

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 Jules Haddock.

The CHAIR — I welcome to the public hearing today Ms Jules Haddock. Thank you for attending today, Jules. 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. Thank you very much for your submission — numbered 6 — which the committee has received. I would like to invite you to make a short presentation to the committee, Jules.

Ms HADDOCK — Sure. Thanks for the opportunity. I have just reread the submission, because it was written a while ago, so I have refreshed myself. Most of our issues have been around the usage of the NDIS since the pilot project began here in Geelong. Probably one of the first points was the lack of plan flexibility, particularly because we had an incident with our son where he had suicidal ideations and did not want to go to school. The school system is just backlogged, obviously, with kids lining up for psychologists, so there was going to be a wait there. So I contacted the NDIS, and it was a very long and arduous process that just seemed to dissipate and dissolve. In the end we sort of gave up in terms of trying to get a psychologist put onto the plan ASAP. As a family we managed to deal with that scenario ourselves.

My concern now is that the plans have been locked in for two years, so how do we foresee possible changes and predict that? Particularly because he is 15, there are a lot of social anxieties present in his life at the moment. That is one of our major issues at the moment, that having no flexibility of the plan we cannot foresee as parents what his needs are going to be two months from now, let alone two years down the track, and our experience with trying to change the plan really saw us throw our arms in the air.

The other issue I suppose that we have had too is with using the portal, that it just is not a user-friendly sort of service, particularly when you are trying to explain your current needs. So we literally threw the portal out the window and tried emailing, but even then we were waiting weeks for email responses and for reimbursements. They have finally come through, but it took me quite a number of emails saying, ‘Where is our payment back?’ — for a program that we as parents were funded for through NDIS.

Probably the lack of care planning knowledge around autism was the first thing that really hit me, though. With our first care planner it was heavily suggested that he should go in the holidays and join a YMCA program. I said to her, ‘Do you understand autism and his social anxiety?’. Just to suddenly throw him into a roomful of people — he does not know the room, he does not know the people — there would be no benefit other than a big glorified meltdown, which the staff on the day would have to deal with. We just had the strong feeling that the care planner really did not have her head around what autism was about, particularly with the social anxiety that is really present in his life.

The other issue too was that we had used a speech pathologist. She felt that she had run her gauntlet at one stage, but then he started to have lots of issues. He is, like many kids on the spectrum, often the butt of bullying, particularly on buses where there are uncontrolled environments. So we thought we would get a speech pathologist back in to help him sort of read the scene a little bit and develop some of his autism skills. But the onus was on us to prove whether we needed a specialist or not. How do we prove that, other than the school backing us? It was only when we got the paediatrician to write a very stern letter that we got a response to that. It took a lot of work, and I felt — understanding, having worked in the system myself for years — I had got my head around the service sector, but I thought at the time that if you were a parent that did not understand your rights and could not advocate well, that probably would not have happened. But even as someone that does understand the system, I was getting pretty frustrated.

In the end, where we are left now, we have no idea where the speech pathologist has gone. She has just literally disappeared. We had one service come in that said, ‘Look, we don’t have enough staff so we will refer you to another service’, and the speechy has vanished. That is sort of where we are left now. I am at the point of going, ‘Well, I’m a bit over chasing the specialist services’. It is funded in his plan but, like I said, we have no idea where she is.

The other issue for us, and it is probably because we are Surf Coast residents, is the respite that we were using at the time just really was not appropriate in terms of what our expectations were. I was hoping for an active respite support model where he could go out and not be at home — go and do some things that interest him — but the plan made no allowance for travel, so it had to be at home.

The staff that came around — their age and gender — it just did not work for him. He said, ‘Why have I got someone that smokes and sits around and watches television?’. In defence of the council, I think that is more of a systemic sort of issue, because it is hard to get a young person into HACC programs when they might only get an hour here and an hour there, but for us as a family we were hoping to get someone that was sort of more aligned with his age group, so to speak. He felt he was going out with grandma all the time, but in the end he could not do that because there was no mileage to cover any sort of out-of-home time — and we just put a halt to it because it was distressing him too much to have what he felt, and we could see what he meant, that age inappropriateness.

So they are probably some of the less fortunate things. But there are some good things that have happened as a result of, I suppose, NDIS. One of the things is when the plans are getting made I must say the staff are not hesitant to support if specialist services are required, and that is a really good thing. The problem is that two-year gap. What happens if you suddenly need a specialist within two years? The other really great thing has been that Leisure Networks have recently come into our plan as sort of like community connectors, and they have worked very closely with the school. Because Yaz is Aboriginal he could do his work experience a little bit earlier than the average kid — he is in year 9 — and as a consequence of that, Leisure Networks spoke to the school and set up work experience, and starting Thursday, he has a job out of that. That is a really great outcome that has come through that program.

Probably the other positive — and again, as a parent who is a fairly strong advocate — when I first signed up with NDIS for Yaz he was going to a computer group called The Lab, which is specifically for kids on the spectrum. I had to battle to actually get funding for that, because it was not, in the early stages, recognised as a suitable program for children on the spectrum. But I actually contacted The Lab, and NDIS now sort of support that, but we have had difficulties of late trying to get our money back each time we pay for that. But we have now got a Surf Coast group going, which is great for our end of the region, through that.

It is like anything. We have been very aware it has been a pilot project and there were going to be hiccups on the way, but I think at the end of the day the major issue was feeling that the onus of proof is always on us. Nobody knows their children like their parents — particularly, I can say, for me, because with my background as a trainer and also working in community services I know what is out there — but I am always left thinking if you were a parent that did not have that knowledge, did not have advocacy skills, there are so many services that you would probably miss out on. So that is a bit of our experience.

The CHAIR — Thanks very much, Jules, for sharing that. How old is your son now?

Ms HADDOCK — He is 15.

The CHAIR — I just want to ask a little bit about the process that you went through originally to have your son assessed and diagnosed. Could you perhaps talk through what that was like and whether there were challenges in that? Before I do that though I just want to note that you have actually addressed a couple of issues that we raised with the NDIA in terms of travel allowance which they claimed was available. You might want to go back with that.

Ms HADDOCK — Well that might go back to the shire then, because the shire was saying that there were no dollars.

Ms McLEISH — It might be more rural and remote too.

Ms HADDOCK — So it might be that administration side that we are not sort of privy to, but the shire had said there were no travel dollars. The last lot of respite was in-home respite.

The CHAIR — If you could just perhaps talk us through what it was like to go through that initial — —

Ms HADDOCK — Initially he was obviously having behavioural problems, particularly once he was in prep. That was when I suppose it became apparent that there was something going on and CAMHS got involved. The psychologist we were working with was fantastic and diagnosed him as having quite severe — —

The CHAIR — Did you have to pay for that psychologist?

Ms HADDOCK — No, I do not think we did.

The CHAIR — Was it through the school?

Ms HADDOCK — Yes, he was at school then, so I do not think we did. But the initial assessment was severe anxiety and no autism. I actually had to push for an autism assessment; the psychologist we were dealing with at the time did not feel that he was on the spectrum. To cut that story short, the autism team did the assessment and he was not diagnosed with Asperger's, he was diagnosed as being on the autistic spectrum. I knew that; I think I just needed it officially stamped.

The CHAIR — Who was part of that assessment team?

Ms HADDOCK — Well, it was 15 years ago. I would have to pull it out, but I know that there was either an OT or a speechy plus another psychologist, or it might have been a psychiatrist, I am not sure.

The CHAIR — Do you think you received good support after that diagnosis?

Ms HADDOCK — Not overly, no. No, no specialist services. We had no OT assessment done until I think the early stages of NDIS. I have worked in the system, but I do not know about the specialist services and did not realise how important the OT sensory assessment was to him. Along that journey no-one had ever suggested perhaps an OT sensory assessment would be a good thing for him. As it turns out, they are some of his real trigger points as well. It is like piecing the puzzle together backwards in terms of his behaviour, but it was never suggested in the early stages that we have specialists. But that was 15, 10 years ago.

The CHAIR — But looking back on that, what advice do you think would have been helpful to you at that time?

Ms HADDOCK — Obviously we were sent to a paediatrician. From a really early stage it would have been great to have a more theoretical understanding of what autism meant. We sort of knew it generically and from we could glean and read ourselves. But as I said, it turns out that his sensory issues are quite impacting, and I often think if we had known that, we would have had that assessment done earlier. There would have been so many things — for example, even down to plastic raincoats we were putting on him that we had no idea were actually causing him to have meltdowns just from the material. I think if we had had more guidance in the earlier stages about the importance of getting those really early assessments done, that would have been great.

The CHAIR — And perhaps some advice about what being ASD would entail for you as parents in the future?

Ms HADDOCK — Yes.

Ms McLEISH — Thank you, Jules, for coming in and sharing your story. You talked just briefly before about the Laboratory and in your submission you mentioned it, and one of the comments you have is:

There is no more relevant and beneficial program for a child on the spectrum!

Can you tell us a little bit about the Laboratory — how often you go, what it offers, what makes it so special?

Ms HADDOCK — Yes, sure. Yawan's focus area has always been computers, which I think for a lot of kids on the spectrum is the world. Trying to engage him in socialising with other children over the years was really difficult, as they did not have the same interests. But the day he walked in he was at home, and the conversations were starting, the chatter going on amongst the kids, and the mentors are just brilliant because they do not just silo the kids behind computers. Occasionally they stop them and work on some social interaction with the kids, but they are really powerful. As a consequence he has actually developed friendships through that. Some of them remain sort of cyber-based, but without fail every Monday he is standing at the door with his laptop under his arm ready to bolt out the door because it is a safe place for him to be.

The other side of that program too is that they develop the skills of the kids. They are constantly harnessing the expert, I suppose, in them, because this is their love area. Even taking him to a paediatrician, he will never talk to other kids in foreign environments, but if he spots someone in the waiting room from the Laboratory, it is me going, 'Come on, hurry up'. Normally it is the other way round.

Ms McLEISH — Can you describe the environment, because you said when you walked in it was immediate, so I was imagining computers around the room, but then you said he has his own laptop?

Ms HADDOCK — All the kids bring their own devices to it, so they just set up a room with tables and occasionally have big screens. The one at the community centre, which I think is great — the community centre in Torquay are running it — is just a room with tables going around it. It is really simple, low cost but incredibly effective.

Ms McLEISH — Who runs it?

Ms HADDOCK — The Laboratory are based in Melbourne. All I know is they are based in Melbourne. They started the group here in Geelong. It started to get so many bums on seats, so to speak, that they started other classes. Because we are in Torquay, we had the tyranny of distance, so I approached them and they were fantastic in saying, ‘Yep. If you think the numbers are there, we’ll start running a group’, which they are doing now up there as well.

Ms McLEISH — I have just got another question about the care planners, because you said earlier that you thought that they did not really understand autism and the social anxieties.

Ms HADDOCK — When it was first set up, the plan, so it was sort of in that pilot project.

Ms McLEISH — So do you think things have improved since then? I guess you probably speak to other people.

Ms HADDOCK — Being a trainer I do have some feedback from some students who have children who are on NDIS and some of them do get a little bit frustrated. They feel that the planners do not necessarily have the skill base. It is hard enough for us as parents to get our heads around the spectrum disorder over the years, so I can understand for a planner to have expert knowledge in all different areas of disability would be quite challenging. Maybe my feeling sometimes is the focus is more around the budget rather than what the drive is behind it. This is the budget and this is what we have got to stick to regardless of what the child’s need is. But I think things are probably getting better. Like I said, I am aware that we were the pilot project so there are going to be some hiccups along the way.

The CHAIR — I think you contradicted again the NDIA when you mentioned the inflexibility of the plan. So you had to go through a review to get that changed?

Ms HADDOCK — No. We were told there was a review.

The CHAIR — But you did not ask for that review?

Ms HADDOCK — No. But the plan review did not actually in the end happen as it seemed too big a process for us, so we gave up. We did not get the psychologists on the plan that we were requiring, so that did not happen.

The CHAIR — In terms of the speech pathologist, you felt he again needed that but it was not locked into the plan and you had to wait two years to change the plan to get the speech pathology back?

Ms HADDOCK — No. It eventually happened, but it took the paediatrician to write quite a bold letter.

The CHAIR — So it was not a simple process? There was not that flexibility that is probably needed for people with ASD to change plans according to changing needs?

Ms HADDOCK — Yes.

Ms COUZENS — Thanks, Jules. I appreciate you coming along today. I have got a couple of questions. You mentioned Leisure Networks earlier. How much of a role have they played in supporting you and your son, and do you see that they have a broader role?

Ms HADDOCK — They have stepped into this year’s plan, and I did not even know about that part of the plan. I think it was a new initiative since we first signed up, but they were just fantastic in terms of the work experience because we want to get him out into the world to fight the anxiety, I suppose. They were just

wonderful. They were just constantly emailing saying, 'Have you heard from the school?', and if we had not, they would be ringing the school. They played a really fabulous role. It was a great outcome. Actually I have not yet told them — I must tell them — that he has got a job, starting this week. So for us it was a good service. I would believe that they would be great for parents that did not know what was out there, because they really went on the hunt and were really person-centred and focused. That is what I liked. It was not about them saying, 'This is what we think is a good idea'; it was actually, 'You tell us'.

Ms COUZENS — Yes, they are a great organisation. I was just wondering whether there was some way of connecting the work that they do with people with autism specifically?

Ms HADDOCK — I know that they have staff available, and we started to talk a little bit about that, but at the moment Yawan just felt like this was all he wanted — just to get the work side. We are very driven by what he wants happening. He is 15 — come on! — a teenager.

Ms COUZENS — Yes, of course. So have you been involved in any other parent support groups at a local level?

Ms HADDOCK — Look, I have connected just to Gateways occasionally with the newsletter. Again it is the tyranny of distance, because some of the parent support meetings are in the evenings, and by the time I get home from work and — —

The CHAIR — We can empathise with that.

Ms HADDOCK — And we have explored, I think it was a tree program or something.

The CHAIR — Treehouse.

Ms HADDOCK — Yes. The kids were a lot younger, and he was not interested. He wanted age-specific activities. But The Lab has just hit the absolute mark with him. It is just fantastic.

Ms COUZENS — So am I right? I thought I heard you say before that you actually initiated the laboratory coming to —

Ms HADDOCK — Torquay, yes.

Ms COUZENS — Torquay? So there is a potential for it to come to Geelong, for example?

Ms HADDOCK — They are here in Geelong, and the issue for us is just having to drive in and out on Saturday mornings.

Ms COUZENS — Sure.

Ms HADDOCK — But now they are doing an evening program in Torquay, which is fine. They were fantastic as an agency, and NDIS are now supporting that. It is just that we have had some issues sometimes trying to get the funds back, because we are just not comfortable using the portal, so I do it by scanning, and I imagine emails just get lost in cyberspace from time to time.

Ms COUZENS — Yes. So from your experience what do you think are some of the keys things that we need to know in coming up with a better system?

Ms HADDOCK — Probably from the early stages of diagnosis understanding the importance of that, the specialist assessment, to really give us some insight into behaviours that were happening and that we had no idea what the triggers were about. Even in terms of the speech pathology, I mean it took me a lot of reading to understand the theory of mind and social pragmatics — it would have been great to know that stuff earlier rather than just, 'He will have issues socially', because that is such a general statement to be told. But maybe some really early education around that so we could be a little bit prepared for some of the behaviours and what they mean and how we could help reduce some of that as well.

Outside that, I understood the services sector, and I do believe that the active support model is great. I do not think that often respite services, through HACC, offer that. It is often the babysitting model, whereas we were really after the — and from time to time they might have had a great staff member who was starting to do that,

but with the nature of that industry people were leaving. But I think it is around that sort of specialist assessment so we could just be a little bit prepared to support him in a bit more depth.

Ms COUZENS — Thank you.

Ms McLEISH — About 10 months ago you indicated in your submission about the reassessment — and we had a bit of a chat about this earlier. You mentioned trying to predict a two-year plan. We had heard earlier that for younger children they might have six months, and then it is typically a year. Has there been movement on that for you?

Ms HADDOCK — No, we are locked in now to a two-year plan. In terms of movement, can we go back to one year or — —

Ms McLEISH — Because it is 10 months since that time, I wondered if anything had changed. So you are still locked into that?

Ms HADDOCK — Yes, we are still locked into the same plan. It is probably now because most of the issues that happen are social based. He does not want to see a speech pathologist because he had a change. We had one service come in and somebody left, and then they did not have room in another service. So it got very much like — he was just sick of having different people to engage and start again with. Things are going pretty well at the moment. We have a great relationship with the school. The school that he is at is fantastic, and most of the issues are centred on bullying.

The CHAIR — Is he in a state school or special school?

Ms HADDOCK — Yes.

The CHAIR — Special school?

Ms HADDOCK — No.

The CHAIR — Just a mainstream?

Ms HADDOCK — Yes, mainstream. But they have been fantastic. Most of his issues are based on bullying, and they are very quick on moving on —

Ms McLEISH — It seems to be common.

Ms HADDOCK — when those incidents happen. One of the things, I did not put it in the submission, but myself and a colleague, in year 7 — and I also did some in primary school — the welfare worker was running education programs for the children around autism, and all the teachers noticed a marked change in some of the behaviours of the kids, that they were quite receptive of and, I suppose, understanding what their little classmate was all about.

Ms McLEISH — That was primary school, you said?

Ms HADDOCK — It happened in primary school and also in year 7.

The CHAIR — I have one last question. You mentioned that you had no confidence in the NDIA portal.

Ms HADDOCK — Oh, no.

The CHAIR — Was it the portal?

Ms HADDOCK — I call it the porthole. I feel like I am lost — —

The CHAIR — The porthole, okay. We will say portal, because that is what you have written in your submission — portal.

Ms HADDOCK — I enter the porthole.

The CHAIR — Just briefly, can you say why and what you think needs to change to improve that?

Ms HADDOCK — Probably from being an adult trainer, it is use it or lose it. It is one of those things you do not use all the time. I file the password in the file and then that gets pushed up the back. I am a people person; I want to actually talk to someone about my son rather than type about my son, and the tone and pitch of typing — you often do not get your message across how you want it to come across. I think, not so much my husband but for me it is just another arduous task. If I have to access anything through it, it is like, ‘Where’s that file? Where’s that password that I need to put in?’.

The CHAIR — Maybe Yaz should do it for you.

Ms HADDOCK — No, that is when suddenly he knows nothing about the computer.

The CHAIR — Obviously there is an issue there with responding to people who access the portal via email — like, they are not getting responded to quickly, there is a delay and perhaps they are not being responded to adequately. Am I getting the right sense of that?

Ms HADDOCK — Well, recently, probably about two or three months ago, I emailed because we had not got our payment back for two terms, and I was told the planner had changed. But we actually did not know the planner had changed.

The CHAIR — So there was no communication around that?

Ms HADDOCK — No.

The CHAIR — So it is a communication issue that is not just face-to-face but also extends to the portal?

Ms HADDOCK — Yes.

The CHAIR — Jules, thank you so much for your time this afternoon. Can we as a committee wish Yaz all the best with his new employment coming up this week. Thank you very much.

Ms HADDOCK — Yes, very exciting. Thanks for the opportunity.

Witness withdrew.