

TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Melbourne — 12 September 2016

Members

Ms Maree Edwards — Chair

Ms Cindy McLeish — Deputy Chair

Ms Chris Couzens

Mr Paul Edbrooke

Mr Bernie Finn

Ms Emma Kealy

Staff

Executive officer: Dr Greg Gardiner

Witnesses

Ms Cathy Talia-Parker, and

Mr Liam Parker.

The CHAIR — Can I welcome this morning Ms Cathy Talia-Parker and Mr Liam Parker. Thank you for attending our public hearing this morning. 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 and will be able to make factual or grammatical corrections if necessary. Can I thank you for your submission, which is no. 38, which I thoroughly enjoyed reading.

Ms TALIA-PARKER — Thank you.

The CHAIR — It was very interesting. I invite you to make a presentation of around 15 minutes, or less if you want, to our committee. Can I just quickly say Mr Finn is an apology for a short while. He has another engagement.

Ms TALIA-PARKER — I am not sure where to start, to be honest. I have a young man, who is 13 going onto 14, and he was diagnosed with autism at the age of approximately three and a half years old. There were no signs — no stand-out signs or features — that I was able to pick up on — neither my husband nor I — prior to that that our son had autism, which is a tricky one because with some children there are some stand-out features and signs, but with our son there was not.

However, once he did get to the age of three he was not picking up language as well as what Liam was, and that was noticeable. He was a little daydreamy, and we just thought that was part of our son at that time. However, as time went on, we soon realised that he was not focusing on his environment or in touch with his environment as a normal toddler should be, even though at that time we still were not thinking anything like autism. I had a little bit of the background on autism because of my teaching experience, but it was very little.

It really was not until we visited a GP about a cold that the GP noticed a couple of things about our son, and he wanted us to visit a paediatrician. So we did. That led us onto another paediatrician, and she later diagnosed our son with autism after some initial testing and discussions. Yes, it was at about that age that our son was diagnosed with autism. They call it ‘classic autism’. There are different things that go with autism, but that is how it was labelled then. Our son’s language became much more reduced; words that he had picked up, he dropped. He had started to drop eye contact, and apparently we were told that with many of our children that does not become noticeable until three years and onwards. They can appear to be quite normal prior to that unless there are really significant things that we notice about the children, yes.

Our son now goes to a lovely special school. We did try a mainstream school. We did mainstream kindergarten and that was a success; however, we did have a lot of support from our ABA therapist, which I should talk about firstly, shouldn’t I? Once the diagnosis was made, it was really very, very tricky to know which path to take. We were directed to go into an early intervention program, then known as Elwyn Morey, at Clayton Monash, which I believe no longer may exist. It was a good program in terms of liaising with different parents and their own children and children that were similar to our son going through the same thing.

We received a little bit of information about what we call ABA therapy, applied behaviour analysis. It was very little at that time, so we were quite confused and did not have much direction in terms of what we were to expect in the coming years, how we were to help our son — we really had no idea how we were to help our son — and what directions to take. It was really because my husband was quite proactive at that time and the internet had become much more useful and it was at our doorstep that we researched ABA, and we found that there was a lot of data and evidence to say that children with autism who participated in an ABA program were likely to have some success and maybe a great deal of success, and that was the path we decided to go down.

Autism Victoria put us onto another organisation that we are still affiliated with, ABIA, and it was that organisation that provided us with information in terms of ABA service providers, who we could call on and get some more information from. That led us to an organisation called ISADD. After speaking with a few different organisations we felt that that suited us, and we took on therapy for many, many years. That was a very difficult time because ABA therapy is very expensive. There is no funding for ABA therapy, nothing whatsoever. There is a little bit of funding that now exists, I think it is where you get two lots of increments and you can put that towards an ABA program. That does exist now; two lots of \$600.

The CHAIR — That is with the Department of Health And Human Services?

Ms TALIA-PARKER — Yes, I think so.

The CHAIR — I know what you mean.

Ms TALIA-PARKER — Yes, I cannot quite remember. It was so long ago, and I know it does exist now too. That was the only funding — many, many years later — that we could actually access for our program, and that was quite hard because my husband was working very long hours. I could not really go back to work because I had Liam, who was also quite young, and I had to be around to be part of this — to set up the program and be part of the program. It is a one-to-one program where therapists and psychologists come home to work with our children. It is very intensive. It was only because of an outside source, something like family, that we were able to fund our program really. We could not have done it any other way.

For me that is very difficult to still think about, because I know that there are a lot of families that would like to be able to access that therapy and still cannot afford to do so, and it is the one therapy that we do have data for. We know that it does work. That is very sad for those families, especially some families I have come across who have more than one child in their own family that has been diagnosed with autism; they are on the spectrum. Even now, I have recently spoken to people that are doing the program and who struggle with the amount of hours they can take on and how they can pay people.

The program for us was a success, really. It gave our son many different skills. We were able to work on such little things, including noticing his environment and being able to point. Up until that point he did not know how to even point. Being able to listen and look at the same time is a big challenge for our children with autism, so there is a lot that goes into that program that starts that off for these children. Socially we were able to work on social interaction, and we were able to work on behaviours that we wanted to reduce — stims, which are stimulatory behaviours — and we were able to give him communication, starting with picture-word exchange and then leading even to some computer apps that had recently come out that our children can access. It did lead to our son speaking, even though he still struggles with that. But the main thing is that he knows how to communicate if he cannot get his words out. A lot of children his age have not been able to get to that point, unfortunately. So we are very happy with the way that went.

Unfortunately mainstream school was very difficult. We had a good year in prep, but then there was a decline halfway through grade 1, and that probably had to do with a lot of factors. We perhaps did not choose the right school there. Also there were much bigger grade sizes. There were 28 children in that group — a lot for inexperienced teachers to deal with who did not really have any background on autism or on what it would be like to teach a child with autism or even have them participate within the classroom.

After quite a stressful year we got towards the end of that year and decided that we would look at special education, even though we were very reluctant to do that because we wanted our son to participate in mainstream. However, after we did go to special education, we found Katandra School in Ormond that would fit our son's needs. After some assessing, he was able to enter that school before the school year ended and become settled and ready to start the following year. They were smaller groups. Teachers that were special-education trained were able to understand our son and his needs a little better. It turned out that he wanted to go to that school, so we were very happy about that.

That is a higher functioning school, and as our son got older, because his verbal language had not increased — they are a more academic school — we had to look at what was going to happen to our son afterwards. That school would go until the age of 12, similar to a grade 6. The following year our son was going to be in a grade 5/6 class, and he was not really coping academically. His needs were not being met, so we then had to think about which school we were going to look at for our son. We also wanted to look at schooling that would enable him to stay on in a secondary situation, at least until the age of 18. That was a very tricky one. There were not a lot of special education schools that we were able to choose from within our area. Also visiting a lot of these schools does not necessarily lead you to believe that your child is going to fit into that school.

So we ended up choosing a school that was out of our zone, and we were happy with that — Bayside Special — and our son has been very happy there. However, because of that, we were not able to access buses. They have an amazing bus access that is funded by the department of education, but because we were out of the zone, even after trying to access that in different ways — writing and speaking and all sorts of things — we were not able

to access that. So trying to go back to my teaching job became very difficult, even though our son was very settled at that school. There are no before-school programs or after-school programs that we as parents can access at these schools. There was not at Katandra and there is not at Bayside, for different reasons, so legally we are only allowed to get our children there. We cannot get them there before 8.45, and mornings are not such a big deal, but then there are early finishes. We need to be there by quarter to 3, 10 to 3, to pick them up, so trying to go back to some full-time teaching for me proved to be very difficult in terms of being able to do a quarter to 9 start at a school or, as I would have done, an 8.30 start.

The CHAIR — Cathy, could I just remind you that we only have half an hour, and we want to hear your comments and everything, but if you could perhaps wind it up so we can ask some questions.

Ms TALIA-PARKER — Sorry. So that has been the tricky thing for a lot of parents. A lot of mums have found that they have needed to work out ways of being able to work or hold a job and keep their children happy in a school that they are happy with. I just want to say that with the choice of schools, even with children with higher functioning needs, their parents also find it quite difficult in terms of placing their older children in schools, because we just do not have the choices to be able to even put our children that are higher functioning into schools that are mainstream schools because of other factors. They would not be able to cope. I do not know what else at this point I can say.

The CHAIR — Thanks very much, Cathy. That is a very comprehensive presentation. How old is your son now?

Ms TALIA-PARKER — He is 13. He will be 14 in October. He is a young man now.

The CHAIR — And Liam — you are a little older?

Mr PARKER — Yes, by 18 months.

The CHAIR — And I notice you go to Xavier?

Mr PARKER — Yes.

The CHAIR — Does Xavier have any students with autism at the school?

Mr PARKER — I am not too sure. We definitely have students with special needs. There is actually a boy in my year, who — I am not really sure — may have autism. I have been with him since year 5, and he has always needed aides to help him in the classroom. Xavier is a very expensive school, and with the support he needs there, I can only imagine what the parents are paying for schooling.

The CHAIR — Thank you. I am curious to find out, if we get a chance, what it is like for you as a sibling of a brother with autism, and what that has meant for you, but I will get to that in a moment. I just wanted to ask a quick question. You mentioned the cost of the ABA. Would you be able to put a figure on that? I know obviously you have been using it for a number of years.

Ms TALIA-PARKER — Yes. Look, we — —

The CHAIR — Are you talking thousands?

Ms TALIA-PARKER — Oh, thousands.

The CHAIR — Thousands and thousands? Like \$20 000, \$30 000 — a ballpark figure?

Ms TALIA-PARKER — Yes, we were looking at \$20 000. It was like having a second mortgage.

The CHAIR — And is your son receiving ABA?

Ms TALIA-PARKER — No, our son does not receive ABA now. He does some speech. He keeps up his ABA because I also became ABA-trained, and the whole family became familiar, so we do, yes.

The CHAIR — You mentioned that it was extremely helpful as an intervention when he was first diagnosed.

Ms TALIA-PARKER — And extremely helpful as an early intervention; that is so crucial, which I did not say. ‘Helpful’ is not even the word for many of our children.

The CHAIR — You mentioned that your son was diagnosed when he was around three years of age. You would have been about four and a half at the time, Liam. Can you tell me as a family what would have been helpful to you after that diagnosis, because clearly from your submission and what you have told us today, you were pretty much left floundering, not knowing where to turn to and where to go for help? Can you perhaps tell the committee what supports would have been good at that time?

Ms TALIA-PARKER — I think we were missing that umbrella, like I think I mentioned, where we needed some steps and guidelines in terms of once our son was diagnosed. We needed to know more about autism and we needed to know about what things we could expect, because from that point on of course the child does decline more. That was the first thing. If you become part of a network, which I did, you can find out from other parents a little bit more about that, but there really was not anything coming from professionals.

From there, once we had that diagnosis, we really needed a person or an organisation that could say, ‘Well, if you would like, there is this that you can try with your son, and you can go down this path or you can go down this path, and it will lead to this or it may lead to that’. We really did not have that. I believe now there are organisations like that. One I heard of a while ago, where a mother with a daughter has put her own organisation into play. People go to her and she is able to access all the things that that family is needing and also do paperwork, make phone calls and find out about services around their environment. Yes, we really did not have any of that. We did not know what services there were, if there were any, and apart from Autism Victoria and ABIA, we really had nothing else to go on.

Ms McLEISH — I just want to follow up a little bit about the applied behavioural analysis. Who delivers that?

Ms TALIA-PARKER — First, a psychologist assesses the child through a private organisation. Once that assessment is made, she or he puts a program together that would suit the child and then that is delivered by sometimes the psychologist herself or himself. But we had what was called a senior therapist, a case manager that oversees the program, and then you employ therapists who have done the training to implement the program along with a case manager. The psychologist would visit perhaps four times throughout the year to reassess, to look at the program and to make changes et cetera, even though the case manager is doing that on a continual basis anyway.

Ms McLEISH — What is the training that the case managers undertake?

Ms TALIA-PARKER — The training that case managers undertake is, unlike me, where I have done a level 1 ABA training, they go on to do further levels of ABA training.

Ms McLEISH — Who delivers it? Where do they go to learn that?

Ms TALIA-PARKER — There are different organisations. ABIA deliver it. That is where I did mine. There are also some in the bayside area now that deliver that training for parents and for people that want to actually become therapists. The people that deliver it — for example, the person that delivered it when I went was a highly trained ABA therapist that had done it for years and had also worked in America, because they have been quite big on it for years and years.

Mr EDBROOKE — Thanks for coming in, Liam and Cathy. I just have a couple of questions. What kind of support did you receive after your son’s diagnosis and who from?

Ms TALIA-PARKER — My support group was really my ABA group, I have to say that, and the network that I made through Elwyn Morey where other children and mums were going through the same thing. Really, that support came through my ABA group and therapist, who were there almost every day and even weekends.

Mr EDBROOKE — Okay. I imagine it is a very testing time, but when you are choosing a school for a child with different abilities, just in your experience, what were you looking for and what helped you make the decision?

Ms TALIA-PARKER — I guess we were looking for a school that would accept children with challenges. All children have challenges, but obviously there were more in this case. We wanted a school where our therapist could attend the school, and this school was quite accepting of that. That is not always the case at all schools. Some schools do not like outsiders coming in. We really just wanted our son to be able to integrate with children of all kinds because at that stage it is very important. Our son went when he was six because we did an extra year of kindergarten. The role modelling becomes very important for our children because they start to learn to look at other children's behaviours, so mainstream children are most beneficial at that point, rather than going to a special education situation where you do not get much of that role modelling.

The CHAIR — Liam, just quickly if you want, can you tell us a little bit about what it is like having a brother with autism and perhaps some idea of what would have been supportive for you when you were younger or even now?

Mr PARKER — It is definitely a different environment, growing up with a brother who has autism. You know, in social situations like in a supermarket my brother always used to have a lot of temper tantrums, quite often knocking shelves over with food and stuff like that. I am not really the expert on these things, on my brother's sort of support. I am just there to look after him as his brother, but as far as I have noticed, his school and the ABA is really the only thing that has held him up, and of course us as his family as well. Look, I just grew up to deal with it myself. I accepted it and I love him. Autism or not, it does not make a difference to me. That is all I want to say.

Mr EDBROOKE — You must be very proud, Cathy.

Ms TALIA-PARKER — I am. He has been a great brother.

The CHAIR — Thank you so much, Liam. Thank you very much, Cathy.

Ms TALIA-PARKER — You are welcome. Thank you. Thanks very much.

Witnesses withdrew.