

TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Geelong — 19 September 2016

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Witness

Ms Stacey Smith.

The CHAIR — Stacey, welcome. Thank you for your patience.

Ms SMITH — That is okay.

The CHAIR — We would like you to present for about 5 minutes, thank you very much.

Ms SMITH — I have a lot to talk about. I am focusing on adults, because I feel that it is something that is probably the gap in what you have heard through the whole inquiry. I will just read this out.

The CHAIR — That is fine.

Ms SMITH — My name is Stacey Smith, and I am 32, a mother of three autistic daughters, and I have been officially diagnosed with autism spectrum myself. I also have ADHD, anxiety, depression, selective mutism and sensory issues. My role is not just one of a parent but of one who provides a safe place for autistic women to access support from their peers — a sisterhood where they finally feel like they belong and not like an alien living on planet Earth amongst the rest of the population. Called Sisterhood of the Autistic Woman, it is a predominantly online support group with 287 members Australia wide. We organise local catch-ups every now and then, and they are based both in Geelong and in Melbourne. The sisterhood extends to another group for parents of girls, called the Sisterhood of the Autistic Girl. This group has 1100 members worldwide. Both groups are unique, because they acknowledge the different presentations in autistic females and the common barrier we face together. Autistic women and girls are in a minority within a minority, and we desperately need a voice.

What I would like to talk about is the lack of services and supports for autistic adults. Women are underdiagnosed, due to the lack of professionals specialising in the female profile and how they present differently. When you encounter psychologists, not all of them know about autism. That is your first barrier, whether you are an adult or a parent. You finally get into a psychologist, and it might be six months, a year, and nothing is happening, because that person has not done all the work to really know what they are talking about. Then for girls it is harder again, or for women, because they do not specialise in seeing beyond the mask. There is only a handful of people Australia wide that are psychologists that understand and have the level of qualifications that women need to access support.

Another thing is the cost of assessment. The cost of assessment is so hard because generally, if you are an autistic adult who is a parent, you generally have autistic children. Being in my age group, a lot of us are getting diagnosed later in life because we did not have the awareness to diagnose earlier. So you have got parents that are struggling to pay for their children's diagnosis and then they put themselves last. There is a lot of impact with mental health on the parent who is autistic, because they are just wearing so many hats and it is very hard to manage.

Problems in the workplace — understanding sensory issues, flexibility, shutdowns, selective mutism — need to be spoken about to employers. How does somebody with autism like me who can work — at the minute I am not because my role is as a carer for my children, but I have been in the workplace — make them understand my issues? How would they take me seriously? Who is there to advocate for me? I do not do too badly advocating for my children. I am pushing myself and trying to advocate for autistic people, but if I was to re-enter the workplace, who is my backup? Who talks for me? Who helps me? Who educates the employer? What do I do when I am coping so well and then all of a sudden I am not?

In autistic adults it is not always about meltdowns. That is common knowledge, meltdowns. What about shutdowns? Do you understand shutdowns? Most adults have shutdowns rather than meltdowns where they cannot speak, they cannot do anything. They cannot do the housework. They need quiet, they need to be alone, they need to be away from people. If I got to the point where I was coming to a shutdown, how do I express that to people at work? How can I even verbalise it if I am not verbal?

Ms COUZENS — So where have you worked?

Ms SMITH — Kevin Paisley Fashion Eyewear, Optiks. But the role is customer service really. To get by, I scripted everything I said. I realised I would have a script for this situation and a script for that situation, so I would find it very difficult if the information changed. I find it very difficult if there is a new product out; I would need to get a script together for that. If the situation changed, I have had instances where I actually cannot

recognise people — facial blindness. So I would get myself into situations where I have served a customer and they have come in in the afternoon and I forget who they were. There are so many issues, and that all adds to stress and anxiety and piles up.

But re-entering the workplace, who do I disclose to? How do I disclose? Who has ever helped me to disclose? Who is there to say that I cannot work in, say, the Westfield shopping centre — that particular store — because of the terrible lighting? I always end up headachy. The noise and everything about it — the sensory issues — send me off, so I would get sensory overload. If I was going to go back to work, I would not want to work there now knowing what I know. How do I tell my boss that?

Ms COUZENS — Does your boss know?

Ms SMITH — No, because I am not working at the minute. But if I was to go back, and it is possible I could get a position back there if my home life freed up, but as I said I have to be a carer for my daughters — if that situation arose and I was going back to work — how would I approach that? Who helps me explain that to them? They would just think it is trivial. They do not understand the impact, so how could I advocate that?

Also it is the same with healthcare professionals across the board, whether it is a dentist, and especially for mothers, midwives, hospitals, babies, GPs. They do not understand. They do not know how to help you. I am looking for a new dentist because every time I take my children to the dentist I have got to go through what they have and what their issues are and why they will not speak back when they are asked questions. You say ‘autism’ and then they have a whole opinion about autism, and all of a sudden I am defending it, ‘No, it is not overdiagnosed. No, they don’t give out diagnoses easily’. I get so frustrated that I try and shut it down by saying, ‘Well, I’m autistic too’, and then they question that.

The CHAIR — Can I just ask with dental treatment, clearly that is an issue for a lot of autistic people to have to go to the dentist. I am just very mindful of time. What would you see as a solution, particularly for children at the moment who need to go to the dentist who often have to have a general anaesthetic to be treated?

Ms SMITH — The dentist has to have an understanding of sensory issues. You cannot just focus on children, because these children are going to grow up. They internalise it more, but it is just such a minefield. I have had a really bad experience as an adult at a dentist. I hate going. I was very nervous. I was stimming a lot, so I probably was not giving eye contact and I was moving like this. He asked if I was a drug taker or drug user, and I got so upset. I was bawling my eyes out. I could not understand why, and now I look back and I know I must have been not looking where I should have been looking. I must have been moving a lot. I was very nervous, so immediately they thought, ‘You’re a drug user’, and kept on asking me all these questions to that effect. It was like, ‘I’m just here; I don’t want to be here. I want to get treated’.

So, yes, children, but also adults, please. We need help, we need understanding. You do not grow out of autism. Things are just as hard. Like the lighting in this room is horrible. I wish I had a hat. If I was in here all day, that would have an effect on me. These things do not get spoken about, because people have an image of an autistic adult who probably has an intellectual disability. Autistic adults do not all have intellectual disabilities, but that is what people picture.

I really hate any functioning labels whatsoever, because they do not represent individuals. High functioning just means without an intellectual disability. There is nothing more to it. If you want to talk about yourself or your child and your strengths and weaknesses, you focus on your strengths and weaknesses because that is going to tell the person more about you than the words ‘high’ or ‘low’ functioning. So I encourage every school and everybody I meet to not use that, because it does not give you any information. Does ‘high’ or ‘low’ tell you how to help the child or the adult? No, it does not.

Comorbidities with autism, such as anxiety, depression and even things like anorexia nervosa, need to be treated in the context of autism. Unfortunately, like I was saying with psychologists, they might know about alcohol abuse, anxiety, marital problems, but do they know it in the context of autism? No. That is such a niche. For adults that are experiencing things, whether it is domestic violence or eating issues or anything — or just simple anxiety — if they do not understand how it affects an autistic individual, that person will not get help. They will not get the help and understanding they need, and that is the feedback I get from my group, the adults group, I call them my ladies. I provide them with as much support as they provide me with, but we feel so isolated, alone

and not understood, even with professionals. When they need help, they try to reach out for help, and they will have a bad experience and then they will not go.

Ms McLEISH — Sorry to stop you, Stacey. When you meet other women like you with autistic kids and you get together, is it easy to socialise with them?

Ms SMITH — Yes, it is amazing. I spoke at the Amaze conference at the start of September and that was called 'All In'. It was the benchmark for autism conferences because it really focused on autistic adults and had a lot of autistic speakers. They had a quiet room.

The CHAIR — I was there.

Ms SMITH — You were there?

The CHAIR — And our staff were there.

Ms SMITH — Yes. I got to speak, and I knew a lot of people. There are a lot of people I knew of but had not met in real life, and meeting these women from my group, and some I already knew, it is just like we can just be ourselves and we just enjoy and understand each other and it is like we have known each other our whole lives. Yet when we go to social situations within our own lives, we feel like an outsider. We do not want to be there; we do not belong.

The CHAIR — The networking and the social media are clearly an advantage for the group.

Ms SMITH — The chatting and not the vocal is a big advantage. We have gotten to a point where we can have some catch-ups. The next little meet is an organisational workshop, because we all need help with organisation. We have organised that, so this is going to be, I think, 10 of us doing that organisational workshop.

The CHAIR — Stacey, I am really sorry to interrupt. Could you perhaps wind up, because I am very mindful that these people have to go back to Melbourne tonight.

Ms SMITH — There are just a couple more things. Dr Emma Goodall spoke at the conference. She is an autism adviser for the department in South Australia's education department. She is autistic, and she just gets it. Why don't we have more autistic adults in advisory roles? We need that. If there is policy regarding autism, give autistic adults their voices, because they are the ones who understand.

The way autistic people do not understand neurotypical people is the same way neurotypical people do not understand autism. I have just figured that out this year. It dawned on me, because I was trying to explain something to a teacher, and they just did not get it. To me it was so obvious, and then I realised it is because I am in tune and I have got the autistic thinking. If you are trying to help people with autism in any aspect, you need autistic people in those roles.

Nursing is a big one. I have got a friend who is a nurse in Melbourne. She struggles with work, but she wants to be that support person who knows about autism that can help patients. She has just applied for a research role around autism. You will find that most adults with autism have a special interest. If they are an advocate, one of their special interests is autism, so they will be very keen to make change and help others. We are like a tribe, and adults are like the tribe elders, so that is how we can help.

The other thing is as well as advocates we need coordination supports, whether it is helping them gain that tailored autism-friendly services — basic health care, education, parent support. It is very hard to coordinate all this on your own. As I said, there are heaps of hats — you are doing this, you are doing that, you are doing everything for your children. Everything is difficult. Everything takes so much extra work. You are fighting for everything. Nothing is easy.

It would be good if there was some person in a role that you could sit down and meet with that could work out a plan for you and your family, could help you access services that are autism-friendly, whether it be the dentist or whether it be anything — social groups — but a person who understands autism that helps the family unit plan, because it always falls on the mum, and the mum always comes last, and they find it hard to gain access to services themselves and to know who is safe and who is not safe. We generally stick to our safe people. If we

had that one-on-one person that could help us plan therapies or whatever we needed help with, that would be great. As the last thing, I will just quickly go into assistance animals. We own and are training a puppy for my daughter. She absconds — severe anxiety around people. We are trying to fundraise the money. We are using a service called Service Dog Training in Melbourne, run by Hans, who is not for profit, with the goal of having a fully trained assistance dog that can go everywhere with my daughter and pass the public access test.

What I would like to bring up is the government has a bias towards large organisations training the dog for you rather than the disabled person having the choice, being empowered to use an organisation to own or train a dog. We would like people accredited under the Queensland government assistance dog act to recognise as an equivalent partner to the listed ADA and ADI members. ADA is Assistance Dogs Australia, and ADI is Assistance Dogs International. We want the same rights and recognition that your organisations have, and we want the choice. Doing it yourself is not for everybody — it is a lot of hard work — but we cannot get anyone to help. By the time we got Smart Pups to call us back, I was already well down the track of doing this ourselves. For the people that cannot plan and do these sorts of things, there is nowhere for them to go. We are doing that ourselves, but we have only got so much to give, and every time a little bit frees up, I fill it with too much stuff.

The CHAIR — There are a lot of people like that, Stacey.

Ms SMITH — Then I shut down, and then I cannot do anything. It is a juggling act, and we are not good at the juggling. We are not good at the prioritising. We are not good at the organisation. We need help, we need recognition, we need understanding and acceptance — and we exist.

Ms COUZENS — Thank you very much.

The CHAIR — That is a wonderful way to end. Thank you very much, Stacey. We really appreciate it. You have covered a lot of ground there.

Ms SMITH — Yes. Thanks for making the time.

The CHAIR — My pleasure, our pleasure. That concludes our public hearing today. I thank Hansard, the secretary and the staff.

Committee adjourned.