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, 22 MAY 2018

Secretary to the committee:
Ms K Harkins (Ph: 620 70524)

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.

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Amended 20 May 2013

The committee met at 1.47 pm.

O'DEA, MS KARNA
HECKENDORF, MR DAVID
MILFORD, MS JANET

THE CHAIR: Good afternoon, everyone, and welcome. I formally declare open this public hearing of the Standing Committee on Health, Ageing and Community Services inquiry into the implementation, performance and governance of the national disability insurance scheme in the ACT. The committee will be hearing from individuals and carers with lived experience of the NDIS in the ACT.

I remind witnesses of the protections and obligations afforded by parliamentary privilege and draw your attention to the privilege statement on the desk. Can you confirm for the record that you understand the privilege implications of the statement?

Ms O'Dea: I do.

Mr Heckendorf: Yes.

Ms Milford: I do as well, yes.

THE CHAIR: Proceedings are being recorded for transcription purposes. We will get underway with five-minute statements from each of you, and then we will have questions from the committee.

Ms O'Dea: I have two participants in the local NDIS—a daughter with quite severe autism and cognitive limitations, and a son whom I suspect under the current scheme might be excluded if they bring up autism level 2, which is quite amusing. I wrote a submission because—I will be blunt—I am sick of seeing a lot of other parents who cannot advocate for themselves being screwed over. I am talking about my lived experience as a carer. I am talking about caring for quite hard people. These are the ones with what is euphemistically called "challenging behaviour".

Challenging behaviour can be aggression. I think it is called oppositional conduct disorder if they have enough brains to be able to do that. My son can pinch, bite and scratch with the best of them. I can pinch, bite and scratch with the best of them because I am not putting up with being pinched, bitten or scratched. But I have found these are the common themes, and they were also mentioned by Camilla Rowland and I think the carers lady, Kerry Smith, or whatever her name was.

Challenging behaviour is not properly addressed in the NDIS, and that brings me to another issue: providers are still cherrypicking. I can name or two three providers who do not want difficult people because they are difficult. But I also would say that maybe those people do not get enough funding so that they can employ one on one for those people, so that would be a fault of the NDIS and the provider. I also think all providers should be like aged-care people—they should be registered and regulated. There should be some penalties if they do not accept all comers.

The other thing is that I am really, really angry about respite. People in the NDIS like my two only live in the community because they have what are called informal supports. Informal supports are the families that provide the infrastructure, which look after these people. In the case of our son it is me, my husband—who is now my boy’s primary carer—and his sister. My daughter is now in a group home with another girl who has similar challenges. I will not name that girl but the care has been quite good. If I had Lucette living with me I would buy a unit and push them over the balcony—and I am not being funny. She is really, really hard work, and unless you look after somebody who is like a toddler you do not understand.

I was so ropeable last year with the debacle at Marymead. What you need to understand is a lot of parents like me who are doing the hard yards are still only in the caring game because they get a break from the caring. If we did not get every second weekend off I would not be caring for my son. I have been doing this gig for 30 years and I am fed up to the back teeth. I also have a husband who is sick every now and again and who drops his bundle, which annoys me because I am still working.

But I am saying to you that what you need to understand is the NDIS is not only about the participants, particularly in the case of people with mental illness or cognitive limitations. You need to look after the people who are basically providing the care, and the NDIS is predicated on informal supports, which is usually only the family. And I am sure you are getting a lot of submissions with families saying, “I’m looking after Billy. Billy’s a pain in the neck. This is what I need for Billy.”

I really, really get tired of seeing stories in the paper like the story of an elderly man who is 85 or so who has a 48-year-old son. The NDIS needs to step up to the plate to help facilitate those parents to transition these children to supported accommodation before the parents drop dead. You need to do the transitioning while the parent is able. I think that poor man’s wife had died. There used to be a scheme under the ACT government that catered for older carers, I think it was 65 and up. They provided adequate respite, and I think they also started to encourage people to consider what they were going to do with Billy, Mary or Sara. You need to think about that because you have to remember that families die.

I am sorry; I love my normal daughter. I do not think she wants to inherit her two disabled siblings like she inherits the lounge suite. She might keep an eye on them but she is not going to care for them, so that is why I am using the care provider Care Plus Services and we are looking at an intentional community with another friend to cater for my son. I expect the ACT government to step up to the plate for that because, I am sorry, you are really not out of that space despite what you would think, and I am not being rude. That is the reality of it.

You need to help older parents with things such as estate planning, supported accommodation and what they are going to do with these children when they die. Who is going to keep an eye on them, because most of them will need somebody to look after them, whether it is a sibling, a cousin, a circle of support or whatever trendy thinking people can come up with?

THE CHAIR: Thank you very much.

Ms O’Dea: I have not finished. I will be quick. The other thing you need to realise in

Canberra is that you need a provider of last resort. This is to deal with the very difficult people who all the other providers reject. And can you please exercise goodwill and stop buck passing between yourselves and the NDIS.

If people relinquish they relinquish because they are so fed up and desperate. You cannot leave those people in Marymead or the Disability Trust house or Ricky Stuart House; there needs to be an arrangement whether they are under 18 or over 18, because they still need care due to their cognitive limitations. Yes, I really do want you two to work together with parents to work out who is the provider of last resort. Who is going to take on these difficult people? Please do not leave them languishing. As another parent I know who has relinquished her child said, "I have relinquished his care because I cannot do it anymore. But I haven't relinquished my child." You need to bear that in mind.

So they are my issues, and I really do want you to understand that you are signatories to the NDIS agreement. You can say to them what the ACT people need, and it is not all the NDIS. The NIDS, I have found, have had some very good people and, because I can advocate, I have on the whole got what I have needed. But it is not just funding; you need the supports in place and you need to look after both the caree and the person who does the caring. If my husband gets very sick—I will be blunt—I am relinquishing my son because I do not want to be a single carer. I do not have the mental wherewithal. That is why my friend and I are looking into an intentional community, and we expect the ACT government to help us with that.

THE CHAIR: Mr Heckendorf, you have provided and tabled your opening statement, so thank you very much.

Ms Milford: I am a carer—but I prefer "support person"—for my son who has a psychosocial disability, having a chronic, severe ongoing mental illness and complex needs. I have been a strong advocate for the inclusion of people with a psychosocial disability into the NDIS and, importantly, for their complex needs to be understood by the NDIA. Our son's initial NDIS package made a positive difference in his life and in ours. He has never had so much ongoing relevant support. Being considered a success story, I became involved in promoting the NDIS, presenting and advising in many forums.

When his first annual plan review was due, we all prepared for the interview and attended with some trepidation. We were quietly confident that current services and supports would continue and were hopeful that additional requests would be granted. It was then an immense shock and very distressing when we received the new plan. The funding was less than a quarter of the original plan. How were we going to pay for current services and support? In addition, and somewhat absurdly, NDIA had added a plan manager to employ other services but with inadequate funding for these services.

My advocacy work was now a very cruel, ironic joke. There was no explanation from NDIA, no covering letter as to why they felt this cut in funding was justified. We were devastated. The consequences of this were terrifying. The new plans would have left our son with only token NDIS support, and we were too frightened to tell our son, knowing that this would have an adverse impact on him and the progress he had made to date.

This process highlighted that the NDIA seemed to have very little understanding of psychosocial disability. What damage were they inflicting on people with psychosocial disability and their carers and families by giving them funding, hope and a better quality of life one year and then taking it away the next? This reinforces what has continually happened to them in the past.

After an urgent plan review and ongoing negotiations we clawed back a lot of the funding to produce a valuable package to continue with current support services, along with a plan manager to manage the plan. This was not completely satisfactory, but it was an improvement.

We also realised that we were not alone, as we found out from our service provider, who is working with NDIA on behalf of their other clients who also had their funding slashed. After further negotiations, corrections, seven plan revisions and with the assistance of Community Services, we received a workable plan with better funding.

During this period one of our key workers had not been paid for over five months and our service provider had delays in payments as well. The NDIA computer system was problematic, and even NDIA staff were unable to fix their own data errors without generating another plan.

Our plan manager discovered that a data entry by NDIA had shifted the decimal point, resulting in underfunding for one key worker. Our service provider was also having problems with the NDIA recognising the correct payment rate for their staff during the mental health recovery focus practices. NDIA insisted in paying them at a lower rate that was less than core support.

We are very worried and apprehensive about our upcoming annual plan review. We do not want any further trauma or anxiety in our lives or to have to deal with the fallout of any funding cuts in our son’s plan. Having to continuously fight for his funding is something we do not want to contemplate. We cannot continue to do this for the rest of our lives. We should not have to fight.

THE CHAIR: Thank you. We will take questions from the committee. I will go first, with a question to Ms O’Dea. It is in relation to respite services. What sort of respite is currently provided and what level of funding is provided for that respite?

Ms O’Dea: My son got a very good plan this year of $220,000. That is because he leaves school at the end of the year. That will be a whole new ball game, but I have already started the transition process. He goes to Marymead. He needs one-on-one. He is high needs; he is large; he is 6 foot 2. He can be difficult for other people. But, as I said, he will not try it on with me because I have no patience. I have no patience at all with government and I have no patience with my son.

But Marymead have been pretty good. They have had some very good carers. A lot of the boys and girls I have seen at Marymead would be similar. They would have severe to moderate autism. They have cognitive issues and they have challenging behaviour. Marymead has always stepped up to the plate, or usually stepped up to the plate.

Twenty years ago they took on the difficult ones no-one wanted. A lot of the providers only want the cute, cuddly ones. I am sorry, I have not met many cute, cuddly ones. A lot of them have issues and, at the least, you live it. I can only talk about autism at the lower end of the spectrum. But even the high functioning ones can often have mental health issues. They can have OCD. They can be equally as trying for the people who look after them. I will be honest. I think parents do a pretty sterling job. I have met brothers and sisters who are still doing a sterling job. I sometimes think, "Why are those poor siblings still carrying the can?" They probably have had their childhoods marred to some extent.

People say, "You should not say they are a burden." They are a burden of care because you worry. I cannot just up sticks, go away and have a lovely holiday with my spouse. As Vicki knows, we have been married for a very long time, but everything is planned. I went to Norfolk Island last year because I was knackered. Do you know what "knackered" means? It means that we are ready for the knackery—to go. My husband could not come with me. I am getting really tired of that. I want a life where I do not have to always think, "What am I going to do with the person I have to look after?"

I am sick of caring. I am so sick of it. I do not think you understand until you care for somebody. If you look after somebody with dementia, that can be very hard and very tiring, but they die. People who are physically hale and hearty last a long time. That is why I want my son in very good supported accommodation. It is so that I actually can be his mum, not his carer, his warder, his custodian. I am very tired of it.

THE CHAIR: What does that $22,000 incorporate? Is it enough to fund the respite that you think is adequate?

Ms O'Dea: Getting every second weekend off means, for example, that my husband can go to Sydney to have a look at the museum of funny medical things at the University of Sydney. I want to do that. We are going to a retreat next weekend. Sometimes when he is sick, he spends the day in bed and I go to the library in peace. They are not exactly world-shattering things. I do a lot of dog walking, partly for my son's benefit and partly for my own benefit. I can catch up with my sister-in-law and go to the films. I cannot just bugger off whenever I like because you cannot leave my son. You cannot take him to the films. I do not think he would cope going to church. We go separately to mass because we are Catholic. That is the reality, but I am getting really tired of the reality. If my husband died, I am sorry but I have friends who are single carers, and it is a very hard thing to do.

MS LE COUTEUR: I am interested in anyone's views on this but particularly Mr Heckendorf's views about options for review. You talked about the ACT government and how previously it was clear how a plan and support could be reviewed. Now that does not seem to be the case. Could you talk more about that and the needs you have for it?

Mr Heckendorf: As you would be aware, there has been recent media coverage that has said that reviews of plans—not annual plans but requests for reviews—have been taking up to nine months in the ACT. You spend eight and nine months and you have an annual review anyway. It makes the whole review process a joke because you are not achieving very much by having such a long review process. Does that cover your question or was there more?

MS LE COUTEUR: Is there more that could be done in the ACT?

Mr Heckendorf: Under the previous regime, if you had significant disabilities, the chances were that you had a relationship with Disability ACT. Disability ACT knew what was going on, spoke to the service providers and came up with solutions, and often very creative solutions, and so forth. It was not perfect. The funding was always an issue but you were taken care of at the local level. There seems to be a real paranoia of opening the floodgates if the NDIA agrees to anything out of the ordinary or provides for something that is not standard.

MS LE COUTEUR: Do either of you ladies have a view about that question, about review options, given you both have had issues with—

Ms Milford: With their plan review?

MRS DUNNE: Yes.

Ms O'Dea: I have had actually good plans. I am sorry to butt in on you, Janet. The staff I have dealt with—I have actually asked for the plan—have been very good. My daughter Lucette gets an enormous plan because it is 24/7 support. Actually, I have found with the NDIS that the money has been quite generous for us. That is my experience, but there have been a lot of cruel stories in the press. They all have a foundation. The worst was a man with motor neurone disease being told he did not need a lift in his car—he bought the van himself—because he may not last. How long might a man with motor neurone disease last? Stephen Hawking had motor neurone and he lasted a long time. That was a cruel, nasty and rotten thing to say to some poor devil suffering from that. That disgusted me.

MRS DUNNE: In your case, you seem to have had a review process.

Ms Milford: Yes, we had a review process. We asked for a face-to-face meeting and we asked for someone with a background in mental health. We got the face-to-face but the person obviously did not have any background in mental health. There was the clinical manager, a support coordinator, me and my husband at the review plan. We had all written our bit. Because I am an advocate, I knew the process. I had a carer's statement and everything else. We were all saying that the support should continue, and we wanted a few other things.

We had no idea at the interview how it went—absolutely none. Our support coordinator said that she had been to several interviews and she never knew what the outcomes were going to be, because they were all different, and that you did not get an idea at the time. Also, the compulsory questions were mostly on physical disability. There were not any on psychosocial. The person we had obviously had no idea. My son was actually unwell during the interview. His clinical manager had to talk to him. But the guy would have had absolutely no inclination that anything was—had no idea.

So we had no idea when we left. I could not really expand on a lot of things. It was a kind of strange interview. Anyway, we thought that it was working—we had never had so much help—and that we were actually making progress. But he needs ongoing, continuous help, probably for the rest of his life. It fluctuates and it is hard.

The other thing, too, is that if it is a parent and a child, there is often tension. I have heard this from other people too. It has destroyed relationships between family members because often the carer has to tell, in front of the person—especially if it is an adult child—how bad they are to get the supports that they need. That can be absolutely ruinous.

When we first went, I did a carer statement. Mental Health Australia has a carers' checklist that you can go through and fill in. They have lots of information from all the documents that you have put in—from your practitioners and from reports that you might have had. We put in as much information in the first instance as we possibly could. We also put in the impact on the family and the carer, what we did and all this. I think, based on the forms that you have to fill in, they have enough information there without having to interrogate you in front of the person you care for. If they really need to, why can't you have two interviews? Why can't you take the carer aside and have a separate interview?

Ms O'Dea: Yes, good point.

Ms Milford: Often in a situation there is more than one perspective. It is not until you get a few perspectives that you get the true picture. With something like psychosocial disability, it is very complex. It is very hard. You have years of experience of what works and what does not work. In the psychosocial disability or mental health space, we talk about recovery focus. Recovery does not mean getting better. It means giving them hope and giving them recovery-based practices that capacity build, that get them to be able to live a more independent life. It also takes a long time and a lot of repetition to get them to that stage. You probably have to keep doing it, but it is to give them independence and self-esteem. I could go on.

MRS DUNNE: I will follow up on that because this is something that came up in evidence elsewhere, Ms Milford. You touched on recovery.

Ms Milford: Yes.

MRS DUNNE: There seems to be a perception in the NDIS that if they put enough money in an early program they will need to do less in future because people will get better.

Ms Milford: Well, they will not necessarily get better. If they have a severe chronic mental illness it does not mean they will get better. And, within that, it fluctuates and they need different kinds of help at different times. I mean, a lot of people say they might need more help when they are ill, but if they have got funding in there for job training, if they are unwell then they cannot do the job training. It is not just when they are unwell; it is when they are well as well. It is quite complicated.

MRS DUNNE: I do not want to put words in your mouth, but could you summarise that your experience was that you dealt with people who did not have sufficient understanding of your son’s condition to make the right decisions?

Ms Milford: Yes. And it did not seem that he had read some of the documents. I guess because he did not have the background he probably was not asking the relevant questions. I was ready to explain and talk and blah, but I had nothing. It was just a strange interview, which demonstrated to me that he did not know anything about psychosocial disability. I think he knew a little bit about anxiety but not the anxiety that our son experiences or people with mental illness would experience.

He had no depth of understanding, and he had no training. We were asking for the same supports, plus a plan manager, so that we could employ people that were not registered with NDIA and they would look after the finance, and they gave us a plan manager but we did not have enough money to pay for the support we already had.

MRS DUNNE: How long did that take, the review process? You clawed back some money, but what proportion of it did you claw back?

Ms Milford: In the first instance we had an interim plan which was really reduced. In three plans it was still reduced and then we got probably up to about 80 per cent back. We did not get it up to what it was before, but nearly. Then we had another one that was increased, and another one that was the same. Our service provider had a lot of clients who had had their funds slashed and they were working with NDIA to get them to understand. They use qualified staff. You have to be a peer support worker who understands capacity building and is recovery focused.

With some degree of psychosocial disability, goals and aspirations could be anything from: “I want to get up out of bed in the morning” to “I want to get a job” and anything in between. And it is even difficult for them to be able to articulate that. We used peer support workers—Your Choice I think, but I have written it all in my submission. They were able to work with my son over months—it depended on his medication, how well he was, what time of day et cetera—to get him to say what his goals and aspirations were. We also put in what he needed. It is his plan and it is his choice and control, and it is to make a better life and a more independent life for him.

What made a big difference when we got the plan was that we had managed to get a transfer for housing. It is absolutely appalling the housing they are put in; they are put in amongst drug dealers and criminals, and it is just a nightmare. He was in Brian Hennessy, and we refused to let him out of there until he got better accommodation. So we managed to get a transfer to a better environment, in a little townhouse that was much, much better. It was near us and it was in a neighbourhood with other people with disabilities and older people, and he was safe. He felt safe. The problem with most of them is that they do not feel safe, and that adds to the trauma et cetera.

MRS DUNNE: And that contributes to them being unwell.

Ms Milford: Yes, it does. And it also affects the workers who are trying to help them because they do not want to go into places like that. They miss appointments. It is traumatic for the workers to go into places like that to help them. Anyway, that was a big plus, and it was also a big thing to be able to implement his plan. The only thing was that he only had one bedroom, and it would have been better if we had two so that in the event he became unwell we could have someone stay overnight and it would save calling in a CAT team or taking him to emergency or getting him into the psych ward. It can be managed, but you need somebody to be there. And, because it is a one-bedroom unit, you cannot have that. But there was no way we were going to go back to Housing and say we wanted another unit because God knows where they would have put us.

MRS DUNNE: That lengthy process, how long did that take?

Ms Milford: For the first plan, or the—

MRS DUNNE: From when you had your funding reduced until when you got it back up to 80 per cent.

Ms Milford: I have got dates. Our initial plan was from 20 May 2016 to 19 May 2017, and then we had an interim plan—we were away when the end of it should have taken place—and that was drastically cut. So that was 2 June 2017 to 1 September 2017. Meanwhile, we got an interview in July. So we got a plan on 5 July then we got another plan on 17 July, another plan on 18 July, another one on the 19th, one on the 24th, and then the final one on 26 October. It was because the computer system would not allow them to go in and correct or be flexible—that was part of the reason—to change data. They had to regenerate a new plan. I do not know if that has been fixed.

MRS DUNNE: It took essentially five months to claw back up to 80 per cent?

Ms Milford: No, the final plan we got was a much better plan, and it was more than we had before. But it was in stages.

MRS DUNNE: And you are about to start another plan review?

Ms Milford: The plan from 26 October is the one we are on now.

MRS DUNNE: So that runs for a year?

Ms Milford: It runs for a year, yes. I have heard you can get two-year plans, but I think that is new, so I do not know. That would be good, because it is very stressful. As carers and as families, we are all traumatised, especially in mental health.

MRS DUNNE: All of you have substantial plans. Is the funding inside that flexible or are there particular buckets of money?

Ms O’Dea: It is allocated to buckets. The 150 is a bucket for Mal’s respite. I am sorry, I have not brought his plan. There was so much for capacity building, which amuses me. It took Malcolm two years to learn to peg out clothes on the line. I mean, he can learn, but you have to be constantly on his case. I do not know about Malcolm; he is not going to write the great Australian novel or get a Rhodes scholarship. I wish he could, but it took me 10 years to teach him to read and that was bashing it in and bashing it out. He can read, but I do not know.

I heard the priest Peter Day, who runs HOME, and he said that they got tired of telling bureaucrats that sometimes these people are not going to improve; they are just going to be at the level they are and maybe you just have to accept it and realise that unless Jesus comes back there is not going to be a miracle. Seriously, you could get rid of the NDIS if the government funded Jesus's return, but he is not coming back in our time. He could heal all of them, but I have not seen it happening.

Ms Milford: In our case the NDIS was our last hope, and it is the last hope for a lot of people. It did give us more choice and control. We were not a charity case just to be given what they thought they could give us and it would only last six months or something. The scheme has huge potential if it is done properly. We were able to have ongoing, continuous support, and that is what you never get. And you never get specific help for that individual's needs, and that is what the NDIS is supposed to do. It is supposed to give them a better quality of life.

There was a big push to put my son in a group house. He had been in a group house before and he did not want to go back. We have all been in group houses as teenagers or whatever. Would you want to go back to a group house because it would be safer and it is manageable and easier to control? The NDIS has enabled him to stay in his unit on his own, with the support. He needs all that support around him. His physical health is pretty bad, so that needs a lot of support as well.

MRS DUNNE: But do you have flexibility? Some people have more flexibility than others.

Ms Milford: There is some flexibility. That is what we found, too: some of the headings kept changing, and I think that was one of the problems. We had a key worker, who we have still have, and we were so lucky our workers carried on providing services and supports when they were not getting paid. That does not happen for everybody. In a lot of ways we were lucky because I had been familiar with the NDIS from the beginning and I am also an advocate. But there are consumers who have no-one. Sometimes the support worker is the only person they have got and that support worker is not allowed to advocate for them.

There is a shortage of advocates. We have only got ADACAS, and I think Carers have got a couple of advocates. In New South Wales all the advocacy agencies have gone to the wall because they all got block funding and now they get nothing. We need advocacy for these people because they do not have a voice.

MRS DUNNE: Mr Heckendorf, do you have flexibility in your funding?

Mr Heckendorf: We do. My wife and I are both physically disabled, so we have carers coming in from six in the morning for most of the day, until 9 pm. Our main agency at the moment is trying to argue that for all of my wife's lifting they should have double staff. The NDIS has refused them funds based on that premise. We personally would prefer not to have double staff because having both her carers and then another carer for me in the house at the same time or having two carers all day every day would just feel too crowded. We just do not feel the need is there to have double staffing for the lifting and so forth.

But going back to your original question, at the moment we self-manage our plans because in a few months we are moving interstate, to Queensland. In order to facilitate the changing of jurisdiction, we have decided to self-manage so that we can engage the services we need going into a jurisdiction that does not yet have the NDIS rolled out. Self-funding gives us the flexibility of buying in the services we need. The downside, though, is that even though we can engage the specialist services we need, we cannot engage the non-traditional supports we need.

Ms Milford: I did not answer the question about the flexibility. We found that sometimes the headings were changing, and that is why some workers had difficulty getting paid. There is some flexibility, but some of them have to be categorised under headings. I think if you have a plan manager and you can employ people outside who are not registered you get more flexibility. They say it is self-managed, but we do not want to self-manage because it is not sustainable. We are going to die or not be able to do it, and it causes tension et cetera.

MR PETTERSSON: Mr Heckendorf, in your opening statement you say that your conjugal supports were funded before the NDIS. Why are those conjugal supports not funded now?

Mr Heckendorf: I think it is because of ignorance when you mix sex workers with disability with government funding. As if one was not stigmatised enough, when you multiply it threefold you get people ducking for cover, trying to find different ways of avoiding funding that type of service.

MR PETTERSSON: But public servants previously said it was okay?

Mr Heckendorf: Yes.

MR PETTERSSON: But now that it has gone to the NDIA to approve it, they say no?

Mr Heckendorf: And the NDIA itself in the first two years approved it, although with each plan it became more and more vague, like: “We didn’t want to know about this, but keep it there and we will see what we can do for you.” But this year the delegate actually wrote to us and gave us two pages of reasons why it is not covered under the NDIS. If you are interested I can provide you, through the secretariat, with a copy of that decision.

MR PETTERSSON: That would be a good idea.

THE CHAIR: We are at the time where we have to close this particular segment. When available, a proof transcript will be provided to give you an opportunity to check the transcript and make any corrections needed. Thank you very much.

BANNISTER, MS LOUISE
FANNING, DR VANESSA
MUIR, MRS KARINA
MUIR, MR CLIVE

THE CHAIR: Welcome. I remind witnesses of the obligations and protections provided by parliamentary privilege. I draw your attention to the pink privilege statement on the table before you. Can you state for the record that you understand the implications of the privilege statement?

Ms Bannister: Yes, I understand.

Dr Fanning: Yes, I understand.

Mrs Muir: Yes, I understand

THE CHAIR: Thank you for attending today. We will commence with opening statements from each of the witnesses. Ms Bannister, would you like to start?

Ms Bannister: Yes. I am very nervous. I hope I can get through this. I have given everybody a copy of my submission in case I can't. I was very excited about the introduction of the NDIS scheme. It was going to be such a positive, life-changing event. The reality has been far from this. I have found the process—

MRS DUNNE: Take a breath.

THE CHAIR: You can take a break for few minutes if you like and we can come back to you.

Ms Bannister: I found the process very disempowering. Thank you. I have become very depressed and anxious about my future and my relationship with my partner. I promised myself I was not going to do this. I am sorry. I will pull myself together.

For me, the issues have been around the lack of transparent communication for the entire NDIS process. There should be options for good two-way communication. You should be able to see and comment on your draft plan. Where else are you expected to agree to and sign a contract before even being able to read the fine print first? I am on my third plan now. With this third plan I actually asked to see a draft and I was allowed to. Previously, I was not and when the plan arrived it was completely a surprise. It was not what we discussed.

If there are issues around funds approval you should be given the opportunity to supply the necessary extra information prior to being told that you have been unsuccessful and will need to go to decision review. Everyone I know has had to go to decision review. Surely this indicates that the current process is broken. I know a lot of people who are on the NDIS plans and they have all gone to decision review. I am currently going through the process at the moment.

The plan document is not useful to someone who self-manages. It provides me with details about me, which I already know, but gives me very little detail or guidance on what I can spend my allocated funds on. I was allocated $147,000 in my core funding last year and no-one could explain to me what it was for, except that it definitely was not for my requested major home modifications. The money was put into my core budget, and my core budget is substantially for cleaning and gardening. There needs to be an easy communication channel for participants seeking clarification on different or unexpected amounts in their plans.

I am also concerned about the NDIA second-guessing approved OT and physio report recommendations. The NDIA needs to recognise and respect these experts. My OT has written her reports four times over my three plans, regarding my major home works. Once again, her recommendations have not been accepted outright. This time I have been asked by the NDIA to supply quotes and yet another OT report for installing a platform lift in my lounge room instead of raising the floor level, even though my OT has clearly stated in every report that a platform lift is not a viable option in our very limited space.

We have put a lot of love and money into our home to make it ours. I do not want my home to look like a hospital or institution. Surely it is not unreasonable to have a home that is accessible, well designed and aesthetically pleasing to the eye. In another lifetime I would have liked to be an interior decorator.

Planners have all suggested that we look at other accommodation options, which we have explored. The short answer is that I do not want to move, nor could we afford the move. When I contacted the Ginninderry developers last year, I was told that there were no suitable properties for me at the moment within my budget. They suggested that I contact a developer who was building a group home in the Dickson area. I was rather shocked and taken aback by this suggestion.

I am married with a family. Our local real estate agent rang me a couple of months ago to say that they had found another possible property. The real estate was valued at $799,000 and it would still need major bathroom and other modifications to make it wheelchair accessible. That is 6½ times our original mortgage, which we still owe $80,000 on due to the renovations we have done over the years. My partner is due for retirement next year; so I just cannot see us taking on that sort of cost now.

I would also like to raise today my concerns about the rumblings that the taxi subsidy scheme is earmarked to cease. If I lose my taxi subsidy I will lose my ability to participate in the workforce and my many community roles. I will also be in danger of becoming seriously isolated. I am a very active community member and disability advocate. Social engagement is an important part of my keeping mentally well. My NDIS transport payment is only $94.50 per fortnight. The taxi fare to my current place of work is $45 each way. I am also registered as a casual teacher at CIT. It costs approximately $70 each way to travel to CIT.

Can the ACT government please work to ensure that the taxi subsidy scheme is not lost and that people with disabilities are not left stranded and isolated in their homes? I thank the committee members today for their time and deliberations. Many thanks for letting me tell my story.

THE CHAIR: Thank you, Ms Bannister. Dr Fanning, would you like to provide an opening statement?

Dr Fanning: Thank you. I am not sure whether I am the only one coming before you who is not on the NDIS. The reason I am not on the NDIS, I believe, is a failure of communication and a failure of transition arrangements between the ACT government and the NDIS. I was diagnosed with multiple sclerosis, which, as you probably know, is a progressively disabling neurodegenerative condition, in 1998. I have been on the disabled pathway for 20 years.

For most of that 20 years I have funded my own requirements, but in 2013 I applied for support from the ACT government, under the enhanced services offer grant, and I received one. The letter I received at that time said that I was a person considered in priority need. I was advised that it was successful in April 2014 and I think it was paid in May 2014. The letter that I received from the then minister, Joy Burch, said that she hoped that it would help me meet my needs pending the launch of the NDIS in July 2014.

From that correspondence, and from the chain of events, I assumed that I was a registered recipient of disability assistance in the ACT and that my details would be made available to the NDIS, as per the transition arrangements on the NDIS website, and that I would be contacted in due course. After I became aware that my peers with multiple sclerosis were being contacted by the NDIS, I rang the NDIS and asked when I would be contacted. They said they had no record of me. By then I had turned 65. So they said, “Sorry; too late.”

I wrote to the ACT minister; I wrote to the federal minister; I wrote to the chair of the NDIA; I wrote to my local member. I had made an initial inquiry of the Ombudsman. I made every representation I could think of. To be fair, the then minister for disability, Chris Bourke, was very sympathetic to my situation and basically said, “Surely, this is not the way the system is intended to work?” But the end result was that I was told there was absolutely no discretion under the legislation for me to be admitted to the NDIS, even though at the time it was launched in the ACT I was of eligible age, I clearly had a permanent and worsening disability and I was a resident of Canberra.

I met all the criteria and I was trapped by what I would describe as a “gotcha” mentality on the part of the NDIS. I was very disappointed that, although the ACT minister made representations to the federal minister, at no stage did the ACT government acknowledge that my information should have been made available to the NDIS. I should have been asked if I wanted my information to be made available to the NDIS or they should have advised me on what I needed to do.

I have had a career in government. I had to retire eventually, due to the impact of my illness. But I am thinking that if a person like me can be caught out by an administrative requirement like that and be excluded from the NDIS basically because of an administrative error, whatever the reason for that administrative error, there is a serious problem for people who are living in much more marginal situations than I am or for people with a cognitive disability.

Going forward, it would appear that there is absolutely no discretion in the legislation for me to be admitted to the NDIS post hoc and the assistance for which I am eligible now is simply aged care. My disability is totally non-age related and I have very specific requirements. The kind of assistance I need is the kind of assistance that I want to help me stay well, to engage in the community, to continue my voluntary work and not to be socially isolated, like my neighbour here. Under aged care, I have no choice of provider, so I cannot go to a specialist in neurological conditions. I have to go to the physiotherapist that is available through aged care. I have a limited choice.

There are a whole range of differences between what is available under aged-care support and under NDIS support. The NDIS support is, quite rightly, an insurance scheme. The government expects people to work until the age of 70 and to continue to participate in the community. That is exactly what I want to do. That is exactly what the NDIS is supposed to support and, of course, to provide support to my husband. He also has some health issues. If anything should happen to him, I would be in very grave difficulty indeed because I depend very much on him for assistance in my daily living. I think I will pause there.

THE CHAIR: Thank you, Dr Fanning. Mrs Muir, do you have an opening statement?

Mrs Muir: Yes. This is basically a summary of my submission. I would like to thank you for the opportunity to talk about my experience with the NDIS and also for your continued support. I am going through my second review at the moment. You have provided advocacy and support for me through Wendy Kipling.

I entered the NDIS with many hopes and dreams. It is a great Australian initiative, an insurance scheme based on United Nations principles. I can live in my own home and have a solution for my children if my husband is unable to care for me. I can now directly employ support by self-managing, due to the high education level of Canberrans and the number of tertiary institutions. That is important to remember.

I am very lucky. My husband and I have work history in interviewing, writing job descriptions, negotiating agreements and mentoring staff. I can develop and implement health and wellness plans with exercise physiologists who share my dreams of innovative health outcomes.

To turn to the NDIS, I needed to accept that I am permanently disabled, that my disabilities are degenerative and can only get worse. I have major psychosocial disabilities, Parkinson’s, rheumatoid arthritis and rare genetic hemiplegic migraines. The NDIS did not seem to use any existing record system to smooth my past into the scheme, nor did it implement the Productivity Commission’s inquiry recommendations from health groups I belong to.

I had to advise all my medical professionals, including my Oxford graduate neurologist, how to write impact statements about my disabilities. Since joining, it has become apparent to me that the NDIS has several major issues that seriously impact its ability to deliver necessary and reasonable person-centred support to me.

The NDIS does not seem to be adequately resourced with appropriately skilled people to provide trauma-informed care. The Blue Knot Foundation is a national leader in the needs of one in four adults in Australia who have experienced childhood trauma. They say that there are often major consequences for victims of abuse when services are not trauma informed.

The basic trauma-informed principles are fivefold: safety, trustworthiness, choice, collaboration and empowerment. Conversations with me should be informed by these principles. If it is a safe environment, it is a collaborative approach and people engage in a way that helps them to feel empowered. It is a trauma-informed way of relating and will minimise the risk of any underlying trauma being compounded and minimise the risk of re-traumatisation for me.

The NDIA lacks a record management system to efficiently track who I am, to assist in the planning process and to alleviate the stress of each plan review. I need to re-explain my disabilities, my goals and my progress against these goals, including impact statements against outcomes, over and over again.

Staff at the NDIA are removed and isolated from me and cannot support me now, with Feros Care as the local area coordinator in the ACT. I believe this isolation builds a level of distrust, ignorance and misunderstanding between NDIA staff and me. This results in uninformed, inconsistent and inadequate decisions by the NDIA regarding me and my plans.

Many people with psychosocial disabilities have felt betrayed and disempowered. The process of plan review is flawed. It is tedious, stressful and, in my case, damaging to my health and wellbeing. Instead of a simple review of my plan each year with slight adjustments, I must start from scratch and, because of the inadequate systems and resources and the isolation of staff, plan outcomes are impossible to predict. They appear to depend on the planner assigned by the system rather than on my needs.

I am scared about my future with Parkinson’s and its cognitive changes to my brain. I cannot keep learning new language and rules, provide annually copious medical reports and empirical-based evidence to NDIA staff who know little about me. As my husband and I age, I do not want to figure out which slice of my disabilities is funded by Medicare, NDIS, ACT Health or my private health insurance.

The current system repeatedly triggers my obsessive compulsive behaviour, a by-product of Parkinson’s medication. Having to repeat my history is traumatic. With nearly all major plan reviews I have had long admissions to hospital, ironically triggered by a scheme which is meant to support me. I have shared my private life with many NDIS service providers. These are strangers I need to invite into my home. I am fearful and traumatised as my complex case care goals go to their boards. I am upset when they cannot help or I need to change my needs to fit their skills.

My personal concern, in analysing the safety and quality framework, is how come we pay so little for support workers to daily look after the most vulnerable members of our community, do not mentor and supervise them, give them no career path, have me worried about who will come, and leave me responsible for telling service providers that they did not turn up for work? Finally, this is not person-centred care.

THE CHAIR: Thank you for your testimony. We will go to questions. We are running slightly over time. However, I think we will have to extend in order to incorporate the number of questions that we need to ask. I will kick off and ask about the funding for coordination that was not provided in your latest plans. When you did have that funding, what was it used for? What has the change been now that, I am assuming, Feros Care has taken over that responsibility for coordinating?

Mrs Muir: Feros Care has provided no support coordination for us. Probably for about our fourth or fifth plan that came out in September last year, we were given a lot of money but no support coordination. Feros Care said that they would go back and organise the house renovations that had missed the plan, which had been sitting on the NDIS portal since July 2017, and ask for support coordination.

What we got instead—in January there were two changes of personnel in Feros Care, and we did not even know what they submitted to the NDIS—was less than one-fifth of our plan in September, with no support coordination, no house modifications and, again, as with the September plan, this incredible 1½ thousand for us to engage an independent contractor to write a report to the NDIS, with no explanation of what that report was to include.

THE CHAIR: Do you think it is their role as the local area coordinator to track outcomes under your NDIS plan?

Mrs Muir: I do not know what their role is; no-one has ever explained it to me, and they definitely have not. I have not seen anyone from Feros Care since we had a very good gentleman who advocated for us and got us our plan in September. Since then we have seen one lady, and she only lasted in Feros Care six weeks. The lady that we have now, I have had one phone call from her to tell us that our new plan was out. She was excited. She thought we would be happy. She did not know what the value of the plan was before. I have never heard from Feros Care since. We actually went and sat in the NDIS office at Braddon to facilitate a second review of that plan in September.

MRS DUNNE: I asked a lot of questions the last time around; so I will pass to Mrs Kikkert.

MRS KIKKERT: I am okay with questions for the moment.

MR PETTERSSON: I had a question for Ms Bannister. You had $147,000 put into core funding. You did not know why it was there. You did not do anything with it. Is it normal for large amounts of money to appear in someone's package?

Ms Bannister: It is on the portal, yes. My previous plan had been about—I cannot remember exactly but I think about $27,000 for most things. So when we got this extra huge amount we just assumed it was that they had approved the modifications. I asked for advice. I tried to get on to the NDIA and I was unsuccessful.

I went to a local service provider who has been assisting me with various NDIA questions and has offered me some support coordination when I need a bit of help, because I am self-managing. They suggested that there had been a few mistakes like this that had happened. What they would normally do is quarantine the money somewhere because they knew that all this stuff was going to come in for the modifications. Then when the quotes came through, they would release that money into the appropriate bucket and I could access it.

They said what had happened was that, instead of quarantining that money, they had accidentally put it into my core funding. They said, “So do not panic; just go ahead, get your reports done, get your quotes, submit them all, and when you put them all in they will realise that there has been a little bit of a glitch and they will just put the money in the appropriate bucket.”

MRS DUNNE: They will just fix it up.

Ms Bannister: We have heard nothing. We have had all our paperwork in. I think my planning meeting was in October-November the previous year. We got all of our reports in by the beginning of March, and we heard nothing until June-July. I got only two emails within five minutes of each other saying that we had been unsuccessful for various odd reasons. They said my modifications had not been approved because there was no building mentioned in my plan.

MRS DUNNE: Presumably you live in a home.

Ms Bannister: At the time of the discussion with my planner, we had originally tried to put a granny flat in for my daughter to move into out the back, because she is actually one of my carers. Ironically, after putting a lot of money into that, our building permission was denied because we had not made it wheelchair accessible. This was because it was for my daughter. We were trying to make it as big as possible for her. It did not have a wheelchair accessible bathroom in it. They turned it down because it needed to have a much larger bathroom.

Then we just flipped it. We decided to look to see if we could get a bigger loan and build a granny flat for us and put my daughter in the house. That got squashed because my daughter ended up moving out and buying her own little place in the time we were trying to mess around with all this.

In all this, we went to see the planner. We told the planner that these were all the things we had been looking at. She said, “Go ahead and investigate the granny flat option.” She did not think that was a good idea, anyway. She said to look at alternative accommodation elsewhere in Canberra that might be accessible—that is, sell and move, or look at modifying your home.

We tackled all three of those things. As I said, my daughter moved out in the meantime. She moved out in the middle of January, after my plan. So we stopped the granny flat idea because we could not afford to do that unless she was actually renting our existing home off us.

We started looking at other homes. That did not appear to be a good, viable option. So we went back to doing the modifications—the three steps that she suggested that we do. Again, as I said, we went through the NDIA-recommended OT again—this is the second time I have used her—to look at this new option of actually just raising the floor in half of my house by one step, because I have a split-level home. That step is getting bigger every year and it is getting harder every year.

I got my builder to give me a quote; she got her builder to give quotes. We put it all in.

She wrote up all the reports. I think that is the one she had to write twice because they changed the formatting halfway through. She had to redraft the report. We put that all in. Again, we did not hear anything until June-July when we got the two emails saying that it had been turned down.

MRS DUNNE: Had you already modified your bathrooms previously?

Ms Bannister: We have done as much as we can to the house. It is only a very small house. It is only about—I am not sure—I think 10½ or 11 squares. Everyone says we have a lovely ensuite. That is actually our one and only bathroom in the house. It is only a very small bathroom.

We took out a bathtub and put a second toilet in to allow much bigger circulation space and opened the shower up so that I can actually get in. We have taken out walls. We have put a deck and a ramp on the front of the house so that I can get in through the front of the house because there is a drop-down from the front door into the lounge room. We have done as much as we can on our own over the last 10, 11 years but we could not solve the floor problem.

MRS DUNNE: You cannot solve the floor issue.

Ms Bannister: No.

MRS DUNNE: You also, Mrs Muir, have a requirement for modifications to the home?

Mrs Muir: Like Louise, we have done most of the renovations ourselves. We have a son who is a commercial builder. Just before my husband retired, we renovated the house to suit my needs. We were only talking about a path access down the backyard and a railing on the ramp that my son put in.

Mr Muir: We just got funding for that in the last couple of weeks.

Mrs Muir: In the last two weeks under the second review. It had been sitting on the NDIS portal since July last year. It had been written by an occupational therapist in 2016.

MRS DUNNE: Dr Fanning, you have fallen through a hole. You said you had been accepted into the disability scheme in the ACT and therefore had expected you would just be transferred. What gave you that expectation?

Dr Fanning: Firstly, I had been classified as being in priority need and, secondly, the wording of the letter from the minister said, “We hope this helps you achieve your goals, pending the launch of the NDIS in the ACT in July.” And this was about six weeks, eight weeks before the launch.

MRS DUNNE: When the NDIS was launched did you make any approaches to the NDIS or you waited for them to come to you?

Dr Fanning: I was under the mistaken impression that my information would be transferred to the NDIS. On the NDIS website it said at the time something like "What do I need to do?" in the frequently asked questions, and the answer was: "You don't need to do anything. We will be in touch with you."

MRS DUNNE: How long did you wait before you were in touch with them?

Dr Fanning: I have lost track of this a bit, but I think it was under 12 months. It was early in the following year.

MRS DUNNE: By which time you had ticked over?

Dr Fanning: By which time I had turned 65.

THE CHAIR: Were there any appeal rights that you explored?

Dr Fanning: Yes, I appealed.

THE CHAIR: You went to the AAT?

Dr Fanning: No, I appealed the decision with the NDIS. I considered going to the AAT. I took legal advice about that, and the lawyer said, "The legislation is extremely unusual and allows absolutely no discretion to the decision-maker. You will only win in the AAT if they have made an error in law," and they had not made an error in law.

I have to say I was so stressed and angry and upset. Like Louise, I had really thought the NDIS was going to make a huge difference to my life, so I was full of confidence that this was going to be a benefit to me. To find out that I could be so arbitrarily excluded and that no redress was available to me was devastating. In the end I thought it was detrimental to my health to pursue this. As I said, I wrote at least half a dozen letters to everyone I thought could have the power to change that decision. I thought surely the minister or the chair of the NDIA has the power to make an ex gratia decision, or whatever they call it, an act of grace?

MRS DUNNE: Are you aware of anybody else in similar circumstances?

Dr Fanning: Yes, I am. It must surely be a common problem. As I said, I am not ignorant about government; I am not inexperienced. It just came as a total, devastating blow for me to find out that I had been excluded basically due to a technicality. I think the only thing that might have made a difference would have been if the ACT government had gone to the NDIS and said, "It was our mistake. We should have contacted Vanessa Fanning," or "We should have given Vanessa Fanning's details to you," but they did not do that.

MRS DUNNE: Did you ask for that?

Dr Fanning: Yes.

MR PETTERSSON: Anecdotally, how many people do you know of who are in a similar situation?

Dr Fanning: Probably half a dozen.

MS LE COUTEUR: And that is just in the ACT?

Dr Fanning: Yes, but that would be a tiny proportion, I would think.

MR PETTERSSON: They are just the ones you are aware of?

Dr Fanning: Yes. I have to say, I think the age 65 cut-off is very arbitrary and discriminatory, but that is another issue. But why should someone 65 or over with a non-age-related disability be excluded, given what we know about people's life expectations and work expectations? We are changing the pension age, we are changing the retirement age, but we are saying that at the age of 65 people are not entitled to have the support of the NDIS. If one of you were to have a car accident and become a paraplegic at the age of 65, you would not get any support.

MS LE COUTEUR: I presume the government would say there is a whole aged-care system, which presumably you have some knowledge of.

Dr Fanning: Yes.

MS LE COUTEUR: Would you like to talk about how the NDIS differs? You have made it fairly clear that you think the NDIS is a superior system.

Dr Fanning: The aged-care system is designed to help the frail elderly, and a lot of people with a disability are actually in very good health and are capable of working and participating in the community. They want to and expect to participate in the community. The sort of assistance I want is exercise physiology and all the things I need to enable me to stay well and strong.

A really stark and good example of what I think I may need in the quite near future is vehicle modification, and I am not talking about just a simple modification. The first thing you have is a simple modification which enables the accelerator and brake to be changed around and you have hand controls, and that costs about $10,000. That is not available under aged care. Then you may progress to a wheelchair-accessible vehicle where you can drive your wheelchair into the vehicle and transfer over to the driver's seat, and that is significantly more expensive again. No hope of getting that under aged care. That is a really good example of a benefit that is available or assistance that is available under NDIS that is not available under aged care. Another significant difference is that NDIS, because it is rightly an insurance scheme, is not means tested and all aged-care assistance is.

MR PETTERSSON: In regard to the quote for equipment that your planner came up with which was denied, can you explain to me how the planner came up with an estimate of price which was rejected even though you had a bucket of money sitting there?

Ms Bannister: Because they have had previous clients that have asked for that piece of equipment. It was for a smart drive for this chair, so it is a motorised battery pack that fits on that gives you some extra momentum to the chair so that you do not have to push as hard as often. At the time of the first rendition of this it was about $7,000. She said, “It is $7,000. Put that down.” There is now a newer version of that out that is just over $9,000. When my OT and the equipment rep came and we did a trial of the equipment it became quite obvious that I needed an additional piece of equipment.

My main aim is to be able to get down to my local shopping centre by myself. I normally go up the cutaways and gutters backwards—it is just the way I do it—and you cannot do that with the smart drive. I would have to go forward at quite a speed, so I would need an extra little wheel at the front. It is a wheel about this size that fits on the front of the chair that allows you to go up gutters and across rough ground and things. That is an extra $1,800-plus. The quote came out at about $10,000 or $11,000 but they had actually given me the $7,000 towards it. So I had $7,000 sitting there towards equipment. I did not have at the time the extra $4,000 to top it up myself, so it was just straight out gone.

THE CHAIR: You have suggested that there might be an issue with the NDIS in how they deal with quotes generally. What do you think the issue is?

Ms Bannister: One of the problems is the time it takes. Most standard quotes are 30 days or, if you are lucky, 90 days. And the process takes so long that they expire. A mate of my lovely daughter has now quoted on the mods four or five times. He has actually been very kind and he has drawn it out so that it is a six-month quote or an eight-month quote. This time he has actually said that if it goes on much longer we are going to have to add 10 per cent to that. I do not know how you can build that into the process, but a quote needs to be a little bit more flexible because of the time it takes to get approvals through.

Dr Fanning: Could I add something to my previous answer? Another important difference between aged care and NDIS support is supporting people to stay in their own home. Like both my fellows here, I want to stay in my own home and I have already substantially modified it to enable me to do so. But if and when MS progresses—hopefully it does not, but say it does—it often progresses to a point where the kind of support you need to stay in your own home just is not available under My Aged Care. Very often quite young people with MS have to go into aged-care facilities, which is catastrophic for them.

I certainly would want to stay in my own home. I do not want to go into an aged-care facility, but if something happened to my husband and if my condition progressed to a degree that I often see among people with MS, then I would have no option but to do that because the assistance to stay in my own home just is not available under My Aged Care.

MS LE COUTEUR: Mrs Muir, you said something about it being difficult to work out whether your issues are due to disability or ageing, and so one of your issues is who is responsible and who is going to fund what.

Mrs Muir: You mean whether it is Medicare or the NDIS or ACT Health?

MS LE COUTEUR: Yes. Can you say a bit more about that?

Mrs Muir: We have submitted lots of medical statements. For example, I have major oral health issues at the moment. One of the side effects of Parkinson's is that you do not produce saliva, which of course leads to a lot of decay. Also, due to my rheumatoid arthritis, which I have had for a long time, I have used very strong autoimmune suppressants, and there are also my psychosocial disabilities.

I have gone from specialist to specialist. I am now under a prosthodontist, and he has identified about 14 or 15 drugs that I have taken in the past for these disabilities or medical conditions which have has contributed to the problems that I have as well as the saliva. If you go to the NDIS they say that Medicare covers oral health. Medicare gives money out to each of the states and territories. I have even raised this with a delegate of the minister for disability in the ACT. I said, "If I look at the ACT Health site it says that only in an emergency situation or if you are on a disability pension can you access dental services." So that means I do not get anything from anyone.

THE CHAIR: Thank you very much for your testimony today. A transcript of the proceedings will be provided to you to make any corrections. I now declare the public inquiry closed.

The committee adjourned at 4.23 pm.