

TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Geelong — 19 September 2016

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Ms Deirdre Wirth.

The CHAIR — Good afternoon, Deirdre. Thank you very much for your interest. I have seen you sitting in the public gallery this afternoon.

Ms WIRTH — Good afternoon. I am interested because I am the grandmother of three autistic grandsons. The third grandson is severe. He has autism, and he is intellectually disabled because he has got very little speech. He was born normal but regressed at one and was diagnosed just before he was three. It was a very long time from being told they thought he had autism to getting a diagnosis. They had to pay to have it done privately because the waiting list to have it done officially was so long, and then it was another long wait to get any help at all from a service provider. Then the woman who ran the service provider was on sick leave for six months, so basically the other people were trying to run it. By this stage they did ABA. They paid for that treatment themselves, because they were told that early intervention was the only thing that would help him. They paid an enormous amount of money and did an enormous amount of work, because you have got to set it all up. She had to pay people to come and do the classes, but she had to set it all up and everything. That was good, except for the cost.

The next year she wanted to toilet train him, and he could not handle both — and she could not handle both either — so she concentrated on the toilet training and succeeded in that, although it was 18 months to toilet train him, so you can imagine the mess. He was a poo smearer. That was an enormous task, but she did that. Then it was time to go to kinder. A lady that was one of the helpers with the ABA was a psychology student, and she was prepared to go and do the course so she could be his carer at kinder, but it was not allowed. She could go and do the course, but she would get whoever they gave her. He had to go to kinder, and his carer was a mum who was just a mum. I do not think she knew anything about autism. You had to be firm with him. Michelle was, and she knew how to handle him, nicely but firmly. I think this other lady was frightened of him, and so he probably only lasted six months before my daughter pulled him out. She said, ‘All he’s doing is frightening the other children’. So I was really disappointed that she did all this herself, arranged this fabulous person, and he could not have her. I am not criticising the other lady, but what a waste.

Anyway, he eventually got to a special school and they are absolutely marvellous. Now he is 13. He has been aggressive all along and he is going through puberty now, so at the minute he is dreadful. But at school the people are absolutely fabulous. But she has learnt that the school has been promoting them having the HPV vaccination, because it is a sexually transmitted disease. She said to the paediatrician that there is no way he is ever going to be able to form a relationship, and she was told that they are at very high risk of sexual abuse because a lot of them end up in homes because eventually the parents cannot handle them. So that is another worry in years to come. Even if he did live at home for a long time, eventually she is going to die, isn’t she?

They have got normal life expectancy, so I am concerned about when she cannot cope with him or when she dies. What is going to happen? She says she hopes he will end up in a shared home, hopefully in a rural setting similar to the special school environment where there are people around and they are not in their own little room where anybody could be doing anything. There are people around, and even though it is very one-on-one type of thing, there are still people around and you have not got that chance of misbehaviour.

When I told her I was coming, she asked me to say that she feels there is a very big focus on the high-functioning people, because they are so vocal and they are so particular. They go on and on, and there is not much of a voice for the severely impaired. A lot of the parents are that busy just simply looking after them that they cannot form groups and things. The other two boys are Asperger’s, really. But they are quite different in themselves too. There are other problems with them, but she sort of coped with them. Even so, they had to pay for everything. Her husband had a good job, so they never qualified for anything. She spent hours filling out forms for this, that and the other, but did not qualify for this reason and did not qualify for that reason.

She was supposed to get council help for basically babysitting the other children if she had a doctor’s appointment or something. I forget now how much it was, but just say it was supposed to be 8 hours a fortnight. For her to take him to the Royal Children’s or something, it is an hour each way, you are not going to get the appointment on time and you have got to see the person. She can only get it in 2-hour blocks. That was the only time she needed it, because I could help her a lot. But at times I could not. She simply had to make appointments when I could be there, even if it was for the other children. They get neglected really, because so much time goes into the severe one. You could not leave him with anybody. She only ever leaves him with us. Nobody else minds him other than us, because it is not fair.

Even with us he plays on his computer, but he screams if things do not go right. Because he cannot speak, if something goes wrong, he screams. He knows more about the computer than we will ever know. We cannot help. She says, 'Just leave him'. If you go near him, he will hit you because he is upset at that time. She has to really just let him calm himself down. The other day she was driving him to school. At the minute he is sewing. He likes sewing, but he will not stop until he is ready. So she is at school and he does not want to stop the sewing, so she said she just had to let him finish it and then calm himself down, because that is all you can do. Another man from the special school came over with a little dog. She thought, 'Now he's going to stab the little dog with his needle'. The other man was trying to help. Apparently with his child the dog settles him. She said even though this man was trying to help and he knows something about it, he could not help because they are so individual. That is where it is so hard. At times she has looked after other people's children that have got it, and she has said, 'I really don't know what to do, because they are so different to him'. But I do congratulate you on trying to make a difference, because it certainly does need work.

The CHAIR — Thanks, Deirdre. I think we are very well aware of that. Thank you very much for your presentation. Pass on our best wishes to your daughter and her children.

Witness withdrew.