

TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Melbourne — 10 October 2016

Members

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Mr Steve Ager.

The CHAIR — Steve, welcome to today’s public hearings and thank you for attending. 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 occur today, and you will be sent a proof copy of the transcript and will be able to make factual or grammatical corrections if necessary.

Thank you for your submission to the inquiry with regard to your 10-year-old son, Andrew. I would like to invite you now to make a short statement to the committee, and then we will ask you some questions. You have been allocated around half an hour.

Mr AGER — No worries. If I could first apologise for not being available in Geelong when you travelled down there. No doubt the recurring theme that you heard during the submissions is about routine and stabilisation of that routine. So when school holidays are school holidays, guess what? They are school holidays, so you go and try not to have any issues.

I am advocating today on behalf of my 10-year-old son, Andrew. I have some pretty general concerns with the way that ASD funding is managed in the state, particularly in the Department of Education and Training and in further education. I am not going to sit here and allude to the fact that I may have a silver bullet solution to it, but I think it is important for me to be able to air these views to you so that you are aware of what is happening and what has happened at the grassroots level in regard to having a child in Victoria on the spectrum. Would you like me to give you some examples?

The CHAIR — Actually because your submission was fairly comprehensive, I am quite happy to accept what you have put in your submission.

Mr AGER — As I am too. I do not want to sit here and rehash that submission again.

The CHAIR — Absolutely. No, that is fine. You did actually refer to education. I actually want to ask you a question, Steve, in regard to early intervention therapies and programs that Andrew may have accessed. You mentioned in your submission about your thinking of it as the ‘black arts’.

Mr AGER — Most definitely.

The CHAIR — And that you were perhaps a little bit anxious about what an early intervention program would look like or what the therapies might be. I thought maybe you could perhaps tell us a little bit about that.

Mr AGER — Certainly. Andrew was diagnosed at the age of three. As a result of the diagnosis we were put in touch with Gateways Support Services down in Geelong. I have nothing but the utmost respect for Gateways services, and the case manager that they gave us was very, very good at what she did. As a result of his diagnosis and the early intervention support that was available, Andrew has gone from being assessed as ‘low-average’ and not likely to be very successful at school to at least being on par with his peers.

I put that result squarely down to the support that he got from the early intervention package. That was in the form of speech therapy delivered by a Gateways occupational therapist and psychological therapies and assistance by a person in private practice in the Geelong region. Also as a result of that funding we were able to gain a second year of kindergarten funding from the state government. His birthday falls in February, so he was due to go to school pretty well before he turned five at the end of February, and that gave him an extra 12 months in a mainstream kindergarten, once again with all of those therapies that I have already mentioned provided by Gateways and the person in private practice, which in my view helped set him up for school.

That is the good part of it. The bad part of it was when we got the diagnosis we were strongly advised to go and see such-and-such psychologist and such-and-such psychiatrist in order to get a positive report in regard to obtaining funding for Andrew. My wife and I thought that this was not only a little bit dishonest but did not sit well with us. I guess any parent would really want to know where their child is, not where they are in regard to submitting an application to make sure they secure funding from the state government. We went for that option. We took him to the psychologist in private practice and actually found out where Andrew was. I feel strongly about that because, as a result of that assessment, I think we were more accurately able to steer the therapies into the areas that he needed and hence the outcome that we had.

Once Gateways was finished, and they only looked after him up until he went into mainstream primary school, back then in the Geelong region — and I do not know whether it was the case when you took evidence down there — in the outside area of Geelong there is a severe shortage of therapists — that is, speech therapy, occupational therapy or psychological support. The nearest one that we could get was Scope, which operates out of Newtown, which is a suburb of Geelong, and they do a fantastic job, albeit today Andrew was supposed to have speech therapy in inner Geelong, which takes 45 minutes for us to drive there, and then we found out that his speech pathologist was no longer there because he secured a job with another government department somewhere, and it is going to take another six months to secure another speech pathologist.

As I alluded to in our submission, the other ones in our local area are not NDIA registered; therefore, unless you are paying for it yourself, it is hard to find a specialist, and if we have to fund it ourselves, both my wife and I are war veterans, both retired from the workforce, so we do not have a lot of disposable income to splash around on things, even though we deem them to be important. In that way it has become a little bit difficult to get him the help that he needs in Geelong, which is not even really classed as regional Victoria.

Ms McLEISH — I am just interested to know, with the time of diagnosis, were there any signs that you picked up beforehand or you think that the doctors or the maternal and child health nurses might have been able to pick up on? Did they pick up on anything?

Mr AGER — No, it was actually my wife. I must admit, I have been married before and have two other children from another marriage, so it was a second time around for me. I could not see anything dramatically different in the way that Andrew was developing to my other two sons when they were going through the same stage. I am by no means an anti-vaxer campaigner or anything like that, but it just seemed quite unusual at the time that when he got his first set of injections he stopped speaking. We took him back to the doctor, and it was as a result of that that he was not diagnosed straightaway, but we were strongly suggested to take him to somebody that may be able to help.

We secured, in our opinion, a very, very good paediatrician in the Geelong area, a Dr Chris Cooper. He sat on the fence. He could not make his mind up whether Andrew was displaying autistic behaviours or not. In the end the clinical psychologist from Gateways, their speech pathologist and their occupational therapist put him through a battery of tests, and that was when the diagnosis was delivered. To answer your question in short, no. The maternal health nurse was not worried. We referred to his Blue Book at all times. His head circumference was right, his length was right, his weight for age was right and, if he was a horse, you would probably get top dollar for him. There was nothing there. It was mainly that he stopped speaking or communicating. At that stage we took him to the doctor and hence the paediatrician.

Ms McLEISH — What you think has been the best intervention that he has had that helped most?

Mr AGER — The best intervention would be the speech therapy, because the speech leads onto reading which leads onto comprehension which leads onto spelling which leads onto understanding what people are saying and how they are saying it to you so that in his way he can at least attempt to give you an appropriate response. It does not always work, but speech would probably be the cornerstone for him.

Ms COUZENS — Thanks for coming today. We appreciate it. In terms of education, in your experience what do you think the education system needs to do to ensure not only early intervention but that programs are put in place for autistic children?

Mr AGER — What I firmly believe is that the whole of the department of education needs a really good shake-up in regard to ASD and Asperger's and whatever other labels you want to put on them. Why do I say that? The teachers that dealt with Andrew in mainstream schooling were the same age as me, in their mid-50s, so that means they would have gone to university 30 years ago, maybe more. When we finally dragged them kicking and screaming to the table to have a support group meeting, they would openly say, 'We know nothing about autism. We know nothing about your son's affliction', to which we would say, 'What are you doing to manage them?'. The short answer was nothing.

Ms COUZENS — So they were not interested in looking at — —

Mr AGER — They were not interested at all. They did their teaching degree that long ago. I quote the old saying, 'Don't backchat me; I know boats' — 'Don't backchat me; I have been a teacher for 30 years, and I

know what I'm doing'. Time and time again we asked for somebody from the teaching staff to be identified — for example, who was going to be his teacher in the next 12 months — and to be sent away and do a course with Amaze. Amaze run courses for educators to get them ready for the next 12 months. We met with resistance every time. This went on for the first three years until the first lot of school holidays in year 3. There was an incident at school, so I just did not take him back and enrolled him in a private school.

Ms COUZENS — Is that working well?

Mr AGER — Most definitely.

Ms COUZENS — Are they specifically focused around autism, or was it just their skills were — —

Mr AGER — No, they are not. They are a mainstream school, but I think they are more interested in building the person on what the person can be built on than what they are in the government system. I am not going to sit here and bag the entire education department. My background is defence. I know that if I walk into a school that has got under 100 students, the student-teacher ratio is pretty good. That is in St Leonards. I would hate to think what it is in some of the growth areas in Victoria. When I was going to school there were 60 kids to one teacher and things like that. It was not as if they did not have enough time to do it; they just did not have the will, and I think that in the will are the skills. They did not have the skills because they did not want to get outside their own paradigm and step out of their comfort zone and do something that would assist.

One of the questions you asked for the submissions was: do you think there are more autistic children in Victoria? My answer is yes. We have more children. I go to a teacher at his new school and they will say, 'What kids aren't on the spectrum?'. That was not what happened when I was going to St Leonards Primary School. Everybody is on the spectrum in one form or another; it is just the level of difficulty and the level of being able to take things in. He is different in that way.

Which brings me to a point, if you do not mind, while we are talking about the education system. In the changeover from early intervention to mainstream school Andrew was identified for level 3 funding from the state government, which we were very, very grateful for. That funding did not follow him to his private school. Is that a problem? Well, I have already said that I have not got a lot of money to throw around on things, but I have to find his school fees. I am happy to do that. But I would also be happy if he would be able to have the same levels of support that that money — and I think it was about \$24 000 or \$25 000 per annum — would bring to the table in regard to assistance in the school for a student on the spectrum.

My problem with it in the state system is that the headmaster, or I should say the principal, has veto over where it goes, and I disagree with that. Case in point, when I have asked him to at least investigate sending an educator on an autism-friendly course, with \$25 000, \$5000 of that could have been expended on that. Their cornerstone solution to children with Asperger's and ASD in the school is to employ a teacher's aide.

As I have also alluded to, when we finally dragged them kicking and screaming to the table for a student support group that is supposed to happen every quarter, the principal decided to bring the education department southern manager for disability support in schools. To have somebody at that level freely sitting in front of my wife and me saying that, because a kid gets \$30 000 from the state government to come to school in a wheelchair does not necessarily mean we spent \$30 000 on ramps and roundabouts and all the rest of it. As a taxpayer, that does not sit well with me. As a constituent, it did not really sit well with me. Every time I beat a path to my local member's door, all I got was the same story. It is the principal's say, and to be quite honest, I do not think they have got the skill set to be able to manage that money, except put a teacher's aide on. It is not an employment solution; it is supposed to be there for a solution for children on the spectrum going to mainstream schools, which leads onto that first question. Are there more kids with ASD? Yes, there are and there are going to be a lot more of them in your state schools. Why? Because in Geelong, for example, we have one special needs school, Nelson Park — —

Ms COUZENS — We have actually got two.

Mr AGER — There you go. To get into Nelson Park, this magical — I do not know what the proper term for it is — psychological profile score of an IQ of 70. If you have 70 or below you go to Nelson Park; 70 and above you go to a mainstream school. If you look at ASD in total, not everybody is going to be below the 70. There are going to be some people on the top end of the scale who need to go to a mainstream school. So if they

need to go there, then they need to have those support mechanisms in place, and there are far better things to put in place that just teacher's aides, in my opinion.

Ms KEALY — Thank you very much for your submission and your time today, Steve. It is greatly appreciated. I just wanted to ask you some questions around accessing services in a rural and regional area. It is something that you have outlined in your submission. You have had challenges, not just accessing services, but also you feel there is a price burden or cost burden on accessing those services. Do you think you would have better access to services if you lived in Melbourne?

Mr AGER — Most definitely. If you look at the organisation Amaze and the network that they have, it is all Melbourne-centric in my view. All their courses of instruction are Melbourne-centric. Yes, they might run one or two in Geelong, but I do not think there are enough therapists down there to be able to take those courses. To get to the crux of your question, and it is only my opinion, no sooner had Julia's signature dried on the NDIS than the price for delivery of services in the Geelong-Barwon region mysteriously rose to the same amount that they would pay for you to go and see a psychologist or an OT or a speech pathologist. They went up exponentially pretty well overnight.

Then there is the drama of getting the right person in the right place at the right time. Andrew has also been getting physiotherapy for the last 18 months. The physiotherapist that he had has resigned from Scope. The new one that has come in took over four months to be appointed. She is a Melbourne resident. She is driving from Melbourne to Geelong every day, so you cannot get an appointment before 9.00 or 9.30, because she is on the road. You cannot get one out of school hours, because she is on the road to get back to Melbourne.

Do you take him out of school? Is the physio vital to him? Well, yes it is, but is what he is going to learn at school vital? I would tend to steer that what he is going to learn at school is going to be a little bit more vital. It is not half an hour that he is going to miss at school; it is the 45-minute drive there, the 45-minute drive back and the half an hour that he is going to miss as well. So they are hard to come by. If you can get them to go to school, in Andrew's case and in the case of my wife and me it cost \$180 for the therapist to go from Scope to Drysdale, which is around about 45, 50 kilometres, to deliver the session at Andrew's school. That is providing they can meet the school's guidelines to get in on the grounds to be able to deliver the services.

Ms KEALY — At either a state or a federal level, what do you think the government can do better to improve access to those services for people like Andrew?

Mr AGER — Well, the quick solution would be to throw more money at it. In Andrew's case his NDIA budget is around about \$1200 travel for each therapy that he receives: OT, speech. At \$180 a pop just to get them to his school to deliver a therapy, you can appreciate it does not take long for that \$1200 to go. So my easy answer is: throw more money at it and give the travel vote more money, or make the providers under NDIA more accessible so that they can make the employment conditions for therapists more flexible — that they do not have to live in Melbourne or work in Geelong, or if they do that they can deliver the therapies at a time that is convenient for both the client and them as well as their organisation.

Ms KEALY — So if you could have access to those allied health professionals locally and maybe more people trained to go into those areas, would that be — —

Mr AGER — I think it would. With speech pathology by itself, there are three listed in the *Yellow Pages* in the St Leonards-Drysdale-Ocean Grove area. That is about a 30-minute drive. Anything over that, I think, is starting to get a little bit unworkable.

Mr FINN — Steve, thank you for your contribution to this hearing, and it is certainly very worthwhile indeed. I am interested particularly about your claim to being humiliated by the state school teaching staff. How did that come about? Is it a lack of understanding? Is it just a refusal to change? What led to that situation?

Mr AGER — What led to it was it was suggested by them that Andrew be picked up early, so instead of the school day finishing at 3.15, pick him up at 3.00 and get him out so all of the end-of-day running around and noisemaking could be done without him. This went on for one term, and then at the next student support group meeting it was decided to change that and to get him ready for longer hours at school — that he remain there for the full core hours of the school thing. So I would turn up at 3.15, 3.20, to pick him up. On this day in question I was waiting and waiting and waiting for him for about 10 or 15 minutes. I could hear Andrew yelling, and I

went onto the school grounds and stood near the door of his classroom. I was there for a good 10 minutes watching the interaction between a visiting library teacher and a teacher who I think was full time at school, who were just basically laughing at Andrew having a meltdown, in regard to his autism. He was obviously at the end of his thing. They were unaware that I was there.

The visiting library teacher — the system is called MARC. What the acronym stands for I do not know. All I know is that they bring the truck into the school. Once a week kids change their library books over. He was in charge of Andrew's class. So my assumptions were that he a) was not aware of the change in knock-off time for Andrew, b) was not equipped to deal with a child on the spectrum having a meltdown and c) was not equipped to deal with the parent standing there watching him and then not realising that he had been seen — a couple of them had been seen — doing the wrong thing. From that day forward I did not take my son back into that school, and as a result of that I made application to enrol him into a private school, and that is when we found out that he had lost his funding.

Mr FINN — It is impossible for me to believe that what you are telling me is true. Your son lost his funding because he went from a state school to a private school.

Mr AGER — That is correct.

Mr FINN — Same disability, just a different school and he lost his funding.

Mr AGER — Just a different school, and the funding does not follow him to a private school. I understand the private school does get some form of funding. The advice I was given by the deputy head of the school that he currently attends is that it is nowhere near as generous as the level 3 funding that he was receiving from the state government for being in a state school.

Mr FINN — Were you given any explanation as to why the funding was cut?

Mr AGER — No. In actual fact we were of the opposite opinion, because on the changeover from early intervention to mainstream school in the first instance it was explained to us that his funding stayed with him no matter what.

Mr FINN — Did you make some inquiries as to what happened?

Mr AGER — Certainly did.

Mr FINN — And what response did you get?

Mr AGER — My local member stated that there are bags of money available at this point of time — that is, 12 months ago — and I am still waiting for these bags of money to appear to assist me and my wife to put my son through school.

Ms KEALY — Can I ask: did you put in a formal complaint about the two staff members to the education department?

Mr AGER — Yes.

Ms KEALY — Oh, good.

Mr FINN — I am just very concerned that if we have a situation where parents are denied the choice of where to send their child under threat of losing their funding, then we have got a major problem on our hands, I would have thought.

Mr AGER — It was a strong indicator for our decision to send Andrew to a private school, thinking that apart from his academic fees that that funding would be there to assist him with his learning at school. So it is not about the money to send him to school; it is about the money to facilitate school for him.

Mr FINN — And that is a decision of the department of education or somewhere else.

Mr AGER — That is my understanding.

The CHAIR — Thank you very much, Steve. We appreciate your time today, and good luck. Good luck to Andrew as well.

Mr AGER — Thank you.

Witness withdrew.