

TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Geelong — 19 September 2016

Members

Ms Maree Edwards — Chair

Ms Cindy McLeish — Deputy Chair

Ms Chris Couzens

Mr Paul Edbrooke

Mr Bernie Finn

Ms Emma Kealy

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Executive officer: Dr Greg Gardiner

Witness

Ms Sarah Hayden.

The CHAIR — Hi, Sarah.

Ms HAYDEN — Hi. I have got so much I want to say in 5 minutes.

Ms McLEISH — Talk fast.

Ms HAYDEN — I talk fast anyway. People are always telling me that. I would like to talk for an hour, because I have so much that I would love to say, but I will try and cover the main things that I think are the most important and have not been covered.

I am the mum of four children, two of whom have autism. I have a 19-year-old girl with autism and a 12-year-boy with autism, so I come from the perspective of having both the sexes and also going into the older age. I remember naively thinking when she was younger that it would get easier the older she got, and I have actually found it has gotten much, much harder. From speaking to psychologists and other professionals, I have heard that that is often the case.

There are a couple of areas I want to cover. One of them is hospital. We had our first hospital visit as an adult with autism recently. My daughter has been in hospital several times when she was younger, and it was at the Royal Children's Hospital or a local hospital where she was cared for as a child, and that was quite acceptable — the fact that she had ASD was okay.

This is the first time as a 19-year-old. She had a pretty serious horseriding accident a few weeks ago and ended up in the ambulance, then in emergency and then in the adults ward of the Geelong hospital, which was the most horrendous experience.

She would have liked to speak today, but it would have been too nerve-racking for her, so she has passed on quite a bit of information that she has asked me to pass on — and also from my own observations.

Hospital for a child with autism: my daughter has a lot of phobias around medical staff, ambulances, needles, hospitals — very, very severe to the point where she would have to be held down. That was very misunderstood, because they looked at her. She is a beautiful-looking, normal-looking 19-year-old girl, and the hospital staff I found were very unable to accept the fact that this was somebody who looked normal, as one of the nurses said to me, and that she was coping like a toddler or a brat or something else that I heard many of the staff talking about and addressing. I was not allowed to stay with her during procedures or overnight, they told me. I said if that was the case, I would have to take her home, because she would not be able to stay in there by herself; it just was not a possibility. So suddenly she was being treated as an adult and not as somebody who, even though she has a high IQ — she has high-functioning autism — she in a lot of ways has the mentality of somebody probably a third of her age.

She was kicked in the pelvis, so a lot of her examinations were done in the lower pelvis. They would ask me to leave the room because she was an adult, and she would be sitting there holding my hands terrified, or my husband, and the doctors would say, 'It's not appropriate. You're an adult. You're okay'. I ended up losing it at the staff. I found out that none of them knew that she had autism, so despite the fact I had explained it to them when they came in, they knew the accident she had had, they knew the fact that she had internal bleeding, she had this, she had that, they had no idea she had autism.

I thought about what we could do to help people with autism. Is there something we can put above the bed to explain? I ended up speaking to one of the nurses and saying to her, 'Are you aware that my daughter has autism?'. She just looked at me and said, 'No. Is that why she is acting like this?'. I said, 'Yes. It is the first thing I said when she hopped in the ambulance'.

In her words, she said to me that she had felt belittled. She said that she felt that she was misunderstood, she was ridiculed. She said she was treated like a bratty teenager and was made to feel like it was unacceptable for her to want an adult in the room with her at all times. She did not eat for the three days she was in hospital. She did not eat, because I explained to them that she would only eat white food. She has a lot of food phobias. They would not cater — even a small spoon. She cannot use a large spoon; she can only use a small teaspoon. Nobody would bring her a teaspoon — just little things that for her would have made a huge difference. Probably if you were at a children's ward they would be comfortable catering for. It was the little things that made her life really, really hard in hospital. That was our hospital.

Another thing: we have tried to make her a little bit more independent in the last year in allowing her to catch the train from Geelong to Melbourne if we know there is somebody at the other end. The only couple of times she has got on public transport she has had horrific experiences. I buy her a myki card myself with her concession card. Recently she travelled with her ticket, but she forgot to have her healthcare card with her. When the officers came up, they said, 'Ticket'. She handed the ticket, and they said, 'On what grounds do you have this?'. She said, 'My mum bought it for me'. She could not understand the literal wording.

Basically they took her off the train, took her into a room and told her that she could go to gaol. By this stage she was having a full-blown meltdown. They would not allow her to call anybody, so I had to drive hours to pick her, basically in a foetal position having a full meltdown. I contacted the police, who said that it is not an uncommon thing to get a phone call from a parent of a special needs child who, again, looks normal. The public transport police manhandled her. They pulled her off the train. She had a literal misunderstanding of, 'I don't understand what you are asking'. They said, 'On what grounds do you have this ticket?'. She said, 'My mum bought it for me'. 'Don't be a smart-arse', they said to her.

She had a concession card because she has a healthcare card. She did not have her healthcare card. I actually had it on me because I had gone and bought her myki and I had forgotten to give it back to her. I contacted Autism Victoria and said, 'Is there a card or a band?', and they said, 'No, we don't have anything like that', so I am in the process of trying to work out whether there is something we can get for public transport — a ticket on a myki that says, 'I have a disability. I have autism. Can you call my mum'.

If there was something like that, that could have avoided so much stuff with her, and it is such a simple thing. It is not until my kids are getting older that I am realising that every age they get to there is going to be a whole new set of problems, especially those high-functioning kids with ASD, who look normal, as everyone keeps telling me, but in reality are still very much like they were when they were six or seven. Developmentally they are not actually changing a lot, but physically they are.

She said to me after we got home from hospital last week, 'The hardest thing about this, Mum, was that everyone expected me to be like an adult', whereas at the children's hospital, even when she was 18, they still accepted that she was a child because she was allowed to be in a children's ward. For an adult with autism to have to be in an adult ward and act like an adult, and for everyone around her to expect her to act like an adult was really traumatic for her. She just went into meltdown mode where she did not want to talk, and I would start talking for her. I actually had some doctors saying, 'Stop. We're asking her'. They could not understand that she could not even speak anymore, she was so petrified. Again when I questioned the doctors, 'Are you aware she has ASD?', they said, 'No, we did not know'. They had not read the file on coming in. Anyway, that was hospital.

For school we ended up homeschooling her all the way through high school. We tried four different schools in year 7, and not one school was able to cater for her. Despite the fact that she had just been diagnosed with ASD, they were unable to understand that they needed to change things. We tried private schools, public schools and Christian schools. I ended up pulling her out and homeschooling her all the way through to the end of year 12 through DECV. She ended up really excelling and getting an academic excellence award. But we just found that there was not one school that was able to adjust their thinking or their teachers. We are now finding the exact same with my 12-year-old son, who is in grade 6. I had one teacher say to me the other day, 'He's so naughty. He just rocks backwards and forwards on his chair all day'. I just looked at the teacher and said, 'That's called stimming', and she said, 'What does that mean?'. This is the teacher that I was given because she was meant to be an ASD professional. I said, 'Have you ever even been to a PD day, let alone understand some things?'.

Like somebody else said earlier on, he will often sit there for the whole day and just be totally ignored because he is high-functioning ASD. He does not make noises. He does not draw attention to himself, so he will sit there quietly, too scared to ask anyone for help, and he will literally just be ignored for the whole day. Then I will get a phone call before report writing to say, 'We're not able to write a report, because he has not done enough work', and I will think, 'Hang on a sec, you've just gone the whole semester without ensuring that he is actually following along and catching up'.

Because they were both diagnosed after the cut-off age, we have never received one cent of funding for either of the children to get anything. We are not in the NDIA area, so we are not yet eligible for that. We have had to battle our way through and try to work out ourselves what to do and where to go. That is the main thing.

I know you wanted me to cover social media. Did you want me to mention a couple of things?

The CHAIR — Just very quickly.

Ms HAYDEN — My daughter's whole world is social media. She does not have any real-life friends. All of her friends are on social media. She runs a very successful blog and Facebook page talking about living with ASD, and it has gone viral around the world. She will regularly get inboxes, messages and comments. She is very, very naive and vulnerable and will often get people requesting private videos or conversations with her online, and she will do it straightaway. I will say to her, 'How do you know that it's a mum with two kids?', and she will say, 'Because they told me that they are'. It is beyond her comprehension that anybody would lie or that anybody could put up a fake profile picture. For her it is that vulnerability and naiveté which is really concerning. Even as a 19-year-old she just takes everybody at face value. She will say to me, 'But Mum, why would they say they were a mum with two ASD kids if they were not? What else would they want?'. She is a beautiful-looking girl, and she says, 'What else would they want?'. She does not understand.

She also often talks about how hard it is for her to understand emotions, even when face to face with somebody. It is so much harder for her without seeing a face and with there just being words on the screen. She is often attacked on social media. She will often get people commenting on blog posts and stuff now that she is getting a little bit viral. The keyboard warriors come in with comments like, 'You're just pretending to be autistic so you can get attention', and things like that. People can get quite nasty, and they do not realise that she will go into 12 hours of meltdowns and crying and being really upset. She cannot understand the meanness or all of the things that come with social media.

In the early days I and other people would say, 'Why don't you just take her off that?', but what they do not understand is that for a lot of ASD people that is their world. She does not work. She spends most of her time in her room — in her safe place — and her entire world of friendships and communicating is social media. If we take that away from her, what has she got? It is about trying to create some kind of safe space where she has got friends and people she can communicate with and where she can use this public platform to be a really great advocate for somebody living with ASD, but it is also about attempting to protect her from the people in the world who are not going to be very nice or who may want something from her other than what she is there thinking that she is giving. There is just that naiveté around it, so it is about education, I think.

The CHAIR — Thank you very much, Sarah. I am sorry to hear that she has had to experience all of that trauma.

Witness withdrew.