

TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Shepparton — 15 November 2016

Members

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Ms Cindy McLeish — Deputy Chair

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Witness

Mr Ben Snow, parent.

The CHAIR — Welcome to our public hearing, Ben.

Mr SNOW — Thank you.

The CHAIR — Thank you for attending today.

Mr SNOW — I brought these for a reason I will get to in a moment.

The CHAIR — Thank you also for your written submission to our inquiry. I just need to read this little spiel, if that is all right.

Mr SNOW — Sure.

The CHAIR — 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 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 invite you now to make a 15-minute presentation to the committee. Thank you for bringing in the lovely photo of your family.

Mr SNOW — Thank you very much for the opportunity to speak at the inquiry today. My name is Ben Snow. I am 43 and I am the director at a large local accounting firm. My wife, Michelle, is a qualified early years educator. She has put her career on hold to allow our family to access services for our children that we are currently getting out of Melbourne. My son, Bailey, who is six — that is Bailey there in prep at Moomba Park Primary School in Fawkner — has level 3 funding and has an aide, or access to an aide, through the schooling. I believe you had an opportunity to speak with Tony and some of the parents from the IDEA program at Moomba Park. I am huge advocate for those guys. They are amazing.

The CHAIR — We have visited the school, yes.

Mr SNOW — Obviously that is a mainstream school, and it runs a unique inclusive program specifically for autistic kids within their programs. Bailey was diagnosed at 2 years and 10 months with classic autism. As parents we probably knew at about 18 months that really there were some issues. Bailey attended intensive early intervention programs through ABA therapy — applied behaviour analysis therapy — which was centre based. There were twelve other children, and it was in North Melbourne. He started that at the age of 3. It was four days a week of one-on-one therapy for two and half years until he achieved school age.

Our daughter, Mia — there is little Mia there — is 2 years, 3 months. She will probably also get an ASD diagnosis. Despite not yet being diagnosed, we have been getting an abbreviated version of ABA from 12 months through the same Little Learners program for Mia. My wife and kids currently spend five days a week in Melbourne and return to Shepparton on weekends. I reside in Shepparton for my business, which is the only way we can really afford to access these services.

As a family or as a parental group, Michelle and I have been overly vigilant with our kids' behaviours as Michelle's family has a prevalence for autism, with both her brother and her only nephew being autistic. We embarked on a journey that, sadly, is out of reach for many families due to the costs. We were spending \$70 000 a year just for the program, and we also rent a place in Melbourne as a secondary home for the family, which costs \$25 000 or thereabouts, and you can imagine your living costs and travel costs back and forth. My family still comes home every weekend, which is great. Of course that is after-tax dollars, so it is quite a fair amount to get that point.

We are astoundingly proud of where Bailey is at with his progress. Through the previous and current ABA programs he has developed such things as language and comprehension, social interaction skills and coping mechanisms for sensory issues. Personal hygiene was a big one, such as toileting and brushing of teeth and so forth, as well as pedalling a bike and kicking a ball — all things that a lot of neurotypical children probably develop normally and parents would never understand what is behind the scenes to get a child to do that. They are amazing programs. It has also given us as a family some structure and coping mechanisms to be able to deal with both good and bad behaviours — reward and redirect — and all those sorts of things as well.

In terms of the issues we face, both personally and from a larger perspective as a regional thing, because that is what this whole process is about, I feel that we have lost and will continue to lose quality skilled people from our region, who will leave to access services in metropolitan areas because they are just not available here and that the cost to our area of losing those people will never be identified.

There is the pressure in support of trying to maintain a family unit when you are spending so much time apart. Obviously the children could really use the full family, the parental unit, there to support them. My wife does a lot of running around apart from the average school runs just to get to therapies for both the kids and so forth, and she is pretty much doing that as a sole parent a lot of the time. I certainly miss my wife and kids a lot.

The choices for services in Shepparton in my opinion are just not enough. The ECIS, which we were entitled to at about two and a half for Bailey, was wonderful. The people were wonderful. We dealt with the assessment team, and the speech and OT access was really appreciated. We were also under the guidance of Peter Eastaugh, who is a very well known paediatrician in the area. He has a lot of experience and is great with kids with autism. Again, he put us onto additional speech and OT-type services, but you are getting 2 hours a week at best. It is just not going to cut it; it is never going to cut it. We saw ABA therapy as our only opportunity to throw some resources behind something, once you deal with the grief of autism and what you are dealing with, to give our children an opportunity to have one-on-one and intensive therapy. Bailey is doing 28 hours a week of therapy one-on-one. It was probably barely enough, but it was great. Two hours a week — I know it is something, but it is really just not enough.

I suppose I had better come to the point of my submission. Really, at the end of the day, there were three main things. There was me advocating for the ABA and the type of program that is. I know there are other like services out there — I know there are many different service providers — but there are none in Shepparton, which leads me to make my next point. The people in Shepparton, even Peter Eastaugh, really had not come across ABA or even knew what it was. Over in America it is a known program; it is an evidence-based program. It is sad that the knowledge of that has not even reached Shepparton let alone the access to services for it.

The second point is the availability for regional families. It is not only the availability and the need for people to have to travel to get access to this, but obviously the cost is out of reach for the average family.

Early diagnosis — and everyone who deals with autism would advocate for this — at the end of the day early diagnosis is critical. The parents know deep down when something is not right. They need to step up and they need to be their kids' biggest advocates, like the paediatricians or anyone in the service providers who are dealing with them. The first few years of the child's brain are just so formative, and learned behaviours, once they get past a certain age, are just so hard to change. Those characteristics and the neuroplasticity of the brain start to become more of a challenge to mould.

With Bailey we see the possibility of adult independence and him being a productive member of society. Mia, being at high risk, has been doing early intervention in an abbreviated type of ABA therapy. She has learnt some critical social skills, such as shared play, joint attention and also some of her language subset skills.

I suppose at the end of the day I am here to support the ABA and bring it to the Goulburn Valley to help our town and the children and families here to cope, with the best possible intervention that is available. The reason I have brought my photo, as much as it is a beautiful photo — and it is; it is a lovely one to look at — is that it often hides what is really behind the scenes. That day Michelle and I had had some quite bitter fights leading up to the photo being taken. Bailey wanted to roll around in the dirt. There were two other families waiting to get photos done. Mia was not interested at all. That photo is actually photoshopped from about 100 different photos that we got there to try and get everyone smiling and looking in the same direction. It is happy to look upon as a nice photo, but it is not happy to reflect on as a nice memory. Often what people see on the outside is not what is really going on behind the scenes. The other two photos I have shown you before were genuinely happy photos that were more recent, and the kids were involved and interacted. That is what we are sort of getting out of what we are doing at the moment. Anyway, thank you for the opportunity.

The CHAIR — Thanks very much, Ben. Technology is a wonderful thing, and I am a great believer in photoshopping. It works a treat. Thank you so much for your very honest and warm presentation to the committee. I imagine it is very difficult living away from your family every week, week after week, so we really appreciate your time today. You mentioned that you are a fan of ABA, and the committee has heard a lot

about ABA over the last little while. Forty hours a week, I think you mentioned in your submission, is funded federally in the United States. Can you tell me where in the United States it is federally funded for 40 hours, because — —

Mr SNOW — I do not have the information in front of me, and subsequent to this I have found out it is state by state, so there are certain states that have it and it is not federally funded.

The CHAIR — That is what I thought, yes.

Mr SNOW — I came across it because one of the families that was attending Little Learners with us had two kids. Both were on the spectrum and both were attending the program at \$70 000 each, and they were in a situation where they had to choose which one of their children was going to continue on.

The CHAIR — I think the international recommended number of hours is 20 hours a week. Is that correct?

Mr SNOW — Yes, my understanding is it is 20 hours at three years old and then it increased as to the age — —

The CHAIR — Depending on the child's needs, of course. You mentioned the cost of ABA, and if it is not too impertinent of me, I would like to ask what the financial cost is to you and your family of engaging with ABA. I think you said 28 hours a week for your eldest child — that is outside of school hours?

Mr SNOW — No, that is school hours.

The CHAIR — Just the therapy itself, not necessarily the travel — without the extras — —

Mr SNOW — Yes, so the actual program we took on was a centre-based program. There were the psychologists from Autism Partnership in conjunction with CISCA, who are the therapist group — I believe they have joined together now. The children actually attended a centre. Traditionally the model is — and it still gets done out there quite a bit — that there is a therapist that the families would hire, independent to the psychology department. The psychology department would write the program, I would see the program and the therapist, and the therapist would run that. That has its challenges: it is significantly cheaper — it can come in at around \$30 000 or \$40 000 a year — but you have got therapists that come and go all the time who need to learn the program and who need to understand the children. The centre base has other kids to communicate with, it has an opportunity for social interaction and it also has the ability for therapists to rotate through the system so that they can be re-taught and trained and shown. That is why we took that one.

The CHAIR — So Bailey is funded at the school, at Moomba Park Primary School, which the committee has visited — we probably saw him there but did not know at the time — then outside of school hours he has 28 hours of therapy.

Mr SNOW — Not any more. As of when he started at Moomba Park, he does not do the ABA anymore, mainly because the therapy is built into their IDEA program. If it was not, we would certainly be doing hours outside. During school holidays he still attends a holiday program through Little Learners, which we used to attend, so he still getting some.

The CHAIR — Do you and Michelle practise ABA at home?

Mr SNOW — To the extent that we apply the principles, to a limited degree. There is a lot of relationship that we build up with the psychology department along the way. They work on mechanisms for dealing with behaviours, whether they are good or bad. That needs to be both applied at the ABA level and followed through at home. So there is certainly the follow-on. We do not necessarily do the token-based approach at home, but we do do the timeout type of approach and the, 'This is not appropriate behaviour' type of approach. We use the same language. So I suppose carrying through the language and the behaviours that they would otherwise get in that setting is what we do at home, yes.

The CHAIR — Moomba Park Primary School has a very successful integrated model. Is there anything there at that school, any aspects of that program, that you think could be improved?

Mr SNOW — Bailey is only in prep, so we are still coming to terms with how it sort of works from being one on one to him now being in a public school setting, I suppose, where he is in the class with 20 other children. I suppose just to elaborate there, each day the children that are on the spectrum and some of the other additional-needs children are extracted out into a specialty group for an hour at a time and given a social interaction type of activity or program to do. So that is really, I suppose, the specifics. All the children who are additional needs access that, but then obviously just in your normal course of events if there is disruptive behaviour and so forth, the kids can be extracted out and worked with. Bailey needs less and less of that as we go along, and I understand that is happening with all of the kids. That might be just standard and what happens in a lot of primary schools. I am just an advocate for what they are doing there. I cannot pick too many holes in the way they run it. The teachers we have dealt with are great. There might be other teachers that are not so good there; I am not sure.

The CHAIR — So after Bailey was diagnosed did you find that there were support services available to you here in your community?

Mr SNOW — Yes. We first accessed the ECIS program, which gave us access through — —

The CHAIR — Through the department?

Mr SNOW — Yes, that is correct. It gave us access to a range of speech and OT therapies. I do not think there was a long waitlist on either of those. The time to get into those was not ridiculous. I think it might have been a month's wait for each to get access to those services. From what was available and what probably is still available now I could not knock what they had there. That is the only access that he had to services. We also chose at that time a speech therapist as we wanted someone who actually had better credentials in dealing with autism, so we went to a private speech therapist there and did not end up using the ECIS one.

The CHAIR — What about for you and Michelle? Are there any support groups available to parents of children with autism or support groups for children with autism that you access or that you know of?

Mr SNOW — Michelle, I know, had involvement with the RISE program in Shepparton, which was an early kindergarten for kids with additional needs, specifically with ASD. It was like a playgroup where kids got to play together, but mainly the parents got to interact with each other. Michelle has always reached out where she could — —

The CHAIR — Most playgroups are like that.

Mr SNOW — Yes. Michelle has probably done her most reaching out through Little Learners. There were the parents of Little Learners through the school, so it was other parents at the school more so than accessing services. I suppose we are a private family, as much as I am happy to be in the public domain for this sort of advocacy. But no, we really have not accessed them, to be honest. I am sure we need them. We both go mad at times.

Ms McLEISH — Thanks Ben. I wanted to get a bit of a feel for the diagnosis time. You were living in Shepparton with Bailey, and when you got the diagnosis, as I think you have mentioned, you were not really surprised, and you said Mia is already showing some signs. So what was it that you noticed in particular, first of all, about your children before diagnosis?

Mr SNOW — There are going to be very few people in the world that will really understand or that go through the same process that we went through. Michelle had an understanding of her genetic predisposition to carrying a child with autism. From the moment that we found out we were having a boy, I was elated and Michelle was devastated because of the prevalence specifically in boys in her family to ASD. So from day dot — apart from what you could find out on Google, which is an immense amount these days — Bailey was on watch with everything from how he interacted with his toys. We noticed things early on around spinning and getting caught up on specifics, so spinning wheels and continuous spinners — inappropriate play, I suppose — joint attention and shared play, inappropriate play with toys, language delays. We went and accessed La Trobe's early diagnostic clinic at 12 months down in Melbourne, and they basically put us on the watch-and-wait list to see what happens — which is pretty much the same for Mia.

Bailey did a lot of the stimming-type activities with his hands, like a lot of the motorbike hands and the fingers and those sort of activities, and the routine-based stuff and the regularity and monotony of things. He did not really engage with other children. It was tricky because he always smiled a lot and always maintained reasonably good eye contact, but when you spent enough time around him, you knew you did not get that when it mattered and regularly. It was probably the small things, the red flag things that you tend to look out for, I suppose, in the early years, in the formative years. There is a lot of information out there that sort of tells you what to look for with the red flags and so forth, and with our predisposition, we put two and two together pretty early on.

Ms McLEISH — Have you thought about schooling beyond Moomba Park?

Mr SNOW — Every day. We have obviously got Mia and we have got to consider how her schooling works. We have obviously got Bailey. We have thought about whether we stay in Melbourne and continue to try to make this family dynamic of the Melbourne-Shepparton thing work. I have met other families — you become aware of them along the way — that are doing secondary education, and you speak with them and find what is available out there for them. I understand locally in Benalla there is quite a good program for — —

Ms McLEISH — EdSpace.

Mr SNOW — Yes, that is correct.

Ms McLEISH — Yes, we were there yesterday.

Mr SNOW — Fantastic.

Ms McLEISH — And we are heading to Dookie this afternoon.

Mr SNOW — Yes, that is the other one, and they are through the Mansfield services. We have spoken to Mansfield and we have spoken to Benalla, and we are probably just going to wait and see about Bailey's level of sociability. It is probably the social side of things that Bailey will struggle with, and that is what we will do — just assess where he is at, whether he is mainstream or whether he needs something a bit more specific. Yes, as I said, every day, but we have not come up with a conclusion on what we are going to do yet.

Ms McLEISH — Just with regard to the ABA, you said it was centre based. Where did you actually go for that?

Mr SNOW — That was just at the start of Flemington Road in North Melbourne.

The CHAIR — In North Melbourne, and Mia is having an abbreviated version?

Mr SNOW — Yes, that is right. They have actually moved. They have amalgamated their two centres; one was in Maidstone and one was in North Melbourne — to a new North Melbourne facility.

The CHAIR — So Michelle scoots her there while Bailey is at school.

Mr SNOW — Yes.

Ms COUZENS — Thanks, Ben, and thanks for sharing your family story — and it sounds like a pretty amazing family. I am really interested to hear your views on what sort of recommendations this committee can make to government to ensure that children with ASD are actually getting the support they need, along with their families. So have you got anything in particular that you can identify? Obviously you are paying your own way in a big way, and there are obviously lots of families that cannot do that. But in the general sense, is there anything that you think is really important for this committee to take on board around what changes can be made?

Mr SNOW — Parents of children with autism need the ability to throw all of their weight behind something so that they can move on from the grief and actually put it into action. Whatever program is available, if you can only access 2 hours of speech and OT and that is all that is ever going to be available because ABA is not mainstream enough for society or the cost is too much, then the parents need to be given the tools to have a set

program around home, which is hard enough when you are dealing with what you have got. At a minimum, that would be the starting point.

My view is that it is a bit of a chicken-and-egg type scenario. Is the cost of ABA the biggest problem or is it the fact that nobody knows about it so people do not access it? What Amaze and other groups have done with autism awareness in this country, particularly in Victoria with Amaze and so forth, is just fantastic. It is really good, and I assume that is why there is so much more diagnosis now. It is just awareness of what is out there.

Girls on the spectrum still obviously have a large degree of being left out because they present differently, and that has got its own challenges. Clearly diagnosis is the key behind everything. Until you have got a diagnosis or at least an understanding that you are dealing with an ASD matter, you really have no grounding, no floor to work off. That is clearly your key point. The continued awareness of autism, the training and having appropriate paedies and the public system here in Shepparton to allow that analysis to happen — whether it is done like La Trobe do at their early diagnostic clinic or whether it is something a bit broader — certainly needs to be brought to the fore.

My view is I think, all right, ABA needs to be affordable, but predominantly people need to be aware of it, and if we get awareness of it, then we will get access to people that are prepared to go and study in the therapy area and we will get the schools looking to having teachers actually getting trained at a base level at least with additional needs children but specifically for us with autistic children. It is probably about upskilling everybody, bringing awareness, and then there needs to be the backend funding.

Clearly from a pure economic sense — and I am an accountant so I will talk this way — the money spent in the formative years versus the cost of latter year dependency and intervention or institutions and so forth, there is no parity. To my way of thinking, I do not know whether it is a matter of being able to give tax breaks to people who are investing their money back into additional needs children or whether it be a direct handout to the actual people providing the services. It is funds and awareness; that is my opinion.

Ms COUZENS — Yes, and I think you have already highlighted the regional and rural issues. Being from a regional community and being close to rural communities, I know the difficulties. The fact that your family is living in another city sort of reflects where things are at for families like yours. One of the things I am interested in hearing from you is around the NDIS and where you see that linking in to your situation, if in fact it does.

Mr SNOW — We have been to NDIS sessions. We still have no idea what is going on. It seems from our understanding it is nearly an individualised situation, so what your situation is will be different to the next person's situation, and that gives no clarity to us around what that means. Does it mean we get more access to services? We have heard along the way that you may get something like \$40 000 towards your ABA or you could get up to that sort of amount for your children. But that was a generic throwaway line from someone. There is nothing specific to our situation. We do not know. Bailey has got the FaHCSIA funding along the way. Does that mean he is limited in getting anything further?

Mia has not got a diagnosis yet. I am assuming that things would not be available until a diagnosis is there, and that is fine, but again we have got no idea. As much as there has been the effort to get the information out there about NDIS, to me it comes across as so vague and undefined. And we are not silly people. I think we are educated enough to understand what we read and what we learn, and we just cannot understand what is in front of us.

The CHAIR — Thanks, Ben. I am going to play devil's advocate for a minute. We have heard a lot about ABA. We have heard from a lot of people who support ABA. We have also heard a lot within the autism sector from people who do not necessarily support ABA, the reason being that there is a perception that ABA forces children who are on the spectrum to fit into society when there is a belief among some in the autism community that children or people with autism should be accepted by society for who they are. Do you have a view on that?

Mr SNOW — Have you got a couple of hours?

The CHAIR — No, we have got 2 minutes.

Mr SNOW — I am hugely supportive of that underlying comment itself. From our perspective, I do not want to change Bailey. I do not want to change his quirks, his niches, the little bits and pieces about him — that

is what makes him. I actually adore the kids because of who he is. If we move house, it is not a big deal; he drops a chip on the car and he just loses it. His quirks and nuances are what makes him and who we love. I do not want to take that out of him. I just want him to have a coping mechanism. He does not have societal understanding. He does not have that ability to understand the interactions, because he has learnt out of a book and not out of interaction with other people. I just want him to have a coping mechanism to get by in society. His quirks will be what makes him who will be. He is obviously going to be loved or hated for it. I fully support the people who say that. I think I have made my point.

The CHAIR — Thank you very much, Ben, it is much appreciated. Thank you again for coming along today.

Witness withdrew.