TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Melbourne — 29 August 2016

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Ms Susan Pearce.

The CHAIR — Susan, thank you very much for attending our hearing 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 to be able to make factual or grammatical corrections if necessary. Can I invite you now to make a presentation, and can I thank you also for your public submission to the inquiry.

Ms PEARCE — Chair, members of Parliament and other committee members, my name is Susan Pearce. You can see from my submission that I have a son, namely, Simon, who is 9 and turning 10 next month. He has moderate to severe autism and ADHD. Like I just said, he is turning 10 but he has a social age of around 6, and an intellectual age of 11 or 12. This makes it really difficult when you are buying him presents. Unfortunately while we know that Simon is high functioning, at present we do not know what area he excels in. It is very difficult to break through Simon's autism and to find out what he is thinking and to maintain his interest.

In the submission you can see our journey with Simon — and most parents with children with ADHD will tell you it is a journey. During our journey we came across a number of areas that need to be improved to better assist kids with ASD and ADHD. We have got both.

The first concern is that there is no written information for parents of children suspected of having ASD, which could be given to parents at time of diagnosis, just to tell parents what the process is and what ASD is. When you go for the initial diagnosis you do not know what is going to happen. When we first went the paediatrician gave me the diagnosis. I picked myself up off the floor and then I came to realise that I needed to understand what we were facing — my husband is here as well. From personal experience we half knew that Simon had ASD but we did not know the extent of the process or what we needed to go through and we did not understand what complications it was going to cause. Up to that point our only experience with ASD was *Rain Man*, the movie.

The first paediatrician we went to simply dropped the bombshell and sent us to another paediatrician for assessment. We were given no information about ASD or about the process and no reassurance of the process. There was no contact information to provide services to help us to organise Simon. Most parents are left in the dark when they come to terms with the diagnosis. Usually the next stop is the internet to find out what you need to do for your child. Unfortunately if you do research over the internet, you are most likely to be bombarded with misleading information or wrong information about services that are available overseas and that are not available in Australia. Most books I found on ASD provide information about services in the US and the UK, which are very different to the services in Australia. Some services differ from state to state, which makes it even more difficult. So if you get onto a New South Wales site or a Western Australia site, the services they provide and the number of hours they provide is completely different.

I was fortunate in that I got in contact with Amaze — a fantastic organisation — which were able to explain to me the process and what I needed to do. They actually took the time on the night I rang at 5 o'clock. The CEO was on the phone to me, talking me through it. He also had a counsellor on the phone that night to talk to me about it because we did not know what we were dealing with. I must admit that the first job was to find a new paediatrician who was more helpful and understanding, which I have found. He is a great guy.

It would be useful if there were some form of brochure that you handed to parents to take away to relieve some of these fears, not just explaining what ASD is but the process you go through and who to contact. It could contain referral points so parents could go to the internet and find the right information. If copies could be held with maternal health nurses or at doctors' surgeries and kindergartens that might prompt parents if they notice the symptoms. They could read the brochure and say, 'I must talk about my child'. It would help diagnosis early. One of the best things they could have in the brochure is a statement that says, 'Parents, you have done nothing to cause your child's ASD. Nothing you have done can cause it'. I know that is something that Darren and I found out with Simon and it would have been a big help to get us on the journey.

Another area is that remarkably there are no services for siblings of children with ASD. These siblings are left to their own devices or are required to help with the child with ASD. It is a balancing act for parents to make sure that both children feel special. We are very fortunate that we have a very caring daughter who is very protective of her little brother and very understanding. From an early age she realised that something was different with Simon. She realised and accepted that she is his best friend and, at times, his only friend. Our daughter has dealt with her brother's ASD by finding friends at school, and those friends have joined together and talk about the ASD. Unfortunately, with funding, Amaze's support services for siblings do not start until age 12. They have a camp at age 12, which is fantastic. But most kids by age 12 have come to terms with their sibling and do not need that much support.

Another big area of concern, and my major point, is that there are no facilities for children with high-functioning ASD or autism. Unfortunately parents have to put them into a special school. They are great, by the way. They are great for their social disability, but it means that their intellectual prowess is compromised because they are stuck with kids that have intellectual disabilities as well. While the environment is important to improve the social skills, unfortunately it means that the academic development of high-functioning children is compromised. Rather than reaching their full potential as future leaders and thinkers they settle for achievements that are less than what they could achieve. An alternative for these children is to be placed in mainstream education with part-time aides — not full-time aides, part-time aides. This results in bullying and them being made to feel out of place.

The social environment does not get easier as these children grow. It becomes more complicated as hormones and puberty result in scenarios which are puzzling to these kids. With the unevenness of development children with ASD, such as in the case of Simon, could be aged 10 but instead act like a child of 5 or 6. This may make children with ASD regress, meaning that the effects of ASD can be more pronounced.

Parents with children with ASD find it an impossible decision. There is no alternative which can be offered to provide a supportive social environment while allowing these children to academically reach their full potential. Believe me, with Simon growing older this scenario has kept my husband and I awake at night. We see our older child being given opportunities and academic extensions that are fantastic. Yet we are unhappy and frustrated that Simon does not get these opportunities. We have looked into the private education sector, which would be able to provide the environment for Simon, but due to the fact that funding is not available in the same amount for private schools as it is for public schools the cost would exceed the school fees, and that is of no benefit to the school.

It is frustrating for parents of children with ASD as we are forced, through no fault of our own, to choose between two options for our children, which do not meet their needs. When you have a child with ASD you are their voice — you are their advocate. I can understand current financial restraints on everyone. I am an auditor and an accountant by profession, so I understand that government's need to be prudent in their funding choices. However, is it not time that we as a community establish schools for high-functioning ASD kids? These kids are our future thinkers. Remember that Albert Einstein, Bill Gates and George Washington were and are on the spectrum. Look at what they have achieved. What could our kids with high-functioning ASD achieve if they were given a special environment where they could meet their potential and feel safe and secure. Thank you for your time and I hope this helps in your decision-making.

The CHAIR — Thank you very much, Susan. Thank you for sharing with us the journey you and your partner have been on with Simon.

Ms PEARCE — That is all right.

The CHAIR — You talked a lot about Simon and about what is available to him and what is not available to him. I guess the question I really want to ask is: what support is available to you as a parent of a child with ASD?

Ms PEARCE — There are support groups around, but because we live not close to the CBD — we are out at Rowville — there are not a lot of support groups around there. We have found through family and friends that we have got our supports. You know the old saying that you know who your friends are? Oh boy, you know who your friends are when you have a child with ASD, because they are the ones who support you, and your family is so very important — they support you. We are lucky. We now have both sets of parents in Victoria, and they are a great help.

The CHAIR — If you did feel that you needed some support as a parent, you and your husband, what would you like to see?

Ms PEARCE — Just a group where kids can play together and parents can talk in an environment that is not structured — like, have a barbecue and just sit around and talk: 'Oh, my kid has this'. The playgroups were the best thing with Simon. Because I had the one child who was different, I found that my playgroups were there to keep me sane, because when I walked in having 2 hours' sleep, late — usually an hour late for playgroup — I had had an argument probably with my husband, or had an argument with my other daughter, I could walk in there, I could dump everything, and I knew that I was in an environment where I felt they understood, they knew. I always felt better when I left.

The CHAIR — You mentioned your daughter and that there is no support for siblings of children with ASD.

Ms PEARCE — Yes.

The CHAIR — If you had to suggest something that would be made available to siblings, what do you think that would be?

Ms PEARCE — Something that was just once a month, where the kids could go and say, 'Oh, my brother did this', or, 'My brother's being annoying with this' — where they could just go, relax and talk to other siblings in an environment where they are not under pressure, they can just sit around, whether they are playing Wii games or they are playing Minecraft or playing Lego, where they can just sit and talk to other kids and it is not — —

The CHAIR — So like a peer support group, but for siblings of children with ASD?

Ms PEARCE — Yes, like a peer support group. I think that is important, especially when the kids are growing up. Twelve is a great age, but my daughter knew that there was something different with my son at age six, seven, eight — and we could not get her anything to help her. We were in an area where there were not a lot of kids with ASD, so she was sort of the odd child out. So something like that would have been fantastic.

The CHAIR — Thank you. Over to you, Cindy.

Ms PEARCE — I brought along his homework that he does, just so you can see the difference in the ages. That is his maths homework, and that is his writing. As you can see, kids with ASD have a lot of fine motor skill problems, so their handwriting is usually shocking and a lot of time concentrating is a problem. So he will write — and on the next page he has got his writing. That is his maths.

The CHAIR — He has got all the answers right.

Ms PEARCE — Yes, it takes a while. I drew the pictures, ignore those, but the writing is his handwriting. Now he is 10, and his handwriting is probably of a five or six-year-old. So it is not that these kids do not know the stories; they know what to write, but they just cannot get it out.

The CHAIR — Thank you for sharing that.

Ms McLEISH — Thank you, Susan. I actually really enjoyed reading your submission because it was laid out into sections, with the 'Primary school' and 'Assistance' and 'Current issues' — —

Ms PEARCE — Like subheadings.

The CHAIR — Like subheadings.

Ms PEARCE — Yes. I am an accountant.

Ms McLEISH — I found that really useful. I want to just focus on one of the additional assistance areas that you have mentioned, speech therapy. A lot of people have talked generally about speech therapy, but can you tell me, drill down — —

Ms PEARCE — What it is?

Ms McLEISH — How it helped you?

Ms PEARCE — Okay.

Ms McLEISH — How you got to it, because I hear there is a lot of shortage, difficulty getting it, and then how it helped?

Ms PEARCE — We were lucky. When he was first diagnosed we did not have the early intervention that they have for the younger kids, where you go to, say, Iloura. I could not get in to any of that. So basically, they had on the council website speech therapists and OTs. It might have been on Amaze's website. I went through the list until I found somebody who had a free opening. So I grabbed them, and we have stuck with her. She has been brilliant. She can get Simon to verbally explain things. Like, he will go and write a story with her, or he will verbally tell her what he has been doing. These kids do not sit there — like, you cannot have a conversation with Simon. You get dribs and drabs of information, what he wants to tell you, but you cannot say to Simon, 'What did you do at school today?'. You will get one-word answers.

Ms McLEISH — My 18-year-old gives me those answers too.

Ms PEARCE — My 13-year-old does the same thing.

The CHAIR — My 24-year-old does.

Ms PEARCE — They usually grunt at you, and I can understand, as teenagers. But saying to Simon, 'Do you feel sick?', you will not get an explanation. For Simon, to find out if he had an earache, we would not find out until he was running a temperature of 38, 39 degrees and was really sick, because he would not tell us. He did not have the verbal skills to tell us. So speech therapy helps him to verbalise as well as write what he wants to tell us. It has helped us, so that we can now have communication with him.

Ms McLEISH — Do you pay for that yourself?

Ms PEARCE — Yes. Between the speech therapy and the OT, we pay privately about $200 a fortnight, and that comes out of our pocket.

Mr FINN — Susan, how much early intervention did Simon have?

Ms PEARCE — His three-year-old kinder teacher was the first one to pick up on that he had autism. She could see the differences. She picked up on it, and they got in touch with the council, and the council came and sat us down and said, 'Look, we think you need to' — basically he did not have a lot of early intervention. The kindergarten paid for an aide for him, and the aide was there specifically for Simon. The council paid for an aide for him for four-year-old kinder, but he did not have the extensive early intervention that you can have. He basically went to a mainstream kindergarten for three and four, and had privately speech and OT once a week — now it is once a fortnight. That is all we had. We could not get in to programs, and when you have got a child at three and a half and you cannot get into the program until he is nearly going to school, it is pointless.

Mr FINN — Yes.

Ms PEARCE — It is past. It means that you have to then spend the time teaching them to read, doing the maths homework. I know these are things you do with a normal kid, but you have got to be there, hands-on, doing those types of things more intensely and trying to sit on them to make them actually do it, because they do not want to sit down.

Mr FINN — I know. You mentioned earlier that specific schools for high-functioning children would be a good idea. Now there is debate, as you know, amongst the community as to what the best way of going about this is. We heard in fact earlier today from Amaze that their view was that it would be best if we get as many kids into mainstream schooling as possible. What is your take on all that, because I am a bit caught between the different sides at the moment?

Ms PEARCE — The problem is with mainstream schools, we understand, you have got 30 kids to a class; special schools have got 8 to 9. Putting them through the mainstream, yes it would be lovely and great — if you have got the aides, if you have got the funding, if you have got the teachers that understand ASD. Like the previous gentleman said, if they do not understand autism and the spectrum, it is pointless. We sat down when Simon first was at school age — the school principal pulled us in with the two kinder teachers, and they said to us, ‘We are not equipped to be able to look after Simon. We suggest you go to a special school’. So we went searching for special schools. That was the decision. This is our local primary school, where I was school council president at the time, so it was not like we were not contributing to the school. Our daughter went there.

It is great to send them to a mainstream school, but then you have got to realise that kids are cruel — they can be bullied, they can be picked on, especially in high school. They are already going through puberty and hormones, why stick them with ASD as well? You are tying two hands behind the kid’s back. I do not agree that you put them into a mainstream school and hope that they can survive, because they are not going to get the help they need. Even if it is a class in a school that specialises in ASD, high functioning, or a class in a special school that has that for these kids, it would be far better than what you are dealing with at the moment, because you are dealing with — —

Special schools, while they are fantastic, they are great — I highly recommend Simon’s school Emerson, and academically we know he is smart, but they are having trouble getting through to him, let alone sticking him into a mainstream school and hoping to hell that the teacher, with 29 other kids, can get through to him. This is the problem. These kids are smart. They are bright.

Mr FINN — Could that be helped by the raising of expectations in autism-specific schools?

Ms PEARCE — No, because your special schools have everything from kids with intellectual disabilities to physical disabilities. You have got the whole spectrum. They are a dumping ground for kids that do not fit into the mainstream parameters. They stick all these kids into special schools and all the teachers have got to cope with all these varying different things.

Mr FINN — If there were more autism-specific schools and expectations were raised in those schools — I think we have got about four or five around Melbourne at the moment — —

Ms PEARCE — There are two in our area.

Mr FINN — Two, okay. If expectations of a child’s ability and what they are capable of were raised in autism-specific schools, could that be a part of the answer?

Ms PEARCE — It could be part of the answer but most autistic schools do not do the VCE. These kids are put into VCAL. These could be our Bill Gates, our Albert Einsteins — and we are putting them into VCAL because we do not think they can cope with the VCE. It is frustrating as a parent because you can see it.

Mr FINN — Is that the lower expectation problem?

Ms PEARCE — Yes. It is like they are looking for the lowest common denominator and that is what they have to do. But that is the problem: these kids do not fit in anywhere and as a parent it is very frustrating.

Mr FINN — Yes. Susan, thank you.

Ms COUZENS — Thanks, Susan. Do you have a view on whether the NDIS is going to be beneficial in your circumstances?

Ms PEARCE — I do not know. It is very hard to find out whether Simon is even on the register for the NDIS or to what extent it is going to cover: whether it is going to go to the school to cover his funding at school, whether it will cover private. It is still up in the air. We do not know.

Ms COUZENS — It generally goes to the individual.

Ms PEARCE — Well, that is fantastic but the problem is that Simon, apart from speech and OT, does private swimming lessons. They are $400 a term, to have one-on-one swimming lessons. It is going to get to a point of where you go: do you pay for the private or do you pay for the public? Do you give it to the school or do you not? It is going to be a difficult situation. I do not know whether the NDIS is going to be the bees knees, I am holding my opinion until I actually get involved in it. Our area, which is Knox, does not get it until 2017.

Ms COUZENS — So that is next year.

Ms PEARCE — Next year. We are all waiting with bated breath to find out what is going to happen.

Ms COUZENS — So have you had consultations or something in the area?

Ms PEARCE — I do not know if there are consultations; I have not seen anything. But because we are so far down the track as 2017 we are waiting to see it all. I have got hopes that it might ease it. We do not expect the government to pay for our child; do not get me wrong. We both work, we are both in professions, we are willing to pay for our child, but just having a little bit of help would be nice because at times it can be costly.

Ms COUZENS — Yes, definitely. Thank you.

The CHAIR — Thank you very much, Susan, for presenting to us this afternoon and all the best for the future.

Ms PEARCE — Thank you very much for your time.

Witness withdrew.