

TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Melbourne — 12 September 2016

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Witnesses

Ms Susan Pavey, general manager, and

Dr Amanda Sampson, Autism Behavioural Intervention Association.

The CHAIR — Welcome this afternoon to our public hearing, Susan Pavey, general manager, and Dr Amanda Sampson, from the Autism Behavioural Intervention Association. Thank you for attending here this afternoon. All evidence at this hearing taken by the committee is protected by parliamentary privilege as provided by the Constitution Act 1975 and is subject to the provisions of the Parliamentary Committees Act 2003 and other relevant legislation. Any comments you make outside the hearing will not be afforded such privilege. It is a contempt of Parliament to provide false evidence. Recording of the proceedings will commence today, and you will be sent a proof copy of the transcript and be able to make factual or grammatical corrections if necessary. I would like to invite you to make your presentation to the committee today. I think you have a PowerPoint for us?

Dr SAMPSON — Yes, we have.

The CHAIR — Also, thank you for your written submission to the committee.

Dr SAMPSON — Thank you for seeing us. We are very appreciative of your time. I am Dr Amanda Sampson. I am an obstetrician and gynaecologist and the mother of a 23-year-old adult male child with autism who still lives at home with me. This is Susie Pavey, who is the CEO of ABIA. We are here today to represent the Autism Behavioural Intervention Association.

This association was set up in 1997 by a group of parents who were desperate for treatment for their young children with autism. At that time there was no access to services. Often it was a 12 to 24-month delay before early intervention centres could see their child. ABIA has become the peak body for ABA, or applied behaviour analysis, services in Victoria. The group of parents who set this up brought the ABA skills and knowledge to Victoria and continued to provide services in the area of autism training in ABA information and support to parents.

I want to just spend about 5 minutes talking about ABA and explaining exactly what it is. I presume you have already had some talks, and I do not know exactly what you have had, but ABA is an evidence-based, early intensive behavioural intervention. It has been widely researched since the 1970s. There have been multiple publications associated with ABA services and treatment of young children with autism.

I guess the key components of it are the intensity of the treatment and that it is a comprehensive treatment for young children with autism. The intensity — you have been talking just before about 20 to 25 hours — in fact the original research suggested it needed to be 30 to 40 hours, and the hours have gotten cut back as people have gone, ‘Well, maybe we don’t need to do quite so much because it’s going to take more money if we do more’. But in fact the early assessment that gave 50 per cent recovery rate was for 30 to 40 hours a week. ‘Recovery’ is no longer the term used; it is actually ‘50 per cent best outcome’, and I will talk about that in a moment.

It is a high-repetition, one-on-one, in-home treatment for the very young children — two, three and four-year-olds — and some of that time will be spent in kindergarten if they are age appropriate. It involves positive reinforcement — the most important factor in terms of teaching is encouragement — and parental involvement, so they learn the skills to manage their own children with autism. It is data driven and individualised, so the data that is obtained from each of the teaching incidents is recorded and then assessed and then reassessed for the next program.

It is multidisciplinary, so it accesses speech areas, social areas, play areas, academic areas and behaviour areas. That is what I mean about it being comprehensive. It is truly comprehensive. All behaviours can be taught. So if you think of speech as a behaviour, if you think of toilet training as a behaviour, if you think of stopping headbanging as a behaviour, then that is what we do, and we individualise it to each individual child. We work closely with other groups like speech pathologists and other specialist groups that we need from time to time, psychologists in particular. I had a lovely slide, but it is gone. It does not matter.

The CHAIR — Our apologies.

Dr SAMPSON — Do not worry; it does not matter. That is fine. It has been shown by numerous researchers that a large proportion of children undergoing early intensive behavioural intervention using the ABA techniques will demonstrate substantial gains.

Visual presentation.

Dr SAMPSON — The outcomes are: 50 per cent best outcome — what that means is children go to school without an aid, they go independently; 25 per cent are moderate gains — some of those children will be in usual schools with an aid, others will be in special schools; and 25 per cent show minimal gains. I would like to say at this point that everyone thinks, ‘Minimal gains; that means they have gained nothing’. It does not mean that at all.

I will highlight that with a family story of a friend who has a 26-year-old woman with autism living with her. This woman has an extraordinarily low IQ — it cannot be tested. She is not toilet trained at the age of 26. She lives at home with her family. She did years and years of ABA. When she started ABA she was sitting in the corner headbanging and rocking and was unable to be communicated with. The house would be smeared with faeces if she was left unattended for any period of time. This woman was an amazing woman who did a lot of ABA with her child and employed many people to help her do that. As an adult this young lady can walk around, she can be independent in the house.

She is not toilet trained — that is the major issue — but she has a communication system, the picture communication system referred to previously by the speech pathologists here. That means that she has over the years learnt 100 words. It does not sound much, does it? But she can walk up to her mother with her book, point at the sandwich and say, ‘I want a sandwich’, which means instead of having a tantrum on the floor and the mother guessing, ‘Oh, is your nappy dirty, or is it something else?’, she can respond. It has made their life tolerable. That girl still lives at home. You can imagine that if she had not done ABA, that child would have had to go into support, 24-hour care, because it would have become unbearable for the parents. So ‘minimal gain’ does not mean gain that is not worthwhile, and the effort was absolutely worth it.

There are also some non-specific benefits of applied behavioural analysis, and it is really to do with behaviour training. It has to be recognised that behavioural techniques apply to all children and can be applied to all children with disability. It underlies teaching excellence, and the best teachers do this naturally. Good parenting also relates to behavioural techniques. ABA enables parents to manage difficult behaviours throughout the life of a child, and I can attest to that with my child at different times, having the skills to work out what the problem was and how I was going to deal with it and manage it all by myself. ABA is a skill for life. We were better parents to our other children because we did ABA. There is no doubt about it. That is my little section on ABA.

I would just like now to address the inquiry terms and talk a little bit about our submission. The first point was about prevalence, and probably many people have spoken already about this, but the prevalence is obviously on the rise and has been rising at an alarming rate over the last 20 years. The rate of autism amongst two-year-olds in the 2010 paper, the second one down there, at 1 in 120 is a Victorian study from La Trobe University.

The availability of services, the Helping Children with Autism package, was just a godsend in so many ways when it came. The inadequacy of it, and it is a pity to talk about that straightaway, was that it was \$10 000 for two years and then it stopped.

Ms PAVEY — \$6000.

Dr SAMPSON — Sorry, \$6000 for two years. My apologies. ASD does not stop; it just keeps going. It goes into school age, and children need ongoing support for all sorts of activities, not just school but for extracurricular activities, for sporting activities. There were very few services with a behavioural bent in schools. Parents have had to fight to get behavioural therapists into the classroom to help their child learn effectively in the classroom. Few children’s sports are inclusive.

Just so that you understand what we do, we felt that this was an area that we should be addressing, and so after the last maybe 6 to 10 years we have worked primarily on providing short courses in behavioural techniques for parents, for teachers and for other groups. This summarises a lot of our courses. For parents we offer information sessions and an ABA provider registry. We offer level 1 training for parents and therapists, advanced training, online training which is starting this year. We have been presenting many, many short courses to teachers — to preschool teachers, to kindergarten teachers, to teacher aides — behaviour management courses and there is ongoing school consultancy and ongoing need.

Ms PAVEY — If I can just add, this was our way as an organisation to try to bridge that gap between the lack of introductory behavioural training for services and organisations outside families who are already doing intense ABA at home. So it was our way of upskilling parents if they wanted to do an ABA program and get them introduced and referred on to ABA service providers. It was our way to build the capacity of therapists who are required to work in the home and have parents access the therapist register. It was also our way of aligning ourselves with the education system and making sure that our training is aligned with the Victorian Institute APSTs — which are the Australian professional standards for teachers — to make sure that when the teachers are doing the introductory level training course, it is underpinned by the principles of ABA and they can walk away understanding what it is they should be looking for.

Finally, we have been responding to a number of carer and respite services that have been calling us just in desperate need to know how they can support even teens and adults. ABA as a methodology being an intense home-based intervention, we are finding that demand for our service is creeping into early childhood, primary, secondary, and now carers and respite workers are also wanting to know what they can do to better support teens and adults with a behavioural approach.

Dr SAMPSON — Finally, making it work as a sports coach is in development at the moment to try to encourage people with autism to enter all facets of community life. So at ABIA we have been trying hard. We are a parent-run organisation. We are not large, but in the last 12 months, 700 people have accessed our programs.

I think this is important point about how one responds to issues. As an example we will use in a classroom, we can either respond to the child's behaviour as it happens or we can be proactive and say, 'We know that things are going to happen with children with autism in different areas of their lives. Let's be proactive and train the people who will be dealing with them, who will be teaching them, who will be supervising them in whatever capacity'. We believe that is a really important concept, and so because of that we believe that ABA behaviour-based training should be provided in all undergraduate education and psychology degree courses or teacher aide courses, special education and physical education courses if we are going to integrate all people with autism into all facets of life.

Ms PAVEY — For our introductory level 1 ABA therapist training program at the moment, the majority of attendees — we have 14 to 16 attendees at any one session and we run this program twice a month — are university students who are studying either psychology or education. They are looking for work experience so they can gain entry into a masters level, but they are also looking for work experience that is aligned with their study, and so they go on to sit under our therapist register and are employed by either our families or our service providers. We often speak to them and ask them what level of training they currently receive in their undergraduate training, and most often the response is, 'Very minimal. We are lucky to have one tutorial to talk about disabilities in general and approaches in general'. What they are gaining through our three-day introductory level program is more than they have received in their whole undergraduate study.

Dr SAMPSON — We will keep moving on.

Ms PAVEY — The last point there, the Victorian Institute of Teaching has already developed the Australian professional standards for teachers. They have already stated that teachers need to do 20 hours of training aligned with their standards. We are just recommending that 10 of those hours should be aligned with behavioural-based training.

Dr SAMPSON — That is 20 hours per annum for them. We talked about the outcomes for ABA, but I think it is important in terms of NDIS services that we recognise that we do need adequate hours. There is a lot of data to suggest that under 20 hours is not effective in the main. That does not mean it does not give some effect, but it is not effective in terms of comprehensive treatment. If you are looking at comprehensive treatment of a child with autism, dealing with all aspects of their disability, then more than 20 hours is really needed; 20 hours is a bare minimum.

The NDIS should only be funding evidence-based programs and services, and this is extraordinarily important. We feel very strongly that the ABA service — the ABA comprehensive treatment — is well evidenced, well researched throughout the world. Providers should be able to demonstrate quality assurance that actually their practice is attaining the standards that we have set down here, where 50 per cent make substantial gains. In fact

one of the service providers in Melbourne presented data at a conference that we ran two years ago to say that that was exactly what had happened.

Inquiry term (d), the social and economic costs of inadequate services: there is no doubt that from our own Australian data — this is December 2010 Synergies Economic Consulting — the annual cost of autism with a midpoint was about \$10 billion. Five years on it is thought that it is probably double. From that it is probably \$20 billion now, and we suspect that, like many others, these costs would blow out even more if we did not take into account the education services and other things that do not meet the needs of the child with autism. For instance, this did not look at loss of parental income.

Just to show you some of the world literature, this is a more recent study on the costs of autism in other countries. In the USA it is \$2.4 million for a lifetime cost for autism; in the UK, \$ 2.2 million — this is all in American dollars. If you were ASD with no intellectual disability, then the cost was much less at \$0.92 million. The largest cost components for children were the special education services and the parental productivity loss, and that is huge within the community. That applies to Australia as well, I have no doubt. During adulthood medical costs became much higher, and obviously living accommodation and individual productivity loss contributed greatly to higher costs.

As an example of that, my son, who has an IQ of 60 when he tests but probably functions at more like an IQ of 80, works three days a week in supported employment. Without ABA I doubt that he would be working; he would be taking services, not contributing to the community.

The estimated costs of ABA always sound horrendous — absolutely horrendous — but you have got to understand that they are not forever. They decrease with time as the child goes through school and then into adolescence. This is from a Utah actuarial cost assessment, and you can see quite clearly how the graph decreases with time.

The question is: can we afford not to do ABA? There have been two very good studies from the US — one in Texas, one in Pennsylvania — both of which showed that three years of early intensive behavioural intervention versus 18 years in Texas versus 22 years in Pennsylvania would save on average about US\$200 000 per child for that period of time. Ganz in 2007 — I recommend this article to you — is really the best assessment of the cost benefit and the cost of autism services, the sorts of things you have to take into account when you are looking at how much it costs to have a child with autism. Thank you.

The CHAIR — Thank you very much. It is a very comprehensive presentation. I have a couple of questions. You mentioned the NDIS and the potential for that to cover the 20 hours of home-based ABA. ABA comes in once the child is diagnosed, not before diagnosis?

Dr SAMPSON — No, that is not quite true. The NDIS is currently allowing children who have needs and who are suspected to have autism to be funded for ABA programs because it is recognised that the actual diagnosis is very difficult in the very young and that the benefits of ABA are widespread and not just to do with autism. The benefit of ABA goes across all disabilities.

The CHAIR — Having said that, you have already started to think about expansion into mainstream education?

Dr SAMPSON — Absolutely. Not thought about it, we are.

The CHAIR — So there is the potential then for expansion into the health sector?

Dr SAMPSON — In what sense do you mean?

The CHAIR — For example, the public health system, so not just GPs being trained, but nurses, doctors, specialists, surgeons, emergency department staff.

Dr SAMPSON — Yes. I think Susie can talk to that. We had very little access in general to the health sector. The health sector has been very difficult in terms of accepting that this is a method of treatment of children with autism that is worth thinking about.

The CHAIR — Why do you think that is?

Dr SAMPSON — I can say that as a medical professional. I think it is because it costs a lot of money. If you imagine when you have a child with autism, you see a doctor. Doctors give drugs or they give a treatment or they do a diagnosis or they do something like that, but they do not run a program at home that takes 20 to 40 hours a week, one-on-one teaching. They do not have that skill; they do not have that knowledge; they do not understand it. It is really education that that very young child needs, not medicine. But at the same point, they do not fall quite into the education sector either because they are not four yet, so they are not going to kindergarten yet. So we have had this gap over many, many years, where this particular group of children who need early intensive behavioural intervention have fallen between the gaps. Going back to your question, which has just lost me — where was I heading?

The CHAIR — I was talking about expanding it to the medical profession, the public health system.

Dr SAMPSON — Yes. And that is the basis of it, that it probably does not quite fit into the health system. There was a time when people could access some Medicare repayments as treatment if the doctor prescribed this treatment, but I do not know how much it was and we certainly did not access it in the past. So it is an interesting point, but it does not fall under Medicare. It falls into the gaps.

Ms PAVEY — I think also what currently is being funded. If you look at some of these transdisciplinary models where you were saying earlier in the previous presentation families may be getting 2 to 3 hours of therapy a week, we are advocating the intensity, and the intensity is married with the cost of the program because you need two to three therapists. Sometimes families will improvise where Mum or Dad will do some of the therapy. They may do 5 hours of therapy or 10 hours of therapy a week, and they will employ another one or two therapists to top up the hours that are required. But whatever way a family comes together to do that 20-plus hours a week, it needs to be 20-plus hours to get these outcomes is what we are advocating.

The CHAIR — And it has to be home-based?

Ms PAVEY — Yes.

The CHAIR — Okay, because your reference was to home-based — —

Dr SAMPSON — In fact it is cheaper because you do not have to run a centre, you do not have to run a building, you do not have to do all of that; it is actually at home. If you think of a two-year-old with autism, you do not take a normal two-year-old out of home, unless you absolutely have to, and put them in a centre for five days a week. To get 40 hours a week, you need to do five days of 8 hours. So from a child's perspective, particularly one who is delayed, to be in the home setting, to be in a place of safety while they are learning, is really important, with parents being involved, families being involved and everybody doing the maximum for that child.

The CHAIR — And so the therapy actually works even when the diagnosis is later — in age?

Ms PAVEY — Not as well. There is definitely an optimal time for starting ABA. It is thought to be at two and three and that probably around three is optimal. When they are two, they are a bit young. You know what two-year-olds are like. They need a lot of repetition, but they are also not able to spend much time in therapy. So a two-year-old would start at 10 hours a week.

The CHAIR — It is problematic when lots of young children are not being diagnosed until later in life.

Ms PAVEY — That is right. So they have to start young, and then three-year-olds are able to do many, many hours of treatment because it is so much fun for them; they love it — and four-year-olds as well. So the optimal outcomes are achieved.

The CHAIR — Is there a registration or accreditation process for ABA practitioners.

Dr SAMPSON — That is a really good question. I should have left that slide in.

Ms PAVEY — In the US, yes.

The CHAIR — Not in Australia?

Ms PAVEY — Not in Australia. There is no certification body.

Dr SAMPSON — That is not quite true because many of the service providers are psychologists and therefore they are registered with AHPRA. Whereas in terms of somebody who is set up as an ABA supervisor or service provider, there are a whole lot of different people who do that. So there are some people you would think of as being grandfathered, who started working with families like mine 25 years ago and who then became so expert in it that they became supervisors running programs. Many of them under the supervision of experts from the US may not have any qualification, but that does not mean they are not excellent ABA service providers.

Then you have a group of people who did psychology, and even though their psychology degree did not give them much in terms of behavioural teaching, they have gone on to learn it on the job and have become very, very good in it, so they may not have a specific behavioural qualification. Then you have this new qualification from the States primarily, the BCBA, which is a behavioural consultant. That is a general course in behavioural management not particularly targeted only to early intervention and young children with autism, which is the most critical programming that you can do, but it is obviously really relevant for school-aged and older children, and some of them will then become expert in the very young children.

The CHAIR — And I assume there will be a compulsory requirement for a working with children check for anyone working in ABA?

Ms PAVEY — Yes.

Dr SAMPSON — Absolutely.

Ms McLEISH — A lot of my questions were actually picked up in that last bit that Maree asked and some of the comments that you have made. Are there many critics out there of ABA? You have mentioned the GPs.

Dr SAMPSON — I do not know with the GPs so much. I think there is a lack of knowledge that is huge. There is a lot of misunderstanding and there has been a lot of misrepresentation about what ABA is. Then there is this unspoken sense that you should not tell someone there is a treatment available if they are not going to be able to afford it or perhaps the doctor, for whatever reason, thinks that it is too difficult, that it sounds so hard, that it is probably not going to be as good as people say it is. So I think there has been this sort of war that we have fought for years about it, that there are people who will say, ‘Yes, it sounds great, but they live all the way over there’.

Over the years I have seen people all around Victoria run ABA programs. Anywhere where people find out about it and want to do it, mothers and fathers will make it happen. It is amazing how they do it. They will mortgage their house. They will not buy a house, they will rent. They will do all these things to pay for it. It is unbelievable what people will do, because what it gives parents is control — control out of therapy hours, control when nobody else is there in the middle of the night and your child is not sleeping. You have the skill to know what to do. What people have missed up to this time about ABA is that ability to manage your child whenever you need to.

Ms McLEISH — You mentioned that you have your little team of perhaps two or three therapists and a large number of hours, and as a parent you may be able to take on some of those. Then you have just gone on to say that it equips you quite well. How can parents keep the costs down? Is there a way that they can deliver more hours rather than less hours to keep that down, or are they better to have external people do the lot if they could afford it?

Dr SAMPSON — Our ABA therapists maybe get \$19 or \$20 an hour, people who work with young children with autism, so they are very low paid.

Ms McLEISH — This is after they have done their level 1?

Dr SAMPSON — Yes. We are talking about a group of people who are very low paid to start with, so the problem is how do you keep the costs down? Sometimes it is by not perhaps getting as full supervision as you might get. The service provider might only come once a month for something like that instead of once a week or once a fortnight.

Ms McLEISH — The service provider probably being a psychologist?

Dr SAMPSON — Yes. Parents will do some of the work, as you said, and other family members will do some of the work, volunteers from time to time will do some of the work or mostly it is just by not doing adequate hours.

Ms PAVEY — Ideally you would want the team to be external because of the stress and the pressures associated with it. It is separating yourself between being mum and being therapist. I can vouch for that myself, where I have been mum and therapist. You need to take yourself out of that parenting role and put on your therapy hat. Ideally we want your program supervisor, who is the person — the expert — who writes the curriculum and falls under the banner of the service providers, to come in on a fortnightly basis to review the current goals, to review the current progress and then set the next set of goals. They come in fortnightly. They also mentor the therapists. So over and above that three-day course, which is not enough obviously, they all set four or five goals that those therapists are working on at a time, and they will mentor those therapists in order to learn how to deliver the next set of goals for the next fortnight. That external help is really important, but if families cannot afford to pay for that program externally, they will then offset the costs by doing some of the therapy hours themselves.

If I can just add too, with ABA, once parents learn the skills of ABA, whether they are part of that therapy team or not, ABA does not switch off. If you are in the park, if you are at your grandparents house, if you are at a social outing, if there is an opportunity for that child to learn, as a parent you are probably going to give it a go at that point in time. So it is a life skill. It is something that you take with you above and beyond that initial two to three-year training period.

Ms McLEISH — What about the consistency of the therapists within that two to three years?

Dr SAMPSON — That is going to vary enormously. If you get one who is just starting, they are not going to be as good as someone who has been doing it for two years.

Ms McLEISH — I meant if they stay for three months and move on.

Dr SAMPSON — Some of them will, but mostly they are very dedicated, extraordinary people who really like working with these little children with autism. In terms of funding, I would like to say that I am also a patron of the Learning for Life Autism Centre, which raises money on a yearly basis to subsidise programs for children with autism. They, I hope, will be presenting to you and put in a submission at some point in time. But that organisation was set up as a not for profit to raise funds to help children from families who could not afford to put their children through an ABA program, and specifically for that reason.

Mr EDBROOKE — Thanks for coming in, Amanda and Susan. In regard to using ABA in schools in the mainstream education system, what kind of support have you got from VIT so far?

Ms PAVEY — It has been fantastic.

Dr SAMPSON — Overwhelming almost. They are just so delighted to have a well-structured program which is exactly the right size to fit into one of their curriculum days, or over three curriculum days — however they decide to do it. They have been raving about it. They really love it.

Ms PAVEY — We just presented at the Education Show last week, we were invited to be part of the mini autism conference. There were two seminar rooms that had, I think, 396 seats. I could say probably 380-odd seats were full for both seminar sessions.

Mr EDBROOKE — It sounds extremely positive.

Dr SAMPSON — We feel like we are on the beginning of a wave. We feel like the wave is just taking off. We just hope we do not become inundated as one of the few providers of these training programs. We are looking towards how we can expand and how we can make this happen, because at the moment there is no public funding for this. We charge for every course. Parents and teachers — everyone — have to pay the cost as it goes, so we are looking at that thinking, ‘Oh my goodness! What is going to happen?’. But many service providers are also moving into schools. We have many, many service providers on the list, and many of them

are doing school consultancy as well — going in, assessing children, giving treatment plans and doing that sort of thing as well.

Mr EDBROOKE — That is good news.

Mr FINN — When a child is diagnosed with autism, as things stand now they usually go to their doctor or their community health centre or somewhere like that and get the traditional early intervention as we know it. What is the difference between that early intervention and the early intervention that you are here to tell us about today?

Ms PAVEY — It is intensity.

Dr SAMPSON — It is intensity and it is the one on one. There is really hardly a comparison.

Ms PAVEY — The data collection is an important component of the delivery of the program.

Mr FINN — If the traditional early intervention program gave 20 or 25 hours, would it be on a par with ABA?

Dr SAMPSON — There are some centre-based groups that have been doing something similar to that. The data that has come out of those groups has never been as robust or as reputable as the home-based early intervention that we have been talking about. That does not mean that it could not be as good, but 20 hours is probably the problem, that the intensity is not there.

Mr FINN — Say 40 hours, if we had 40 hours of the traditional early intervention?

Dr SAMPSON — Yes, but we have to come back to the facets that we talked about in early intervention. What we are talking about is one on one. As soon as you put a child in a centre, you will get more group activity, which is great, particularly if they are ready for socialisation and ready for group activities, but at the very early learning stages when you are teaching a child to learn — when you are teaching a child to imitate, to make sounds, to take an interest in life and to understand consequence, that you ask a question and you expect a result and there is a consequence if you do not, either nothing or a reward — then you need to do that one on one until they are on top of that. That is usually why centre based does not work as well, because home just keeps going until it is the right moment to stop, but centres tend to say, ‘10 o’clock is the break time’.

Mr FINN — Okay. You mentioned before something that I am sure we all agree with — that is, that programs should only be funded if they are evidence based.

Dr SAMPSON — Absolutely.

Mr FINN — To your knowledge how many non-evidence-based programs, if I could call them that, are there in the marketplace at the minute?

Ms PAVEY — The Raising Children Network website has got a list of all the providers that have access to the HCWA funding. They have got a rating scale. I think we have got it on one of our slides here. ER is the effective based on established research evidence, which is where ABA and the Early Start Denver Model sit. EE is effective based on emerging research, EB is based on best practice evidence, EO is effective but should not be used in partnership with other eligible therapies and NE is not effective. When you look at that list of providers, I do not know the exact figure, but there are a lot of therapies that do not come under ER.

Dr SAMPSON — Back to your question about early intervention centres, I have never seen data published by any early intervention centre in Victoria about what their outcomes are. Their outcomes are not what we are talking about. We are talking about this comprehensive treatment that takes two or three years for most children with autism that attacks and tries to deal with all facets of their development. Early intervention centres are looking at the year-to-year funding for children with disabilities and they work on a short-term basis. They do not go, ‘Where did we start at the beginning of the year and where did we end up at the end of the year?’. They do not do that. They do not say, ‘Oh, we did really well’.

There are funny stories. I remember Angus, my son. I paid for him to go to an early intervention centre when he was two and a half and I paid for the teacher because he was so unmanageable that he had to have a teacher as

well. This cost me some enormous amount of money every week for 2 hours. She got all excited, 'He said such and such today', and I thought, 'He's been saying that for six weeks'. So the excitement was around something that was not even relevant to that early intervention; he had just generalised it into that situation.

They need to do what we do, which is publish data. We publish data on where a child starts, rigorous psychological testing, and we look at it two or three years later and say, 'Where have we ended up?'. Our aim is to increase the IQ of our kids back into the normal range.

Because we missed our slides, this is the important one that we missed. Typically developing peers are the red line. You can see them progressing along at a fairly steady rate. The child with autism is delayed, and that is the yellow line down below. When you start ABA your aim is to cross lines to catch up. If you go at the same rate as a normal developing child, you will never catch that child. You will always be behind. So you actually need the intensity to catch up.

The CHAIR — Thank you so much. A lot of food for thought there. Your evidence has been invaluable. Thank you very much for your presentation today.

Dr SAMPSON — Thank you very much for having us.

Witnesses withdrew.