

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

Witness

Ms Ann Mafi.

The CHAIR — Good morning, Ann. Thank you for coming this morning. All evidence at this hearing taken by this 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 that 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. Ann, thank you again for coming along this morning. We have invited you to present for around 15 minutes.

Ms MAFI — Thank you. I became a single parent, and not by choice, of a child with autistic traits and developmental delays, who is turning nine this year. My son's disabilities are a constant reminder of what I feel I need to achieve for him in his lifetime and what he needs to achieve for himself, and these everyday challenges can be overwhelming at times. I want to contribute positively to my son's learning development, socially and mentally. Despite his disabilities, this will pay it forward for my son to contribute back to society in a positive way.

Our journey began in 2011, originally from New South Wales and with only a secondary diagnosis. The only thing New South Wales could offer my son was early intervention once a month and to be in mainstream school with a satellite class that could have up to 30 students — not good enough. My son was non-verbal, non-communicating, no eye contact. Meltdowns due to my son not understanding what people were asking him to do, and my son in return not being able to carry out instructions, only led to my son becoming aggressive and being segregated even at his long day care centre in Wagga, New South Wales. So misunderstood became the normal life for us and so my search began.

There are so many families that have been misdiagnosed or not diagnosed properly until the age of six or seven or even later in life. After being referred by a speech pathologist to Autism Spectrum, they contacted me and rearranged to come to my house and monitor my son at his long day care facility, but only for five visits. After the five visits, they gave me a secondary diagnosis and the name of a paediatrician who specialised in diagnosing autism spectrum, ASD. So we went to see the paediatrician in the hope that she was going to give us the reason why my son was changing all of a sudden and be able to assist me in referring me to other specialists, like psychologists, speech pathologists and occupational therapists. But after two years none of the above happened and no diagnosis. All I got when I asked her, 'Do you think it's time for a diagnosis?', was that she replied, 'I don't specialise in that area of expertise'. Miscommunication, disappointment — I was discouraged and absolutely heartbroken for my son and a lot of wasted time that could have been spent in seeing someone that did specialise in that field of expertise.

So after two years and no diagnosis in Wagga, not seeing any speech or occupational therapist, I packed my son up in the car, left a great job and went to Sydney in the hope of finding a diagnosis, became homeless and was offered a place for my son to be tested in Sydney, but unfortunately with no job and no money to pay over \$1300 for the assessment. I openly discussed my financial situation with them, as directed within the package information, and assumed that I could come to some sort of financial arrangement that would assist me and still get the proper diagnosis for my son, only to be told that they could not help my son or me at that time and that we would be put to the back of the waiting list. I am only one, but I am sure there are many.

It took a long time to search the Net and source information that was useful for us. Unable to afford the assessment, I kept looking on the Net for any government funding assessments and success. I found and contacted PECAT, Parramatta Early Childhood Assessment Team, in Parramatta and arranged to find out what the process was to have my son diagnosed. Again, another six-month wait and my son was now nearly four years old, again in another long day care centre. I found myself having to explain about my situation when it felt like no-one was continuing to listen: 'I am repeating myself and they are not qualified to look after my child with disabilities. Do I work or stay at home?'.

My son and I then travelled on holidays to Nyah West, not far from Swan Hill, to visit family in 2013. I hit a kangaroo, as you do, and found employment while waiting for my car to be fixed and decided to stay after hearing about the Swan Hill Specialist School. I approached the school and had discussions about the enrolment process, what it involved, and decided that we would do this process.

The whole process of gathering medical reports, being tested with speech pathologists over a period of time and finally being tested by the psychologist took just over six months, but to finally hear that he was going to be

accepted in the school brought me to tears. Finally I could rest for a while, knowing that my son and I could settle and that my son's educational and emotional wellbeing was going to be okay — for now. Thank you.

The CHAIR — Thanks very much, Ann. Obviously you have had a very rough road, with you and your son and getting to this point now where you are living in Swan Hill and your son is attending the specialist school. I understand that it is a very supportive environment for him and he is doing very well. Is that right?

Ms MAFI — Yes, that is correct.

The CHAIR — Thank you for sharing that with us. It is really important, and it has actually provided a really good context around New South Wales access to services compared to Victoria. If your son had been diagnosed earlier and had been able to access therapies, do you think that would have made a huge difference to where he is now?

Ms MAFI — I say yes, because he was different. He still is different. Whether a child has traits or not, their behavioural traits do not change. In their whole life they do not change. As parents, we can try to afford therapies and try to make things better for them, that is an overwhelming challenge that we face on a regular basis. They might have a small milestone that they achieve, and they go to the next year and they might move up a class, but my son has dual enrolment — three days at the specialist school, two days at mainstream in Kerang — and it is constant.

You do not stop when you go home. It is trying to improve his way of life. I want my child to contribute to society, disability or not, so we are behind the eight ball already trying to move forward to where some people do not even — you know, they are already there. And trying to give him what everyone else has is a constant struggle, you know? There could be a better way of doing that. There has to be.

Ms McLEISH — Are you living in Swan Hill or Kerang?

Ms MAFI — Kerang.

The CHAIR — Do you have family around and support networks around?

Ms MAFI — Not now. I also care for my ageing mother.

The CHAIR — Christine has been trying to find out if there are any ASD support groups in the region and clearly there seem to be none.

Ms MAFI — Gannawarra shire used to run My Time. It was run through the local council and that was fantastic, but it was run at a time where if you were not working, it was fine. It did not target working parents. As you know, for most parents with children with disabilities, it is a struggle to pay for all these other therapies. You have to have two parents working; if you are lucky, you have two parents working. They put together a group of services, so you could go into the group and not have to go and look somewhere else. So they provided that information for you.

Ms COUZENS — Do you think it is valuable having the support of other parents in the same situation?

Ms MAFI — Definitely.

Ms COUZENS — Where you can sit down and just have a go?

Ms MAFI — Definitely. I mean if you go to the supermarket — anyone will tell you a child with ASD is not going to function normally in a supermarket, let alone anywhere else. We understand other parents that have the disabilities and the everyday struggles — the financial struggles, the therapy, everything that you have to do to try to bring your child to the next level. Talking to another parent who has been through all of that is just fantastic.

The CHAIR — What grade is he in now?

Ms MAFI — He was assessed last year at grade 2, but I am already in that mode of 'What happens to my child when he gets retested?'

The CHAIR — I bet you are.

The CHAIR — And that is when he is in grade 6?

Ms MAFI — That is correct. The lack of funding for aides in high school means you have to be severely intellectually disabled. That is my understanding; correct me if I am wrong. I have this fear of: is it going to be enough for him when he goes from grade 6 to high school? And what is going to be there for him at the end of that? Like at this stage there is nothing, and do I then have to take care of him at home? You are in a catch 22. I am a single parent. The government is not going to like me sitting at home. How am I supposed to explain to them that my child has needs and requirements?

Ms COUZENS — What do you think would be a solution to some of those problems? Have you got any ideas or views on that?

Ms MAFI — Yes. For a start, in my process of having to explain myself to every place that I went to — Centrelink is the last person that should have our information. I think maybe under the national disability insurance scheme, once we come into the system, that information is there first off. You take all that information. It becomes a national database, so if I was to move to Perth or if I was to go to Brisbane, if I had to go somewhere else, they can sit there on the computer and punch up all that information and have details of my son and everything that is associated with my son at their fingertips. We do it if you want your medical records on file, so why can we not do that for children with disabilities?

Ms COUZENS — I think that is the idea of the NDIS, which does not come here until 2019, I think.

Ms McLEISH — How does your son get to school?

Ms MAFI — There is a bus that comes to Kerang that picks him up.

Ms McLEISH — That is a special school bus?

Ms MAFI — At the special school, yes. I work part-time, four days a week, so he is in after-school care, and that is amazing.

Ms McLEISH — At the special school they have the after-school care?

Ms MAFI — No.

Ms McLEISH — At Kerang?

Ms MAFI — In Kerang. There is one carer with family day care that specialises in working with children with disabilities — Viv Credlin. She has won awards for her work, but again she can only take children up to a certain age. What happens to me if I want to continue to work to help do these other things for my son — where does he go? Because I am in Kerang; I am not in Swan Hill. There is nothing in Kerang. There is nothing on offer. Even the long day care centres only cater for children up to a certain age, so am I supposed to leave my child at home by himself?

The CHAIR — There is no school holiday program that your son could attend that would be inclusive of students with ASD?

Ms MAFI — No, not in Kerang.

The CHAIR — Are you aware of any in Swan Hill?

Ms MAFI — I am aware of the council-run program, but that is open to everybody.

The CHAIR — Does that cater for children with ASD?

Ms MAFI — I am not quite sure.

The CHAIR — Thank you so much, Ann. Really appreciate it, and thank you for sharing that with us. Very informative. Thanks again.

Ms MAFI — Thank you.

Witness withdrew.