



COMMONWEALTH OF AUSTRALIA

# Proof Committee Hansard

## SENATE

SELECT COMMITTEE ON AUTISM

**Autistic people in Australia and a national autism strategy**

(Public)

THURSDAY, 11 FEBRUARY 2021

MELBOURNE

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## SENATE

### SELECT COMMITTEE ON AUTISM

Thursday, 11 February 2021

**Members in attendance:** Senators Carol Brown, Hughes, Steele-John.

#### **Terms of Reference for the Inquiry:**

To inquire into and report on:

On 27 November 2019, the Senate resolved to establish a Select Committee on Autism to inquire into and report on the services, support and life outcomes for autistic people in Australia and the associated need for a National Autism Strategy, with particular reference to:

- a. current approaches and barriers to consistent, timely and best practice autism diagnosis;
- b. the prevalence of autism in Australia;
- c. misdiagnosis and under representation of females in autism data, and gender bias in autism assessment and support services;
- d. international best practice with regards to diagnosis, support services and education, effectiveness, cost and required intensity;
- e. the demand for and adequacy of Commonwealth, state and local government services to meet the needs of autistic people at all life stages;
- f. the interaction between services provided by the Commonwealth, state and local governments, including:
  - i. health and mental health,
  - ii. education,
  - iii. employment,
  - iv. justice, and
  - v. housing;
- g. the social and economic cost of failing to provide adequate and appropriate services, including to support key life stage transitions of autistic people;
- h. the adequacy and efficacy of the National Disability Insurance Scheme (NDIS) for autistic people, including:
  - i. autism understanding within the NDIS,
  - ii. the utility of the Early Childhood Early Intervention Pathway for autistic children,
  - iii. the ability of the NDIS to support autistic people with complex needs, including those transitioning from prison settings, and
  - iv. the adequacy and appropriateness of supports to empower autistic people to participate in the NDIS planning process, and exercise self-determination through choice and control over their support services;
    - i. the development of a National Autism Strategy and its interaction with the next phase of the National Disability Strategy;
    - j. the adequacy of funding for research into autism;
    - k. the social inclusion and participation of autistic people within the economy and community;
    - l. the capacity and sustainability of advocacy, self-advocacy and self-determination supports for autistic people, including mechanisms to self-represent to government as enshrined in the United Nations Convention on the Rights of Persons with Disabilities;
    - m. any bill that relates to matters within the scope of this inquiry that is referred to this committee; and
    - n. any other related matters.

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**GOLDFINCH, Ms Debra, Chief Executive Officer, Irabina Autism Services**

**MOLINA, Dr Jose, Chief Practitioner, Irabina Autism Services**

**Committee met at 09:03**

**CHAIR (Senator Hughes):** I declare open this hearing of the Senate Select Committee on Autism. This is a public hearing and a Hansard transcript of the proceedings is being made. The hearing is also being broadcast by the Australian Parliament House website. The committee recognises that people use many terms when talking about autism. The committee is aware that there are people in the autism community who prefer identity-first language, people who prefer people-first language and people who use the terms interchangeably. The committee acknowledges that each member of the autism community will have their own opinion on terminology. The committee also understands that each person will have a preferred way of communicating and self-describing. The committee respects that language is an individual and highly personal choice. In the context of this inquiry, the committee will use identity-first language.

Before the committee starts taking evidence, I remind all witnesses that, in giving evidence to the committee, they are protected by parliamentary privilege. It's unlawful for anyone to threaten or disadvantage a witness on account of evidence given to a committee, and such action may be treated by the Senate as a contempt. It's also a contempt to give false or misleading evidence to a committee. The committee generally prefers evidence to be given in public, but, under the Senate's resolutions, witnesses have the right to request to be heard in private session. If a witness objects to answering a question, the witness should state the ground upon which the objection is taken and the committee will determine whether it will insist on an answer, having regard to the ground which is claimed. If the committee determines to insist on an answer, a witness may request that the answer be given in camera. Such a request may, of course, also be made at any other time.

I would now like to welcome Irabina Autism Services. I understand that information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. I now invite you to make a short opening statement and, at the conclusion of your remarks, I'll invite members of the committee to ask questions.

**Ms Goldfinch:** Irabina Autism Services celebrates the initiative of the Select Committee on Autism and is thankful for the opportunity to bring forth this testimony. Irabina was founded in 1970 by two families. We're a non-profit, family centred organisation dedicated to helping individuals with autism, along with their carers and families, to reach their full potential and remain active participants in their communities. The advent of the National Disability Insurance Scheme provided individuals with autism with unique and unprecedented levels of support, focused on improving their wellbeing and increasing their independence and opportunities to participate in their communities. Unfortunately, there is a group for whom these opportunities remain almost as remote and inaccessible as before the introduction of the NDIS. Individuals with autism requiring extensive levels of supports due to their extreme behavioural presentation and complex needs continue to regularly experience exclusion from learning, disempowerment in their communities and refusal of support and services. The reason for this is the extremely limited number of services providing effective and sustainable support to individuals with autism presenting with complex behavioural needs. Recognising this very concerning gap, Irabina developed Australia's first severe behaviour clinic specialising in the provision of behavioural support to individuals with autism presenting with severe behaviours of concern. The introduction of this clinic has met with significant interest from the community, receiving weekly referrals from schools, emergency departments, human services agencies and other disability service providers, all unable to provide these individuals with the appropriate level of care and support they deserve. Despite the commendable efforts of the NDIA and their commitment to support individuals with autism presenting with complex behavioural needs, the experience of the large majority of these families continues to be that of frustration, disappointment, helplessness and despair. These families and their experiences is what we'd like to respectfully speak to you about today.

**CHAIR:** Dr Molina, is there anything you want to add?

**Dr Molina:** No; thank you.

**CHAIR:** Senator Brown, do you want to start rather than me this time?

**Senator CAROL BROWN:** Okay; thanks, Chair. Thank you so much for coming here today to give evidence to what is an extremely important committee inquiry. In your submission, you talk about the prevalence of autism and how it has sharply risen from, I think, the 2015 ABS figures that you quote. Are you able to tell the committee why that is the case? Is that in terms of diagnosis? You also say in your submission that, at best, diagnosis is poor. Would you be able to elaborate on those statements?

**Dr Molina:** I'll touch on the first point first. There are multiple elements that are probably playing into that increased prevalence. Different people have different opinions, but I think it is safe to assume that there has been a significant impact in terms of awareness in the community, which has resulted in parents seeking support and a diagnosis not only more frequently but also at an earlier stage. There's also an increased level of awareness in service providers about the prevalence of autism and the presentation of the diagnosis, which is therefore increasing the number of referrals for diagnosis. There have also been some changes in the diagnostic criteria that probably impact these figures. However, I think it's important not to dismiss any potential environmental influences that may be playing into a diagnosis that are still unknown. There are quite a few specific research initiatives out there that are still evaluating those environmental factors that could come into play. They shouldn't be dismissed, but certainly all the changes I mentioned before would have had a very strong impact on the prevalence of diagnosis.

In terms of your second question, yes, I would—and I think you can speak to the families' experience about this. The experience is certainly poor at best, I would say. There are some very clear guidelines established by the CRC in terms of what an appropriate diagnosis of autism should look like. It involves multiple assessments, evaluating all the complexities that an individual brings with them, whether they've got a diagnosis of autism or not. If you go out into the community, it would be very rare to find clinics that are following these guidelines. In many cases they're providing a diagnosis with what I would consider insufficient information. There are also considerable waiting times for this diagnosis to be provided. Again, if you follow the guidelines of the CRC, you'll see that promptness in the response is paramount in this case. In that sense, the subjective experience of families is not only that of frustration, as we said before, around not having enough information to go with it to make decisions, but also very, very long waiting times at a time of their lives when they're agonising about the diagnosis that their child might have.

**Senator CAROL BROWN:** Your organisation is supportive of the CRC guidelines, so why aren't the guidelines being followed?

**Dr Molina:** I think there's significant pressure from the consumers to get a diagnosis. I think it's still possible for providers that are willing to provide a diagnosis with insufficient information as per the guidelines to do so, and that continues to be accepted. That is something that should change.

**Senator CAROL BROWN:** In your experience, how often are the guidelines not used when people are trying to get a diagnosis for themselves or for their family members? Do you have any idea?

**Dr Molina:** It's hard to say in terms of percentages, because you have to remember that a lot of our participants come with no diagnosis at all, and we are the ones providing the diagnosis. It would be safe to say that probably at least more than half of the cases that are referred to us don't comply with the guidelines.

**Senator CAROL BROWN:** Is there anything you want to add, Ms Goldfinch?

**Ms Goldfinch:** I think the delays also occur because of the low numbers of practitioners on the ground. I feel that it's necessary for government—I'm not talking about the federal government necessarily but state governments as well—to consider some of the initiatives where we are taking a clinician away from general services and putting them into the education department or things along those lines, because it then leads to even fewer of them. We need to be a little bit innovative in the types of programs and practices that we have. Perhaps there needs to be a greater utilisation of an allied health model, and the development of programs in that way, so that there are more clinicians available to do diagnoses and to enable us to get more children in early, given early intervention is really important.

**Senator CAROL BROWN:** Has your organisation had a look at independent assessments? I know the committee is going to look at this in more detail, but I just want to quickly get your view on independent assessment, because it seems to go to the heart of what you're talking about.

**Ms Goldfinch:** If I can, I will talk specifically about complex behaviours in that context. What I've found over the past four years in having a particular focus in this area as CEO of Irabina is that it has been a very traumatic experience for every single one of my parents. I think it goes to the lack of awareness, the lack of knowledge and the lack of skills necessary to even write a plan for these families. They are told that the behaviours, which are extreme—our program is for the most extreme behaviours in autism—that it's minor and that they won't be funded. My significant concern is that, if we're using people that really do not have the necessary skills to create a very significant assessment, it's going to be a failure. Again, we need to be really careful about who is doing the assessment and what skills they have to make judgement on what they're hearing. There's the impact to the family. With the participants that have extreme presentation, it's really the carer, the parent, who is the one who is going to be delivering the complexity.

**Senator CAROL BROWN:** In your submission you talk about support for caregivers and family members. What measures do you consider are needed for them to have better support?

**Ms Goldfinch:** They're quite extensive. I work with some incredible parents when it comes to their ability to look after their children, maintain family life and get the appropriate care that they need. And it's not just within the disability framework; it's also education and health—every possible impact that there could be on the family's life. They need people who are going to be there and supporting them. I think we often come to it from, 'This is what the system says we have to do.' These people don't fit the system. My first excitement about the NDIS was that this was actually going to be about what the individual needed, and I think it's lost in complex behaviour—whether that's autism or other areas. We really need to start with looking at the family unit and to start with the really person-centred practice. Where is the person? Where is their family? Where is their community? What's the broader impact?

If we can take a young person that's presenting with complex behaviour—let's say a young 10-year-old—and get them to a point where they can learn to manage their own behaviours, the impact to the parent is that they can for example, go back to work. Even if it is not to that extent, they can actually engage with their other children. They can engage with their other children. Siblings are suffering out there. They are really feeling the impact of what it can be like to live with a sibling who has a complex presentation. Parents do separate. I know they say that they don't, but my records are telling me that they do.

**Dr Molina:** Siblings as future carers as well.

**Ms Goldfinch:** Yes. We developed a program that we funded ourselves around the sibling because when we look at them we see that they are the carers of tomorrow. We also need to think about the rising numbers in autism. If we're talking complex, what is going to happen when we get to aged care? It's something we really need to address now.

**Senator CAROL BROWN:** I'm aware that there was an organisation that was putting programs together for siblings, but I'm not sure if that program still exists. Are you aware of any organisations that purely do programs for siblings?

**Dr Molina:** When we were researching the programs that existed out there to design our own, there was a fairly significant one in Australia. I am sorry, but the name escapes me.

**CHAIR:** Is it Siblings Australia in Adelaide?

**Dr Molina:** Yes; that is the one.

**CHAIR:** They don't have enough funding, but they do have some.

**Senator CAROL BROWN:** So they are still operating? That was the one that I was thinking of.

**CHAIR:** Yes, they are still operating. We'll talk to them at another time. We will now go to Senator Steele-John.

**Senator STEELE-JOHN:** Thank you. Firstly, I want to take you to page 3 of your submission. You provide a lot of academic definitions of what behaviours of concern are. I just want to start by trying to get you to articulate at its most basic level what you mean and what is meant by 'behaviours of concern'.

**Dr Molina:** That is a very good question. Again, this is one of those cases where different literature and different agencies and individuals will use different terminology. It is something that we've had to navigate ourselves. We decided to go with the term 'behaviours of concern', and, if I were to explain it in a succinct sort of way, I would say that the three main things that would make a behaviour qualify as a behaviour of concern from my point of view would be behaviour that directly impacts the well-being of the individual or others around that individual, particularly citizen rights—the right to be safe and have an adequate level of health. The second thing would be a behaviour impacting the individual's capacity to learn or to acquire new skills—so essentially being disenfranchised or removed from school or any other similar opportunities for learning. Then, lastly, it would be a behaviour that impacts the individual's capacity to meaningfully participate in their community. So the three key elements there would be well-being, learning and independence. So if one of those things are affected by the behaviour. I would consider those behaviours to be behaviours of concern. In terms of severe behaviours of concern, I would say that it's a behaviour that is chronic in nature, that impacts at least one of these areas in a way that it is unlikely to decrease without appropriate support. But you'll find many definitions out there, of course.

**Senator STEELE-JOHN:** Yes, of course. I firstly taking the last two aspects of that around education and community. In educational settings, is that if that causes a negative impact when interacting with unadjusted educational setting or when interacting with an adjusted educational setting?

**Ms Goldfinch:** That is a great question—thank you. One of the biggest issues with these young people is that they are actually not in any education setting. They can't get to school and, if they do, they are often there for short portions of the day because the system doesn't know how to manage the behaviours to enable that child to get an education.

**Senator STEELE-JOHN:** Yes, I'm definitely aware of that. I'm just trying to figure out how you interpret the delineation points between behaviour of concern that exists as a result of coming into contact with a barrier or trigger in the environment that might be ameliorated and a behaviour of concern triggered or existent within the individual.

**Dr Molina:** Yes, that's a very good point. There is a term out there that's being used more and more that I quite agree with, which is 'environment of concern', that speaks to some of the points that you were making—that is, an individual's behaviour is in many cases a reflection of the environment in which they have to function. I think the point you're trying to make is that there are many environments, in particular in the education system, that are less than conducive to learning, so individuals that would not be presenting with severe behaviours of concern had they been placed in a more appropriate environment or with more appropriate levels of support will engage in these behaviours. When you look at the case or you read about the individual, you have to consider the environment in which they've been placed. In many cases, it's certainly the environment that is playing into this dynamic, which then causes the behaviours of concern. It is something that always needs to be looked into.

**Senator STEELE-JOHN:** Absolutely. In terms of the principles that guide your organisation and your practice, is your work guided by the medical model of disability or the social model of disability?

**Dr Molina:** Again, that's a very good question. It's a bit hard to differentiate. We try and have a holistic approach. Particularly with severe behaviours of concern we incorporate both elements. I would say that both elements are equally important in the sense that there are many issues of a medical nature that could be playing into an individual's behavioural presentations. Those need to be evaluated and ruled out before any behavioural intervention is put in place. As Deb was saying before, the family, the social environment in which this individual is placed and the social demands that will be placed on this individual are as important as any medical element that could be playing into their behaviour, so it's a bit hard to differentiate between either one of them. As I said before, we try and integrate them in practice.

**Ms Goldfinch:** Yes.

**Senator STEELE-JOHN:** I just want to make sure we're talking about the same thing. I'm not talking about social pressures. Maybe we've missed a step. Are you both aware of the social model of disability?

**Dr Molina:** We may have a different understanding. Could you explain to me what you mean by that.

**Senator STEELE-JOHN:** The social model of disability sees disability as a product of barriers in society that are created and maintained by ableist thought processes. For instance, in my case, I've got cerebral palsy, which causes me not to be able to walk. That is an impairment that I have, but the negative barriers associated with that impairment are created and maintained by ableism in society and ableist barriers in society. To address the negative implications of that impairment, one looks to break down the barriers in society and places responsibility for that adaptation upon the society more broadly, whereas the medical model of disability—again using myself as example—would see me as having an impairment and the barriers that come with that impairment as being a result of something which sits intrinsically within me, and that therefore, as something that departs from the norm, it is for me to modify my life and my behaviours or my aspirations to fit the norms that exist within society. So, there are two very different conceptions of what disability is and where the onus of change lies in creating an inclusive society. Does that make sense?

**Dr Molina:** Yes, it does.

**Senator STEELE-JOHN:** These are pretty standard discourses within disability policy and work. It presents a particular challenge with this concept of an articulation of behaviours of concern because it becomes difficult to reckon with the very individualised nature of the conception. It seems to me—

**CHAIR:** Senator Steele-John, can I ask you to get to a question, because we're running out of time.

**Senator STEELE-JOHN:** In the clinical practice that you offer, what does it look like for you to actually suggest environmental adaptations to the folks that you work with? Do you roll that into the work that you do, or is it mostly shaped around trying to change individual behaviours?

**Ms Goldfinch:** We both want to have a comment on this one.

**Dr Molina:** I'll keep it brief so that Deb can have a turn. Thanks for the clarification. To go back to the original question, in practice—and that's probably what you're alluding to—it's hard to differentiate between both

things. At least, that's the way I see it. In an individual case, there will be, for example, some communication goals that we'll see within the individual, so we would support the individual to achieve those communication goals. The hypothesis would be that if we are to increase those skills then the individual would have a better capacity to communicate his needs and therefore not require, or need to rely on, behaviours to navigate the environment.

But also—and I would say this is for the majority of the cases—we look at the environment in which the individual is immersed and, as you mentioned before, the barriers to that individual achieving the goals, in terms of the NDIS, that were initially set. In many cases, the barriers may be systemic, and we address those on an individual basis. We would speak to the family, to the school and to the community in terms of how things need to be changed, in terms of not only the social environment but also the physical environment, so that the individual can successfully bring about the changes that are set in their goals. So in practice we would be integrating both.

**Ms Goldfinch:** My comment is to point out that we're not talking about a general disability impact here. It's important to understand that these are people that are being removed from society. They're being discriminated against. Significantly, in many instances they are not able to articulate in any form because of the presentation. Whether it's been an environmental impact or internally regulated, they are not able to communicate. What we need to be able to do is give them that opportunity to be able to communicate. That might mean that carers are making decisions and parents are making decisions. But, to be honest, I think that's their absolute right as the carer. The impact on these young people, once they've learnt to communicate—the difference is absolutely amazing.

I was commenting on this to Senator Hughes this morning. We had a young fellow who was 12 years of age. He was impacting his mother. He would aggress against his mother a hundred times a day. He is now communicating really well, and it's been 100 days since he impacted his mother. That family is saying, 'We may be able to get him back to school, and that means he's going to have a life.' He says, 'I think I can get a friend.' That's what this is about. That is what this real change to people living with complex behaviour is about—to give them exactly the same rights that every single one of us has.

**CHAIR:** Thank you, Senator Steele-John.

**Senator STEELE-JOHN:** So, he could communicate—

**CHAIR:** Senator Steele-John, we've only got six minutes left, and I would like to get a question in before that. I want to come back to the complexity of these behaviours. Are we talking about people who are generally verbal? And when we're talking about 'impacting' their mother, we're talking about violence. We're not talking about upsetting the applecart in a household; we're talking about physical acts of violence towards the mother.

**Ms Goldfinch:** Absolutely. I see mothers present with black eyes or broken limbs, siblings that have been removed from their homes. I've got parents that have built a padded room for their child; a mother and a father that do not sleep at the same time because they are living in fear of the impact of that child on their sibling.

**CHAIR:** We're talking about behaviours at the extreme end.

**Ms Goldfinch:** Absolutely.

**CHAIR:** We're not talking about a physical disability where physical changes can be made. We're talking about—

**Ms Goldfinch:** That's right.

**CHAIR:** Would most of these people that we're looking at have intellectual disabilities as well as autism? And when we talk about communication challenges, verbal versus nonverbal—

**Ms Goldfinch:** Yes, absolutely. You're talking about the extreme—forgive me for the use of the word—deficit. It's the opposite end of having the skills there right at the other end. One young fellow that wasn't able to communicate in any way, we started him with one PEC. Now he has a full deck that he's able to use and communicate around.

**CHAIR:** Can you clarify that for those that don't understand? Could you explain what a PEC is for those that might be listening and don't understand?

**Ms Goldfinch:** Picture exchange communication. It's a communication tool where you have a small photograph and the person can learn to use that photograph to communicate with you. We have many young people that are able to communicate in that way.

**CHAIR:** I remember that we had magnets on our fridge of food and everything else. My son was non-verbal, or preverbal.

**Ms Goldfinch:** And as I said, you can start very simply and work with one thing. That's basically how our program starts. It's just one thing. And the difference in them if they're not injuring themselves. I had a young child that they thought had retina detachment from force trauma to their face. This is not those people that you generally see around in the community. The families and the children are being held hostage by their autism.

**CHAIR:** We're not talking about people at level 1 autism. We're talking about severe behaviours associated with level 3 autism, the type that quite often is hidden away and not put out there as 'autism is awesome'. We're talking about the very, very severe end of the autism spectrum.

**Ms Goldfinch:** Absolutely. As I was saying about being kept hostage, they're hostage because they can't leave the house. They don't have any friends. I've got siblings of one young fellow who can't go on play dates because the mother can't get them there and they certainly can't have play dates in the house. The mental health impact to those children is significant.

**CHAIR:** Have you done any research or had a look at what the economic costs are both around supporting the individual, supporting the family, but also the non-participation in the workplace, then the impacts of social isolation, mental health et cetera on the rest of the family?

**Ms Goldfinch:** We've got a paper we're finalising at the moment. Would you like to talk about that, Jose?

**Dr Molina:** As you mentioned, we're working with the draft of paper. The very global figure that we're using at the moment is about \$9.2 million in a lifetime

**CHAIR:** Per individual?

**Dr Molina:** Correct.

**CHAIR:** I'd be really interested to have a look at that when that's finalised. What are the benefits and is there any—we quite often talk about quality and effective and quantity of early intervention. If a child who is at the more severe end of the spectrum and has issues with verbalisation—and that obviously can be a function of their behaviour when they can't communicate their wants and needs, particularly as they get older—if there were better early intervention accessible, particularly to those families that have challenges in running a strong home based program, what will we look at from an outcome perspective?

**Dr Molina:** We couldn't agree more. That is something that we always talk about, even outside of the space, in what we call the general services space, where you find mostly the typical participants that you mentioned before. We always think in that prevention space: are these children at risk of developing those behaviours later on? And what kind of support does the family need to prevent that from happening? I would say that the lessening of the impact of those presentations, it is definitely decreased with early intervention.

**CHAIR:** We hear from a lot of non-clinicians with their opinions, but Dr Molina, as a clinician, could you maybe outline the concept of function of behaviour? With these complex behaviours, the behaviour doesn't start out of nowhere. Maybe you could explain for the sake of the committee what a function of behaviour is and how through early intervention we can perhaps modify that?

**Dr Molina:** In simple terms, the function of the behaviour is, let's say, the force driving that behaviour or the reason behind that behaviour. It is usually linked to the outcome produced, in many cases, by the environment from that behaviour. A typical example would be, as you mentioned, a client or a participant with, say, a diagnosis of autism, intellectual disability, a language disorder, and perhaps some other diagnosis. That participant may be unable to communicate their needs. They've learnt over time that if they engage in certain behaviours, those needs will be met. So they will understand those contingencies. Then the likelihood of those behaviours occurring in the future when similar circumstances are presented will then occur. A typical example would be a participant who really likes an iPad or food—

**CHAIR:** So banging their head on the wall, and then they get an apple juice.

**Dr Molina:** Correct.

**CHAIR:** They know that if they bang the head on the wall they're going to get the apple juice. If they punch their mother, they'll get the iPad.

**Dr Molina:** Correct. They would have started with perhaps a behaviour that occurred by chance. Then the parents provide something to placate the behaviour. Then the contingency occurs and then the individual learns, alright, when I engage in this behaviour this is the outcome. If it's a desirable outcome, then that behaviour is more likely to occur in the future.

In terms of treatment, to answer your question, a thorough evaluation of those functions is essential, because otherwise you're basically guessing and you're doing a disservice to the individual by not providing the outcome that they really seek. That is the ethical thing to do, to identify what it is that this individual wants and how can

we best provide him with an alternative behaviour to obtain the same outcome—not to suppress that need or want, but rather to provide him with more appropriate behaviour in terms of not impacting his wellbeing, independence or opportunity for learning.

**CHAIR:** My final question: do you think there's a really good understanding in Australia of function of behaviour across clinicians?

**Dr Molina:** No. There's a very poor understanding in Australia.

**CHAIR:** I think I would agree heavily with you there. I thank Dr Molina and Ms Goldfinch for coming today. If you've got anything further, feel free to send it straight to the committee. We are extending the time of our reporting date until March 2022, and there will be an interim report in September. So anything that you can send through that you might need to support us, particularly that paper you're doing, of course, would be greatly appreciated.

**BAILIE, Ms Janet, Autism Connect Advisor, Amaze**

**HAYDEN, Ms Chloe, Amaze**

**SHARKIE, Ms Fiona, Chief Executive Officer, Amaze**

[9:42]

**CHAIR:** I'd now like to welcome Amaze. I understand that information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. I invite you to make a short opening statement, and at the conclusion of your remarks I'll invite members of the committee to ask questions.

**Ms Sharkie:** Thank you so much and it's good to be here. Thank you for the opportunity to speak this morning. I want to outline basically that Amaze is what we call the peak body for autistic people and their families in Victoria. Our principal functions are providing evidence based information and support through our phone line. We also have a policy function within Amaze, where we provide advice to government for systemic reform, and we're not a service provider.

Specifically, the things that we'd like to cover today are things that we believe the committee will benefit from knowing, from a Victorian perspective, about what we've been doing over the last five years, working with governments around much of the road that the committee is traversing in terms of starting from a parliamentary inquiry in Victoria into autism in 2015, moving on to today where we have a five-year Victorian autism plan, and, in December, the minister for education here released an autism education strategy. As part of that—if the committee will indulge us—we'd like to talk about two particular features of our work and what we think is really working at that systemic level to change attitudes and behaviours towards autism. You've just heard from our colleagues at Irabina about the service provision level, but we're really working to change the attitudes, behaviours and systems that are in place to support autistic people of all capabilities in Victoria and hence in Australia.

The two main planks of that is our public education campaign. I'm aware that all the members of the committee are not from Victoria. This campaign only aired in Victoria—this time last year, actually. We're almost on the 12-month anniversary. This campaign was designed to challenge the community's attitudes towards autism. We determined this from the first report into community attitudes towards autism in Australia, which we did in 2017. That report showed that, whilst 98 per cent of Australians had heard of autism and 86 per cent of Australians had a personal connection to autism, only 29 per cent knew how to support autistic people—and those 29 per cent are largely going to be parents of autistic people. So there's a huge gap there. The research also showed that four per cent of autistic people and their families thought the community knew how to support them. So it was a big job to do with that. Coming out of the parliamentary inquiry and the Victorian Autism Plan was to run a public education campaign.

We have sent the committee the link to the campaign because we know that many members of the committee would not have seen that. I'm not sure if you have had the opportunity to see it, but there were three 30-second television advertisements that ran. Chloe Hayden, who is an actor, featured in one of them. Have you had the opportunity to see it?

**CHAIR:** No. I didn't get it till late last night and I haven't; sorry.

**Ms Sharkie:** They only run for a minute and a half. I don't know whether you'd be able to watch or have a look at them.

**CHAIR:** I'm sure we will have a look at them tonight, but we didn't get them till late yesterday.

**Ms Sharkie:** That would be great. The campaign aimed to get people to challenge their behaviours. One advertisement showed a mother with a child in the supermarket. There was also one with Chloe in a workplace, in an office, and then one with an autistic man with intellectual disability with his carer in a cafe situation. The campaign was called Change Your Reactions. The evaluation was very strong in terms of achieving the aim, with people saying, 'It made me stop and think about my behaviours and about how I would change.' The campaign finished just as the COVID shutdown came. So for people to change their behaviour afterwards was a bit hard, but 20 per cent of autistic people and their families said they'd already started to see a noticeable change in behaviours. So I'd love Chloe to give a two-minute update on what it meant to her to be in that ad and also why it was important.

**Ms Hayden:** As Fiona said, I was acting in one of the ads. The scenario of the ad that I was in was a workplace environment where the lights are very bright and everything was very noisy and the co-workers were like, 'Oh, she must be hungover' or she must be this, that and the other, without thinking, 'Oh, maybe she's autistic'

or that maybe there was something else going on. I am my own boss. I've never worked a nine-to-five job, but I have had this exact same situation happen, whether it be at school or whether it be when I'm out with my mates. It is getting better but, at the moment, the way that people see autism is two very different stereotyped ways. They either see us as completely incapable and completely unable to do anything or, if you don't present as autistic, like me, and you look neurotypical and able-bodied and everything is fine, they think that there are no struggles and no issues so it can't be autism; it has to be something else. In the same way, if there is a young child having a meltdown in the supermarket it is never, 'This child is having a meltdown. Maybe they are autistic. Maybe the lights are too bright. Maybe there is something that is hurting them. Maybe there is a sensory trigger'; it is always, 'They're having a tantrum; maybe the parents need to do better, or maybe this kid is just a bad kid.'

The way that we see autism at the moment is very stereotyped and very stigmatised and very harmful towards the autistic community. That is something that we really need to change. We really need to do better, because this isn't a new thing. Autism has always been around and autism always will be around, and it's not fair that at the moment the only people that get to live and thrive in society are those that are neurotypical. We need to also create inclusive environments in workplaces, schools, supermarkets and just in general life where autistic people have the ability to thrive because of who they are, not in spite of who they are.

**CHAIR:** Ms Sharkie, have you finished your statement?

**Ms Sharkie:** If you could just indulge me for another moment, I would like to talk about Autism Connect. Amaze was awarded a grant from the NDIS ILC funds a year plus ago to expand our autism adviser service to a national helpline, which we will do by June this year. Autism Connect is a free service, and it will be Australia wide. It provides independent and evidence based information. The idea has always been that we provide families and autistic people with information so that they can make decisions for themselves. I just wanted Janet to give a bit of a recap on some of the really challenging situations that families have found themselves in and her experience as an adviser.

**Ms Bailie:** The largest number of people who call us are actually family members seeking support at different stages, whether it's trying to get access to diagnosis or trying to get services. We know that it's very hard to get in to see allied health professionals at the moment. We've had a real increase in the number of autistic individuals calling us. Over the last 12 months, we've had a real increase in autistic individuals contacting us or people who are identifying as autistic and wanting to actually explore that identity or get a diagnosis. We also get calls from professionals, allied health professionals, support coordinators for the NDIS, case managers and family violence support workers. The Department of Defence has a counselling service, and one of their counsellors contacted me recently for support for one of her clients.

The kinds of questions that we get are broad—we could get anything—and sometimes the issues are not necessarily autism related. Sometimes they'll just talk about their kid playing video games and it's like 'Well, that sounds like a teenager to me; that doesn't necessarily sound like autism.' A recent example of a call that we've had was from a woman whose son was at an SDS school, a special developmental school. The IQ is below 50 to attend an SDS school in Victoria. Her son was 18 and was exiting. She was actually ringing to ask, 'Who do I go to now that he can't see a paediatrician? Who manages us now? Where do I go?'

**CHAIR:** What is the answer—just for those listening with kids who are 17? Where do they go then?

**Ms Bailie:** Often it will be an allied health professional or a health professional. It isn't a health issue, if you know what I mean. The NDIS definitely make that delineation between what's disability and what's a health issue. So, in terms of that, it doesn't necessarily need a health professional to be overseeing it. It's perhaps more about neurodevelopmental. So an occupational therapist, a psychologist or someone like that might be involved with the family. This family were only using NDIS for continence support. So it's kind of like, 'Oh, you're in a special school. You're getting everything from the special school, so you don't need other therapy support.' So I was like, 'So you've not had an OT that is helping with sensory integration?'

**CHAIR:** Or independent living skills, social and community participation—all those categories.

**Ms Bailie:** That's right. She also said, 'The school is saying that day service is his only option post school.' I said: 'No. What does he like? What does he want? What are your goals? What would you like him to achieve? Let's work on helping him with that,' and I sent her a whole lot of information.

We introduced the complex call-back system maybe 18 months ago. We rate the complexity of our calls, from one, which is low, to four or five, which is high. If they're four or five, we get triggered to bring that person back three weeks later to do a bit of a check in: 'How are things going? I gave you a lot of information. How did you go with it?' And the case of this woman was a really positive one. It's the empowerment model that is really good. I gave her information about understanding her rights, and she said: 'I'm cutting out the middleman. I'm not even

going to the support coordinator. I'm making the phone calls myself. I'm using all your links that you sent me as homework. I explore something every night and look through things.' I think that's the crux of the Autism Connect service—that independent and empowerment model of helping them to understand.

One of the biggest areas we get a lot of calls around is education inclusion. I have a colleague that trains teachers in autism inclusion. Most of the teachers don't know about the Disability Standards for Education. They sit under the federal Disability Discrimination Act. I find it mind-boggling. I've been in the disability sector for many years. We always had to work to disability standards or the charter of human rights. They were displayed in every workplace I've been in. Why aren't the Disability Standards for Education in every school? Why isn't it that we meet our legislative requirements? I know that schools are a state responsibility, but they have to abide by that federal law. I don't know how following them doesn't get down into teachers' leadership in school.

**CHAIR:** I am going to jump in now because I do want to get to questions and we've only got 24 minutes of time left today. I might go to Senator Steele-John first.

**Senator STEELE-JOHN:** Thanks so much for your evidence. I want to go to Chloe. It's fantastic for the committee to get the perspective of an autistic young person. Before I ask you any questions, Chloe, I want to give you the opportunity to add anything to or expand on your statement.

**Ms Hayden:** The main thing that we really need to work on and that I would like to have more of an emphasis on is inclusion for the autistic community within schools, within workplaces and within daily life. I think that that is the biggest thing at the moment. Like I said before, there's always going to be that one group that's excluded, and it's not fair that it's always the same group. It's not always, 'It's this environment, so just don't go there.' It's in schools. It's in workplaces. It's within groups. It's within the most basic things where it's a human right to feel like you're safe—to feel like you're included. At the moment, I can speak as an autistic person myself. I can speak as someone who has autistic friends. I can speak as someone who works within the autism community. The vast majority of us do not feel safe and do not feel included within these environments.

**Senator STEELE-JOHN:** What do you see as the main barriers to that inclusion? Is it cultural? Is it in the perception space? Where do you see those barriers coming from?

**Ms Hayden:** It's a lack of understanding and a lack of a desire to make a change. People have been speaking out for years about how we can have inclusion, about how we can have change, but the stigma that the neurotypical community, the media and all these different people have put onto it—that's who people are currently listening to. People aren't listening to the autistic community and what we need. They're listening to people who call themselves autism professionals but who don't actually have any real-life experience of autism. They're listening to people who have their fancy textbooks but don't actually know anything about being autistic themselves. They're listening to what's easy, to what they know, to what has always been, rather than to what needs to change so that we can have an inclusive environment.

**Senator STEELE-JOHN:** I wish you were a permanent member of the committee. Finally, how important do you think language is in this space, and should we first stop using the terminology around 'severe' and 'profound'—and we've heard a bit of it today, in terms of 'behaviours of concern'—and that type of language? Doesn't it reinforce those exclusionary practices?

**Ms Hayden:** Language is a big thing. I'm a massive advocate, first of all, for saying that someone is autistic rather than that someone has autism. I think that's a massive thing. You can say until you're blue in the face: 'It doesn't matter. Words are just words.' But words are part of our culture, and words are what make people change and what people see you as. By saying that someone has autism, it's creating the stereotype that it's something that they can change—that it's something that isn't a part of them or that doesn't need to be a part of them. You'd say that someone has cancer or that someone has a heart disease. It's something that someone isn't. Whereas you wouldn't say that someone has blackness or someone has gayness. It doesn't make any sense.

Likewise, you wouldn't say with autism—and this is one that people still find a little bit controversial, but functioning labels don't exist. It's DSM-5 for a reason. Functioning labels are stupid, and they make people say and consider that if you're low functioning then your abilities aren't seen and that they don't matter, and if you're high functioning then your struggles aren't seen and they don't matter. If someone looked at Stephen Hawking, they'd say, 'He's low functioning,' but he's probably one of the most high-functioning men that the world has ever seen.

Functioning labels and the use of person-first or identity-first language are so important, and they're things that people don't really look at. I know that the media, journalists, teachers and doctors are very set on using the wrong terminology. You can say it's just words and you can say it's just terminology, but these words and this terminology do affect us.

**Senator STEELE-JOHN:** Absolutely. Thank you so much, Chloe.

**CHAIR:** Senator Steele-John, if you're done, I'll go to Senator Brown.

**Senator CAROL BROWN:** Thanks, Chair. I want to go first to you, Ms Sharkie. You talked about the Victorian autism plan and the Victorian Autism Education Strategy, which sound like the two pieces of work that you've been closely involved in. What about other states and territories? Who's leading the way or doing some work?

**Ms Sharkie:** Thank you for the question. It does vary across the country, but to my knowledge there is no other state autism plan other than Victoria's at this point in time and there isn't a state education strategy. We know in Queensland that there has been some progressive work done on autism with the Department of Education and the establishment of the Autism Hub.

We only have anecdotal evidence, but one of the things that we know, and that Senator Hughes will know, about the level of school refusal for autistic children is that there is school refusal for enrolment, which is unlawful, and sending children home from school early and not recording it as a suspension of the day rather than going to a dental appointment or something. None of that is captured. In Queensland we believe the Autism Hub within the Department of Education is recording those things when they hear about a school refusal for enrolment—

**Senator CAROL BROWN:** This is for public schools?

**Ms Sharkie:** Yes, public schools.

**Senator CAROL BROWN:** We don't have insight into special schools or independent schools?

**Ms Sharkie:** No, none at all. But when that happens the Autism Hub will be in contact with the school and send a support team around it.

In Victoria, the education strategy is also going to focus on building the capability of schools for students that have received state government funding. That's called the program for support for disability. There's a new funding model for that. Most importantly, for the students that don't receive funding at school, there is I think \$500 million going to schools in the state system to build the capability of schools to support students like Chloe. Chloe attended more than 10 schools in her education because there was an adjustment made for her. So, there will be that. It will be supporting those students with higher needs that get individual funding and it will be supporting autistic students.

The important point to make is that this is a specific program for students with disabilities, but the state government is also seeing that there needs to be a specific strategy for autistic students. Again, there are no numbers, but we would think that there are more autistic students in schools than any other disability and that there would be an autistic student in every classroom. So, it is a big number of students.

**Senator CAROL BROWN:** There's a lot of discussion around a national autism strategy. What's your organisation's view?

**Ms Sharkie:** We were responsible for putting this on the agenda. In our federal government election manifesto at the beginning of 2019, one of our key asks was a national autism strategy. The question is: why autism? And it's a good question. Our answer to 'Why autism?' is that we're pretty close to saying that autism is probably the biggest disability in Australia today. We certainly can see in the NDIS figures that 31 per cent of all participants are autistic. The NDIS will provide individual support for many autistic people, but, also, not a lot of autistic people. A specific strategy for autism is needed because of the education outcomes of the group. Year 12 completion is the lowest—the ABS data tells us that survey after survey—and employment participation is the lowest. It's a large group of people and the fastest growing disability, and that's not because there's something in the water; it's because we're learning more about it and identifying it more easily now and people are more aware of it. The NDIS will serve their individual needs, but, unless we fix schools and unless we fix employment, nothing is going to change for autistic people.

Autistic people also say, as Chloe so articulately said, they are not so much disabled by their disability but more by community attitudes towards it. There was Janet's experience of the young man who was leaving an SDS, and his SDS was saying, 'Go to a day service.' His mother rang Janet and said, 'Is that it?' and Janet said, 'That is not it. There is a whole lot more.' But, when you have the school system just shunting these students into that, we've got a lot to do in terms of education and employment. We also see a major disadvantage in health and mental health. In Victoria, we've got a royal commission into mental health. We've made a submission there. Suicide rates amongst autistic people in the UK will tell us it's eight times greater than that of the general population. Startlingly, some stats from the UK showed that primary-school-age children were 28 times more

likely to think about suicide. That is just crippling. We need a strategy for health, mental health, justice, schools and education.

**Senator CAROL BROWN:** The discussion around a national autism strategy has been ongoing for many years. Where are we up to with it?

**Ms Sharkie:** We know that's one of your main purposes with this inquiry.

**Senator CAROL BROWN:** Could I rephrase: what's the stumbling block? Why hasn't it been taken up by government?

**Ms Sharkie:** I would say there are two reasons. One is that, I guess, there hasn't been a focus. The same thing occurred in Victoria. It wasn't until the parliamentary inquiry that it really got on the agenda. In my time in working in this sector, which is seven years—

**Senator CAROL BROWN:** Thirty-one per cent of NDIS participants would focus me.

**Ms Sharkie:** Yes; I would say so. The stats are there. As I say, with the ABS statistics on autism in Australia, we see the low education outcomes. That is not moving. In the five surveys since 2010, that is not moving. Employment participation is not moving. We see disability employment services and, anecdotally, they just don't understand autism. We had the example of a young woman in a regional area of Victoria. She went to a disability employment service. She wanted to work with animals. She was selectively verbal. The disability employment service said to her, 'You would need to have a support person to work with you at that employment.' From my point of view, I don't think animals do too much talking, so we couldn't really understand why she couldn't work with animals and needed a support person. Also, she was able to drive. She had a driver's licence. Again, there's the stigma and preconception. We see that NDIS planners don't understand autism, we see that schools don't understand autism and we see that employers don't, and we know we have a job to do. We have disability employment services that do not understand autism, when it's such a big proportion of the population. There was the mother of the young man who Janet spoke to. It should be understood in the disability employment service. We just don't have the understanding.

**Senator CAROL BROWN:** Obviously, a national autism strategy would be an overarching one across the states and territories. Do you know the reactions the states and territories have to the view that there needs to be a national strategy?

**Ms Sharkie:** In Victoria, there is the state disability strategy, and the autism strategy would fit in with that. The same domains of that will be—

**Senator CAROL BROWN:** And, of course, there is the National Disability Strategy.

**Ms Sharkie:** In Victoria, we've got a state disability plan that the autism plan fits in with. We think that's a replicable model for the National Disability Strategy to fit in with an autism strategy. It can be done where there are the same domains in both strategies and measures and indicators that will be around those domains.

**Senator CAROL BROWN:** The National Disability Strategy has been there for many years now. So your organisation believes that we need a separate national autism strategy?

**Ms Sharkie:** We do.

**CHAIR:** Senator Brown, we have just run out of time.

**Senator CAROL BROWN:** You said that there is a big job to do. On notice, could you put down some points as to what you think is required?

**Ms Sharkie:** To get a national autism strategy?

**Senator CAROL BROWN:** When you said that there is a big job to do, those measures that you were talking about.

**Ms Sharkie:** Most happy to come back to you.

**Senator CAROL BROWN:** And whether the national helpline is 24/7 Australia wide.

**Ms Bailie:** It is 8 am to 7 pm at this stage.

**Senator CAROL BROWN:** Australia wide?

**Ms Bailie:** It will be by May. We will be expanding that to suit WA, even though the Department of Social Services early intervention helpdesk never changed their hours to help us. They were in WA and we couldn't ring them till midday.

**CHAIR:** Maybe if Senator Brown has anything else, we can put those on notice for you. Sorry; I am just trying to keep to time today. I was interested to hear Ms Hayden talk about the importance of having real-life

experience when it came to talking about autism. Could you guys give me a one-minute summation of your real-life experience with autism, because obviously you guys are driving it quite heavily down in Victoria, just so we better understand.

**Ms Sharkie:** Prior to taking this role as CEO of Amaze I had no contact and no exposure to autism. So that's very limited.

**Ms Bailie:** Mine has been extensive disability in general, but I've always had a special interest in autism. When I did my postgrad studies in disability, I did studies in autism. I very much went to those subjects. It's just always been something that I've had a connection to. I think it's that hidden disability that I think Chloe has kind of touched on that. You've got to understand and click in with how someone is thinking. You can't enforce what your outside is; you've got to work with where they're coming from. It's not obvious for autistic people, because it's not like, 'Oh, you're in a wheelchair,' or 'You've got a vision impairment.' You've got to get on a different level. I guess that's what I've always liked.

**Ms Sharkie:** Janet has also worked in adult services.

**Ms Bailie:** I've worked in those services. I've worked in CRUs, in respite services and at outdoor camps for kids with a disability.

**CHAIR:** Ms Hayden, when were you diagnosed?

**Ms Hayden:** I was diagnosed when I was 12, almost 13.

**CHAIR:** What sorts of interventions did you get when that happened?

**Ms Hayden:** I didn't have any interventions. Growing up, mum and dad always just called me their weird, quirky kid. They were young parents and they didn't know anything about autism. I had a lot of trauma growing up from other things, so they never expected it. They just thought it was PTSD; they didn't think it was autism. They were just like, 'Oh, she's struggling because of this and this,' and they didn't think it was autism based. When I did get my diagnosis, I was struggling a lot at school. Like Fiona said, I'd been to 10 different schools by the time I was in year 8.

**CHAIR:** Was that because of school refusal or—

**Ms Hayden:** Partially because of school refusal and partially because I was getting severely bullied by both students and teachers. I would come home most days having been beaten up, being locked in lockers and unable to attend school. This was even before my diagnosis. It was just because of the way that I was and because of a refusal to change and accommodate. Growing up, there was a lot of time, particularly in years 5, 6 and 7, where my mental health was really, really bad. Eventually, one of my teachers brought my parents to the school and said, 'We need to speak about your daughter. She is not coping, and you need to do something about it.' So we went to a psychologist and got brain scans and did all of that and then we went to psych and she diagnosed me as being autistic. The only intervention I guess you could say that I had was that I got kicked out of school. The psychologist said, 'If your daughter spends another week in school, you will not have a daughter anymore.'

**CHAIR:** You are an incredibly articulate and impressive young woman.

**Ms Hayden:** Thank you.

**CHAIR:** I listened to what you said about functional labels and them not having any really impact or effect, or they were something we shouldn't use. For some of us who have children, I will say at the more severe end, because the autism spectrum is a spectrum that goes from level 1 to level 3, and for parents that have children in particular at the level 3 end of the spectrum, who are potentially non-verbal or minimally verbal, who have complex behaviours, who have additional—I didn't ask you and it's not for me to do about additional diagnosis—but people who have additional diagnosis of intellectual disability, ADHD, anxiety or depression disorders et cetera, the quite common comorbidities with autism, isn't it a little bit denigrating to those to dismiss the additional challenges they have? Because their challenges are more significant and more severe, and their ability to articulate, as you have, is non-existent.

**Ms Hayden:** I understand that. I was non-verbal until I was 16. I couldn't speak. I learnt how to—

**CHAIR:** You were not verbal to 16, but you were diagnosed at 12—

**Ms Hayden:** Sorry, I was partially verbal. I could speak to my parents and that was it. Even then it was usually movies quote, song quote, stuff like that.

**CHAIR:** So quite echolalic.

**Ms Hayden:** Yes. Again, it was because we had absolutely no understanding of autism. Autism wasn't a thing that people really understood or knew about. I came from a very small country town. Autism just wasn't known. I

do understand, as a parent of someone who has a different type of autism than I have, that it's a spectrum. But at the moment people are looking at it as a linear line, like 'he's low functioning, he's high functioning'. Autism isn't a linear a spectrum. Autism is a colour palette spectrum. It's a soundboard spectrum, where every single person on the spectrum fits into a different part.

Like I said, I was non-verbal until I was 16. I also have ADHD and some other mental health things as well. There'll be some days where I cannot leave my house. They'll be some days where I go non-verbal again. There are some days where my parents need to feed me and dress me and shower me because I physically cannot do it. On those days you would look at me and say 'she's a low functioning autistic person.' Just because of what someone else says and just because of what someone's abilities are, because of the society that we're put in and because of what their external things are, doesn't change that person's inner abilities. It doesn't change what that person is worthy of and capable of when they're put into an environment where they have the ability to succeed. I understand that there's a DFM for a reason. I understand that some people are level 1 and some people level 5. But function labels are harmful. Using these functional labels and saying someone is high-functioning because of the stereotypes and because of the signals that we've put on those function labels means that those that are considered high-functioning like myself, that my struggles, those days where I can't dress myself or I can't feed myself, where I can't even get out of bed without crying or I can't speak to anyone, diminishes and degrades what those capabilities are.

**CHAIR:** I understand. There's an expression with regard to high and low functioning that just because someone's high functioning it's not how they experience their autism. It's how you experience that autism. I very much understand that. But quite often we don't have huge amounts of time or people that—we've heard you saying that most people don't understand what autism is. So by at least having less sensitivity around, particularly for people who are at the most severe end—I understand that Senator Steele-John has a problem with the word 'severe', but I can tell you that when you live with severe autism you don't have a problem with the word 'severe'. Pretty much neither does the person with the severe autism, because that's what they have. Their ability to communicate, participate, engage socially, the isolation, all of those things—so I just want to be really mindful that we do have level 1 that are, for lack of a better term, high functioning, who are employed, who can participate in society, who may be experiencing some challenges around sensitivity, sensory issues et cetera, communication. I appreciate that. But we also have at the other end of the spectrum people who cannot represent themselves, who cannot articulate themselves, who cannot participate because their impairments are severe. So I just want to make sure that we don't gloss over and denigrate those families who are suffering from significant challenges over a debate about language, because that I find incredibly denigrating to families experiencing it.

**Ms Sharkie:** I guess what we would say in terms of the word 'severe' or the language around severity is that we would say the autism impacts them severely, rather than 'severe autism'.

**CHAIR:** But when you're a parent wiping poo off the wall—

**Ms Sharkie:** Absolutely.

**CHAIR:** you call that a severe behaviour. You're not worried about what the impact of the word is, I can tell you. I think we need to respect those families and not get too hung up on the politicisation of language rather than actually helping these people, because I think that's why some people get a little caught up on. I want to have a quick touch on the hotline. That's in conjunction with the Autism Awareness Australia?

**Ms Sharkie:** Autism Awareness Australia are a partner in Autism Connect with us. They are delivering a specific tool, which will be an online tool, for autistic people and families of younger children to help them navigate their first year of diagnosis.

**CHAIR:** That's awesome. My child's autism was picked up when my mother literally read the brochure that Autism Awareness put in the *Women's Weekly* about what the signs were. My mother read that in a doctor's surgery and called me and said, 'Do you think your son could have autism?' So I'm pleased that they are involved in that. We lived in a small country town, too, and I didn't know what autism looked like. In fact, I rang up and said 'Some people are being very unhelpful that Fred has autism. I don't think so. Who do I go and see exactly?'

**Ms Sharkie:** Exactly. So many people—

**CHAIR:** And we're level 3. We weren't dipping our toes. So thank you for their brochures. That sort of information will be really helpful to have. When you do talk to parents and they call the Autism Connect line, when you talk about guiding them to services, what sort of best-practice guidelines do you use? Do you have a best-practice set of guidelines? When my son was diagnosed, they changed the word 'best-practice guidelines' to 'good-practice guidelines' for some inane and obscure reason. But there was a list of therapy options, and they were ranked as what was research and evidence based. Is there a document that exists like that? Is that something

that you utilise? Do you utilise the Raising Children website, which has good data? Because I think a lot of the time we're reinventing the wheel here. What sort of information do you provide knowing that you're giving best-practice information?

**Ms Sharkie:** I might go first on the bigger picture, and then Janet can go on the practicalities. Yes, we do refer to Raising Children and things, but you may be aware that the NDIS is just commissioned the Autism CRC to do a complete review of early intervention. It looked at the latest evidence that is most up-to-date and all the different early interventions—

**CHAIR:** It's a 500-page-plus report. I've got a copy of it in my office. I believe they're going to do a summary version, which would be very good.

**Ms Sharkie:** A very helpful one or two pages on what best-practice therapies are therapies are would be highly beneficial, I think.

**Ms Sharkie:** Absolutely. We're very pleased to see that latest evidence and the rigour that went around that and also that what it determined was the level of dose was—

**CHAIR:** Intensive, quality early intervention.

**Ms Sharkie:** Yes.

**CHAIR:** It's funny that we knew that quite a while ago, but we're still finding it.

**Ms Sharkie:** I think for those specific ones. Autism Connect is evidence based, absolutely. When I came to Amaze, people said to me 'autism is a quack magnet'. There are so many quacks that there. People google 'autism' and you don't know who else might be. But Janet can speak to that.

**Ms Bailie:** We're absolutely not recommending anything that is harmful. We do direct people to the therapy guide on the Raising Children Network, because it does have that rating of what the evidence is of each therapy approach. Generally, under the old Helping Children With Autism funding package—did your son have that?

**CHAIR:** I have one of them. It's a nice gesture when your therapy costs over a hundred grand a year. Six grand a year makes a huge impact.

**Ms Bailie:** Twelve grand.

**CHAIR:** Twelve over two years, because the autism goes after that!

**Ms Bailie:** I know. Thank goodness for the NDIS, really. Under that, the speech pathology, psychology and occupational therapy were the three therapy interventions that were approved to be delivered.

**CHAIR:** And behavioural therapy.

**Ms Bailie:** Yes, but delivered by a psychologist, OT or—

**CHAIR:** We had stuff delivered by BCBA.

**Ms Bailie:** Under HCWA?

**CHAIR:** Yes.

**Ms Bailie:** That's good.

**CHAIR:** I know there was a push by those three allied health groups to ensure they got exclusive access to it, but no, BCBAs were included. When you go back through and look at Professor Whitehouse's and the CRC's recommendations, behavioural therapy is at the top of the list of what we need to be doing. There's a misunderstanding of what the word behaviour means. I remember—I think this is important—going to a government funded organisation at an early days workshop, who said, 'Because your son doesn't have behaviours, you shouldn't do behaviour therapy.' I'm sorry, but drinking a bottle of water is a behaviour. Washing your hands is a behaviour. Anyone that should be involved in autism needs to understand what behaviours are. I find it absolutely extraordinary that we are still dealing with government funded organisations who don't understand not only that behaviour is everything we do, but they don't understand what behavioural therapy means. It is not punitive; it is not moving people. It's providing support and understanding of functions of behaviour. I think we need to have a little more extensive conversation around that.

**Ms Bailie:** Yes. They think that behaviour is just the challenging behaviour—the hitting out, the smearing, that sort of thing—

**CHAIR:** Yes, that that's the only thing that is a behaviour.

**Ms Bailie:** As you say, it is actually everything we do the whole time.

**CHAIR:** I'm going to probably put a few questions on notice to you at this stage, but I just want to finish with this one. You guys aren't service provider, are you? You are the leading advocacy body in Victoria—am I correct?

**Ms Sharkie:** Yes.

**CHAIR:** We have a situation in New South Wales where the leading advocacy body is also a service provider, fundamentally diagnosis to grave. I have a real issue with that, because to me there's no incentive to move people out of your program if they're the next cheque you're receiving from the special early intervention program, special school to day program or whatever it might be. Why improve people's lives if you can keep them as a cash cow for their entire life? What's your view on that?

**Ms Sharkie:** I think a big part of our bid for the national information line was that we weren't a service provider. So there's nothing in it for us to recommend—

**CHAIR:** You're not referring people to yourselves.

**Ms Sharkie:** No. There is absolutely nothing: not referring to us, not referring to anyone else. Again, we give people the information to make their own informed decisions. That's what we do. This has been a thing within the funding of the NDIA that I think they've grappled with the ILC funding, to say, we'll give it to a service provider, but it's really not a service provision thing.

**CHAIR:** It's really a linkage or communication.

**Ms Sharkie:** I think that's something to be worked out.

**CHAIR:** Thank you so much for your time. We've gone over time a little, and that's my fault. I will catch up with you. I think it's important. I think you're back tomorrow with Australian Autism Alliance?

**Ms Sharkie:** I'm also the co-chair of the alliance, so we will be back tomorrow.

**CHAIR:** We'll talk about that then. That will be very helpful.

**Ms Sharkie:** Thank you and we look forward to your questions. Thank you, Senator Brown.

**LEIF, Dr Erin, Vice President, Autism Behavioural Intervention Association**

**PAVEY, Ms Susie, CEO, Autism Behavioural Intervention Association**

[10:27]

**CHAIR:** I welcome the Autism Behavioural Intervention Association. I understand that information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. I now invite you to make a short opening statement, and at the conclusion of your remarks I will invite members of the committee to ask questions.

**Dr Leif:** Good morning. On behalf of all of the team at ABIA and our members, who include families and service providers, thank you for inviting us to provide evidence as part of this inquiry. Currently there is a high demand for safe and effective educational and behavioural supports for people with autism in Australia. The Australian Bureau of Statistics estimates that almost 70 per cent of Australians with autism have a severe or profound disability, and over half of Australians with autism are not receiving the services that they need. Unfortunately there is a significant shortage of skilled professionals to meet this demand. In addition, the autism intervention market is booming, which can make it difficult for families to identify those therapies that are supported by the best available research evidence.

The Autism Behavioural Intervention Association was founded 25 years ago by a group of parents who were unable to access evidence based interventions for their young children with autism. This group set up early intervention services and programs for young children in Australia in partnership with researchers and clinicians from around the world. Today our mission is no longer to deliver services, but rather to share information about safe and effective educational and behavioural supports for people on the autism spectrum. We do this through advocacy and training. Our training programs, which are designed and developed by ABIA, provide professionals and parents with practical skills to deliver a range of evidence based supports. The evidence based supports we strongly advocate for are underpinned by the science of applied behaviour analysis and include models such as early intensive behavioural intervention, the early-start Denver model, positive behaviour support and school-wide positive behaviour interventions and supports. Such supports, when delivered by teams of well-trained professionals and parents, have been proven to promote the independence, inclusion and community participation of people with autism and related conditions.

Each year ABIA trains over 700 people, including educators, allied health and medical professionals, support workers and parents to deliver evidence based support. Since the organisation formed in 1997, ABIA trained professionals have supported thousands of Australian families in homes, child-care centres, schools and community settings across the country on a daily basis. Professionals trained by ABIA support autistic individuals' learning and development as well as the family unit.

Recently, in response to COVID-19, ABIA moved its face-to-face training workshops online and expanded its suite of self-paced online trainings. We anticipate that this recent pivot to online training will allow us to extend our reach across Australia and do more in regional and remote areas where access to training is noted to be scarce.

We also advocate more broadly for evidence based support for autistic people. We do this by providing timely and free information to families and professionals about safe and effective interventions via our website, our parent advocacy packet, our biannual conference and our professional development events. We are also creating a new way to connect to families, service providers and therapists through our ABA Connect therapy directory. The goal of ABIA Connect is to make it easier for families to find and access evidence based services in their area. We are happy to answer any questions that you have about ABA or the models of support that we advocate for, and we are grateful for this opportunity to speak with you this morning.

**CHAIR:** Thank you. Ms Pavey, did you have anything that you wanted to add?

**Ms Pavey:** Not at this stage.

**Senator CAROL BROWN:** I'm sorry, I missed the first couple of moments of your statement. Do you receive federal government funding or any government funding?

**Dr Leif:** We don't.

**Senator CAROL BROWN:** How would someone train as an ABA professional? Where do they go to do that? Is there a university based program?

**Dr Leif:** There are lots of layers. It's a tiered model of support. At that entry level we provide training for people who may work as ABA therapists or who are parents or educators who may be participating on a team to deliver services to children or students. That training typically happens within the context of a training organisation like ABIA. We offer training that allows people to become a registered behaviour technician, or

RBT, which is an entry level credential in applied behaviour analysis. At the university level we offer a postgraduate degree in applied behaviour analysis for individuals who want to go on and become professionally certified as a board certified behaviour analyst, which is a credential that is considered indicative of professionals who have met a minimum standard of competence in the delivery of ABA based programs, not just for autism, but for individuals and organisations with a range of needs. So it is a tertiary education qualification, and there are course sequences that are verified by an international body that meet those requirements.

**Senator CAROL BROWN:** What obstacles do the professionals that practise ABA say that there are? I'm thinking of what we've heard about issues around the education setting and health setting.

**Dr Leif:** We conducted a large-scale national survey of ABA practitioners in Australia last year. We're currently writing up the results for publication. We asked them specifically to tell us the largest barriers that they face when designing and delivering ABA based programs in Australia. The number one barrier was access to high-quality training, supervision and support on the job. We're a young workforce or an emerging workforce. We need to make sure that professionals are practising within the scope of their competence. That means that they need supervision. That's also a requirement to maintain your credential. They find it quite difficult to access high-quality supervision from expert clinicians who have been working in this space for a long time, given the lack of people that are professionally credentialed in Australia. Other barriers relate to being able to have their credential recognised more formally by the government, feeling like they are constantly having to self-advocate for the profession.

**Senator CAROL BROWN:** What does that mean—recognised more formally?

**Dr Leif:** Currently the board certified behaviour analyst credential is international. It's awarded by a credentialing body that sits in the United States. As Holly mentioned previously, that BCBA credential was recognised on the Helping Children With Autism package documentation as a credential that was recognised to deliver evidence based services. However, when that program came under the umbrella of the NDIS, the BCBA credential was no longer recognised in any NDIS documentation or pricing guides. So there's been confusion about whether or not BCBA's are actually eligible to be registered providers with the NDIS and to deliver evidence based services. What we're trying to do is set up a working group under the umbrella of the Australian Association for Behaviour Analysis to establish a national system of self-regulation of ABA professionals, firstly so that parents can identify those professionals that have the appropriate skills to deliver such programs; secondly so that we can contextualise an ethics code in an Australian context and enforce our code of ethics; and thirdly so we can start to lobby government to recognise behaviour analysis as a distinct profession in Australia that is different from psychology and different from education.

**Senator CAROL BROWN:** How long has this association been operating?

**Dr Leif:** Our association?

**Ms Pavey:** ABIA—25 years; but the American association, the credentialing board—

**Dr Leif:** The ACB credentialing board since 1998, and the Australian Association for Behaviour Analysis since 2014, I think.

**Senator CAROL BROWN:** I'm just trying to get my head around this. You've talked about lobbying so you're recognised, an Australian credentialed recognition. What's the issue?

**Dr Leif:** First of all the issue is numbers. We're a small group. Currently we have, I think, about 122 board certified behaviour analysts in Australia, compared to 45,000 in the United States. We have additional layers of credentials. The credential is also in other countries as well. I don't have the exact numbers. We also have maybe about 100 registered behaviour technicians at this stage. We have small numbers, so we just aren't the loudest voice at the table. We're not recognised under AHPRA at this stage. AHPRA keep their professions under a really tight lock and key, so they're quite resistant to adding new professions into their circle. What we're really looking at doing at this stage is following the model of Speech Pathology Australia to become a self-regulating profession.

**Senator CAROL BROWN:** I want to go to your first recommendation, which talks about establishing national autism reporting requirements. Can you elaborate on what you mean there? What form do you think that should take? Do you support the call for a national autism strategy?

**Ms Pavey:** We do. We've got that as one of our recommendations. Obviously, the autism strategy is really important. We want families, carers, people with lived experience and the like to have the opportunity to be heard.

**Dr Leif:** In terms of your first question, I think you asked about a national autism reporting requirement.

**Senator CAROL BROWN:** Essentially, I want to know what sort of form—you and other submissions talk about the need for data on diagnosis and how it needs to be clear and collected, which is not happening. So I just wanted to know your view. You talked about this reporting.

**Dr Leif:** We're not really in the diagnostic space so much. We know there are other professionals who are well skilled in diagnosis and are doing quite a bit of work in that area. Our space is more around being accountable for the interventions that are delivered for people with autism today.

**Senator CAROL BROWN:** What do you mean when you say 'establish a national autism reporting requirement'?

**Dr Leif:** We need information about how many Australians have autism and how many people are actually getting the support that they need, and what are the barriers that people with autism and their families face in accessing the NDIS, knowing where to turn to get good information about services, and also knowing what interventions are promoting more longer-term improvements and enhancements in quality of life. Across the board, when it comes to autism, we don't have great long-term studies with follow up data. Those are hard studies to do for a lot of reasons. But we need those data. We need to be demonstrating that intervention effects are not temporary, but they actually bring about meaningful long-term benefits for the person at the centre of that process. A national database could help us work collaboratively to get that information in one centralised area, to be able to share and address important research issues.

**Senator CAROL BROWN:** Publicly share? Data collected that is made public?

**Dr Leif:** We have to respect confidentiality. That's always a big thing in doing research. But if there are ways that we can look at working with people like the Australian Bureau of Statistics to summarise those data and make those summaries publicly available, that's important. We need to be doing that.

**Senator STEELE-JOHN:** I take you to page 5 of your submission, where you talk about a fear that public misinformation and mischaracterisation of ABA may lead to policy reform and government positions that prevent people with autism from accessing effective interventions. Can you explain a bit more about what misinformation you are referring to there?

**Dr Leif:** One issue that we encounter is that applied behaviour analysis is often represented as a single intervention for autism amongst many different interventions. When we use the term ABA therapy, we've dug ourselves into that problem a little bit. It's actually not really the correct way to think about ABA. I don't even like to use the term ABA. Applied behaviour analysis is a framework for delivering a range of different evidence based educational and behaviour support practices. Within the framework the central components are that we conduct an objective assessment with the clients to determine their strengths, their preferences, their goals and their needs. We include the person and their family in the planning process and design individualised support plans to help them meet their goals. We use a variety of different evidence based tactics in the program, some of which focus on teaching new skills, some of which focus on changing the environment around the person, and some of which focus on working collaboratively with caregivers, parents, teachers and others to change their behaviour and how they interact with the person with autism.

Finally, there's an emphasis on ongoing data collection and data analysis to help us understand when the strategies are working and bringing about meaningful improvements for that person; but more importantly, to help us detect when what we're doing is not working and needs to be changed. So really, there's this emphasis on data driven decision making.

That is not one type of therapy for autism. That is a holistic framework. Under the umbrella of that framework we can deliver speech pathology interventions, occupational therapy interventions, educational interventions. In our study that we conducted last year, we identified about 20 different evidence based teaching tactics that ABA professionals were incorporating into their programs, and about 10 to 15 behaviour support strategies.

The problem is that ABA is represented as but one of many different autism interventions. The question then becomes, should we do ABA or speech pathology? Should we do ABA or occupational therapy? That's the wrong question. The question is: under what conditions should we do both applied behaviour analysis and integrate speech pathology and occupational therapy into the framework?

Parents often struggle. Parents told us as part of our survey that they often struggle when speaking to the NDIS about the support that they want for their child when they are looking to get ABA based interventions. They've heard things from NDIS representatives, such as ABA isn't evidence based; ABA is harmful; ABA is too expensive; and ABA isn't necessary—the gains don't generalise of the gains aren't important. Those are all misconceptions that are actively being disseminated through a government organisation. That needs to change.

**Senator CAROL BROWN:** You mean the NDIS?

**Dr Leif:** Yes.

**Senator STEELE-JOHN:** That's very interesting. Thank you for that. Could you help me understand the approaches a bit more. You said you conduct an assessment. You call it an objective assessment. And one of the things that it looks for is people's strength. Did I hear that correctly?

**Dr Leif:** You are correct.

**Senator STEELE-JOHN:** Given that an assessment of somebody's strengths is inherently a subjective view and is very socially contextual, how does one go about an objective assessment of that?

**Dr Leif:** That's a really good question. I agree with you: it is a social construct. These assessments are evolving to make sure that we're collecting information in a lot of different ways. It's not just one thing. Part of that assessment is going to be time spent speaking with the person with autism or the key people around the person with autism to determine what they view as their own strengths and what others view as their strengths. In addition, what are their values? What do they want to accomplish? We call that an indirect assessment. That really relies on the use of open ended interviewing to get to know the person.

But often we work with people who don't have the vocal verbal behaviour or speech to readily answer those questions. In those cases we have to rely more on observational assessments. We might set up a context where we're engaging with a young child who doesn't have speech. We are enriching the environment with a lot of activities and things that others have reported that they think the child likes. Then we let the child play and observe where the child chooses to allocate their time. We look for things like gestures, other behaviours that could be indicative of communication, and we use that as indicators of what the child's strengths and preferences might be.

We also use developmental scope and sequence assessments, where we present learning opportunities to the child. We observe what the child can do independently, what they can do with some help, and what they're not demonstrating independence or they're actively trying to avoid or get away from. We use all of that data combined to paint a picture of the person's strengths, preferences and goals.

**Senator STEELE-JOHN:** Thank you very much.

**CHAIR:** Thank you for being here. Why do you think that we've got so many misconceptions about what behaviour is and people who purport to be educators around autism in early days workshops et cetera having zero comprehension that behaviour is everything we do, not just a bad behaviour?

**Dr Leif:** It's not content that's integrated into tertiary education courses.

**CHAIR:** We've got the biggest cohort of people with disability, with autism, in the NDIS. We've got a situation where we know we're getting almost one in every classroom. There'll be an autistic child in every classroom. We're still not educating teachers how to understand this. We're not educating teachers about what behaviour. It's not just autistic people who have behaviour. It's all of us, too.

**Dr Leif:** Right.

**CHAIR:** As someone who has relied on behavioural therapy for a long period of time, I can tell you that it works pretty well for non-autistic kids as well, and understanding their function of behaviour. I want to talk about the data. One of my frustrations around the early intervention early pathways with the NDIS is that we really don't know how those funds are being used. We don't know what sort of follow-up is being done. We don't know if we're fundamentally throwing good money after bad. What we do know is that if you go to a speech therapist or an OT, it's not so much about what happens in that session; it's about teaching the parental carer what to do during the week. You go to a speech therapist for an hour, but you don't go home and read Mr McGee 25 times, as instructed by the speech therapist, to learn about predictive text. That's not going to be a skill that child develops in that one hour speech session. It's when they develop over the 25 times it's read during the week. Why do you think there is a reluctance to taking of data, when it could inform all of our decision-making processes so much better?

**Dr Leif:** The first thing I want to mention is that I think we have here the wicked problem of choice and control. Is that it? I think it's the right thing to do. I think autistic people deserve to choose how they want to be supported. But then we have to accept the fact that people are going to be choosing supports that maybe aren't supported by evidence or there's no data. We're relying on the person experiencing those interventions to tell us how they're helping them. That's valid in and of itself. When it comes to data collection more broadly in the provision of evidence based supports for people with autism, it's hard; it's time consuming—

**CHAIR:** But there are apps now, Helper et cetera, that can work between service providers, that everyone can know what page everyone else is on, that everyone can identify what skill you're working on, whether it's toilet

training, crossing the road, use of money, practising appropriate conversation, whatever it might be. Every service provider, every support worker can say not only what's being worked on, but when it was last worked on, what were the successes, what were the deficits, all of those things? Why wouldn't we be looking towards that? And do you think there would be benefiting us doing so?

**Ms Pavey:** Absolutely. ABA programs are comprehensive, and the intensity of ABA programs means that you have that team of people around the child early on that are collecting that data. It's also time-consuming. We don't have enough professionals currently in Australia that are trained to be able to deliver the intervention and take the data in this manner. But also other allied professionals are not trained in that way, in the way behaviour analysts are.

**CHAIR:** So speech therapists and OTs don't tend to take data on the successes.

**Ms Pavey:** They take data.

**Dr Leif:** It depends. The thing is that there's so much variability.

**CHAIR:** It depends on the quality of the service. There are OTs that like to sell you earphones to listen to music that will cure autism.

**Dr Leif:** That's a problem.

**CHAIR:** A few of us have experienced that one. That's a cracker. It's right up there with chelation, in my view.

**Dr Leif:** At least among the folks that I surround myself with, we say that extraordinary claims require extraordinary evidence. So people saying that by listening to music you're going to cure autism should be the ones that we're asking for the most robust data to demonstrate the effects of that type of thing. Like Susie said, I think it's a training issue. There just aren't enough professionals who have had exposure to this type of program design and the importance of letting the data guide the decision-making process.

**CHAIR:** Are we getting away from the term ABA? There are voices within the autism community who have never actually had behavioural therapy, but are quite often diagnosed as adults or are self-identifying, yet object to ABA on the grounds that it is somehow punitive, which is, quite frankly, offensive. But to come back, when you talked about how you assessed that child, it's fundamentally play based for early childhood—would that be correct?

**Dr Leif:** Yes. Another point of confusion that has come up within our field is the idea that ABA is behaviourally based, whereas there's another class of interventions that are naturalistic, developmental, behavioural interventions, which implies that just doing ABA isn't developmental or natural, which is incorrect. One of the most commonly used teaching strategies is what we call 'natural environment teaching', where teaching occurs in the context of everyday activities. What makes it different from just parenting is that it's systematic, it's planned, skills are broken down into small teachable components, there's a systematic way to give the child some help and to then gradually fade out our help over time, and there's a method of data collection so that we can ensure that what we're doing is effective. You could say that a lot of what you're recommending is just what parents should do. Of course. But parents don't do that as a systematic therapy. We're trying to make it a systematic, holistic program—

**CHAIR:** You'll be able to correct me, but handwashing—is that nine or 11 steps? It's taught in a backward, chained way. It's one of the first ones we learnt.

**Dr Leif:** It's all individualised.

**CHAIR:** That's the one that most people don't understand. But it is based on positive reinforcement.

**Dr Leif:** Of course.

**CHAIR:** You would teach it with the positive reinforcement being at the drying of the hands, because that's the closest part of a successful completion of a task, and you would work backwards to the recognition of when your hands need to be washed, with every step in between, which would include turning on the tap, putting the soap on, washing your hands together, rinsing your hands. All of those steps are then taught individually, one by one, with data collected and positive reinforcement, whether it's time to play with Thomas the Tank Engine or time on the iPad. One of our positive reinforcements was going to play with mum. It is actually play based. It is positive reinforcement based, and there's no punitive nature to it. So, there are misconceptions around this framework. To be honest, teaching someone to wash their hands is an IT program that you're just teaching using the framework of behaviour analysis.

**Dr Leif:** Exactly.

**CHAIR:** We've got a lot of misconceptions out there and we've got a lot of deliberate misinformation about what the framework is.

**Dr Leif:** I think positive reinforcement is also misunderstood.

**CHAIR:** I know very well what positive reinforcement is, but could you explain the concept of it.

**Dr Leif:** Sure. We often conflate positive reinforcement with the delivery of rewards. A reward is a thing, right? It's something that we think is kind of cool, kind of nice, that the person really likes, and we're going to withhold it and only give it to them when they do what we want them to do. That's not positive reinforcement. Positive reinforcement is a process whereby some event that follows the behaviour strengthens that behaviour. Positive reinforcement affects all of our behaviour all of the time. It's what we call a basic principle of learning.

When we design programs for kids with autism, sometimes we have to rely on what we call more artificial reinforcers like iPad time or access to Tiny Teddies. But what we're really trying to do is pair those arbitrary reinforcers with more social, naturalistic reinforcers—social praise, recognising when a task is complete, feeling proud of your own accomplishments—and establish what we find reinforcing as a reinforcer for young children with autism, who often haven't quite developed those classes of social reinforcement.

**CHAIR:** Due to developmental delay. I think that, sometimes in the criticism of this, we're not acknowledging that there is significant developmental delay, where you have kids who are two or three years of age whose developmental age is six months—and that's only because six months is the lowest the assessments go. How do we address this? I know that there's pushback within the NDIA around this. They keep telling me that ABA is clinic based. Honestly, when I was told that last time, there was a very big folder put down with 40 hours of data taken in a home setting in one week, and I asked how that's not naturalised, generalised teaching in a home based setting.

How do we overcome this? Clearly there's a distinct bias. We've got voices and views of people that have never experienced it, don't understand it and are not clinicians. They are self-declared, without the clinical experience, yet they are influencing what we know is evidence based and what we know is best practice. In fact, I asked the question previously about what guidelines they use. ABA was the top evidence and research based therapy in the good practice guidelines that I have. That hasn't changed. Every insurer in the US is now required to fund ABA because it is recognised in the US as the best evidence and research based framework for autism therapy. Why is it here? It's not in Germany. It's not in the US. It is not in Ireland or the UK, where there is broad acceptance and understanding of this being one of the most effective frameworks for early intervention. I'm just going to call it behavioural therapy with data. Why is it that in Australia we allow these fringe voices to come through. They don't have personal experience and aren't clinicians, yet they seem to be influencing the broadest, most significant disability service provided through the NDIA. Why is that happening, and how do we address it?

**Dr Leif:** Great question. First, I think it's important to note that those voices are coming from people around the world. I don't think this is a unique scenario that we're facing in Australia. I also want to say that people with autism should be empowered to have a voice at the table and that we should listen to them, and I'm glad that this Senate inquiry offers an opportunity for that to happen.

**CHAIR:** But when you're talking about a two-year-old child or a three-year-old child who's non-verbal, where's the voice? We seem to be unable to distinguish between the adults who are capable of articulation, who never had these sorts of therapies and who have a more dominant voice than particularly the parents—parents are constantly dismissed by this group—and the children themselves, who have no ability to communicate for themselves. And, even if they weren't autistic, they wouldn't, because at two or three you're not self-determinant. Why is it then that we have adult voices, who never experienced it, diminishing the role of parents and undervaluing and taking away from the need to give that child support, particularly at the most severe end of autism? They are diagnosed by two or three. They aren't those who were diagnosed, or self-identifying adults, in their 20s. These are kids who were diagnosed very early in their life. Yet somehow or other we denigrate their experience and their need for proper supports and interventions because it doesn't fit with the viewpoint of an autistic adult who never experienced the therapy personally or who is not a clinician or who is not professionally diagnosed.

**Ms Pavey:** There's a lot of work to be done with regard to the PR of applied behaviour analysis in Australia and what the evidence states. There's also a lot of work to be done with respect to raising more awareness and growing as a sector or as an emerging profession. We don't have a loud enough voice. We don't have or receive government funding. A lot of these groups will put in applications for the likes of ILC grants and receive millions of dollars—

**CHAIR:** I know of one that got a million dollars. They wrote to me and told me my son's therapy made him more vulnerable to sexual abuse and assault. If I find them getting another dollar, I would be the first person out there screaming. It is absolutely abhorrent—and the abuse that I get. I'm sorry.

**Ms Pavey:** I have members of our organisations that have gone all the way up to the AAT and received full funding and retrospective funding for their ABA programs once they've done the hard yards, proving that this program or choice of intervention is what they want for their child. That choice and control needs to be recognised. They've received full funding. But, again, it appears to be the families who have access to the knowledge and the education who are able to fight that fight to receive the funding. So, there's a lot of work to be done across many areas, but it primarily comes down to advocacy, funding and having a bigger voice.

**CHAIR:** Yes. Thank you very much for your time today.

**Proceedings suspended from 11:03 to 11:16**

**LEGGE, Mr David, Deputy Chair, I CAN Network**

**ONG, Dr James, Evaluation, Program Support and Policy Analyst, I CAN Network**

**SKALTSIS, Mr Adon, I CAN Network**

**SKALTSIS, Ms Gabrielle, I CAN Network**

**VARNEY, Mr Chris, Chief Enabling Officer, I CAN Network**

[11:16]

**CHAIR:** I welcome representatives of the I CAN Network. I understand that information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. I now invite you to make a short opening statement, and at the conclusion of your remarks I'll invite members of the committee to ask questions.

**Mr Varney:** Fantastic. We'd like to acknowledge the traditional owners of the land and pay our respects to elders past, present and emerging. Welcome to I CAN Network. We're Australia's largest autistic led service provider. We provide mentoring services to over 1,500 autistic young people in every state and territory now and around one hundred and twenty Australian schools in Queensland and Victoria. Our vision is a world that embraces autism. We provide autistic led group mentoring to nine- to 20-year-olds through online and school based programs and training and consultancy services to schools and workplaces.

As a proud autistic person and I CAN Network's founder, it was my own network's belief in me which helped me embrace an I can attitude and demonstrated to me how important it was for every autistic young person to have a network which believed in them. It's been this philosophy which has driven the growth of I CAN Network. Today you'll hear from Dr James Ong, who was my first ever supporter. You will also hear from Aiden Skaltsis, who is 16 years old, is autistic and has been in both our Parkdale Secondary College program and our national online program.

Our purpose is to prove what autistics can do. We are one of the leading employers of autistic people nationally. We have a 50 per cent difference: 50 percent of our staff must be autistic. In practice, we currently overwhelmingly exceed this. Today, we employ 59 Australians, 47 of whom have a disability. Forty-six of those 47 staff are autistic. Twenty-eight of the 46 autistic staff are autistic women. Twenty-two of the 46 autistic staff started their journey with I CAN Network as teenage participants in our group mentoring programs. We've developed them from training mentors in high school to now fully fledged staff running their own I CAN programs. For this group we have been a second home and a second family

Our philosophy at I CAN is that the autistic spectrum is a circular spectrum. Each of our mentees and autistic staff have their own unique area of this spectrum. We respectfully do not use functioning labels in I CAN network because at times such labels can create false assumptions. Instead, we use the language of support requirements, which is our personal choice. We use this because we know that everyone has their own unique strengths and support requirements.

As an example, amongst our staff there are autistic adults with high communication skills and at times crippling anxiety. We have staff who are non-speaking and whose different experience with communication has meant that they can arrange a typed message in an extraordinary way. We have some student mentors who are non-speaking and whose experience of schools and community has made them extremely courageous advocates for students with a disability.

The core belief behind my vision for I CAN Network, which James shared, was that an individual's autism or their connection to autism positioned them to connect with another autistic's experiences, such as their experiences with anxiety and processing differences, and connect with them in a powerful way. It's for this reason that the outcomes we seek in our program are self-acceptance, optimism, belonging and confidence. The key ingredient through which we achieve these outcomes is the storytelling and relatability provided by autistic mentors. Increasingly, we're seeing our programs become more diverse. We now run autistic girls programs in Caboolture, Queensland, and Northcote, Melbourne, where schools have requested autistic girls programs.

Senator Hughes, you and I last met on 19 July 2019—I love my dates. We discussed the opportunity for the national online program to cater more for autistic young people with greater support requirements and to be more interest based. I'm happy to report that one and a half years on, I CAN Network has positive results to share in these areas. When someone gives me a challenge, I like to stick to it. We run a primary school online program. I CAN Imagination Club. We run afternoon and evening sessions of online mentoring. We run identity based online mentoring for autistic and queer or LGBTIQ+ program. We run interest based mentoring for autistic young people who love anime, who love Minecraft, screens, tunes and characters and animals. We rapidly

upscaled our capacity to support the most vulnerable autistic young people during COVID-19. During COVID-19, our online mentoring service grew a staggering 300 percent. We delivered online mentoring to 919 young people nationally in 2020. Our graph to you on page 7 of our submission, which depicts March to May 2020, shows that 82 per cent of our participants during this time experienced high anxiety and just under 10 percent had an intellectual disability.

We were grateful to connect our young people for our AWETISM 2020 Virtual Expo, which engaged autistic young people in every state and territory in a wonderful celebration of the diverse strengths and talents of autistic young people.

We're positioning our national online mentoring program with its engagement now of 1,000 autistic young people in 2020 to become Australia's national mentoring program for autistic young people. We want this program to become Australia's premier initiative for facilitating positive identity in Australia's autistic young people. By the end of 2025 we see this program as the national platform through which the country can facilitate a strong sense of belonging for the emerging generations of autistic Australians. Achieving this in the short term will require an additional investment of \$1.5 million in I CAN Network to build up our management infrastructure to help us engage up to 3,000 autistic young people nationally per year by the end of 2023. With the right investment, we aim to engage 5,000 autistic young people per year by the end of 2025. I now welcome Adon Skaltsis, 16 years old, from Parkdale Secondary College, to share his opening statement.

**Mr Skaltsis:** Hi. My name is Adon Skaltsis. I am 16 and attend Parkdale Secondary College. I'm here today to tell you why I like I CAN. I first joined an I CAN group at my school. During the COVID-19 lockdown my mum organised for me to join the I CAN online mentoring program. I really liked the program on Tuesday nights. I met other people with autism and mentors like Chloe. I really looked forward to the I CAN sessions because the people were friendly. They gave me time to use my device to communicate. They asked me questions. They helped me feel comfortable. I could show pictures and objects and sign. Chloe was really good because she really made me feel comfortable. I hope we have an I CAN group at our school again soon. For me I CAN has helped me think about the things I like and what I am interested in. Thank you, Chris for I CAN.

**Senator STEELE-JOHN:** Thanks so much for your evidence and for what you do. It's been fantastic for me, not knowing about your organisation previously, to learn more about the model and its broader applicability across the disability space generally. I want to take you to page 12 of your submission, where you make the point that current NDIS activities do not improve the social connections of autistic people aged 15 years and older. I want to know a bit more about this from your perspective and why you think this is.

**Mr Varney:** It's a great question. We'll just get oriented to the right page to understand the exact context behind the question. Could you repeat the last limb of your question?

**Senator STEELE-JOHN:** Your reference there to the fact that in your view current NCIS activities did not improve the social connections of autistic people, particularly aged 15 years and older. I'm wondering why you why you think this is and what's causing that.

**Dr Ong:** In regard to the last line of the first paragraph, there has been high demand from autistic people to establish social connections. This is something that has been well demanded by all autistic people, because autistic people are more likely to feel lonely and not have as many social connections amongst each other. We did note that current NDIS activities do not build social connections amongst autistic young people. This is an unfilled need that has been present not only in NDIS statistics, but also the ABS statistics on autism in 2018. I CAN Network national online programs fulfil this unmet need by building social connections amongst autistic young people where autistic young people are able to connect with each other from not only their own area, but also all across Australia. The social connections is one of the highlights of the online programs that we have seen amongst autistic young people, both in a quantitative sense and also in comments that we've received from participants.

**Senator STEELE-JOHN:** Excellent. I understand. Thanks very much for that. Can I ask you additionally about how your other social connective function works and some of the challenges you've experienced with it? I'm thinking of the fact that many autistic people also have a co-occurring support needs that are derived from other impairments that we might have. What has it been like building a shared understanding and a shared culture of meeting people's impairment needs and support needs beyond those that come from being divergent?

**Mr Varney:** It's a great question. I guess it's an art form. The first thing is that when you're running a group mentoring program, especially an online group mentoring program, you take people as they are. We don't quiz young people on what co-occurring conditions in the session they might have. It's a friendly, safe environment where moderated prompts are given and young people are given time to talk or type their responses. The activities

are carefully chosen and the skill, in terms of what we train our staff to deliver, is how they wrap around the delivery of their prompts, their own stories of being autistic and managing whatever co-occurring conditions they might have. So it's very much a storytelling space with moderated, safe discussion. Success at the end of a mentoring session looks like young people owning the delivery of the session as much as possible. You don't want it to feel like there's facilitation. You want it to feel like a safe young people's space where they've got a high amount of control.

**Ms Skaltsis:** If I could just add a comment, observing Adon participating in a number of the online sessions, the thing I observed was access. There were a range of different people within the group that may not have easily been able to access a community place to go and actually meet socially. So if it was out in a public place, a lot of those people were able to access mentoring online. I think that access is really important, especially for families with children with disabilities, to get them out of the home and into a setting. There's a lot of anxiety, an issue in doing that. It cut a lot of that out.

**Senator STEELE-JOHN:** Fantastic. Thank you so much for that. I've observed similar spaces, and a lot of what you're saying really chimes with what I've seen in those spaces that have worked successfully. Finally, in relation to page 19 of your submission, where you make two recommendations, which really go to getting federal government for autistic led social enterprises and promoting future pathways for autistic people. Could you elaborate on these recommendations for the benefit of the committee and for those listening at home too, in terms of what you'd like to see happen in these spaces, including but also beyond further funding.

**Dr Ong:** Recommendations 6 and 7 were inspired by the statistic that not only do we see low labour force participation amongst autistic young people, but also relatively high unemployment rates compared to people with other disabilities and people without disabilities. Those statistics have worsened between 2015 and 2018, when the ASACA surveys were being conducted. At the same time, we also see that Australia has a need to increase innovation in all areas of the economy, not just its traditional manufacturing base, but also its high-end knowledge base such as medicine, social impact and social justice. So with recommendation number 6, a viable way in which we can tap into the untapped potential of autistic young people is to enable autistic people to establish small businesses and social enterprises where they can not only carry the ideas that they can generate with their neurodivergent thinking of life and to bring forward their unconventional thinking and their ideas to life, but also be able to start a small business where they could pursue such ideas. This was recommendation 6.

With recommendation 7, that looks at setting up or sponsoring events where companies and universities are brought together to talk about future pathways for autistic young people and adults. A prime example of such an event, where we can bring autistic young people together with companies and universities to increase their knowledge of what autistic people can do, is our AWETISM Expo, where we ran a face-to face-format in 2019 and then a virtual format in 2020. In these forums autistic young people are able to display their talents and special interests to other people in a way that dispels some of the myths and misconceptions of autistic young people. The AWETISM Expo is also an excellent opportunity where universities and companies can be brought together to learn more about the potential of autistic young people and to be empowered to see how they can accommodate autistic young people in their company, in companies like university environments, so that they can excel in the given company and university environment to contribute massively to the company/university. That was a recommendation 7.

**Mr Varney:** To the heart of your question, there are two things to add colour to it that James shared there beautifully. We had such a journey creating autism-sensitive employment practices and policies, creating service lines. It was intensive, which is why our board's been an absolute blessing. We've got a non-executive director here with us today. We do think that initiative set up to support disability led organisations from the federal government should have an orientation towards supporting the human resources development of those organisations. Typically grant schemes in the federal Department of Social Services Information, Linkages and Capacity Building scheme are very much about the delivery and reach to people with a disability. But equally, having a focus on developing the back end office human resources function of the disability led organisation is important. Similarly with developing autistic school leaders. We shared the stat earlier that 22 of our 46 autistic staff had come from a high school program. That has been a wonderful venture of love and support for us. We call them training mentors, but it's very important that schemes at a federal level are encouraging organisations to have similar initiatives.

**Senator CAROL BROWN:** Thank you for your submission. Adon's opening statement also mentioned that he would like to participate in another I CAN online forum at his school. Why is that? For what reason does the program finish? Why did it finish at this school?

**Mr Varney:** It's a fee-for-service model. So we've got two business streams. Adon has been in both. So a school purchases our school based mentoring program. Parkdale Secondary College is one of the biggest mainstream secondary schools in Victoria. It's also a school that has made a huge effort to be inclusive of non-speaking autistic students. We were at that school for three terms in 2019 and had a terrific experience. Budget can be an issue for a government high school. In Victoria we are about to see a four-year phased approach to roll out the disability inclusion package, which basically means that Victoria's government schools are far more connected with the NCCD. Previously I would say that personnel in the government school system haven't necessarily been as educated on NCCD data as their Catholic educator counterparts. The advantage with this new package in Victoria, called Disability Inclusion Package, is that it plugs in the NCCD system with Victoria's government schools, which will mean effectively that a government school principal's budget will inflate more for these programs. At the moment Parkdale is hoping to take the program, and we're offering them a \$2,000 scholarship. On the other flipside, our second service is the national online service, which is NDIS funded. That responds to parent demand. So we partner both with schools and principals and with parents.

**Senator CAROL BROWN:** When did the I CAN program start?

**Mr Varney:** It started in 2013. James and I got together and started setting it up. Then the actual first delivery of a mentoring session was in June 2014.

**Senator CAROL BROWN:** And you do continuous evaluation on the program?

**Mr Varney:** Rigorously. Every six weeks we report on our national online program, which is James's portfolio, on everything from evaluation rate, completion, satisfaction rate, cancellation rate, retention rate. It's all reported up to our board and our stakeholders.

**Dr Ong:** We also report on the outcomes of our school and online mentoring programs in our social impact reports and our reports to our stakeholders. We take evaluations very seriously here.

**Senator CAROL BROWN:** In your submission and in other evidence that we've heard here today, you've talked about the Queensland government and the Victorian government and the education departments, about the work that they're doing around autism education strategies, which you've been involved in in both states. That's correct?

**Mr Varney:** Yes.

**Senator CAROL BROWN:** I want to ask you the question around a national autism strategy and your views. I also want to ask your view about the current National Disability Strategy, which has been around since, I think, 2010 or maybe earlier, and the need for state and territory based autism education strategies and broader in terms of health strategies and so on.

**Mr Varney:** I CAN Network endorses the need to call for a national autism strategy. We did endorse the Australian Autism Alliance's discussion on a national autism strategy. We would say that there needs to be intensive discussion about the wellbeing of autistic young people in a national autism strategy. The reason why we spoke about our national online mentoring program is we do see that that is positioned to become a wonderful platform to facilitate positive identity for autistic young people.

The national autism strategy is such a cross-cutting thing. When we look at education, it's its own sector. It's incredibly intricate. If you look at the work that Queensland and Victoria did to develop their funding systems, it was intensely rigorous and had several different layers of consultations. So I think the purpose of the national autism strategy would be to signal that autistic Australians matter and to bring together different pieces of legislation, interpret them, and create some schemes that multiple autistic led, autistic focused organisations can partner with.

**Senator CAROL BROWN:** And you don't believe that there's a pathway for all that to occur under the National Disability Strategy?

**Mr Varney:** When I was in consultations about the National Disability Strategy, the threat I took away was that it was focused on educating mainstream Australians about the value, the experiences, the contributions, the voices of people with their disability.

**Senator CAROL BROWN:** Various iterations have changed, obviously. I'm just trying to get an understanding of what people think that the National Disability Strategy has actually delivered.

**Mr Varney:** In all honesty, I think the PR around the National Disability Strategy was not necessarily strong. I speak in every state and territory about autism and disability. The first I heard of it was when we were being consulted on putting together a submission. Maybe I live under a rock. I don't necessarily think I do. I was surprised. We did have an encouraging experience in the consultations. The question of how is this different to the

NDIS for me was clear when I could hear that the bent was educating mainstream Australians about the experiences of Australians with a disability. We did write a submission that talked about how the federal Department of Social Services could partner better with disability led organisations.

But to answer the heart of your question. I think the National Autism Strategy would need to be a subset of the National Disability Strategy. What is very important is making sure that a National Autism Strategy would discuss the nexus between autism, disability services and mental health. In our online program 80 per cent of our young people in our online program experience high anxiety. Twenty-seven percent experience depression. I think it might be 11 percent that experience suicidal thoughts. There's data that says that autistic young people are nine times more likely to attempt self-injury. That nexus with mental health is very important to cover, which I think the National Autism Strategy has the best chance at achieving.

**Senator CAROL BROWN:** I want to quickly ask about your comments around the NDIS. You say that there are Easy English booklets to make it easier for people to read and understand the NDIS; however, these booklets may not have been utilised by the local area coordinators to guide autistic parents on how the NDIS process works. Can give us an understanding of why you believe that to be the case?

**Dr Ong:** We have found that there are Easy English booklets on the NDIS that can be handed out to people that don't quite understand the process of the NDIS. However, from our perspective, we have seen that there have been some parents, particularly autistic parents, in our national online mentoring programs, that feel overwhelmed, particularly if it's their first time, on how to utilise their NDIS plans to achieve their child's goals. So in our experience, I CAN network has had to guide some parents on how to use their NDIS funding and how NDIA managed plans cannot be used to pay for I CAN Network's mentoring programs. It indicates to us that parents, particularly autistic parents, aren't being briefed sufficiently on how they can use NDIS funding to pay for our programs. I CAN Network is not an NDIS service provider. We have a lot of parents who are funded by the NDIS to use the funds to achieve their child's goals.

**Mr Varney:** We're a service provider, not a registered provider.

**Dr Ong:** Recommendation number 2 supports the need for the federal government Department of Social Services and National Disability Insurance Agency to work with autistic organisations such as I CAN Network to make parents more aware of resources that can be used to clarify NDIS plan information and also to develop new resources that better cater to the sensory needs of autistic young people, autistic people and autistic parents.

**Senator CAROL BROWN:** I was just going to ask for some more stuff around making the NDIS more user friendly.

**CHAIR:** Perhaps you could put that on notice, as we are running out of time. I'd like to clarify just a couple of things, and then I will come to you, Ms Skaltsis. But just to clarify about I CAN. I participate in one of your programs. It is a business, not a not for profit.

**Mr Varney:** Yes.

**CHAIR:** And we do need to be mindful that we are a service provider and that there obviously are commercial interests.

**Mr Varney:** Yes. Technically we are a public company limited by guarantee, a DGR.

**CHAIR:** Just for transparency, I think—

**Mr Legge:** It is not for profit.

**CHAIR:** It is not for profit?

**Mr Varney:** We receive public funds and we manage public funds. We have our own donations stream, and then we have—

**CHAIR:** The commercial side.

**Mr Varney:** Yes. The businesses.

**Mr Legge:** The commercial enterprises. They don't distribute profit or anything like that.

**CHAIR:** I think for transparency we need to be mindful of that. Ms Skaltsis, it's so great that Adon's here. I noticed that you said he participated in the online program. What sort of additional supports did he have, or did he have additional supports—I'd love to hear from him—did someone sit with him; did he have assistance with his augmented communication tool, keeping focus on the program? What sort of supports were in place to ensure that participation was substantial?

**Ms Skaltsis:** He mostly had my support. I noticed with other students that they often had parents. Some, not all of them, were there, particularly when they needed the augmented communication device. So we often were

muted during the session so Adon's various other noises were not made. Then we would practise writing the answer on a whiteboard and then type the answer in. The format of the mentoring session is very good in that it gives you time. You have the question, you know it's coming, so it gives us time to work out what that response is going to be.

As we've worked with Adon through the mentoring program over time, we've had a number of different—I think we were involved in about six of the sessions, I think. He gained greater independence over that time. He gained lots of social skills in terms of listening and giving the response, as well as that concept of being within a group.

**CHAIR:** Was that just one six-week program that you did, or you have done multiple programs?

**Ms Skaltsis:** It is multiple programs. He has done the program at school, where he was in a group with 10, then multiple at home. On a couple of occasions he had another carer, so if I wasn't available there would be another carer that would sit with him to do the same thing.

**CHAIR:** But there was that requirement. We had the same issue. We eventually gave up because, even with support workers sitting there, it can be challenging, the online stuff.

**Ms Skaltsis:** That was one of my recommendations. I would actually like to see a lead into some of it, like some of it group and some of it on one one, because I think that process of communicating online with another person for these guys often depends on the person's level of communication skills. At Adon's level of communication skill, he needs that one-on-one to start with. But the sense of community that he got and the enthusiasm with which he ran to the screen, set up the computer, connected it to the TV, all of the skills that he developed in that process were very significant.

**CHAIR:** I've got a question that might seem a little bit out of the realm, but with some of the people that we talked to early this morning, we were hearing about the cliff that occurs at the end of high school. So when our kids turn 18, they no longer qualify for the pediatrician; they're not in the school system; where to next? You're obviously close to the cliff. Adon's 16. You're heading towards the cliff. What does it look like? What supports are there? What information are you getting? What do you need?

**Ms Skaltsis:** As soon as Adon turns 16 I no longer get a carer's allowance. We have to apply for a disability pension. That's a massive process. It's a big gap. He's only 16. We still haven't got that sorted.

**CHAIR:** Adon, I'm trying to talk to mummy.

**Ms Skaltsis:** At school it is a massive risk. Things are all good in year 7, year 8 and year 9, but when you go into year 10 suddenly you've got people suggesting you go to VCAL—that's Victorian Certificate of Applied Learning. It's a work related program in school, which is not a normal VCE program. You're suddenly forced to make a decision: are you going to stay with an academic type curriculum, or are you going to go towards a work related curriculum? Adon and many kids with learning difficulties appear to be guided towards vocational programs. However, for kids who have autism like Adon, it requires you to be independent. It requires you to function quite differently, in fact, and it disregards the core skills that I think you really need before you make a vocational decision.

In school that's a big difficulty. Then we also have the problem of thinking about where we are going to go post school. Adon spent two years in this vocational program, and the vocational program really wasn't leading to anything. So we have actually asked ADON to go back and repeat year 11 and stay in the VCE program and get more of his core basics—sentence writing, numeracy skills et cetera.

**CHAIR:** Is that in a support class?

**Ms Skaltsis:** That's been extremely challenging in the school situation. I had an assistant principal say to me, 'How can I ask a VCE teacher to have Adon in their class?' I'm a teacher—

**CHAIR:** By providing the appropriate supports? I don't know. I'm thinking out loud.

**Ms Skaltsis:** I'm a teacher in the school, so it's a very difficult situation. But I just push on and say I believe we can do it. I'm a teacher, and I believe we can have a child who has his difficulties in a VCE class because we all can cater for difference and differentiate with what we're doing.

So he's currently enrolled in a school where the only subjects he's in are my subject, which is food studies that I teach, and a music class, which took a lot of negotiating. But he's now in a music class. That's not every lesson of the week; that's for the practical lesson and a single lesson. He's unable to be in the English class, because basically there are 25 kids in the class and the level at which the English class are functioning is beyond what he can do. So my recommendation was we have a lot of literacy support people in the school and whether or not they

can develop a literacy program that he could work on. That's been accepted and they are looking into developing a literacy program.

But in the schools there are not people in secondary schools, in our school, who are well enough skilled to really ascertain what level Adon is at and how to step him up to improve his skills. We found during COVID time, where we employed our own people through our NDIS funding, we were able to actually get them to work with Adon with very basic things and make a very significant improvement. We're very grateful for NDIS funding in that time in supporting us, because that was really integral to his success even today.

**CHAIR:** A lot of kids with autism just couldn't function in that online environment.

**Ms Skaltsis:** No, but thanks to NDIS you can have a carer to support accessing to be able to get onto a computer to complete activities. Adon's lucky because I'm a teacher and I have been able to put things there for him. Moving back to school, he's currently enrolled partially. We've also organised to put it in a TAFE program, which is on a Wednesday through Chisholm TAFE, and that's about to begin. We'll see how that goes. He did participate in a TAFE program one day a week last year.

We were very much encouraged by the school to take him out of school this year and put him into a TAFE program. We looked at Holmesglen TAFE in Victoria. But going to the orientation process for that TAFE program, although they said that it was a program to develop independence et cetera, from seeing other students there and also going to the space—the space was a room with absolutely no windows. They said that we would have to send a carer with him. We don't have NDIS funding to send Adon with a carer to a program five days a week. So that eliminated that as an option. I also felt that developmentally he wasn't ready to be there. It was better for him be in a school situation.

So it's a cliff. There's a lot to juggle and there is very little guidance or support. As a teacher and a parent, I would like to see people, perhaps like me, who have been through the process who are able to support other parents with their children, because I feel there's a big gap. There's not a gap in terms of parents support; it's how to navigate the pathway.

**CHAIR:** Thank you very much, everyone. I'm sorry we've come to the end of our time. If you've got anything further I'm sure you will, Mr Varney. And Adon, thank you for coming. It was lovely to have you here.

**AYTON, Mrs Merrin, Co-founder, Different Journeys**

**MUNTER, Mr Daniel, Assistant Treasurer, Different Journeys**

**SPENCER, Ms Mel, Executive Officer & Co-founder, Different Journeys**

**SPENCER, Mr Kean, Board Member, Different Journeys**

[11:59]

**CHAIR:** I welcome the representatives of Different Journeys. I understand that information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. I'd like to invite you to make a short opening statement, and at the conclusion of your remarks I'll invite members of the committee to ask questions.

**Ms Spencer:** I'm here today to represent the diversity of our community. I'd like to start by asking you to imagine that you're a 16 year old autistic, and it's your birthday. Every other child has a party, but you don't have any friends to be able to have a party, so instead you spend it alone and miserable in your room. Maybe you're a 20-year-old autistic person who suffered from seclusion and restrictive practices or was repeatedly told at school that you were no good, so you believed them. Now you're at home with nowhere to go, no job and no education, and life doesn't have any purpose. This then becomes a pattern, and, suddenly, for three years you haven't left the house. Isolation is a major part of the life of an autistic.

Alternatively, imagine you're a parent of an autistic child. You know they need help and support but simply can't find it. You are being shunted between a fragmented mental health and disability sector, with nobody to help guide you. Your family is falling apart around you, and there is no help, only judgement. This impacts not just your autistic child, but their siblings and your own relationship—that is, if you have one. Navigating a service system that fails to understand you or your needs is a major challenge for exhausted parents. Now imagine that, like so many in our community, your autistic person has become violent. You're too scared to ring the police for fear of different and more strict repercussions. You feel judged as a parent and you're also judging yourself. Living with fear impacts more than just the young person and their carer.

Imagine yourself in the shoes of a family whose 14-year-old has just been diagnosed with autism. It's a relief to know that there's something you can do now instead of grappling for solutions. But where do you go to find those supports? How do you link him with others in similar circumstances? How do you find your tribe? This is what Different Journeys does. Our purpose is to provide social platforms that connect autistic youth and autistic adults and their families in an inclusive, safe and supportive environment.

My stories are real. We hear them every day. They are a part of our community and they need help. The reason we started Different Journeys was to create opportunities for autistic people and their families to come together and support each other. As volunteers, we can only do so much. We get bits and pieces of short-term funding. It's small change really, but it helps keep us afloat, and we leverage every dollar. But we need more and we need to be able to expand our services and respond to more individual stories. There is a vast unmet need that confronts us every single day. We want to be able to imagine a world where autism is not a difficult word. We want to ensure that our autistic community can and will contribute in a meaningful way, whilst educating the non-autistic community that we have capacity. We just need a bit more scaffolding.

Autism is for life. We need support with many facets of our life over the journey. It should be a better journey—a different journey. There are other organisations out there doing great things. We don't want to replicate or reinvent what they do, because what we do is unique. But it's in dire risk. We genuinely want to keep partnering with all the other organisations, because, together, imagine what we could do and imagine the opportunity for our autistics. The current statistics don't need to be so grim.

**CHAIR:** Thank you for that, Ms Spencer. I'll go to Senator Brown to start.

**Senator CAROL BROWN:** Thank you for your opening statement. In your submission, you give support for a national autism strategy and say that it should be developed as soon as possible. What in your organisation's view would be the outcome if a national autism strategy is not developed?

**Ms Spencer:** Currently, it's really fragmented. The whole service, navigating it, finding support, is fragmented. If you think about it, you've got Education, you've got Centrelink, you've got the NDIS, and then you've got the medical professions. You've got to try and navigate all of this. I'm hoping that having a strategy might help simplify it and support families who can't find that support. Also, it would have to have multiple representations. The autistic voice is very important, but so are the carers—the carers are getting lost and not being heard and validated, and that's something that needs to be included—and parents that can speak up.

I'm getting off track here, but I know that you've got the Carer Gateway that the federal government is currently funding. I have to write a script for carers to make that first phone call to ask for help and support. They won't do it voluntarily, because they don't value themselves and their voices. They've been told so many times, 'It's parenting,' or, 'Surely you can step up and do better parenting.' That voice is something that's a real gap, and I would like to see that within an autism strategy.

I would also like to see a consistent message, because everywhere you go they're giving you different examples. It depends on who you speak to. A national autism strategy would help with the NDIS and the problems that we have with the NDIS and getting support. It would be something that the NDIS would be able to refer back to instead of parents being told, quite frankly: 'You need to step up and do some better parenting. Your child's under 12. You don't need any more support. You have to step up. You can't go to work. That's just your role.' These are some of the stories that we're hearing all the time.

It is about the cohesiveness and also the ability to understand. If you move states—you see this on the Facebook page, where they're always moving states. They have to start all over again. If we had a national strategy, that would be alleviated because the rules would be the same everywhere you went.

**Senator CAROL BROWN:** That's what you talk about in your submission when you talk about gaps and mistakes. It's essentially about having the same opportunities throughout the country.

**Ms Spencer:** Yes. It's like the cliff you talked about before. It's so major. It depends on who you are, where you are and what ability you have or your child has to navigate that system and understand.

**Senator CAROL BROWN:** I want to go to that, because we often talk about post-school pathways and how difficult that is. As I was listening to the previous witness, Ms Skaltsis—and I want to know whether you get this feedback as well—she talked about a program that might be suitable for her son. She was told that he could only do that if he had a carer, but the NDIS won't fund a one-on-one carer.

**Ms Spencer:** No, and then we have the other support where the NDIS may fund it but the school won't allow it in. It's a bit of a difficult scenario that is quite common. What she said was actually right. One of the things that I think is a real gap is that there's a lot of systemic advocacy, but there's no real individual advocacy. What we're finding—and I can use examples. Instead of clashing with the NDIS or Education or wherever you're going for your meeting, it's about understanding how to behave. You're emotional. All these people are giving you advice on the phone about how to conduct yourself in a meeting, but, when you get to that meeting it is your child they're talking about and it's very hard to remain objective. Having someone who's been through the path with you to help guide you through that meeting and model appropriate behaviour and model how to do things—that's where there's a massive gap. If we're going to meetings with them, they get better results and they come out more empowered, and then they go and talk to the next person and then they share that information. It's like a ripple effect. But there's no-one to use. All the helplines that are currently available are just online. If you ring and ask for help, they send you a list of about 20 things. You're already struggling, because you're asking for help, and then you have 20 things to research and look at. It is really overwhelming.

**Senator CAROL BROWN:** Did your organisation have any input or consultation with the Victorian government around the Autism Education Strategy?

**Ms Spencer:** No. I individually meet with the education department once every three months, but I was not involved in any of the consultation. I've got lots of good stories. I learn what they're doing or what they're supposed to be doing, and then I can feed it back at our events to our community. He shows me where the stuff is for them to find. I've built up my own relationship with them.

**Senator CAROL BROWN:** Of course, on the flip side, it's all well and good having a strategy or a plan, but it has to be properly funded.

**Ms Spencer:** One hundred per cent. This is what we're finding. They've got these great ideas, but it hasn't dribbled down. Primary school is probably more challenging than secondary school.

**Senator CAROL BROWN:** Moving on to the National Disability Insurance Scheme, how can they do it better? Let's face it, we've heard so many stories about inappropriate language, and services and supports not being adequately funded or funded at all. How can they do it better? Let's start at the LAC level and work our way up.

**Ms Spencer:** LACs won't deal with me anymore. I run three plans, Merrin runs two and Kean runs one. What we're finding is people don't know what's possible. Even the LACs are in concrete thinking. You get the NDIS plan, and, if you think about it, you've never been allowed to dream. You have this child with a disability and you're pretty much told: 'This is your life. It's going to be pretty grim.' Prior to the NDIS, with an autism diagnosis, you had to accept the crumbs that were left over, but, with the NDIS, the opportunities are endless. It's

about educating what's possible. I have spoken to LACs. I've offered to go in on my own time and actually speak with them about how it feels to go in. None of them have ever taken us up on the offer. The LACs need to understand a day in the life of someone with autism. I remember Tony Attwood making the quote about the tides. Autism is like a tide. It comes in sometimes and it's very autistic, and at other times it looks like you're coping. That's something that's really hard to explain to LACs. They just see what they see. They don't see all the work behind the scenes. They don't see the journey that you've been on and how much organisation is involved. Every time I go to a planning meeting—and I've got two coming up, if the NDIA can decide whether we're having one—and I feel judged every time I go in there, and I'm an articulate parent. Other parents work themselves into a frenzy and they then go mute in their meetings. They don't even know they can take support in with them. There are so many other opportunities. I think that's a real gap. Maroondah council have a really good example of a working system. They've employed an NDIS person. It is a free service to anybody in the community in Maroondah.

**Senator CAROL BROWN:** Where is it?

**Ms Spencer:** Maroondah council in Croydon. Rather than me being negative all the time, this is what's working. She is a consultant who will meet directly with you. She will help you prepare for your plan or she will help you transition for your first plan. She doesn't do it for you. She will also attend your planning meetings. There are my carer statements that I've just done. I send them to her and say, 'Is this acceptable? Is this meeting the current guidelines?' She will send back: 'What about these questions? Have you considered these?' She is such a success. No other council has done it, but it's something that works, and it's a free service. There are lots of people out there charging you a lot of money.

**CHAIR:** Is she an employee of the council?

**Ms Spencer:** Yes.

**Senator CAROL BROWN:** Why did they decide that was required?

**Ms Spencer:** I met Kim on her second day—the day before my first planning meeting. It would be five years ago. Maroondah council employed her to help people transition, because they recognised that was a gap. No other council's done it. She is by far the most knowledgeable person. I would love for you to speak with her about the whole NDIS thing. She's most knowledgeable person about the NDIS that I've ever come across. It's for anybody who is a Different Journeys member, regardless of where they live. Because Different Journeys is a Maroondah based organisation, they can access her. That's something that works and it works really well. It's been so popular. They're not getting rid of her. Councils don't have the funding anymore because of the NDIS. The disability access officers are often no longer specifically for disability. That's a problem too, because they suddenly have four or five portfolios as well as disability. Disability is huge in itself. There are so many elements to disability, and then you have families.

**Senator CAROL BROWN:** She was initially funded through the NDIA?

**Ms Spencer:** No. She was initially funded through Maroondah council, who made that decision. If you'd like to speak to her, I'm more than happy to give you her details.

**Mr Spencer:** All the youth and adults were in the council program and, when the NDIS came in, the council programs stopped. All the people started ringing the council saying, 'What do I do with my child now?' They got so many calls that they said, 'This lady is an expert. She's great for that. She knows the NDIS.' They were feeding so many calls about 'What are we going to do with our children that have been going to the same program for the last 10 years?' When the program stopped, because the NDIS has taken over, they needed someone to help those children.

**Senator CAROL BROWN:** I think it was envisaged that the LAC would do that.

**Ms Spencer:** I've never heard from anyone, in my five years of being on the plan, checking in.

**Mrs Ayton:** In fact, in more cases than none. As Mel said, both of us have our plans coming up soon and I haven't heard anything, and yet we know they're finishing at the end of this month.

**Ms Spencer:** My plan is due in three weeks. I rang the NDIA and said, 'What's going on?' and they said, 'They just going to roll it over.' I had the direct contact for the planner that I've had for the last couple of years, and she said, 'No; you're having a review.' And I'm a parent who can articulate this. Imagine if you are a parent who can't and you're so burnt out with your caring role. That just becomes another added stress on your life. Why I'm really impassioned about the NDIS is that there is opportunity that my children have for the first time. They are going to be successful contributing members of society because of the NDIS. Without the NDIS, they would have probably also been sitting at Centrelink because no-one believed in them. Through the NDIS, they've been

allowed to build up a team to believe in them. That's what I'm seeing. Every time we have an event, the parents come in with their notebooks—'What else can we do?' People come in saying, 'I'm not going to get on the NDIS. It's too hard.' They've heard all the negativity. But through coming, sitting and hearing that peer lived experience, they say, 'Maybe I'll try.' It might take them six months, and they come in every month, saying, 'This is what I've done,' and I say, 'This is where you can go. This is where you can connect.' I don't have the answers for everything. Everyone's different. But it's about knowing where to go and having the confidence that you've actually got some backup if it doesn't go well. You might say, 'What do I do now? This is what's happened,' and they don't have anywhere to go.

**Senator CAROL BROWN:** That may be one of the issues that has been raised. When the NDIS came in, there was all this expectation, as if it would just roll over into those activities that other local councils or state governments used to do, but a lot of them vacated the field. Now we have to get them back.

**Ms Spencer:** Also, on the flip side, if your child is diagnosed at 14 and they're in a mainstream school, and they've been struggling for a long time and have this diagnosis, particularly girls, where do you go? Parents are looking and they don't know the teenagers. They're rebellious. They're already not wanting to engage. I had a parent ring me a month ago, and her child has been in and out of a psychiatric ward. They finally diagnosed. The parent had never even been told there was carer support available for her and her husband, and they were about to say, 'I don't think we can have her living with us anymore.' I said, 'No. Don't worry. You've come to the village. In six months, this is going to look so different. She's been to four events, she's listened to all of our advice and she's followed up. She said, 'It hasn't even been six months and I can already see improvement in my life.' She had been accessing services. She was in the youth psych wards, and no-one had told her about Carer Gateway or how to access the NDIS. These are things that they need to be walked through. They are in crisis.

It's the same with the individuals. We get lots of them coming in and parents are just bursting into tears because, for the first time ever, their child is sitting there eating and sitting there engaging with someone else. It might be that they have to get them there because there's free Wi-Fi and they can order what they like off the menu. That might be the reason that they've got there, because you've got to do it on their level. We make assumptions that anyone can go out to dinner, but what if you can't? They put green garnish on top of every bit of food that you order, but it doesn't say that on the menu, though, does it? So the teens kept sending their meals back because they didn't order the green garnish.

We've been learning transferable skills, and we've started to employ some of our carers. These carers haven't been in the workforce for 10 years—and do you know what they told me? They said, 'Don't pay me; I'm not worth it. This is how they believe in themselves. Then we've got autistics. We've employed one young man. We had made assumptions and we have learnt some lessons. Everything I asked him to do he did but, when he wasn't doing anything, he sat down because he couldn't think or process. So what he needs to do is scaffolding. It might take six months of scaffolding before we can let him go by himself. So we're learning as we're going because of the assumptions we make for this cohort. That's why employment is a problem, too—because we're making all these assumptions and not actually really understanding the niche. The DES providers and everything are letting us down with that too.

**Mr Spencer:** And even with COVID—the change with COVID. In my stepson and my daughter's plan, they have money in their plan to go out and have social activities, but they couldn't go out and do social activities. So when their plan comes around, they go, 'Oh, you didn't use any of your funding, so you obviously don't need that next year.' But, obviously, we couldn't go out because there was COVID in Victoria and we couldn't leave the house. What we actually needed the funding for, as people have previously said, is someone to help with their Zoom. My son now says that Zoom is illegal and that, if he has to have another Zoom, he's going to call the police because it's illegal. That's his belief because he's linked COVID and Zoom and the virus and all those things because he hasn't been able to get out. He's the kid who wants to go out and play basketball, but basketball wasn't on. We're now being told that because we didn't use the funding, 'Obviously you didn't use it, so you don't need it next year.' And we're like, 'No, we actually need double next year versus what we had this year.'

**CHAIR:** Senator Steele-John?

**Senator STEELE-JOHN:** I don't have any questions at this stage, but I want to thank you for sharing your perspective. It has been really interesting to hear.

**CHAIR:** I just want to have a quick chat with you about social inclusion. We've had evidence previously from people who obviously have quite adept social skills that a lot of people with autism don't have. I noticed you talked about the garnish on the food and also the need to get people to actually go—people who have never had that social interaction, who have never sat next to a peer, and whose life pretty much involves school, which is

pretty isolating IT online, parents and siblings, and not much outside that. Can you walk us through what benefits you've seen from facilitating that social inclusion not only for the person with autism but also their family?

**Ms Spencer:** Absolutely. First of all, they learn how to walk into an event. They learn how to say hello to the person on the door. They learn how to read a menu. They learn how to articulate their order in a way that's meaningful for them. They learn how to give feedback if it's not okay. They learn how to sit at a table. I think a really good example is that Club Kilsyth, where we have one of our events, said, 'We threw hospitality 101 out the window and we had to re-learn how to manage this cohort,' which they then transferred across every element of their restaurant. They had to change the way they were doing things. I've had to learn budgeting. The kids get a budget, then they go in and they've got to find a meal within that budget. So there are budgeting skills. There's sitting down talking to people. There's learning games. Merrin, being a school teacher, introduced the cahoot as part of our gam. That cahoot is something that's commonly used with schools. A lot of these kids have never seen that before, so they've had a meltdown in the event. The same thing with the allied health. They've seen that same child at school the next week, and cahoot's on, they'd already been exposed to it, so they knew what to do so they could participate. To see the smile on the parents' faces—we cater to all abilities.

One of the greatest things that it gave me, one of our parent participants becomes non-verbal, and he brings his support worker in. They sat there at a table playing cards against humanity with the whole table. He kept winning because he was giving out the best answers. It was inclusion at its very best. Someone once turned up and said, 'I'm not autistic', and of course everyone avalanched them because they're really proud about the fact that this is somewhere they can come that they're safe.

**Mr Spencer:** Even things like learning how to use an eftpos machine in an environment where it's not Coles where you have to self-checkout and learn all those things. They have the ability to do that. My son is now 20. He doesn't have a driver's licence. To get a proof-of-age card is hard. To go and ask for an apple cider or a beer, he would get questioned. It's a normal thing that most 18- to 20-year-olds want to go and have a drink with their mates. They can go and do this in an environment that's safe. It's not a night club, it's not a normal bar with people who go 'Who's this idiot?' or that type of comment. Those types of social activities, after that teen or that cliff, which you've heard a lot about today—we all talk about the cliff—the minute they turn 18, all the people they know are driving cars and having drinks and going to parties. That stops for them. Our events help to facilitate those things, and it's great to see my son now—

**CHAIR:** I'm with you. Obviously a lot of parents experience social isolation when they go through having a child with autism. You'll start me off if you start. Parents suffer from a lot of social isolation in full-time caring roles. It's really exhausting. Why is it that some groups in the autism community feel that need to denigrate the parent experience, to remove the parent experience, to criticise parental interventions and activities because somehow we're not allowing the autistic person to be wild and free and we're inhibiting them by parental involvement. What is behind this? We've got Mr Spencer, who I'm going to cry with in a second, because we all understand the emotion and the isolation and the grief and the reality of what the diagnosis means and the challenge. I'm hearing about the cliff. I'm about to hit high school, and that makes me sick to the stomach.

**Unidentified speaker:** And puberty!

**CHAIR:** Puberty—awesome! I can't wait till we have a session on that one! There are all these things that parents drive, but parents also go through self-isolation. They have challenges. They lose friends. Divorce is very, very common among parents that have autistic children. Why are parents attacked and vilified? Why is this allowed to continue? How does what you do assist parents who are really just doing the best things for their kids?

**Ms Spencer:** We empower the parents because we bring them with us. We make them feel that they're included in the decisions. I've learnt so much along the way. I'm not sitting here as someone who's never had therapy. I've had heaps of therapy. That's obviously now going to be documented everywhere.

**CHAIR:** I know plenty of people who probably should. It's okay.

**Ms Spencer:** I'm sitting here as someone who's accepted a lot of help and support. I know that when I'm okay that helps my kids. Modelling to my kids that I need help and support models to them that it's okay to ask for help and support.

**CHAIR:** When you talk about modelling, you're providing a scaffolding. You're providing a framework around how to understand emotional situations, teaching of behaviour, your behaviour as well as theirs.

**Ms Spencer:** A hundred per cent. One of the other things that really important is that we get really disempowered as parents, because we've got people attacking us from the autism community saying, 'You shouldn't be doing that!' Maybe they were diagnosed in adulthood, so when they were a teenager they didn't have an autistic brain. I realised through my own children that I'm autistic. I just don't want to pay \$2,000 for a

diagnosis, but that's another story. I know now that I'm autistic, but when I was younger, I can see all the patterns and I can see how I was autistic, or am autistic, but I didn't know. I didn't have an autistic hat on then. So it's very hard to make judgements, and things are changing. Whilst I believe that the autistic voice is very, important, and we need to hear it, the parent voice is important too. If we bring the parents along it's supporting the autistic child. If we keep telling the parents how bad they are, how is that actually helping to embrace, embellish and empower the autistic individual that they're caring for?

**Mr Munter:** The vilification of carers is something that's been around for a long time. I remember specifically, back in the days when my mum was trying to get the diagnosis for me, and they couldn't quite pinpoint what it was. Allied health professionals would tell her that it was due to her being a single parent and her inability to parent and cope with my behavioural issues. So this is not a new story. This is something that's been around for a long time. It's due to a lack of advocacy and a lack of information about what autism is and seeing role models and experiences in the community. Advocacy and openness and actually being able to get the information in a way that's able to be processed is really important. The Amaze ads that were put on last year with those scenarios actually helped open up a lot of advocacy in that regard as well.

But just to quickly point back to a previous question, we were talking about social isolation and people's ability to connect in the community. We recently put out a Different Journeys survey to our community, which has 96 different participants across different carers, autistic individuals and such. Ninety per cent of the entries said that the thing that they got most out of Different Journeys was actually social connections and friendships. We see groups of people, like Mel was saying before, who didn't have people coming to their birthday. Parties were isolated for three to four years or even longer. I just saw the other day that they had a Super Bowl party and they had five of them going over to someone's house to watch the Super Bowl. These are things that we're not structuring for them. We're not setting up these events for you to go and hang out and have some friendships. These are the things that they are creating because they're empowered and they feel like they have the skill set to do so.

**Mrs Ayton:** In terms of giving the carers the voice, that is so critical. As Daniel said, for so long the people out there in the allied services have been saying, 'How are you managing, how are you managing the kids, you're not responding to their needs or you're being too soft.' They've been browbeaten for so long that they're just too afraid to speak up and say, 'No, it's actually that my child has an issue. We need to work out what the triggers are, what's actually causing this.'

At our events, we actually set up a new families table for the carers. We have an allocated person who sits there for peer support, who has lists of services. We quite often refer to Kim because they haven't got an NDIS package, and then all of a sudden they're overwhelmed with the support they're getting. They say, 'Why haven't we ever had this type of support before? Someone's actually talking to me. Someone's explaining. Someone's showing me. I just need to be shown how to do it and I can do it.' But it's such a logistic nightmare, the maze, and they've been hit so many times. It's your fault or you can't do this, whether it be through education, whether it be allied services, even their families, they're just being bombarded with all this negativity that they are too afraid to speak up. So their voice gets lost. That's what very clearly came up in our survey.

**Ms Spencer:** We were wondering if we could table that.

**CHAIR:** Absolutely. Just send it through and it will go to the committee.

**Ms Spencer:** We sent through a video that was done, for you to have a look. The other bit as well is, everyone keeps saying that we need to look at ways to make ourselves financially sustainable. This event—I'm probably working 50 hours a week with no pay.

**CHAIR:** And your caring responsibilities.

**Ms Spencer:** Yes. Everyone says just charge under NDIS. But if we charge under NDIS, we ostracise half our community.

**CHAIR:** Because they're not NDIS funded, and you can't use a non-registered provider.

**Ms Spencer:** Or NDIA. And a lot of our cohort are not on the NDIS. I've been really grappling with this. We just put our prices up for our swim night from \$5 to \$10. I was really feeling sick about that because there are families out there who are doing it tough, who don't have NDIS, who can't access any of these supports. So, if we take that away, if we start NDIS charging, we will lose half of our community.

**CHAIR:** I just want to confirm: you pay \$10 to go to a swimming event—

**Mrs Ayton:** That includes dinner and a barbecue and—

**CHAIR:** You provide social connections and support for parents versus what we pay for a single allied health professional. I'm just trying to get my head around it.

**Ms Spencer:** We charge \$12.50 for them to attend our peer support events. That includes a free soft drink on arrival.

**Mr Munter:** And that runs for 2½ to three hours per event on a Sunday.

**CHAIR:** Okay. Thank you so much for appearing today. Unfortunately, we've run out of time, but if you've got anything—

**Unidentified speaker:** Sorry.

**CHAIR:** No, you're fine. Do you know what this is? This is an autism parent apologising. Stop it. If you've got anything else that you do want to send through to the committee, please feel free to do so. Thank you very much for your testimony today.

**STAHOLI, Mrs Natasha, Strategic Relationships and Policy Adviser, Yellow Ladybugs**

[12:36]

**CHAIR:** I now welcome Yellow Ladybugs. I understand that information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. I'd invite you to make a short opening statement, and at the conclusion of your remarks I'll invite members of the committee to ask questions.

**Mrs Staheli:** Thank you, first, to the committee for giving me the opportunity to be here and speak today. Yellow Ladybugs is an autistic-led non-government organisation dedicated to the happiness, success and celebration of autistic girls, women and gender-diverse autistic individuals. In addition to running social events that enable autistic girls and individuals to connect with their peers, we have a strong advocacy mission to address the many challenges, barriers and disadvantages autistic girls and women face. We are proudly pro neurodiversity, and we strive for a world where autistic individuals of all genders and in all their diversity are heard, seen, valued, accepted and supported in order to realise their full potential.

In our detailed submission to the inquiry, we have made nine separate recommendations in response to the terms of reference. These recommendations all draw on the lived experience and professional expertise of the actually-autistic community. We would like to acknowledge the input of the autistic individuals who shared their stories, knowledge and experiences as part of our submission to the inquiry. It is safe to say that there is no corner of this inquiry where the specific challenges and support needs of autistic girls and women are not an important conversation in their own right. However, I would draw your particular attention to the commitment to inquire into and report on the misdiagnosis and underrepresentation of females in autism data and gender bias in autism assessment and support services.

Autistic women and girls currently comprise around one in four autism diagnoses in Australia, but research and strong anecdotal evidence suggest the actual prevalence of autism amongst women and girls is considerably higher. Autistic girls and women have been overlooked for many reasons, including prevailing stereotypes of what autism looks like, the gender bias of standard diagnostic tools, and the way girls are socialised and viewed in our society. More generally, we know that many autistic girls and women are being missed or having their needs invalidated because of their more hidden or internalised autistic presentation. The impact of this oversight extends well beyond access to diagnosis and exposes delayed vulnerabilities that autistic girls and women experience, including economic disadvantage, inequality in health care, especially in the realm of mental health, restricted access to education and employment, and limited access to communities and their autistic peers.

In short, we need to do a lot better at understanding and supporting autistic girls and women, and this commitment to action needs to occur at a national level. The development of a national strategy on autism would be an excellent start. But to be truly meaningful it is critical that autistic input is prioritised throughout the development of this strategy and that autistic-led organisations such as Yellow Ladybugs, along with many others, have a seat at the table. This representation is needed to ensure that the principle of 'Nothing about us without us' lies at the heart and centre of the strategy and to ensure that the full diversity of autistic experiences, including those of marginalised groups such as autistic girls, women and the autistic LGBTIQ+ community, are represented. Equally critical is that this autistic representation continues into strategy implementation, including policy and program development and delivery.

We have a lot to do, and Yellow Ladybugs looks forward to working with the committee and the wider autistic community in the months and years ahead. Thank you.

**CHAIR:** Thank you. I will start with Senator Steele-John.

**Senator STEELE-JOHN:** Thanks so much for your submission. I think it makes a really valuable contribution to the evidence that we have seen so far as a committee. I want to take you, first of all, to the provision of mental health services. Could you expand on what you see as the drivers of the barriers to mental health services for autistic women and girls and what might be done at the federal level to address that.

**Mrs Staheli:** Where do I start? We know that autistic girls and women have a much higher rate of comorbid mental health issues, and a lot of this is compounded by the mental health practitioners and the system itself not understanding in particular the hidden needs of autistic girls and women. We've surveyed our community extensively on this in recent years. In 2016, we made a report to the United Nations Office of the High Commissioner for Human Rights on precisely this issue. We surveyed around 2,000 people around the world on that and came through with some really startling information. That particular submission is included in our submission to the committee.

But we know that it is not just autistic women but girls, primary-school-age girls, that are having severe mental health crises, and the system is failing them. There is often simply nowhere to go. We anecdotally have so many

stories from our community of parents taking their child to emergency in a state of extreme crisis and being sent home because there's simply nowhere for them to go. We know the system is built around support for mental health conditions, but the moment autism is mentioned it becomes an autistic problem, not a mental health problem. Again, the system fails our girls and our women. We know that there are some very frightening statistics around suicide, self-harm and depression. We know from our community that autistic women are often discriminated against directly because of their autism diagnosis. We know that there is not enough knowledge in our public mental health service about autism, let alone autistic girls and women. We know that rural, regional and remote access to mental health support for autistic girls and women is simply not there. There's a lot. We also know—and I think this is an important point to make—that many autistic women are also mothers, and, for them, the help and support that they might need from a mental health perspective is significantly lacking.

What can we do about it? That's a very good question. I don't know if we have the answer. This is something we as an organisation really want to start examining a lot more closely and consider how we can effect change in this space. It needs to be at a national level. There's no question about that. It needs to involve autistic girls, women and the community in any discussions that take place.

I would add just quickly that we submitted to the Victorian mental health inquiry that took place last year. We did a standalone submission. We also worked with Amaze and Different Journeys and collaborated with them in the submission that went through under Amaze. We are quietly working away behind the scenes to see what's come out of the recommendations of that particular inquiry and how autistic input can be fed in at every level. We would imagine something similar at a national level. But it's a long journey. It's a long process and we're just at the beginning.

**Senator STEELE-JOHN:** From personal experience in trying to support autistic friends to seek mental health help, it can be devastating when you convince somebody to take that step, which for anyone is hard, and then they quite obviously interact with a mental health professional with no experience of the neurodiverse brain and how that intersects with other mental health conditions. Do we need stricter standards for psychologists and psychiatrists that are training so that they actually have that skill set?

**Mrs Staheli:** Yes, absolutely. They need lot more training and a lot more understanding. I would add to that point, too, that we know for many autistic women their first encounters with the mental health system are actually being misdiagnosed—often with bipolar disorder, borderline personality disorder, anxiety or depression. These are the labels that they are given. Autism comes very late in the party and that's another factor within that. Much more training for health professionals, psychologists and psychiatrists is very important.

**Senator STEELE-JOHN:** Finally, because I know we're against the clock: you mentioned in recommendation 2 that it's really important that organisations involved in these processes are autistic led. I know that quite often there can be conflagrations of tension in the community and in policy spaces when we talk about autistic led organisations, and that parents feel shut out of the process. That can be quite a difficult conversation for everybody involved. I want to get your perspective on why you see it as being so important that the organisations that take the lead are, in fact, autistic led organisations.

**Mrs Staheli:** I guess the starting point for that was in my opening statement and in the principle of 'nothing about us without us', and the value of lived experience being so important in this conversation. I would add to that that Yellow Ladybugs is an autistic led organisation but we're also a parent led organisation. The majority of us are parents of autistic children. Many of us are autistic ourselves. We come through this with a parent perspective as much as we do an autistic perspective and we don't see the two as being mutually exclusive at all. Our approach is always one of positive, constructive change and we think that is absolutely achievable within the context of being autistic led. We're demonstrating that here in Victoria in the input we've had into things like the state autism strategy and the education strategy. We're extremely grateful to the departments here in Victoria who have taken that message on board and who have engaged with us and enabled us, and others, to do so in a really constructive manner so we do start to see that change.

**Senator STEELE-JOHN:** Okay. Thank you so much.

**Senator CAROL BROWN:** Thank you for your submission and your opening statement. You have talked about, and your submission talks about, how autistic women and girls are often misdiagnosed and underdiagnosed, leading to adverse consequences. Can you expand on some of the key factors that contribute to this issue? I know you've already touched on how they might be addressed. Do you have a view around the various diagnostic tools and the CRC guidelines?

**Mrs Staheli:** Sure. I would preface everything I say by stating, obviously, that I'm not a clinician and I don't have diagnostic experience, but I do have a broad understanding of what's going on here. What we're seeing is the

starting point for many families when they feel that their daughter is struggling and they don't know why. They go to the GP and they might even say, 'Look, we're wondering if it's autism'.

We know that there are still too many GPs and too many pediatricians who are not expecting to see a girl in front of them. They're expecting a boy who's probably non-verbal and displaying very stereotypical behaviours. Many girls come in. They can be extremely shy. They might not talk, they might not want to, but they'll seem to be playing with a toy. They might answer the questions. They might look the professional in the eye. There's that very basic level of dismissal that happens that this person can't possibly be autistic. I think that's one very significant part of the problem that continues today. We know it does because we hear from our community day after day that it does still happen.

I think the diagnostic tools are also part of the problem. They have been built around, again, stereotypical observations of autism. If you are not a skilled diagnostician, when you're assessing a girl through those tools, you might not see what's actually going on. We actually made that point to the Autism CRC when their terms of reference for the national guidelines came out. In terms of the guidelines themselves, we followed that whole process with interest and we did submit when the opportunity arose to provide commentary on that. In principle it's a great idea and it should benefit autistic girls and women. There is a recognition within the guidelines of specialist training for understanding autism in girls and women. Our concern is whether that training is actually going to happen in any meaningful way across the board. We also stated our concern at the time with the approach being taken with a two-tiered diagnostic process, where if it's not straightforward the person goes through to a second tier of diagnosis, and that many girls and women are going to be forced through that, which is more time, more money, more waiting.

So we're cautiously optimistic. I don't know how we go about changing the diagnostic tools themselves. That's beyond the scope of all of us, I think. But it is a conversation that I see happening a lot more now that there is a recognition that part of the problem is within those tools themselves.

**Senator CAROL BROWN:** That was really my next question, which you've already answered. You've got nine recommendations here. The recommendation around the National Autism Strategy really goes to your other recommendations, I would imagine. So you're fully on board with the voices that are asking for a National Autism Strategy?

**Mrs Staheli:** Yes, we are.

**Senator CAROL BROWN:** Given that this view seems to be very prevalent throughout the autistic community and peak organisations, why do you think it hasn't been taken up yet by government?

**Mrs Staheli:** I don't know is the honest answer to that. I suspect it's been too hard in some ways. We're probably at a very different place in terms of understanding autism now than we were even 10 years ago. With things like the NDIS and the prevalence and the prominence of the autistic community within that setting, I think it does speak to a sense of urgency to start addressing this now. I'm talking about all facets of the autism community here. Voices have gotten louder and there are more autistic adults and their families. I'm talking about issues like employment and these sorts of things that, again, probably weren't happening a little while ago. I think we've seen a greater exposure to the discussion at a national level. I think the NDIS has been a factor in that. When you look, for example, at what's happening here in Victoria with the state government's commitment to develop strategies around autism, I'm sure that feeds into that. It just seems like very good timing to me.

**Senator CAROL BROWN:** You may not be able to answer this, but do you think that the NDIA are doing enough work around autism?

**Mrs Staheli:** That's a hard battle. If you're talking about families and individuals and their experience with the NDIS and the NDIA, the consistent message we're getting is that it's still a battle. There's not enough understanding about autism, let alone autism—

**Senator CAROL BROWN:** Within the NDIS, you're talking about?

**Mrs Staheli:** Yes. When you're talking about the LACs and at that sort of level, our community fight really, really hard to get recognition that they or their child needs support. I say this in full disclosure, we are the recipient of an NDIS ILC grant, and we do think at the level of information and linkages and capacity and the commitment to support community organisations. That sort of thing I think is a very positive step. I'm not sure how that is translating into the actual service delivery side of the NDIS.

I was lucky to sit and listen to Mel Spencer just before me. She gave a very passionate explanation of the power of change that lies within the NDIS. When families do get the support they need, when individuals do get that support, it is life changing and it is proof that it can work and that it can be of immense benefit autistic to

individuals and their ability to reach their full potential. So there's an enormous amount of potential there, but I think we've got a very long way to go.

**Senator CAROL BROWN:** Yes. The NDIA may be able to play a greater role in terms of research.

**Mrs Staheli:** Yes. I honestly hadn't thought of that, but that's a very interesting idea.

**CHAIR:** I was interested to hear your comment on the gender bias of diagnostic tools. Can you elaborate on that? Having just regone through a whole assessment and WISC tests and these sorts of things, I'm not sure I understand what you mean about gender bias.

**Mrs Staheli:** I'm not a clinician, so I cannot bring that professional expertise to this commentary, but when you look at things like the ADOS, these tools are often observational. The clinician is there observing the individual's behaviour, what they're doing, and asking is it meeting these particular things? My understanding—I do have references to this which I would be happy to supply to the committee, the papers and research that have been done in this space—is that these tools were developed in a time when it was only little white boys who were being diagnosed and it was their behaviours that were being observed. That's not all that autism is. For many individuals—we know this for a lot of girls and women, but not exclusively at all—we know that for boys, for the gender diverse community, particularly those who've internalised their behaviour in their autism and who might have an ability to mask and mimic and camouflage, that they are not behaving the way that the observation expects them to behave. I'm not saying that they are behaving in a way that's a female presentation of autism at all. We don't say that's the case, but we do think they have been observed through the lens of a stereotypical understanding of what autism is.

**CHAIR:** But aren't they being observed to meet the diagnostic criteria? By changing the tool you're changing the criteria, aren't you? The presentation needs to meet different standards. Someone made the point to me earlier, and the more I think about it today I think they're probably right, that losing Asperger's as a diagnosis has probably created more confusion and challenges, because level 1, which we accept as Asperger's, looks very, very different to level 3. Level 1, what we used to call Asperger's, doesn't present anything like classical autism. Are we even talking about the same condition, in some ways, when it comes to outcome, opportunities and where the scope is? I'm just interested in your view. Do you think we've potentially taken a hit, gone backwards, made more confusion within the community, because we've lost Asperger's and the traits that it had, which are very, very different from classic autism?

**Mrs Staheli:** I'm not sure we have. I can only speak anecdotally about this from what we get told from within our community, that when parents and families find a pediatrician or a psychologist, if they're going through the diagnosis process and they're lucky to find the specialists who do have a good, broad understanding of autism as a full spectrum with many different facets and behaviours coming through that, when they find those people, the diagnosis process runs relatively smoothly, because you've got someone skilled who's able to make those judgements. We know that autism assessments are largely subjective. They're able to make those sort of subtle, nuanced differentiations.

We know that a lot of our community are being diagnosed at the moment. A lot of them are not level 1. A lot of them are coming through level 2. That is because there is a growing understanding around different support needs being required in different contexts and an understanding that sometimes individuals on the autism spectrum can present in a certain way that is not actually how they are feeling, what they are experiencing internally. So I'm not sure that that's what has mattered I think what hasn't changed is that there are still too many specialists and professionals out there who simply don't see autism in girls and women. You can go through those diagnostic processes and then they will say, 'She answered my questions. She looked me in the eye. She discussed her interest in animals or things like that.' These are non-stereotypical things that lead to them being dismissed.

**CHAIR:** In the old days that wouldn't be considered classic autism. That would be considered Asperger's.

**Mrs Staheli:** If it would have been considered autism at all. It used to be—I couldn't tell you the exact date—that the ratio of female to male diagnosis was one to 25.

**CHAIR:** You said it's one to four now. Do you think it's higher?

**Mrs Staheli:** That is the statistic that is accepted at the moment. I think there needs to be a lot more research done to actually see what the real ratio is.

**CHAIR:** I think we've accepted that girls are much better at masking quite often. They do tend to appear more social. They tend to be more compliant for mothers of daughters versus mothers of sons. I think everyone would understand that, with or without autism.

You've mentioned the poor training of diagnosticians. What do you think we could do better? One of the things I'm interested in is particularly the early diagnostic stage. We do know that the earlier we get to early intervention, the earlier we get to that quality and quantity of intensive and effective early intervention, the better everyone's outcomes will be. If we've got a vaccination program for kids, why, when they're going to have the vaccinations done, aren't we ticking off developmental milestones, which of course is an indication of either a global development delay, which can be autism and all those sorts of things, so that we're actually starting to look, specifically for first-time parents. You don't know what they're supposed to do, when they're supposed to do it, all those sorts of things. Do you think that something like that would help diagnose girls earlier? Girls that aren't diagnosed till they're 12 or 13, were they hitting developmental milestones when they were 18 months, two years, 2½ years of age? Were they not hitting them, or were they hitting them and all of a sudden at 12 or 13, when social awkwardness has kicked in and something is there, that an autism diagnosis is being given, but it really might not correlate back to when they were toddlers, at that early stage.

**Mrs Staheli:** What we hear from a lot of our parents of girls who were diagnosed later is that in hindsight they realise that their child probably wasn't hitting their developmental milestones, but it wasn't obvious what was going on at the time. A lot of families will say, 'Yes; we've been struggling. We know our daughter has been struggling from the earliest days, and it's taken us five years to get any recognition.' For a lot of them it's not a surprise, but it becomes more obvious when they're a bit older. When they look back, they say, 'Actually, there was something different, but we didn't see it and nobody else saw it.' Early screening is something that could be very valuable. I say this with personal experience, because I was one of the lucky ones who was attending a maternal and child health nurse appointment for my younger child, who was a baby, and the nurse looked at my older child and said, 'I think I'm going to refer you. I think you need to go to your GP for a referral to a paediatrician.' I hadn't seen anything at all. So I was one of the lucky ones to find someone who, when my child was 2½, saw something that was worth investigating. It needs broader knowledge and deeper knowledge in all of the fields. The national guidelines covered this—looking at the screening tools before you get to an actual diagnosis process. We need a broader and deeper understanding of autism within the sectors and a commitment to some sort of screening program that might start picking these things up. That's going to be beneficial to the individuals involved.

**CHAIR:** You're right. It does seem to be luck in so many circumstances, as to diagnosis. If my mother hadn't read the fabulous Autism Awareness Australia's flyer that they put in *The Australian Women's Weekly*, I don't know where we'd be, because I certainly didn't know it was autism. My mother read it in a doctor's surgery, called me and asked whether I thought my son had autism, and I said, 'No,' but he most certainly does. Thank you so much for your time today. If there is anything further that you would like to contribute, please feel free to send it through to the committee.

**Proceedings suspended from 13:06 to 13:59**

**WHITE, Mr Jason, National Manager, Business Development and Engagement, Specialisterne Australia**  
[by audio link]

**CHAIR:** I now welcome Specialisterne Australia. I understand that information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. I now invite you to make a short opening statement and, at the conclusion of your remarks, I will invite members of the committee to ask questions.

**Mr White:** Specialisterne welcomes the opportunity to speak with the select committee regarding our 2020 submission. Our submission listed two streams of suggested recommendations around the improvement of employment conditions for autistic Australians, including changes to existing services, and the longer term role of government to drive systemic change. Both streams contain short-term, medium-term and long-term recommendations to, in our view, be truly impactful and drive sustainable change. We don't need to reinvent the wheel. We don't need to consider re-engineering everything. There are a number of already existing programs and services that we feel can be improved by engaging with more specialist services and gaining knowledge to be more successful. Obviously, it would involve some new initiatives that could continue to drive innovation and improve the prospects of autistic jobseekers in Australia for the future.

**CHAIR:** Senator Brown, would you like to start?

**Senator CAROL BROWN:** Thank you, Chair. Which programs that currently exist do you think need to be improved? Also, I wouldn't mind your view on Disability Employment Services and the employment strategy that's driven out of the NDIA and DSS.

**Mr White:** Certainly. My background before joining Specialisterne was in Disability Employment Services, so I'm quite used to how that program operates. I was acutely aware of the bright lights of that program, where it did quite well, and obviously where it fell short. The continual feedback that we're getting from autistic jobseekers in Australia that have been linked with Disability Employment Services is that it's a frustrating system. It's a frustrating system that often is staffed by people who don't have a solid knowledge base of working with autistic jobseekers, and it's a very transient industry, so jobseekers become disenfranchised with that system, with it being the only system that they think they can go to, where they'll be understood. They have staff that are quite transient. They don't stay in the same role for very long, so autistic jobseekers are finding it quite frustrating having to front up to an interview to basically tell their life story, coming in for a fortnightly meeting, and then, within two or three weeks, finding out they've got a brand new consultant and they have to tell their story all over again. It's relatively problematic that you've got no minimum entry requirements for people who are staffed within the disability employment services sector to have any kind of baseline understanding of broader disability, and certainty of autism.

Some of the feedback that we've got from people at the head of Disability Employment Services is that they've conceded that there are cohorts of people within their generalist case loads that are harder to work with than others. Unfortunately, some of the feedback that we've got is that they view some autistic jobseekers to be harder to place than others, for whatever reason that is. I think it's because of the general lack of understanding. I would also say that I believe that the program guidelines for Disability Employment Services lend themselves to a program that rewards program providers for the speed with which they can place someone from their original registration period. It kind of puts providers in the position of looking for the quick wins and not always looking for jobs that are suited to the actual jobseeker. We know from specialists and from our perspective that the whole process of selecting and assessing talent needs to be a patient process so you really get to understand the individual and understand their strengths, certainly in relation to employment—what some of their transferable skills may be and what the interests and motivations are—but also understand what some of the accommodations at the workplace may be so that you can advise employers on some of the reasonable adjustments they may need to make. Unfortunately, they are seldom afforded the time to spend to really develop that relationship with the candidates that they're servicing.

**Senator CAROL BROWN:** Could you also expand on what programs you think are going well or what programs, with some improvement, would be able to meet those needs?

**Mr White:** I think it's across the board. There will be elements of pretty much every program that we have in place already that have some amazing stories. We should champion those stories, because they're doing amazing work. We've got some really committed people working within these different programs who do get it, who do understand it and who will go out of their way to work with an individual to see them achieve their employment hopes. Overall, I just think it's the make-up of the programs in general that it doesn't lend itself to offering that more patient process.

When I think about the way in which Disability Employment Services providers work with employers—I mean they're there to support individuals, but I'm not sure that even the Disability Employment Services providers have enough understanding or resources or tool kits to be able to talk to their employers about how they may be able to make some basic, reasonable adjustments to making that transition for someone on the spectrum into employment a lot simpler. There's still a heavy reliance on the Disability Employment Services providers being that first pillar of support for the individual, whereas the specialist perspective is that we think that's backwards. We think the paradigm needs to be shifted the other way. We really need to be spending the time building the capacity and the confidence of our employers because, at the end of the day, they're the ones who are going to be supporting these individuals in the long-term, not the providers.

I think the same could be said for all of those ancillary programs that come off disability employment services. It's the same issue whether it's jobactive, whether it's the school leaver employment service or whether it's any of those types of programs. We have people who perhaps don't have an appreciation of or the experience to work effectively with autistic jobseekers.

**Senator CAROL BROWN:** What do you think government can do to encourage, in the first instance, employment service providers to change the way they are getting autistic clients ready for the job market, job interviews? What can we do, in talking to industry, so that they have a greater understanding of autistic people, and to try to improve their employment opportunities?

**Mr White:** If you look at the funding guidelines for a lot of these contracts, a lot of these organisations are legacy organisations that were born from programs gone by. You've got the same people who ran those programs and they've just transitioned across. They've gone from Job Network to JobActive—they've just gone along in the trajectory of how these different programs have evolved over the years—but essentially the thinking has pretty much been the same.

I believe there probably needs to be some sort of top-down encouragement, advice, pathway in order to encourage providers with these contracts to be able to look at the funding that they're receiving from government to provide services for autistic jobseekers, to say, 'Yes, we're giving you money to support these individuals, but you can actually use some of the funding that we're providing you to seek specialised services to help you bridge the knowledge gap, so you can be more effective for a wider cohort of individuals.' From the employer perspective, all that knowledge at the moment, in terms of how an employer can engage with somebody with a disability more broadly, and certainly some with autism—at the moment it's only really coming from those systems, it's not really coming from anywhere else. It's excluding a huge candidate base if employers are only resourced at the moment to seek that kind of information from the DES system or, to an extent, the JobAccess program. There could be some bolstering to what JobAccess could provide so that employers, in isolation, could come to JobAccess and obtain a suite of tools and resources to be able to really look at how an end-to-end process of a positive autistic hiring program may work. So, they can then provide that information and then bring that on board.

**Senator CAROL BROWN:** You've been in the disability employment sector for quite a while, so you would be aware that a number of years ago the government revamped the Disability Employment Services program, where a number of organisations packed up or sold to larger disability employment services, but they also changed the way in which funding was provided in terms of disability type. Have you seen any improvement in employment levels since that change?

**Mr White:** Not us personally, no, because we've been largely removed from the DES industry for about the last five years. We don't have any more contemporary, up-to-date information on whether that has been impacted or not. What I can say is that some of the issues that I described earlier, the same can be said for the people who are assessing autistic individuals at the Centrelink or NDIS level. I think there's still that lack of understanding. In my history, I've found the experiences of the people who are providing the assessments on behalf of Centrelink, who are providing those employment services assessments to autistic candidates looking to be linked with DES, their individual backgrounds can be quite varied. They can be anyone from a clinical psychologist right down to a counsellor, and everything in between. I've been to some appointments where we've had a physiotherapist provide an assessment on someone with a neuro condition and they didn't really know much about it at all, and they're providing information that will indicate what the funding level's going to be for that particular individual. They would then be referred over. These issues I've described sit across the entire sector.

Going back to Disability Employment Services, again, it's a very compliance driven program. When you're talking about autistic participants in particular, there's enough weighting given to some of the qualitative outcomes of some of those employment outcomes. Those providers that are doing it are doing a great job, but

there's no weighting given to those based on the qualitative outcomes. We know, working with an autistic population, that sometimes it's those qualitative outcomes that far outweigh the cognitive ones.

**Senator CAROL BROWN:** In your submission you acknowledge the increased investment and commitment, both of business and government, but it's interesting that there is still no specific system based response in terms of autism employment.

**Mr White:** No, and I think, with regard to autism and employment, if we're coming from an employer standpoint first of all, so in isolation, employers are generally hemmed into quite rigid and robust recruitment processes that are kind of being grandfathered throughout any organisation. Sometimes there's a big reluctance there to branch out and offer some reasonable adjustments to that recruitment process, because then you have issues of it not being a process of merit if you're allowing or affording different types of accommodations to different types of applicants going through a process.

One of the issues that we're talking to both federal and state governments about at the moment—there have been ongoing conversations over the last 12 or 18 months—is around how do we educate our hiring managers to become aware of some of the reasonable adjustments that they can make to their existing recruitment processes so that they can be more accessible to a wider cohort of jobseekers without disrupting the integrity of the recruitment process? That's a very major talking point at the moment, and I think there's a lot of work that can be done there. But the positive thing is that, in certain pockets, there are different agencies that are further ahead in the game than others.

**Senator CAROL BROWN:** Who are those agencies at the federal level?

**Mr White:** At the federal level we're working closely with Services Australia and the Australian tax office. For quite a while now the Australian Bureau of Stats have been looking at increasing their internal capacity to be more accessible to a wider cohort of jobseekers.

At the state level, we've been working closely with the New South Wales government. The Public Service Commission of New South Wales commissioned a wonderful program last year called the New South Wales Tailored Talent Program. In the face of COVID, they managed to exceed their job quota for that particular pilot program. It engaged, I think, nine New South Wales government agencies to really challenge the government's quite rigid recruitment processes. The notion of that program was: if we do what we have always done, we're always going to get what we've always got; we're never going to change. The Public Service Commission really encouraged the whole of government to invest in adopting a pilot program so that they could see what's possible with sort of challenging the status quo.

**Senator CAROL BROWN:** The federal government has a seven per cent target for the federal public service, as you would be aware. There obviously has to be some sort of revamping of a national disability employment strategy. I'm not talking about particular programs within particular departments that are directed to actually hiring; I'm talking about something broader that might sit under a national autism strategy. But certainly there needs to be a targeted and maybe even mandated response. What do you think?

**Mr White:** I agree. I don't think it necessarily needs to come from either top down or bottom up; I think it's probably a blend of both. I think we can meet in the middle somewhere—and that will be probably par for the course somewhere down the track. One of the issues that I see at the moment is that there is no real way for an autistic jobseeker to identify which type of service provider understands autism. It's not really clear. Basically, it's just a roll of the dice.

Because of the changes to DES, there is freedom of movement now for individuals. So they are allowed to bounce between employers if they are not getting what they need in terms of service expectation. But if there was a way for providers being able to identify that they are an autism confident provider, I think that would be the start at that level. I think the same could be said from top down and the role of federal government to have well-established processes in place and training in place for their staff or their hiring managers, so that, for any available job opening, there is a clearly identified pathway for an autistic jobseeker to identify if this particular opportunity has reasonable adjustments available for existing jobseekers. It's not clear at the moment. The onus is on the jobseeker to seek that out. Unfortunately, as soon as a jobseeker asks for reasonable adjustments, we're at the point now where, again, I think they are put into the too-hard basket again and they're seen as being someone that's going to require more time. Again, it's something that definitely needs to change. But it's not because people don't want to be better in that space. I don't think the education is there, I don't think the framework is there, I don't think the resources are there and I don't think the tools are there so that it becomes a much easier option for a hiring manager to make some of those reasonable adjustments. I think we can start both at the top down and from the bottom up.

**Senator CAROL BROWN:** Given that autistic people are 31 per cent of the NDIS participants, do you have any information that you can share with the committee around how LACs and planners are dealing with the employment question within plans?

**Mr White:** I don't personally. The one comment I will make is about the issue that we are seeing with the NDIS. When the NDIS framework was rolled out, well before the NDIS rolled out proper, one of the concerns we had was that the eligibility criteria only really looked like it addressed a very small percentage of the cohort that we were working with in an employment perspective and many were going to miss out. One of the issues at the moment that we're finding is that, for those that do seek out NDIS and aren't eligible, there's no further information that they are being provided to tell them what's next. If they are not eligible for DES and they're not eligible for NDIS, there is nothing else for them to fall back onto. But I don't have anything specific to question.

**Senator CAROL BROWN:** Thank you for answering my questions.

**CHAIR:** Senator Steele-John?

**Senator STEELE-JOHN:** Thanks for the information you've given so far. It's good food for thought. I just wanted to go quickly to your submission. There's a page where you detail the number of people that you have placed under your program. I think it's 131. Is that right?

**Mr White:** I believe that number might have been correct at the time of writing the submission.

**Senator STEELE-JOHN:** I just wondered whether you could give me any kind of gender breakdown on that. Is it overwhelmingly men or women? What do the statistics tell us?

**Mr White:** That's a fantastic question. It's been largely skewed to the male demographic since the dawn of time in terms of the gender breakdown in employment programs. We've historically worked largely in technology and we believe that, although the gender balance is slowly increasing back to some kind of balance, we're nowhere near there yet. But we're probably not in a different boat than the discussion around women in STEM, which are finding the same problems. They're finding that the participation uptake in STEM roles is hugely skewed towards the male demographic. There are amazing initiatives out now to really encourage women in STEM, and we are certainly part of that journey as well. But we are seeing that there has been a steady uptick in female participation and interest in our programs, particularly over the last 36 months.

**Senator STEELE-JOHN:** Awesome. Do you have the breakdown to hand?

**Mr White:** It's roughly sitting at about 15 per cent female participation and 85 per cent male.

**Senator STEELE-JOHN:** Is there anything you've noticed about different challenges with placing women in the workplace? What do you think is driving that beyond those broader issues with STEM and the rest of it? Are there any particular challenges that you've experienced with preconceived ideas in workplaces or those kinds of issues?

**Mr White:** I don't believe it so much at the workplace stage; I think it is before that. I think it's possibly the way that job ads have been presented in the past. I don't know exactly what it is. We try to be purposeful in making it quite open that these jobs are suitable for everyone. We don't always drill down on the specific coding languages or things like that are perhaps needed for a job. We try to describe the culture of the organisation and the type of mindset and the skills that someone needs to have in terms of attracting a broader cohort. That seems to be working for us at the moment. Of course, having a gender statement in most of our job ads now has been incredibly important. Once we have female participants in our training and assessment program, there are no differences in how those are conducted in terms of issues and things that you need to work through, performance or anything like that.

**Senator STEELE-JOHN:** Thank you very much. That'll do me, Chair.

**CHAIR:** Thank you, Senator John. Mr White, I just want to touch on a couple of issues with you. At the moment, if someone wants to maintain their disability support pension, they're only entitled to work 15 hours per week. Is that correct?

**Mr White:** I think it can be up to 28 or 30, depending on your circumstance and your age.

**CHAIR:** Okay. We might have a look at that.

**Mr White:** And the amount of work.

**CHAIR:** What is the scale of the programs that you're running? We know that some of the larger corporates in Australia have implemented autism hiring programs. They are multilevel, huge organisations—some of the largest companies in Australia—yet their autism programs consist of employing maybe 10 people. That's really

not going to make any substantial difference. What sort of scale are you operating at, and if they are smaller programs is there the opportunity to scale them up?

**Mr White:** Great question. We've got a couple of large corporate partners at the moment who are up to their second program, going from their pilot into their second iteration of a positive autism hiring program. We work with our corporate partners on a three-year rolling model. In year 1, we're working with them on a pilot to help them establish a baseline understanding of what autism is, what autism in the workplace is, what some of the challenges are, why people with autism are missing out on employment and some of the reasonable adjustments their hiring managers can make not only to the recruitment process and the HR business part of it, but also as managers to support and develop their autistic staff once they have them in their workforce. That's year 1. It's us being transparent and showing them our process, end to end, so they can appreciate what's possible—

**CHAIR:** What sorts of numbers would go through in a pilot program?

**Mr White:** It's typically been around 10 people for a pilot program. Somewhere around 10 is the average number.

In year 2, or program 2, we like to encourage our clients to (a) increase the numbers and (b), which is probably more important than the numbers, increase the diversity in the job roles. We think that's critical, because if an employer focuses on just employing software testers and that's all they do for two or three iterations of the program then they're not going to learn anything beyond creating a pathway for autistic jobseekers for those types of roles. So, we really encourage our employers to broaden the breadth of the job families that they invite into these programs. Year 2 is about establishing some BAU activities at the client level, broadening some of those employment opportunities and then bringing in a wider group of people across the business. Year 3 is the business taking the training wheels off, taking the lead in the end-to-end process, but leaning on Specialisterne for that expertise and support along the way.

**CHAIR:** Have you hit year 3 with any clients?

**Mr White:** We're about to hit year 3 with one of our federal partners this year. That particular federal agency has had a couple of cracks at it before. They partnered with Specialisterne independently.

**CHAIR:** As we enter year 3, what kind of numbers are we looking at?

**Mr White:** We're hopeful for somewhere between 10 and 30 in the third year, which would be fantastic. There was another government agency last year with their second iteration of the program—basically year 2—and they were able to commit 30-plus placements in their second year, which was phenomenal.

**CHAIR:** Are they all IT and cyber based roles?

**Mr White:** They're largely IT roles. But certainly we're getting more calls now, as you'd probably appreciate, in the data space, big data, where candidates don't necessarily need to have a predisposition to understanding programming and coding language; they can be people that can understand datasets, people that are quite familiar with and are okay to play around with Microsoft Excel at a basic level. People that have those core skills and have the motivation for those types of jobs—people that have that kind of inquisitive mind—tend to also do quite well through our programs.

**CHAIR:** What about jobs outside of that space? Not everyone's cyber, IT, techie driven. What are the opportunities for those who might, for example, be interested in food service or being a chef? Are there those sorts of opportunities?

**Mr White:** There will be. There has to be. That's the answer. The answer is that there have to be opportunities across the board. We're at the tip of the iceberg at the moment in terms of where we've found success. We know we need to do more to be able to show those other industries that there's a different way to recruit. To go back to some of my earlier remarks, I think that's the key. Yes, Specialisterne does work with some larger national and multinational employers, but there are some employers that are five- or 10-people operations that would love to employ autistic talent, but there's no information to allow them to understand how to go about recruiting differently to attract an autistic jobseeker.

One of our biggest challenges moving forward—and it's in our strategy—is to work with different types of industry to understand the way their business works and to explain to them and educate them on how they can make those reasonable adjustments to their existing recruitment processes so that they can be more accessible to autistic candidates. At the end of the day, looking at the Specialisterne recruitment process, if we can work with an employer and understand the role that they're looking to recruit for and if we can extract some of the core requirements of those roles and turn them into practical competency/skills based assessments then we're going to be able to invite autistic candidates to come through that process and demonstrate to that employer that (a) they

can do the job and (b) that they've got the skills to do the job and they're motivated to do the job, and (c) we'll also get to meet with that individual and work out some of the reasonable adjustments and accommodations for the individual that we might need to educate the employer on before they transition them into a job.

**CHAIR:** When you're talking about accommodations that are being made, are any of these people that are going into these roles going in with a support worker to support them to get through the transition and adjustment, or is that laid at the feet of the employer?

**Mr White:** No. Part of our overall end-to-end service offering is that once an employer gets to a position of selecting someone, and we go through that onboarding period, our client partners are committing to a portion of what we call ongoing business enablement and support. That's Specialisterne coming in and continually working with the hiring managers through that transition period. When the person commences employment, we're bootstrapped for at least the first three to six months of our program to make sure that the individual and the hiring manager feel well supported in that initial transition period. We're there to help address any issues in the workplace.

As most people could probably appreciate, an employer that's doing this for the first time doesn't know what they don't know before they embark on a program like this. It's very much a learning experience on the job once they've commenced the program, and they've got someone from Specialisterne working with them. The first three to six months is a bit of a learning on the job as they go, learning more about the individual they're bringing in and understanding their individual qualities, like their communication preferences and their learning style. We're continually working with the employer and the individual throughout that process so that the employer feels very confident in supporting that person and developing them long after we've gone.

**CHAIR:** Thank you, Mr White, for your time today. If there's anything further that you want to send through to us, please feel free to send it through to the committee.

**Mr White:** No problem. Thanks very much for the opportunity.

**FIELDHOUSE, Mr Michael, DXC Dandelion Program Executive, DXC Technology**

[14:32]

**CHAIR:** I now welcome DXC Technology to the table. I understand that information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. Before we continue, is there anything you want to say about the capacity in which you appear today?

**Mr Fieldhouse:** I look after the recruitment and sustainment of the program. DXC is an international company of about 200,000 people globally, with about 10,000 people in Australia—

**CHAIR:** I'm going to invite you to make a statement in a second, but at the conclusion of your remarks I will invite members of the committee to ask questions. Over to you.

**Mr Fieldhouse:** I'm really here as an employer. DXC is the largest employer of autistic people in Australia. We've employed close to 150, 160 people. We built a program, which we started in 2013, and that program currently has 120 people in it. We also have about 70 work experience opportunities. We also funded Specialisterne to be here too. We provide the seed capital for that.

To give you a little background on how I'm aligned to this kind of mission, I have two very close friends who have autistic kids—one who's profoundly autistic, who has an intellectual disability and is non-verbal, and the other who is classed as Asperger's and is autistic. That's how I got into this mission. I'm very much here to help provide any information from an employer's perspective, as we've been employing people for close to seven or eight years. We've also open-sourced our program—there are over 600 organisations globally, across 91 countries, that have used a lot of our material. One of the biggest users is Disney, which we didn't expect. So that's a little bit of background.

We've been funding a lot of research in this area through La Trobe's OTARC. You probably have Professor Cheryl Dissanayake talking. She's been—

**CHAIR:** Tomorrow, I think.

**Mr Fieldhouse:** Tomorrow—okay, great. She's been our lead researcher on our program. It's probably one of two programs globally that have evidence based research underneath them, which is quite unusual—but it's also very good as a way of actually understanding what's going on with autistic individuals in the employment structure. I'm very happy to explain any of that.

**Senator STEELE-JOHN:** Thanks for your time. I just wonder whether you could give us a similar breakdown in terms of the autistic folks that you employ, based on gender.

**Mr Fieldhouse:** Yes. I would say a good percentage—probably close to 90 per cent—of our people are male. It's quite interesting: when we do recruitment for data science roles and cybersecurity roles, we're finding that a third of all applicants are female. That's been quite unusual for the last two years. That's what we're seeing, and we've basically been hiring on those stats, so a third of all participants now are female or autistic.

There is a couple of challenges in that. We find that a lot of the individuals we do have haven't been diagnosed early, so they're usually being diagnosed later in life. There's a couple of studies around that, one by Stanford University about camouflaging. There's also a little bit of research going around on borderline personality disorder. I'm obviously not a specialist in that, but there is a lot of work being done in those areas about misdiagnosis.

**Senator STEELE-JOHN:** That increase that you've seen over the last two years—is that the result of any particular strategy you've put in place or is that just a trend you've observed?

**Mr Fieldhouse:** I think we've got better at creating a narrative about the jobs we are providing. When we've talked to a lot of female individuals, we've got better at describing what a day in the life is like, rather than having a job description which is dot-pointed. Obviously, I'm not female, but they relate to that a lot more: What does the job really look like? What does the environment look like? So we've got better at doing that.

**Senator STEELE-JOHN:** Awesome. Do you have any kind of target around that, moving forward, in terms of achieving a parity in the number of people that you place?

**Mr Fieldhouse:** Yes, we definitely do. I think we've got better at changing our attraction model. We're working with a lot more autistic female groups, like Yellow Ladybugs. I hope they're talking tomorrow as well.

**CHAIR:** They were here this morning.

**Mr Fieldhouse:** To give another example, we're doing a lot of work in the UK at the moment and we're talking to Spectrum Girls. We do see the autism community from an employer's perspective: it's very fragmented. It's required us to be quite innovative in how we integrate with these other community groups.

**Senator STEELE-JOHN:** Awesome. And can you tell me what your target is, or is it just still something you're working out at the moment?

**Mr Fieldhouse:** We aimed initially at starting at about one per cent of our employees being on the spectrum. That's something we've already achieved locally, in Australia. So we're now aiming at two per cent. What we're trying to do a little bit differently now is very much to focus on—being an IT company, I think that's kind of what you have to do—working through giving more people support so that we have more people go through that experiential kind of experience of having employment. Our program is very much focused on sustainment. It's not about the recruitment; it's about the sustainment. That's the biggest issue.

To give you an idea of employment around autistic people—this is the second wave. The first wave happened in 2000. Merrill Lynch was the first employer to do it. That failed. A number of programs have failed.

When we interviewed these people in 2013—being an IT company, we do a bit of research to find out what's gone wrong—we interviewed the chief HR officer out of New York, and also a company called Freddie Mac, another big company. They're the two leading organisations that were hiring people in 2000. The biggest challenge they found was the sustainment process. It was not recruitment—getting people in—but actually keeping people in jobs. There are a number of reasons for that. One that came through was lack of employer training—coworker manager training. You have to remember that this was 2000, so there was a lack of coworker manager training.

No. 2, and we really only understood this through our program, was the mental health challenges. I'm happy to talk a bit about that. That's a really big issue in sustainable employment. A lot of the people fall out of employment. I remember first trying to engage beyondblue to have this conversation. Eventually DXC and ANZ bank funded the research. So, we actually funded the research into this area. But mental health issues around sustainment was a big challenge.

The third probably was life skill issues. By that I mean making sure that individuals go to the dentist. You might think that's a very simple thing, but for somebody with autism who has sensory needs, going to the dentist is a nightmare. We have stories about people waiting until all their teeth are a bit rotten and then getting put under a general anaesthetic to fix them. You can imagine that from an employer's perspective that's a very difficult thing. So, they are really the three major challenges that came through when we interviewed people in 2013 about their programs in 2000.

**Senator STEELE-JOHN:** Thanks very much for that.

**Senator CAROL BROWN:** As you say in your submission, you're bringing an employer's perspective about what is required for sustainable long-term employment. My question—one I think you know would come to you—is: what can government do to assist in sustainable long-term employment?

**Mr Fieldhouse:** There needs to be a support structure for them. For large corporates like us, we can actually afford that. We've put that in place. To give you a perspective—

**Senator CAROL BROWN:** How would that be delivered?

**Mr Fieldhouse:** I'll give you a little bit about the cost first, and then at least you can get the perspective of a small business. For a large corporate like ours, it's costing us to support somebody in that program, and our outcome is about 16 months. So, we see people get independent past that. It costs us between about \$20,000 and \$40,000, depending on the individual, to provide that support, per annum. It tapers off at about 16 months. I think the hard part for smaller business—if you think about it, that's for one individual, and we have very high outcomes, and obviously we have a lot of research behind it—is that there's very much a cost-prohibitive element to it. So, it's actually about working out mechanisms that can then be rescaled and support local businesses. For example, I was just looking on SEEK before I came here. In Australia alone there are 25,000 jobs available in trades and services. In IT it's 13,000. Not everyone's going to go into IT. There's a statistic that says that effectively about a third of autistic individuals end up in the STEM area. That was a *Scientific American* study.

**CHAIR:** Sorry—could you just clarify: a third of all autistic people end up in the STEM area? Of all autistic people?

**Mr Fieldhouse:** Yes. That's what the stats from *Scientific American* affirm.

**CHAIR:** Even though we have huge underemployment within the autism community?

**Mr Fieldhouse:** They have an interest in STEM. How they end up in employment is another question. They've got an interest in STEM. That's from a *Scientific American* study. So, there are two-thirds who are not interested in STEM, if you take that element. From a government perspective, it's taking a lot of what we do from a large corporate perspective and being able to scale that down to a level that a small business can adjust. I think

that's a really critical one, because that 80 per cent of employment happens at the small business level in Australia. So, I think it's about making sure that occurs.

I think the other one is making sure that there are good mental health supports for individuals in the workplace. That's a difficult one. We've been developing a program just around mental health. It's actually allowing GPs, psychologists having appropriate funding, maybe NDIS or DES, to allow that support to occur for that individual. That's just a couple. Probably the other one is that I think there are still a lot of stereotypes around what autism looks like. I think that's a stereotype. That's a lot of people taking what they see in a child and then extrapolating that to what they see as an adult. It's very, very different. That's a couple of things. One is education; and, again, how do you break some of those stereotypes down?

**Senator CAROL BROWN:** That's good. Have you had a look at the Disability Employment Services and how they're performing?

**Mr Fieldhouse:** DES itself—

**Senator CAROL BROWN:** Yes.

**Mr Fieldhouse:** We've been asked to help. We've got a program under Minister Anne Ruston at the moment to take Dandelion and take those components and uplift DES and capability to deal with autism. We're only four months into that program.

**Senator CAROL BROWN:** Have you had to look at the gaps in their service?

**Mr Fieldhouse:** This is what I think the government recognised, that there were gaps. There's stuff that we've filled with Dandelion and we're now mapping that. So it gets down to one, education of the DES provider around autism. What does autism mean? Then we're dealing with a lot more disabilities than just autism. We recognise that. There's then the ability to say, how do you actually educate the employer? That's another big step, and that takes time. Why IT? People ask why there are a lot of autistic people in IT. IT is naturally geeky anyway. There are a lot of geeky people. We're innovative in our environments. As an industry we've only been around for about 20 years. It's going ahead and making sure that employers get that level of education.

Then there is ensuring that the DES providers provide appropriate onboarding and sustainment services for the individuals. Sustainment services can be broken up into executive functioning, so helping them with executive functioning, helping them with life skills. The things we thought we would never have to build are things like financial management. We had to build a financial management package to tell people how to read their payslip and what it means and what superannuation means. We had to build a program. We did a nutrition package. If you asked me, as an IT person, would I ever be building on a nutrition package, we built a nutrition package. That was one of the challenges. We found weight gain in a lot of our employees because they basically had bad habits. More money fuels bad habits. It was getting those elements in.

When you look at DES, you have to look at the sustainment elements and what programs are going to be in place to ensure that the individuals get the appropriate level of uplift, given that they've got developmental challenges, to ensure that they are successful in the workplace. A great example we've learnt off Israel is positive relationships in the workplace. We've got a collaboration with the Israeli Defence Forces program Ro'im Rachok. One thing we learnt off that was positive relationships with the same and opposite sex. They do a lot of training up front, and that deals with a lot of human resource issues. We've taken that material and repackaged that and do positive relationship training.

**CHAIR:** Can you explain that? I'm not quite sure what you mean when you say positive relationships.

**Mr Fieldhouse:** Workplaces are a very complex set of relationships. We've had challenges where individuals don't quite know what the boundaries are of—

**CHAIR:** We're talking about appropriate behaviours?

**Mr Fieldhouse:** Appropriate behaviour, yes.

**Senator CAROL BROWN:** Going back, we've had submissions and evidence given to the committee around a lack of awareness of autism within the employer groups. I think you would agree with that.

**Mr Fieldhouse:** Yes.

**Senator CAROL BROWN:** And also a lack of awareness by DES providers—not all of them, but generally—and the challenges that autistic people have with a DES provider. In terms of the project that you are undertaking through DSS, I'm trying to get an understanding of exactly what it is that they've asked us to do. Have you identified the gaps and services that the DES providers need to step up to?

**Mr Fieldhouse:** One was from our own learnings. Fifty per cent of our individuals come from DES.

**Senator CAROL BROWN:** How do you get them?

**Mr Fieldhouse:** Through the community. Interestingly enough, a lot of the community—

**Senator CAROL BROWN:** But not by DES?

**Mr Fieldhouse:** They actually are referred. They're in DES, and then it comes back in a way. So through our marketing. When they're given to us they say 'here it is'. What we found with some of the gaps—what we had to build is a program. If we can just hire people and there weren't issues it would just seamlessly integrate. Where there is a lack of knowledge is about that sustainment part. That's a really big challenge. No organisations are really coming to grips with that. Maybe I have a little bit of empathy on that side of it, because that's still forming in people's knowledge.

For example, we use different performance management systems for autistic individuals to help have good conversations. We took that off Israel. Israel has those kinds of tools. They use an assessment tool to help with understanding the sensory needs. We took that tool out of Israel. They do 150 people a year. It's the largest program of scale. We learn through that.

**CHAIR:** Did you say EY Israel?

**Mr Fieldhouse:** Just Israel.

**CHAIR:** At DXC they take 150 people, is that it?

**Mr Fieldhouse:** No, Israel does, the Ro'im Rachok program. It takes 150 people a year.

**CHAIR:** Who runs that program?

**Mr Fieldhouse:** It's funded by the Israeli Defences Forces. They've funded that starting in about 2014. That's the largest program. We identified some of those issues when we were interacting with the DESs. Basically, as a DES only provides limited sustainment support functions, that's what we had to really pick up at the back end. No-one really knew about nutrition or mental health issues. No one really knew about these things.

**Senator CAROL BROWN:** How about the DESs relationship with employers, in terms of raising awareness of autistic people as potential employees?

**Mr Fieldhouse:** I can't say across the board, but I know that a lot of DESs do find that difficult to convey. To give you an idea, we built a tool with Google, Microsoft and JP Morgan Chase around doing that. We built a tool to help with better awareness in our own population. A lot of those tools are only two or three years old, that those tools have been developed. A lot of those tools we're trying to provide to DESs to give them the ability to uplift their knowledge to the employers. That's lot of work in progress.

**Senator CAROL BROWN:** Do you know where the disability employment rate sits at the moment?

**Mr Fieldhouse:** No, I don't know.

**Senator CAROL BROWN:** It's interesting to hear about your project. We'll be looking to see how that goes. How long have they given you?

**Mr Fieldhouse:** To the end of this year. We're only four months. The key part of the outcome, the hypothesis, by us providing Dandelion as a toolkit to DESs, if you think about it as a tool kit, as a programmatic structure, will that actually uplift DESs or not—this is the hypothesis—uplift DESs in their capability to employ autistic individuals? What we've been very good at is giving all the structure and the programmatic and the tools associated. If we could give that to the DESs and a programmatic structure to work through, can that increase the actual outcome of employing more people with autism? That's just the hypothesis. We're only four months in, but we're working through that.

**Senator CAROL BROWN:** Have you turned your mind to support for the kids that are transitioning out of education into employment—school leavers?

**Mr Fieldhouse:** We've actually created a in an initiative called the Neurodiversity Hub. The Neurodiversity Hub is run by Untapped. That is taking a lot of our material and translating that into a higher education setting. What we've found is—this is just me travelling across the globe and looking at lots of models—from a higher education perspective we're probably about three to four years behind in how we work with autistic individuals. To give you an idea, in the US there are over 50 autistic programs across colleges. Each of those programs costs sometimes between \$3,000 and \$7,000, because obviously how education is paid for is very different there. Probably the leading one is in Rochester Institute of Technology. NASA recruits from Rochester Institute of Technology. Their program is oversubscribed. I would like to see some of those programs being introduced into Australia. They're run very much outside the disability unit within the university. People subscribe to them. To give you an idea, one of the universities that has a program, which they call a neurodiversity program, is Stanford

University. You've got ones at Carnegie Mellon. There's a new one being started up with the University of California Los Angeles. That was just being released. They're very much focused on doing all of that preparation work about executive functioning skills, life skills, to help individuals get work early.

**Senator CAROL BROWN:** What about our universities?

**Mr Fieldhouse:** We're about four or five years behind.

**Senator CAROL BROWN:** There's nothing like that?

**Mr Fieldhouse:** Nothing like it.

**Senator CAROL BROWN:** In any of our universities?

**Mr Fieldhouse:** No universities at all. That's a big gap. To give you an idea, in the US you get invited to an internship, what they call co-ops. The university supports the individuals in those co-ops. They're doing all that support framework. So you think about Dandelion being transferred back down into a structure and a higher education perspective. They're doing really well. There are colleges that are really good at it—Landmark in Vermont; as I mentioned, Rochester does NASA and they do some of the FBI; and they've also got programs now in Florida. As I said, there are 50 programs that you can choose from now

**Senator CAROL BROWN:** How about state government and any initiatives that have been put in place? Earlier today we heard some evidence around the Victorian Department of Education. They've got a new education strategy and plan and some funding to go with that. We've also heard about Queensland, and you've referenced the Queensland government in your submission as well. What projects or initiatives at state level are going well? Unfortunately, it doesn't seem that there are a lot of initiatives nationwide at the state or territory level.

**Mr Fieldhouse:** The ones I've seen globally that we're missing here, one is Project Search, which is focusing on more profound autistic individuals. That's a very good program. I'd like to see that implemented here. It's very much focused on individuals at high school doing more work experience early rather than focusing on their HSC or VCE. That's a really good program.

**Senator CAROL BROWN:** Whose is that?

**Mr Fieldhouse:** It's from North Virginia. It's run out of the state government there. I think that Drexel did the research behind it, but don't quote me on that.

That's a good program. And the autism unit in Queensland is very good, I think. They have an autism hub and that's starting to help educate high schools about the opportunities a lot better. What they miss out on is having employer engagement against that. What are the potential roles that people can actually participate in in the future? It's very much focused on high schools and helping individuals through high school but, of course, what they're really missing is that employment focus about what things you can do. What are your capabilities? It's also giving people hope, and I think that's important.

I haven't seen anything replicated in any of the other states on that. The other one I have seen, which is probably a decent program, is out of Singapore. I think it's called the autism network group. They focus very much more on trade jobs. When you go there you see them doing jewellery work and there's an on-site bakery, so they do baking. They do a lot more trade work. I think that model is a very good model as well.

**Senator CAROL BROWN:** Do you have any information to share with us in terms of the success of these programs?

**Mr Fieldhouse:** I haven't seen any evidence based research, unfortunately. That's one of the things we do have: I know how many. We have a 92 per cent retention rate in our program and probably 90 per cent of them are still in jobs. We know that. We know that they're moving, which I think is important, not just in a job but across jobs and up. We monitor pay increases and so we see that kind of movement within the organisation. But we do still see the challenges they have, particularly with mental health.

**Senator CAROL BROWN:** Okay, thank you.

**CHAIR:** When you talk about executive-functioning courses, nutritional courses, financial education and those sorts of things, why aren't DES doing these? It would seem that if you're working in the disability space that these are pretty strong fundamentals to be laying out for people.

**Mr Fieldhouse:** I can't comment on that. We were very surprised that we had to build a lot of these programs ourselves.

**CHAIR:** And we're obviously talking about a particular age of autistic adult now—

**Mr Fieldhouse:** Yes, age—

**CHAIR:** Obviously, those who are receiving quality early intervention at this stage—supports at school and, particularly, NDIS funded—should be supported through these much earlier now.

**Mr Fieldhouse:** Yes. I think it's getting that education more focused coming backwards as well. But when we've built programs, like a nutrition program, we've had autistic people build the nutrition pack, so it's quite detailed. If you ever want to see a fire and safety drill go from one hour to four hours then invite some autistic individuals to come in. It's quite interesting. But at that level of detail that has to occur specifically.

We've done that with nutrition, with financial management and with positive relationships, as I mentioned, which I think is important. We learnt that from Israel. One of the things that Israel does very well also is mindfulness training. They do a lot of yoga to help people deal with stress and particularly in how to recognise anxiety. They recognise that. I think it's realising how you build a catalogue of services, if that makes sense. Obviously, I'm a commercial company so I look at things as a catalogue of services. But how do you build a catalogue of services which allows individuals to purchase from that catalogue of services? They could be delivered by using an NDIS package as a nutrition package or a financial awareness package. I think those are critical, especially for long-term sustainable employment.

**CHAIR:** Yes.

**Senator CAROL BROWN:** What's the name of your project with the DSS—

**CHAIR:** Dandelion

**Mr Fieldhouse:** I'm with the Dandelion program. We've called the initiative at DSS the Autism At Work program. That's just not to mix things up.

**CHAIR:** What's the difference with that?

**Mr Fieldhouse:** We're not doing the employment ourselves. DES is doing the employment, if that makes sense. Our program is for ourselves; we recruit people and employ them. Yes, we have clients, like government, who we share the program with. But DES does the recruitment and they're using our toolkit, if that makes sense, directly with other employers.

**Senator CAROL BROWN:** Will you be including any sorts of estimates around additional funding required or will you build the program and then hand it back to the department?

**Mr Fieldhouse:** We have the toolkit already. We're rolling out that toolkit with about eight DESs. That's what we're doing at the moment. Most of them are based in Queensland. Think about the hypothesis: how do we get more individuals recruited through a DES model? That's the hypothesis. We give them all the tools, we give them all the structure, and we give them all the things we know. Can they actually have a better outcome in doing that?

**CHAIR:** The outcomes aren't great.

**Mr Fieldhouse:** The outcomes aren't great.

**CHAIR:** The outcomes are actually appalling at the moment.

**Mr Fieldhouse:** I'm not disagreeing with you. We give them all our learnings, which we've been very successful in doing. We've had over 600 organisations using that download. If it doesn't work, that hypothesis is a part of it. We'll know what the outcomes are.

**CHAIR:** Just to clarify, 120 people are currently employed through—

**Mr Fieldhouse:** [Inaudible]

**CHAIR:** There's obviously been quite a bit of investment made in developing this toolkit. It would have been quite expensive.

**Mr Fieldhouse:** Yes; absolutely. We've spent probably over \$2½ million on research alone.

**CHAIR:** That's an awful lot of money for 120 people.

**Mr Fieldhouse:** Yes. When we started it, we wanted to make a difference. That's it. That's all we wanted to do: make a difference.

**CHAIR:** How do we scale this up? It's an awful lot of money and we have a huge cohort of unemployed autistic adults and a lot of them have skills and capabilities, with the right support, and have growth opportunities with support as well. We're not even at a drop in the bucket at 120 people. We see some of the banks hire 10 people in programs. It's an awful lot of money for, really, not a lot of bang for the buck.

**Mr Fieldhouse:** Remember that this is what we are funding ourselves.

**CHAIR:** I know that, but there is government funding that flows to you.

**Mr Fieldhouse:** Yes. That's through our clients. There's no grant to do that. It's funding we've taken from our clients to deliver services. For example, we're rolling out at the moment—and this is about scale—through our own organisation. We're hiring another 24 people. That's outside of Australia, in the UK. We've taken all that IP and we're actually using it. If you ask about what can we do locally, I think that's more the question. It's about ensuring that the disability employment service models are more industry aligned. I think that's one thing that's missing in DES. What's unique and why we've actually been successful in our own industry is that we know our own industry. We know IT.

**CHAIR:** Is this one of the issues? We have had submissions made to us, and certainly people have reached out to me directly, that their adult child's going through DES and their child is put through multiple training programs and there are zero jobs in the end. There's the real sense from the parents in particular that they're just being used as a cash cow for organisations to be paid for providing a training service, with zero intent of having a job at the end of it. They're not training them for jobs that exist.

**Mr Fieldhouse:** If you're industry aligned, you know what jobs exist. We know that there is a demand in IT for legacy work. What I mean by 'legacy work' is mainframes. Everyone's moving this way, but there is a massive gap in the market. Our next push is to move people into that market, into the growth area, which is legacy maintenance. That's one of our big pushes for this year: moving people into that area and looking after mainframe banking systems and things like that.

**CHAIR:** What kind of scale of jobs would you be talking about? What are the numbers, across the country and not just your company?

**Mr Fieldhouse:** If you look at the stats, there are 13,000 IT jobs in SEEK at the moment.

**CHAIR:** Internationally, one of the things we know is there's a massive shortfall when it comes to data, and those jobs can be done anywhere.

**Mr Fieldhouse:** Yes. What we find with data analytic jobs is that they're more on site. You have to interpret that data with the client. We're seeing more of those jobs in the country like cybersecurity, and we're an IT firm. What we see a lot more is in the traditional outsourcings in India, the Philippines and Vietnam. What I mean by those jobs is maintenance and application development. Those are the kinds of jobs that will be more available globally for anyone. It's not really about the data science jobs. They've got to be more local jobs, with cybersecurity and also legacy systems, because you have to have knowledge about legacy systems. You can't just offshore them. That's where we see the opportunity. If you're going to get DES to scale, you have to have industry alignment. I can't speak for the healthcare and aged-care industries. I don't know about those. But if you're going to—

**CHAIR:** A lot of kids with autism want to go into hospitality. The number of them who love to cook is extraordinary, but I have not yet been able to find, except for Krofne, anything that relates to food service.

**Mr Fieldhouse:** Yes. If you look at what Singapore has done, they've actually built a bakery. It's great. If you ever get the chance, look at the Singapore model for trades and services.

**CHAIR:** If we could travel, we probably would.

**Mr Fieldhouse:** That's an opportunity. It's about getting industry groups aligned. I think that's No. 1, so that you have knowledge about the industry and employing them. What jobs are going to be available at the end?

**CHAIR:** There's no point in training if there are no jobs.

**Mr Fieldhouse:** Exactly right. What industries are growing and what industries are not growing? If you look at aviation now, it would be shrinking. We know trade services are growing. On SEEK, there are the largest number of vacancies: 25,000 people. We know IT is growing. Getting industry alignment is critical. The next part is strength based assessment tools against that industry. What I mean by that is ensuring that somebody's motivation, firstly, is aligned to the industry. It's no good having them going into IT if they want to do cooking. And then you have their strengths based assessment against that industry. Therefore, you've at least got the intake correct. The second part is how you actually get the demand generated, getting the employers on board. The employers need to help them educate—help them understand. It really gets down to the coalface. How do you actually provide the management to take somebody on but also sustain it? People are working in their day-to-day job and they want to deliver an outcome. How do you give them the tools for that sustainment process? It takes the lift off the manager to say, 'Why should I employ this person?' to be honest. That's what you have to get to.

**CHAIR:** I think it was JP Morgan—I could be incorrect—in the US that ran a particularly successful program. They found that the team—I'm going to say data analysts, but I could be wrong; technology is not really my field—the analysts, or whoever they hired, who were autistic were, in a reasonably short period of time,

outperforming the non-autistic teams a number of times over. There was almost a resentment at the success and the outcomes and productivity of the autistic team versus the neurotypicals, who were not up to performing at the same intense level.

**Mr Fieldhouse:** We helped JPMorgan Chase start their program. I was in New York advising them.

**CHAIR:** That was operating at quite a scale.

**Mr Fieldhouse:** They have about 180 people at the moment in both the US and the UK. I catch up with them every week at 12 o'clock at night. Part of it for them is to really help in this. SAP is close to about 180 people as well. At the moment, our people are at 120, but we've probably had about 170. The key part is: how do you scale way past that?

**CHAIR:** Yes; because, until we can—

**Mr Fieldhouse:** How do you scale? The key part to doing that is really getting systems in place. This is what corporates are trying to understand: how do you get systems in place to create environments for success and actually ensure managers and co-workers are supported, so they can make the necessary adjustments themselves. The individuals can then self-actualise enough and understand how to make their own adjustments. I was reading a stat today that individuals today are going to have 17 different jobs and five different careers. That's a lot of transition.

**CHAIR:** Probably not our autistic workforce. They're probably going to have a lot more stable—

**Mr Fieldhouse:** We have to prepare people to change, through those changes. That's one thing that's constant.

**CHAIR:** Thank you very much. If there's anything else that you want to provide to the committee—

**Mr Fieldhouse:** I'm very happy to help you with that.

**CHAIR:** feel free to do so.

**MILLER, Ms Emma, Clinical Director, Learning for Life Autism Centre**

**WOOD, Ms Sarah, Head of Psychological Services, Learning for Life Autism Centre**

[15:15]

**CHAIR:** Welcome. I understand that information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. I invite you to make a short opening statement, and at the conclusion of your remarks I'll invite members of the committee to ask questions.

**Ms Miller:** I'll start by giving you a little bit of background on Learning for Life, and where we fit in the big picture of autism services in Victoria, and then I'll hand over to Sarah and she can talk more about the specifics of the submission we put in.

Learning for Life has been operating since 2004. We're a not-for-profit organisation and our mission is to provide the highest-quality behaviour based interventions to young people and their families, regardless of their financial circumstances. Our goal is to help develop in these young people and their families the skills they need to go out into the world and live whatever life they choose to live.

In our early years we were focused primarily on early intervention and providing best practice behaviour supports to children across Victoria. This included, because this was prior to the NDIS and TACA and everything, a huge focus on fundraising and grants so that we could provide the recommended therapy hours to our children. Our intervention is a home based intervention. We have a centre which we use for some of our meetings and some of our programs, but the bulk of our supports are delivered in the community. We value extremely highly the importance of therapy being tailored to the individual—so you could come into one of our sessions and the kids will be running up and down the hallway, going off to the park or going off to kinder, supported by our therapist, or you could come into a session and it will be a much more formal learning environment with visual supports. It will be very clear, obvious targets that are going on. Our overall premise is that there's a level of adaptation needed in the learning environment, otherwise we wouldn't be there, but that that level is entirely dependent on the how the child is. We only manipulate the environment as much as we need to manipulate it to see the skills start to develop, basically.

So early intervention is our primary service. Feel free to ask questions on that, if you're interested at all. We also conduct research in this area; Sarah can answer questions on that. Over the years, as our students have grown, we've moved into school transition services and social skills groups. Then we moved into school behaviour support programs and staff training as well as our whole schoolteacher training program, which is called Inclusion Works. These school-aged kids and the challenges we see in this area were the primary focus of our submission. I'll let Sarah talk through that.

**Ms Wood:** Our work in schools began when we started helping support our early intervention clients transitioning into school. In terms of today, our school transition program can last anywhere up to a year and involves one of our therapists working with the child in the classroom to help them generalise their skills into that environment. Then, over time, the schoolteacher and any aides that might be working with the child start to use the strategies that are modelled by our therapists, and we then slowly fade our therapists out over a period of anywhere between four weeks and the whole school year. As with our early intervention programs, this transition program is extremely individualised to the child and the needs of that particular school.

We also have a program supervisor, someone like myself, who would be overseeing that program. They are conducting regular school observations and attending any meetings—SSG meetings, that kind of thing. Once we then fade those therapists out, a lot of our children transfer into what we call our school behaviour support program, which means our program supervisor continues to support the school and the child, supporting in the home as well if that's also necessary. As we've expanded, we've begun to accept new referrals into that school behaviour support program—so kids that haven't necessarily completed early intervention or haven't completed early intervention through Learning for Life.

That brings us to the particular group of students our submission focused on. This group of autistic students tend to have adequate language skills and cognitive skills but engage in high rates of behaviour of concern that places them or people around them at significant risk. Over time we've received more and more referrals to support this group of autistic students.

I'm not going to repeat all the details outlined in our submission, but I do want to highlight that normally it's not the child who's the complexity in this case. We can generally figure out fairly quickly what the function of the behaviour is and what strategy is needed. The hard part is then navigating the systems for that child. Convincing the school that the student's behaviours of concern can be addressed is often a first big step. Then we need to

identify and support the access to the funding to allow the strategies to be implemented in both the home and the school environment. And then we can finally get to training the appropriate school staff and parents to implement the strategies. As such, for our program supervisors, a lot of time is spent writing reports and conducting meetings just to make it possible for the positive behaviour support plan to be implemented. All this slows the progress of the students, meaning that in the long run they need far more support.

I'm going to leave it there and leave it open to you to ask questions about anything.

**Senator CAROL BROWN:** Following on from your statement, why is it so complex in terms of actually getting to the point where you're putting in place your program in terms of behaviour?

**Ms Wood:** I think it's because of the funding models. There is funding within the department of education, and then there is NDIS funding. But there's a gap in terms of these kids whose primary deficit is that they engage in high rates of behaviours of concern. Within the education system we rely on things like IQ scores and language scores in order for that child to get access to funding. These kids often perform quite well on those scores, so they don't meet the requirement for funding. Similarly, I would say that it's easier to get these kids funding within the NDIS system than it is within the Department of Education, but those barriers still very much exist. And of course then those barriers exist where there's a very fine line in terms of how much of that NDIS funding can be used within school.

**Senator CAROL BROWN:** But are there barriers within the school itself?

**Ms Wood:** Yes. Then, because of all of this, it often means that we're not brought in until behaviours have got to really significant points. Almost all these kids are on reduced attendance at school, have been suspended. I've had prep students who have been formally expelled from schools on multiple occasions.

**Ms Miller:** And I think the other thing there that's quite a big barrier is the inconsistency, even from one school to another. That presents a scenario where we have a lot of trouble informing parents of what to expect as well—even back to our school transition program, where we would send our therapists into that first year of school. If we can do that, hardly any of this later-on stuff is likely to happen. The later-on stuff is much less likely to happen. Even within one Victorian government area—all state schools within the same area—we can have one school tell us, 'Your therapist absolutely cannot come in and support the child.' It's just totally not able to happen. We can have another school say, 'That would be so fantastic; what a great idea.'

**CHAIR:** And this is at principal level?

**Ms Miller:** Well, it's extremely difficult—and then we'll have a third school saying yes, they can absolutely come.

**CHAIR:** We have the same thing in New South Wales. It's basically driven by the principal.

**Ms Miller:** Yes. It must be, because they're all within exactly the same catchment area. So it must be at a principal level. But what that creates for us is a real difficulty in being able to advise families and help families, and then the barriers.

**Senator CAROL BROWN:** How do your clients come to you? Is it a school approach, or a parent approach?

**Ms Wood:** In terms of the school group of kids who come to us, typically it used to be parents. A lot of parents would say that they were just googling 'autism' and 'behaviour' and they came across us. They'd be ringing us saying that the kid had been suspended for the 10th time, or something like that. But now that we've been doing this for a while, we are getting more and more schools coming. I have multiple clients now, and it's the schools that provide those ongoing referrals.

**Senator CAROL BROWN:** And I can't remember whether you said how many—129 state, Catholic and independent schools?—you work with.

**Ms Miller:** At the moment we have 69 students in our program—58 at primary school and five at high school. That's across the financial year.

**Senator CAROL BROWN:** So you evaluate your program and you've got details around the success of your program?

**Ms Wood:** We evaluate our early intervention program, and we had the outcomes of those programs published about three or four years. We don't do it as formally with the school consultancy children because they're so different and varied in terms of supports they need in the programs. But, because we work on a model of ABA or behavioural interventions, everything we do has evidence. Everything we do with the children includes collection of data on their progress and all of that kind of stuff. So we can produce data at an individual level on any of our clients at any point in time.

**Senator CAROL BROWN:** In your submission, you talk about the NDIS and the delay in funding for complex behaviour. Can you just speak to that a bit more?

**Ms Wood:** Yes.

**Senator CAROL BROWN:** This is the NDIS complex support needs.

**Ms Wood:** That's a particular element. It's a kind of extension of the NDIS to try and provide support for adults presenting with significant behaviours of concern. But, because the group that we're working with tend to be in that primary school age range and we kind of first start with them, we typically find that they do not. When we approach the NDIS and ask whether we could have that additional support and have them put onto that pathway of the NDIS, we're told that they are basically not old enough yet. It is really not until they're coming into contact with the justice system and that kind of thing that they do meet the criteria for that.

**Senator CAROL BROWN:** We heard some evidence earlier today about how difficult it is for participants to access that complex support needs.

**Ms Wood:** We've only had one client that met that criteria eventually, and it's been a really positive experience. It's amazing how much it just opens up more availability to support for that young person.

**Senator CAROL BROWN:** Do you think that someone has to reach crisis point before they receive support funding?

**Ms Miller:** No.

**Ms Wood:** That's why one of our recommendations in terms of the Department of Education is that there doesn't necessarily need to be a funding criteria for this group of kids, because the way the funding works is the students then get the funding for the whole of primary school or the whole of secondary school. These kids have a lot of really strong base skills and, if we get in there early enough, we can make really significant changes just with a year of funding. But we need the funding to be able to actually provide the program properly for that year in order to be able to get that. And that's obviously only going to happen—

**CHAIR:** And in the school environment. There are some interpretations of the NDIS where they don't let you in.

**Ms Wood:** Yes.

**CHAIR:** I personally don't agree with that interpretation. Senator Brown, the NDIS has parameters where basically school is the function of the state education departments. But what—you're expecting these kids to do their 20 hours of therapy after school hours? It is just ludicrous!

**Ms Wood:** For this age group we're not even talking about 20 hours of therapy. For someone like myself, you come into the school once a week for a couple of hours, do some direct work with the kid, the teachers and aides to help show them how to implement these strategies and then slowly kind of fade that support out.

**Senator CAROL BROWN:** Do you find that, even if they're NDIS funded, that they're funded adequately to receive the recommended supports?

**Ms Miller:** Sometimes and sometimes not. There's such a vast array. Some children have so much funding and they absolutely have adequate funding to go to school, and some children have absolutely nowhere near the funding. We can pretty much never work out how that's come about, which is one of our challenges.

**Ms Wood:** I would add, except for advocacy. It's the families that have the time and the ability to really work out how the system works themselves and then can go and advocate for themselves. They're the ones that come out with the better packages. But it's got nothing to do with the skill level or the difficulties of the child. Some clients have so much money that you think, 'There's too much; there's no way we are going to use all of this,' and then other kids where you are going back and asking for more within months.

**Senator CAROL BROWN:** We've heard today that the Victorian government or the Department of Education have an autism education strategy. Was your organisation consulted? Did you provide a submission?

**Ms Wood:** No, we weren't consulted. I believe ABIA presented earlier this morning here.

**Senator CAROL BROWN:** Yes.

**Ms Wood:** I went with them and had a meeting with the Department of Education last week about the strategy. This was obviously, after it was released. They are now at the stage of working out what that will actually involve. So we certainly do consult with them. But our understanding after that meeting was that it's not ready for the kind of practical level in terms of what these supports will look like on the ground.

**Senator CAROL BROWN:** You made some comments around not being invited into a school. That is not just restricted to Victoria, as you would be aware. Was that access to students raised and part of the strategy?

**Ms Wood:** Previously, many of us in this area have raised suggestions that there should be some type of list of providers, such as ourselves, who are external to the Department of Education but could be given to schools so that they could access help earlier. We've always been told that, for various reasons, that's not possible and that's inappropriate. In this meeting that I had last week, though, there was one comment that indicated that may be part of this strategy and that there's some acknowledgement that external providers such as ourselves have got the skills to be there on the ground and supporting these kids. So perhaps this strategy will include at some level supporting school leadership to identify people like ourselves.

**Senator CAROL BROWN:** And, obviously, the acknowledgement that autistic kids deserve an education.

**Ms Wood:** Yes. That's a start, which is great.

**Senator CAROL BROWN:** Ms Miller, I think you mentioned in your opening statement teacher training. Could you please give me some more information about that and how that works?

**Ms Miller:** Sure. One of the programs that we run, which we have run through getting grants to run it and which we have run largely in rural schools—we have run it in one city school but the rest of the schools have been rural schools—involves us putting one of our program supervisors into the school one day a week for the year. That's specifically with the idea of upskilling the teachers through having weekly access to a person who can help them write the individual learning plans and help them write the behaviour support plans. It's different to PDs. It's done within the environment—within the community—so that we can set up plans for actual students. It is a much more practical way of them learning how to do it. That is one of the program that we do take data on and do teachers surveys on before we start and when we end. That's actually our Inclusion Works program. It was only run in five schools.

**Senator CAROL BROWN:** Five?

**Ms Miller:** Yes.

**Senator CAROL BROWN:** How many teachers have you put through the program?

**Ms Miller:** All the teachers at the schools are involved in it. They're often quite small country schools and in high needs areas, because the schools that are in high needs areas are the easiest ones for us to get philanthropic grants towards helping out.

**CHAIR:** So it's not funded by the state education departments?

**Ms Miller:** No.

**Ms Wood:** I'm actually starting my PhD in a couple of weeks time, and it is to analyse this program more specifically. I will work with Monash Uni and plan to run it across six different schools and collect longitudinal data, because at the moment we've got data in terms of the teachers' attitudes to inclusive education and that kind of thing when we start the program and then at the end of the program but we want to extend that and continue collecting that data a year, two years and three years after the program is finished to see how long you can sustain that. If we can change the attitudes of teachers and schools, it makes the jobs of people like us, school psychologists and that kind of thing much easier because you can just come in and start working on changing and supporting the child rather than having to convince all the adults around them that this child actually can make changes, we can get somewhere with this and we just need to tweak some things.

**Senator CAROL BROWN:** Are those private schools or government schools?

**Ms Wood:** Yes.

**Senator CAROL BROWN:** It seems that it's a critical part of providing education to have a level of awareness of disability. But, yes, it will be interesting to see how that rolls out further.

You've talked about it early intervention and you've talked about transitioning at critical points of autistic students' education journey. Do you do any work around when they transition out of education?

**Ms Wood:** No. At the moment, our oldest clients are probably about 15 or 16, so they haven't quite reached that kind of level, but it is certainly something that we discuss in terms of what we might have to do to support that transition or whether we whether we expand to start offering that kind of service.

**Ms Miller:** It's about capacity. We're a small not-for-profit. The NDIS is the most wonderful thing to come about in, certainly, my existence, but it has increased capacity issues within organisations like ours. Our primary focus has been early intervention, so in general that's where we've put our energies in trying to keep bringing in staff and that sort of thing. We're hoping the NDIS will mean other organisations come up as well. Other organisations that have the adult years and the transition out of school years as their real point of interest and point of knowledge will, hopefully, step up as well, but we may end up going there.

**Senator CAROL BROWN:** We talked before about adequate plans and supports that are required but not funded. Do you have people coming to you with their children that cannot get NDIS funding at all, as in they're not accepted as participants?

**Ms Wood:** On occasion there are some of the very-high-functioning school-age kids. I do have a few clients whose parents have just decided not to go through the application process at all, but under my recommendation I don't think they would get any funding. But in most of the cases I can still support those children under Medicare instead of NDIS, and that's adequate. These are the kids that really just need to touch base once a month or something like that, and so 10 sessions in a year is adequate.

**Senator CAROL BROWN:** Thank you.

**CHAIR:** It was just really interesting listening to you about when you're out with schools and all those sorts of things. Of course, if we had proper intensive early intervention, we probably wouldn't get to this point.

**Ms Wood:** Yes.

**CHAIR:** I want to ask you some technical stuff, in a way. You're familiar with the term 'extinction burst'?

**Ms Wood:** Yes.

**CHAIR:** Would you like to explain it? I know what an extinction burst is, but maybe do this for the benefit of everyone else. I have a very simple analogy I use to explain it, but could you explain an extinction burst for me?

**Ms Wood:** Yes. An extinction burst is when we've implemented a strategy to change a child's behaviour. An extinction burst means that initially we get an increase in the behaviour before we start to get it going down. So, technically speaking, if we get data and we're seeing that—

**CHAIR:** It gets worse before it goes away.

**Ms Wood:** we actually know that we're on the right track. It actually tells us we've made the right decision and it is going that way. So the way that I often explain it to families, parents and teachers and things like that, to the child, something worked. Yelling out in class worked.

**CHAIR:** I use the example that they throw a stapler when they don't want to do maths class, so they get sent to the principal's office. When all of a sudden they've still got to sit there and do maths, we're going to see them throw a chair or something else—

**Ms Wood:** Yes, exactly.

**CHAIR:** but they're still going to have to sit there and do maths. Eventually the kid realises: 'Well, hang on. I'm still going to have to do maths whatever I do, so I may as well just do the maths.'

**Ms Wood:** That's right. It makes sense that they're going to try other things that are similar to the original behaviour that worked before they come around to the point and go: 'Nothing is working. I need to actually follow the instruction.'

**CHAIR:** Because they got what they wanted, they got to avoid maths by being sent to the principal's office.

**Ms Wood:** Yes.

**Ms Miller:** For the younger kids, although not a school example, there is the example of the lollipop in the supermarket. You've got a child who's cried every time for a lollipop. They get the lollipop each time, and then the family decides to implement the behaviour of not giving the lollipop when the child screams. You can guarantee that the child's going to scream louder, maybe push things over or whatever, and that's the burst, because the game has really changed in that situation.

**CHAIR:** So you get it. I get it. We know it. I went to a positive partnerships workshop, which is funded by the federal government and supposedly has people that know what they're talking about training parents and teachers. One of the leaders of it said, 'Oh, well, if that behaviour gets worse, maybe you need to try something else,' at which point I jumped up and went, 'No, let me explain this to you.' But we have this situation with very fundamental behavioural techniques and people that have experience in behaviours understanding the function of behaviour. Whether you're a parent like me or a professional clinician like you, we understand that, yet we have people that are purporting to educate teachers and educate parents who have zero comprehension of behaviour, the function of behaviour and how things are affected by it. How do we change this? This is obviously one thing that we're looking at, but have you ever met a teacher that knows what an extinction burst is?

**Ms Wood:** No.

**Ms Miller:** No, but, if you bring it back to the willingness to take some data—

**CHAIR:** Yes. I go back to how we talked a lot about this morning along with the need for data.

**Ms Miller:** Yes. If you can get it back to the willingness to take data then that data educates pretty quickly.

**CHAIR:** So ABC: antecedent, behaviour, consequence. There is all this stuff that people understand, but most teachers have never been taught that.

**Ms Miller:** No, but I think that has improved—certainly in Victoria. I agree on the extinction burst—that many people wouldn't know what I was talking about.

**CHAIR:** I didn't know if you were going to come at me with a different term, but anyone that's done anything about behaviour and data understands it.

**Ms Miller:** The ability to take ABC data certainly is improving within schools, and it certainly is much more normal now to walk in and say, 'We're going to take data on that,' and for that to be understood. You're definitely still quite likely to get pushback on it, because teachers are busy. It's extremely busy, and that's why it comes back to the need for other supports to be funded within the classroom. If you've got an additional aide in the classroom that might come from some short-term funding or something like that, they can be taking that data, and that pretty quickly makes it clear to everybody what needs to happen.

**CHAIR:** So you go in as a program supervisor as opposed to a shadow? Is that's the sort of relationship, or do you also put shadows into the classroom

**Ms Miller:** That is just for that transition.

**CHAIR:** And, again, that's up to the principal to accept it.

**Ms Miller:** And that's a bit we have a lot of trouble with. Longer term, when we're coming in with the older children, we don't put shadows in. We work with the school to try and get that in.

**CHAIR:** When you say older children, how old do you mean? High school?

**Ms Miller:** No, after prep.

**CHAIR:** Oh, okay. We call it kindergarten in New South Wales. So it is only after that first year.

**Ms Miller:** That's all that we provide, in part because—

**CHAIR:** Do any of your students then continue on with their shadow?

**Ms Miller:** Yes, definitely—many, if not most.

**CHAIR:** Excellent. You mentioned before that a lot of the programs that you run are generalised. They're set out in the community. They're not necessarily clinic based. You would have seen this through parents and families, I'm sure. Certainly, I've seen it. I used to live in a small country town that had a very diverse population with a range of academic qualifications, intellectual capabilities and socioeconomic standing. It was a very diverse community. There were some families—and I've certainly seen this across Australia—who just aren't really capable of running a home based program, because of the intensity, the additional therapist, taking of the data, running the programs, doing the speech, doing the OT and then following through with the activities for the week in whatever structure that is. How do we balance that? There seems to be this really big push. We did an ABA based program. I had to be the therapist, because that was how we had to do it in a country town, yet I was told the other week that ABA is a clinic based therapy. I nearly put the folder down with the 40 hours of therapy that are done in the home environment per week, and they want to tell me that's clinic based? So there's a really big misunderstanding about what's clinic based and what's home based or generalised, but there are also differences between families' capabilities in delivering these programs, and we seem to be getting bogged down on just going in one direction rather than having the opportunities for both. If you go over the US, they have specific schools that start from two years of age that are clinic based. Fundamentally, they're a school based system. Parents can still go to work because their kids are there all day every day. So how do we bring that back together, one or the other? Obviously you need generalised skills for it to be naturalised and carried on into the home environment, but how do we break down the stigma that only generalised words when there are so many families that can't do it?

**Ms Miller:** Our home based program—and the fundamental reason why we started as an organisation— involves us sending therapists there. So we hire therapists, we write the program and we provide the stimuli, because parents shouldn't have—

**CHAIR:** Program supervisors and juniors?

**Ms Miller:** Yes. So it is program supervisors and juniors delivering up to, I'd like to say, 40 hours of therapy, but—

**CHAIR:** No-one gets that.

**Ms Miller:** I don't think we've had a kid do 40 hours for a very long time, realistically.

**CHAIR:** No-one gets that. We all try to.

**Ms Miller:** So we provide the therapists, we provide the program supervisor, we provide the timetable and we provide all of the stimuli.

**CHAIR:** In that program do you do things like OT stuff like fine and gross motor skills? Do you do daily living? Do you do speech?

**Ms Miller:** Yes.

**CHAIR:** So really you are using a framework that encompasses all the elements but is not exclusive. So you're not that type of behavioural therapy; you're using that therapy in that team to deliver all of those speech OT kinds of elements—

**Ms Miller:** Yes. We're not just delivering, say, discrete—

**CHAIR:** Toilet training.

**Ms Miller:** Yes. We'll have toilet training in there. We'll have whatever.

**CHAIR:** The data sheet is up on the wall.

**Ms Miller:** Yes. If the family goes bike-riding on a Sunday, we need to teach the kid how to ride a bike.

**CHAIR:** That's the only skill you teach from the front rather than the back, because of the safety element and wearing a helmet.

**Ms Miller:** Exactly.

**CHAIR:** I paid attention all those years ago!

**Ms Miller:** If the family doesn't go bike-riding on a Sunday then that's not a high-priority skill for that family.

**CHAIR:** And tying shoelaces versus buying velcro shoes is not a priority, but toilet training and sleeping through the night are.

**Ms Miller:** Absolutely. But I think families are asked to do way too much, and the biggest problem with the NDIS in those early years is that it puts so much on them. These families are already under so much pressure.

**CHAIR:** Would clinic based help a lot of these families? The kids could go to a clinic and could potentially go to almost a preschool environment where they go from nine to three every day?

**Ms Miller:** Families have to have the choice. We need both. We need clinic based and—

**CHAIR:** There is nothing wrong with clinic based where they go nine to three, get those supports and get the mix of play.

**Ms Miller:** Absolutely not. We need both, and families deserve choice.

**CHAIR:** And then the parents can work. One of the things that we're hearing when looking at a home based program is that one of the parents has to stop working.

**Ms Miller:** Oh, totally, but there are other families that want to do have it.

**CHAIR:** But you have to have the choice

**Ms Miller:** You have to have choice, absolutely, and that's also for our families. From diagnosis onwards, choice gets harder and harder. You've got less choice of schools. You don't get to go to whatever school you choose, because that school's going to say no. That school's going to say, 'Maybe, but we'll see.' Absolutely, clinic based services have a massive role in it. Home based services have a role in it. The more choice that a family can have, the better that is for the individual student and the family.

**CHAIR:** We do know that, if early intervention was of good quality and the right intensity, we potentially wouldn't be seeing the complex needs coming out.

**Ms Miller:** Years of research suggest that.

**CHAIR:** For some we haven't talked about it, but we know that.

**Ms Miller:** Yes. That's done. That can be ticked off.

**CHAIR:** Don't worry; they're still working on Wakefield and vaccines, but one day we'll get that! One day no-one will say that anymore!

Thank you very much for that today. I really don't have anything else, but I'm just so excited that you actually knew what an extinction burst is, because it's surprising how few people do. Thank you for being here. If you've got anything else that you'd like to give to the committee, feel free to send it through.

**BRIGNELL, Dr Amanda, Postdoctoral Research Fellow and Speech Pathologist, Department of Paediatrics, Monash University**

**COX, Dr Georgina, Research Fellow and Clinical Psychologist, Department of Paediatrics, Monash University**

**URE, Dr Alexandra (Alex), Research Fellow and Clinical Psychologist, Department of Paediatrics, Monash University**

**WILLIAMS, Professor Katrina, Professor of Paediatrics and Head of Department, Monash University**

[15:57]

**CHAIR:** Welcome. I understand that information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. Do you have any comments to make on the capacity in which you appear?

**Dr Ure:** I work in a clinical capacity with Monash Children's Hospital and the Royal Children's Hospital.

**Prof. Williams:** I have a research director role and a clinical role at Monash Children's Hospital; I'm part of the Department of Developmental Paediatrics.

**Dr Cox:** I'm a clinical psychologist at the Royal Children's Hospital.

**CHAIR:** I now invite you to make a short opening statement, and at the conclusion of your remarks I'll invite members of the committee to ask questions.

**Prof. Williams:** This is a little bit scripted, because we had the chance to prepare. To begin with, we want to note that we realise the terminology in talking about autism is not always straightforward, so we will interchangeably use both the terms 'autistic children' and 'children with autism' and only intend the deepest respect in the use of those terms, although we realise that not everyone likes all of those terms. We're also going to use the term 'children'—by that, we mean children and youth. That age group is our area of expertise collectively, not adults. We're going to use the word 'care' to mean providing what is needed—so in a very broad sense of the word.

As you heard in our introductions, we are a team of clinician researchers. We have all worked for years in clinical settings and also have higher degrees and expertise in research. We've worked, as did other contributors to our submission, who couldn't be here today, in the area of big data and making better use of existing data, best use of existing evidence and optimal research design and completion. We work in busy hospital and community settings, and, as you heard, with Monash University.

We want children and families to receive the care they need in a timely, well-coordinated and integrated way so that they can achieve outcomes they value. For example, we've heard from families in our clinical work and through research that they would like to improve their activities participation and quality of life. We value any outcome that they value. Despite the best efforts and enormous amounts of research, care development and service development throughout Australia and internationally, there are gaps in our knowledge and delays and inequity in providing best care for children and their families.

We think, in our collective expertise and experience, the best way to change this is to get organised in Australia and to create national and evidence assets that are enduring and can be used by many, and to ensure that innovations and improvements for care and the way we educate professionals tap into the very best of state-of-the-art innovations and discovery and are part of the services in which those innovations and improvements will be delivered. There's often a gap between that, and we're used to working in a setting in which we're able to embed those strategies. In doing that it creates an opportunity to understand our need and unmet need, and to think creatively and curiously about what will change that and improve things for children and families. If we can do that it will also have positive impacts to ensure optimal health service design and will inform policy. In doing that we would hope that we are on the path to assisting families to achieve what they want and the best outcomes that they can imagine.

**CHAIR:** No-one else wants to say anything? No. Thank you.

**Senator CAROL BROWN:** You said there's a need to get organised. I have to say that that view has been voiced to this committee by a number of submitters. How might this lack of coordination be addressed?

**Prof. Williams:** I'll start, and then I'll let others speak. Starting with what I was talking about to begin with, the opportunity to understand the existing data about autism and the services they access in Australia is lacking. I've been around long enough to have been present when the person who was the minister for disability at the

time, and then later a leader of the opposition, declared that there would be a national autism register. I was part of a working group that met with the AIHW to talk about putting forward a proposal for that to happen.

**Senator CAROL BROWN:** How long ago was that, sorry? You didn't name the minister, so I couldn't work it out.

**Prof. Williams:** Sorry; it was Bill Shorten.

**CHAIR:** I think we can all figure it out!

**Prof. Williams:** Sorry; I'm terrible with dates and names. I remember it was Bill Shorten, but I can't remember the date, sorry.

**Senator CAROL BROWN:** Somewhere from 2007?

**Prof. Williams:** Yes—quite a long time ago, when he was the minister for disability. So we had developed with the AIHW a national autism body and three options for creating national data. But, unfortunately, that went off the table. I think national data is imperative.

But I also think that time has passed since then and I've continued to learn and gather expertise. The AIHW could do an enormous amount to collate existing data, but it will become the most valuable asset if we bring in people with lived experience and clinical and education expertise to help to maximise the use of that data. We should use the data to generate important questions, to understand what we're doing in Australia and to know what the needs of people are.

**Senator CAROL BROWN:** That need for a national autism register is still there.

**Prof. Williams:** Yes.

**Senator CAROL BROWN:** Since that went off the policy agenda, do you know if that conversation has come back on? Has there been more recent discussion with the government about a national autism register?

**Prof. Williams:** That's a good question. I think that at different times different groups have probably approached government about that. I know there's been a lot more recent discussion about genetic databases and biobanks. If you have an excellent register you can certainly combine the two. But there have been some other pressing issues, I guess, so it hasn't been front and centre.

**Senator CAROL BROWN:** You've mentioned some things, but what benefits would it bring?

**Prof. Williams:** The AIHW already releases reports about numbers of people with autism and other disability. Some people don't like the word 'register'. Terminology is always tricky; other people talk about 'data assets'. But if you maximise the use of it you can turn it into something—and I hope this makes sense—that's living and breathing. It's not just data that ends up in a repository and isn't used but it's data which is accessed by people who are thinking about the applications and use of it.

You can do trials embedded in registries which enable them to be more efficient and less expensive. You can collect data in an ongoing way so that you don't just have that one point in a person's life but you have follow-up. In doing that, you can use the data to create an idea of predictors and also very valuable information about outcomes. That allows clinicians to be better informed when they're talking to families about what's coming next so that families can then plan. Really, when they're established well and embedded with the people who are registry data asset experts and clinical and lived experience experts then it becomes the bedrock or foundation of everything else that can follow.

**Senator CAROL BROWN:** You would have followed the discussion that's been had over a number of years now around the call for a national autism strategy.

**Prof. Williams:** Yes.

**Senator CAROL BROWN:** Do you have a view on whether there should be a national autism strategy?

**Prof. Williams:** I've been involved in lots of discussions around strategies in a variety of different areas. I guess it depends on what's included in the strategy and how possible it is to make it operational. But if the strategy speaks to an endeavour to create excellence in our understanding, based on existing data, existing evidence and the implementation, as well as some of the more practical elements that we know children and families struggle with—care coordination, equity and access—then it would be a step in the right direction.

**Senator CAROL BROWN:** Were you involved in the National Disability Strategy at all?

**Prof. Williams:** No, I wasn't.

**Senator CAROL BROWN:** It seems to me that we have a National Disability Strategy which has been ongoing since about 2010—

**Prof. Williams:** Yes.

**Senator CAROL BROWN:** Often, when I talk to people about the National Disability Strategy they're not aware of it—it's sort of gone off the boil for the last six years.

**Prof. Williams:** Yes. It's the utility of it. I was aware of it. And there are some elements that could be applicable to the autism community.

**Senator CAROL BROWN:** But any strategy needs to be appropriately funded if it's going to work.

**Prof. Williams:** I agree.

**Senator CAROL BROWN:** One of the things that came up in the submissions and the evidence today was that girls and women were under diagnosed in terms of autism. The current tools and methods that diagnose autism, are they appropriate? Or do you agree with the view that girls and women are underdiagnosed in terms of autism?

**Prof. Williams:** We saw that as a question in the inquiry, but as a group we didn't feel like that was a place where our expertise and the kind of work we do is best suited to respond to that. So we didn't include anything on that particular topic in our submission. At the moment, just very broadly, autism is a behavioural diagnosis. Stop me if you've been hearing this for days and from people in lots of different states. As far as diagnoses go, there are opportunities for the person who's doing the assessment and for the way that information is presented to them to vary. It is not the same as a genetic test or another form of investigation—

**CHAIR:** It's subjective observation.

**Prof. Williams:** Yes, and it's based on a person's behaviour, which will change, and we know with children is more changeable depending on their environment and circumstances, perhaps because they have less autonomy than adults. So I think the subjectivity of it is more important in younger people, who have less agency and control in their own lives. There are lots of pressing issues in the autism world around accuracy of diagnosis and moving beyond diagnosis towards thinking about the needs of children and their families that are more dimensional or multiple spectrum away. Those can be applied equally across females and males. Alex, would you like to comment?

**Dr Ure:** I would want to talk about the systematic review that you were involved in, Katrina, when you looked at the accuracy of diagnostic tools. This is Katrina's work that I'm talking about, so feel free to step in.

**Prof. Williams:** I thought you might have wanted to talk about the male-female issues.

**Dr Ure:** What's interesting to look at is the diagnostic accuracy of the ADOS, which is the tool that's commonly used and is considered to be gold standard for assessments for autism currently. Of course the diagnosis is subjective. Assessing autistic behaviours within a diagnosis using the ADOS is also subjective. Relying on a diagnostic tool alone is not an accurate way of diagnosing autism. In your systematic review, your Cochrane Review, you found that the diagnostic accuracy was quite poor across the diagnostic tools. There were three that you looked at. In particular there are concerns about the use of the tool when there are children with comorbidities, intellectual disability.

**CHAIR:** Does that include the pedicab?

**Prof. Williams:** No. It was for preschool children and it was for tools for diagnosis of autism, not for the broader assessment of this more dimensional activity function and participation kind of approach. It was the ADOS, the ADI-R and the CARS, they were the three tools in which there was diagnostic test accuracy data available. We planned to look at six but three didn't have evidence at the time. So there are inaccuracies, but no one is suggesting—and indeed the people who created the ADOS are not suggesting—that the ADOS should be used in isolation. It's just that there are situations in which we know that it is.

**Senator CAROL BROWN:** When you look at the number of girls that are diagnosed, as opposed to boys, does that raise any interesting questions?

**Prof. Williams:** It raises lots of interesting questions, but it's not unusual in the neurodevelopmental area for there to be a male predominance of issues. That plays out also in ADHD and in some other neurodevelopmental conditions. So it raises questions in two ways. Is it real—so the underdiagnosis question—and is it helpful in understanding aetiology or cause? There's been a lot of exploration of aetiology and cause. As we know, autism is a very big spectrum. If you've met one person with autism, you've met one person with autism. So a child who is also likely to have an intellectual disability, the gender ratio there comes down to approaching two to one males to females. But up in the other end of the spectrum, within the normal range or high IQ, the male to female ratio has been thought to be even higher than four to one, like seven to one in some reports or eight to one in others. So it's quite hard to disentangle what's going on there and it is quite hard to think about that.

It's also not unusual in some of what are commonly thought of as mental health problems for females to outnumber males. Anxiety disorders, for example. There is the issue, is that detection, is it presentation or is it real? And if it's real, why? There are very strong voices on either side of the debate about underdiagnosis of females. I think the jury's still out, but more evidence will assist.

**Senator CAROL BROWN:** You've touched on in a national set and the need for more evidence. What is it? Let's put aside the national data set. Where should the government be looking in terms of directing some more research into autism?

**Prof. Williams:** I'll start and I'll let other people speak. We work across neurodisability, and as a group collectively we see children and families with high needs. I think whether you're involved in medicine or allied health or education, it's quite easy to make the argument that you go where there is most need first. That's where we're basing our research. There are two things I'll talk about, because the people that were involved in this mission weren't able to be here. One is that we know that children and parents are left waiting for a long time for a diagnosis. We know that the new Australian guidelines suggested thinking about activity and participation and dimensions of development to get children to care before diagnosis. We were advocates of that view.

I've had a PhD student recently close to submission working on a coaching while waiting approach with families, so that families can develop agency and start identifying the goals they have outside a diagnostic frame and then seeking the care and support that they need. First signals from that study, not yet published, are very encouraging that it was liked, it was deliverable by telehealth and with greater identification of outcomes and meeting some goals.

**Senator CAROL BROWN:** When would that be published?

**Prof. Williams:** The person was just on maternity leave. I'm hoping April or June. The protocol is published. Thank you for reminding me.

Another area that a lot of people—parents, carers and people working in non-government organisations—have been talking to me about is children with behaviours that place them or others around them at high risk and who, when they present to hospitals, become behavioural emergencies. Again, I've been working as a clinician-researcher with a talented senior nurse who has been developing and using state-of-the-art strategies to teach simulation training, which is very commonly used for physiological emergencies but had not previously been used much in paediatrics for behavioural emergencies, to train nursing staff to prevent, ameliorate or deal with a behavioural emergency. Very broadly, those families and children are an area where we need nationwide preventive early intervention and an optimal care approach. I hope—maybe not in my working career, but soon after—that with prevention strategies we see far fewer of these children presenting in crisis to emergency departments, which is a big problem at the moment.

They are two areas whose need has sprung out of our working within hospital and community settings and our many networks and relationships with others. But I'll hand over now, because the others are working in other areas.

**Dr Ure:** I'm just going to jump in to go back to your question, Senator Brown, about where we think we could start with autism research. To go back to Katrina's initial introduction, what we're hoping to do is integrate our research into our clinical practice. At Monash, we are setting up new clinics funded by research to support the kids and families that really need that support within the paediatric setting. By including vulnerable families and families who are often not included in research studies—that are in isolation—we're hoping we can integrate and understand the real needs of the real families on the ground who are coming to a public health service but also think about including them in research and closing the gap between the research and the clinical practice. We're trying to work together. We have a couple of different clinics being set up at the moment—Amanda's will be focusing on minimally-verbal children, and I'm looking at the vulnerable families—to not only see what we can do better to support these families but also encourage them to participate with us in research down the track.

**Senator CAROL BROWN:** In terms of the 'coaching while waiting' that is due to be published anywhere between April and June, once that's happened, what happens?

**Prof. Williams:** Do you mean once that research is done, or—

**Senator CAROL BROWN:** Once the research is completed, is published. I think you said the protocol was already published. What happens now?

**Prof. Williams:** How do we get it to change into practice?

**Senator CAROL BROWN:** Yes.

**Prof. Williams:** What the PhD student has had time to do is what we call a pilot and feasibility study. What we would hope to do next is take that as research to scale. Optimally, if we have funding for that, we get that PhD student to do it as their postdoc and we embed it in the clinics that we work in. It improves recruitment. It makes it 'real world'. We offer it, and families can consent to be involved or not. Then we have really high quality evidence, but we will also have seen how it could work in that clinic, which is very similar to other clinics around Australia.

**Senator CAROL BROWN:** When you say 'funding', where's that from?

**Prof. Williams:** That's the sticking point. NHMRC is currently funding—I think, from the last round—less than 10 per cent of trials, so we would be competing with other trials about prostate cancer, for example, to try and get funding for 'watching while waiting'. Also, quite a lot of groups spend a lot of time writing grants for that kind of thing. We spend time working with philanthropy, which has been fantastic and has supported quite a few of our endeavours. But it really is about how you source the funding to do that work. The more we can embed it in the clinical service, the cheaper it is, but it still costs some money.

**Senator CAROL BROWN:** Would that be the same process as the work of the talented nurse that you talked about? I think you called it 'early intervention, prevention'.

**Prof. Williams:** Yes, simulation training for nursing staff and other staff and emergency staff. It's the same process. If we can get some core funding, they go in and do it within a health service.

**Senator CAROL BROWN:** So the service that she works for wouldn't necessarily fund it once it's—

**Prof. Williams:** No, because the next phase of both these pieces of research is the scaled-up trials, so they wouldn't fund them. In theory, the value of data is that once you've got evidence of effectiveness you might be able to convince the hospital to fund it—but not always.

**Senator CAROL BROWN:** Should there be another avenue developed by government to fund putting into practice initiatives and projects like these, other than the current one?

**Prof. Williams:** The government would already have the NHMRC and opportunities for centres of research excellence, for example. But they do contain and constrain the kinds of applications you put in, and the success rates are low, as I mentioned.

**Senator CAROL BROWN:** They often set the priorities.

**Prof. Williams:** Yes. Other countries have developed more autism-specific funding strategies and then designated centres of excellence. You've probably been hearing about that through the submissions. I think a model of that could work well in Australia. If that model were well-organised and connected to the national data and evidence assets that I mentioned at the beginning then it would be a very powerful force, not just for helping, improving and reaching the desired outcomes of children and families in Australia; it would have impact internationally.

**Senator CAROL BROWN:** You would have seen work and research undertaken and published and pilots that have been evaluated and that looked like they worked just going nowhere?

**Prof. Williams:** Yes, sadly.

**Senator CAROL BROWN:** Do you have any idea what percentage of those pilots don't proceed any further?

**Prof. Williams:** It's hard to put a line on it. Sometimes the clinician-activist within us will then have to break ranks with the evidence-based-researcher in us and take an expedient path such that we might be told, 'You could do it at a smaller scale, and we'll fund it for a while, but we're not going to fund you to get that very high quality evidence that's going to change everything for Australia.' I think that internal dissonance occurs for clinician-researchers, and it could be easily overcome.

I'm not quite sure of the exact amount of money that we're talking about here, but those two kinds of trials could be run embedded, if systems are set up—which we're doing through our clinics for routine-outcome assessments—for probably less than \$200,000 a year and maybe even considerably less. Whereas when you go to the NHMRC for a full-scale trial that is not connected to a healthcare service you have to ask for funding for every part of every widget and everything that you do, and it becomes a lot more expensive.

**CHAIR:** You talked a little bit earlier about data and how important it is in everything that we're doing to understand the data. Do you think, when you look at the NDIS and its sustainability and getting the best longer-term outcomes, that there would be value in data collation throughout the early intervention pathways?

When I talk about data, I mean: what's the level of funding that the family had that's then reflected in what kinds of therapy options were undertaken, how many hours per week, what the outcomes were and what programs were

being worked on? And most clinicians in that early intervention space would be taking something from the data anyway. But what I mean is that there was a reflection of outcome, because we could actually see which interventions were being used successfully and we could see the families who were making particular gains forward and what types of therapies they were using. And we'd actually be able to make some informed decisions, as opposed to: 'Here's a package; off you go, and we'll see you in a year or two.' Do you think there would be value in the adoption of an early intervention pathways data program?

**Prof. Williams:** Absolutely. And in the hands of AIHW and other data asset registry experts it could all be integrated, and it could be integrated with where they're getting services from other things, such as what medicines they're taking and how many times they presented to hospital.

**CHAIR:** For example, say there was an app on the parent's phone that connected to all the child's clinicians, GPs, paediatricians and everyone, and everyone could enter what they were doing—records of visits, medications, records of therapies, programs et cetera. In effect, your whole team would be able to see what you were doing, but also you'd be getting the data.

**Prof. Williams:** Yes, and actually a lot of that data already exists, so it doesn't need to be re-entered; it can be captured—with permission, obviously, from the children and their parents or carers. Jacquie Roberts and I were involved early on in the NDIS. We were consulted to write a report about what should happen with the ECEI for autism in Australia, and exactly what you've outlined was listed in our recommendations.

**CHAIR:** Why hasn't it been adopted?

**Prof. Williams:** Nothing should happen without outcomes being assessed and taken into account in terms of—

**CHAIR:** Especially when you're looking at taxpayers' dollars, because at the end of the day the NDIS funds are coming from taxpayer dollars, and I think we owe it to them that the investment is coming with a return.

**Prof. Williams:** Absolutely, because the perfect model—

**CHAIR:** It's an insurance scheme.

**Prof. Williams:** The insurance model—just the term creates controversy—the notion is perfect for early intervention in that you're putting in an investment up-front to diminish—

**CHAIR:** Your outcome's better.

**Prof. Williams:** your longer-term costs. But to do that in an industry, obviously you would have this data collection, because you would want to be sure that what you were doing was moving things in the right direction. Also in that report—and it's something Georgie's been working a lot on—we talked about working with parents, particularly around the time that they are first aware that their child has differences to other children. They're entering the NDIS and being asked how to navigate it at a time when they know the least that they'll ever know about their child and what they need.

**CHAIR:** And probably going through a period of their own grief and—

**Prof. Williams:** Yes. As well as the interventions we talked about, we're very keen on helping parents and carers, who are their child's greatest asset, to be the best they can be, but to not wait for them to become their child's best advocates before the services are delivered. The NDIS has gone partway towards that with its early pathway for the first year. But currently it's possibly not sufficiently personalised, based on need.

**CHAIR:** Yes, but I think some of that early pathway exists pre-diagnosis as well—

**Prof. Williams:** Correct.

**CHAIR:** because there is an appreciation—and the public hospitals are the responsibility of the state—that there is a delay in public hospital diagnosis. Obviously some parents go the private route, but that delay has been recognised by the NDIA, hence the pathways payment.

**Prof. Williams:** Correct. And I think the NDIA is moving in this direction that ideally pathways that are needs based rather than diagnostically based will be optimal, because within autism—but other conditions also—there's a wide variation in what the needs are and the types of supports and interventions that will be optimal. Georgie, did you want to talk a bit more about the parenting?

**Dr Cox:** I've been working with parents of children with autism for a number of years clinically, and now this is my focused research area. From our perspective, we really feel that more research and more services are needed to actually work with parents from the moment that autism is suspected, because, like you were saying, we know it's a really stressful time for parents. We feel that being able to integrate that parent wellbeing perspective from the very first moment would have a really preventative approach and would create really positive mental

wellbeing in the parent but also in the child. But, research-wise, there's still a long way to go in terms of knowing what types of programs are effective, for exactly that reason: the data isn't being collected on the ground and some of the data that is collected is within research studies, and sometimes these studies end up going nowhere, so we actually don't know what the long-term outcomes are for the children and for the parents. That's something that we're really strongly advocating for: more research in a really innovative way.

If anything, COVID has really shown us that a lot can be done with telehealth, probably more than we thought was possible before. One of the barriers that I think we all see, especially Alex, with the really vulnerable, complex families, is that time is a massive barrier to parents being able to seek their own psychological support. Finance is as well, because, by the time a parent has put their money into seeking therapies for their child, there's not much left over for themselves. To give a clinical example, in private services, a parent might come to you and they might have a mental health care plan, but there's still a gap. There's still the difference in terms of the Medicare rebate. Advocating for creating a funding stream for parents to be able to access services for their own psychological wellbeing alongside their child is something that we think is really important, but we don't think that should be done in isolation. We need the data in order to do that.

**CHAIR:** There were some things I noticed in your submission. You commented on the increase in the number of children that are being diagnosed. Is that happening at a particular level? For example, we're getting better at diagnostics, particularly of children at level 1 that may have presented as, perhaps, just naughty children or whatever, because they had reasonable verbal skills or were functioning at a higher or lower level of autism. Are we seeing more at level 1 or are we seeing more across the board at the three levels? Is there a particular area where we're seeing that increase?

**Prof. Williams:** Internationally, there's been a reported diagnostic shift or 'drift', as they call it, and it is happening at both ends of the intelligence spectrum. This predates my career. I started my PhD in autism in 1998, when the incidence was four in 10,000. People that I speak to and work with, and colleagues that were working in autism prior to that, were saying that, if a diagnosis of intellectual disability was made, then a diagnosis of autism spectrum disorder often wasn't made, even if the child had autistic characteristics. So there's been a shift to adding autism diagnosis at the lower IQ end of the spectrum. Then, just as you've described, in more able children there is increased recognition and diagnosis of autism. It's a pity Tamara couldn't be here today—Dr May, who does a lot with existing data with our team. The other shifts are in the slightly older age groups. We can't be sure, but it implies that they're more able because they got further along in life before someone brought them in to be diagnosed. The older age groups and girls in the older age range is where there's been an increase.

**Senator CAROL BROWN:** Is there a difference across the states in the increase in diagnosis? There is a national register in Western Australia, isn't there?

**Prof. Williams:** There's a state register. I published incident data from my PhD. At the time, Dr Emma Glasson was running the autism registry in WA. We use quite different methods, but the incidence of newly identified children at the time was very similar. Subsequently, I worked with Dr John Rea and we tried to ascertain the prevalence of autism in Australia from existing data, and there were very big differences between the states at that time. We had to use different datasets and different administrative data, and it was differently available. But what else is different about WA is they've got a very well-organised and coordinated state-wide system, and they've got a smaller population and more geographic isolation.

**CHAIR:** And [inaudible] back in those days.

**Prof. Williams:** Yes.

**CHAIR:** There seems to be a much more proactive stance coming from WA.

**Prof. Williams:** Yes, but their prevalence is sometimes lower than in other states and was, I think—I am trying to remember; it was a while ago—at that time, probably because of adequacy of services without the diagnostic label, in other ways, children with similar needs could access—

**Senator CAROL BROWN:** Do you have any information around gender from WA?

**Prof. Williams:** I don't know the information about gender from Western Australia. So, yes, there is variation, and it's very unlikely that there's a causal driver to variations between the states in Australia, which brings us to where many epidemiologists and myself have landed in that there are other drivers to what we're seeing in the prevalence that's reported for diagnosis in Australia and the global changes over time.

**CHAIR:** On some of the delays in diagnosis, obviously, we talked about the systematic issues in the hospitals. Also, I think—speaking from experience—a lot of parents don't know what they're looking for. They don't know what developmental milestones they should be hitting and when. You can have a girl first and then a boy and everyone says, 'Don't worry; boys develop later.' There are all those sorts of things that parents—particularly

parents who have young children—don't know what they should be doing about or what they are looking for. Do you think that perhaps there could be the introduction at vaccination of a timetable—like, asking whether they are doing shared experiences with you, are pointing to things, are making eye contact, are saying 'moo' and 'woof' and whatever they are supposed to say at whatever point—that those developmental checks could happen at that time? Those vaccination schedules are at the time of some pretty significant milestones for children. So, rather than us reinventing the wheel, maybe utilising the same sorts of services just to do a check-in, to just—

**Prof. Williams:** They are. The last time I checked—

**CHAIR:** In a formal sense?

**Prof. Williams:** Yes.

**Dr Ure:** Child and maternal health nurses rather than—

**Prof. Williams:** And GPs.

**CHAIR:** Talking to a lot of people, they're not getting that check. It might be nice in theory, but there's not a formal reporting or a formal—

**Senator CAROL BROWN:** With both my children, the child and maternal health nurses were fabulous. We did that for 18 months, I think.

**CHAIR:** But is there a referral? From what we are hearing, it is not commonplace; it's not across the board, particularly in a CALD community where people don't understand. There are lots and lots—and in rural and regional, it doesn't happen. We're not doing it across the board as a national program. The vaccination program is a national program, but there is certainly not a referral system afterwards either. It is like, 'Oh, they really should be saying that,' which is—

**Prof. Williams:** There are lots of issues with that. There is what we can call an inverse care law as well—that people who need it the most get it the least. You also talked about parents not knowing and not going, but there's another group of parents who have become, for a whole variety of reasons, very anxious about the possibility of autism and are seeking help a lot and early. It's very tricky to get that right. But in all but Queensland there are supposed to be state-wide strategies for connecting with the carers and parents of young children to check in around their development. What is disappointing is that it's not done consistently nationally so that people use different approaches and different tools and that confuses everyone—

**CHAIR:** State based.

**Prof. Williams:** State based. And it often doesn't reach those most in need. It's tricky. Then the other thing about that kind of early identification is that people do frame it, rightly in my view, as surveillance rather than screening because, again, the tools don't perform well enough to—they're not diagnostic tools so you have a lot of false positives and false negatives. False positives go into services and take up time and false negatives go home and think they never need to be checked again. Obviously I'm giving extreme options there.

**CHAIR:** I reckon you should put a couple of autism mums in there because after we've been through it ourselves, I reckon we're all pretty good at spotting our kids a mile off! Walking on the toes, putting your hand on something when they want—all those things that seem to be very, very common. Even the circumference of the head. Anecdotally, boys have huge heads. Honestly, there is data that their heads are bigger—all those brains in there for those beautiful babies.

**Prof. Williams:** That's right. You want it to be something that is fit for purpose for that child in that family and as accurate as possible, and that's tricky to rollout at scale when you're dealing with something that is not the giving of an immunisation, which is tricky enough, but the actual interpreting, watching and assessing of behaviours. Certainly there are key flags that people with experience would see and once you've seen them you would be worried about them. But how good then is the system? I'm posing that question because I think not yet in terms of, again, sort of more of a coaching and opportunities for support and direction for children and families, rather than: I go and wait in a long queue to see what the answer is to: do you have autism or not? There's primary care, secondary care, tertiary care layering and development that's needed. Again, it's why it's good to have people who are familiar with actually providing care in the service system as well as research involved because none of these things operate in isolation. Some kids go from the primary care option into an ECEI program and out and never need to hit secondary and tertiary care. Others are going to move through that system and need all elements and all levels of care and then all elements and all levels of the education system and the community services system.

**CHAIR:** I appreciate that you might not be here to answer this, but one of the things that has concerned me looking at research and where research is being conducted is that very little research is done on adults with

autism. Obviously you're paediatrics so it's different but what do we do about that? There is so little money going into looking at adults with autism. We have a huge cohort within the NDIS. We know they're underemployed. We know that if they're properly supported there are opportunities that they could be undertaking. But still we're seeing absolutely no research.

**Dr Cox:** I think that's a really interesting question. Although a lot of our work is focussed on children and adolescents, we're starting to do some research looking at parenting and autism and what is it like to parent as somebody who identifies as being autistic. We're just starting to look at some of that literature and bring all of that together. There are a few research studies out there but you're absolutely right there are not enough.

**CHAIR:** I'm interested in adults and their interaction with justice system.

**Prof. Williams:** There are people in Australia who are particularly interested in adults, I think—

**CHAIR:** There's a woman in Adelaide—I can't remember her name—who does a lot of work in the justice system.

**Prof. Williams:** Yes. And there's a stream, through the living with autism CRC, focusing on later life, so it's true. I'm hoping that research is on a developmental journey, because when you look back at where autism research was full stop, back even in the late 1990s, it had a flurry around secretin curing autism and immunisation causing it in 1996—

**CHAIR:** Professor Wakefield and all the joy he's brought us since then.

**Prof. Williams:** Prior to that there was very little autism research. Since then it's really grown and expanded. I'm thinking that a lot of emphasis has been on diagnosing children and those children are growing up so we now need a developmental experience within the research world. I think internationally, in Europe, people are moving to be more interested in adults living with autism. So, yes, we agree. I think research across the board can be of benefit and it needs to be in the right place in the right time and of the sort that is useful to meeting people's needs.

**CHAIR:** Thank you. That concludes today's proceedings into the committee's inquiry. I thank all the witnesses who have given evidence to the committee today. Thank you so much.

**Committee adjourned at 16:50**