

TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Geelong — 19 September 2016

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Witness

Ms Nicole Stephenson.

The CHAIR — Hello, Nicole. We have seen you sitting in the audience today as well, nodding away.

Ms STEPHENSON — I have been, yes, nodding away. I am very passionate.

The CHAIR — Thank you very much for presenting this afternoon.

Ms STEPHENSON — I sort of came last minute. I just wanted to say to Deirdre how lucky your grandkids are to actually have you as an advocate in their lives. Well done!

I am actually a little disappointed that the NDIA have not stuck around to have a listen to us speak. I would have thought that that would have been one of their top priorities, so that is quite disappointing. I have a 15-year-old son who is on the spectrum. I tried early intervention and had him assessed when he was in kindergarten. He was seen to have just speech problems, and that was through Gateways. Then it was going to take 12 months for him to be assessed again. I am a qualified primary teacher and I am not willing to wait that long, so I travelled 3 hours to the other side of Melbourne to see Dr Rick Kefford and had him diagnosed there.

The CHAIR — How much did that cost you, Nicole?

Ms STEPHENSON — It would have cost over \$1000, because there were numerous visits, and considering he also works from Geelong, that was quite interesting. My son's plan: 18 months ago we started the whole process of the plan with the NDIA, and only recently had that approved. The last six months of his plan: to me, the plans are just a piece of paper, nothing happens. That is all they are, a piece of paper saying that you get this amount of money, that you do not actually get access to. He was actually given over \$13 000, and I have actually mentioned to them, 'Take every single cent away from me; I don't want the \$13 000, all I want is this' — and that was my son. He is not very social and loves to do art classes. He goes to Geelong Fine Art School. I note that when the NDIA were talking, and they were talking about mainstreaming, it actually made me laugh a little because their response to me wanting him to do those art classes was, 'It is not ASD-specific, therefore it is not covered by the NDIA'. I found that very, very interesting.

In this art school that he does go to there are three children who are on the spectrum, but there are also neurotypical children in there. I find that that in itself — if we are wanting to have our children be able to go out into society and be able to interact with society — is so important, for them to be communicating not just with people on the spectrum but neurotypical people as well, because that is what the world is. So I have been fighting for over six months to have this approved, and it is not going anywhere. They have told me to review the plan. They said it is going to be a lengthy process. I have had numerous phone calls, numerous emails. My support worker has tried the same thing, to no avail.

I had a phone call two days ago from a senior supervisor from the NDIA — I could not believe it; I finally got a call back — and she mentioned to me that she was going to take over that role, and she has never got back to me when she said she was going to get back to me. But I am used to that. It is funny in that I had not mentioned anything about that I was actually in the process of organising a rally, and the last words she said to me were, 'Now that I am actually going to take this on myself, I heard that you are looking to go to the media and do this rally. Are you still going to do that?'. I thought, 'Well, I've got nowhere with you, and it's not just for me; it's for everybody else as well'.

I will look back at my notes: the art therapy; integrating into the community. In regard to school, there are not really many options when it comes to school. I am lucky that I have a very hardworking husband, so the only school that would have been okay for my son was Covenant College, a private school. We are able to pay those fees and have him go to Covenant College. They have been fantastic with him, but for those who do not have those means, it really makes me upset to know that they are not going to get those same opportunities. That is quite hard.

In regard to the art therapy and it not being ASD-specific, they said it is not actually considered a therapy as such, which it is, because there has now been a childcare centre in Geelong that has actually put that as an NDIA-approved program. I could not understand why the art therapy he was going to would not have been considered the same. He does not communicate very well with others, and halfway through the session they all put in a gold coin and they get fish and chips, and it might not seem like a big thing for everybody else, but he actually comes back and goes, 'Mum, I socialised with the kids. I asked' — such and such — 'how is your

painting going?', and he would never do that. So this sort of thing is a necessity, an absolute necessity, and I just feel like I am fighting tooth and nail and getting absolutely nowhere.

The CHAIR — Thank you very much, Nicole; it is much appreciated. I hope your son does well with his art.

Ms STEPHENSON — Thanks very much.

The CHAIR — We have one more presenter, who has requested to be in private. Could I ask the gallery to leave, please. Thank you again for your presentations this afternoon; they have been much appreciated. After our next speaker we will conclude the hearing. Thank you very much.

Witness withdrew.