TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Melbourne — 10 October 2016

Members

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Witness

Ms Susan Rees.

The CHAIR — I would like to welcome Ms Susan Rees to this private hearing. Thank you for attending today. 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, and 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. Please let the committee know if you would like your child's name redacted from the transcript. Think about it and tell us at the end. Thank you for your attendance today, Susan, and we might hand over to you for your presentation.

Ms REES — You are welcome. I feel very flattered that I have been asked to come today. You must have liked what I wrote in my submission. Before I start I just want to let you know to interrupt me if you have any questions that you want to ask me. I would like to ask you if you have teenage children.

The CHAIR — Yes, well, they have been and gone, really. I have brought up four of them.

Ms REES — Okay, most people have, and I guess — —

Mr FINN — Two teenagers and two almost teenagers — scary.

Ms REES — Yes, it is.

The CHAIR — Do not worry. You will survive it, Bernie.

Ms REES — Hopefully it will end one day, but not until they are in their late 20s apparently, not adolescence.

Mr FINN — So I am told.

Ms REES — It has been altered. Does anybody have an autistic child?

Mr FINN — Yes.

Ms REES — So you are aware of what it means to have a child — —

The CHAIR — And one of our committee members was a teacher of children with special needs.

Ms REES — Adolescence, I suppose, is an instinctive need for a developing adult to move away from their home base and look for a suitable partner to bear children with; hence the overwhelming desire to bond with their peers, seek out sexual partners and reject parents. It is also a time when we need to find out who we are as an individual, we form our own opinions, take risks — sometimes huge risks — and seek out adventure, all of which are extremely worrying for a parent, as those risks can sometimes be potentially life threatening. The reason I am talking about adolescence is because we can all identify with it. We have all been there and we know how difficult a time it can be.

Autism for my daughter is like being in a perpetual state of adolescence multiplied by 100 in intensity. She is completely self-absorbed. It is not that she does not care about you; she loves you when she wants something. She is an expert at manipulation and can butter you up quite well. She can be very polite and help around the house — that is, until you say no. That is when she gets really angry and that is when we need to hide our wallets at bedtime, and this happens every night. We have to put away our money because she just takes what she feels she wants.

It is not that she means to steal — she knows that it is wrong to steal — but what she wants just overrides everything else. She has racked up about $4000 on her credit card. It is not as if we do not give her what she wants. She wanted a ticket to a Taylor Swift concert that was on here recently. She wanted a VIP ticket, which was about $600. We said, 'No, but we'll buy you a ticket so you can go' — a general admission ticket, which I think was about $100. That was all okay, and then we discovered that one of our credit cards was missing. We discovered that she had spent about $1000 on this VIP ticket that she got through the internet. It was a late sale. We did not know how to punish her for that. We made her pay it back out of her pocket money. She is 20 now, my daughter.

She began as an adolescent when she was a toddler. She had no fear. If she went to the beach, she would walk into the water and go out as far as she possibly could without realising the depth. She would walk until her face was up to here. That was pretty scary — one way — because she could have gone under, so we had swimming lessons that we kept up for some time because of that.

She had no fear about being away from her carer for any length of time or any distance. I think toddlers usually do have that sense of fear if they are away a certain distance from their care. That was pretty scary going to shops and that sort of thing. I really should have had a leash, I guess, but I could not bring myself to do that to her. One time I was at Glen Huntly Road shopping strip, which was a bit scary because of the busy roads. She just disappeared out of a shop one day. That was it; she was gone. I rushed out to look for her and could not see her anywhere. I spoke to someone on the street who said, ‘I saw her down at the automatic teller trying to draw some money’, so I went in that direction and I passed the toyshop. As I passed the door she was coming out on one of those ride-on toys with the owner chasing her. That was a pretty scary time. I nearly called the police.

Ms McLEISH — How old was she then?

Ms REES — She was probably about four. Another time, around about the same age, she climbed up onto the roof. A fellow was quoting on our roof to have it replaced, and she climbed right up and got onto the roof. That was pretty scary. I tend to laugh about these things because it is in the past, it has been and gone, and nothing major happened with these things, and I think you have got to have a sense of humour to cope.

I guess with your neurotypical child the stage of adolescence will end at some point, you would hope — not with everybody, I suppose — but with my daughter I cannot see it ever ending. That self-absorbed attitude will never end. That is part of her makeup; it is part of who she is. She was a very happy child when she was little, and she still is a pretty happy person, but she gets obsessed with people. She is a sociable kind of autistic person who does not know boundaries and will just approach. She has no idea of other people and that they need space. She will go up and talk to anybody, and that is pretty scary too, that she does not have the skills that go along with socialising with people. We have tried to teach her, but she is pretty stubborn.

This developed into stalking. She was stalking a boy in primary school. She went to a special school, and she would not leave him alone. She would actually go out onto the football field. He would be out kicking a football, and she would be out there standing right next to him, wanting his attention the whole time. The school resolved it; the school were really good. I think I mentioned in my initial submission that the school was Ashwood School, and it is a really brilliant school. Of course special schools teach independence skills. She has had a lot of instruction on that, but still will not cook. I do not know how much training she has had in cooking, but still it does not translate to home at all. So that was one boy in primary school, and another boy in secondary school.

When she was younger she would not sleep. She would be up for an hour every night, and she did not sleep through the night until she was six years old. That was pretty trying. I was sleep deprived, and it prevented me from doing things that I wanted to do and from working in my chosen profession, which is drafting. I have a degree in industrial design, and I have a diploma in building design as well, and I have never put those things to use.

My pregnancy was not planned. We had difficulty with having a child, so we went through a whole process with that. I will not go into that. So she was a surprise pregnancy. Prior to that I had accepted that we were not having children, and so I went back and did a degree, and then in my final semester I fell pregnant. So that did not quite work out as hoped. She was a beautiful baby. She was so calm, and she was just easy. That was the best time, when she was a little baby.

She is 20 now, as I said, but she had a psychotic episode last year and has now been diagnosed as schizophrenic, which is another thing we have to deal with. She has an intellectual disability as well as autism, and now she has schizophrenia as well, which meant, last year, during a psychotic episode — which was three months total — that I had to live with that and deal with that until she was on medication. It took us a while to find a psychiatrist who could deal with autistic people, who specialised in that field. So she was put on medication. Actually I wonder if she has been psychotic all her life, because all of a sudden, once the medication kicked in, she has become a lot more manageable — meaning not that she is manageable now, but better than she has been ever. So that was good.

Ms McLEISH — How long did it take for the medication to kick in?

Ms REES — Two weeks. But it took us a while to find a psychiatrist. I visited a number of psychologists and psychiatrists before I could find someone that she could relate to. I had to do that research myself.

So that was a pretty horrifying time, and I could not leave the house without her. She was back obsessed with this boy when she had been in primary school, who shifted to Bendigo. She would pack her suitcase with picture frames and glasses and anything that she could grab hold of — her suitcase was full of just stuff you would not need on a journey — and she would be heading out the door to catch a train to Bendigo. That was a pretty harrowing time. The psychiatrist said she should have been committed at that stage, but there was no way I could let her be committed into a place with drug addicts and highly aggressive people. That environment would not have made things any better for her.

My working life has been non-existent pretty much, because of all the things that we have had to deal. Just recently we had a holiday, my husband and I. We had to have carers come in. My daughter does not really cope well with staying in other people's houses, so we needed to have carers come in and stay overnight with her; otherwise, as she does not have siblings, she would have been on her own, and there was no way we could have left her on her own for two weeks while we went and had some respite. We magically got a case manager, which I have never had before, and it was just heaven having this woman help us out and access buckets of funding that are allocated in all sorts of areas that the average person just would not know how to access or where to go or who to ask. A case manager knows all this. In the past we never qualified for a case manager because our daughter's condition was not serious enough.

Ms McLEISH — Where did the case manager come from?

Ms REES — MOIRA, southern region.

Ms McLEISH — Was that through the NDIS or human services?

Ms REES — No, the NDIS does not kick in until 2017 for us, mid-2017, so we have got to wait for that. But at the moment we get a carer from the council, subsidised. We still have to pay $3 or $4 an hour, which is not a lot of money. We have had her since our daughter was about three. We have had that once a month, 6 hours a month, and we also had an interchange family that MOIRA arranged when our daughter was little, and that has been fantastic, but that finished when she turned 18. The family is still interested in looking after our daughter, but she is not interested in going there.

That is another thing. Socially it is really difficult finding social situations for her, because she does not want to be identified as being disabled; she desperately wants to be normal, and of course that will never happen. Her school friends — she has some lovely school friends — have made the effort to keep in touch with her, but she does not want to have anything to do with them because they have a disability, which is really sad. I can encourage her and coax her and take her along to events, but for her, she has to want to go, and that is where you just cannot do anything more about it, as a guilty parent.

The CHAIR — Susan, I am just mindful of time. Do you mind if the committee starts asking a few questions?

Ms REES — That is fine.

The CHAIR — We have got your submission, which was very informative, and thank you for that. I had a question. We have heard a lot this morning about ABA therapies. Your daughter was diagnosed at two and a half?

Ms REES — Yes.

The CHAIR — And you chose not to have ABA therapy. I am just curious as to why you chose that and if you did actually access any other early intervention services.

Ms REES — Yes. We did access other early intervention services — the Bayside SDS was one. We looked at ABA, and it was recommended at the time by Autism Australia. They are called Amaze now; they were a different name then. But we did not feel that was suitable for our daughter. To get her to do something that she did not want to do was not an option. Plus it was super expensive. You had to pay out of your own pocket for that, an hourly rate for round-the-clock educators to come into your home and do that privately. It did not gel with my style of parenting, with our style of parenting, I suppose too — making someone sit down and do tasks over and over and over again repeatedly until it was rote. It was learning by rote. I do not know, maybe in hindsight she would have benefited from that, but I do not know.

But she did well. I did scour the system for suitable early intervention places. She was at Port Phillip, which we were not entirely happy with because she used to have a tantrum every time we went to the front door, and the teacher would try to drag her in, which was not an appropriate way to deal with her. You had to coax her in. You had to give her a reason to want to go in. Patience — I had to have a boatload of patience with her.

And with Bayside SDS, they were brilliant, the teacher there — and a lot relied on the teacher, the actual teacher who was dealing with her. They had to have some sort of understanding of her and of autism, which is not an easy thing to understand. I do not know if you have had any education on the subject, have you?

Mr FINN — No.

Ms REES — We did. That study that we had was brilliant too. That was something I found, Monash Uni, that was invaluable — absolutely invaluable. It was a study on parents. I wrote about it. I do not know if you remember reading about it. It was Bruce Tonge and Avril Brereton, who have presented here I think already.

The CHAIR — No. They are going to.

Ms REES — I thought I read a transcript. No? I think they are due to. Maybe I am wrong, but they developed that study back then with Nicole Rinehart. It was at the time supposed to be made into something that would be available to all parents of autistic children. I did get in touch with Nicole Rinehart about it, but apparently it has not happened and it is now a book that is accessible.

Ms McLEISH — I just wanted to ask a little bit about the intellectual disability, because when you were at Amaze — or, when you went through, Autism Victoria — did they understand that there was that comorbidity of the intellectual disability at the same time?

Ms REES — At the time Amaze were not helpful at all. They were just steering me towards ABA and that was it. That was really the only option that they gave me at the time. I believe they have improved a lot since then, but no, at the time that was all that was available.

Ms McLEISH — What is the nature of the intellectual disability? How does it manifest?

Ms REES — I am not sure. What do you mean?

Ms McLEISH — What does it look like? I mean, if somebody was meeting your daughter or talking to her, would they know that she has an intellectual — —

Ms REES — Probably. I guess it transfers to skills like maths, English, written English. She is pretty good at written words. Her writing is terrible. Maths is really difficult. She does not understand divide or multiply. That is her understanding of maths: plus and minus are about all she can get. You need that for money skills. With money skills she is not too bad.

Ms McLEISH — I was interested that you said that she had a lack of fear, because somebody earlier had said their child was frightened and anxious, and you have got the opposite here.

Ms REES — Yes, it is. And I think, too, with girls they are more sociable. Girls with autism often slip through the cracks because they are naturally more sociable than boys.

The CHAIR — And good mimickers.

Ms REES — Yes, and that has a hell of a lot to do too with her. She will repeat phrases that she really does not know the meaning of but somehow she will repeat them in context, and her understanding of language is not nearly as good as her spoken word. It is difficult to communicate.

Ms McLEISH — Have you hooked in with any of the groups that deal with the girls and autism specifically?

Ms REES — Yes. There was a psychologist called Danuta, and I am not sure of her last name. I could find out for you if you like. I was in touch with her; this was when we were looking for a therapist. She deals specifically with girls and in girls groups, and I was really interested to get my daughter to go along there, because she deals with girls mainly with Asperger's. My daughter was in an Asperger's group. It was called Connecting Teens, so it did not have the word disability or autism in the title and she did not know until she left that the other kids there did have Asperger's. That was great. She loved that group, but that again stopped when she turned 18. It was formed actually by a woman whose son had Asperger's.

Ms McLEISH — So she has only recently — —

Ms REES — Yes, and I suspect that this psychotic episode was caused by the changing environment. She has stopped going to school. She had been used to going to school since she was five, the same school.

Ms KEALY — Thank you very much for your time today. Apologies for being late to the hearing. I have just arrived from the country. I just wanted to ask you some questions about the supports that have been provided to you. You mentioned that case management had only recently been provided to you, and you have spoken about some of your journey and the surprise that it was to become pregnant, and I imagine once your daughter's diagnosis was given to you that would be challenging as well. Were there supports offered to you through any time on your journey up to today, or did you seek out any supports, and what would you prefer to have found and what would you like to have seen to make it easier for you?

Ms REES — Nothing has ever been offered, nothing. It has been up to me to find it. Alfred CAMHS was our first point of contact. They made the diagnosis. They referred us to the department of human services. The department gave us a list of services to access. We were on their books for three months, and then I was sent a letter to say, 'Sorry. You don't need us anymore, so bye-bye'. That has been pretty much all of it.

I now no longer have a case manager. Just last week I was told that we had used up all our funding and we have to reapply again in six months time for a case manager. That was just devastating for me, because it felt so good to have someone there, and now it has been withdrawn. The same thing happened in kindergarten. My daughter had an aide, which I had to fight for as well, in four-year-old kindergarten. It was a brilliant kindergarten. The teacher was fantastic; she really made my daughter feel welcome, and the aide was withdrawn at the final term because my daughter was doing so well. So I battled to have her back again, because what if my daughter were to deteriorate in the final term? She only had a year there — one year. It did not seem a lot to ask for her to be given the full year of an aide.

Actually I will have to read you out a statement that the case manager made. She is the case manager that I do not have any more, but I would really like to get her again, and I have no guarantee as to whether she will be our case manager again. You just strike up a rapport too with the best people, I think. She works at MOIRA. She read my submission. She said:

> Thanks Sue it was a really interesting read and I really appreciate the struggle you have had in trying to obtain supports for [your daughter]. Sometimes when you are sitting on the other side of the desk you sometimes forget the real lives that people are living, not that I have any excuses for the disability system that is constantly letting individuals and families down but I like to think that maybe we have progressed just a little over the years. I keep a positive spin on what is a bad situation all round for families, but if I don't I will forget why I do this job. I hope that through this process it can allow you to be heard and understood, allowing you to speak your experience on a level that could potentially have a huge impact. The need for improvement is immense and hopefully you will be one tiny step closer to making change. Congrats on stepping up and telling your story!!!

She is pretty disappointed too with the system, and she works in that system. Does that answer?

Ms KEALY — Yes, it does. Thank you very, very much.

Mr FINN — Just a couple of questions. It has been described to me that when a child with autism turns 18 it is as if they fall off the end of the planet. Is that your experience too?

Ms REES — Pretty much, yes. I got a letter when my daughter turned 18 from the department of human services, because she has been on the disability pension since she was 16, which was also a battle. At first she was refused that, and we had to reapply. Eighteen is the magical age when everybody is supposed to be an adult, but that is not the case. She was expected to manage her own disability pension, and they were questioning me as her parent as to whether I should be managing her money, so to speak. That was the nature of the letter. So I had to prove that she needed supervision with that money. That money she would go and spend on a truckload of lollies.

Mr FINN — You have not had the phone call that we get every couple of years asking if he still has autism?

Ms REES — Really?

Mr FINN — Yes.

Ms REES — No, I have never had that one.

Mr FINN — We look forward to that one.

Ms REES — Where from?

Mr FINN — From the department. Social security, is it?

Ms REES — That is unbelievable.

Mr FINN — Yes, it is extraordinary.

Ms REES — That also highlights the need for education in society. Autism is a really difficult thing to understand. When you tell people of your experiences, they think, ‘Oh, yeah, my child does that’, but you have got to multiply the intensity and the frequency phase — hundreds. They do do the same things, but on a completely different level.

Ms COUZENS — Susan, you talk in your submission about your daughter attending the Transition to Work program. Have you found that effective? Do you think she will move on into employment from that program?

Ms REES — It is hard to say. She has been there a year and a half now on the Future Young Adults program. It is partially funded.

Ms COUZENS — Is that time limited?

Ms REES — Yes, it is. Three years is what she gets with that. She enjoys going there, which is the main thing. Again, she goes to Dandenong for that. She goes on public transport, which is good. At our local one at Oakleigh there were some bad experiences. I went there, and I was not happy at all with their attitude. They were not really interested in the kids. I do not know what it was, but a few of her classmates have been withdrawn from there because parents were not happy with it. She has had one work experience trial. They try and get them into companies. The coordinator there has a lot of trouble finding companies that are interested in taking on people with disability.

Ms COUZENS — So she was at Big W?

Ms REES — Yes. That really did not work out too well. She was there a few days. She was supposed to be putting price tags on items, and she was tearing them up and shoving them under a coat rack somewhere. She was really, really interested in the money and did not see the need to do anything for the money. It was not a completely happy experience, but it took the coordinator a long, long time to get my daughter in there, because the manager at Big W had had some really bad experiences with places that were training people with disabilities in the workplace. I think he had one person who lasted 2 hours; that was it and they left, which is not good.

Ms COUZENS — The staff who they are working with, so the people that were working around your daughter, did they have any training or support to work with her in that job at Big W?

Ms REES — This is the thing. This is what the coordinator did. He told me the other day that he went there with my daughter initially and was going to spend the morning with her and the staff member to try and get them to understand her and what they needed to do to communicate with her, but the person — the young girl who was there, the staff member — insisted that he leave and, 'Everything will be fine'.

They liked her. They really liked her and found her friendly and outgoing. She is a very likeable girl. He should have insisted. He should have set something up to help her. While she was there she was going to her lunchbreak and she saw a little girl wanting something on a high shelf. She stopped and helped her to do that. For her to delay her lunchbreak is quite something.

Ms COUZENS — Just on the mental health issues, have you found that much more challenging now that your daughter has a mental health issue as well as autism and intellectual disability?

Ms REES — To tell you the truth, the medication has made a massive difference.

Ms COUZENS — So you make sure she has that medication?

Ms REES — Oh, yes. She has to have that medication. The GP initially put her on antidepressants. That was not the issue. She is still winding down. She started off on a high dose of the antidepressant and the antipsychotic medication and gradually over the last 12 months or so has been reducing it. She relies on me to tell her how to live. Initially she was really tired — tired all the time, falling asleep at The Bridge and falling asleep in the car if I took her in, but that has improved a lot. She is a lot better now. She has not had a second episode yet. If we took her off the medication, she may. I have got to rely on the psychiatrist.

The CHAIR — Thank you very much, Susan. Much appreciated. Thank you for your time today, and I also thank you for your submission. All the best to you and your daughter. You need to advise the committee if you want your daughter's name redacted from your submission.

Ms REES — I think I will, just for her.

The CHAIR — Okay. That is fine.

Ms REES — Because that will be on the website and it will be posted everywhere. I would not want her to read that.

The CHAIR — Thanks very much, Susan.

Ms REES — Thank you. Thank you for listening.

Witness withdrew.