

TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Melbourne — 12 September 2016

Members

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Ms Cindy McLeish — Deputy Chair

Ms Chris Couzens

Mr Paul Edbrooke

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Witness

Mr Christopher Reid.

The CHAIR — Christopher, thank you for attending our public hearing this afternoon. All evidence taken at this hearing 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. Chris, thank you for your written submission, submission 66, which talks about your experiences and your daughter, Claudia; is that correct?

Mr REID — Yes.

The CHAIR — We would like to hear from you, if you would like to present to the committee for a short time.

Mr REID — I have just made a small opening — —

The CHAIR — The photo, yes, we got that, so thank you very much.

Mr REID — I just thought it helps us to think about it, that this is what I am here for. I would like to open by saying how much I appreciate that the Victorian parliamentary Family and Community Development Committee is investigating ways to improve services for people with autism. I would also like to acknowledge that my local representative the member for Burwood, Graham Watt, also has a keen interest in this inquiry, but is unable to join me today due to a prior commitment.

Some of the issues I discussed in my written statement are unique to my daughter. I also do not consider myself a representative or spokesperson for parents or carers of children with autism; however, when I meet the parents of other children at Claudia's special school, it is surprising, and possibly a little disturbing, how common some of the problems are.

While I recognise that health and education and social security can be more a federal government responsibility than a state government, I would like to take this opportunity to reinforce two areas mentioned in my written statement that perhaps this committee can help address.

The first of these is respite care. Like other parents, I believe that the amount of respite care that our local council provides, which in my case is the City of Monash, is only 4 hours a month, and this is hopelessly inadequate. Children with autism often have severe separation anxiety and would not see carers long enough to be comfortable to be at home without their parents, particularly when the respite carer is not always the same person. Practically speaking also, 1 hour per week is not enough time for parents to be able to do much once you include travel time et cetera. In combination, these considerations effectively defeat the purpose of respite care.

The second is the continence support scheme. Children with autism often have sensory issues affecting their toilet training. I and other parents consider the continence support service funded in part through a state government service called SWEP, or statewide equipment program, to be too few and too far between.

In Claudia's case, a drive from Chadstone to the nearest continence support service in Ringwood is best avoided when possible, because she starts to be get claustrophobic with drives longer than 30 minutes and tries to escape from her car seat.

While I realise that there is only so much the state government of Victoria can do — they cannot wave a magic wand and make everything better — I am hopeful that an inquiry like this can create better outcomes for children and other people with autism in Victoria. Sometimes all it needs is recognition and support of a good idea.

For example, one day on my way to the MCG, in between the buskers and charity collectors I saw a stand with a man selling picture books designed for children with autism. Curiously, this \$5 book *Going to the Toilet* by Danielle Phillips has possibly helped my daughter's toilet training more than the continence support service. Perhaps the committee could consider whether this or a similar book could be placed in special schools to assist children with special needs to use the toilet correctly.

It would also be helpful if children's sensory needs were supported more widely. Melbourne has only two special-needs dental surgeries, and to my knowledge no special-needs hairdressing salons. Perhaps there could be incentives for dentists and hairdressers to retrain and offer these services, or an accreditation process for hairdressers that cater specifically for special needs children.

We would also welcome any practical assistance the Victorian government could provide to assist parents of children with special needs pay for their therapy and other medical services. One idea I proposed previously was an equivalent of the *Yellow Pages* featuring only the businesses of parents with children who have special needs. Unfortunately the department of education knocked back my proposal on the grounds that the department could be held responsible for any negative outcomes, despite my argument that people obviously would not sabotage their businesses and, failing that, they know where their kids go to school. Perhaps the committee could consider a way that this proposal could work while addressing the department of education's concerns. Thank you again for your time, and I will be now happy to take your questions about my original statement, this speech or anything else related to my or my daughter's experience.

The CHAIR — Thank you very much, Christopher. We really appreciate that you have taken the time to put your submission in. Clearly, despite the problems we have here in Australia, it is a lot worse elsewhere. I think you mentioned Indonesia and your Indonesian experience.

Mr REID — Yes, just the awareness, even amongst medical staff there.

The CHAIR — I just wanted to ask you about the diagnosis, when Claudia was diagnosed. Perhaps you could tell me a little bit about the process that you went through and what kinds of information and support you were offered after the diagnosis?

Mr REID — I should explain that we were just visiting into Australia each time. Basically we exhausted all avenues within Indonesia for finding out what was going on and did not get a satisfactory response.

When Claudia was three, I was back for a couple of months. We were able to get her hearing tested. She aced the hearing test, but the waiting list was so long that we could not then take it to the next level and investigate other things, like the potential for autism. We had to go back to Indonesia, where I worked, so it was not until the next time we came back, in December 2012, that we were able to get an appointment with a paediatrician, who even then was like a friend of the family. I would not have known where to go if it was not for that. So we had one appointment where they said, 'Yes, it is autism', and then we had the next appointment, which was, 'Okay. This is what happens next in terms of applying for early intervention therapy'. My wife had to get an Australian tax file number just to be able to get any social security, which was weird considering we were in Indonesia.

We did return to Australia about six months later, but it still took us about another three months to jump through all the administrative hoops, get a tax file number, register at Centrelink, register for this, that and something else, so it was not until I think about October 2013 that we were actually able to start some early intervention therapy.

The CHAIR — And by that time she was?

Mr REID — She was five and a half. Having said that, we were still able to use the full complement of funding in one and half years.

The CHAIR — So it was a bit more of a challenging process for you because you were crossing two continents at the time?

Mr REID — We were back and forth. We were not able to get the support from Indonesia obviously, but even when we got back there was only so much we could do remotely. That prevented us from hitting the ground running when we were actually staying in Australia.

Mr EDBROOKE — Chris, could I grab a copy of the book?

Mr REID — Yes. It did have a copyright warning on it, so I only scanned the cover of it. It is very simple, but like it says in the blurb on the back, children with autism are much more visual learners than other children. I suppose one similar thing we do is have a photo board at home. On the photo board the last photo is always a

photo of our place, so she knows she is not going to get abandoned, transferred or moved away. She did have quite a severe separation anxiety. Even when she was five we would have to carry her sometimes. She would refuse to walk long distances. She was afraid of falling behind. She was getting pretty heavy by then, too. I blame Claudia a little for my right knee starting to play up a little. It might not just be that.

Mr FINN — I probably do not have questions because I think, Christopher, you have explained your position extremely well. Perhaps if I could just ask where do you personally and Claudia go from here?

Mr REID — See, that is the thing. We feel like the job is only half done in terms of helping her to cope with daily situations. The early intervention therapy was really good, but Medicare has now rolled back to 10 sessions a year of the mental health care plan, which can be used for occupational therapy or psychology. We decided to go with the occupational therapy, just because she was seeming to be learning more coping skills through that than with the psychologist, and five sessions a year of speech therapy. At the moment we are seeing a speech therapist every two weeks because once she was able to speak, it opened a whole new world. She can indicate preferences, she can say what she wants to do and she can make choices. Through that it has reduced the frustration for her and reduced the challenging behaviours that her parents have had to help her with.

Mr EDBROOKE — Thanks for coming in, Christopher. Just a point: most of the special developmental schools I have worked in have got picture boards like you mentioned actually in the toilet. It is pretty similar to the book. That could be something just to take away. You mentioned your local MP has been advocating for you. That is really good. In what way has that worked for you?

Mr REID — I suppose what I would say is that he has taken a personal interest in terms of my submission. He read the submission and rang and spoke to me about it. He has also encouraged me. Originally I was like, ‘Aren’t health and education more federal things?’. He said, ‘Well, yes, but don’t feel like there is nothing you can do. You can certainly say your piece. You can certainly try to do your best, and you never know what might happen out of it’. I must admit that I have never met any of you people before, so I was not quite sure what to expect. I suppose it was more of a supportive role rather than, ‘Yes, you should meet this person’.

Mr EDBROOKE — We are glad you came in, Chris. Can you just give me a run-down on the financial impact this has had on your family?

Mr REID — Originally I was working in Indonesia as an English teacher. I then had a work-at-home job doing an online travel business. That was not sufficiently profitable in Australian dollars for me to be able to do that now, so I have now got another job in the travel industry, which involves me working away in an office. That is good because it helps pay the bills and I can be more financially supportive, but it is hard for me to be as practically supportive as I would like to be. It is a common thing. Parents of children with special needs often have this dilemma. They can be practically supportive or financially supportive, but it is hard to be both sufficiently at the same time.

This was where my idea for the *Yellow Pages* came in. Parents of children with special needs would help other parents of children with special needs. It would create a community and would help them to be both practically supportive — not just to their child but to others — and financially supportive, because people would be able to do the jobs they would like to do. People who run their own businesses often have more time to be at home than people who are travelling long distances to the city for work or something like that. It would also be financially supportive because you would be supporting their business, and the money would not be going to some multinational for profit; it would be going to help. By supporting that family you are indirectly also supporting their child with special needs.

The CHAIR — One last question: what do you think about the NDIS, and will Claudia benefit from that?

Mr REID — I must admit that I have only been to one information session at my daughter’s school about the NDIS, so my knowledge about how it is different from Medicare is limited. I do believe that it is great that goals can be tailored to her needs. I suppose I am just a little sceptical about the fact that we can have high intentions and everything, but it might be difficult for us to find a limit to what is possible. We do not want to aim too high, because we do not want to push Claudia too hard, but at the same time we want to challenge Claudia to aim higher.

The CHAIR — I understand exactly what you are trying to say.

Mr REID — This is in terms of both communication skills and practical skills. I think I mentioned in my written statement that we want her to one day get to a place where she is able to look after herself both practically in self-care skills and also in things like shopping and having a bank account.

The CHAIR — I assume she is still receiving support services. Is she having any behavioural therapy?

Mr REID — Yes, she has occupational therapy and speech therapy at the moment. Speech therapy is once a fortnight. Occupational therapy, I think I have mentioned in my written statement, we have rolled back to once a month because beyond Medicare we cannot afford much more than that.

The CHAIR — She had some earlier ABA.

Mr REID — Yes, previously it was fortnightly. We sort of came to a point where the early intervention funding was used up and we had to make some difficult choices, but we thought that speech therapy was helping her the most. Occupational therapy is also good because she can now nearly write her name. She wrote her name on my Father's Day card this year, which was quite impressive.

The CHAIR — What a special day for you.

Mr REID — Usually we do a dot-to-dot guide for her for Granny's and Grandad's cards. I will have to talk to the school about that. It is funny, one of her four long-term goals for the next school year is that, as well as the toilet training, she can write her own name. If you give her a typed version of her name, you can get her to copy it onto where you need her to write it.

The CHAIR — That is fantastic. What a great goal to have. It sounds like she has already achieved it, if she can write it on your Father's Day card. Thank you so much, Christopher, for coming in today. We really appreciate it. Thanks also for your written submission. Good luck with everything. Best wishes to you and Claudia.

Committee adjourned.