

TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Melbourne — 10 October 2016

Members

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Ms Sarah Wilson, convenor, Applied Behaviour Analysis (ABA) Parent Support Network, and president ABIA (Autism Behavioural Intervention Association).

The CHAIR — Good morning, everyone. Welcome to this public hearing for the Family and Community Development Committee’s inquiry into services for people with autism spectrum disorder. This is the fourth public hearing to be held by the committee in a series of hearings that will continue through to the end of the year, both in regional Victoria and Melbourne, and it may in fact go into next year given the demand.

Today we will hear from a range of people, including parents, carers and people with ASD. We will also be hearing from the ABA Parent Support Network, Specialisterne Australia and later in the day from the Department of Education and Training. These proceedings today are covered by parliamentary privilege and, as such, nothing that is said here today can be the subject of any action by any court or to any proceedings for defamation.

If you have any special needs today, please see the committee staff, who will assist you. We have made available a separate room as a quiet room if anyone wishes to make use of that today. That room is the multipurpose room, which is just down the hall from this room. Again, please see our staff if you require assistance.

I would like to call Sarah Wilson. Welcome, Sarah. You are the convenor of the ABA Parent Support Network. Thank you for attending here today. All evidence taken by the committee at this hearing 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 occur today, and you will be sent a proof copy of the transcript and be able to make factual or grammatical corrections if necessary. I would like to invite you, Sarah, to make a 15-minute presentation to the committee. Thank you very much.

Ms WILSON — Thank you very much for having me here. As you can see, I am a parent of a child with autism. I am also president of the ABIA, the Autism Behavioural Intervention Association, and I am a founding member of the ABA Parent Support Network.

I would like to start today by thanking you for listening to us parents. We are very keen to share our views. I would like to start by outlining briefly my story of my own experiences of what it is like to have a child with autism, and then talk a little bit about the ABA parent network and then address each item of term (b) of the inquiry. I am also a teacher, so you can ask me questions about that.

My daughter’s name is going to be mentioned in the video, but I would prefer her identity to be kept private in the transcripts. If you are able to delete her name, that would be useful. There is no sound, but that is okay.

Visual presentation.

Ms WILSON — That is a video I made several years ago after we had finished her therapy, and we were trying to use it for fundraising purposes. By the way, if there are any questions as I am going, please just interrupt or move me along.

My story is my daughter was diagnosed at two years old — nearly three years old. At 18 months I had taken her to a private paediatrician in Sydney, a very well-respected paediatrician, who told me that this is definitely not autism, which shocked me because I was just like, ‘Oh, my goodness, that’s autism’. I did not expect that. We did see a speech pathologist when she was two because she had some words and then dropped them, and we thought she might have had hearing difficulties, which we checked out. The speech pathologist put us onto a developmental paediatrician, and the developmental paediatrician diagnosed autism over a year after I had first seen that first paediatrician.

Everyone I know that has been through the autism process has a different story about how they reached the diagnosis point. There were no ABA therapy recommendations until we had reached the developmental paediatrician — not from our GP or from the paediatrician. When I called Amaze to get the FACSIA funding, which is no longer in existence, they advised us against doing ABA, and luckily, I chose to ignore them.

Ms McLEISH — Sorry, is that Amaze?

Ms WILSON — Amaze, yes. At the time that was Autism Victoria.

Mr EDBROOKE — What did they base that on, Sarah?

Ms WILSON — It was a volunteer on the phone, and she said, ‘Look, it’s a lot of money. I haven’t heard that there is a lot of progress that happens with these children’. I think that she was just a volunteer and ignorant about ABA.

Mr FINN — How long ago was that, Sarah?

Ms WILSON — That was in 2009 or 2008.

Mr FINN — I think Amaze has probably come a long way since those years.

Ms WILSON — Yes, I think so, and when you think about my story and my experience, it is five years since we stopped ABA. We invested in ABA. We spent our savings. We had a big, fat house deposit, which is now gone, and five years later we are still renting.

People talk about the money with ABA, but actually it is the time and effort that is required for ABA to work that is the big investment. I could not work. We had a home program, and I managed the therapists and my daughter’s schedule. It was a great investment. When the therapist would go home on the weekends that was when my husband and I would step in, and we would become the therapists and just reinforce what she was learning. We would not sit down with her and do exactly what they were doing, but as situations arose and required it we became therapists.

So we invested in it, and we did ABA for three and a half years. We started at 40 hours a week. We were told that the more hours that you do, the more effective the treatment is, so we thought, ‘Great, we’ve got the money. Let’s do it. We’ll do 40 hours a week’. We started at 20 and we just wanted to see how much she could cope with it. She loved the therapy, so we just kept going. We just kept adding hours until it was completely full. She did therapy from about a couple months after diagnosis until she was six years old when she was at school. The last six months was therapy in a mainstream school. She still attends this school. She has no aides; nothing is required. Her teachers treat her like any other regular child in the class, and she copes just fine.

The CHAIR — How old is your daughter now?

Ms WILSON — She is now 10. She turns 11 in March. She is in this mainstream primary school without support.

Obviously during the ABA therapy time I was having a really, really tough time of it. It is a unique experience, and I wanted to reach out and meet other parents who were going through the same experience. I tried a regular autism support group, but it was a bit sad. I did not feel I could share the gains that she was making. She was making a lot of progress. She was starting to talk and starting to interact more and play with other children. I felt bad sharing these experiences when their children were not having the same gains.

So I started my own ABA parent group with some friends that I met, and we got together and we talked about things that are specific to ABA — things like: how do you get the money; where do you get the money; where do you get therapists; how do you hire a therapist; how do you know what a good therapist looks like; what kinds of programs are you doing; or we are running across this particular difficulty — how do we manage that? It was that kind of thing. Now we have a Facebook page for ABA parents. We have today, I think, 224 members, and some of those members are outside of Victoria but most of them are within Victoria. It sits under the auspices of the ABIA.

Under term (b) we will start with health. Our experience as parents — I did ask people on Facebook. I said, ‘I am talking to the inquiry. What do you think? What would you like me to tell them?’. So this is what we have all come up with together. They say that GPs do not refer to developmental paediatricians early enough.

The CHAIR — Is that because GPs in general have a lack of understanding of autism, or is it that they just do not understand that there are referral places for children to be sent to?

Ms WILSON — I think it is both — probably more the former. There is a bit of a wait-and-see kind of attitude with GPs. The first time I went to the paediatrician when my daughter was 18 months old, he kind of said, ‘Let’s wait and see what happens’. I think it is just inexperience with autism. Also GPs have such a short

time with the child. The consultation is about 15 minutes, where as a developmental paediatrician saw me for an hour and while we were talking she was watching what my daughter was doing in the background.

Ms WARD — Did you pay for that?

Ms WILSON — I did pay for that, \$380, which at the time I thought was a lot of money, but that was before ABA, which cost us a lot more. ABA just costs a lot because it is one-on-one therapy, so you have to pay a therapist's wages for the time that they have, and the more time that you want them to be there the more you have to pay for their wages.

The CHAIR — We have 10 more minutes.

Ms WILSON — Yes, no problem. Thank you. I believe that paediatricians are ignorant. Parents get desperate. When there is this wait-and-see attitude parents get really, really desperate. They try things that are not evidence-based, things like diets or other therapies, and they feel that their lives are hard. The kind of life that I was living before ABA was unacceptable to me. It was something that I would have run away from possibly. I did think of running away. So parents get desperate to try anything. I was ready to try anything, and luckily for me it was ABA. But we should have the right to make an informed choice, and an informed choice means that all of the therapies are laid out in front of you: these are the ones that are evidence-based; these are the ones that are not; this is how much they cost. But I think GPs and paediatricians are a bit afraid of presenting those choices, especially when the best one comes with such a huge price tag.

Most importantly what is forgotten is that the effectiveness of any autism treatment hinges on the parents' mental, physical and emotional health. I was a wreck. When you are living with somebody who screams so much every day and you are just trying to get through the day it is very hard to make good choices about treatment. I, myself, saw a psychologist. Again I paid for that. I saw a psychologist for — I do not know — six months: every week for a few months and then every two weeks and then once a month, and finally she said, 'You're okay'. Because my daughter was getting better during that time as well, I started feeling better. But you cannot have an effective autism treatment like ABA without the parent being present, being active and being part of the treatment.

The next one is education. We were lucky because close to us was an ASD-friendly school. All of us parents talk about what the best schools are — you know: who is likely to accept therapists, which schools do not, are they ABA friendly, are they not? Many families relocate to be within the school zone, so as a result ASD-friendly schools get several kids with autism in each class. I know that as a teacher that is very difficult, especially when there is not enough funding for aides or therapists to be in the classroom, because you have all these difficult behaviours to deal with. I should not say 'difficult' in terms of that the child is troublemaking. They do not mean to have these behaviours; they are from anxiety mostly. They have good reasons.

I feel that educators and aides are not adequately trained to support ASD students. I know this from my own teacher training. I did a postgraduate diploma in education at University of Melbourne. It was a year-long program in 2002, and it had 1 hour of a lecture to deal with all disabilities and 2 hours of tutorial discussion time to deal with all disabilities. I know that that has changed, and it is a lot better now, but there are still a lot of people that are my age and older in the education system that need education on this.

The CHAIR — The in-service teacher professional development has started in terms of disability support.

Ms WILSON — I know. I had to do that training myself to keep my credentials, and I think that is a wonderful start.

Okay, so disability services — lots of parents that I spoke to had mixed feelings on their experience. Some of them said that they were great; some of them said that they were poor. My feeling is that they are really disjointed — that there are lots of forms. It is very time consuming. You can see the daily process of the child's behaviours and the daily running of the household does not leave much time or energy to deal with forms. Usually you have to fill out a form for Amaze, a federal one, a state one, one for Medicare — it is a lot of work. ABA parents find they need to fund their program independently, mostly. And parents of ASD children should have access to evidence-based ABA.

Let us have a look at some of these. This first one is mine. These are anecdotal comments from our Facebook page about the costs. Some of these are personal friends of mine, so I have seen them go through these struggles. This one is mine:

It cost us our house deposit. We still rent eight years after [our daughter's] diagnosis.

Someone else said:

We anticipate our costs for 2.5 years of ABA to exceed \$100 000.

The price tag of our ABA therapy experience was at least 150, and that is just for the therapists. That is not for equipment. We did a bit of speech pathology on the side. We dropped that because ABA included speech and communication strategies. But, yes, it was a list: 150 000. Someone else said they were forced to sell a family property that they had had in the family for generations to pay for ABA. Another woman said that:

To pay for ABA my family had to hold a fundraiser.

They raised \$80 000, which is amazing. Someone else took on a night job to earn extra money. A father said that he took long service leave and then worked as a private contractor to earn more money.

Another woman said:

My husband's ex-wife accepted reduced child support.

Other statements from parents include:

My older children receive less support than I would like to give.

My eldest child has just finished high school and needed support at TAFE, but we can't afford it.

The financial burden of ABA made me turn to my friends and family for funding, and this has ultimately strained those relationships.

So autism affects not just the child; it affects the whole family and the greater family as well. Other statements include:

In the last year of the full-time program, (kindergarten with ABA shadow) my husband relocated from country Victoria to a better paying job while I stayed in the country with the children to maintain therapy.

So they actually had to separate for a short while. I will keep going.

Sports: there are limited clubs that accept children with autism, and I think that is again lack of training on the sports club. Coaches are not trained to support children with ASD, and volunteers have limited knowledge of skills to support the needs of a child with autism. When they do have the knowledge, we parents find out about it. We all talk to each other, and that club gets inundated — like the schools.

Employment and housing: when we get that diagnosis and we have got a child like my daughter, my first question is: do we have to support our kids their whole lives? That is our biggest worry. Then what happens to my daughter after we have gone? What happens when parents are not there?

We know from various news items and evidence that employers are usually not willing to employ workers with ASD. Housing is mostly out of reach right now, but without work it is impossible. ABA teaches independence. Early intervention means that our children with ASD are best equipped for the future in the long term.

In summary, here are some quotes from some of the parents in our parent network:

ABA doesn't just teach the child how to cross the road or sit still on the mat at school, it teaches the child how to learn.

Skills that they use throughout their whole lives.

Despite the costs, ABA is the best possible intervention for our children, our families, our communities and for ourselves.

ABA guides me on how to be an effective parent. I will use these skills for life.

In our Facebook group we have a really great joke: we use ABA on our husbands.

The CHAIR — Does it work?

Ms WILSON — Yes, it does. We do not regret a thing. Even though it costs us this much, we would do anything to get our children to independence. So we do not regret the great — and that is me and my family too; we do not regret anything. But wealthy families should not be the only ones who can access ABA for their children. Thank you. Any questions? Did I run to time?

The CHAIR — Yes, you did, but we have given you half an hour, and now we have got to ask you questions. We will give you another 15, I think, just because there are a lot of interesting things to come out of your presentation. Thank you very much, and thank you for your submission as well.

Ms WILSON — You are welcome.

The CHAIR — I will try and restrict this to one question, if that is okay, or one group of questions each. The ABA program that your daughter did was delivered by a therapist and by yourself and your partner as a coordinated effort?

Ms WILSON — No, we went through a service provider called Autism Partnership. A psychologist came every two weeks and would look through what the therapist was doing. The therapist would take data on a daily basis, a session basis, and the psychologist would look through the data. She would also look at some of the programs that the therapist was not doing. So we had a 3-hour meeting every two weeks.

The CHAIR — The delivery of the therapy, though, at home, you and your husband were required to learn the skills to deliver that?

Ms WILSON — Yes; correct.

The CHAIR — Which kind of raises some issues around parents who do not have capacity to learn or then deliver to their children, so it is kind of challenging I suppose. It is not only the cost that is perhaps prohibitive; it is also that knowledge and that skill that is required on an ongoing basis by parents to administer the therapy. You mentioned in your presentation the number of hours per week that is recommended by the federal government.

Ms WILSON — Yes.

The CHAIR — What do you think? Is 20, 24, 25 hours a week enough, or should it be more, should it be less or should it be based on an individual's need?

Ms WILSON — I think it should be based on an individual's need. Twenty to me seems like the absolute minimum. If you have got parents that are very active and very good at reinforcing the program, then 20, 25 hours could be sufficient, also depending on the child's need. But for us that 40 hours in that first year was when our daughter made her biggest gains. I mean, I would definitely say 30 hours a week for each child, but obviously — —

The CHAIR — Some children may not require 30 hours.

Ms WILSON — Some children would not require that.

The CHAIR — I just have one last question before I hand over to other committee members. There are those within the autism sector who do not consider ABA to be the be all and end all of therapies.

Ms WILSON — Right.

The CHAIR — Even though it is evidence based and there is a lot of good information out there about its success. Why do you think that is?

Ms WILSON — I think many adults with autism see that that is part of who they are, and ABA kind of challenges that a little bit. I am trying to put it — adults with autism are really great at expressing themselves, and I really — —

The CHAIR — Some.

Ms WILSON — Yes, some, and I love that; I think that they should express themselves. I think that is wonderful; I hope my daughter expresses herself that way. For me, my daughter was living a life of fear — daily anxieties; that is why she screamed so much. ABA was treating that fear. For me, a life lived in fear is half lived. I think that is how the expression goes.

The CHAIR — So you do think it is about not wanting to change who they are? Is that the crux of it?

Ms WILSON — Yes. I think they feel that the symptoms of their autism constitute who they are.

The CHAIR — So it is an identity thing.

Ms WILSON — So it is identity; it is part of their identity.

The CHAIR — And for those of course on the spectrum who cannot communicate, it is a whole different story.

Ms WILSON — Correct.

The CHAIR — I hand over to the Deputy Chair.

Ms McLEISH — Thank you for coming, Sarah. You mentioned word gets around pretty quickly if there is a great sports club or a great school. Do you think it is better to inundate particular schools or sports clubs or spread the load?

Ms WILSON — I think the load should be spread. I think I mentioned in the written application that I sent to you that private schools have the choice of being able to accept who they like as their students, but if they were mandated to, say, one ASD child per class, then that would help spread the load a lot. Because they can look at a child and say, ‘No, this is too much work for us. We don’t have to accept this child when we can accept another child who is going to get better grades and be less work for teachers’. By the way, not all private schools are like that. There are some wonderful schools that are happy to accept children with autism, but we do find that private schools do exclude children with autism. But that would spread the load a little bit more, and I think that is a better thing to do. If we mandate schools to accept children with autism and to accept ABA therapists, then we parents would calm down a little bit and feel more comfortable with our children going to their local school.

Ms McLEISH — Just with the sports and sporting clubs, can you give the committee an understanding about what it is that somebody at a sporting club can do to make participation stronger or easier for that sports club?

Ms WILSON — Yes. I think, for example, we were very lucky because we were introducing our daughter to swimming. We went with the therapist to the swimming pool and introduced the therapist to the teacher that she was going to have. They were open to that. Then we just talked a little bit about how we were introducing swimming, they gave their point of view and we kind of shared — I think sharing experts with sports — —

Ms McLEISH — What about team sports? A number of people have talked about swimming, but what about soccer, football or netball or something along those lines?

Ms WILSON — It is a bit more challenging.

Ms McLEISH — Have you got an example of where it has been done well?

Ms WILSON — Yes. Some parents know where it is done well, and they send their kids there. Sorry, what was the question again? I am a bit nervous.

Ms McLEISH — That is okay. Have you got an example of what a club did to make it easier for the kids that came along?

Ms WILSON — Some clubs are just naturally ABA friendly because they believe in positive reinforcement and they believe in praise — ‘Yay, you did it!’. They can also break the skills down for that sport into smaller parts and let the child learn that way. Some teachers and therapists do this naturally without ABA training, and

it is a very effective method. That is what ABA hinges on — breaking things down into tiny parts and then rewarding each part.

Mr EDBROOKE — Thanks for coming in, Sarah. I am just interested in whether there is any evidence that ABA is something that can be used on adults with ASD, not just kids and for early intervention.

Ms WILSON — We emphasise early intervention because the brain is still developing and so it is much more effective. You would have to talk to the ABIA about this, but they do have programs for teenagers and older children, and adults as well I think.

Mr EDBROOKE — Because that is one thing I have heard in these hearings, that a lot of people are picked up quite late and diagnosed quite late.

Ms WILSON — Yes. It is still effective, it still helps that person, but it does not have the same amazing results like what we have, just because there are so many ingrained practices that have happened; whereas with a child's brain you can really steer it into a different direction.

Mr EDBROOKE — Thanks — and a lovely video, by the way.

Ms WILSON — Thank you; a pity the music did not work.

Mr EDBROOKE — The other thing I just want to know is — knowing you are a teacher and as a former teacher myself — I am trying to get a realistic sense of where you see the teaching industry going as far as being able to give professional development to teachers to give them the skills and knowledge and the strategies to do with ABA. Knowing how many PDs you would do a year, in your opinion how is this going to come into play ideally for you in schools?

Ms WILSON — There are some great PDs out there. The best ones are run by psychologists who are service providers, and they are expensive as a result. So schools, with their limited funds, tend to go for cheaper PDs which are run by people who are not — what is the word I am looking for? — who do not have the same experience or the same qualifications or understanding of autism. I do think that it is changing and that it is getting better, but it is the older teachers in the profession that need to understand inclusive practices in particular. The number of stories I have heard about children being excluded from the classroom because they are anxious and have a meltdown — the teacher thinks quickly, 'Right. I can't deal with that because I have got these other children', so out of the classroom they go, whereas ABA therapy would teach them, 'No, they can go into a smaller part of the classroom and be helped to calm down within the classroom and be kept there'. Because if the child is taken away from the classroom, that is often what they want so you are essentially rewarding them for the meltdown, and that is against ABA practices.

Ms COUZENS — Thanks, Sarah. I appreciate the stories. They are great. I am really interested to know what your view is on bringing ABA into the public school system and how that might work. Given your experience, what do you think would be the best possible outcome for bringing that sort of program into, say, the public school system?

Ms WILSON — Yes. I think this is done really well in the United States where there are some ABA schools, and it is also introduced into mainstream schooling. Having a therapist there full time if needed is the best way, and then ABA is all about the child gaining independence. So that therapist is not there forever; they are there to guide the child as needed, and then slowly you can fade the hours as the child is becoming more and more independent.

I think that mixture where you have your ABA schools for those children that really need it, who are further down the spectrum and need more help, and then every mainstream school being able to accept therapists and have therapists on hand as needed — and one for each child. There are lots of schools that say, 'Okay, we've got 15 hours of funding from this child and we've got 5 hours of funding from that child. Let's put them together in the one aide and put them together in the same class'. That can work really well, but sometimes it does not. You have got to look at each individual child and what they need. My daughter is different from most of the other children. They all have separate needs, and you need a separate program.

Ms COUZENS — Have you had any experience with the NDIS?

Ms WILSON — No. We are five years after that. Our daughter is now 10. We finished when she was six and a bit.

Ms COUZENS — Are there any other parents in the group?

Ms WILSON — I have got my cousin in South Australia who has a child with — it runs in families — and she has been very happy with NDIS as it has been rolled there so far. So far the parents that I have spoken to have said that it is good, but that is anecdotal. It is just a few people, because it has not been rolled out in Victoria yet. It is coming soon, right?

Ms COUZENS — Yes.

Ms WILSON — Great.

Mr FINN — Sarah, thank you for coming in today. I wonder if you have had any discussions with the education department about rolling ABA into our education system, as Christine has suggested. If so, what has been the attitude from the department?

Ms WILSON — I have not contacted the department. I would like to contact them; I think it is a really fantastic idea.

The CHAIR — They are presenting this afternoon. You can stay and listen if you want to.

Ms WILSON — I have to go in to work. I can work now. It is great to be able to work again. I am still loving it. Look, I think that I would say exactly what I mentioned to Chris, that ABA is flexible. It can be brought into schools and be very effective in schools. I think the first problem is teachers are very — —

Mr FINN — Have you discovered that the education department is not big on flexibility?

Ms WILSON — That would be my experience, yes — in other matters, not just this. I think many teachers feel, ‘Oh, there’d be someone else in my classroom. That means someone else is in control. I don’t get to run the class like I want to’, when actually the opposite is true. The therapist says to the teacher, ‘Okay, what are we doing today? How can I help you?’. It is a very helpful role. We do find, as parents, once we introduce therapists into the classroom, and teachers have a little bit of experience with it, they love it and they do not want that therapist to go as much as we do. But the therapist’s job is to fade hours and fade away as the child gains independence.

Mr FINN — From what you were saying before, you were almost suggesting that ABA be introduced in autism-specific schools as a mandated form of teaching at those schools. Is that what you are getting at there?

Ms WILSON — Yes. I think that would be fantastic, and that is certainly practised in many other countries, including the UK, the United States, Canada to an extent and the Scandinavian countries.

Mr FINN — Just one further question: we all know the importance of early intervention. What is the main difference between ABA and conventional early intervention programs if I can call them that?

Ms WILSON — I am just going by what I have heard from other parents who do not do ABA; they will do speech therapy and occupational therapy. They have some limited success with that. Some people seem to have some success with that, but I find that most parents are unhappy because there is not the intensity and it is only dealing with a couple of the aspects of autism, whereas autism, as we know, is behavioural difficulties and psychological difficulties as well as communication and socialisation. Some of them try to introduce that socialisation element, but when you are working 1 hour a week it is just not enough to give the child positive experiences of interacting with others. It needs to be a daily occurrence.

The CHAIR — Thank you very much, Sarah, for your presentation this morning. It is much appreciated. We have gained some very useful information.

Ms WILSON — Great. Thank you.

Witness withdrew.