

TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Melbourne — 12 September 2016

Members

Ms Maree Edwards — Chair

Mr Paul Edbrooke

Ms Cindy McLeish — Deputy Chair

Mr Bernie Finn

Ms Chris Couzens

Ms Emma Kealy

Staff

Executive officer: Dr Greg Gardiner

Witnesses

Ms Florence McIver, and

Mr Mike McIver.

The CHAIR — Welcome. I just have a couple of things I need to read out before we start. Welcome to this — what we are now having — private hearing, and thank you for attending this afternoon. 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.

This hearing is being conducted as a private hearing, at your request. Although only the committee and parliamentary staff are present at the hearing, the evidence will be taken down and become public evidence in due course. Thank you for your submission, submission no. 18, in relation to your son. If you would like, you can make a brief presentation to the committee.

Ms McIVER — Sure. First we would like to say thank you for giving us a voice. It has not happened in 25 years, so it is great to be here; we are thankful for that. We hope that our testimony can be used further than just data gathering. We would like to think that it helps change and improve the situation for individuals and families living with ASD.

To sum up our experience, I would like you to visualise this. I like to compare our journey so far — and likely to be for as long as we live, as a matter of fact — to be like climbing our own Everest. The path is steep, it is hard work and it is ongoing. I cannot remember every giant boulder we had to go around or every crevice we had to jump over or every slip under foot that sent us back; it was just long and arduous. We suffered exhaustion along the way, and we stopped to think to try to find a better way but found none, so we kept going. But it is like in a weird dream: the mountain keeps growing, and you never ever get to the top. If there are two things to remember about our testimony, they are the constant battle, I suppose, and the lonely battle; it feels like you are doing it on your own.

I will summarise the key challenges we face first by touching on the past and then on what we believe our future challenges might be. Our son was diagnosed at age two and a half, and he is now 25. It was like we had to reinvent the wheel on our own. After talking to other parents, I do not think we are on our own. We have been faced with being our son's only advocate, and we have had to seek funding for most of his life to cover most of his basic needs. Starting with education — kinder, primary, secondary and tertiary — every time, funding had to be sought and, every time, in a different bucket. This bucket runs out, and this one needs to be filled up. And every time, it involved a lot of research and determination and time on our part.

I cannot understand why the system cannot kick in when your child has been diagnosed and you then get a human being, preferably, allocated as a caseworker to lead you along the way — somebody who knows the system and can tell you, 'In the next five years you're going to face this challenge. This is what you do. See you in five years, and ongoing after this'. To me it is important to have a human being — I think other people have spoken about that as well — because you are literally grieving, and you need a human to talk to and not a 150-page booklet with confusing information in it.

So education was done, and then we said, 'Well, after school how is he going to fill his days? What does he do now?'. Unlike the previous chap you had, he is not high functioning. Our son has got also a mild intellectual disability, which I think is more linked to his autism than a disability itself. He has been labelled like this because the system has one test, and if you are not compliant with the test, you get a bad score, and hence he had a bad score. But he is much more capable than he appears to be.

So we went through the 150-page booklet looking for either placement or work or other activities, and we found that he was a little bit too slow or too different to fit in in the standard setting and he was a little bit too high functioning to be in most of the placements that were available in the booklet. That is autism for you; he falls in between, and he does not seem to be well catered for.

So when we looked at employment, as parents we were lucky enough that he had a disability pension, but in looking for jobs you always fear that you might lose that disability pension, and to us that is like a safety blanket; it is like a safety net for parents. Especially as you age and you face your own mortality, you say, 'Well, what is he going to have when we're gone?'. It becomes one of the very few concrete things that you know will be there to help him when you are gone.

Despite that, we still think that for his physical and mental health, he needs to be active in the community through volunteering, work and social interactions, and we have looked for opportunities for him. First we were offered supported employment; \$8 a day does not even cover transport there. We thought it was insulting and demeaning, and we did not think it was for us. Then we went to disability agencies, employment agencies, and like the previous person, they never found him a job. We found them, and then they applied for the funding to find employers and to find subsidies.

And then we found that the subsidies only worked for up to 8 hours a week, and they would never find him anything more than 8 hours a week, and 8 hours does not fill up your week. So we looked for some more, and we had to be creative and work around the system. But unfortunately the jobs that we found were all temporary. They all seemed to be attached to the philosophy of management, their social conscience or their empathy, and when management has changed, the jobs have gone. Our son no longer has a job, so the battle is ongoing.

Then there is his health. In the past two years our son has regressed cognitively and socially, and we do not know why. We have been to countless doctors and professionals, and they do not know. We think it is mental illness that seems to have been added to the mix, and we are told it is not unusual in young adults with ASD as they come to realise that life will be very different. As very little is known about the brain and where ASD comes from and as literally no two autistic children are the same, knowledgeable mental health support is hard to find. Our son is almost non-verbal, which makes it even trickier to diagnose anything.

And what about the future? As you can see, the quality of his life depends entirely on our advocacy success, and what happens when we are gone? Financially the pension does not cover the cost of living, and then there is NDIS maybe. We are a bit cynical about the prospects, to be honest. We have been refused a caseworker for two years now that we have been looking and knocking at the door of disability services. We have been told that the waiting list for an ISP, which is what I have lastly asked for, which is an individual support package, to get him into a day centre to keep him busy during the day is now measured in years. It is no longer in months — in years — so I cannot see much money coming from there. Most of the financial support that is required I think will be coming from us again, so we work to be able to pass enough on to him for a life that we think he is entitled to live.

And what about living arrangements and accommodation? Will he be independent? Unlikely. Will he be living with his sibling? Unfair. Can he go to supervised accommodation? Impossible to access. Most of the ones we have heard of are organised by parents — again, financed, built and managed by parents. It is a huge financial and a huge task to organise.

And his health. What about his mental health and his ongoing support? If we have now that in the mix, we need to think about that in the future. That leads to his own problems relating to obesity. He also has, like most kids with ASD, a sexuality that is more complex, so we need some help potentially with that.

And the research. More research is needed to understand why and how. At the moment we are only treating the symptoms in most of these services that we have received. More researchers and health practitioners are talking about ASD as a symptom and no longer as a simple diagnosis. We know these kids are wired differently, but is there anything that can be done to improve their symptoms? With the advance in the area of neuroplasticity, is there more that can be done? All these questions to us are hope — they represent hope — something which as parents we must never lose sight of.

As you can see, we have got lots of questions and lots of uncertainties and a lot more climbing ahead of us.

The CHAIR — Thank you so much, Florence. Did your son ever have any intensive therapy, behavioural therapy?

Ms McIVER — Yes, he had. In the first few years he was very aggressive. When his brother arrived, when he was two, that triggered supposedly autism in him, or it sort of came out, and we had to go to intensive behaviour management ourselves through a centre at the time called Canterbury something centre, which was on Canterbury Road. It is now a retirement village.

Mr McIVER — Canterbury Family Centre.

Ms McIVER — That is right. Then we went to Biala, which was an early intervention centre, and that lasted a couple of years until the funding came for kinder and then went on. We did our own. We did a bit of ABA, which was available at the time, and a lot of physical therapy to try to get movement. That was the rationale behind it. That is all I can think of at the moment.

The CHAIR — Did those interventions help?

Ms McIVER — I think the behaviour management, yes, worked. It worked mostly for us, I suppose, to understand and to manage him. He was very difficult to manage. Then when he came to the age of about eight, somehow something triggered and he settled down — he became a pussycat and a teddy bear — but until then he was very difficult, but I think it helped. It helped with him being able to cope maybe in a kinder situation and being able to sit down for longer periods of time. Then when he got to school he was pretty good.

The CHAIR — Does your son live with you?

Ms McIVER — Yes, he does.

The CHAIR — You mentioned in your submission, and you mentioned it just before, that you were not too sure about the NDIS, so you currently do not have an ISP for your son.

Ms McIVER — No.

The CHAIR — And you live — —

Ms McIVER — In Camberwell, so it is November 2017.

The CHAIR — So you have not been to any information sessions.

Ms McIVER — Yes, we have.

The CHAIR — I get the sense that you do not feel that it is going to help your son.

Ms McIVER — We have been to one information session that was organised by the City of Manningham. We went and attended that. That explained what it is aimed to provide. We are just cynical about where this money is going to come from. When we see our son's needs, they are literally enormous — the amount of work we do for him. I am like his personal secretary. On top of that I have to have a job and I have a practice to run. It is impossible to measure the amount of time. Literally it is 40 hours a week I have calculated. When I try to do the ISP application, I can measure it as 40 hours a week of time put towards our son. It is hard to imagine how that could be funded.

The CHAIR — Are you on the waiting list with the ISP?

Ms McIVER — Not yet.

Ms McLEISH — Thank you for coming in. Could you tell me a little bit more about your son? What does he like to do?

Ms McIVER — There is the son that used to like to do things, and there is the new son of two years ago that does not like to do anything. Before that our son was interested in the universe, volcanoes and science, and he would be interested to go to things like the planetarium. He was interested in those sorts of things. He cannot read very well, but he can read enough to get out and travel and to read the TV magazines or something and see what is coming on on TV. He just flicks through books and tries to find some interest. He loves going to the movies, and he still does, but in the last couple of years his demeanour has changed and he is not really doing much. At home he is literally going from Xbox to the TV to the iPad to the computer.

Ms McLEISH — And is that how he fills his day?

Ms McIVER — That is how he fills his days, so in between we take him out. We try to take him out for an hour at least a day for a walk. We take him out for lunch. We are both self-employed, so when we go out of the office we always take him out with us or go and do the food shopping with him or whatever to try to get him out.

Ms McLEISH — You work close to home, do you?

Ms McIVER — I work at home.

Ms McLEISH — So you have that flexibility.

Ms McIVER — Yes, we have that flexibility. I could not have had another job otherwise.

Ms McLEISH — You said at eight he became a pussycat and quite gentle. I have often heard that there are seven years and kids can change quite differently — you know, the 7, 14, 21 sort of thing. Did he stay like a pussycat until the last couple of years?

Ms McIVER — Yes. Very compliant, very easygoing. He does not necessarily have the motivation to please, but he does not have the motivation to object, so in a way he is compliant.

Ms McLEISH — Does he complain about being bored, or is he content with doing what he does?

Ms McIVER — Sometimes he does. Sometimes he looks bored and he paces — ‘What’s happening now?’ sorts of questions — but otherwise he does not. No, he does not.

Mr FINN — Thank you for coming in. I do not have any questions. You are the ones clearly with the questions. I just want to say that you have outlined only too well the problems faced by far too many people, not just in this state but across the country at the moment, who live with autism, because we all know that it is not just a child who has autism or an adult who has autism; it is the families that have autism. I think you have outlined the problems very well, and I know that we will be working as a committee towards resolving some of the issues that you have raised — as many as possible in fact. We really do want to make a difference here. As the father of a 15-year-old boy on the spectrum, I know fairly substantially what you are going through, and it is not fun. But this committee, I am very, very hopeful, will make recommendations which will make a real change to your life and the lives of so many others. Thank you for coming in.

Ms McIVER — Thank you.

Mr EDBROOKE — Thanks for coming in. I concur with Mr Finn’s comments. I have just one really quick question. Is your son seeing any therapists or psychologists or specialists at the moment?

Ms McIVER — Yes, he is. He is seeing regularly a GP and a psychiatrist. We have been through three psychiatrists, we have been through four GPs, we have been through neurologists, we have been through neuropsychologists, we have been through epilepsy specialists — —

The CHAIR — Does he have epilepsy?

Ms McIVER — No, he does not, but he had symptoms that were very similar and we were questioning some of his behaviour with twitches, headaches and other things.

The CHAIR — So he has not been diagnosed with any other comorbidities?

Ms McIVER — No. We have had so many different treatments which have had adverse effects. We are now just keeping to one psychiatrist. Every single medication he has been given has sent him absolutely nuts.

Ms McLEISH — So he is on no medication.

Ms McIVER — He is on no medication at the moment, no.

The CHAIR — Florence, I just wanted to ask one more question. Can you confirm that you would like your son’s name redacted from the transcript of hearings?

Ms McIVER — Yes, please.

The CHAIR — Thank you. And thank you so much for coming in today. As Bernie has already mentioned, we appreciate that there are many families such as you going through very similar things and who have done for

a very long time. We are very conscious of that fact, and the whole point of this inquiry is to make things a little better.

Ms McIVER — Thanks. I think for us it is mostly the frustration of seeing what the potential is in your child and nobody else being able to see it or being able to help you to get there.

The CHAIR — We are hearing that loudly and clearly from many. Thank you very much.

Ms McIVER — Thank you for your time.

Witnesses withdrew.