

# TRANSCRIPT

## FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

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

Shepparton — 15 November 2016

#### Members

Ms Maree Edwards — Chair

Ms Cindy McLeish — Deputy Chair

Ms Chris Couzens

Mr Paul Edbrooke

Mr Bernie Finn

Ms Emma Kealy

#### Staff

Executive officer: Dr Greg Gardiner

#### Witness

Ms Sally Smith.

**The CHAIR** — Welcome to our public hearing today, and thank you for attending. All evidence at this hearing taken by the committee is protected by parliamentary privilege as provided by the Constitution Act 1975 and is subject to the provisions of the Parliamentary Committees Act 2003 and other relevant legislation. Any comments you make outside the hearing will not be afforded such privilege. It is a contempt of Parliament to provide false evidence. Recording of the proceedings will commence today, and you will be sent a proof copy of the transcript and be able to make factual or grammatical corrections if necessary.

Sally, we would like to invite you to make a presentation to the committee for however long you feel comfortable with.

**Ms SMITH** — Okay. Thank you very much, and thank you for having me this morning. My name is Sally Smith, and I was diagnosed with Asperger's, or actually autism spectrum disorder level 1, at the age of 34. I wanted to share my story today because I think it is important that it is recognised that people who are high functioning, and who may seem quite intelligent and able, still do need support, and certainly that has been my experience. I did fine in school. I got very good grades. I was a loner, but no-one ever suggested that I needed help in any way or anything.

When I was 18 I moved away to go to university. I came from a small country town, and I always knew that I would have to move away from home to go to university, so it was just expected and that was fine. I did not really enjoy the university lifestyle. The first year I lived on campus and I really did not like it. I remember hearing someone say once, 'Oh, I don't like all these Asian people here because they just want to learn and they're not involved in all the social activities', and it was like, 'That's what it's for!'.

I moved away and lived in private accommodation from my second year. It was after that that I began to self-harm to cope with everything. I was just overwhelmed. I saw a GP about that, and he referred me to a psychiatrist, so for the rest of the time that I was at university I saw that psychiatrist regularly, usually twice a week, and that would have been for four, or four and half years, something like that. I do not think I would have made it through university without that regular support person just to be able to talk about things, whatever was going on; it was really beneficial to me. I did still self-harm for pretty much the entire time I was at university, but I think it would have been much worse if I had not had that support person.

When I finally finished I was qualified as a teacher. I decided I would go back to the country to a small country school. I thought smaller class sizes, small school, I would cope better with that.

**Ms McLEISH** — Was it primary?

**Ms SMITH** — I was qualified for primary and secondary; I taught secondary. I did not cope with that very well at all. I found that classroom management was just beyond me. I could not control the students. I very quickly realised that I was not doing well, and in the first school holidays I attempted suicide. I was then assigned a case worker through mental health, which continued to work with me. I remained suicidal for that entire year. I was hospitalised multiple times, purely for my own safety.

**Ms COUZENS** — Were you still working?

**Ms SMITH** — I did continue working. I cut back my hours, I think; I am pretty sure. But it was felt by myself and those working with me that without that employment I really had no reason not to kill myself, whereas at least if I was working, certainly during term, I had this obligation that I would continue and work, and it was more during the holidays that I was at risk. I continued working the next year, but I cut back to, I think, two days a week. I was better than I had been the year before, but I really still was not coping, and I decided by the end of that year that I needed to resign, and I really have not worked since.

I was fortunate to get married the year after that, so my husband supports me, which is very good. I have two children, and I think the most well I have ever felt in my life in terms of mentally and happiness was when I had babies. I love having babies and I love looking after my babies. As they get older it gets more difficult, but I still love them. But those first couple of years having a baby is the best I have ever been. Then a few years ago now my husband lost his job and I found that time very difficult and very stressful. I was looking for work, but I was also frightened of getting work because I do not feel that I could cope with work — certainly not a full-time job. I did not know what kind of work to look for, because I am qualified as a teacher, but I knew that when I had been a teacher I had not coped well.

So it was difficult, and I again got to the point where I was constantly thinking about self-harm, but I did not actually do it. I wanted to avoid that because I thought, 'Once I start it will be very difficult to stop'. So I looked for help. I went to my GP. She referred me to a psychiatrist, due to my mental health history, rather than a psychologist. When I rang up to make an appointment I was told, 'It will be two months till you can get an appointment' and I remember thinking, 'How in the world am I going to survive for two months?'. But I did. When I saw him it was the worst I have ever been treated by anyone I have ever seen through all the psychiatrists, psychologists and everyone else. He just said, 'You don't want to work and you just want someone to say you can't work'. He could not understand that I was saying, 'No, I want someone to help me work out what I'm capable of, what is reasonable to expect, because I do not feel I can work full time'. I wanted someone to help me say, 'These are things you can do. This is how long you can probably work for'. Yes, that was really quite devastating at the time. Fortunately my husband found employment a couple of months after that, and that took that stress away, and I have been quite okay since. I have not really needed to seek help from anyone else. I guess that is it.

**The CHAIR** — Thank you for sharing that, and thank you for your written submission as well. What made you go for a diagnosis?

**Ms SMITH** — My nephew was being assessed for autism, and my mother was reading a lot of material about it. She read something by Tony Attwood about girls on the spectrum and said that it sounded a lot like me, especially things with previous diagnoses I had had and how they fitted. She felt that I had been misdiagnosed in my 20s, and because of that I thought that it did sound reasonable and what I read on it resonated with me. I had a feeling of, 'Yes, that's me. I'm like that'. I decided to be diagnosed partly because of the bad experiences I had had when my husband was unemployed. I felt that if I had the diagnosis, that might be the key to being up to get help when I wanted help instead of just getting sort of funnelled into the mental health system and treated as having borderline personality disorder, which often has very negative connotations.

**The CHAIR** — Where did you have the diagnosis?

**Ms SMITH** — I went to Ballarat. I emailed Amaze for a list of people who could diagnose who worked with adults, and it was either Melbourne or Ballarat. There was not even anything in Bendigo, which I was quite surprised about. My parents live in Ballarat so it was just more convenient for me to go that way. My kids could stay with my mum while I went and saw the psychologist.

**The CHAIR** — Were you surprised at the result?

**Ms SMITH** — No, I was not. I was pleased. I did not know whether I would be considered on the spectrum, because I am sort of highly functioning really and I had been able to succeed in school and university without any academic issues. But I was quite pleased to get the diagnosis. I do really find it very helpful to have that sense of, 'That makes sense of so much that happened in the past'.

**The CHAIR** — Looking back on your primary school years and secondary school years, would you say that there were signs that you were on the spectrum that you can see now, and how did that impact on your schooling and social life?

**Ms SMITH** — I did not have a lot of friends in primary school or in high school. In high school basically during recess and lunch I would sit and read a book. Usually I would sit in a corner and read a book. Sometimes I walked around reading a book. But that was what I did, and that was who I was. I think partly because it was a small town I was just accepted as being quirky and it was not really considered a problem as such. Academically I always did very well, and I really enjoyed school in the academic sense. I was one of the top in my class in most subjects, and I just saw school as, 'Well, school's for academics' and I was particularly bothered by the fact that I did not have friends. Well, you know, I had a few. I was always in the reject group. You had the popular girls and the other girls. I was always one of the other girls, and I had no desire at all to be part of the popular group. There were a couple of times when I was invited, and I just went, 'No, I don't want to'. The idea of hanging around in a big group of people just did not appeal to me. So certainly it was clear that I had social issues, if you were to put it that way, as a child. There was no way you could have not known that, but I do not think anyone ever suggested that I had anything that needed diagnosis or assistance, because I was not difficult. I just sat and did my work, got my work done and did not cause problems for anyone, so there was no need to address anything from the school's point of view, I would say.

**The CHAIR** — Since your diagnosis have you sought out any support groups or advocacy? Have you felt the need to meet people who are on the spectrum of your own age?

**Ms SMITH** — Only online. I found a very good Facebook group of women with Asperger's which is very helpful. I find that really good because there is a lack of in-person support. If I wanted support, I would probably have to see a psychologist. I would have to pay for that, and overall the kind of ongoing person I would need I would not be able to afford. This Facebook group is a place where you can say what you are feeling and share. Different subjects come up, and there is just that feeling of connection and being understood.

**Ms McLEISH** — Thanks, Sally. I have enjoyed your presentation. Can you tell me, when you reflect on your school time, was it a happy time or was it just another time?

**Ms SMITH** — I think I was quite unhappy by the end of high school. I remember despising PE, because we had to do PE, and I hated it because it was a team thing. I knew I was no good at PE, and I knew that the people who had me on their team did not want me on their team. They said, 'You have to do PE, because you have to get out and move. It's good for your brain, rather than just sitting and working', which I would have preferred. I always thought that PE made me far more depressed than anything, and I hated that.

**Ms McLEISH** — I thought it was the key to life.

**Ms SMITH** — And there were other times that I know that I remember thinking, even in my teen years, that I would eventually end up seeing a psychologist or a psychiatrist because there was something wrong.

**Ms McLEISH** — Was there any bullying?

**Ms SMITH** — I think I probably was bullied, but I did not know it.

**Ms McLEISH** — The girl who read the books.

**Ms SMITH** — I was socially oblivious enough not to care what other people said or did, but I think there were times when I was bullied. I know that by the time I got to the end of high school younger kids on the school bus were blowing spitballs at me and things like that on the way home from school, so I suppose that is a form of bullying.

**Ms McLEISH** — When you went to university you lived on campus.

**Ms SMITH** — For the first year.

**Ms McLEISH** — Was that at Melbourne or Monash, or?

**Ms SMITH** — Monash in Clayton.

**Ms McLEISH** — You were in the halls of residence?

**Ms SMITH** — Yes.

**Ms McLEISH** — Did you enjoy being in the halls?

**Ms SMITH** — No.

**Ms McLEISH** — Not at all?

**Ms SMITH** — I hated it.

**Ms McLEISH** — That is why you moved into the private — —

**Ms SMITH** — Yes.

**Ms McLEISH** — When you said earlier that people that are high-functioning like yourself still need some sorts of support — and you had mentioned psychologists — what sort of support, and what are the times you feel like you need support?

**Ms SMITH** — Particularly transition times. For example, when I thought I might have to go back to work, I think the only way I would be able to successfully maintain a job would be to have very strong support in that at least first six months at the job, because there would be so much that I would be bewildered by. I need a person to whom I can say, ‘This happened and I don’t understand why this reaction occurred. I just don’t know what I did or what I should have done’. I just need a person — it does not have to be a psychologist — a person to whom I can say, ‘I don’t understand. I need help’, and that kind of thing.

**Ms McLEISH** — Could that person belong to the company?

**Ms SMITH** — I do not think so, no.

**Ms McLEISH** — I was just thinking about big banks and things like that. Big corporates often have somebody like that that can help people through.

**Ms SMITH** — I think I would find it too intimidating if it was someone within, because I would want to be able to be totally honest, and often you need someone who is outside so that you feel, ‘I can talk about whatever, and they’re not going to be able to pass this on in some way that’s going to get me in trouble’.

**Ms McLEISH** — Where would you think you would find this support person? In an ideal world, if you need this type of support, where would you think that they would be based? A private practice, or are you thinking that there would be an organisation in town that would offer such services? Have you given it that level of thought?

**Ms SMITH** — The best way I have thought of it is as a kind of a caseworker in the same way that I had a mental health caseworker when I was suicidal.

I guess they would be from the government, then. I do not know how that would work, but someone who could work with me, or whoever the person is, who you would know for a long period of time and you could see them regularly, whether that be once a week or once a fortnight, to have that debriefing, and also a person who knew what other services were available. So if, say, I was working and began to go on that path to suicidal thoughts or whatever, that they could say, ‘Look, I can see that you’re going to need extra help. Let’s refer you this way or that way’. It would be best if they had a good understanding of available services, but they would not necessarily have to be qualified as a psychiatrist or a psychologist. I like the idea of a caseworker more, because they could refer you to, say, employment services if that was where you were needing something.

**Ms McLEISH** — Have you had any experience with Centrelink or employment services?

**Ms SMITH** — Very little, because fortunately my husband works. As I said, when my husband was out of work and I saw the psychiatrist, that was no help at all. He basically just said, ‘Just ask Centrelink. If you want to be assessed for how much work you can do, go to Centrelink’, and I thought, ‘Well, that’s not really what Centrelink does’, but that was his sort of —

**Ms McLEISH** — They do have caseworkers that help with various situations. I was just trying to think if that is a good location for someone or not.

**Ms SMITH** — I rang a couple of employment agencies while my husband was out of work, but because I was on a parenting payment and he was on Newstart but with an exemption from looking for work because — anyway, I could not get the employment services. They said, ‘You have to be referred by Centrelink’. So I found that quite disappointing, because it was like, ‘Well, couldn’t you just help me anyway?’. So, yes.

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

**Ms COUZENS** — Thanks, Sally. Thanks for coming along today. Have you looked at what sort of employment future you might like to go into?

**Ms SMITH** — A little bit. I have considered doing a cert. 3 in child care. I think that I might be able to manage that because it is a fairly low-responsibility job. It is more just being an assistant, and I think I might be able to cope with that. I still do not think I could ever do full-time employment. I just think that the stress it puts on me, I need too much recovery time to manage full-time employment, especially if I have a family at the same time, because they obviously need things from me as well. Even as a mother, there are days when I cannot

manage to prepare a healthy meal for my family at the end of the day because I have done too many other things, and by that time of day I am just overwhelmed, and I do not, so we have takeaway or whatever. I would like to be able to see someone — I do not even know if it exists — like an occupational psychologist or something that would be able to work with me and say, ‘These are your skills’.

**Ms McLEISH** — They exist.

**Ms SMITH** — That is what I wanted, but I have never been able to find one. ‘These are what you can do, these are things that you’ll find difficult and these are jobs that may be appropriate for you’. And again the same looking at, ‘Given your situation, working two days a week’ or ‘working four days a week’, or whatever, to have someone else work through that with me and work it out, because on my own I do not have the confidence to do that. I also think if I were to work, it would need to be modified to enable me to function to my best ability. My husband, for example, is probably also on the spectrum. He is in IT, and he has negotiated with his work that if people want something from him, they email. He does not like phone calls and he does not like meetings. He has said, ‘If you call me into a meeting, at the end of the meeting I will have no idea what it was about’, because the stress on him to actually be in the meeting and participate in the meeting means that his mind is so focused on that, he has no idea about the content of the meeting. So that kind of adjustment would make it possible.

**Ms COUZENS** — You mentioned earlier around having that support leading into your employment and so on, so would you see that as a role of an advocate perhaps?

**Ms SMITH** — Possibly. I was thinking a caseworker, support person, but advocate is probably a very similar idea.

**Ms COUZENS** — So you would see that as something really valuable for getting back into employment?

**Ms SMITH** — I would, yes, but they would also need to be able to provide support around social and emotional issues that may arise going into work but may not be directly related to the job itself, but it is a connection in the stress that that creates.

**Ms McLEISH** — So different skills than a regular advocate.

**Ms COUZENS** — And you mentioned getting home and getting the household organised or whatever while you are working is also quite a challenge.

**Ms SMITH** — Yes.

**Ms COUZENS** — So having an advocate or a case manager or somebody looking over that — —

**Ms SMITH** — Exactly. There may be home services that may be appropriate, or there may be — I do not know what else because I am not that aware of what is out there.

**Ms COUZENS** — Clearly that is another thing that needs to be addressed about the awareness of what is out there.

**Ms SMITH** — And how to get it.

**Ms COUZENS** — Information for families about where they can get information and access services? Yes. Given your experience, having gone through school and now being an adult with children of your own, what would be the key things that you would like the committee to consider in its recommendations in terms of provision of services or resources or having advocates or having — you know, whatever you think is — —

**Ms SMITH** — I think one of the important things is that autism or Asperger’s or whatever does not stop in childhood and that when you become an adult the consequences can actually be worse — of not having support — whereas most of the support seems to focus on children and aides during schooling, and there is very little. I think there is now, in terms of universities, more recognising and assisting people with autism to fit in with universities, but I was not diagnosed when I was at university, so I do not know if that existed then. But certainly if you want people with Asperger’s to be able to be successful and to suffer less, they need support throughout their lives, and I would love to see some kind of place where you can go to access a support person

if you get to a point in your life where you are realising stress is going to increase. Whether that be you are having a baby, looking for work, promoted, demoted, whatever, that there be people there who can be consistent and an ongoing support. I think it is probably more beneficial if you can develop a relationship with someone even when you are well so that they can recognise when things are getting too much and they already know you, because getting to know someone is very hard for a person on the spectrum.

**The CHAIR** — Sally, when you had your children — and I do not know how old they are now, but perhaps you can tell us — how did you find that in terms of social activities, taking your children out to do different things? How did you manage that?

**Ms SMITH** — My children are eight and five, so my youngest is at kinder at the moment and will start school next year. I forced myself to take them to playgroup. So when my oldest was about 18 months old, I thought: she needs to be around other people. I always knew that a social aspect of things was going to be lacking for my children, because neither my husband nor I are very sociable people. We do not go out. We do not hang out with friends. We do not invite friends over, so there really is no-one except our family in our house.

So when she got to 18 months old I thought, ‘Now is the time’, so I spoke to the maternal child health nurse about what playgroups were available. She did not really know. Some of the ones she mentioned were not running anymore. Eventually I found one just through local advertising and I started taking my daughter there. Again initially it was very, very hard to go to playgroup, and it created a lot of anxiety, but once I had been doing it for a while it became part of our routine, and I still go to playgroup with my now five-year-old. She has been going to that playgroup her whole life. I saw it as something that was important for my children, so I made sure that I did it, and I have enjoyed it for the most part once I got over that initial — it is really that doing something new is very hard; once it becomes part of your routine it becomes much less difficult.

**The CHAIR** — Sally, thank you. You are extremely articulate, and you have a very keen understanding of what it is like to be on the spectrum. Christine mentioned advocacy, and I just thought to myself: you would make a very good advocate yourself. So if you are looking for future work, I think you should consider advocacy or even perhaps in the special-needs sector within the school system, because having an understanding of what it is like to be on the spectrum is genuinely half the battle. Thank you again for coming along today; it is much appreciated.

**Ms SMITH** — Thank you.

**Ms McLEISH** — Can I just ask one final question? You might be aware that the DSM-5 has changed the definitions, and having had that diagnosis of Asperger’s — that is what you were diagnosed with?

**Ms SMITH** — I do not think I was; I think I was actually diagnosed as autism spectrum disorder level 1 but with Asperger’s in brackets. It was right on when it was changed over, and I think I was diagnosed under the new system.

**Ms McLEISH** — I wondered if you had a comment about — moving away from the Asperger’s.

**Ms SMITH** — I prefer the term Asperger’s because I feel if I say, ‘I have autism’, then I have to say, ‘But not like blah-blah — I am high functioning’. Whereas if I say I have got Asperger’s, that is more understood as your sort of nerd, geek kind of person.

**Ms McLEISH** — High functioning. Okay. Thank you very much.

**The CHAIR** — Thanks very much, Sally. Much appreciated.

**Ms SMITH** — Thank you.

**Witness withdrew.**