

# TRANSCRIPT

## FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

### **Inquiry into services for people with autism spectrum disorder**

Melbourne — 12 September 2016

#### Members

Ms Maree Edwards — Chair

Ms Cindy McLeish — Deputy Chair

Ms Chris Couzens

Mr Paul Edbrooke

Mr Bernie Finn

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#### Witnesses

Ms Tamsin Jowett, president, and

Ms Bronwyn Carter, volunteer consultant to the board, Aspergers Victoria.

**The CHAIR** — Good morning, everyone. Welcome to the second of the public hearings to be held for the Family and Community Development Committee's inquiry into services for people with autism spectrum disorder. Today we will hear from a range of people, including parents and carers and people with ASD. We will also hear from peak bodies Aspergers Victoria, the Autism Family Support Association, the I CAN Network, Speech Pathology Australia and the ABIA association.

These proceedings today are covered by parliamentary privilege, and as such nothing that is said here today can be the subject of any action by any court or to any proceedings for defamation. If you have any special needs today, please see the committee staff who will assist you. We have made available a separate room as a quiet room if anyone wishes to make use of that today. That room this morning is numbered G4 and is just down the hall from this room. Again, please see our staff if you require assistance.

Could I welcome to this morning's public hearing Ms Tamsin Jowett, president, and Ms Bronwyn Carter, volunteer consultant to the board, from Aspergers Victoria. Thank you for attending this morning. All evidence at this hearing taken by the committee is protected by parliamentary privilege as provided by the Constitution Act 1975 and is subject to the provisions of the Parliamentary Committees Act 2003 and other relevant legislation. Any comments you make outside the hearing will not be afforded such privilege. It is contempt of Parliament to provide false evidence. Recording of the proceedings will commence today, and you will be sent a proof copy of the transcript and be able to make factual or grammatical corrections if necessary.

I would like to invite you now to make a presentation to the committee. If you could keep it to around 15 minutes, that would be much appreciated. Thank you.

#### **Visual presentation.**

**Ms JOWETT** — Thank you, Chair, and thank you to the committee for having us speak today. I am Tamsin Jowett. I am the current president, and I started working at Aspergers Victoria as a volunteer seven years ago. I am a lawyer by background, and I used to work in corporate affairs. My son was diagnosed aged 7, and now he is an amazing 15-year-old who is in the audience because he wants to see what happens at an inquiry. Bronwyn is here because she gathered all our member feedback and compiled it into this amazing submission, which we were blown away by, and I would like to thank her for that.

We wanted to prepare these slides to give you a bit more of a story behind our submission. Aspergers Victoria is the only not-for-profit and ASD organisation dedicated to support Aspergers — and across the whole life span, right through to adults. Parents, carers, siblings — it is the whole spectrum. We find that our members have a different set of needs. They do not see themselves as having a disability — and they do not. We provide them with empowerment. We get them. We know their strengths, and we will help them discover them. That includes the parents as well. We are entirely volunteer run, which we find builds the capacity of the volunteers themselves, and it provides such passion in the way they deliver what we do. Everything is by peers, for peers. We have a dedicated information hub. We are the only provider of peer groups right through the life span. We provide dedicated information events, and we are a source of research for a lot of the universities.

We were started in 1991 by parents — this was before Aspergers became a diagnosis — so we have been running for 25 years. Our membership has grown; we are nearly at 700, and we have had a huge increase since the DSM-5 came into effect. We have had over 4000 people come through our doors. Our volunteer hours last year were 200 hours per month average. This year it is over 400 hours per month. We have only had two government grants, that is actually more than usual, this year. We have none of the funding, and many of our members receive no funding support.

Our impact is that especially people with Aspergers come to us, and they find acceptance. They find friendship with peers, and often this is when they have had no other friends. At our groups they will celebrate their birthdays because they have had no-one to celebrate their birthdays with. We provide them with self-insight so they understand where they are coming from; they understand their strengths but also understand their difficulties. We give them knowledge to empower them, and this is all with no judgement, so they can take off the pretence of trying to fit in. They can just be themselves. This is all around capacity creation with our people. They are not treated as if they are disabled with us.

We did not refer to this in our submission. The We Belong survey was done by Aspect — I think it was 2013. In that survey it came out that around 60 per cent of diagnosed autistic people are Aspergers. The majority were

18 years and over, and Tony Attwood, who does regular talks for us, says you double that for the undiagnosed and misdiagnosed, who are in the justice system or they are in the mental health system instead of being helped by us. The findings, which were confirmed by our surveys, are that the adult population have high levels of mental health and wellbeing issues; they have inadequate levels of support in education or the workplace; more than 25 per cent are involuntarily unemployed, and 25 per cent of those are underemployed if they do have a job. The ongoing support needs they found in the survey were social interactions and relationships, finding a job, accessing just basic leisure activities that are suitable, dealing with bullying and discrimination and accessing professional services.

We think that Aspergers have different needs to the rest of the spectrum. They have a different neurology. They are like an Apple computer versus a Microsoft computer, so their brains just work differently. They are differently wired. They do not have intellectual disability or impairment to be Aspergers, and they have strengths which are often overlooked. They have amazing innovative thinking — as Tony Attwood calls it, originality in problem solving. They come in at such a different angle on problems; no-one can anticipate their ideas. They usually have average to well above average IQ. They have language abilities; they are not in the part of the spectrum where language is an issue. However, they can interpret language literally, which restricts them. They have amazing factual knowledge and special interests. As my Jack was saying, he is a bit of an expert in history, especially the *Titanic* and ancient Egypt.

They work all hours if they are in a job. They are so focused. They thrive on a routine. They have amazing memories. My Jack has a photographic memory, and that is quite common. He turns a photograph into a visual memory. He is a straight talker — and many of them are. Perfectionists: they will make sure that it is absolutely perfect, but sometimes in school this means they will give up because it will not be perfect — scribble all over it. Unbelievably logical, and yet so compassionate. And they can have talents; they do not all have talents, but things like perfect pitch is not uncommon. I was talking to a teacher at VCASS, and she estimated that at least a quarter of their students had Aspergers, some undiagnosed, but they managed; they have supports for them.

However, each of these brains can have difficulties. The reading of social situations really limits them and creates social isolation. People misunderstand them, ostracise them, because socially they stand out. They have development delays in primary school, but they are clever — they can catch up with the right supports, if taught the right behaviours. They can have inflexible thinking — especially as they get into adulthood we find they get more inflexible — and they have organisational challenges and very strong sensory sensitivities, which will affect them in school, the workplace and on public transport. All of this creates high anxiety. They are operating at a high level. They are treated with judgement, exclusion, and they are treated as if it is a disability, when it is not.

We thought we should highlight that there are missed strengths. Many scientists, composers, IT gurus, artists and actors have been credited with Aspergers. You can see Einstein; Keanu Reeves is diagnosed; Bill Gates, many say he might have it; Satoshi Tajiri, who created Pokémon; Mozart; Beethoven. There is more. Silicon Valley has more people diagnosed with Aspergers than anywhere else in the world. They are mainly CEOs and innovators of industry. Tony Attwood lists the key professions, with medicine being no. 1, and especially surgeons. How many surgeons do you know who have amazing social skills? They come in, they operate, they go. But at the moment not many people with Aspergers would pass the UMAT test without serious support.

Their strengths offer so much, but our community forces them to fit in. We crush their unique thinking and unrealised strengths and make them work in a way that does not suit them, so we get behaviours that kick back. They are intelligent and capable and creative, and they become stultified by their social deficits, their anxiety, past experiences and people who treat them as if they are disabled, which in some cases we find include parents. They are told that their child is disabled, and then they go along with that, but they are not — so often they are not. There are strengths there.

Going forward, we are moving from a cost-driven economy to an innovation economy, and at the moment we think that this economy is going to be without the potential offered by Aspergers minds — the groundbreaking developments. So they are square pegs in round holes. They are the invisible end of the spectrum. To start with, education lacks flexibility. The teachers are not given flexibility in how they teach them. The teachers may not be trained in how to be flexible. Funding finishes. VTAC, it is so hard to get allowances for these kids, so they have to sit exams with high anxiety, which does not suit them. They start with mental health issues that limit

them in school, and then they are treated by disability services. A lot of our kids will not go to the tertiary wellbeing services because they do not see themselves as disabled, so they drop out of uni.

There is a lack of understanding in all these key institutions. In law enforcement there was one I heard of last week with a boy on the tram. The inspectors got on and said, 'Can I see your ticket?', and he said, 'No'. It was in his back pocket. It was literal thinking: 'No, you can't see it, because it's in my back pocket', but he did not say that, so they pulled him off the tram and harassed him, and he will probably not go on public transport again.

Most autism organisations also focus on the obvious needs, and those that are funded; we do not. Often we find they do a diagnosis so late for services. Most of the people coming through at the moment are adults and also women, who are diagnosed even later. We are finding they are coming to us disempowered by the community, not empowered to use these amazing strengths that they have got. So they fall through the cracks. They feel disabled. We have school refusal, so common, and they are being homeschooled or they are in special schooling like Currajong. There is this tertiary overwhelm, so they drop out of uni. We have got this wasted talent.

Then they have got employment challenges. There is a lack of flexibility in how they do their jobs. The exclusionary employment practices: they have to write CVs telling everyone about their talents, but they are so literal they will not sell themselves in that way; interviews that require social skills. They are often put into unsuitable employment, as Specialisterne said in their submission. It ends badly. They become an economic burden in the mental health system and other areas instead of making this creative contribution.

So what is needed? A lot. We need the right community attitude to empower them, value their innovative minds for the future of our economy; then you are going to get better economic and health outcomes. We need public acceptance and inclusion of the neurodiversity, not seeing it as a disability — not inclusion because they have got a disability but just because they have got a different mind. We need a government-backed campaign around this; an appreciation of the positives of Aspergers; more around anti-discrimination and bullying; flexibility across all the sectors; training across the health sectors; and integration. How many doctors do not pick Aspergers because they are managing to cope? They are much harder to diagnose in the system, and the doctors do not see them. And even the diagnostic tools they have got are inadequate — the IQ test, the WISC, the way it is worded, it tricks them.

We need training and recognition in law enforcement and justice so they do not end up in the wrong part of the system. Proactive early diagnosis, mentioned by OTARC, would help, and services from there to help them flourish, find their strengths. We need more funded research on Aspergers, because at the moment it is becoming this huge autism umbrella, but these guys have specific needs, and we think we need more tracking of level 1, because that We Belong survey is probably one of the only surveys we have got that is of value.

We thought we would get some specifics for you on the education changes, which we noticed you asked quite a few people about last week. We think it has to come from the top. The principals, not just the teachers, need face-to-face training, not online training, and this needs to go right through to university so that they understand these kids and can read them and encourage them. The mainstream schools need flexibility to support but also to extend them, because these guys are amazing at certain things like maths, art or performance. We need schools, but we need the funded options for those kids who cannot work in the mainstream schools, so ACE, the Aspergers secondary school stream petition, and Currajong, which is essential, and more options like that for these kids.

We need funding and transition for secondary and tertiary. There is no transition to help them through, and it is a huge change for these kids. We need a VTAC system with flexibility so that these kids can sit exams in a suitable way. And we need help in schools through a social curriculum. It has been proved by Autism CIC that this improves academics and wellbeing, not just for those on the spectrum but for everyone. Executive function programs, organisation skills — that would help everyone. Sensory-friendly education would help everyone as well. Changes in the environment — quite simple.

And we need to move from it being disability units at university and tertiary level. There need to be some other names so our kids will go and seek help. And then we need Victorian government funding of STEM and other talent programs, which is recommended by Specialisterne, which I know they are not presenting, but we thought we had to mention it to support them.

In employment — this is our last slide — there was an American study that found 87 per cent of autistic youngsters who are given assistance found a job. Only 6 per cent who did not receive the support were successful, so support is crucial. Also you need it from the other end. You need a business case and the benefits of Aspergers promoted so it becomes driven by the top — the CEOs understand why they should employ these amazing people — and the Victorian government needs to reintroduce specialist support for Aspergers into employment. We need STEM allocations; these guys are brilliant at STEM.

We need a neurodiversity employment service. The DES is just not capable; it is a disability-based model. We need autism hiring programs, including in the government. What we would suggest is an autism at work week, which is all around acceptance. We are not just awareness — no more of just awareness; this is acceptance. These people are important in our community. We need to implement the willing to work. The Victorian government needs to be a lead employer of neurodiversity, and we need the workplace gender equality and diversity agency it mentions. Structural change around recruiting practices needs to be implemented. We hope to empower employers and create support in the workplaces so employers and the staff help out people thrive. Thank you to the committee, and let us know if you have any more questions.

**The CHAIR** — Thank you very much, Tamsin, and thank you also Bronwyn for coming along, and welcome Jack. It is nice to see you here today. Can I thank you for the work that you do with the groups that you work with. I know that it is all volunteer work and it is much appreciated. All volunteer work is often not recognised, so thank you very much for that.

**Ms JOWETT** — Thanks very much.

**The CHAIR** — Just a couple of questions to start with: you referred quite a bit in your submission to diagnosis.

**Ms JOWETT** — Yes.

**The CHAIR** — I noted that there was a particular mention there of women and girls and the failure to diagnose Aspergers in women and girls, and I might get you to perhaps go to that in a moment. But my first question really is about the change that has happened with the criteria and the lesser emphasis on Aspergers as distinct from other forms of autism. What impact has that change had on your organisation and its members?

**Ms CARTER** — We have noticed an increasing demand for services, and in the last five years we have had a threefold increase in demand for our services. That is why we have been trying to expand our capacity, and we were successful in receiving a volunteer grant from the commonwealth's volunteer grant scheme for \$5000. But the challenge we are faced with now is how to expand our services to cater for that increasing demand when we are still reliant on volunteer labour. The equivalent organisation in the US, for example, they have paid staff who provide executive management and administration and professional services, and so that makes a huge difference. They have a much greater capacity to provide the services that are needed.

**Ms JOWETT** — And we find when we meet these girls we can see it ourselves, and a lot of it, it comes down to knowing them very well. And when they go to these professionals, they do not know them well enough to be able to pick the behaviours. Even my Jack, they kept saying, 'Oh, no, no; he's all right', until one day Richard came along to the appointment with the paediatrician and he got anxious and the behaviours came out, and she went 'Right, now we'll go for diagnosis'. She had been seeing him for over 18 months and she would not go for diagnosis, so imagine the girls who are fabulous mimics and know exactly how to fit in.

**Ms CARTER** — What we hear from members is that health professionals are reluctant to diagnose, and so you have got this sort of — —

**The CHAIR** — Why is that?

**Ms CARTER** — I think it is lack of knowledge and also the fear of the stigma.

**Ms JOWETT** — The stigma.

**Ms CARTER** — So what we hear is that diagnosis is only helpful if people want it and if it is going to make a good difference, but if it is perceived as making a bad difference, having an adverse effect on the person, then it is going to be avoided. You know, I can see why people do that; I can relate to that in my experience. That is

why we need to move away from a disability model. People do not identify with having Aspergers as being disabled, and we know that there are lots of people who have different neurological makeup and who do not need a diagnosis and do not have a diagnosis. Understanding neurodiversity, I would say there are a lot of complexities and a lot of subtleties that you are not aware of and you do not understand unless perhaps you have had personal experience. So the challenge with the training for health professionals is to have face-to-face contact with people who can discuss their experience.

**Ms JOWETT** — And also face-to-face training of those professionals, because there are online modules proposed, but that is not going to be enough.

**Ms CARTER** — There is some research that shows that the best way to get rid of stigma is to actually know people, to actually have personal contact if not friendships and family relationships, but at least face-to-face contact. There were people speaking at the state-run autism conference last week who gave a great presentation. It is lovely to see the insight and the confidence and the pride that people can have when they are in an environment of acceptance.

**Ms JOWETT** — Empowerment.

**Ms CARTER** — Yes, and there were people being empowered. As a person who is not a member of the Aspergers Victoria board, I would like to take this opportunity to acknowledge the work that Aspergers Victoria do. I am aware that Aspergers Victoria over the years — and they continue to — nurture individuals, individuals who have gone on to be very empowered, such as some of the people who spoke at the conference last week and some of the people who are speaking at these hearings: I CAN Network, Yellow Ladybugs. With Aspergers Victoria, it is often not acknowledged the extent of the support they provide. They nurture individuals who go on to create and establish other important groups, who tend to get more of the media highlight and focus.

**Ms JOWETT** — But then our members do not want to be in the media. A lot of our members do not want to disclose. They do not see themselves as needing to.

**Ms CARTER** — Yes, which is fine. But the organisation is faced with the challenge of how to continue to do what they do, and that is why I was very happy to help them. I am using my professional skills in doing surveys and writing research reports. The findings that we have talked about, that were found in the Aspect study that was done a few years ago, are reflected in the survey of our members that we did: issues around access to diagnosis and health services, but also employment — support to gain and sustain employment — and supporting secondary school and tertiary education, and also access to social skills training. All those things were brought out in the survey that we did of the members.

**The CHAIR** — Thank you. It was a great conference. Paul, Bernie and I were there.

**Ms McLEISH** — I want to follow on the theme from the Chair around diagnosis. Thank you very much for coming in and presenting and the great work that you as volunteers do. The picture you have created on the slide show about the high-functioning end, can you give me a little bit of a range of what you would see of the abilities of functioning within Aspergers, because the number of people that I know did not fit what you put up there? I am just trying to get some, I guess, clarification so I can understand a little bit better.

**Ms JOWETT** — Like with my Jack, when he is anxious, he cannot operate, he cannot function as well. So at the moment a lot of these kids are in environments where they cannot function, so there are behaviours and things. They do not seem capable, and they are treated as if they are not capable because the teachers cannot manage them. If you provide the right environments and the right supports, you will see quite a different child. That is why often you will hear the parents saying, ‘What I hear about this behaviour at school, he doesn’t do that at home; he won’t do that at home’. So they do not know why they need a diagnosis.

**Ms McLEISH** — So what about the kids that actually do not make it to mainstream schools with a diagnosis of Aspergers? I know one very closely, and that still does not describe the person I am thinking of who has that label.

**Ms JOWETT** — The supports that are provided by schools like Currajong are essential for those kids.

**Ms McLEISH** — He is in his mid-20s now, and he has had this diagnosis for a very, very long time.

**Ms JOWETT** — Has he had support services?

**Ms McLEISH** — Absolutely.

**Ms JOWETT** — Has he been to support groups?

**Ms McLEISH** — I suspect so. He does not fit high IQ or high functioning, but he has that label of Aspergers, so my question is around: what is the breadth — —

**Ms JOWETT** — It is supposed to be average to high IQ as part of the diagnosis.

**Ms McLEISH** — Who has put that in it? Who says that?

**Ms JOWETT** — That is the criteria that was set by the DSM.

**Ms McLEISH** — Okay, so previously.

**Ms JOWETT** — Yes, and then the triad of impairments.

**Ms CARTER** — So there is a range of diagnostic labels that have been used over the last few decades. I guess one of the main points we are trying to make is to maximise the potential of any individual. It is the misunderstanding or the misdiagnosis that may have happened along the way that has compromised that person. I am sorry. I am trying to think of how to — there are so many complexities and subtleties in the — —

**Ms JOWETT** — The other thing is it is not just the DSM. In Europe you have got the ICD, which is different again, and that still has Aspergers in it as a diagnosis at the moment. So in England Aspergers is still quite well known. I mean, they are talking about moving to the DSM model, but Aspergers is quite acceptable in the UK.

**Ms CARTER** — One of the challenges I have come across is the lack of understanding about anxiety as being a trigger for difficult behaviour — so, for example, sensory sensitivities. If the anxiety is misinterpreted as bad behaviour, then the response to that compounds the problem, whereas when people are given space to avoid the anxiety-provoking environments, then everybody copes better and the behaviour does not become problematic.

**Ms JOWETT** — Given tools, like Rudy Simone, when she came to talk for us — she is Aspergers, from the US — she has a toolbox that she travels with which includes headphones and various things to manage the sensory environments that set off her anxiety so that she can cope. So she just says, ‘Here’s my toolbox’, and she will put on the earphones if it all gets too much, and everyone just accepts that.

**Ms CARTER** — So if the anxiety is assessed and understood for what it is, then the meltdown-type behaviour and the flare-ups or the withdrawal — social withdrawal — can be minimised but still also needs to be understood.

**Ms McLEISH** — Yes, and I guess what I am thinking of is not the flare-ups;; it is not the meltdown; it is just the day-to-day — —

**Ms CARTER** — Functioning?

**Ms McLEISH** — Functioning, yes.

**Ms JOWETT** — With Aspergers there is often comorbidity, so that is the other aspect; the ADHD and other things that complicate it even more for our kids.

**Ms McLEISH** — Yes. I am not talking kids that flare-up either.

**Ms JOWETT** — And adults.

**Ms McLEISH** — Can I just follow up on one of the things that you mentioned before, about the American study that had 87 per cent of people that had been assisted. We have had other submissions — we have had lots of submissions — that actually say that some of those sorts of things do not work. What is it about the

American one that you think worked, because we have heard evidence — or not heard evidence, but I have read evidence from somebody else — that says the opposite?

**Ms JOWETT** — That was from the *Economist*, so I have included that for reading if you are interested, and it goes into what has been done in the US. I cannot remember it off the top of my mind. I just went through so much material before this.

**Ms McLEISH** — That is good. Thank you.

**Ms CARTER** — It is the last reference on the list.

**Ms JOWETT** — I think it is the last, the *Economist*. There are some fabulous articles about what is happening in America, and if you look in the Specialisterne submission, they have got some great stuff.

**Ms McLEISH** — Thank you very much.

**Mr EDBROOKE** — Thanks for coming in, Tamsin and Bronwyn. In what seems like a former life now, I was actually a schoolteacher and a special developmental school teacher as well, so I have seen some of the challenges facing some of the kids with neurodiversity in different schools. I just wanted to take the conversation to the education sector for a minute and just wonder if you could tell me a little bit more about your views on the advantages of creating specialist schools just to cater for kids with ASD who have a higher IQ than average.

**Ms JOWETT** — There is a move at the moment. There is the Aspergers secondary school, or the spectrum school. They did not manage to put in a submission. I think there are definite advantages because not everyone is going to fit in the mainstream system. I mean, how can they think that everyone will fit into that model? Even with support there are going to be kids who cannot cope. I think we definitely need options. Currajong is a very busy school, with Aspergers kids coming in who have had awful experiences, and often they will get them back into the system — that is the idea of Currajong — but I think to have a school that is dedicated would be pretty amazing.

**Mr EDBROOKE** — Sure.

**Ms JOWETT** — I mean, you have got Rossbourne House, but that is private. You have to pay for that.

**Mr EDBROOKE** — Yes. Just a follow-up question: what feedback have your members given the government's program for students with disabilities?

**Ms JOWETT** — The thing is, they do not see themselves as disabled.

**Ms CARTER** — No, so I am not sure what — —

**Mr EDBROOKE** — PSD?

**Ms JOWETT** — PSD? We do not know about — our community does not see themselves as disabled. We saw out there there was the inquiry in September 2014 around that.

**Ms CARTER** — At school, the issues are dealing with sensory sensitivities and different learning styles. From my experience, what I would say is that it would be wonderful if in mainstream schools there was — from my experience, I would say all schools need to have a neurodiversity policy because — —

**Ms JOWETT** — Not a disability policy.

**Ms CARTER** — Yes, a neurodiversity policy that acknowledges that children learn differently and some students have sensory sensitivities, and when they withdraw or they do not attend school or they have flare-ups, that this is caused by anxiety and sensory sensitivities, it is not bad behaviour, because when that is misinterpreted it compounds the problem instead of being inclusive. My experience is at a different point on the spectrum, and in mainstream schools, if it was possible to be able to say, you know, that you have a neurodiversity policy, that would actually remove the need for some children to go and seek diagnosis, because if your child is different and not fitting into the mainstream, to be included you would not necessarily need to go

and get a diagnosis if we understood the varied learning needs of the students and we understood sensory sensitivities. If a child needs to remove himself from the classroom — —

**Ms JOWETT** — So a similar model to the NDIS approach. I mean, we still get told quite a lot with the NDIS that it is unlikely a lot of our members would get support.

**Mr EDBROOKE** — Yes. I think it is worth acknowledging your organisation is quite progressive. There are still quite a lot of schools and quite a few parents who do actually consider their children as disabled.

**Ms JOWETT** — Yes.

**Mr FINN** — Thank you to Tamsin to Bronwyn for coming in this morning. I think it is important that we establish that you, as an organisation, want to make Aspergers distinct from the rest of the spectrum, if I can put it in those terms. Would that be fair enough?

**Ms JOWETT** — Yes, definitely. We find that our members really have a specific set of needs, and being volunteers we just cannot deal with the rest of the spectrum needs. It works for us to focus.

**Mr FINN** — Have you gone to any lengths to push that to this point?

**Ms JOWETT** — What do you mean by that?

**Mr FINN** — As in there are people who make these labels and put people in categories and boxes and all that sort of thing. Have you spoken to governments and bureaucrats about ensuring that Aspergers is kept separate from — —

**Ms JOWETT** — We have been trying to, I think, since I became president. Even with Lyndel we came and saw you. That was really the start of us talking to government. It has now become more part of what we are doing. I think we have to in the way forward.

**Mr FINN** — One of the issues that intrigues me, I have to say, and one that I am trying to get my head around is the issue of a cure, because I proposed very early on in my role a cure for autism. There were some on the spectrum — and I assume many who would regard themselves or be regarded as having Aspergers — who got very, very upset with the word cure and said, ‘There’s nothing wrong with us. We don’t need a cure’.

**Ms JOWETT** — Absolutely.

**Mr FINN** — Now on the other hand, down the other end we have people who are down on their knees every night praying for a cure. How do you propose that we deal with this, because it is challenging to say the very least? Is it a case of we push for a cure but we do not make it compulsory?

**Ms JOWETT** — For the majority it is a genetic disorder. You are not going to cure that anyway, but why would you want a cure? There are a lot of strengths offered by having diversity. Trying to solve the puzzle is the other thing that people talk about. It is not helpful thinking, and it is not a helpful approach. I think it helps society as a whole to include and to welcome different ways of thinking. At the moment the business models are all about cost cutting, everyone fitting in, HR managing systems, everyone is the same, and we are not going to be an innovative economy with that approach.

**Mr FINN** — How would we go about it? And I know you put forward I think some very good ideas today about how we change attitudes in the employment sphere to people with Aspergers. How do we go about changing the attitudes of employers toward people with Aspergers, keeping in mind these are people who have the best interests of their business at heart and clearly are wanting to do the best thing by their business? How do we get that message across to them that people with Aspergers are, as you say, performance oriented, they are excellent and perfectionists and can make a real contribution?

**Ms JOWETT** — I think it is putting the business case to the very top. You know, these amazing strengths that they are missing out on, and the adjustments are not huge to enable and empower these people to deliver amazing results. You have got the studies coming through from Specialisterne about what they do, and there is also Silicon Valley in the US. There have been decisions by a lot of the IT companies to deliberately employ these people in specific jobs — I mean, the data analysis. These people have already proved how amazing they

are, so I think it is gathering that data. That is why I say we need more information on the abilities, and gathering information I suppose is the other one, so that you are armed and ready to prove your business case.

**Mr FINN** — Just one more: how many people do you think have Aspergers in Victoria?

**Ms JOWETT** — I am not sure in Victoria, but I know that the Aspect survey, they were estimating there were around 220 000 with autism in Australia at that stage diagnosed. I think they came up with around 97 000 — —

**Ms CARTER** — I have got some figures for Victoria if you are interested.

**Mr FINN** — We would love to have those.

**Ms CARTER** — I do not think good figures are available, but I have just taken a quick look at what is available. If you take the 1 to 2 per cent as the incidence, then there is 60 to 120 000 people in Victoria. But if you take Tony Attwood's comment, the incidence may be double that because of undiagnosed or misdiagnosed. We do know that in the mental health system and the drug and alcohol system there is a high incidence of people with undiagnosed ASD, so we could have 120 or 240 000 people in Victoria. There are not good epidemiological studies done, but if you take the figures that we do have, you can come up with an estimate. So we have got up to a quarter of a million people there. But it is a bit like saying: how many undiscovered caves are there under the ground? You do not know.

**Ms JOWETT** — And Tony Attwood, there was a statistic I did not mention that 1 in 4 people diagnosed have a drug or alcohol or gambling problem. So if they end up falling out of the community, they are going to end up needing support in other ways.

**Ms CARTER** — I think this highlights the importance of prevention. There is some research that shows that people with Aspergers are less likely to use drugs and alcohol, but once they do use, they are more likely to become addicted and also the addiction is likely to have a greater impact on them.

**Mr FINN** — The area of early intervention is something we talk about to no end for children. Given that the diagnosis of Aspergers is usually much later in life, is there an equivalent of early intervention that we can provide for people with Aspergers?

**Ms JOWETT** — At the moment, no, really. I think there needs to be a lot more done around adults. Adults are the majority coming to us. We are kind of the main thing at the moment that can help them, but we are just volunteers, and we need more services around that to help us help them.

**Ms CARTER** — What can make a big difference in picking up individuals who do not get picked up in early intervention are neurodiversity policies in schools.

**Ms JOWETT** — Or beyond, in employment.

**Ms CARTER** — If there is an awareness in schools that students have different learning needs and different ways of communicating and that is picked up in schools, then instead of not doing well in school those children can be encouraged and catered for.

**Ms JOWETT** — As adults too, as employees.

**Ms CARTER** — Then they will do better moving into employment.

**The CHAIR** — I just have one question around rural and regional Victoria and what particular challenges people with ASD might have in those areas. I think about four of us are regional members, so there is a particular interest.

**Ms JOWETT** — Yes, we get asked so often to come to regional areas, and it is part of our plan going forward, but it is about capacity. There are organisations there that we direct people to. They cover the whole spectrum.

**The CHAIR** — Can you tell me what they are?

**Ms JOWETT** — There is the Bendigo autism advocacy with Beck Kelly, and there is one in Benalla as well. There is a Ballarat group that had an expo recently. There are a few around. We are trying to get our tentacles out further, but we keep finding that we get overloaded in Melbourne. We know that there are more services need.

With our information hub we are dealing with queries. We are giving them information and empowerment just through email and telephone calls. That seems to be a main way that we help. Those queries come in from all over Australia and internationally at the moment. Our website gets hits from all over the world because people are realising that it offers quite a lot of information about level 1. They are told they are level 1. There is no information about level 1. A lot of psychologists, like Richard Eisenmajer, our patron, will say, ‘You have level 1, but it used to be called Aspergers, so go and join Aspergers Victoria, because they will give you help and support and empower you’.

**The CHAIR** — Thank you very much for your presentation this morning. Can I thank you for your submission. It was extremely useful, and there was lots of good information in there for the committee. Have a good day.

**Ms JOWETT** — Thank you very much to the committee. If you have got any more queries, contact us.

**Witnesses withdrew.**