

# TRANSCRIPT

## FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

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

Swan Hill — 14 February 2017

#### Members

Ms Maree Edwards — Chair

Mr Paul Edbrooke

Ms Cindy McLeish — Deputy Chair

Mr Bernie Finn

Ms Chris Couzens

#### Witnesses

Ms Sherri Cincotta and

Ms Elissa Plumridge, directors and program facilitators, Creating Connections Australia.

**The DEPUTY CHAIR** — The committee welcomes to these public hearings Ms Sherri Cincotta and Ms Elissa Plumridge, directors and program facilitators from Creating Connections Australia. Thank you very much for attending; we notice that you have been in the audience for some time. All evidence at this hearing taken by the committee is protected by parliamentary privilege as provided by the Constitution Act 1975 and is subject to the provisions of the Parliamentary Committees Act 2003 and other relevant legislation. Any comments you make outside the hearing will not be afforded such privilege. It is a contempt of Parliament to provide false evidence. Recording of the proceedings will commence today. You will be sent a proof copy of the transcript, and you will be able to make factual or grammatical corrections if necessary. The Chair will return in a moment, but please if you could begin with your 15-minute statement, which will be followed by questions.

**Ms CINCOTTA** — I will introduce myself. My name is Sherri Cincotta. I am a director, co-founder and program facilitator with Creating Connections Australia.

**Ms PLUMRIDGE** — My name is Elissa Plumridge, and I am Sherri's counterpart: co-director and also co-founder.

**Ms CINCOTTA** — Thank you for having us here today to give evidence. We are very, very grateful for the opportunity. We would like to note that today we give evidence from a personal and professional capacity. From a professional perspective we are education consultants who specialise in autism; and from a personal perspective — myself — I have three children on the spectrum with varying needs.

**Ms PLUMRIDGE** — And I have children on the spectrum as well, and I have also been diagnosed autistic myself.

**Ms CINCOTTA** — Through our work and our own personal experiences we have identified a crucial gap in the education system for people on the spectrum, where students attend mainstream school settings. Our own experiences have shown that people who are verbal, regardless of their day-to-day challenges associated with autism, are somewhat misunderstood and are subjected to unrealistic expectations based on the assumptions that they can function similarly to a neurotypical student.

**Ms PLUMRIDGE** — We believe that every student has the right to be educated, with their learning needs provided for, but it is our experience that autistic students are often expected to fit within education, with little support for those inherent characteristics of autism. Often there is a lack of understanding of the sensory impact of the learning environment; that noise, lights, smell, touch and movement, amongst other things, can all have debilitating effects on a student's ability to engage and learn if not managed appropriately.

We are also aware that there is often insufficient understanding of the need for visual information, and the importance of providing visual backup in the learning environment to support information processing and to alleviate that sense of not knowing what is coming next, because that is very important for people on the spectrum. Without adequate visual support, the student's executive functioning is often impaired and there is potential for high levels of anxiety, which again impacts on their ability to engage.

Also, we often see a greater need for support through the process of change and transition, both every day and in the larger transitions that take place. Transitions that are poorly planned or that lack information or consistency impact on a person's ability to learn, to engage and even simply to feel safe in their environment, and as a follow-on, there may then be challenging behaviours that arise from this. There is often a lack of understanding as to why behaviours are actually occurring in the classroom in the first place, which leads to situations that can alienate autistic students and negatively impact on mental health, self-worth and the ability to continue learning.

**Ms CINCOTTA** — We find that all too often behaviour is managed after the fact, and often within the education system, for example, behaviour management plans are circulated throughout schools highlighting students' challenges, with a list of consequences for their behaviour. This type of system sees the student being reprimanded for behaviour that has often occurred because the school environment is simply not set up to understand and cater for the differences in sensory and learning needs. School staff can be somewhat disadvantaged, as many have not been trained to recognise and implement the most suitable and adequate support for their students.

In the work that we do in training teachers and support staff we focus on the idea that behaviour is a way of communicating needs and wants in response to their environment. It allows us to communicate beyond words. When behaviours are first noticed it is important to record everything that is occurring at the time to work out what the person is trying to tell us. Ultimately the aim is to recognise the triggers early on and provide accommodations to support the person, with the goal of reducing that impact and hopefully the negative behaviour.

We are big advocates for encouraging natural consequences for behaviour. Detention, exclusion, suspension or similar punishments often have no relevance to the student and there is no natural learning that can occur from this punishment. In fact for many students who want to escape the classroom this can simply reinforce that behaviour.

**Ms PLUMRIDGE** — We think that professional development should provide schools with the opportunity to learn about the best possible support for autistic students. In our experience it is practical teacher education that focuses on working with those autistic characteristics, and it is desperately needed. Aside from the theory, without that practical training teachers can find themselves in a position where it is difficult to provide adequately for student needs, and often when teachers are seeking support from us it is without the backing of funding or the ability to pay for training.

Through the work that we do with Creating Connections Australia it has also become evident to us that there is a huge need for greater understanding and knowledge about autism and other sectors beyond education as well. Sport and recreation opportunities are not always accessible, again because environments may not cater for the needs of an autistic person. In my own family's experience, coaches who have been open to adjusting their approach and the way that they communicate can have an incredibly positive impact, but it is often the luck of the draw with clubs and facilities, and when supportive networks are not available, then generally it means that there is just no access.

We continue to work with young adults who find it difficult to gain employment because employers are unaware of the challenges that autistic people face on a day-to-day basis — things such as the way in which the work environment is set up. Noisy, crowded workspaces, bright and overstimulating rooms, and the requirement to be social with other colleagues are just a few things that cause an issue.

**Ms CINCOTTA** — In addition to this there are situations where young adults on the spectrum are expected to adhere to general job application requirements — for example, interviews where they find themselves in situations that are incredibly uncomfortable, causing them great distress. Interviews are anxiety-provoking situations for any person, let alone an autistic person who lives with anxiety every moment of the day. The tragic result is that within the interview the young person often freezes, shuts down completely and is unable to answer those vital questions. The interview panel often sees this as non-compliance, little initiative, no desire to work and that they are not worthy of a job. The young person already feeling worthless and useless from the interview process is then delivered the disappointing news that he or she is ineligible for the job.

We once worked with a young man in this situation. Even though some of the staff knew him personally and the challenges he had with anxiety, they continued with the interview process, asking him ambiguous and confusing questions. He was unable to answer effectively and his standard answer was often, 'I'm not sure'. He did not get the position based on the interview itself, even though he was volunteering in the role and had the characteristics suitable for the job.

Health services is an area that is in desperate need of autism education. My own experiences with my children have highlighted the disastrous impact of a system that does not understand how to support autistic people. Quite often health professionals have a very narrow view of what autism is, and families and autistic people themselves can feel isolated and anxious about navigating the systems that do not understand them.

We have worked closely with various disability service organisations throughout Victoria and New South Wales to assist them in supporting both their clients and employees who are on the autism spectrum. Having had my own children cared for by various disability support networks it has been my experience in the past that even though the support workers are very caring and nurturing they have not had adequate training in autism and at times have been unable to recognise things like the early trigger signs of meltdown due to sensory or information overload.

We highly recommend that the disability sector has compulsory autism education and training. In our experience while some staff have had general autism training most ground-level staff within the field have no formal training in autism from a practical, hands-on perspective and lack the understanding of how best to support people on the spectrum.

**Ms PLUMRIDGE** — When autism education and training is accessible, practical and relevant, then we find that everybody benefits and, importantly, outcomes for autistic people are likely to improve. We hear that from the people whom we support in our work. As a company Creating Connections Australia provides training and professional development that focuses on helping people understand the needs of the autistic person. Everything we do comes from the perspective of understanding the person themselves and what they need and want to be the very best they can be. Our training aims to help develop a person's sense of self, to feel good about who they are and to encourage them to become independent and confident in how they engage in their learning and their environments.

Our workshops and training sessions bring a unique mix of professional knowledge and lived experience. Our social skills professional training program based on our unique autism-friendly model aims to educate and train participants to develop their own social skills programs that are individualised specifically to the person's needs and wants and to work with and alongside their strengths. We have provided a hard copy of some information for you here today.

We also suggest that autism education and training include autistic perspectives. There are really no better qualified people to provide insight and knowledge than autistic people themselves, and those undertaking professional development would benefit immensely from learning from who they are learning about. Thank you again for having us here today.

**The CHAIR** — Thank you both very much and thank you for your submission to the inquiry. Thank you also for the great work you are doing in this field. Clearly we need a lot more people who are able to go out there and educate people about ASD.

**Ms CINCOTTA** — Thank you.

**Ms PLUMRIDGE** — Thank you.

**The CHAIR** — You mentioned, I think it was in your submission, that you actually started a parent support group in northern Victoria?

**Ms CINCOTTA** — We were on the committee. It was about six years ago?

**Ms PLUMRIDGE** — A bit longer than that now. It was probably about eight years ago.

**Ms CINCOTTA** — Eight years ago.

**The CHAIR** — And it is still going?

**Ms PLUMRIDGE** — Probably not at the strength it was at the time.

**Ms CINCOTTA** — No. There was a group of us who were very proactive and wanting to support and help other families living with autism.

**The CHAIR** — There seems to be from what we have heard this morning a real lack of support services for families, carers and people with ASD.

**Ms CINCOTTA** — And I guess when we were on the committee, even back then we were running little training sessions for parents and families to help their own situations.

**The CHAIR** — One of the things that we have been interested in throughout this inquiry is the gender difference — the way that boys present with ASD and are often more frequently diagnosed, and the fact that girls often go under the radar. What is your view on that and have you seen that? Is that your experience?

**Ms PLUMRIDGE** — Can I say from my own personal experience that within our household three of the four of us in the household are diagnosed autistic, and I and my daughter make up two of those people. I was

not diagnosed until I was 35 years of age, and that came after my children's diagnoses. When we start to look at and really understand a little more about how autism does present in females, we find it is very much the case that often they fly under the radar and are not recognised.

**Ms CINCOTTA** — I have three children, and the two youngest, being the boys, were diagnosed quite early and my daughter, being the eldest, was not diagnosed until she was 13, because it was not as obvious. She just tended to fit in and mimic a lot of what her friends were doing, until it become obvious to me, when I started to look, that a lot of her issues were anxiety based.

**The CHAIR** — Yes, this is what we are hearing quite frequently. In the mainstream education system clearly you have referred to the fact that there are a lot of misconceptions about autism and particularly how it presents in individuals who have low needs. Can you just elaborate on that a little bit? I think we have a good understanding of the fact that often there are comorbidities for people with autism, in terms of intellectual disability, ADHD and other mental health problems, but in terms of those that do not have the same needs, the expectations I think are a little different.

**Ms CINCOTTA** — Yes. I guess with my two boys it is a really good example of how that looks. My youngest goes to a special school and is non-verbal, and you can clearly see that he has those autistic traits, because he does a lot of flapping and pacing and, you know, there are mutterings, so you can clearly see that he is autistic. My other son, on the other hand, is a very intelligent boy, he is verbal and he attended a mainstream school setting. I think the misconception is that he should be able to function like everybody else does — the neurotypical student — because he presents differently. I think that is the misconception. But then he struggles with anxiety, and he struggles with his words when he is in a moment of overload. In fact, he shuts down completely and you do not get anything from him. It is those sorts of things that I think impact on our kids who still portray those characteristics or still have those inherent characteristics of autism but they are not so obvious.

**The CHAIR** — Given the vast difference between individuals who have ASD, teaching people how to understand ASD I imagine must also be very difficult because of the vast array of behaviours and intellect. How do you teach a program where you have to cover so much?

**Ms CINCOTTA** — We have actually a really good workshop in that.

**Ms PLUMRIDGE** — Whilst we are all different — all of us who are autistic — there are some general things that we have in common. For a start, if you look at the diagnostic criteria, where we look where there are special interests or there is a need for routine and repetition and sameness, just that very point there — that there is that need for sameness and routine — highlights that within school settings we need to have better systems for letting students know what is going on through the day. What are we going to be doing, do we have a schedule for the day, how are we supporting moving from one activity to the next and how are we supporting kids in going from one year level to the next? Whilst there may be little differences in how we do that, it is still a general underlying theme.

Again, we know that with autism there are difficulties with executive functioning, so we know that one really good way of assisting with how we self-regulate, how we manage the information around us, working memory — those sorts of things — is by having visual supports. Whether a visual support is a timetable on the desk or whether it is a reminder that goes in the iPad or the computer — however that may look — we know that that is a really good strategy that we can use. It may not work for everybody, but it is something that is really important for people to understand and to then tweak to how it is going to best suit the person who they are supporting.

**The CHAIR** — Just one question around the training that you give: do you go back and see what the outcome of that training is and the success of it and whether it is being implemented well?

**Ms CINCOTTA** — We provide feedback forms at the end of every workshop that we do. You know, there is always constructive feedback, too, that we get and we take that on board and we make changes, but a lot of our feedback is based on the people that attend the workshop liking the idea of listening to what we have to say because we have lived it as well as knowing the theoretical knowledge. We have tried and tested these.

**Ms PLUMRIDGE** — Can I add to what Sherri said then? One of our programs, which is a social skills professional training program, we run over a three-day period. How we structure it is that it is actually over

three weeks, so the participants come on day one and they go home with homework — things that they need to work on within their own environments. Then when they come back the next week they get the opportunity to debrief on what they have done, to ask questions and then to move forward with the next part of what they are doing. They take home more homework, and then when they come back we look at it again. We actually work with them on that third day to actually prepare their own curriculum that they will take away, that is individualised specifically for what they need themselves.

With one group that we worked with earlier last year, we brought them back together as a group two or three months later and we were amazed at how well they had come along with what they were doing and how positive they were feeling about the impact that they were making with the students that they were working with.

**Ms McLEISH** — Thanks for coming in and presenting. Can you give me a feel for the number of families that you have dealt with over the years through Creating Connections?

**Ms CINCOTTA** — We have had some families attend, but we often find, I think, that it is confronting.

**Ms McLEISH** — I do not mean families all over, but if it is just a parent.

**Ms CINCOTTA** — I think indirectly it is — —

**Ms PLUMRIDGE** — It is a small percentage, compared to the professionals.

**Ms McLEISH** — My question is more around the schooling. I was just sort of getting a feel for the number of people that you come into contact with, because we have certainly heard from people that are very worried that their children have been bullied at school because they are on the spectrum or for different reasons and the parents are really stressed about that, as you can imagine, because their children have been very stressed. A lot of parents have talked about homeschooling. In fact, I have met very many parents who have pulled their children out and who have homeschooled them, often because they have autism. Have you got experience of that or have you heard people?

**Ms CINCOTTA** — We also, as part of the work that we do with Creating Connections Australia, have one-on-one consultations with parents, carers and families, and the feeling that we often get is that they are needing support and some practical strategies and ideas to implement at home but also how they can work that into the school environment. I guess a lot of what they say, too, is that they note they feel like they are not understood.

**Ms PLUMRIDGE** — Can I add to that with my own personal experience with my now 15-year-old? In the middle of last year we had to make the decision to pull him out of full-time school. He still was maintaining part-time attendance at school. It was not for bullying, but it was for the fact that he was not managing in the school environment as it was and his mental health was suffering. We made the decision that that was the only way to build up his sense of self again and give him a chance to make it through the rest of his schooling, so he continued part time at school and we made up the difference at home.

**Ms McLEISH** — And you felt that was a great option?

**Ms PLUMRIDGE** — It was the best option that we had at the time, and it certainly improved his outlook.

**Ms CINCOTTA** — I have a very similar story too with my son. We tried the part-time schooling mid last year, and then he continued on with schooling for the remainder of the year, but again affecting his mental health, so much so that I guess it impacted on our family life. So I made an agonising decision to pull him out at the end of last year, at the end of year 10. We have sourced another type of education that best suits his needs. It is not homeschooling, but it fits what he wants to do.

**The CHAIR** — So was there no capacity for you, as trainers, to actually educate the staff, the teachers, at your children's school about what their needs were?

**Ms CINCOTTA** — It is up to the school, though, if they decide not to. I think probably part of the misconception is that in a small town we are seen as parents, not the education professionals that we actually are.

**Ms PLUMRIDGE** — We are still viewed as parents.

**Ms CINCOTTA** — We are still viewed as parents, and that is really disappointing because we have the experience and the knowledge to be able to help support and provide the best possible strategies to help these kids, not only our own but other kids.

**Ms McLEISH** — And are you aware of many parents that have homeschooled their primary children?

**Ms PLUMRIDGE** — I think it is growing.

**Ms CINCOTTA** — It is growing.

**Ms McLEISH** — What do you think the reasons are? That disengagement?

**Ms CINCOTTA** — The same issues.

**Ms McLEISH** — Self-esteem?

**Ms CINCOTTA** — And that bullying. There are bullying issues, but there are also the misunderstandings I think about these kids who appear to be — —

I do not want to quote the word.

**Ms PLUMRIDGE** — Should be able to cope.

**Ms CINCOTTA** — Should be able to cope, but they do not.

**Ms McLEISH** — And we have heard parents today say they look like everybody else and everyone's expectation is that this kid can cope.

**Ms CINCOTTA** — Yes.

**Ms PLUMRIDGE** — And the system is not set up to cater for their needs.

**Ms McLEISH** — And do you know when parents do the homeschooling, if they are able to follow the curriculum for six months, whether they want to put their kids back?

**Ms CINCOTTA** — Some I think stress that it is difficult at times.

**Ms PLUMRIDGE** — We did work with one family last year, and I do not think the child will ever go back to school because of the trauma.

**Ms COUZENS** — Thank you for coming along today. Just getting on to the schools, we have heard there are a lot of schools that do good programs and there are a lot of schools that do absolutely nothing. What do you think the solution is to that?

**Ms PLUMRIDGE** — A magic wand.

**Ms COUZENS** — Putting the wand aside — —

**Ms PLUMRIDGE** — I think in some respects there has got to be a willingness to admit that things can be done better, because often the schools that bring us in to work with their staff — —

**Ms CINCOTTA** — They have seen the need. They have identified that they need help.

**Ms COUZENS** — Within their school, though, isn't it?

**Ms CINCOTTA** — Yes, within their school.

**Ms COUZENS** — So do you think some of it is a staff training issue as well — that if there is not an interest there or they are not going to staff training and think 'Oh yeah, half my kids have those behavioural issues'?

**Ms PLUMRIDGE** — We find that when we have publicly run workshops, where people can opt in to come to our training, the enthusiasm is at a higher level than if we go into a school, where we may get a lot of the staff who are really enthusiastic and excited to learn more, but we always get a percentage who would rather look at their laptop.

**Ms COUZENS** — Can you explain the Creating Connections autism-friendly approach to social skills and what that actually is?

**Ms PLUMRIDGE** — Social skills have been somewhat of a special interest of mine for quite some time. It probably started when my son was young and he wanted to be very social and be around other children but just did not have the skills to be able to do so, and there was nothing in our area that was going to be able to support him. We would travel to Melbourne on school holidays for three 2-hour sessions over a week, and I knew that that just was not going to cut it and provide what he needed. So I made the decision myself that we needed something local, and we had an organisation that backed me on that and said, ‘Yes, let’s give it a try. Let’s go for it’.

Over the years as we went through those programs — and social skills were something that Sherri focused on as well in her autism studies — we realised that a lot of the programs that we were looking at needed tweaking because they came from the perspective of a non-autistic person. What somebody who is not autistic wants socially can be very different to what an autistic person wants. Even within the non-autistic community you have introverts and you have extroverts, and they have very different social needs. But a lot of the programs we were looking at were set up to train people to perhaps be social in ways that did not suit the autistic person. Once we started to look at doing things differently and to really look closely at that autistic perspective, we found that people were more comfortable, that the participants were more comfortable in what they were doing and that their skills were relevant and appropriate for what they wanted out of life, and that is where our autism-friendly model came from.

**Ms COUZENS** — I think you said before your focus is on professionals rather than — —

**Ms PLUMRIDGE** — No, that just happens to be where — —

**Ms CINCOTTA** — No, it is not. That is just what generally ends up happening.

**Ms COUZENS** — So if, for example, there was a support group of parents who were asking for a workshop of some description — —

**Ms PLUMRIDGE** — And we have done that before.

**Ms CINCOTTA** — We have done that before.

**Ms COUZENS** — So you have done that before? Okay.

**Ms PLUMRIDGE** — We have provided workshops for support groups of parents.

**The CHAIR** — I actually have some more questions, but we are out of time. Would it be okay if our secretary puts them to you, and you reply in writing to us?

**Ms CINCOTTA** — Yes.

**Ms PLUMRIDGE** — Yes.

**The CHAIR** — Because there are some quite pertinent ones around education that I think we would like to put to you. Thank you again for your time today, much appreciated.

**Ms PLUMRIDGE** — Thank you.

**Ms CINCOTTA** — Thank you for having us.

**Witnesses withdrew.**