

TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Melbourne — 29 August 2016

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Witness

Ms Narelle McCaffrey.

The CHAIR — I welcome to the public hearing today Ms Narelle McCaffrey. Thank you for your attendance here. 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. Thank you very much for your submission to the committee. I invite you now to make a presentation to the committee. We would like you to keep it to 15 minutes. Thank you.

Ms McCaffrey — No problem. Members of the committee, I would like to thank you for inviting me to speak at this hearing today. I wish to talk about the two issues I raised in my submission — motherhood as an autistic person and education.

I am the mother of three autistic children. I feel I have an innate understanding of my children and their autism. I can understand and relate to their need to be away from people, the pain different noises can cause them and the need to immerse oneself in a special interest. I also understand the experience of being on the social outer because these are my experiences to. We might play or communicate differently from some others. We might process the world around us differently and maybe learn better in different ways. I truly believe that this is okay and do my best to teach my children this too. I love and embrace all that my children are and who they are. I can show my children how other people do it or how other people see things without expecting them to follow suit.

Currently a lot of resources and research around adults is focused on the transition to adulthood, including transition to work and to independent living for those on the spectrum. I applaud this but, at the same time, feel that there is a cohort being forgotten or ignored — that is, autistic mothers. We exist and probably in numbers greater than can be predicted. Most of us have been diagnosed after the diagnoses of our children and at great personal expense, while others remain self-diagnosed because of this cost.

I and other autistic mothers face a number of unique difficulties. This may be in part due to societal expectations of mothers, the notion that autism affects more males than females and the idea that autistic parents, let alone mothers, are the exceptions to the rule, given that autism in adults is seemingly forgotten. Although we are all different, it would seem the difficulties autistic mothers experience are similar.

Work carried out at the Autism Research Centre at Cambridge in the UK found that autistic mothers are more likely to have trouble with time management, multi-tasking, domestic duties — we can be awesome mums but pretty hopeless housekeepers — organising play dates and other social opportunities for children, speaking with health and other relevant professionals about their children and advocating for their children and themselves, or more so than their typical peers.

One of the cognitive theories used to describe autism is executive function — or dysfunction. That encompasses the ability to plan, organise, prioritise and complete tasks as well as impulse control and self-regulation. I can be task driven and successful in the workplace — when I was working — yet not in the home. In order to function well with a clear mind, I need order around me, yet I find it near possible to create and maintain this order. My house is a constant mess, so I end up feeling overwhelmed and anxious to the point of being unable to act. Although I am not a bad parent, I think that I could be better at it if I could maintain that order, have that order and have the help and support to do so.

Many autistic mothers feel misunderstood and do not feel comfortable asking for help out of fear of judgement. No matter what though, raising children, autistic or not, is really hard when you are dealing with your own issues. It is hard to juggle your own needs when juggling the those of your children. Services to help are non-existent. The times I have reached out to different organisations for help, intake workers seem unknowing when considering what to do, or that is what it felt like to me anyway.

Our existence as autistic mothers needs to be acknowledged and services to help and support us need to be established. The status quo is not good enough. So in that regard I would really like to see something like a mental service where someone comes into the home to help out without judgement or offers guidance online even, a mental service to help autistic mothers to self-advocate and to advocate for their children, and health and mental health services to have an understanding about autism and women and that are equipped to work with us.

The CHAIR — Thank you very much.

Ms McCaffrey — I have got some more. The second issue I wish to address is education, in particular the way autistic students are supported in mainstream schools. My issues are as follows. The PSD funding allocation is determined by a deficit-based model for eligibility and is not based on needs. For example, my son is currently in grade 1. He has excellent language skills, so he does not qualify for funding. Yet his needs are not being met. They are complex in nature and will take significant effort from all involved to work through, address and support. He dislikes school and school refusal is becoming an issue — and he has only just turned seven. I guess you could consider him as a student at risk of disengagement.

Additional funds allocated to language programs as part of the new funding are not really going to help unfunded students with good language skills. A struggling student is not going to attract more equity funding if they have a highly qualified parent or one that earns a respectable income. Creating an inclusive culture in some schools is going to be a real uphill battle. The mindset of school leadership will need to shift significantly. Teachers will need more support in running an inclusive classroom, more than a few PD sessions — and one is mostly relied on — can offer. They are inundated with these modules to complete, so another one will just be one more. This is a real disservice to our kids.

To finish, I would like to share a story. It is about an eight-year-old autistic boy. He was determined to have language skills at a level deeming him ineligible for PSD funding, so he attended a mainstream school. He has struggled from his very first day at school. Meltdowns were frequent and his mother was called to collect him early most days. She reports that one time she had not even made it out of the school building when that call was made. His teacher was not equipped to work with him. The school asked that this boy's hours spent at school each day be reduced. Without being aware of any options, she agreed, so he was effectively for about half a year. Since then, things have continued to be a struggle.

We fast forward to this year. When allocating classrooms, this child's sensory needs were not considered. As a result, he effectively removed himself from his peer group into an adjoining room. The door was open. His behaviour spoke volumes of his struggle. He felt alienated and misunderstood and definitely not accepted. It was put to his mother that he might not be ready to participate in school camp — that he might make unsafe choices, putting himself, peers and staff at risk. He often spoke about killing himself.

As of about two weeks ago he has been attending the Baltara School, a school for disengaged kids or kids with behaviour problems. In the last week I saw him with a smile for the first time in years. The difference, according to his mum, is that he is not being judged. He feels just like his peers. Classes are really small, with a staff-student ratio of about one to two or three. The learning environment is much quieter and classwork is individualised. At some stage he will have to re-engage with his mainstream school. But how can his learning needs be met and how is he going to be supported when he returns, if things do not change?

How can we let our kids feel as though their lives are not worth living?

The CHAIR — Thank you so much, Narelle. We really appreciate your time today. Can I just say congratulations. I believe you are doing your masters in disability.

Ms McCaffrey — That is correct.

The CHAIR — That is pretty good. Congratulations and good luck with that. You mentioned a couple of things in your submission and in your presentation today around being an adult with autism and being diagnosed. I just wonder if you could perhaps tell us the journey, how that came to be and what was your experience of being diagnosed? How did you actually get to be diagnosed, who did that and, on top of that, what therapy services you have accessed, if any?

Ms McCaffrey — I guess I probably did not consider autism at all until my daughter had been diagnosed. She is just like I was when I was a kid.

The CHAIR — Can you perhaps explain what you mean by that?

Ms McCaffrey — No, not really.

Ms McLeish — What did you notice about her that was like you?

Ms McCaffrey — Not wanting to talk to people, enjoying being in her own kind of world.

Ms McLeish — That is what you liked?

Ms McCaffrey — Yes, exactly. I kind of figured: if she is, then what about me? That played on my mind for probably years, a couple of years. I thought, ‘No. You’ve got to actually know for sure. You can’t keep wondering’. So I sought out a psychologist that I knew diagnosed adults. They are very few and far between, so there was not much choice. So that is how that eventuated.

The Chair — Were you surprised?

Ms McCaffrey — No, I definitely was not surprised. If I had not been not sure, then I would not have taken that path.

The Chair — And since then, since that diagnosis?

Ms McCaffrey — I found that diagnosis to be really positive. A lot of my childhood makes sense, like thoughts and feelings. It is like, ‘Okay. That’s why’.

Ms McLeish — It is comfortable, is it not, once you know that?

Ms McCaffrey — Yes, exactly. And it has kind of given me permission to be myself, I guess, not what other people think — —

Ms McLeish — Think you should be.

Ms McCaffrey — Yes.

The Chair — How did that compare with the way your children were diagnosed? Was it easier for you than it was for you to have them diagnosed?

Ms McCaffrey — I think I am probably one of very few who did not go through a grieving process or feel upset at their kids’ diagnosis.

Ms McLeish — Because you knew what it meant.

Ms McCaffrey — Well, not initially, because I was not diagnosed when my first two were, but I guess I did see similarities in myself and thought, ‘I’ve done all right, so with better support, then — —

The Chair — Did you have to take your children to psychologists to get diagnosed as well or was that done through a different process?

Ms McCaffrey — When my daughter was diagnosed I did not know where to go, no idea. My mum worked for the local council in the area of early childhood stuff that I think was part of the Better Start program years back. She had worked with an occupational therapist who worked closely with a developmental paediatrician. So we went there. Prior to that I had seen two different paediatricians who both said, ‘No, she’s just shy. She’ll blossom’. Clearly they did not know much about girls and autism. So we saw this developmental paediatrician a number of times. We took her to have an assessment with a speech pathologist. I do not know why he did not send us to a psychologist; we saw an OT instead. It took a few months, that whole process.

The Chair — So their pathway to diagnosis was very different from yours?

Ms McCaffrey — Yes, that is right.

Ms McLeish — Thanks, Narelle, for coming in and sharing your story and that of your children with us. Can you tell me about when your children were diagnosed — and they are young still — and whether they are involved in any sport or outside school activities, non-sports stuff? Are they involved in anything?

Ms McCaffrey — They do swimming lessons.

Ms McLEISH — How does that go?

Ms McCaffrey — Hit and miss. It depends on the teacher.

Ms McLEISH — There is a different teacher?

Ms McCaffrey — As they progress through levels. So at the moment my daughter, she is nine and she is starting to do okay, and my seven-year-old, he probably needs quite a bit of support — more than her.

Ms McLEISH — How do the swimming instructors cope?

Ms McCaffrey — I think some swimming instructors do not cope very well with my middle child, nor my youngest who is not the greatest of listeners and does not stop moving — his head moving — at all. I think I have had parents look at me from the sidelines thinking, ‘Your kid, my God!’.

Mr Finn — I think, Narelle, speaking as the father of a child with autism, I know exactly where you are coming from on that score.

Ms McCaffrey — Yes.

Mr Finn — You mentioned a moment ago or a few moments ago that the diagnosis made you feel better about yourself; it sort of gave you a reason. Apart from saying, ‘Well, that explains that’, did it have any practical bearing on your life at all — the diagnosis?

Ms McCaffrey — No.

Mr Finn — No?

Ms McCaffrey — No.

The Chair — Here you are.

Ms McCaffrey — Here I am.

Ms McCaffrey — Yes, not at all. Like, where do I go? There is nowhere.

Mr Finn — Nowhere to go; yes, okay. Well, the practical change may have been what sent you here, so that is that, I would have thought. Are your children old enough to realise what had happened when you were diagnosed? What was their reaction?

Ms McCaffrey — I did not go, ‘Oh, guess what?’. When we talk about autism it is like, ‘Well, you might be autistic and so are you and so is mum’. That is just our normal, and we have friends who are on the spectrum as well. Everybody is different, and this is our difference.

Ms Couzens — Thank you and welcome today. Thanks for coming along. In your submission you talked about having some sort of home service because of your own experience. How do you think that could be developed or put together? What were you sort of thinking?

Ms McCaffrey — I would like a service where someone comes and helps me clean my house. I cannot do it by myself. I can write lists of things to do, but for some reason I just cannot.

The Chair — So something like a home help service?

Ms McCaffrey — Yes, a home help service. I do not expect it would be someone doing it for me. It would be to do it with me, so almost like a mentor, so it is without judgement.

Ms McLEISH — Do you see that you would be able to do that yourself eventually, or do you think that that would need to be long term?

Ms McCaffrey — I have no idea. I guess ideally it would not have to be ongoing, would it?

Ms COUZENS — Narelle, are you involved in any parent support or advocacy groups as an adult with autism?

Ms McCaffrey — Yes. I attend a real life support group in my local area for parents.

The Chair — Parents who have autism or parents with children?

Ms McCaffrey — No, parents with children.

Ms Couzens — So you as an individual with autism, do you have any other support groups?

Ms McCaffrey — Just on Facebook.

Ms Couzens — So is that other adults with autism?

Ms McCaffrey — Yes, other women. Some are parents, some are not.

Ms Couzens — But there is no formal group that you are aware of?

Ms McCaffrey — No, not that I know of.

The Chair — Do you think that would be beneficial for you if in your local suburban area — Roxburgh Park — there was a support group for adults with autism, particularly adults who were diagnosed late with autism? Do you think that you would find that supportive and helpful, particularly in relation to practical solutions to some of the issues that you find difficult or you think that are issues?

Ms McCaffrey — I think I would probably find something that was more specifically for mums to be more beneficial rather than broadly adults. I think our experiences are so I guess unique almost compared with a lot of other adults that are diagnosed late.

The Chair — Thank you very much, Narelle. We really appreciate your time this afternoon, and good luck with everything and all the best with your masters.

Ms McCaffrey — Thank you.

Witness withdrew.