

# TRANSCRIPT

## FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

### **Inquiry into services for people with autism spectrum disorder**

Melbourne — 10 October 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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#### Witness

Dr Anna Middleton.

**The CHAIR** — Welcome to these public hearings, Dr Anna Middleton. Thank you for attending today. 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 be able to make factual or grammatical corrections if necessary. Thank you for your submission. It was very interesting reading. You are a parent of a child with autism, and I will hand over to you, Anna, to make a short presentation to the committee.

**Dr MIDDLETON** — Fantastic. Thanks very much for having me here today. I work as a general practitioner in Coolaroo, and I am the parent of two children.

I want to start by talking a little bit about my elder son, Toby, who is now five. He was diagnosed with autism spectrum disorder a few months before his third birthday. When he was first diagnosed he had a number of challenges. He would not follow instructions. He did not acknowledge any rules. He was nowhere near being toilet trained. He needed to be restrained at all times in public places, either in a pram or by being carried, because otherwise he would run off. As a result we spent a lot of our leisure time in fully fenced playgrounds, but even then I had to be constantly following close behind him in case he dashed in front of a swing in full flight or helped himself to another family's picnic lunch. Visits to friends' or relatives' houses were spent trying to redirect him often, as he tried to operate their blenders and coffee makers and other kitchen appliances, or trying to shoo him away from their garage doors, where he would hover, trying to peak in at their lawnmowers or whipper snippers.

At that age he had a very large vocabulary, but his language was not really used in a very functional way. He did not know how to ask for what he wanted. He could not answer most questions that he was asked, and he did not speak for the purpose of sharing with another person or enjoying conversation. He also never uttered a word to anyone else apart from me and my husband and sometimes to my mum, and he was completely disinterested in other children and sometimes even oblivious to their presence, and that included his little baby brother.

When he was diagnosed, despite that at the time I was a trainee general practitioner, I was quite confused about how to start going about getting help for him, and I had read a lot about how important it was to get to an early diagnosis and early intervention, but I did not really know what that was or where to find it. So I ended up looking at websites such as the Raising Children Network, which did have a list of what seemed to be thousands of different therapies, with the advice that not every therapy is right for every child. So we still felt quite lost with that. My husband and I took him to a few speech and occupational therapy sessions, which at the time were not helpful because my son was unable to interact with the therapist at all.

During the diagnosis period I had also read about ABA, and I had read about it mostly in online forums. You have already heard a lot about ABA this morning. Given that there was some evidence behind it, we decided to give it a try, so we contacted a behaviour analyst, who came to our house to do an assessment of our son. As soon as she started her assessment, probably within the first minute or few, I knew that ABA was the answer and was going to work for our family. In the 3 hours that she spent with my son he followed instructions, he listened, he played games, he did puzzles and he actually spoke with the therapist, and these were all things that up until that point I had no idea that he could do. For the first time I saw that my son had the ability and the intelligence to learn and with a bit of help would one day be able to sit and learn in a classroom with other children.

Fast-forward to today. It is now two and a half years later. Among numerous other things he has achieved those school-readiness skills and will be attending a mainstream primary school for prep next year. We are, however, planning to send an ABA therapist with him to school part time at probably an estimated cost of \$8000 per term. Although he now has the skills to learn effectively in a classroom environment he still has high levels of anxiety, and I worry that without the additional support of a behaviour therapist at school he might get too anxious and start refusing to go.

I would like to move on to discuss the financial side of things now. When we started ABA, like Sarah talked about this morning, we had money sitting in an account that we were saving to go towards our house deposit, and we made the decision to keep renting for the foreseeable future so that we could fund Toby's therapy with our money. Our local area is now under the NDIS. However, our family are yet to be put on the system for whatever reason, so I do not yet know what funding might be available for our family, but I am hopeful about it.

We as a family were very fortunate to be able to afford Toby's therapy and to have very generous family members who have helped us to cover the costs as well, but as ABA programs cost tens of thousands of dollars every year, for many families they are out of reach.

As I said earlier, I am currently working as a general practitioner in Coolaroo, and that is quite a disadvantaged area of Melbourne. I do see a number of families with children on the autism spectrum who have absolutely no hope of accessing any of this intensive early intervention. When these families come to me with questions, I do not really know what to recommend to these families, because I do not see that what is available is going to make that much of a difference to their child's life, so hopefully by the time the NDIS rolls out in that area there will be more options for these kids to access intensive early intervention.

I really feel that access to ABA therapy has made a significant difference to Toby's life. Given this and given the current available evidence I do think that ABA or similar types of intensive early behavioural intervention should be funded for all children with a diagnosis of ASD, both as early intervention and, as discussed earlier, support in a classroom environment. Ideally what I would like to see is an increase in centres similar to the current Autism Specific Early Learning and Care Centre in Bundoora, which also runs an intensive early intervention program for very young children. I would like to see an increase in these so that every child with an ASD diagnosis has access regardless of age. However, along with this I do think that we need to see more research in the area of intensive behavioural therapies and their outcomes, particularly in terms of emotional wellbeing and self-esteem of teenagers and adults who received these types of therapies as children.

Importantly I would also hope that the increased knowledge of that and access to intensive early intervention would lead to improvements in the regulation of the industry, in that therapy providers are monitored to ensure that their premises are safe, that the practices they use are transparent and that they always have the best interests of the child at the forefront. That is all I have to say. Thanks for your attention.

**The CHAIR** — Thank you very much, Anna. You mentioned your son's name. Did you want that printed?

**Dr MIDDLETON** — I do not mind. His name can go on it.

**The CHAIR** — That is okay. That is fine. Toby?

**Dr MIDDLETON** — That is right.

**The CHAIR** — You mentioned in your submission as one of your recommendations for funding that each child diagnosed with autism should receive 20 hours per week of early intensive behavioural intervention or similar until primary school, particularly the provision of this in a day care setting similar to the current ASELCC. There was another recommendation there around school-based ABA programs, which we have already heard about this morning. I guess the question I have is in relation to that 20 hours per week, which is internationally known as the minimum requirement. I think, as I mentioned to one of our other presenters this morning, that 20 hours is not necessarily all given by a therapist and it could actually be parent-based therapy. Yet of course many parents do not have the ability or the capacity, given that many parents of children with autism also have autism or other comorbidities. Do you think, instead of mandating it as 20 hours for everybody, that it could be a more individualised approach?

**Dr MIDDLETON** — Yes, I do think that it should be more individualised. I am not of the opinion that more hours is necessarily better. I think it should be taken as a case-by-case basis. More hours with a therapist might lead to more learning or a higher IQ, but at the same time I think you need to look at the wellbeing of the child. For a very young child, being exposed to 40 hours of therapy per week might not be in their best emotional interest.

I also agree that some of the therapy can be delivered by the parent. When we first started with Toby we did not do 20 hours. We did about 14 or 15 hours directly with a therapist, but my husband and I provided a lot of therapy outside of those hours. Actually I think a lot of the gains were because of that, because we were working it incidentally into our everyday life. So I think for capable families fewer hours might be sufficient with really good parent training, but for families who struggle to provide that themselves I think the 20 hours delivered by an external provider would be more appropriate.

**The CHAIR** — As a GP, obviously you mentioned that you struggle with determining whether to refer people to ABA or whether not to, because of the financial cost and a whole range of other reasons as well. I guess what I am asking is: what do you think is needed then for GPs and paediatricians to provide information and support to families who are presenting to you with a child who is on the spectrum?

**Dr MIDDLETON** — I think GPs probably do need more education about the different types of interventions available, where they can be accessed and the evidence towards them. In my general practice training — in the training program — I do not think I learnt anything about autism spectrum disorder. In medical school I probably had a 1-hour lecture on autism, and I worked in paediatrics as a junior doctor for six months. Again I did not really come across autism. So everything that I have learnt I had to learn by myself, and a lot of it came from my own experience with my own child, as opposed to coming from my training. But I do think that it would be not too difficult to introduce further training to current general practitioners. The Royal Australian College of General Practitioners do release regular publications and they have a lot of online learning resources. I think it would be quite straightforward and easy to put the information out there. It just has not been done.

**Ms McLEISH** — Thank you. I was very interested in the question that the chair just asked you as well. I want to just pursue that a little bit further. Are you thinking that the college needs to do more and medical schools need to do more around this and also with the paediatricians?

**Dr MIDDLETON** — Yes, I think probably more in terms of the GP college rather than medical school. In medical school there are so many areas and I think there is not that much time to learn that much more about it, but I definitely think that as general practitioners so much of our casework is with young children and we really do have that capacity to spot these sorts of things early, so it would be really helpful if the RACGP were more involved in training for general practitioners. Also in terms of paediatricians, I think that the word probably needs to get out more there as well. Because I am not involved with the college of paediatricians, I am not quite sure how to go about doing that, but I do think that more training or knowledge would be helpful.

**Ms McLEISH** — Do you have a feeling about maternal and child health centres, about the nurses there and their role?

**Dr MIDDLETON** — I think that they do a very good job. My maternal and child health nurse did pick up that my son had some red flags, but I think because I was a GP she did not say anything. But looking back there were things that she did say to me that tell me she knew there was something that was not quite right about my son back then. I think that they have a very important role. I do know that they do screening tests at certain ages, and I do know that now they are referring very young children on for assessments, for example, at the La Trobe centre for very early assessment. So I think they have got a very important role, and I think that overall they do a very good job.

**Ms McLEISH** — What is the best way to influence the colleges, whether it is the general practitioners or the paediatricians?

**Dr MIDDLETON** — I think probably the best and easiest way is just to contact them. I do not think we need to do anything special or fantastic to influence them, but just give them the information and make a proposal that this is what we could do.

**Ms McLEISH** — Is that about autism generally or ABA as well?

**Dr MIDDLETON** — About both of those.

**Ms McLEISH** — Who referred you to ABA?

**Dr MIDDLETON** — I found out about it myself. I just found out on an online forum and looked at some Facebook groups, and that was how I found out about it. Before that, I did not know anything about it. No-one referred me to it; it was just because I was looking for a way to help my son — and that is how I found out about it. At the time I do not think there was anything much about it on the Raising Children Network, but I have since looked again recently, and I see that one of the sort of foremost recommendations is the 20 hours a week that ABA therapy is recommended.

**Ms McLEISH** — You talked about the therapist and that you knew when your son met the therapist you could see things already — that there was a relationship. Did you lock into the right therapist?

**Dr MIDDLETON** — I do not think so, because we are actually not still with that therapist. We started doing a home-based program and then it all got very difficult, so we moved on to a centre-based program with a different provider. So we have had a few different therapists, and I saw the same skills with both of them. It is more about the training that they have received and the knowledge of how to implement ABA, as opposed to the individual therapist.

**Mr FINN** — Thank you, Anna. I noticed your second recommendation, and you make reference there to the program offered at Moomba Park primary. I have had a fair bit to do with Moomba Park primary over the last decade or so. As we know, we have had to go to war with the education department on a number of occasions just to get the program going. What is the attitude of the department toward the sorts of programs that Moomba Park is offering, and specifically that program at Moomba Park?

**Dr MIDDLETON** — I am not sure what their attitude is towards Moomba Park. All I know is that when I contacted them to see if we could get private therapists into a public school, there was a lot of toing and froing and emailing back and forth and it took me a long time to get a clear answer. In the end I did get an answer, saying, ‘Yes, you’re permitted to have a private therapist in the school, as long as the school is happy with it’. But I did not feel that they were very open to my suggestion.

**Mr FINN** — Did you feel that it is an inflexibility on the part of the department or perhaps just a lack of knowledge?

**Dr MIDDLETON** — I think it is probably a lack of knowledge, to be honest. I do not think they were trying to be particularly inflexible. I think, you know, my request was a bit difficult and a bit hard, so they kind of sloughed me off a little bit until eventually they had to give me an answer, yes or no. But I think if they had more knowledge it would be beneficial.

**Mr FINN** — Do you think an ABA program would be specifically beneficial in an autism-specific school, or do you think it could expand its wings to just about any school?

**Dr MIDDLETON** — I think it could be in any school. I think it would be good in autism-specific schools but also definitely in mainstream schools, and not just at the primary level; I think it would be useful at later levels as well.

**Mr EDBROOKE** — Thanks for coming in, Anna. As a former special school teacher, I had never heard of ABA before and, like you, only in these hearings really heard a little bit more about it. It seems to have rave reviews from people. If it was your job to sell it to someone, how would you talk about the benefits and the positive outcomes, in your case for your child, with ABA and why it has been worth it?

**Dr MIDDLETON** — I would probably say that the benefits are that ABA covers a lot of different areas, as opposed to just one area. So it does not just cover the child’s speech or their behaviour but it covers both of those things and anything else that you could possibly think of that you want to work on. When there is a problem that you want to try to help with ABA, there is always someone who can think of a specific plan and a way forward, so it is all very specific, with clearly defined goals — and I think that that is really important too. The progress is measured along the way, so you know this is the goal, this is how far we have come and these are the steps that we are going to take to get to complete the goal.

**Mr EDBROOKE** — Can you give us an example of that?

**Dr MIDDLETON** — Yes. For example, one of the early goals we worked on with my child was not running off. As I mentioned, he used to just run off all over the place, so one of the early goals we worked on was how to get him to stay with us when we went for a walk down the street, how to play at the park and not run off, and then walk home again. The first goal was that he just had to walk 10 metres. He would walk 10 metres and then at the end of that he would get some sort of reinforcement, which might be we picked him up and gave him a little whizzy-dizzy. When he was confidently walking 10 metres, we said, ‘Okay, now we’re going to walk to the end of the street’, so then that was the next goal that we worked on.

Then we had this elaborate thing about borders at the park and crosses and ticks and where you could go and where you could not go. He loved that; he found that really interesting. So we would work on that. Then it was sort of time based: okay, we're going to spend 1 minute within the borders, and if he can stay within the borders for 1 minute, he gets reinforcement. It just went on like that until we had achieved the whole goal of going to the park, he plays in the park, we go home and that is it. And that is what we do now. He can go anywhere now. He can go to cafes, can go to shops — any of those sorts of places — and knows appropriate behaviour, and we do not need to do ticks and crosses and borders and reinforcements. We just say, 'Great job', and that is enough reinforcement for him now.

**Ms COUZENS** — Thanks, Anna, for coming in today. Most of the questions I had have already been answered, so thank you. Are you involved in any parent support groups?

**Dr MIDDLETON** — Not really. I am a member of the ABA parent support network that Sarah spoke about this morning, which is a Facebook group, but other than that, not really. I have sort of been in contact with other parents who do ABA through the same provider as my son, and so I felt that that was enough support, just having them to talk to, just knowing that somebody else was in the same boat, really.

**Ms COUZENS** — You talked a bit about being a GP yourself and the families that you see. Do you recommend that to those parents?

**Dr MIDDLETON** — The families that I see can barely afford their rent and to eat. I do know that the advocacy networks for ABA say that GPs should be at least putting it out there for all these families, but for some of them I just briefly mention it and they say, 'No, there's no way we could do that'. And for others I think, 'I'm not even going to mention it to this family; they can barely even make it to their appointment. There is no way that this is an option for that family'. That is quite sad and that is why I think that, if there were more centres around like the early learning centre at La Trobe, that would be ideal for some of these families, that it would be a way that their child could really get beneficial therapy and that it would have minimal impact on the parents who are barely coping.

**Ms COUZENS** — Would you say they are in high numbers?

**Dr MIDDLETON** — I would not say high numbers, but I would say in line with maybe 1 in 100 or 1 in 150 — those sorts of numbers.

**Ms McLEISH** — Can I just follow up on that? You mentioned the financial, which is certainly an important element, but also the capability. Now, you and your family are very capable as well. Do you see a number of the people who come through who cannot afford it would struggle with actually implementing some of the — —

**Dr MIDDLETON** — Yes. I think that there is no way that a lot of these families could do it. Often what I do is recommend a book to them. There is a particular book that I recommend, which is based on the Early Start Denver Model, which is similar to ABA and the one they use at La Trobe. I often recommend this book to the parents and say, 'If you want to learn how to do it yourself, you can have a look at this book'. The book is very easy to read, but for some of these families I think even that is too hard for them. I just do not think that they would be able to do it.

**The CHAIR** — Anna, thank you very much for your presentation. You have provided us with some very useful insights, which are much appreciated.

**Dr MIDDLETON** — Thanks.

**Witness withdrew.**