will only need a one-word answer. Is there ever a reason to lock a child with autism in a box?

Ms HAYES — Never.

Ms MULDERY — No.

Mr FINN — That is what I thought. Thank you. I have seen, as I am sure you have seen, families who are totally dominated by autism — the fact that their child or their children in many instances, have autism. Nothing else seems to matter to them. Every day of their lives is consumed by the fact that their children have autism. What can we do to help those people live again?

Mr TUCKER — Obviously there are no easy answers; it has got to be a suite of measures. So, for example, for those of us who are parents and carers obviously — I am not even sure there is a politically correct word anymore — I suppose there is the idea of respite and support for parents and carers and the need to refresh and sometimes have some time away from caring for their loved ones. I do not think any of us want to take it that it is not our responsibility to look after our child, and we have said that in our submission, but what we do not want is this idea that society does not have the same responsibility as it does in some of the other areas of our community to provide the right and appropriate care. So obviously our mission, as the Autism Family Support Association, is that if you can support families more, then you can obviously help the person with ASD. That is particularly our mission, isn't it, Catrina, to try to support families?

Ms MULDERY — That is right. Unfortunately there are not enough support or respite services, and as Michael said, if you get a break from that caring role, you can be refreshed. I think you are right, Bernie, that it consumes families sometimes, and I have heard even people say that the family becomes autistic as well and isolated and not part of the community. I think it is so much better if there is that support so that families can be part of the community rather than feeling isolated.

Mr TUCKER — I think social isolation is certainly a big issue for many families where you have an autistic family member. The challenges involved in going to family gatherings and the tension about what to do in

terms of, say, at a larger family gathering when you have the autistic person who wants to tidy everything or put them in rows. So there are the implications that that has. As much as families are supportive, there are some limits to patience in terms of critical events — weddings, funerals, receptions, birthday parties — so there are many challenges, Bernie, yes. It is obviously just a suite of measures, but obviously we would say particularly our mission is to support families better, and with that link of blood and that love and care that is hard to replace otherwise, although we have some fantastic workers throughout the system, the more we can support families, we say the more you can support the person with autism.

Mr LIPSHUT — If I could just make a couple of points. If the services were doing their job, then families would not be as worried. Unfortunately families have concerns about the services provided at schools and day services and then accommodation.

The other thing I would mention is that the internet has played a huge part. Once families relied on the service providers as experts; now with the internet families — those that you are talking about — spend their time gathering information on the internet. The teachers in the schools and the people in the accommodation and the people at the day services do not go home at night and look up everything to do with autism. They go and do other things, but parents become more knowledgeable than the people that are providing the services to their kids, and that causes a tension.

Mr TUCKER — I think that is the other message, and obviously we are not all experts, but more service providers could listen more carefully, because parents usually know their child the best. Obviously we have got their best interests at heart. Many have become incredibly well educated and knowledgeable, and I think we heard Tamsin talk earlier about the understanding that if more could be taken from that knowledge that families have and channelled into effective support in various settings, then I am sure there would be improvements.

Mr FINN — One other issue that I think is a really, really important one — and I have to say I have no idea how to solve this — is the incidence of violence by sometimes an adolescent with autism toward other members of the family. Now, the family does not want to relinquish the child with autism, but I have heard of instances where members of the family have had broken bones or have all sorts of problems as a result of the violence — not deliberate violence quite often, but as par for the course as a matter of their behaviour. Where do we go with this? How do we tackle this? How can we prevent this sort of thing? How can we protect other members of families who are totally committed to looking after their sibling or their child but at the same time need protection themselves?

Mr LIPSHUT — I think that you need family support, like from a counsellor that can develop some plans within the home. Actually they would need to go into the home and work with each member of the family, because as well as physical assault there is also physical damage, which is a common thing not only in homes but in group homes where people with autism act out in various ways. I have not got an easy answer.

In my own situation my son lives in a group home. The house supervisor had the idea of taking him off his medication, and then one time he was visiting me and he was completely out of control, and I had to call the police and ambulance to protect myself. His paediatrician gave me some medication to use in such situations in the future, which I have not needed to do because he went back onto his medication and has not recurred.

Mr FINN — Just one last one, if I might. You mentioned earlier the need for an independent education commissioner. I am very keen to make this point, and I am sure you might be too. When you use the word ‘independent’, do you mean independent of the education department?

Ms MULDERY — Yes, that is correct. In our experience with families that have had concerns, the common situation seems to be that at the school level the school actually is in charge of mediating on the issue. If that does not work, then you escalate that to the regional office. But what families are saying is that they are not feeling that they are heard, and it seems to be that in the situation where that does not work the only other avenue is going to the Ombudsman or going to the Victorian Equal Opportunity and Human Rights Commission if there is an issue of discrimination. The problem is all this takes time. As I said, families do not feel that they are being heard. For example, in Tracey’s case they withdrew from the process the day before, at the Victorian — —

Mr FINN — This was the department?

Ms MULDERY — Correct. That was in Tracey’s experience. So you see for the family, they want a quick resolution and some of these complaints are dragging on. And in the interim period I think everybody is forgetting that we have got a child where for whatever reason the problem that has not been resolved at the school level then has gone to the region and then has gone outside the department. It is a lengthy process and families feel that they want a process that is independent and quick, and might I say that we might even extend this not only to department, or government, schools, but I think the families feel sometimes the same frustrations in dealing with independent and Catholic schools as well. And the area of education in particular is one area I think where, if we get that right and these children do receive an education, they can become productive members of society to whatever their ability is.

Mr FINN — Do you think the education department has largely failed families with autism?

Mr LIPSHUT — It has certainly failed some; I will put my hand up there.

Mr TUCKER — But I mean there are some success stories we are aware of. There are some children with autism that are doing well in the schools, but clearly we need to do better.

Ms MULDERY — I think what we need to do is that we need data, and data actually then allows us to answer those types of questions. If you go now and ask, ‘Where is the data?, ‘Where are the educational outcomes for children with ASD?’, that will then answer those sorts of questions, and I think data needs to be kept and it needs to be reviewed. We cannot have a system where more money is being poured in and we are not seeing what it is actually producing. That is why one of our recommendations is that for the program for students with disabilities we would like to see educational outcomes as to where this money is being spent. I mean if it was a private business, you would not be pouring money in or doing the same sorts of things if it was not producing results.

The CHAIR — I agree that analysis is absolutely vital to the ongoing success of the program. I just wanted to point out that yesterday the government announced that a new independent panel for school dispute resolution will be established. That is just a new initiative. I just thought I would mention that, because it is something that Parents Victoria has been asking for for 11 years or more.

Ms MULDERY — Terrific.

Mr EDBROOKE — Michael, you mentioned before about the experiences of parents, how they view their kids and how they feel a little bit more educated at times than the people they are dealing with in departments and whatnot, and I have heard that echoed a number of times working in the system, even from teachers where they are almost self-educated. I just wanted to have a bit of a talk about the association’s involvement in the state autism plan. You mentioned that before.

Mr TUCKER — Yes. I think Phil was particularly involved in the committee. Meredith Ward, I think, our previous committee member — I think we have mentioned in our submission Meredith, who is still a member but not on our committee anymore — was actively involved in that period 08–09 leading up to the formal promulgation of the autism state plan. I think, as we put on page 13 of our submission, there were six key areas that were identified at that stage. We would say on some of those things there might have been some progress, but perhaps not as much as ideally we would have liked.

We recently made a submission when it was called for from the disability state plan discussion paper. I think a number of other organisations did too. Obviously it is very broad with its definition, but we thought, as we understood it, that the autism state plan technically was folded into the disability state plan and it was appropriate just as a reminder, and again — as a former commonwealth public servant — I suppose I would just say that we know that many in the department, DHHS and DET, do great jobs, but I guess there is a bit of a plea there for some accountability data reporting back, a report card I guess about how some of these things are done, because we are the last ones that would say, ‘Just pour money down the sink’. We want to see effective spending and effective use of resources. Like that example with my father. I think that was a very effective spending of money by the Austin Hospital in a sense for keeping him out of an expensive hospital bed by just giving right support at the right time.

Mr EDBROOKE — Just to further that line, what sorts of skills and training do you think should be given for people with ASD to work more effectively?

Mr TUCKER — The first thing is I think there has been some drop-off in some of the TAFEs about certificate IV just generally, and certainly obviously we would all like to see that expanded and, I guess, get some more of the right people. As we say, if the work could be more valued, and I know there are so many worthy causes in society and so many areas worthy of support, but we just do need good people in the disability sector. I do not think there is any one model of how to look after people with autism because the spectrum is so wide, but we just do need that sort of training.

Obviously we have seen OTARC; I think they came and saw you. They do great work and research, and I think I have heard the professor say, ‘We just need some capacity building in the sector to get people to have a greater understanding of the special challenges of people’. We were going to use that line about ‘if you have met one autistic person’, but I saw it in a couple of other submissions online. The secretariat has done a great job. It is a real resource, I think — all that information and stuff there that is going to help awareness. I mean, we need more than awareness, but it raises awareness as well; that capacity building to try to get people that really do understand more about autism.

Ms MULDERY — I think that is right. One of our platforms is the skilled and trained workforce and really understanding, I suppose, ASD and how it presents. Look, the problem is if people are not skilled, particularly those that have higher support needs. If I could just give an example in schools. There does not seem to be a minimum qualification for integration aides at all. It seems to me, particularly when you are dealing with some of our children that perhaps present with higher support needs and, one could say, are most vulnerable, that you have unskilled staff with no understanding. I do not understand why that is allowed to occur basically. Tracey, do you want to add to that, about untrained staff?

Ms HAYES — I guess one of the things I have found with my boys is I think you have got some great laws, but we seem to not enforce them. I went and did a few different courses at the Human Rights Law Centre. Even looking at my own children and looking at things a little wider instead of being so narrow-minded, it made me look at things, at how people every day can really directly discriminate against a person with a disability, especially like my boys and some of the things that were said. I think some really simple courses in human rights really made me more aware of that with my boys. I think that applies across the board for anybody, especially in the education department, where I found it very complex and very challenging. You know, there is a culture in the education department, and it has not changed.

I am looking at secondary school for my boys, and we are transitioning at the moment. There are no schools out there in secondary that are very inclusive, especially in the mainstream. Especially with my boys, with little to no language, you are looking at really just the special schools. I want an inclusive school, where my boys can get role models from people who are neurotypical. I have seen a big difference with my boys just going to mainstream already. Yes, it is complex with their behaviours, but they are greatly reduced now, having communication, and also, looking at the education, looking at the curriculum, instead of in special schools where we seem to do life skills. My boys were exhibiting huge big behaviours and anxiety. Put them into mainstream and they are actually following a curriculum, and that has made a huge difference, especially for my little boys, who are now reading and writing. They were not doing that in a special school. It just goes to show that somebody as complex and with as high needs as my boys and the children in the special schools — —

We have got 81 of them in this state. I think there are over 11 000 children in special schools, and most of them have little or no speech. Imagine what we can open up if we give them those supports.

Ms MULDERY — But saying that, we are supportive of the special needs plan that the government is currently working on and we are hopeful that we are moving in the right direction for cultural change as well as for development of the workforce, because there is now a certain amount of training in special needs that teachers have to do and other changes that are in progress, so we are hopeful.

The CHAIR — We are out of time. Thank you so much for your presentation to us this morning. I would like you to know that we have written to the education department and invited them to present to the committee. Thank you again. Thank you for the work that you do for families with autism.

Mr TUCKER — Thank you very much, Chair.

Witnesses withdrew.