



LEGISLATIVE ASSEMBLY FOR THE AUSTRALIAN CAPITAL TERRITORY

**STANDING COMMITTEE ON HEALTH, AGEING
AND COMMUNITY SERVICES**

(Reference: [Inquiry into the implementation, performance and governance of the National Disability Insurance Scheme in the ACT](#))

Members:

MR C STEEL (Chair)
MRS E KIKKERT (Deputy Chair)
MRS V DUNNE
MS C LE COUTEUR
MR M PETTERSSON

TRANSCRIPT OF EVIDENCE

CANBERRA

TUESDAY, 12 JUNE 2018

Secretary to the committee:
Mrs J Moa (Ph: 620 50136)

By authority of the Legislative Assembly for the Australian Capital Territory

Submissions, answers to questions on notice and other documents, including requests for clarification of the transcript of evidence, relevant to this inquiry that have been authorised for publication by the committee may be obtained from the Legislative Assembly website.

WITNESSES

MAY, MS BROOKE220
McINNES, MS GENEVIEVE, Physiotherapist, Therapy 4 Kids233
O'MAHONEY, MS CAROLYN, Director, Therapy 4 Kids233
VRKIC, MS DANIELA220

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Amended 20 May 2013

The committee met at 1.33 pm.

**MAY, MS BROOKE
VRKIC, MS DANIELA**

THE CHAIR: I formally declare open this public hearing of the Standing Committee on Health, Ageing and Community Services inquiry into the implementation, governance and performance of the national disability insurance scheme in the ACT. On behalf of the committee, I would like to thank you for attending today.

This afternoon the committee will firstly hear from individuals who care for young children accessing the national disability insurance scheme. I remind witnesses of the protections and obligations afforded by parliamentary privilege and draw your attention to the pink privilege card on the table before you. Could you confirm for the record that you understand the privilege implications of the statement?

Ms May: Yes.

Ms Vrkic: Yes.

THE CHAIR: I remind you that the proceedings are being recorded by Hansard for transcription purposes. Before we proceed to questions from the committee, would you each like to make a brief opening statement?

Ms May: I am here as a parent. I have three children, two of whom have recently been diagnosed with autism, amongst other challenges. I am here specifically because I put in a submission to the inquiry about my youngest son, who has been having developmental delays and issues for a very long time and for whom we were trying to access help: any sort of help, but in particular NDIS support. He got a plan last week, but it has taken years to get to this point and in that time his challenges have probably increased more than they would have if we had had some support, and we have sort of been at breaking point as a family trying to get there.

Getting the diagnosis, I think, is what meant that we finally got NDIS on board and we finally got accepted. But he is turning seven next month, so he has missed out on that early intervention critical period. It has been very difficult. The diagnosis process itself is very long. I feel as though had we got the diagnosis earlier we would have got onto NDIS earlier. But we are not alone in finding that a really long process. It is also a really expensive process and it requires a lot of push from parents. That process took us more than a year, but it was a year from the paediatrician saying, “Yes, I think he has autism,” to actually getting a report saying, “Yes, he does have autism”—and a couple of thousand dollars, a lot of tears, and a lot of time on the phone advocating for him. It is all unnecessary and it adds to an already stressful situation when you have children and you are concerned about their welfare. In the meantime, he is not getting intervention. All that time I have spent on the phone and all that money I have spent on assessment is time he is not getting and intervention he is not getting.

Ms Vrkic: Before I get to my situation, I would like to say that I concur with a lot of what you are saying. I know a lot of families that are currently in your family’s situation.

My family's situation is a little different. I am the mother of two boys who both have a diagnosis of autism spectrum disorder. The boys are 11 years old and eight years of age, so they are at a different stage to what Brooke has been describing. However, we went through all the diagnosis and starting out in early intervention long before the NDIS came into play, so our scenario was totally different. That is why I feel very strongly and am sympathetic towards what is happening in that area with the problems around the NDIS.

As I said I am a mother of two boys that are diagnosed. My older boy is 11 years of age; he is what you would consider a level 3 diagnosis, which means he is non-verbal, quite severe in some of his behaviours. Being non-verbal makes it very difficult to say what he is like as far as learning is concerned, but there are a lot of learning issues there. Some of them are around the fact that he is very frustrated and cannot communicate. Others are because he probably has a learning disorder that accompanies the autism diagnosis. He also has what is called a sensory processing disorder, so he has issues with sensory. Medically, we do not have any diagnosis for epilepsy or any other comorbid conditions, but we are getting to an age where some of his behaviours have led us to suspect that there could be some other neurological problems going on, and it is causing great distress in our family because the behaviours are escalating and there is a lack of assistance, help and knowledge in that area. It is hard for us to access, partly, maybe, from being in the ACT and some of it just because it is hard to access that.

My 11-year-old has a younger brother who is eight years of age and was diagnosed with autism level 1, which I think would have been considered Asperger's syndrome under the DSM-IV, but was recently re-diagnosed, in the last month or so, to autism level 2. And there was a large discussion around him now having an intellectual disability, because he has a learning disorder. His learning disorder is quite pervasive; it is around all levels of education. He has literacy problems, maths problems and problems understanding. We have had a lot of issues with this particular boy in understanding, but they are higher level problems than we had with my other son.

With our family situation as it is, it has been quite stressful. As I said we have an older son that is 11. He was diagnosed around age two, so for at least nine years I have been around the autism community. I know a lot of people; I have run my own early intervention program at home with this boy, and then the younger one, for nearly eight years, varying from 15 hours a week to 30 hours a week, which my husband and I fully funded until the NDIS came into play in the ACT, in, I think, 2015.

So that is my experience. I have really struggled with the system from the moment we entered, trying to get the right supports and therapy and justify the way I used to run things compared to the way they want to do it and what they want to provide for care. Basically, the whole review, the yearly review process, has been a massive disappointment, and a lot of stress, considering I am going through the stress of having children re-diagnosed and have an 11-year-old with a lot of problems.

THE CHAIR: Thank you very much. I will kick off with questions, and I will start with you, Ms Vrkcic. You mentioned that the NDIS wanted to see a certain set of

supports provided for your children which were different from what you were providing to them.

Ms Vrkic: Yes.

THE CHAIR: What did those supports look like, and were they specific around that, or were they allowing for some flexibility?

Ms Vrkic: I cannot say there was no flexibility, because we were allocated money. With my first NDIS plan, although it was not to the level of funding that we were doing privately—as I said, we were funding up to 30 hours a week of therapy, and they were not funding to that level—I was given a decent amount of funding and they said, “This is flexible. Do with it what you wish, within some guidelines.” I had some guidelines.

It got worse. With the first review, they were saying, “Here is your funding; do what you will with it.” But when I went into those reviews, I would say, “Look, my son has this condition. He has autism spectrum disorder. He is non-verbal. He communicates via an augmentative device like an iPad. He needs X amount of hours per week in order to help him to communicate. If we do not get him communicating, get rid of the frustration, he will not be able to perform any duties out there in the community and be contributing.”

Then there were things like the occupational therapist who said that my son had quite severe dyspraxia, which is a motor planning problem, which contributed to him being less able to use the iPad physically, for him to be able to perform personal care duties like going to the toilet, toileting, showering and all these things that you want him to do in everyday life. They would come back and say, “He will need X amount of hours of this.” These are professional reports. They are basically saying, “It is based on professional, published documentation saying that with dyspraxia you need intensive and repetitive therapy, so we recommend X amount of hours.” You present this to the NDIS and they come back and say, “We have given you this amount of funding.” I say, “That is great. That will give me a therapist appointment with an OT once a month. One hour once a month does not cover that.” Or it is “I have one hour of speech therapy per fortnight.”

It is not just what the NDIS also funds. Even if the NDIS comes back and says to us, “Yes,” and they have: “We will give you funding for speech therapy; we will give you funding for the OT; there is enough for a fortnightly appointment; there is enough for a fortnightly appointment for OT and for speech,” it does not work that way. You need someone to come in there and coordinate.

There is a lot more than just speech and OT, depending on the diagnosis. In my son’s case, it requires a holistic approach, so it requires a team of experts, which they talk about a lot in early intervention but it seems to be forgotten about once you move out, this multidisciplinary approach. It still goes on; it does not matter whether they are seven or 17 in some ways. But what I found was that they would cut out bits and pieces of it. The funding would be X amount, and I would say, “Well, that is great. You have given me a bit for speech, but I cannot just go in there once a fortnight for one hour. Every day there has to be work on this.” Or I would say, “He needs at least

nine hours a week with a therapist doing this. That is a therapy assistant.” “We cannot provide you with that funding, but we have provided you with this.” I am, like, “There’s no point in providing me with that if you are not going to follow through with the other.”

Unfortunately, it never tied in very well with my son. To me, I look at it as a holistic package. I could not get that point of view across until I fought and fought for a review. And this time around I had one. I fought and fought. I got more funding. But with the explanation and the way they put it through, I do not feel that they understood what I was trying to say, which was that we need a holistic approach. It cannot just be ad hoc. It cannot just be, “Yes, we will fund a little bit of work with speech.” You cannot just fund one hour once a fortnight.

THE CHAIR: Was there funding for support coordination?

Ms Vrkić: I did. They saw it a bit differently. Unfortunately, this sort of stuff is intensive. If you want to see results, you need to put in the hours, whether it is early intervention at the age of three, four or five, or whether it is even at seven, eight, nine, 10, 11 or 12, whatever. You have people like Professor Tony Attwood who will tell you that they need this kind of intervention well and truly above the ages of six, seven, eight or nine, that you never give up on speech and whatnot.

I think most of them have given up on my son. They all sit there and say, “We need to give him an alternative way of communicating. You want to do it via augmentative communication via a device.” That requires even more therapy, because now you need to get into the whole motor planning side; you need to also get into the learning disability side. Then, of course, you have the speech therapy side, the communication side: how do we approach getting him to communicate? That is not one hour per fortnight. And if you are going to allocate one hour a fortnight, or even one hour a week, and it results in, I don’t know, \$5,000 a year and you want to give it to all these kids, I would actually stand up and say to you, “It’s a waste of money; don’t bother giving it.” Sorry.

THE CHAIR: Just to clarify, are your two sons both on plans?

Ms Vrkić: Yes; they are both on plans.

THE CHAIR: Do the plans work together?

Ms Vrkić: This time, when I had the last review in April, the gentleman I spoke to, the delegate, was really good like that. He spoke about some of the core funding that would go into getting a support worker to come in and help with the older son. He did speak about how he would think it was reasonable to use some of it to help my younger son as well when, say, I and my husband needed to be there for my older son, so that we could sort of overlap across some of the supports so that we can make it work. To be honest, I think that will help in our family situation to a certain degree, but I really fear going forward.

I spoke to a lovely gentleman this time upon review. In my case, can I just say, I got both of my kids reviewed. The five-year-old got something like \$5,000 or \$6,000

more, whether you want to consider that a lot or not. Probably in the grand scheme, no. I think my older boy got maybe a bit over \$15,000 more because of his level of care. When you put that together, let us say that is \$21,000. I had to go through a review process for that, from September until April to do that, and waste a hell of a lot of time and to me a hell of a lot of money, and do a hell of a lot of jumping up and down. There were a lot of breakdowns from my husband, who is our sole provider in the family. I do not work for money; he does. There was a lot of time away from my children if I had to use whatever funding I already had in place. I can see you nodding. Over that? Over \$20,000?

Am I going to go through this again next year? I will fight next year and the year after. I will literally have to be carried away into hospital on a drip or something before I stop. Believe me, Ms Le Couteur: there are families that are doing that. They are being carried off to hospital; they are having breakdowns over these kinds of amounts.

MRS KIKKERT: Brooke and Daniela, thank you so much for being here today. I am trying to establish where the line of communication failed between you and your family and also NDIS. With respect to when you first contacted them, did the paediatrician write a reference to NDIS?

Ms May: I first contacted the NDIS well before we saw a paediatrician. When I first contacted the NDIS, we were seeking early intervention funding for developmental delay. We had not yet considered autism because we just did not know. He had been having some behavioural problems at preschool. He was in a three-year-old preschool program.

Over the course of maybe six months to a year, he was seeing an OT who came and visited him at the preschool program through the child development service. She did some assessments with him. She said he had significant sensory processing difficulties and a significant delay in both his fine and gross motor skills. Based on that report she said, "You guys should be eligible for NDIS. He really needs the help. There is nothing else that CDS can do for you. We are an assessment service; we are not treating." She wrote us the report, and that was the first contact we made with NDIS.

At that point, after a couple of months we got rejected by NDIS. The man who rang to tell me that Dylan was not eligible said that he needed to have a report from more than one health professional, and that the report from the OT was not enough on its own.

MRS KIKKERT: Did the OT know that?

Ms May: No, she did not.

MRS KIKKERT: She thought her reference was enough?

Ms May: I think it has been a moveable feast. As the NDIS has been implemented, the expectations have changed and the people who are working in the system often are not up to date with what the expectations are. I believe that when it was introduced, having a report from one professional was enough. I do not know that; I was not there, but that is what I have heard. He said, "We need more reports." I thought, "Okay,

that's fine. He needs help; that's fine. I will be calm; I will get some more reports." We then had an assessment done on his speech to say he also had a delay in speech.

At this point he was getting older and his issues were getting worse, not better, so I was thinking, "There's actually something more than just a delay. We're not going to catch up here. There's actually something really significantly going wrong here." We went and got an assessment of speech. At that point, we had been trying to toilet train him since he was three. He turns seven next month and he is still not toilet trained. We were seeing a continence physio. He was being treated for encopresis, which is an overflow of faeces due to not being toilet trained. It is quite common in children with autism. We decided that we needed to see a paediatrician to see what else might be going on. We did that privately, but, of course, there is a waitlist to get in to see a paediatrician.

By the time we got to the paediatrician, she had a good talk with me and said, "Look, I really think it's worth pursuing. Basically, reading between the lines, yes, he has autism, but we need to have it written by the professional diagnosing people." At that point his behaviour was reducing more. We were having daily, multiple times a day, faeces incidents, and aggression at home. In the context of our family, I have two other boys, one of whom also now has a diagnosis of ASD but at that time we were not sure about what was going on with him. As you know, there are competing priorities in families, and life is really hard.

MRS KIKKERT: Of course.

Ms May: We applied again for NDIS. We had not had that diagnosis yet, but now that I had all of these extra reports and evidence, I thought, "Great. At least while we are waiting for this diagnosis, we will get NDIS funding, and we can start getting somewhere with him."

Meanwhile, I am not saying he was getting nothing. I did pay privately for some psychology, and, where we could, we did pay for things, but we had two boys that had extra needs, so we were balancing matters, and we are on a single income. I cannot work because I keep getting calls to pick them up from school. It is very complex. Meanwhile, we were on the waiting list to see the child development service again for the autism assessment.

I put in the NDIS thing again. I had a social worker from west Belconnen—the community centre there. She was ringing on my behalf. I was ringing to say, "How long is this going to take?" They tell you that it will take 21 days, and, when you call and sit on hold for 40 minutes, they tell you that that 21 days is no longer relevant. I do not know why they still put it in the letters because it is not happening.

Finally, in November, I got a phone call to say that he was not eligible for NDIS because he had now turned six and he did not have a permanent disability diagnosis; therefore it would be better for him to access mainstream services. They told me to contact the child development service to discuss the mainstream services that were available.

I contacted the child development service, and they informed me that there are no

mainstream public services available. When I rang NDIS and told them that, they said, “Can you get that in writing for me, please?” I said, “Do I need to ring every single service in Canberra and have it in writing specifically that they are not going to help my child?” This is not about me; this is bigger than me. It became apparent then that we needed to get a diagnosis for him as soon as possible; otherwise we were not going to get any help.

The issue is that, privately, that diagnosis cost \$2,000. That \$2,000 could pay for a few weeks of speech, OT or psychology. However, you have to decide what you are going to do, how you are going to do it, and where you are going to get that \$2,000 from in the first place. We had been on this waitlist for CDS. To get on the waitlist to have the autism diagnosis publicly, you need to have a hearing assessment and a cognitive assessment. A cognitive assessment, paid for privately, costs \$700. You can get it done through school. We go to a Catholic school, and they only do the cognitive assessment if they suspect there is an issue with cognition. I then had to argue with them—not argue with them but negotiate; everything feels like an argument, though—to organise for him to have the cognitive assessment.

MRS KIKKERT: Did the paediatrician tell you that you need a cognitive and hearing assessment done before autism is assessed?

Ms May: Before the public system will put you on the waitlist for the autism assessment, you need to have those assessments done.

MRS KIKKERT: Did you receive this information, though, from the paediatrician when you saw her?

Ms May: She verbally mentioned it to me—

MRS KIKKERT: That is good.

Ms May: and when the CDS received the referral, they send out a letter that explains that to you. When he finally had his cognitive assessment, because he has autism, he went into a room with a lady he had never met before. She tried to make him do things and he very quickly had a meltdown and stormed out of the room. He went outside, fell down a hill, cried, was covered in mud and blood, and we went home.

It took me a few more weeks to negotiate with the child development service, because of the fact that he had not had a full cognitive assessment done, to let him be on that waitlist. By the time all of this had happened, it had been at least six months since that paediatrician had said, “Put that referral in.” We had been rejected again. We were finally on the waitlist but it would probably be April before we got any help.

Meanwhile my son has deteriorated quite a bit, and our family has deteriorated quite a bit. It got to the point where I felt we could not leave the house. He was running away. He was hitting, kicking, biting and scratching. My elder son had to crash tackle him because he ran into a car park; he saw that we were both following him and he was trying to dodge us. He is nine. He should not be having to save his brother’s life.

We decided, therefore, that it was going to be important that we did whatever we

could to get that diagnosis done. By this point we were no longer in any doubt that autism was on the cards. I think anyone that ever saw us by that point knew that autism was on the cards. Even when you pay privately, there is still a waitlist to get in. There is still a big time lapse before you get a report.

Meanwhile, with NDIS, I said I wanted a review because it is not his fault that he turned six; nor is it his fault that the waitlist to get a diagnosis is so long. He is still not getting adequate services. I asked for a review in November, after I got that next rejection. I got a letter in January, saying, “We’ve lodged your review.” So it took two months to lodge a review between that phone call and that letter. I then rang them and said, “I’ve seen the psych now. The report should be coming in any day. How will that affect the review, if he gets this report?” They said, “We’ll put a hold on the review because if the review gets denied again then the whole process will have to start again.” So we put a hold on the review. I finally got this piece of paper that said, “Yes, he has autism,” and sent it off, and then it was quite quick.

They got back to me and said, “Yes, he is accepted into the NDIS scheme.” That was in March. There was about a six or eight-week wait until we had the planning meeting with the LAC, and that was apparently pushed forward because I rang crying on many occasions, including the day when he nearly got hit by a car, because we are in crisis and we need help. It took another month for the plan to be approved, and it got approved last week.

I am very pleased that that has been reviewed, but it is stressful—the constant fight. This is all on top of the fact that I have a child who has a permanent disability. Obviously, I want what is best for him but it is stressful—there are just so many things and it is such a difficult system to navigate. I feel I am a reasonably intelligent, articulate person. There are plenty of parents out there who are not like that. There are plenty of people who are not very literate or whatever. Having regard to the stress and the horrible way it has been for me, so many people must just be giving up, and there were so many times when I wanted to. It is very difficult.

MS LE COUTEUR: Have you actually got any support yet? Are you still going through trying to organise it?

Ms May: The plan has been activated.

MS LE COUTEUR: Have we got the happy ending yet? It does not sound like we have.

Ms May: Not yet, no. We are getting there. It is difficult because he needs a high level of funding, which requires a lot of money, and you do not know exactly when that money is coming through. We started seeing an OT because we knew we could pay for that ourselves for a certain period of time but you cannot start seeing everyone. If it is going to take two years for that money to come in, you cannot go broke in the meantime. You still have to feed these kids. They also have normal, everyday needs.

Now that the plan has been activated, it is also a waiting game of getting into the right professionals. We already have an OT in place, and then there are some of the other professionals that need to come in, and even support workers. That has been a slower

process. We will get there. There is light at the end of the tunnel. Yes, we are just getting there.

MS LE COUTEUR: It sounds like the first part of your story, before you actually got into NDIS, was pretty slow, to be polite about it.

Ms May: Yes.

MS LE COUTEUR: I can think of some stronger words. Because you were not in the NDIS at that stage—and it is the ACT government’s responsibility or any government’s responsibility—what would be the thing that would be most useful before the “you get into it” process?

MRS KIKKERT: Getting early intervention?

Ms May: Early intervention and diagnosis. If the public system had not been that horrendous an issue to get a diagnosis—once you are actually in there and you are having the appointment you can have a diagnosis for that child in a day or two—for some reason it takes 12 months, that would make a huge difference. But I know there are plenty of children who need early intervention support and who do not have a diagnosis, and that is not something to be overlooked either. I think then you are putting some restriction on it in that he needed to have more than one report from one person when he clearly had fine and gross motor delays and sensory processing. Why should he have not had support at that point, regardless of whether he had autism?

If that support is not given to children they give up or it feels like you need to be bad enough to need help. “We are not going to give it to you until you get worse,” whereas you could get in there early and prevent a lot of these things from happening. And there are lots of kids that do just need that boost. They will catch up and then they will be perfectly fine. But if they do not get that boost then that gap gets bigger and bigger and bigger and you see all sorts of other issues happening. I think early intervention is needed. Therapy ACT has closed and all these other things have closed, and it just makes it incredibly difficult for families to get access to that.

Ms Vrkic: Yes. We had Therapy ACT. It was not perfect, but certainly it was something that you could go to. The waiting lists were not as they are today. You could even just make a phone call to say, “Okay, I realise that there is a waiting list for OT or for speech for my diagnosis. Who can I talk to in the meantime about something?” And there would always be an answer. Now you do not know where to go. I do not know, Brooke, if you have got somewhere that you could access any information. I do not think you do.

Ms May: No.

MS LE COUTEUR: You are obviously both two articulate women and are doing the best for your kids. There are going to be lots of families who have not got your resources, for whatever reasons. You have both clearly put a lot of time and energy and love into your kids. How can we work out some way that the kids of families who do not have the resources that you have can get in contact with and be part of the system? Otherwise it is only going to get worse for everybody.

Ms May: I think that that is a big part where schools need to come in—and I know that NDIS has tried to be very siloed and separate from school—but in reality school is compulsory. Every child goes to school. Mine might not go as much as they—

MS LE COUTEUR: Theoretically at least. We have mechanisms to try and enforce this.

Ms May: Theoretically. That is really the first point. You could have a child in a family that does not engage in mainstream services until they enter school at age five or six. That is the first point of contact and that is where these kids that are falling through the gaps need to be picked up, I suppose, and identified. I do not know how that works, whether that means putting therapists in schools on staff. I do not know what that means.

MRS KIKKERT: They did that really well when ACT therapy was around. The preschool teacher would actually recommend the parent to ACT therapy.

Ms May: And that is how Dylan first saw the OT, yes.

Ms Vrkic: But possibly we may even need to go a little earlier than that, even though preschool at this stage would be a good place to identify it—and school. I think we should maybe even be looking back over the submissions of someone like Gay von Ess—I know she is very public about it—and looking at when she had the early intervention playgroups and whatnot. I have a longstanding working relationship with Gay. She did work with my children as well. I saw the playgroups and I saw the early intervention groups that were there. Some families may have an idea that something is wrong with their child and not have a diagnosis but not even know they need to get a diagnosis or something.

You front up to a playgroup because maybe your doctor suggested it or maybe you saw a flyer or someone has put you onto that and then you have that community access where the playgroups might say, “Have you thought about this avenue or that avenue?” And that is earlier than school. You have something, even if it is just that playgroup for two hours a week beforehand, where maybe we can then get in there and put the right things in place, where people can have more access.

I am not saying there are no playgroups around now or anything but the fear is that people do not seem to be able to even access that or at the preschool level there is so much stress—“I can’t even get into a paediatrician,” or “I can’t get into CDS”—that we are not even able to get the most basic information. “Do you think your child has a problem? Here is an avenue for you.” Maybe we just need to have something almost like a—

Ms May: And also reducing the costs, because in my experience it costs money to get onto the NDIS. That gap is getting wider.

Ms Vrkic: But Therapy ACT were part of that.

Ms May: It costs money to see a paediatrician, yes.

Ms Vrkcic: Yes.

Ms May: With another one of my children, we got on a waitlist to see a paediatrician through child development service, and the wait for that was over about 12 months. In the meantime we went privately but not all families can do that.

Ms Vrkcic: But the 12 months is even less now than what a lot of families are waiting to then get their plan going with the NDIS. It is all becoming a lot more—

Ms May: Yes, and when that is a step in the process, you are waiting at every single step. I kept saying, “Hurry up,” and then I would wait, because basically you would run to or fight your way to the next step. Then you would sit and you would wait.

MR PETERSSON: Thank you to both of you for being here. Ms Vrkcic, in your submission you talk about your ability to self-manage the plan being removed at one point. Can you expand on that? Why did they do that?

Ms Vrkcic: I have that answer, finally. It was because they had no idea what they were doing, in a nutshell. No, that is it in a nutshell. There was a very big lack of communication. I was apologised to by the delegate. But, as is now clear, I am strong enough to front that and fight. But it was a bit of a knock being told, “Sorry, you are not able to manage your kid’s therapy and funding because we think that basically you are a risk to your children.” Fantastic! So what was I doing for the seven years prior and the rest of it?

This is really quite interesting. I think I mentioned that when I first got my funding, the bucket was a decent amount, but I was supposed to be trained. I think most people who came into the trial were supposed to be told how to put in claims and how, if we had invoices for therapy sessions, we would then go about claiming them.

I never actually got that sort of training. I am an accountant. I am reasonably intelligent. I know how to use different portals. So I got on it and I taught myself. But I thought it would be okay if I had X number of invoices at the end of a fortnight. When you are doing 30 hours a week, it is a fair bit. I thought I could go in there and say, “Yes, I just need \$5,500 for this,” and then I could go in and say, “I need \$6,000 or I need \$1,000.” What happened was that it flagged something in their system. “She is taking out large amounts of money. She must be going to the Bahamas.”

I can understand why you have those flags in place, but when that flag went up, it was two years ago. So in those two years nobody called to ask why I was withdrawing that kind of money. I had reviews. No-one brought that up. But in this last one, as well as decreasing my funding by a lot without giving me any real justification, after I had got I do not know how many reports and had put so much effort into submitting invoices nicely, I was just told, “Yes, the delegate saw fit to take away your ability to self-manage and plan manage.” When I asked why, she could not explain it to me. I was told, “The delegate thought it was appropriate.” So it triggered a review.

MR PETERSSON: One of the things you mention is that there are certain providers that do not wish to deal with invoicing.

Ms Vrkić: Yes, that came a bit later.

MR PETTERSSON: Does self-managing, as opposed to an NDIA management plan, actually make a difference in what providers will work with you?

Ms Vrkić: Yes, the three make a difference. If it is NDIS managed, you can only use people who are registered. If you are not registered—let me tell you, a lot of providers who I know in the ACT are now deregistering or people will not register because they do not want to deal with half the stuff I have had to deal with. They do not want to deal with it as a business, either.

So, yes, I might go to a psychologist and say, “Can you see my son on a fortnightly basis; the recommendation is this and I have funding.” I am told, “Yes, that is fine.” I say, “Okay, yes, my plan manager is so and so.” But then I am told, “I am sorry; we do not deal with the party providers. We will invoice you.” I then go to the NDIS and say, “I need to access my money.” I am told, “No, you have to do it through the plan manager.” I am like, “Well, I cannot do that.” Apart from the fact that even self-managing has its problems, the answer from the provider is basically no. So you cannot go to that psychologist. But in my case, I was seeing that particular psychologist for a few years with my son prior to this switch.

MR PETTERSSON: Yes.

Ms Vrkić: I said, “Thank you very much; so now my son gets no psychology. Do you realise there are waiting lists,” plus the fact that I would have to go and explain the whole history of my son to someone else. That makes a lot of sense, does it not?” I could not get—

MR PETTERSSON: Was there a disconnection in the services you were receiving as a result of that change?

Ms Vrkić: I managed to—we supplemented. Plus, I fought and I fought. What did I do? Yes, I did stop psychology for a little while. Sorry, I just had to think. The fact that Christmas was in the middle of this and the fact that I was so vocal, I think I got a review pretty quickly compared with some. But this is the problem. When I spoke to the delegate who did my review, he could not believe it. He said, “No, what is the problem? They just have to submit it to the plan manager.” He acted like he was shocked and he had never heard that people do this.

But all the providers I talk to, people in the business, say, “Yes, there are heaps of people out there now that are saying they will not deal with plan managers because of the portal problems that happened in the past. This is all stuff you will have to deal with, love.”

Can I be very honest? I have massive anxiety just logging on to that. It sounds really stupid saying this. My husband laughs at me. I will do anything I can to delay logging on to the myGov website. It is like someone that wants to go in there and do their bookkeeping. I get palpitations. It sounds crazy. It is because I am so stressed.

Since I have even had my rights reinstated, they have not been able to get the bank account stuff right. Every time I call them up, it is an issue. Now I said to them, and I will put it very bluntly, “God help you if you try and audit me again or look over my stuff because the audit trail is a mess now because of you, not me.” I have got scraps of paper and writing on my invoices, “Submitted it on this date, portal did not work.” “Submitted it; didn’t go into the bank account,” or “Some weird amount of money went into the bank account.”

Even now that I have it reinstated, I am wondering whether plan managing might not have been easier. But I have just found obstacles at each point. I am literate and capable of dealing with this stuff. I have families that approach me, because I like to advocate and help these families as part of the Cranleigh School. Even outside the school, they come to me and say, “I do not know what to do. I cannot cope. I do not understand.”

This is where it comes into what you are saying. It is at the diagnosis point. But it is also when you have access and someone gives you a bucket of money. You are told, “Hey, you can only dip your fingers in this far.” And when I did get it reinstated, the delegated apologised, but it was kind of like—it just could have been so simple.

THE CHAIR: Thank you. On behalf of the committee, I thank you for attending today and for your testimony. When available, a proof transcript will be provided to you to suggest any corrections that are needed.

O'MAHONEY, MS CAROLYN, Director, Therapy 4 Kids
McINNES, MS GENEVIEVE, Physiotherapist, Therapy 4 Kids

THE CHAIR: Good afternoon and welcome to our hearing. I remind you of the protections and obligations afforded by parliamentary privilege and draw your attention to the pink privilege statement on the table before you. Could you confirm for the record that you understand the privilege implications of the statement?

Ms O'Mahoney: I do, thank you.

Ms McInnes: I do.

THE CHAIR: Before we proceed to questions from the committee, would you like to make an opening statement?

Ms O'Mahoney: I am a paediatric physiotherapist and director of Therapy 4 Kids, a for-profit, paediatric multidisciplinary business. With me today is Genevieve McInnes, who is a senior physiotherapist on our team. We would like to thank the committee for the opportunity to appear today. We are very grateful for your attention.

Therapy 4 Kids has been in operation in the ACT for eight years. Currently, we have 11 staff providing physiotherapy, occupational therapy, speech pathology and therapy assistance services. We see paediatric clients, the majority of whom are living with a disability. We have been registered NDIS providers for four years.

I would like to acknowledge that many of our clients have benefited greatly from being NDIS participants, and that many children who fell through the eligibility gaps for funding of therapy in the past are now recipients of NDIS plans, which has given them greater access to essential interventions. We firmly support the NDIS and want to see it succeed. The past four years have not been without difficulty.

In the spirit of wanting to see the NDIS reach its full potential, I would like to raise some issues along with some possible resolutions. There are six key difficulties that have arisen since the introduction of the NDIS. To keep to time, I want to highlight three of these. I am, of course, happy to take any questions from the committee that may increase your broad awareness of the disability therapy sector.

Firstly, it has always been difficult in the ACT to recruit therapists experienced in both disability and paediatrics. Prior to the NDIS, I had capacity to employ new graduates and provide them with supervision and mentoring to enable them to advance their skills and capability in providing quality intervention for children with a disability. I now have limited capacity to employ new graduates.

Supervision and mentoring requires significant periods of engagement by senior therapists for on-the-job training, a non-billable activity. Even in the absence of supervision and mentoring, due to the restricted nature of the NDIS pricing structure, we can rarely bill above three to four hours per day per therapist. The rest of a standard workday is spent undertaking tasks not billable in the NDIS pricing guide.

I would welcome a review and rethink of the pricing schedule. However, the proposed

changes in the recently announced independent pricing review move the pricing model further away from something that supports sustainable practice.

Further consultation and full consideration of what disability intervention involves is a critical consideration necessary to prevent the long-term degradation of the therapy intervention provider market. A future review should also consider supporting therapy practices that invest in growing skills specifically required in early intervention.

Secondly, since the rollout of the national scheme, we are seeing fewer babies because they are waiting in an NDIS pathway that generally results in their first NDIS plan when they are between 12 and 18 months of age. Without access to multidisciplinary early intervention in the first 12 months of life, an infant has missed critical periods of development in hearing, vision, language development and hand and arm function, and has missed opportunity for hip-joint development.

My suggestion to the committee is that, on diagnosis, these infants receive an immediate package of money to enable them to access NDIS providers while they are progressing through the NDIS pathway to receive their first plan.

Lastly, we are having significant difficulty accessing trial equipment. Because equipment providers are not based in Canberra, they often prioritise trials in their home locations before travelling here. They have limitations on what they are able to fit into their van, so they may come with alternative equipment or the wrong size. This impacts on the effectiveness of our trials.

It can take a therapist five hours to coordinate a day of trials with numerous participants. We have had several occasions of equipment representatives calling the day before to cancel. This happened as recently as last week, and resulted in 15 hours of non-billable time for my senior occupational therapist.

My suggestion to the committee is to utilise the already existing children and young people equipment loan service, CAYPELS. If the NDIS established a policy for repurposing NDIS-funded equipment to CAYPELS, therapists would have ready access to equipment for trials, and participants will be able to loan necessary equipment while waiting on funding application approval by the NDIS. We are happy to take any questions.

THE CHAIR: Thank you for your practical suggestions about what we should be doing and thinking about in terms of recommendations. Following on from where you left off in relation to the equipment being provided, where does that equipment go to afterwards, once it has been outgrown?

Ms O'Mahoney: Often eBay, the Green Shed, the bin. We get people donating some to our clinic.

Ms McInnes: There is no clear system as to where that equipment can go. As Carolyn mentioned, I am a physiotherapist working at Therapy 4 Kids. I have been working here for the past 18 months. Prior to that I worked in early intervention in the New South Wales system as the NDIS was being implemented there. I have also had experience working as a physiotherapist in paediatrics in the health system, so I have

worked across all areas. I have seen the change in access in terms of time for equipment, and also families being able to access services not in a timely manner.

THE CHAIR: So that equipment is perfectly usable by another NDIS participant?

Ms McInnes: Yes, that is right. When we are looking at equipment, obviously we are looking at equipment that will last for a significant period of time. But we are talking about children, and children grow. They are children who have various diagnoses and conditions. Sometimes that condition can be progressive, so there are changes in their condition which require different pieces of equipment.

MR PETTERSSON: If people are selling these things to the Green Shed or online, why are people buying it? Is it because they cannot get access to first-hand goods?

Ms O'Mahoney: We are finding there are long delays in having equipment provided. There are usually at least 12 months in the process. We have recently had a power chair supplied to a participant, and we had been at that for two years. Some families know what their child needs. They see it on eBay for \$500 and say, "This is just easier." And they will buy that from eBay.

The difficulty is that—and I see the reasoning, the rationale for it—any equipment that the NDIS is funding has to be new equipment. I understand there are legalities that make that necessary. But sometimes they may be needed only for a year, two years, particularly when a child is young or their needs change. That could perhaps be loaned to the next person who needs it, rather than needing to purchase another one.

Ms McInnes: Also, when you are looking at trialling equipment, as Carolyn mentioned, there is often quite a significant amount of time and difficulty with coordinating equipment providers because they are not based within the ACT. To coordinate, they will come only if there is a certain number of families. It is not worth their while to come if there is only one child, one piece of equipment, so you have to then coordinate X number of families to come on a particular day. You have to provide various quotes for the NDIS. You need to say, "I have trialled this piece of equipment and this piece of equipment." If there were a loan pool, that would alleviate some of that time and make the process faster.

MRS KIKKERT: Could you please expand on the recommendations that you have made? You mentioned six.

Ms McInnes: Six key issues.

MRS KIKKERT: You have only spoken about three issues, so I will use my questioning time to allow you to speak more about those recommendations.

Ms O'Mahoney: The other ones include provider registration—the quality and safeguards. We expanded into speech pathology services. I was not able to put that registration through until I had employed a speech pathologist. At that point there was a very long waitlist for speech pathology services in the ACT in general, and a number of our clients were needing that service.

I employed a very senior speech pathologist, and then lodged my application for my registration to include speech pathology. We are yet to receive that. Because speech pathology is not a profession that comes under AHPRA, it gets sent over to the ACT government for them to approve that therapist. I have needed to provide a business plan; I have needed to provide years of profit-and-loss statements. They are asking for written policies on almost anything you can think of. We are yet to be allocated an assessor to look at our case. The clients that we wanted that speech pathologist to see are sitting on her waitlist and have been doing so all year. That is one of my points.

MRS KIKKERT: Did you say that it has taken a year?

Ms O'Mahoney: This year. She started in February.

MS LE COUTEUR: Is she doing other work?

Ms O'Mahoney: I am paying her a high salary because she is very experienced.

MS LE COUTEUR: But is she doing some other work? She is presumably not sitting there all day—

Ms O'Mahoney: She has had periods of sitting there for extended periods of time. I have been trying to utilise her in other ways. We are using her for self-managed and plan-managed participants. We are taking on new clients for her. The bit that upsets me is that, with respect to our clients who are NDIA-managed who desperately need her, potentially, by the time we get registration—and I must say I am tempted to not even bother—they will not be able to see her because her books will be full by that point.

MRS KIKKERT: Can you go on? I want to hear about the other two.

Ms O'Mahoney: Another one is communication with the NDIA. In the trial phase we had fantastic communication between the engagement team and the finance team. That was absolutely imperative, and extremely useful for us. Since the national rollout, we have had less access to the NDIA team. From 1 July, when there are changes being made, we are having recommendations 18 through 21 put in place from the McKinsey independent pricing review.

We are yet to be told what those recommendations will look like. We will need to change businesses processes and practices, and we have not been told—it is less than three weeks away now—what those changes will mean and how we need to change what we do in our business. There are a whole lot of changes we will need to do from a business end to be immediately, from 1 July, compliant with our registration. My appeal is for that engagement team to stay with us. Alice is in the room today; Alice comes off her own bat to our meetings to help us out with that. That is incredibly valuable.

My last point is about the interface with Health and NDIS. As I was saying, a lot of our clients are children living with a disability. Many of them are medically managed in Sydney, because that is where the specialist teams are. They go for their reviews in

Sydney. Any surgery they need happens in Sydney. Their team of allied health, surgeons and physicians all correspond with us—their local team here. Whenever there is an intervention there, it is deemed that the three months after that is a Health responsibility, and we are not allowed to see them under their NDIS plan.

We have had many children for whom we have done the pre-operative planning meetings with the team in Sydney. We have prepared them for surgery. They sometimes have extensive surgery performed, and we are unable to use their package for the next three months to see them.

Ms McInnes: ACT Health does not have the capacity in terms of staffing to be able to see them if they continue on the Health pathway once they came back to the ACT.

MS LE COUTEUR: So they see no-one after the surgery? Has that been the practical result?

Ms O'Mahoney: On a few occasions the senior paediatric physiotherapist has organised for the Health budget to pay for our therapy. We will send the bill to Health, and they pay for the therapy so that we can continue to see them. At other times they get what they can, I guess, from the hospital system. It is a great distress for the families, and it does risk the success of what is often very invasive surgery that they have undergone.

MRS KIKKERT: It is hard to digest all of that.

MS LE COUTEUR: Yes, I really do not know what to say. I will ask about this, because it would seem to be fairly and squarely within the ambit of the ACT to do something: you say you are not seeing nearly as many babies because they do not get into the NDIS quickly. What should the ACT be doing to change things? Presumably, the same rate of babies with needs is occurring?

Ms O'Mahoney: We have discussed this.

Ms McInnes: We have had a number of these cases where a baby has had an MRI diagnosis at the age of four weeks—a clear diagnosis that there is a disability. Once there is a diagnosis and it is directed that they are eligible for NDIS, that is where the gap is, because of the time that it takes for processing to get to that first plan.

One possible recommendation that we have come up with is that if a baby has been given a diagnosis, some block funding should be available for X period of time until their plan is available, so that they can access those early intervention services. The implications of delayed access to early intervention—and you have just heard about that from the previous witnesses—are that it could not only affect them from a functional point of view, with possible long-term effects on their bone development, muscle contractures or joint alignment, but also affect their communication skills, their play, their social development and family relationships.

If families do not have the financial capacity to start therapy privately then there is nothing happening. We have children coming to see us at 12 or 15 months of age who are not yet sitting by themselves and need to have a whole range of other equipment

that they have not been accessing for that period of time.

THE CHAIR: Where is the delay? Once they are diagnosed, is it with the NDIS? Is that where we are seeing most of the delays?

Ms McInnes: I think it is because once they are deemed to be eligible for the NDIS—this is my understanding—Health is not an option for them. Health says, “You’re eligible for NDIS.” So you’re waiting for your plan; then you go down the path of having the funding to access NDIS providers or choose your own provider, whereas Therapy ACT or CDS—

THE CHAIR: Health or the child development service?

Ms McInnes: The child development service. They can access a certain amount of intervention, but they are looking more from an assessment point of view and are not able to provide that ongoing, regular intervention or the amount of intervention that that child or that family may require.

Ms O’Mahoney: I believe NDIS EACH has taken a little while to get up and running. Perhaps these delays will not be ongoing, but there have been a lot recently. I think staff shortages affect all organisations—NDIS EACH is not alone in that—and that can cause delays.

I believe NDIS EACH is block funded to be providing some intervention for new participants until their plan is in place. For periods of time when they may be understaffed, that can be difficult. We wondered whether block funding would be available, and even whether any registered providers could say, “We have this client,” and they could access block funding. Of course, there are checks and processes in place to say, “We have this client; we would like to provide this,” and they release some block funding. That could help to spread the load a little bit. Some organisations at different times will have more capacity, depending on their staffing, than others, but perhaps with enough checks and balances that is an option.

Ms McInnes: Maybe that is where that can help with some of those people who have not yet got a diagnosis but from various reports or standardised assessments there is a recognised delay, as part of their development, that requires some intervention. But they are still on the pathway of getting further assessments to access a diagnosis. There is still some capacity for that family and that child to access some early intervention services.

MR PETTERSSON: Thank you both for being here. In your opening statement you mentioned that the structure for billable hours made supervision and mentoring more difficult. Can you expand on that? How does it make it more difficult?

Ms O’Mahoney: This is in relation to before the NDIS came in, where I had more capacity to do that. That was because the government system, Therapy ACT, was still in place. Having worked, prior to the NDIS, with families with a disability, they had their main team in the government system. A lot of the non-billable or non-face-to-face-time activities—in the disability sector, there are a lot of them—would generally be done by the team sitting in the government sector. A lot of the work that we would

do in conjunction—it would be in consultation with their therapists; we would share the load—often was more face to face. Better start would provide funding for that. More of what I did was directly billable.

With the NDIS coming in, and Therapy ACT no longer existing, it meant that the whole management of that individual comes across to the private sector or the billable sector. There is a large proportion of therapy that is not in the pricing guide, and a lot more of my day is taken up with doing activities that are non-billable. Essentially, my earning capacity has reduced significantly, and there is a lot more pressure on my time.

THE CHAIR: Will the McKinsey report improve—

Ms O’Mahoney: It will be even worse then.

THE CHAIR: So you think it will be worse then?

Ms O’Mahoney: Yes.

THE CHAIR: We are going to have to finish there because we are out of time. I would like to thank you for attending today. A proof transcript will be provided so that you can suggest corrections to the record. I now formally declare this public hearing closed.

The committee adjourned at 2.38 pm.