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

FRIDAY, 11 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.

WITNESSES

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Amended 20 May 2013

The committee met at 9.29 am.

OLNEY, DR SUE, Research Fellow, Public Service Research Group, UNSW Canberra

THE CHAIR: Good morning, everyone, and welcome. I now 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. On behalf of the committee, I would like to thank you for attending today. The proceedings this morning will commence with the committee hearing from a researcher from the University of New South Wales. Can I remind witnesses of the protections and obligations afforded by parliamentary privilege and draw your attention to the pink privilege statement before you on the table. Can you just confirm for the record that you understand the privilege implications of the statement?

Dr Olney: Yes, I do.

THE CHAIR: Can I also remind witnesses that proceedings are being recorded by Hansard for transcription purposes and are being webstreamed and broadcast live. Before we proceed to questions from the committee, would you like to make an opening statement?

Dr Olney: I am happy to make an opening statement if the committee would like me to.

THE CHAIR: Very much.

Dr Olney: My co-authors of the submission send their apologies. Associate Professor Dickinson is overseas at the moment and Associate Professor Carey is unwell today. I will do my best to represent all the research that we have done in our group.

We have done some very broad research into the NDIS from the perspective of participants, from the perspective of people with disability who are ineligible to be participants, the impact on disability service providers of the reforms, and also we are very interested in the governance of the scheme and the implementation in particular of the scheme across government. We have tailored our submission to the particular interest of this committee, but I am happy for you to ask any questions that you like.

Our submission essentially looks at the sustainability of the NDIS and in particular the fact that it hinges on the interface between the NDIS and mainstream services. We are particularly interested in that and we are looking closely at the COAG principles for the responsibilities of the NDIS and other service systems. Also, we are interested in the planning process and in particular the discretionary assessment that is involved in establishing what is reasonable and necessary under the umbrella of giving participants choice and control over their care.

I am happy to keep talking—or perhaps take questions?

THE CHAIR: We will probably be able to elaborate during questions. I will kick off with a question on one of the major issues that you have raised in the submission, the interface between the NDIS and other services, particularly government services. Can you provide an example of one of the issues that have arisen in relation to an interface with a government service not being provided under an NDIS plan?

Dr Olney: We had an interesting example that came up that I think illustrates a few points around this in the research that we did that was called "Choice, control and the NDIS", which was dealing directly with participants involved in the NDIS trial in the Barwon region in Victoria. We were at that stage aware of some emerging inequities in the scheme, particularly around participants' capacity to argue and advocate on their own behalf for funding.

We had a mother of a young child who was part of that research project, and she talked about going into a planning meeting very well prepared with a lot of reports from experts about services that her child needed. He was under school age but ready to move into school. She said that she was interested in him having some therapy to improve his manual dexterity, and when she went into the planning meeting she said, "He needs this therapy to be able to write." The planner said, "That is actually an education goal, so it is not part of NDIS funding." Then she said, "Actually, he needs to improve his manual dexterity to be able to do up the buttons on his coat when he is getting dressed." They said, "That is an excellent goal. We will put that in." It was exactly the same therapy.

It is a small example, but it is an example of how there is this grey area in the boundaries between responsibility for funding and who is prepared to make that call about what service pays for what.

THE CHAIR: What is the solution to dealing with these interface issues?

Dr Olney: I would like to see the COAG principles a little strengthened. If you go through that document you can see that there is responsibility on both sides that is almost identical. I think that we should be setting some clearer boundaries about how the decision is made about what to fund in the NDIS plan and what not to fund. What we are finding at the moment is that that grey area is playing out in the courts and in the media. People are not happy with their plan.

One of the problems with going through the court system for that is the amount of time that it takes. If we set aside the cost, which is another issue altogether, the amount of time that it takes is often longer than the life of the plan. People are reviewing their plans annually. By the time this goes through the system and has been resolved, often the plan is finished.

THE CHAIR: That is through ACAT that you are referring to?

Dr Olney: Yes, it can be.

THE CHAIR: Is it a problem of the scope of these NDIS plans that they cannot include some of the things that may be considered to be mainstream services or services that—

Dr Olney: I think for us, when we looked at it from the perspective of the participants, the boundaries that government puts around services do not exist for the person who is immersed in the situation that they are in. If we talk to somebody who says, "I would just like to have a job and be able to move out of home," or "I would like to do a course," they are not thinking about that in terms of which department or even which tier of government is responsible for that. Of course that is another issue that we have in crossing that boundary between the federal, state and territory government services.

One of the issues that did come up in our research in the trial site was that state and local governments were withdrawing from services before the market had emerged to fill that gap. We did talk to people who were no longer able to access services that they had used before.

MRS KIKKERT: Thank you so much for coming in today. I read your excellent submission. Thank you so much. Many people have made comments that after they have made a submission they have something to add but it is too late. Is there something that you want to add to the submission?

Dr Olney: No. I have certainly had a chance to go through the final report on the evaluation of the NDIS now, since I wrote the submission. Interestingly, many of the issues that were flagged in early research into the NDIS have in fact played out. This suggests to me that we are not operating in entirely new territory here. There are precedents that we can look at in these types of reforms and particularly in a situation where public services are put out to a market, where citizens become clients and consumers in a market. I think we should be looking closely at lessons from other instances of that happening, like vocational education and training or employment services.

There is a tendency, I think, in this particular reform to talk about it as a groundbreaking, new initiative, and we need to see how it plays out. But I would like to see us take more note of research that has already been done on similar initiatives here and overseas.

MS LE COUTEUR: One of the things you talked about in your report is the risk of oligopolistic practices and exploitation and neglect of people with disabilities in thin markets. I would have assumed that virtually everywhere, except maybe some parts of Sydney and Melbourne, there was going to be a very, very thin market. I am interested in some more insights you might have about whether it is possible to run something like the NDIS in Canberra. Canberra is not even in the worst situation; if you are in regional Australia how are you going to access services? And, looking at it from the other side, how is government going to regulate that you have something to access at a vaguely reasonable cost? Clearly there could only possibly be one provider or even half a provider in those areas. How can that work?

Dr Olney: It is interesting. If we take a step back and think about the evolution of a scheme like this, it is really underpinned by the UN Convention on the Rights of Persons with Disabilities, which says that a person with a disability has the right to access services in the same way as any other citizen. In the past we have tended to corral people with disabilities into particular services that are targeted at their needs.

The lofty aim of the NDIS is to say that these people should be included in the social and economic life of their community and the NDIS is the glue that enables that to happen. It fills the gaps that will enable people to access mainstream services.

In the case of thin markets—or, as we are finding now, market failure—the government is saying that this will throw up innovative ideas from the market and people will find ways to deliver these services. I am less optimistic about that. There is certainly a push to review the pricing structure and there are levers government can use to encourage providers to work in areas where there is less potential for profit and there are fewer clients, and to look at ways to bring services together to find some economies of scale.

But if we think about natural partnerships like aged care or other health services, everything is under reform at the moment and no-one has any overarching authority over these services. It is a difficult situation, and the NDIS is designed to say the market will respond to those challenges and the participants will demand what they want. But I feel like it is a bit naive at this stage, for a policy.

MS LE COUTEUR: I think I probably agree with you. In the past a lot of these services were provided on a group basis because clearly there were not the financial supports to do it all individually. The impression I get is that group services are not well funded or at all funded out of NDIS because, as you say, it is based on an individual demand model. Do you have any comments both from the point of view that it would seem to me to be good for some services to be provided on a group basis—because there is also the social element of that service provision, which must be important in some instances—and also from the point of view of sheer economies of scale in terms of provision?

Dr Olney: I will not speak on behalf of the NDIS, but I think they would argue that there is capacity for consumers to group together to keep these things running. Often at community briefings as the NDIS was rolling out people would ask questions about group activities that they were going to and express concern that those groups were no longer funded. The response was, “Well, if eight of you want this thing to continue, then you just pool your resources and keep it going.”

A similar argument is coming up for housing, for example. The idea is that people will be able to pool and find whatever they need as a group, but that is a very sophisticated market. In the time frame in which the NDIS is rolling out I would argue that it is unreasonable to expect the consumer side of the market to be that sophisticated that quickly.

MS LE COUTEUR: And also to be that organised, because traditionally the people who did the organising of getting your half dozen people for the group house were not the individual people so much as the service providers, who said, “Look, we can see there is a demand for this much group housing. We’ll endeavour to provide it.” That seems to be a problem.

Dr Olney: Yes. But the other side of that argument is that in the push for reform people with disabilities themselves were often saying, “This is not the service that we want.” And so we have this tension between some people. It is very difficult for anyone to argue against people with disabilities having the right to choose how their funding is directed. There is a lot of talk about building the capacity of people with disabilities to use this market. My argument perhaps would be to make it simpler. We are talking about equipping them to deal with the world as it is and the portal and all of the things associated with the NDIS.

I think we could turn the focus back to say, “How do we make this simpler rather than focusing on building the capacity of people who are going to be using the services?” How do we make it easier for them to understand what falls within the NDIS and what falls outside the NDIS and how those things work together and where they go when they need someone to help them to navigate this? Online is not necessarily the solution for some people. And, of course, it is then about how we balance that fair go with the funding and the resources that are available.

MRS DUNNE: I think you have highlighted very helpfully, very early in the public hearings, some of the key issues. I will start with the last point about—“simplicity” is not the right word—the level of readability of the process. At the same time it needs to be rigorous but it also needs not to be bureaucratic. Does your research provide any insights into that?

I go back to your first example of the lady who wanted some manual dexterity training. She had enough dexterity to be able to adapt her answer to get the right outcome, but I think about the capacity of the average person who is already dealing with a disability—a young parent dealing with a disability, coming to terms with their child’s disability and probably functioning on not enough sleep and all of these sorts of things—to navigate the system when they are not necessarily sophisticated academics or legislators. One of my bugbears is that not everybody is a legislator and can navigate the system as easily as others.

In a perfect world, how do you create a system which is responsive but fiscally responsible, which is rigorous but simple enough to navigate and which meets the demands of ensuring autonomy for people with disability—in 25 words or less?

Dr Olney: That is the $64 million question. There is no one way that works. People with disabilities are all different, like anyone else. Systems becoming bureaucratic is a fallback risk management strategy by government because it is a way to control the unknown and to protect people from potential harm. In any market reform of services government is aware that there is potential for people to be taken advantage of in that market. The information is imbalanced on both sides.

In the case of the NDIS trial it was evident that an enormous amount of bureaucracy was putting pressure on the people that we spoke to in that scheme. They were carting around enormous amounts of paper and providing information to planners. They were frustrated with the IT system. And as you said, these are people who are under pressure anyway in life. In terms of risk to government, the planning process in particular is a person’s first interaction with a scheme that they are going to be part of for the rest of their life, and if trust breaks down at that point then it is very difficult to retrieve that.

One of the issues was that the planners working in the local area are coordinators, so it did not feel like people were dealing with government; they were dealing with whoever was the local area coordinator. They were not confident that the people they were dealing with were really across the issues. They were not confident that these people understood their disability and their lived experience of what they needed from services.

In terms of managing that in a cost-effective way, it is very difficult to balance choice and control for individual people with disability and not to overly safeguard or protect them from making poor decisions that might impact on their life. And that is the tension that we have. Of course, within the NDIS we have people—and I think parents of young children are a good example of this—who perhaps in their working life are used to dealing with bureaucracy; they are used to confidently sitting across a table from someone and asking for what they want and expecting to get what they want. For older people with disability, particularly older parents of adults with disability, they are not used to thinking about what they want to ask for. They are not confident to articulate their goals. Sometimes they have not thought about what they need and what they want in life because they have not had that opportunity. This is a really huge spectrum of needs and risks and aims and the types of services that people want.

One of the things we look at in terms of that is just slowing down the pace of this rollout. Overseas, similar types of initiatives have been implemented over a much longer time frame, so the market has been given time to develop and there has been the option of a provider of last resort or some protection for people who are not ready to plunge into an open market for services. There are different ways to do it, but we just need to stop thinking about people with disabilities as being a group of people with similar characteristics, because their needs and wants are very diverse.

MRS DUNNE: From your experience and research, what is the best model of rollout from somewhere else?

Dr Olney: There really is not an ideal system like this. But in terms of the best option, it is having some type of last resort for people who are left behind by the market.

MRS DUNNE: Picking up on Ms Le Couteur’s point, that would be people in rural and remote areas. That is a clear risk, especially with a very rapid rollout.

Dr Olney: Yes, absolutely. We spoke to people in rural and remote areas where there simply were not services. Of course, the immediate risk in that, which is also flagged in the evaluation of the NDIS, is that people were not able to access services that were included in their plan, and the design of the scheme is that if you do not access the service over the life of the plan then it is deemed that you do not need it. The other challenge in that is that many people with disability have episodic needs, so they might not need something for a year and then they need it quickly.

MRS DUNNE: And the other point that you raised earlier, especially in relation to Ms Le Couteur’s question, was about integration across sectors and jurisdictional levels. How developed is the thinking in that space?

Dr Olney: I think that the cost involved is potentially huge. If we think about people being able to access public transport, for example, the response to that has been to date, “Oh well, if people cannot get on a train or a bus then we’ll use taxis and we’ll fund that.” But there is a cap on that within the NDIS, I understand. Again, that is something being challenged in the courts. So, in terms of things like health, education, justice—

MRS DUNNE: But also, as you said, there is reform in aged care. Many of the services that are provided in aged care are also the sorts of services that would be provided in the disability sector, but they do not seem to necessarily talk to one another. Some of the providers are across the sectors, but the sectors do not talk to one another, particularly. And in your example of manual dexterity—whether it is writing or doing up buttons—the communication between disability services and education providers is an issue. There is a possibility that it could be very expensive but, in that space in particular, there is the potential for reasonable economies over time. If a child does not learn to write properly because he does not have the right manual dexterity for want of therapy when he is three or four, that has long-term educational impacts as well.

Dr Olney: Absolutely. And the cost over his life course would well outweigh the cost of early intervention. My understanding is that the focus of the early intervention in the NDIS is to think about reducing lifetime cost for individual participants. The frustration is that now disability services are out to market, so that means the providers of those services are compelled to put self-interest before the public interest because they are businesses that are looking for customers—that is what a market is.

If they are working in concert with a state government school, for example, it is difficult to find common ground in terms of the aims of those people to share resources—we are talking about the providers themselves—and to think about how they might work together and share resources. It is a complex system to navigate. Then we have situations in that picture where someone wants to achieve a certain goal by putting together a package of activities that work for them, and those activities might be provided by a private provider, a state government school, a local kindergarten, a local government service, a library, a state government service.

MRS DUNNE: That means that, unless there is communication across all of those providers in that person’s life, the risk of one person working against the other is pretty high.

Dr Olney: It can be, but then the protection for that is the ILC and the local area coordinator. We are finding there is an enormous amount of pressure on the local area coordinators at the moment to simply get people on to the scheme and to write their plans. As well as that, there is quite a lot of pressure on them to understand the local environment they are in. It is complex, and hundreds of services and providers can be involved in any local area that that coordinator is working across. Perhaps the answer is to provide more resources in terms of the linkages at a local level and understanding the environment the person is navigating.

THE CHAIR: Thank you for attending today, Dr Olney. When available, a proof transcript will be forwarded to you to provide an opportunity to suggest any corrections.

MAY, MS FIONA, Chief Executive Officer, ACT Disability, Aged and Carer Advocacy Service

O'BRIEN, MS LAUREN, Advocacy Manager, ACT Disability, Aged and Carer Advocacy Service

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

Ms May: Yes, I do.

Ms O'Brien: I do.

THE CHAIR: On behalf of the committee, I thank you for attending today. When available, a proof transcript will be forwarded to you to provide you with an opportunity to check it. Before we proceed to questions, would you like to make an opening statement?

Ms May: I would. Thank you for the opportunity to come before you today to contribute to this important inquiry. ADACAS is the largest independent advocacy organisation in the ACT. We are really proud of our 27-year history of providing rights-based advocacy to people of the ACT region. ADACAS commenced work on the NDIS long before the trial commenced in the ACT. We have engaged actively with policy development as well as with the NDIA throughout the trial. ADACAS has supported many hundreds of clients with advocacy around NDIS issues.

I would like to start by reiterating our strong support for the concept of the NDIS and the opportunity that it represents for people with disability. We are aware that many people have great outcomes as a result of their NDIS participation. We are committed to working with participants, the ACT government and the agency to ensure that the NDIS delivers on its promise to all people with disability.

One impact of the rollout of the NDIS has been on the availability of supports in the ACT that are not supports covered by individual plans. I am speaking of activities previously undertaken by organisations like the Canberra Blind Society and Capital Community Housing, two organisations that became unsustainable without the core funding previously provided by the ACT government.

Other organisations, such as Radio Print Handicapped, TADACT, SHOUT and Pegasus have also been significantly impacted by the ACT government's decision to withdraw funding, and some continue to face funding uncertainty. I urge the committee to recommend that the ACT government refund organisations which provide ancillary disability services to the disability community that are not suitable to be funded in individual plans.

There has also been significant impact on individual advocacy organisations as a result of the NDIS. There is wide recognition that independent advocacy is a key support for people entering the scheme, navigating the scheme and exercising choice and control under their plans. Advocacy also acts as an important safeguard for people with disability and it is part of the safeguarding framework which is to be implemented by the new NDIS quality and safeguards commission.

Recognition of the need for advocacy, however, has not translated into clarity about funding responsibility or certainty. I refer you to the submission to this inquiry by Advocacy for Inclusion, which argues for the principle of ongoing funding for independent advocacy and the rationale for retaining the funding of advocacy separate to the NDIS.

The ACT government's commitment to the funding of independent advocacy has decreased in real terms since the NDIS rollout commenced. Advocacy for Inclusion used to receive one-third of its funding from the ACT government. That funding ceased in June 2016. Currently, they receive no ACT government funding. While ADACAS funding by the ACT has not decreased, nor has it increased or kept up with the growing demand for independent advocacy.

While we do not keep waiting lists for advocacy, we can see from our records that in the last financial year ADACAS did not accept as advocacy cases 50 per cent of the people who sought advocacy from us. In 2014-15, this figure was 22 per cent. In 2015-16, it was 32 per cent; last year, 50 per cent. I anticipate that it will be at least that high, if not higher, this financial year.

We have restructured our team to enable several staff to focus solely on doing intake information and referral work so that we could provide more than 560 people with this kind of support last financial year. But that is less than the full advocacy support that they were seeking. Unfortunately, it is all that we could do with our resources. Advocacy organisations are struggling to meet demand. People know this and they stop calling us and asking for the help that they genuinely need, because they presume that we cannot help. The actual level of unmet demand is therefore likely to be higher than the figures I have reported here.

Both the ACT and federal governments have a responsibility to continue to fund advocacy. I urge the committee to recommend that the ACT government increase its commitment to individual advocacy funding so that people with disability and their families can access the support that they need. A key contributing factor to the demand for advocacy is the length, complexity and stress of the processes of the NDIS, from the moment you try to get a copy of the access form through to every step to implement a plan that fully meets your needs. And there are many steps which can take many months. Some people need advocacy.

Our observation, after supporting many people on NDIS matters, is that the process of participation is getting in the way of achieving the outcomes envisaged for the NDIS. We have case study examples of this with us today if you are interested in hearing them.

We know the NDIA are working on changing their processes, but they are coming too slowly and are not going far enough to resolve the very real issues people face in attempting to navigate the scheme. For people living with psychosocial disability, the process of the NDIS is making their disability worse, not better. NDIS decision-making appears to be inconsistent, not based on evidence and made by people who do not have sufficient understanding of the disabilities and particular circumstances of each individual. All of this leads to poor outcomes, high demand for reviews and appeals, and puts both people's lives and the scheme itself at risk.

Our submission provided examples of the issues people are having with the NDIS. I note that later in these hearings you will be speaking with the agency. I hope that you will be able to raise some of our issues with them and we look forward to hearing their responses.

In our submission we spoke about the role that the CASP program can play in providing support outside the NDIS and the gaps that have emerged since the NDIS came in. We spoke about the challenges for individuals and families where multiple disabilities co-occur and about the significant issues when the NDIS interfaces with government systems such as health, care and protection, and justice.

We would be happy to respond to any questions you have on these issues. An important area where the ACT government and the NDIS must cooperate is ensuring that there is a provider of last resort. We know that some providers are choosing which participants they will work with and are refusing service to some participants.

This may be because the funding levels are not sufficient for the level of support they require, because the provider cannot manage behaviours that they find concerning or simply because of a falling out between the provider, the participant or their family. Regardless of the reason, it is imperative that people do not end up in hospital or without critical supports because there is no provider of last resort. Governments must work together to solve this issue.

The NDIS is an important—indeed, critical—reform. We all have a part to play in ensuring its success. I hope that this inquiry can lead to real improvements to the scheme and its implementation.

THE CHAIR: Thank you very much. I am certainly interested in hearing some of those case studies, but if we do not have an opportunity to explore those today please feel free to table them if you would like to do so.

Ms May: We can.

THE CHAIR: In relation to your submission, you have mentioned that you would like to see a different role for local area coordination. We were having a discussion earlier about the role of the local area coordinator. What role would you like to see them play in the system?

Ms May: The Productivity Commission outlined a role for the local area coordinator which is very different from the role that they are currently being asked to play by the agency. The local area coordinator, as envisaged, was about being a connector, not just for people who have plans but also for other people with disability who do not have plans, enabling and supporting the rest of the community to interact in a better way and be more inclusive of people with disability, and helping people to access the mainstream supports they need.

These days, all the local area coordinators have time to do is meet participants and do plans and plan reviews. There is no capacity for them to provide that wider connecting and capacity-building support that they were initially envisaged to do. The NDIA have limits on the number of staff they are allowed to employ. That is getting in the way of their being able to employ sufficient planners themselves; hence this hybrid model which they have created with the local area coordinators.

We actually trialled that model here in the ACT during the trial phase. They called them plan support coordinators. They were supposed to do both functions. We learned during the trial that they had no time to do the LAC functions because they were too busy doing the plan functions. Sadly, the lessons that we learned were not implemented in full-scheme rollout. We have this model of the LACs actually doing planning functions. It is not working for people.

THE CHAIR: Are you aware of how many employees they might have in the ACT?

Ms May: I do not know that number, I am sorry. You would have to ask Feros Care.

MRS KIKKERT: Fiona, thank you so much for being here today. You mentioned that the ACT government cut funding in 2016. How has that impacted families?

Ms May: The impact is very significant for people who are trying to seek advocacy funding. I do not propose to speak on behalf of Advocacy for Inclusion and the impact on their service specifically, but I can say that we know that people are seeking advocacy and are not able to get it, either from them or from us, because we just do not have enough staff to meet the demand, as the figures that I presented indicate.

MRS KIKKERT: Do you understand their mental health wellbeing at the moment, or at the time when you were speaking with them?

Ms May: A lot of people approach us in states of high anxiety. Even if they are not people who have a diagnosed mental health condition, the stress and anxiety created by these processes is really, really significant. We know that mental health co-occurring with other disabilities is incredibly common. A lot of people with disability in fact have multiple diagnoses, but these processes are so stressful and so traumatic that people are really struggling to navigate them well.

Ms O’Brien: I will add a case example at this point. ADACAS was approached by a client with psychosocial disability who was needing support to navigate the NDIS. There was limited support available in the community to assist and there was insufficient funding in the actual NDIS plan. The participant in that instance found the process of collating health information and preparing plan reviews so anxiety-inducing and traumatic that they ended up in hospital as a result of trying to engage with NDIS processes.

We are aware of scenarios relating to clients that have existing psychosocial disability. I can think of situations relating to people who go through the review process. I can think of participants who should meet the entry criteria for the NDIS but who perhaps did not have adequate support through the application process. On the face of it, looking at the paperwork, looking at the reviews to try to gain entry, they clearly should have met the entry requirements.

One participant I am thinking of was not able to go through that process because they found the process of going through the appeals so distressing, overwhelming and traumatic that they chose to withdraw their appeal rather than actually continue with the appeal process. It was too overwhelming at that point in time for that particular person to go through that appeal and seek to enter the scheme in that way.

I am very aware that that those situations are not isolated case incidents. Whilst in that second example the person will have an opportunity to apply again at a different point, should they wish to, in the meantime they are not getting the support that they need to be getting or are relying additionally on the health system because they were not able to navigate that process and go through that appeal.

MRS KIKKERT: What happens when they are in hospital and after they are discharged from hospital? Is there someone there to pick him or her up and help them through the process? What happens to the person?

Ms O'Brien: This is where it gets really complicated. There are some funded supports that offer some support, sort of through the health system or family support, depending on the nature of the support that the person requires. But I will tell you about a third example that I have also brought with me. The example is of an NDIS participant experiencing both physical health and also mental health issues, in hospital originally for mental health but then moved over to hospital for physical health reasons. There was an NDIS change of circumstance review. Because the person was so unwell, they needed additional funding in their plan that was submitted very early in the piece.

There was a delay in the response from the NDIS to that because of the staffing issues that they experience. Unfortunately, there were issues then with the discharge at hospital. The participant was discharged into a hotel because they felt unable to go into other housing situations. That is obviously unsustainable, unsuitable and it is a housing option without adequate support. That housing arrangement exacerbated the client's mental health. It means that a readmission to hospital is likely because that process did not happen in a smooth way. That is despite a lot of effort to try to make that happen smoothly.

MRS KIKKERT: Would you have an average cost of treating patients that end up in hospital because they have NDIS-related problems?

Ms May: We certainly could not talk about the cost to the healthcare system. That is a question you would have to ask the health system. We can talk about the numbers of hours of advocacy that we spend.

MRS KIKKERT: Yes, that would be great.

Ms May: Would you like us to do a little analysis of some of our cases and come back to you?

MRS DUNNE: Yes, please.

MRS KIKKERT: Yes.

Ms May: If it related to how many hours we are likely to spend on an advocacy case around these sorts of issues, we could do that.

MRS KIKKERT: Fantastic, thank you. We appreciate that. Thank you.

MS LE COUTEUR: There is clearly a huge need for advocacy, but how inherent do you think that need is in the NDIS model? Even if the bucket of money that the NDIS had was effectively unlimited, it has been set up with the requirement that a disability must be long term or permanent. You would know about all the requirements better than me. If there was plenty of money, would you still have as big a need for advocacy, or is it the case that what is actually happening is that the rules are reasonable but because the money is limited this is the point at which the NDIS basically has to say no, because it cannot fund everybody? Probably it is a combination of both; I would be interested to hear your views on this.

Ms May: There will always be a need for advocacy under the NDIS. If systems were improved there would be less need for advocacy than there is now. We are also doing work with people who have an NDIS plan that they are quite happy with, but they are having difficulties with the service provider they are using or having difficulties transitioning to a different service provider—exercising the choice and control that are inherent in the scheme. Sometimes that takes advocacy support as well. Those issues will certainly not go away until we have, in an ideal world, a market in which the consumers have as much power and control as the providers, and we certainly do not have that currently.

If we look at the aged-care system, the federal government have just announced funding for system navigators, because they recognise that the aged-care system is too complex for the people who are using it. In the budget the other night they announced additional money for system navigation for aged care.

If we look at the NDIS system, the support coordination function was supposed to act as a system navigation function for people, but the NDIS has made it very clear that most people will not qualify for support coordination. Many clients that we work with who might have had support coordination before, and who clearly need that support, are finding at plan review stage that they are not getting support coordination in the plan again. I think the NDIS is not accepting the extent to which people do need that support to be able to navigate not only the NDIS processes but also the market processes, to make sure they can implement their supports.

MS LE COUTEUR: If I am hearing you right, you are saying there will always be a need for advocacy, basically because it is complicated, but you do not think that the need for advocacy is any more than it would be otherwise because of funding constraints. In other words, one of the reasons for complexity and people not getting what they want is not the NDIS attempting to live within its budget. If budget constraints for the NDIS are not the issue, is it just about the inherent complexity?

Ms May: No, it is both. Some people come to us because they get a plan which they are not happy with, as it is not sufficient to meet their needs, and they are seeking advocacy to get that decision changed. The extent to which the plan being insufficient is because of budget constraints versus poor planner decisions or poor evidence will be different case by case. Certainly, there are plenty of people whose needs are not being met by the size of their plan.

Ms O'Brien: You asked what the difference would be if the NDIS had additional funding or a different set-up as to how they could manage their funding. One of the points that Fiona mentioned earlier was the number of planners that they are able to employ, and the planner function having moved from the NDIS in lots of cases to the LAC, therefore taking away from the role that the Productivity Commission had originally expected they would have. That is a very clear example of how the impact of the funding constraints or the way that the funding has been set up has affected the support more generally in the community and increased the need for advocacy.

MRS DUNNE: I will go back to the point that Ms O'Brien finished with, and the one that Ms May started with—the need for a rethinking or a reformulation of what the local area coordination system does. Could you expand on what it should look like in an ideal world and how it would interact with other parts of the planning system in the NDIS?

Ms O'Brien: With the role of the planner, at present the structure is that, if a participant is seen to have a less complex planning need, that role of preparing the plan occurs with the LAC worker. Because the LAC staff do not have the authority to be able to approve plans, that is then sent across to the NDIA, who at that point have to do the approvals and the checking process.

One of the impacts is that the person approving the plan is not necessarily meeting directly with the participant. It is also increasing the amount of work that is occurring between those two functions. If the NDIS had been able to have additional funds for planners, in my ideal world there would be a scenario where the NDIS is doing the plans for all participants and the LAC function reverts to what was originally conceived by the Productivity Commission, which was supporting both people that have a plan or do not have a plan, who need that support in connecting to services—and more than just "here's a list of the providers that work in this area".

MRS DUNNE: Actual facilitation?

Ms O'Brien: Actual facilitation, and actually assisting people to connect to the services that are required. There are some changes that have been forecast to the planner pathway. At a recent provider forum with the NDIS there was quite considered discussion by members of staff working with community services. The proposed model has both the local area coordinator and the planner meeting with the participant. There was some concern about that particular model of having two people meet with the participant. Whilst it has some strengths, it also takes double the time to have two people meeting. It means that the local area coordinator is still perhaps not able to do some of those additional functions around really facilitating and really having the additional depth of knowledge and time to be able to help people find solutions to the things that are occurring.

MRS DUNNE: Did you hear Dr Olney's evidence?

Ms May: We heard the last part.

MRS DUNNE: At one stage, following on from something that Ms Le Couteur said, she referred to the lack of group solutions and that, in a perfect market, the group should be able to coalesce and find that solution. Would you see that part of the local area coordinator role would be to facilitate people with similar needs being able to find a group solution, whether that is group therapy or putting the right combination of people together in a group house?

Ms O'Brien: At present the ILC, the information, linkages and capacity funding, is being provided in order to offer some different projects, and to try to offer things that are available to people with disability that are in the scheme or not in the scheme. Whether it occurs through greater funding at the ILC level or whether the LACs are given additional time and ability to do what you describe, which is to have time to do the additional support about helping people to connect, whichever way it ends up occurring, it is obviously a critical need.

MRS DUNNE: There is a need there?

Ms O'Brien: There is a very clear need for it, and there is a gap at present.

MRS DUNNE: It seems to me that ILC funding is not well understood. Wearing my 1RPH hat, I do not really think that 1RPH fits the ILC funding model. It was pretty much a case of saying, "You're an orphan and you can go there." I think there is not a very clear understanding of what that bucket of money is for; is that right?

Ms May: One of the issues with the ILC is that it has an ambitious remit and an incredibly tiny budget. And it has a funding model which is not suited to being strategic. The funding model is essentially a grants program—short-term grants in a competitive process. Neither of those things support the development of strategic long-term interventions that create real change in the community.

MR PETTERSSON: I want to talk about the idea of there being a lack of a provider of last resort. You mentioned before that there were certain health programs that were filling gaps that were not necessarily meant to be doing that. Can you give us examples of some of those?

Ms May: Certainly. That is the community assistance and support program. It is a program which is funded by the Health Directorate. It is a small program, and it comprises a number of providers who used to do HACC service delivery, if you are familiar with the old HACC program.

The ACT government, very wisely, retained some elements of the HACC program and created this new, small CASP program. Its aim is to provide short-term relief and support for people who need some support, perhaps after a health event of some kind or who have a very low level of support needs. It includes programs like Meals on Wheels, for instance.

That short-term and low-level intervention is not meeting all the gap needs. Certainly, if you have an NDIS plan that is insufficient, the CASP program is not going to cover that gap for you. It is in fact still the NDIS's responsibility to do that. So the CASP program is not a provider of last resort. It provides a little bit of interim funding, if somebody has a newly acquired disability and is not yet on the NDIS and needs a bit of support so that they can get out of hospital for the next few weeks before their NDIS plan might kick in, or for a person with disability who breaks their leg and who would not normally need mobility assistance but is going to need some mobility assistance until the leg is healed. It is for that kind of thing. It is not designed to be a provider of last resort. That is a completely separate, big problem.

MR PETTERSSON: You mentioned that the lack of a provider of last resort has not led to death or very significant lasting harm. Can you give me some examples of problems that have arisen?

Ms May: Certainly. We are aware of a client who at the moment is in hospital because the provider who was providing her supported home environment has said they are not able to care for her anymore. Her needs are too intense, and she has been admitted to hospital. She is living in an institution for the foreseeable future. Her advocate and her family are looking for a solution to that. That solution may mean she has to leave Canberra because there is not a suitable solution here in Canberra. That is a really poor outcome for that lady.

MR PETTERSSON: Are you aware of anyone having to leave Canberra or is it just a looming threat?

Ms May: I do not think any of our clients—

Ms O'Brien: I am aware of a client that did leave Canberra a while ago. There were a combination of things around homelessness and how the homelessness sector worked. The person's housing situation fell through. They did not, at that point in time, have a support coordinator because their needs were so complex that many of the support coordination agencies were not able to assist. That person left Canberra for a period of time in order to try to have somewhere to live, to start with, and to get some additional assistance.

That is an example of someone who needed to leave Canberra. We were advocating for that client, because there was an intersection between housing systems, homelessness support systems, mental health systems and the NDIS—trying to navigate through and find solutions in that particular scenario. That is just one example of where things have not worked and the person has needed to leave.

I can also think of scenarios where, because of the complexity of a person's disability, the way that the service systems usually respond is not suitable for that person; extraordinary solutions are required, and it takes quite a lot of advocacy and support to try to even get near to meeting that person's needs. That person has needed to move in and out of the ACT because of things to do with the complexity of their needs and how complicated it is to get the support they need. That particular person, to my knowledge, at this point is not even on the NDIS, even though they clearly require it.

That is just because of the complexity and the many crises that are happening in that person’s circumstances.

THE CHAIR: We have run out of time. I would like to thank you for attending today. A copy of the proof transcript will be forwarded to you. You can check it and provide any corrections.

KELLY, MS LISA, Chief Executive Officer, Carers ACT

THE CHAIR: I would like to remind you of the protections and obligations afforded by parliamentary privilege and draw your attention to the coloured privilege statement before you on the table. Could you just confirm for the record that you understand the privilege implications of the statement?

Ms Kelly: I understand.

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

Ms Kelly: Yes. Thank you for inviting me to the hearing today. Carers ACT are extremely interested, I guess, in the implementation of the NDIS within the ACT. Just for some slight background, Carers ACT has been operational in the ACT for 25 years. We provide support and a whole range of services for the 48,000 unpaid family carers who reside within the ACT. We have been actively involved with the implementation of the NDIS from conception through to today.

Our involvement has been on a number of levels. We were involved in advisory committees on the establishment of the NDIS. We were also involved in what was called pathways planning. We had grant funding to support carers to support their transition with their participant to the NDIS. We have been a provider. We have provided key coordination, after school care. We currently provide a day program for people with intellectual disabilities. But predominantly what we have done is provide support assistance to carers who are trying very, very hard to struggle their way through what is a very complex and difficult system for them.

Some of the concerns, I guess, that we have in relation to the NDIS and its implementation include the lack of fulfilment of the promise in the legislation, particularly in regard to carers. We see a significant disengagement of the system with carers. We hear story after story after story after story of the disrespect with which carers are treated by the system. We have stories of carers of autistic teenagers being removed out of planning meetings because they are not allowed to speak on behalf of the participant.

We have carers who have written statements that have just been ignored. We have had carers forced and pushed into agreeing to provide more care than they were providing previously or that they intended to provide. We have had carers live in a world and a life of extreme uncertainty since the start of this program. The increase in carer stress, the decrease in wellbeing, the increasing complexity of the work and the role of carers has been significant since the introduction of the NDIS. The majority of our carers tell us that, particularly the carers of participants with disability at a higher end—a lower functioning end, where there is a higher dependency on carers.

I should be fair. We see a lot of success of the NDIS for people who have physical disabilities, people who are high functioning in their disability, where their reliance on a carer is less. We are seeing significant gain and positive gain in that group. At the other end, where there is a higher reliance on family carers, we are seeing significant negative impact on carers in the system. That comes down to a number of different things. Predominantly underneath it is a lack of regard and respect, a lack of consideration for carers and the situation of carers.

Carers are now forced to actually increase their caring role, and not through a lack of funding or support but through the sheer weight of time taken to coordinate a service system for their participant that was never there before. In the past you would take your child or your partner or your loved person to a service and that service would just go, “Cool. Excellent. This is what we are going to put in place. And we are going to get it all organised and get it all sorted.” That ran, and you had a key caseworker who did a lot of that work. That system has gone. Now a significant part of that role falls back on carers. We have stories and evidence of carers saying they are taking up to 10 or 15 hours additional a week to organise care for their participant.

The idea that the NDIS would free carers, would enable carers to return to work and participate socially and economically in the community, has certainly not been fulfilled. And we do not see it changing. We see it actually becoming worse. Living in a world of uncertainty, where I spend 12 months working out exactly what I can have, exactly what I need, entering a service agreement—doing all that work to go to a plan review and have half your money taken away, with no reason, no excuse, no transparency in that decision and being told, “Off you go; good luck with that,” is not a healthy way for families to operate.

Parallel for me is when a family without a disability lose an income and still have to pay for their life, their lifestyle and the changes that need to happen in that. Losing funding out of a plan that was working, that had brought stability, that enabled a carer to go back to work or to engage socially, and then to go to a plan review and be told, “Oops, sorry, we are going to take half that away. And we are going to take it away because, hmm, you didn’t really need it,” or “Hmm, that’s great,” is happening.

We have got stories of young people who were going to the gym for the first time in their lives, participating in physical activities that we know have huge benefits. They would go with a support worker. They were integrating. They would do all the things we wanted them to do. NDIS took the funding away because they decided that that person now had learnt that skill and could do it on their own. The person could not transport themselves. The person would not go without a support worker. The person was actually at risk in the gym without a support worker. The person is no longer going to the gym and the carer now has that two hours, which used to be taken up by that person going to the gym, with the person back at home providing the care.

There is this conception, I guess, in NDIS that people will get better. And some people will. I am not at all pleased in saying that a disability is stagnant and that is how it is always going to be. People improve, people gain skill, people lead independent lives and learn independent skills. But some people will continually need support to use those skills for the entirety of their life. And taking that money away is really, significantly concerning.

We have a story of a carer who was extremely stressed at losing about $80,000 out of her son’s NDIS plan. Her son has a psychosocial disability. He was a success story for the NDIS. He was a poster child. She did media for them. She exalted the NDIS. They took $80,000 out of his plan with no explanation and with no understanding, with nothing. He consequently became highly suicidal, ended up hospitalised. He thought he had his life sorted. He thought he had this independent life. She thought she could go back to being a mother.

All that changed in a heartbeat and with no explanation and with of course no recourse. But you have to live with that through the recourse. And then you have to live forever. Imagine the anxiety that comes up every time you are due for a planning review, when you do not know what it is going to bring and how it is going to change your world and your universe.

We are quite bitterly disappointed at Carers about the implementation of the NDIS. We are not necessarily convinced that everybody is better off than they were. We are not convinced that the principles of choice and control have been met yet. We are not convinced that there is a marketplace that enables choice or control. As a service provider we are waiting for the day of deregulation of pricing because we believe that will increase the marketplace and increase choice and control.

But we need care coordination put back in. We need a functional, supportive, carer and participant-inclusive tack that understands the ACT, engages in the ACT. We need planners who acknowledge and recognise carers as key participants in the care of the people they are caring for and that understand and have knowledge that should be valued and accepted in that space. And we need the NDIS to have open and frank discussions with carers about what actually are they prepared to do and for how long and what is the plan for when they are not able to or cannot continue to do that.

Fundamentally, underneath all that, we need respite reintroduced as a concept under the NDIS because it is a folly to believe that it is there. It is not. It is only there when you do extremely strong advocacy for it. Yet we know that regular short bursts of respite continue to sustain a caring role. And without it carers will, and are starting to, relinquish care, which will have a significantly increased cost on the system.

THE CHAIR: I think you touched on one of the points that I wanted to ask you a question about, which is the extent to which, not only in regard to rates and carer experiences in your submission, the capacity of carers is taken into account in NDIS plans. One of the carers has suggested that that certainly has not been the case. And then we are putting extra burden on carers beyond the support that they provide, that they have the capacity to give. How widespread is that across NDIS plans, do you think?

Ms Kelly: We would certainly see it in about 80 per cent of the carers that engage with us in a way in which NDIS is not working. I need to be fair. I talk to my staff a lot too about seeing the end of NDIS that is not working. We do not see the end that is. We hear a little about that end. I see it in the community and I hear it through my colleagues. I want to say that that is the case for all carers. But I am absolutely aware that we are not hearing from those carers for whom it works and for whom it functions.

We would say that we would probably hear from at least 300 or 400 carers a year that their capacity has not been considered, that carer statements have not been considered. In fact, carer statements are not even asked for anymore because there is a conception now that carers are invited to planning meetings, so why do they need to make a statement?

Our pushback and our advocacy for that is that it is incredibly hard for a carer to sit next to the person they love, and the person they care for, and say openly and frankly, “I don’t want to do this anymore. I don’t want to shower you anymore. I don’t want to take care of your toileting. I don’t want to do that,” in front of the person. The story we hear a lot is that the capacity is not looked at. Where it is looked at, there is not an opportunity to have that discussion in a way that is respectful to the relationship between the participant and the carer either.

Certainly, what we have seen in the last probably 12 to 18 months is a significant increase, about a 60 per cent increase, in calls to our call centre from carers who have lost care coordination out of their plans, who have been given a list of agencies and told, “Good luck,” who are then having to either take leave or reduce their working hours to do the coordinating and planning for those services to come into place. That is not care coordination. That is not support. That is not helping or enabling carers to do their role.

There is a significant burden coming on and we see it specifically in carers of people with intellectual disability, and generally at the lower functioning end of the spectrum. Their roles are coming up more and more. There are at least 50 carers that I am aware of who have had to reduce work hours or leave work in order to actually continue their caring role since the NDIS.

THE CHAIR: And some carers have their own NDIS plan as well?

Ms Kelly: Yes.

THE CHAIR: As well as the person that they are caring for?

Ms Kelly: Yes.

THE CHAIR: How do they align the two plans? Have there been issues there as well?

Ms Kelly: They do not, because often the lines that are permissible in it do not line up. There are rules and regulations that prevent, say, one support worker coming in and providing support to both people in the family at the same time. The complexity is actually more than that. We have got families where the carer, mum or dad, is on a plan and two or three kids are on plans. Can you imagine the agony and burden!

Most carers are now coming to a realisation that to achieve their goals they need to self-manage, because it provides them with greater choice and control over what is happening and it enables them to buy services that are not your traditional support system. Imagine having two plans and having to keep two lots of receipts, account for two lots of services, work with the portal twice!

We have got carers who cannot actually access their children’s plans because they cannot get access to the portal. When we ring and go, “Why can’t they have access to the portal?” they say, “Because the portal is actually under the name of the participant.” “The participant is six.” “Oh, that is just bad luck. It is under the participant.” The participant has to give consent to the carer to have access to the portal. The participant is six. The more plans you get in the family the more time you are spending at midnight on a computer trying to reconcile the services.

Our view would be that a family plan should be invented so that the family can plan how they do service. If a family, for example, has three children on three separate plans, all of whom require after school care support, that is provided by three separate providers, three separate workers, three separate lots of transport providers, because it has to be accounted for in each plan. We say, “This is crazy; you could have one support worker caring for all three of those children and it is far more economical.”

MRS DUNNE: It would probably be cheaper?

Ms Kelly: Yes, far more economical and makes more sense. It is actually more reflective of the way in which family units without disability operate. If that is what we are trying to achieve—and certainly our goal in life is to have families operate and operate well and healthy—then we should be having a system that supports that and supports true integration and true functioning of family.

MRS DUNNE: It could at least be an option?

Ms Kelly: It could be. We have never seen it as an option, ever.

MRS KIKKERT: Thank you. There are so many things in my head at the moment. I am trying to pick which question to ask you. I have a million questions. I will go back to your story about the gym boy.

Ms Kelly: Yes.

MRS KIKKERT: Their funding was cut. Are there no assessments, no questions asked, before that funding is cut?

Ms Kelly: Generally not.

MRS KIKKERT: No.

Ms Kelly: One of the biggest things about the NDIS that we have not paid enough attention to, I think, in the ACT, is the significant change that continues to happen and that we have lived through. If that is difficult for me, as the head of an organisation, to continually stay up to speed with—“What are we up to now? What is the system now? What are the rules now? How is the process now?”—imagine what that is like for carers and participants.

There was a period of time when all reviews were being run over the phone. There was no option to do a face-to-face. The conversation went something like: “Hi. It’s the NDIS. How’re things going?” “Good.” “Great. So the plan’s working for you?” “Yep; it’s going well, thanks.” “Great.” “We are having some trouble spending the money because we can’t find the providers but generally it’s going well.” “Okay, great. Thanks very much. We're in the process of doing a plan review. We'll send it out for you." That was the entirety of the review. It is not much better now.

At least you can now do it face-to-face. There is a bit more depth of conversation. But there is really no engagement that we have seen, such as: "How has this plan helped you meet your goals? What are your goals now? How does that need to be reflected in the levels of funding?" Nor is there a fundamental question asking, "Why haven't you spent the money?"

There is an assumption by the NDIS that if you have not spent the money it is because you have not needed the service. What they have not realised is that sometimes it can take three to six months to get the service up and running; sometimes you cannot find the service to buy. Therefore: "It is unused money. It is unnecessary money, so we'll take it back and take it away. We're not going to do proper assessments around it."

We also see significant cuts happening in psychosocial plans. That is often because the person has been relatively well during the 12 months and has not needed to use services at the level of intensity that it was thought they may need to use them. That does not mean that next year will be different. They lose the funding resource. They lose the safety net to know that, when things start going badly for them again, they have the money to access psychiatry, psychology and all of that. It just goes. They then live a life of going, "What happens if I get unwell this year?"

MRS KIKKERT: Apparently there is no such training for carers who have lost that coordinator that did the coordinating for services before. There is no training. There are no workshops for the carers to get together and discover what they could do.

Ms Kelly: By the NDIS?

MRS KIKKERT: For anyone.

Ms Kelly: We provide a significant amount of capacity building for carers, both in groups and in individual work with carers. Every now and again I see a workshop on self-managing. I do not see it frequently enough. We have used a significant amount of particularly our federal carer support money to support carers through the NDIS. That has been fine for us to do. It is part of the mandate of that funding.

We need to be aware that the service model for carers is changing. That model is going for open tender at the end of this year. A whole new service model will come into place. There will be reduced respite funding. The advice and information service will now be run through the carer gateway nationally. I will not have funding. If I am successful in even obtaining the service, I will not have funding. We are effectively doing case coordination for carers that have lost it out of their plans. We effectively do that for them. We will not be able to do that from late next year. I do not see where that is going to get picked up at this point.

We are also not building capacity in carers to work out how to use the plan; work out how to creatively think about how we can use it. This is where some of that change stuff is interesting. We are seeing problems because so many changes happen. When the first plans came out, they were very prescriptive: "You've got $10,000 that you can use for housekeeping. You've got $15,000 that you can use for personal support." It was very prescriptive and very restricted in what you could use the money for.

Plans now are much looser than that. They will say, "You've got $80,000 for core supports," or "You've got $20,000 for assistance with daily living." Generally, you can use that money for whatever you need to meet your goals with daily living or with core support. Carers and service providers are not aware that that change has happened. They will often ring us and say, "I need a house clean." We will say, "You've got a plan. How come you can't use the plan to house clean?" "Because it doesn't say I can use it for house cleaning." "Yes, but it does say you've got assistance for daily living, and house cleaning is an assistance for daily living, so you can use the plan to do that."

They are not aware. We have not done anything—that is partly our fault at Carers ACT—to build that capacity. We have not helped build the capacity for them to dream again; to work out a shape they might see for their world; how they might help achieve the goals of the participant. I work a lot with what we call our mature-aged carers. These are carers in their 60s, 70s, and 80s with adult children who are 40 or 50 who have lived at home for 40 or 50 years. I talk to them a lot about planning for when they can no longer care. We keep getting to this impasse.

I talk to them about: "What's your dream? What would it look like? If you could create a space and a world for your child, what would it look like?" They look at me quite blankly and go, "Can you just tell me what the options are? Can we just meet the service providers?" It breaks my heart. I sit there going, "We haven't helped you learn how to dream and then how to use the plan." It is much more flexible than a choice-based system to achieve those goals. Carers are often stuck in that same system of asking who the providers are and which ones are good, rather than saying, "This is what I want and how can you help me get that and achieve it?"

MS LE COUTEUR: I have a huge lot of questions. We might have time for a short one which just struck me. You said that deregulation of pricing was one of the things you were looking for.

Ms Kelly: Yes.

MS LE COUTEUR: Can you elaborate on why? What do you think will happen?

Ms Kelly: Yes. I will elaborate on it in terms of respite care or short-term accommodation. It is a classic example for us. We used to provide short-term accommodation. We had block funding to do that. We had to stop when the block funding was taken away because we could not find a business model that would enable us to continue to provide that service under the pricing guideline that the NDIS has. As a registered provider I cannot charge anything more than what the price guide allows me to charge. We had to stop that respite service. A number of people in Canberra stopped providing their respite loans.

The NDIS has now, after four years of lobbying, agreed to increase the prices for respite, but they still have not increased to a level where we could provide high need, high care, one-on-one respite in a way that enables me not to make profit but to simply cover the cost involved. Deregulation would enable me to set the price we needed to cover the cost. It would enable participants and carers to have the choice to buy that service, because that is what they want to value more than perhaps some of the other services they could buy in their plan.

The problem with deregulation for me is that, if you are self-managing and not using registered providers, you can have a negotiated price and you can set a price. But if I am registered and following standards, protocols and rules, I have to follow the price guide. So it is not a fair and competitive market.

MS LE COUTEUR: I presume the reason they have the price guide is that they are scared about people being gouged because they have almost no options or maybe no options. It is: "Take this or don't take it."

Ms Kelly: I agree with the principle of that. I think true competitiveness in a marketplace will manage some of that. If I am going to charge you $100 for a night and the person down the road is going to charge you $250, you will make a decision about which price you are prepared to pay.

THE CHAIR: Unfortunately, we will have to finish up there. We might have to have questions put on notice for those members that were not able to ask you questions.

Ms Kelly: Very happy to take questions on notice and provide more information.

THE CHAIR: No problem. Thank you for attending today, Ms Kelly. When available, a proof transcript will be provided and you can make any corrections to that.

Ms Kelly: Thank you.

Hearing suspended from 11.00 to 11.19 am.

PERISTERI, MS ASIMINA, Occupational Therapist, Occupational Therapy Australia
TAYLOR, MRS LAURA, Occupational Therapist, Occupational Therapy Australia

THE CHAIR: On behalf of the committee, I thank you for attending today. I remind you of the witness protections and obligations afforded by parliamentary privilege. I draw your attention to the pink-coloured privilege statement on the table. Can you confirm for the record that you understand the privilege implications of the statement?

Ms Peristeri: Yes, that is fine.

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

Ms Peristeri: Yes, we would. I will make our opening statement. Thank you for the opportunity to appear before you. I currently work in private practice. However, up until very recently I was actually part of the public health system here in the ACT as well. I am also a member of the ACT Divisional Council of Occupational Therapy. I am joined by Laura Taylor. She is a sole practitioner who provides services to NDIS participants in Canberra and in surrounding parts of New South Wales.

I will provide a little background about Occupational Therapy. We are a professional association and a peak representative body for occupational therapists in Australia. As of March 2018, there were around 350 registered occupational therapists working across government, non-government, private and community sectors in the ACT. Occupation therapists are allied health professionals whose role is to minimise the functional impairment of our clients and to enable them to participate in meaningful and productive activities.

Occupational therapists particularly work with people with a disability and their families to maximise outcomes in their life domains, including independent living, social and community participation, work, learning and relationships. As occupational therapists, we are key providers of services to many NDIS participants.

While Occupational Therapy Australia is a strong supporter of the NDIS and its focus on providing individualised support for participants, members in the ACT have raised a number of concerns regarding how things are progressing with the NDIS. At present, we are experiencing lengthy delays in processing applications, in particular for assistive technology. It can take a considerable amount of time for a participant's plan to be developed, an occupational therapy assessment to be undertaken and then for the item of assistive technology to be approved. By assistive technology, we could be talking about power wheelchairs or other types of equipment that people will require.

In the meantime, while this is happening, participants are left without key items of equipment and therefore are prevented from achieving their goals under the NDIS. In some cases, once the equipment is actually provided it is no longer required because the participant's circumstances have changed. Their functional capacity may have changed over that period of time. Members have also raised concerns that plans often do not reflect the actual needs of participants. If funding for assistive technology is not an issue included in the plan, a participant may have to wait up to 12 months for a review of the plan and then for a new one to be developed.

There is also great variation in the amount of funding provided to participants, as this seems to depend on a planner's level of knowledge and expertise. Occupational therapists are becoming increasingly frustrated by the NDIA's lack of communication and the resulting need to constantly follow up on emails and phone calls. There is a lack of direct contact with the planners, which limits therapists' ability to actually talk through our interventions required and to identify the urgency of an intervention. It also prevents us from keeping track of the process of supplying assistive technology to participants.

A great deal of time that occupational therapists spend consulting with clients and writing reports is actually not billable. This includes time spent arranging trials for assistive technology. For example, if someone has been scripted what we would call a high-end, complex, powered wheelchair, once that wheelchair is actually supplied to the client, the OT, the occupational therapist, often needs to check that the client knows how to use it, that their situation has not changed. We often are not told when this happens. That may not be billable and part of the plan. Also, we are required to provide quite lengthy reports justifying each purchase.

OT's submission to the inquiry touched upon many of these issues. These are prompting OTs to walk away from the scheme. Gaps in service provision, particularly for children without a specific diagnosis, and onerous administrative arrangements have had a negative impact on clients and in some cases have led to providers revoking their registration under the NDIS. Thank you for the opportunity to be here today. We are happy to answer any questions you may have.

MR PETTERSSON: Your submission touches on current funding levels for OTs to travel and how that is affecting the greater ACT region. Can you expand on that?

Mrs Taylor: At the moment, your travel is measured by kilometres and not by time. I travel from the ACT to regional New South Wales and see people very remotely because I see people with extreme, highly complex needs. I have been an OT for a very long time. The travel does not cover it at all. With the new submission of the NDIS it makes it even worse.

I will refer to this paperwork about travel that I have here. Occupational therapy is usually provided in people's homes, so it is unique. It is not like physio. It is not like a lot of the other professions. Because we are a criterion, reference-based occupation, we can optimise somebody's function by seeing how they go in schools or how they go in their home, how they can actually get in and out of their own bed, in and out of their own bathroom or in and out of their own kitchen. We could set up a mock kitchen; we could have a beautiful kitchen here that is very accessible. Homes are not like that. So we have to travel to see people and I think that makes our profession quite unique.

MR PETTERSSON: I am confused. Is the funding based on kilometres travelled or based on time?

Mrs Taylor: At the moment it is based on kilometres. But the NDIS has proposed that it will be based on time.

Ms Peristeri: Twenty minutes.

Mrs Taylor: But 20 minutes only, and a maximum of 45 minutes for regional. It is really not adequate. It does not cover what we need to do.

Ms Peristeri: An example is where I—

MS LE COUTEUR: Not even in Canberra—

Mrs Taylor: No, not even—

Ms Peristeri: I am based in Kambah. If I have a client that is in Gungahlin, it may well take me longer than 20 minutes to get there.

THE CHAIR: I have a question around early intervention, particularly for children requiring therapy. One of the themes that has come up in your submission is timing and lack of communication. When it comes to early intervention, timing is obviously critical. What sorts of experiences are you hearing about and seeing amongst your clients who are children?

Mrs Taylor: From what we are hearing—neither of us actually work with the younger clientele—

THE CHAIR: Right.

Mrs Taylor: but our colleagues advise us that really there is a quite large delay. It can be up to that 12-month period. Of course, if you have a child with significant cognitive deficits or physical deficits, if they wait a year before they can have therapy or before their equipment comes it has an impact. A classic example would be somebody who has cerebral palsy, who has a windswept posture. So their knees are facing one way and their hips are facing the other. If you wait a year before that is supported to try to stop it from getting worse, it can result in that person not being able to get in and out of a car or not being able to sit for a length of time to attend a class. Significant changes can occur with that delay.

THE CHAIR: Then you would probably have to see that person later down the track, I am assuming, in your—

Mrs Taylor: I see people down the track.

THE CHAIR: Yes.

Mrs Taylor: I see them as teenagers onwards. By that stage they generally have fixed postures that need to be supported. I will tell you a story about a client and equipment. I cannot use her real name; so I will call her Kate. Kate is a single mum with multiple sclerosis. She waited over a year for her powered wheelchair. She has been waiting for over two years for an outcome decision regarding home modifications to enable her to be self-caring and independent. She has been waiting for the decision to be made, let alone to get started. Meanwhile, she had been having full-time care to help her. This delay has cost the government a large amount to deliver this help, and it is not her choice. This is only one story. I know of many. This scheme is inefficient and it is hurting the people it is meant to protect.

MRS KIKKERT: How many OTs have left? Do you know, roughly, the numbers?

Mrs Taylor: I think we will have to take that on notice.

Ms Peristeri: Yes, we will have to take that on notice.

MRS KIKKERT: Thank you. I go back to funding—time versus kilometres. What happens when you exceed 20 minutes? Does the cost come out of your own pocket?

Mrs Taylor: Yes.

MRS KIKKERT: That money comes out of your own pocket?

Mrs Taylor: It will. That is new. That 20 minutes is proposed for the NDIS. At the moment it is based on kilometres. However, a lot of people do not actually have travel and kilometres in their current plans, in which case it completely comes out of our own pockets.

Ms Peristeri: We are completely dependent on the person's plan in respect of the number of hours and what we actually provide as occupational therapists. This is why, at the planning stage, right at the beginning, it is so important that that plan is correctly identified, correctly done. My understanding is that the NDIS planners are administrative people, not necessarily people that have a health background. I understand that some of them might. Some of them might not.

What seems to be happening is that the clients or the participants that have good advocates, that can actually attend a planning session and can clearly identify what their needs are and speak out, tend to have the sorts of plans that can be very good for them in the longer term to achieve the goals that were set up—assuming also that the goals were actually correct that were set up at the time, because any intervention that we do under the NDIS needs to be linked to the client's goals.

MR PETTERSSON: In terms of the planners, you said most of them are administrative in nature and do not have any qualifications?

Ms Peristeri: That is my understanding from the ads I have seen for those positions. I understand some of them are at the APS5 level. That is the commonwealth public service level.

MRS KIKKERT: But they also consult with the family members, with the clients?

Mrs Taylor: They do, but some of the clients have cognitive or communication issues or literally are just struggling to get through every single day. And then on top of that they are meant to identify and have the crystal ball of knowing what in the next

12 months they are going to need. They are not health professionals; they have not gone to university for four or five years to be able to predict what will happen. Sometimes they do not want to know what their diagnosis will throw upon them because it is too confronting.

MRS KIKKERT: So would it help to have an OT become a member of the planning process?

Mrs Taylor: I think that would be very useful. In my own experience, if I have had a client over many years, often I know when their plan is due, but sometimes they will suddenly say, "Plan's due next week," and you go, "Oh, thank you for telling me that," so I rearrange my life and I write a report for them that will very clearly outline their occupational therapy needs, their equipment needs and also possibly their physiotherapy needs, their speech pathology needs, their social worker needs, their care needs. I possibly will write a little bit about absolutely everything because there is no guarantee that every therapist that is involved with them can just stop what they are doing to write the report.

I am quite an experienced therapist, and not everybody has that ability to do that. If the participant themselves does not identify: "Oh, I am having a plan review next week," or "My plan's due next month," that will not be written and so they have no way of advocating for what they need. And even when it is written, there is no guarantee that the planner will read it.

MS LE COUTEUR: You said OTs are leaving the NDIS system. Where are they going? Are they privately providing the same services because people are finding it is too hard to navigate the NDIS, or are they leaving the profession?

Ms Peristeri: With the NDIS it is OTs who work in private practice that provide services. There are OTs that work within the public health system, as I did until recently. I do not know specifically what a lot of them are doing. Anecdotally, I know of a couple who have spoken to me individually and have said that they are looking at other income streams. They are not necessarily leaving private practice, but NDIS may have been, say, 80 per cent of their work. The few people I have spoken to are looking at other areas, whether it is working with aged-care providers, because that is a whole other system, whether it is working with insurers, or moving into other areas. It is not that they are necessarily leaving private practice, I do not think; it is more they are looking at decreasing the work they do with the NDIS. Is that your understanding?

Mrs Taylor: I am not sure.

Ms Peristeri: There are just a couple of people with whom I have spoken.

Mrs Taylor: I think we will take that back to OT Australia and get some more clarification on that.

MS LE COUTEUR: That would be very interesting. Carers ACT spoke to us and said that one of the things they were looking forward to is the deregulation of pricing in the NDIS system. They specifically said there were respite care services they used to be able to provide that they can no longer provide from a pricing issue. Is that one of the things your members need? You talked about the travel issue, but that might be more—

Mrs Taylor: The pricing issue and the proposed pricing tier system is something OT Australia is against because we theoretically will be getting a 40 per cent pay cut. We actually provided a submission into that. That is not supported by OT Australia for various reasons. Firstly, if we get a 40 per cent pay cut, a lot of occupational therapists will not be providing services to the NDIS—it will not be financially viable. Secondly, those who stay and do the more complicated people will only be the very experienced therapists, leaving the inexperienced therapists to take the ones that are theoretically paid less per hour. But that also means they are not going to get the supervision they require as a professional and they are not going to get the experience they require as a professional to be able to provide services later on, when the experienced therapists stop working. It a race to the bottom, really.

MS LE COUTEUR: Do you think it is likely to mean people will spend longer in hospital so that they can access OTs in hospital?

Mrs Taylor: That is definitely a possibility—that hospital stays would be lengthened.

Ms Peristeri: But on that cost shifting, if you like, there is an example in our submission of a person who had a pressure injury, the old bed sores. So because they did not get the mattress they needed they went into hospital. Whether you want to call it cost shifting or whatever, that is a state health issue, and NDIS is both state and commonwealth. That is not to mention the problem for the person themselves and their family. Bed sores should be preventable.

MRS DUNNE: Could I ask a question about the future of the profession. What I am hearing is that people are opting out of parts of the NDIS. Is there a risk that the quality of professionals over time will not be as good because the mentoring by the experienced professionals of the newer professionals will be harder to do because they are not working in the same system?

Mrs Taylor: That is definitely a possibility—there will be less mentoring occurring because the NDIS has encouraged private practice. Before the NDIS the majority of occupational therapists would have been employed in a large team, whether it be in ACT Health or Therapy ACT or even work rehab type occupations. Since the NDIS, I would say there has been a lot more shift to private practice. When Therapy ACT closed, the therapists had no choice but to go into private practice or retire or completely change the profession they had studied and loved doing. Having a group-type environment for a profession such as occupational therapy is useful so that they can get that one-on-one mentoring and supervision. As to whether OTs leave or not, we would have to take that on notice.

THE CHAIR: Thank you very much. A proof transcript will be forwarded to you to provide an opportunity to suggest any corrections.

HUNGERFORD, DR JIM, Chief Executive Officer, The Shepherd Centre

THE CHAIR: On behalf of the committee, I would like to thank you for attending today. I remind you of the protections and obligations afforded by parliamentary privilege, and draw your attention to the pink-coloured privilege statement that is on the table. Could you confirm for the record that you understand the privilege implications of the statement.

Dr Hungerford: I do.

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

Dr Hungerford: I would. I want to thank the committee and also the Assembly for this opportunity and for your attention on this critical issue about the implementation of the NDIS in the ACT. As described in The Shepherd Centre's submission to the committee, we are a specialist provider of support for children with hearing loss, focusing on enabling them to be able to develop spoken language at the same quality as any other child so that they can go on to achieve their potential in life.

We have been operating for almost 50 years and have helped over 2½ thousand children. We have been operating for many years in the ACT, and we currently have approximately 45 children here. We support them out of our centre in Rivett. Two-thirds of those children are of early intervention age, before they go on to school. One-third are of school age.

Children who complete our early intervention program, ready to move on to school, typically graduate from the program with the same quality of spoken language as any other child. So for many of them, if you met them, if they had long hair and you could not see their devices, you would not realise that they were deaf. Some children, about a quarter or a third of our kids, do have other disabilities or other complicating factors, and they may have language that is not as good as other children there.

To achieve these outcomes requires a specialist multidisciplinary team. The cost per child per year is approximately $18,000. However, that investment over four years enables these children to go in to school requiring minimal support at school. They tend to graduate from high school at the same rate as any other child, so they have the same academic outcomes. They enter tertiary study at the same rate as any other child and go on to achieve employment et cetera. The actual payback to the family and the individual, and to society and the government, on their investment is very positive.

However, with the rollout of the NDIS in the ACT—and this is in contrast to the trial phase—we have had extended delays, as you have heard from other speakers, to when plans are being approved for children. It may well be that they are over 12 months of age by the time they are approved. The issue there, with children who are born with hearing loss, is that if their brain is not stimulated with high quality auditory signals, the auditory cortex in their brain gradually shrinks away. For every month that they are not receiving the right input, that part of their brain shrinks and they get permanent, progressively worse language delays due to that. We need to start our therapy as soon as possible—hopefully at around two or three months of age. We know that if it is any later than six months, they will have permanent delays.

Alongside the specialist therapy, the children also need specialist hearing support devices, whether that is hearing aids or cochlear implants. Currently, that is provided by the federally funded Australian Hearing service. Under the NDIS they are planning to make that service contestable in the middle of next year. We have grave concerns about that because once you bring in commercial incentives to the provision of hearing aids to children, families with children with hearing loss are hugely motivated to provide the best service to their kids. They will come under a lot of pressure, just as adults do currently, to upgrade their hearing aids and pay a lot of money out of their own pocket for a product that does not provide any additional benefit for their child. Also, Australian Hearing has the majority of specialist paediatric audiologists. Private providers do not have the facilities or the background to do it. We are very worried that, if this contestability goes ahead, families and children will be put at risk.

The aspect that impacts particularly on the service we provide is that the actual funding provided through the system has fallen to approximately half of the cost of service. The reason is that the way the NDIS approach funding is to assume that they will fund direct services, as you have heard from other providers, on a per hour basis. The number of hours they fund depends on the degree of disability that a person exhibits. A baby with hearing loss does not exhibit any disability, because babies do not talk, so you cannot tell that they have a disability. Therefore the planners tend to say, “They only need a small number of hours of support.” And the opposite is true. During those early years is when you need to put in the most support.

In addition, direct therapy from a single therapist does not provide spoken language for a child. We know from local and international research that you need to provide an integrated, multidisciplinary support team, which costs more than the direct therapy. However, the result is that the children do achieve spoken language and their ongoing costs are much lower. That means there is an ongoing reduction in cost to the NDIS. It also means that children entering school will not need the extensive support in school and other follow-on expenses there.

I will give a recent example. One of our families, earlier this month, in May, went along for their planning meeting. The planner said, “We’ll only fund the hours for one discipline and not the transdisciplinary approach. I’m sick of The Shepherd Centre sending in these recommendations, and TSC won’t be funded like this, as it is too much and not necessary.” This is a planner who knows nothing about what is required for a child with hearing loss. They, and other planners like them, are condemning these children to lifelong disability because they do not have the clinical understanding of what they need. That completes my statement.

THE CHAIR: Mrs Dunne, I will throw to you.

MRS DUNNE: Would you like to repeat that?

Dr Hungerford: What the planner said?

MRS DUNNE: No, what you said in response.

Dr Hungerford: These planners are condemning these children to lifelong disability, because with reduced spoken language you get social disadvantage. People presume you are stupid; you become marginalised. You have trouble at school; you tend not to complete schooling. There is a lot of international research showing that children with hearing loss typically are three years behind by the time they end their schooling, and they often end their schooling before they reach the end of secondary school. By withholding—and I believe this is actually withholding, because we know what works—the ability to achieve spoken language, we are actually creating disability rather than preventing the disability.

MRS DUNNE: You said in your opening comments that the sooner the intervention the better. When would you most commonly see a deaf child for the first time?

Dr Hungerford: Typically, between two and six months of age. For a child who is born with deafness, at the hospital they get screened for hearing loss, so we know from a couple of days after birth whether or not they have a hearing loss. There is currently a self-referral process to organisations like ours. There are a couple like us in the ACT. Previously, what used to happen was that we saw the kids from two to six months. Now they are being diverted into the NDIS's early childhood early intervention pathway. As you heard from the representatives of occupational therapy, they are often a year old before they actually receive their first plan.

The introduction of the NDIS has actually created a delay that never existed previously. Ninety-five per cent of these families have no prior experience with childhood hearing loss, so they do not know what is needed. They trust what the system is telling them. If the system is saying: "You should go off to EACH. You'll receive general services. We'll evaluate. Once we've worked out what's going on, later on you may or may not receive an NDIS plan," the families go along with that because they do not know any better. However, the system does know better. We know that, in actual fact, they need to be rapidly streamed into Australian Hearing for their devices and into a specialist provider for their therapy.

MRS DUNNE: Does The Shepherd Centre provide the devices?

Dr Hungerford: No. We coordinate closely with Australian Hearing. Australian Hearing have federal funding through the Office of Hearing Services, as part of Health, to provide the devices and the maintenance of those devices. They do not provide therapy; they do not have the right staff or systems to provide therapy. We work alongside them to provide the therapeutic systems.

MRS DUNNE: Before the NDIS, how did the system work? If somebody had a baby, they had a hearing test in hospital—

Dr Hungerford: Those audiologists in Canberra Hospital would confirm the hearing loss. They would then guide that family into Australian Hearing. At Australian Hearing they would then start the provision of the hearing devices and recommend to the family and provide support to seek out a specialist provider. In Canberra it is us or the RIDBC, the Royal Institute for Deaf and Blind Children. The family would then come to us, normally when the child was between three and six months of age. That was the prior process. What happens now is that the NDIS intercepts them; it takes them out of that referral pathway.

MRS DUNNE: Or crash tackles them, perhaps.

Dr Hungerford: Yes, absolutely. We have proposed to the agency that this is breaking the system. The agency at the top level agree with us, and they are currently reviewing whether or not they can reinstate the use of Australian Hearing here. However, the NDIA as a whole wants to hold on to its early childhood early intervention pathway and wants to put every child through EACH here in Canberra—even when we know that it is clinically contra-indicated for children like those with hearing loss.

MS LE COUTEUR: I imagine that someone in your sector has done their sums, but it costs a small amount—and you clearly said how much it costs—for early intervention. How much is it likely to cost society as a whole if that does not happen? I am not saying this is the only consideration, but clearly it is an easy one to say.

Dr Hungerford: Absolutely. We have done a cost-benefit analysis. We are part of a national coalition of similar organisations. And under that cost-benefit analysis the average cost per child is north of $600,000. For individual children it can be far, far higher. For instance, if a child does not develop functional spoken language they will then need to get lifelong support through an AUSLAN interpreter or some other sort of communication assistance. Those sorts of things would normally cost $40,000 per person, per year. The cost to society is huge. But also, the cost to that individual is mammoth because you are deliberately marginalising them, reducing their opportunity to participate.

Financially the case, we believe, is very, very clear. I think the act is beautiful. The way that act is written is fantastic—that early intervention. You invest more in the beginning to prevent all these costs in the future. Unfortunately, the behaviour that the NDIA is implementing is to ignore that and to treat everybody like they should get approximate support in proportion to the disability that they are displaying.

MS LE COUTEUR: Is that happening for other early interventions? There are lots of things that babies get tested for in hospital. It is not just hearing, is it? Are you hearing from other people that this is the same issue with—

Dr Hungerford: Similar issues exist but normally not to the same extreme. The reason for that is that the methods to enable a deaf child to have spoken language have only developed over the last 20 or 30 years. There are lots of support mechanisms. Speech pathologists can help correct speech errors and things like that. But the professionals who actually work with deaf children to enable spoken language are a small minority of professionals. It is not well known and it is a very specialist area. We are only three per cent of the childhood intake for the NDIA. It has not historically been an area of focus.

Direct therapy provided early is good, as you have heard with physical disabilities and things like that. It is just that direct therapy does not work in our instance. You need disintegrated model disciplinary therapy. Similar things apply but at a less extreme end. Few other disabilities have the evidence to show that, if you do this, this is the actual outcome. We have the wonderful fact, apart from the fact that children have it, that we can measure the fact that they have got a hearing loss and then we can measure the fact that they achieve spoken language. We have got a lot of data that is very, very difficult to generate in other areas.

MRS KIKKERT: We have spent about 15 minutes with you and I am convinced of how critical it is for planners to get it right from the very beginning. Would you recommend that your organisation have a word with the planners to convince them that it is so important for you to be at their seat and explain to them the importance of identifying babies who have hearing difficulties, to actually get them in early rather than later?

Dr Hungerford: When the trial was established in the ACT the NDIA invited us in and we provided those presentations. For the first year or so it was very, very positive and children were getting funded for the support they needed. And we actually saw that the outcomes of the children increased. Otherwise we rely on philanthropic funding, which does not cover all our costs, obviously. However, the rollout occurred and then they moved on to the early childhood, early intervention pathway and introduced EACH as being the planner there, and now they feel as though it would be providing preferential treatment to us if they allowed us to go in and speak to their planners. And they have said that they will not do that. We disagree entirely. But that is what they have said. We have tried a few times.

MRS DUNNE: You are not the only provider in the ACT. Are services provided by—

Dr Hungerford: RIDBC.

MRS DUNNE: Yes, RIDBC. Are they similar?

Dr Hungerford: Yes. Subtle differences but essentially similar.

MRS DUNNE: You and RIDBC would be in furious agreement that when we talk about early intervention we actually mean intervention and we mean really, really early. There should not be a problem. You could go and make a joint presentation as the only providers—

Dr Hungerford: Yes, and—

MRS DUNNE: You are a sort of monopsony really.

Dr Hungerford: That is right. On a national basis that is exactly what we are doing. We have been maintaining a strong advocacy campaign. We have managed to meet with the chair of the board and the CEO to discuss this and they have agreed, in principle, with the fact that the agency has dropped the ball and that wrong things are going on. However, we have been having these discussions with the agency for the last three years—RIDBC and us and the other specialist providers around Australia. Two of those specialist providers have now folded because they cannot exist and provide their services under the systems being implemented. They have now merged into other organisations because they have just run out of money.

We are in fortunate circumstances in that we have sufficient financial reserves to last another four years or so. However, sooner or later we are going to run out of money as well. We have been trying for three years and the agency is now exhibiting at a high level a lot of goodwill, wanting to take action. It is just that we have still not seen any action occur after three years.

MRS DUNNE: Sorry to monopolise this, but is there any capacity for The Shepherd Centre to run a sort of sneaky insurgency, in a sense? Are you able to identify the children who need help or do they have to self-identify to you?

Dr Hungerford: No. Because of privacy we are unable to access the hospital records of who gets diagnosed or the Australian Hearing records of who gets referred to them. However, the system that we have proposed is that the agency hire Australian Hearing as their early childhood partner and then Australian Hearing, who have got all the expertise and who naturally—

MRS DUNNE: And the network.

Dr Hungerford: Then they can carry through that function and do things very, very well. But that is a change to the agency's normal practice of one size fits all. And we are struggling with that.

MR PETTERSSON: In your submission you talk about the gap between the funding that is provided for services and the actual cost of those services and you are, as an organisation, making up that gap. Have you any idea how they landed at the original funding calculation?

Dr Hungerford: They use the professional rate of $175 an hour and then they have a bunch of rules. They use this thing called PEDI-CAT, which is an assessment of the disability needs of a child. The CAT stands for computerised. Because deaf children do not exhibit the classical signs of disability, the types of questions in there are: "Can the child feed themselves? Can the child roll over? Can the child sit up unassisted?" Of course deaf children can do all those things. Deaf children come out as mild and then they say, "If you're rated as mild you can get a total of 20 hours of support a year et cetera." Then they take the number of hours of support, based on the rating system, times 175, equals the package that the family receives.

MR PETTERSSON: It is not the case that they are taking advantage of you because you are a charity—

Dr Hungerford: No.

MR PETTERSSON: It is simply the case that their method of calculation is terrible.

MRS DUNNE: The computer says no.

THE CHAIR: And just to be clear about the cost, I think you mentioned an $18,000 figure. That is over how many years for one child?

Dr Hungerford: No, that is per year.

MRS DUNNE: For four years.

MS LE COUTEUR: For four years.

Dr Hungerford: Normally you would require four years.

MRS DUNNE: But then that is essentially it?

Dr Hungerford: That is right.

MRS DUNNE: Apart from ongoing devices—

Dr Hungerford: Then it is minimal after that, absolutely.

THE CHAIR: And that is your cost?

Dr Hungerford: That is the cost to us, yes.

THE CHAIR: And what are they generally providing for children? Is it varied, I would imagine?

Dr Hungerford: It is hugely variable, depending on each planner in all those. I am sure you have heard lots of reports about that. It is currently averaging across Australia about $8,000. Because we are providing a lot of support for the families so that they can advocate, we are averaging about $9,000 to $10,000 at the moment.

THE CHAIR: It still is a 50 per cent shortfall?

Dr Hungerford: That is correct. Then the 45 children we have in the ACT, that is more than double what we were having previously when we were funded by the ACT government. Obviously the ACT funding was withdrawn and we cannot cover via philanthropic funding the shortfall that has developed.

THE CHAIR: Thank you very much. We have run out of time, unfortunately, but we really appreciate you attending today. When available a proof transcript will be provided for you to make any corrections. Thank you very much.

Dr Hungerford: Thank you.

ROBERTS, MR DAVID

THE CHAIR: I draw your attention to the privilege statement. Could you confirm for the record that you understand the implications of the privilege statement.

Mr Roberts: Yes. I looked this up on your website and read it.

THE CHAIR: Would you like to make an opening statement to the committee?

Mr Roberts: Only to note that in making the submission what I wanted to share with the committee was the experience as a client of NDIS. Since I wrote the submission my view on that experience has not really changed—it remains a bureaucratic and difficult process, often replicative. It is difficult to get accurate advice from that process, which often leads you down false paths, and that takes time.

One improvement I have noted in the submission was the local area coordinators. They accelerated the process and they vetted and viewed the material presented far more accurately than NDIS were able to in previous meetings with them. The only concern I have with local area coordinators is the criteria under which they are required to operate—I do not know what they are—and the performance requirements that might be put on them. That will determine the quality of service we will get from them. We will only see in time, but the experience to date has been quite good with that part of the operation. That is all I wanted to add, but I am happy to respond.

THE CHAIR: One of the issues you have mentioned is in relation to equipment. You have suggested that the NDIA, through their plans, provide an amount of money for equipment without that being specified and that you are not able to trial that equipment. What do you think the NDIA should do in relation to equipment?

Mr Roberts: The problem is the process you have to go through to identify and acquire and gain approval for the equipment. On the one hand, NDIS appear happy to delegate and simply allow people to make choices within a certain amount of money allocated, but some equipment is very specific and they require quotes and a high level of decision-making—for example, in my case hearing aids and assisted technology for hearing. They have created, effectively, a monopoly for the provision of hearing services through the government, where you can only get them through OHS or Hearing Australia. The problem is that you have to negotiate and advocate if the equipment they have is not suitable. You cannot trial the equipment, which is normal practice with anything that is fitted.

Whether it is a prosthetic or whether it is hearing aids, which are a form of prosthetic, they have to be fitted and then trialled before you can be sure that the thousands and thousands of dollars—and in my case it is $10,000 to $12,000—is actually spent. You cannot do that with this system. NDIS require the equipment to be identified, quoted and then they will pay the gap between OHS and what Australian Hearing are prepared to give you. There are a lot of other audiologists out there who are able to provide the same service—in fact, the advice we received from NDIS was all we had to do was get quotes, which we did from other audiologists. We were not aware that we needed to go to Australian Hearing.

The lack of clarity on their part led to around a 12-month delay—and we still do not have the hearing aids—a very limited market for acquiring them and a very tight process for qualifying. So I think they can loosen up the whole thing. There is an entire profession out there that is capable of answering and deciding these things. All they need to do is agree and decide whether they are going to approve and that is it. That would speed it up. They certainly do it with services, and they certainly did a similar thing when we wanted to make the house safe, because I cannot hear the fire alarms. I think there is a lot they can do to loosen up their service and establish external bodies capable of delivering those services without those sorts of monopolies.

They can also remove the requirement to have a defined piece of equipment and leave it open scale enough to be able to trial equipment before purchase. I would view that as essential for anybody who has a disability and needs any form of prosthetic aid.

MRS KIKKERT: You mentioned a couple of things that you want to change. What else is there that you would like to see done differently?

Mr Roberts: Where do I start? If I could talk in general terms first, the organisation has a very high focus on process, and I have not seen a lot of evidence of the focus on outcome. That would be the first thing I would like to see changed. The process is far less important than what you are trying to achieve and whether you have gained the outcomes to have achieved those objectives. It is a fault in many organisations these days, but it is particularly difficult when that process inhibits your ability to find resolution of your own needs. I would prefer the focus to be more on the quality of outcome and defining the requirement than on ensuring the process.

I think they can do a lot to reduce the number of processes you have to go through. In my case we submitted the same information three times and we had to get three separate professionals, some of them within months, providing identical results, to go through this process of trying to find the equipment. They would not accept a referral back to the original submissions made, and in reviewing the plan they appeared to ignore reasonable material. I think they need to inform themselves more completely and respect the material they have asked for and dispose of the duplication in that process. I am not having a go at the objectives of the organisation; I think they are quite important. But the process by which they implement it is a problem.

I could wax lyrical on how organisations operate and how to fix them, but this might not be the right place. As a client, their case management appears quite poor. There is a high staff turnover and information does not seem to flow from staff member to staff member—those who deal with your responses. If it does, I suggest they are not being trained to actually use the material. The relationship between policy and case appears weak. You can ask the same question and get the same wrong answer several times, even after you have corrected them. So the case management could do with a lot of work.

The other problem—it is probably not such a big problem for me because I have the advantage of being used to bureaucracy; although I would prefer not, I have had a life of it—is that people less advantaged are in a very difficult position because you need a tremendous amount of advocacy and coordination and support before you even sit down and talk with them. You need to make sure you have the right evidence. You need to make sure that the professionals are all properly lined up. There is no assistance from NDIS in terms of preparing yourselves for them. There is advice on the website and everything, but that really does not constitute what you need, which is much more direct, hands-on assistance with working through the process and getting ready for it. Organisations like the Australian Deaf Society tend to fill that gap, but they cannot fill it for everybody.

The local support coordinators and local support coordination groups are meant to be the link and help to direct people. I do not know how much that is working in terms of new starts, and I do not think that they are properly resourced. I do not know if the performance indicators they would be using allow them to establish that kind of interaction with the client to make sure their material is of the type that you can now start examining to develop a plan. Basically, if you turn up with the wrong material it is your problem. Nobody is going to help you; you have to find that help. I think more could be done to do that. NDIS does not have to do it, but it could set up facilitation for it. There are probably other things.

MS LE COUTEUR: Has the NDIS led to an improvement, possibly in general but for you in particular, or has it been a step backwards in terms of how we administer support for disability?

Mr Roberts: If I can divide that into two parts, the first part is that the first plan was a disaster and bore no relationship to any material I provided them. No, it did not result in any improvements. In fact, it probably resulted in increased stress in trying to figure it out. The second plan, which was put through the local area coordinators—this was the third set of documentation we had given in to the process—was more correctly attuned to my requirements. I also had a support coordinator assist my requirements and how to source them far better. That coordinator, by the way, is outside that organisation; it is somebody private who I engaged. We got results that worked and we started to get things implemented that worked.

Apart from this difficulty with getting the hearing aids and what is called a Roger Pen—for example, if I was wearing them I would give you the pen and you would talk to the pen—the other things are starting to come on stream quite well. So I am happy that this time around we probably got it right. So it has the potential to be very good. But it is what you have got to do to make it so. But, yes, when you can get it to work it is producing results.

MR PETTERSSON: When you got your first plan, you had it reviewed but it took a month. Did you have an advocate for that? Why did it take that time?

Mr Roberts: Not exactly. What I had was some assistance from the MS organisation in identifying some of the documents I would want. But I did not have a coordinator or an advocate who came with me. I trusted in my own skills, which were not that bad. The negative result, from my perspective, resulted from them paying no heed to the material that was produced. Maybe there was a staff change or something, but the plan that I got was a first-tier plan that would normally be issued to anybody with a chronic illness and did not address any of the things I wanted. I think the problem was they had to get it out. They took a bit of time to do it, and looked like everybody else's first-tier plan; it did not look specific for me. I think it was just a way of getting it out the door and that nobody looked at my material.

It took a long time to sort it out because we kept getting incorrect advice about how to sort it out. In the end we had to wait a year and roll it into the second plan. I do not know exactly why it failed, but those are my assumptions. Having gone through a second plan, what the support coordinator did, who was basically my advocate, was no different to what I did. I do not know why it went wrong for that particular plan, but what was disappointing was the failure of any process to be able to correct the mistake they had made.

If I could get a window into NDIS I could pretty quickly tell you what the problem was. But as a client, that is what I am assuming—staff turnover, failure to review material before doing a plan and simply producing a plan based on condition rather than specifics for reasons of efficiency, which ended up being costly and inefficient both for the public purse and for us.

THE CHAIR: Thank you for coming today. A proof transcript will be forwarded to you to make any corrections.

Mr Roberts: If you have any further questions or need further material, I am more than happy to help.

THE CHAIR: Thank you.

FOX, MR STEPHEN, ACT State Manager, National Disability Services

THE CHAIR: On behalf of the committee, I would like to thank you for attending the committee today, Mr Fox. I remind you of the protections and obligations afforded by the parliamentary privilege statement. Could you confirm for the record that you understand the implications of the privilege statement.

Mr Fox: Yes, I do.

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

Mr Fox: I will make a very brief statement. In our submission we have tried to address the terms of reference for the committee and look at those issues of interface and implementation from the perspective of the engagement and connection with the ACT government and ACT processes. At the same time, that is in the context of the implementation of the scheme as a whole.

With respect to issues that have probably already been canvassed extensively with the committee, and certainly in the submissions that I have read on the committee's website, we would place them in four large areas. Firstly, there is planning, and issues in respect of being able to correct plans and have flexibility in the management of those plans. Secondly, there is the portal, and issues around the utility of the portal, the ability to understand, when errors are encountered, how to correct those errors and the mechanisms for people who are making claims to be able to understand what is going on and, when issues do arise, how to resolve them.

The third area is pricing. We continue to believe that, even after the McKinsey pricing review, there are still issues to resolve in relation to the adequacy of some of the pricing and the mechanisms and processes for determining prices. The last area is communication. We have noted that there have been some significant improvements—and indeed improvements in all of those areas, to some extent. But communication has been a significant issue, which you will no doubt already have heard from many of the people who have given evidence before you.

Our members, who are delivering direct services to people with disability to enable them to exercise that choice of control in the community, have experienced that problem of being able to contact relevant people within the agency on a very regular basis—and, if they have been able to contact people, to be able to get action and a response in an appropriate fashion.

Those are the sorts of things within the scheme itself that we have been contending with, and they have a number of flow-on effects. Our submission, as I say, attempts to address the key areas that we see, in terms of the interface and some of the areas where we think some design features of the scheme as a whole could be improved. On the interface, we think that areas regarding health and education in particular could benefit from better or wider processes involving the sector. In relation to design, we suggest that, particularly with organisations that are delivering information and linkage services or allied services, there should be more recognition of the community value and the community engagement that those services have.

THE CHAIR: You mentioned in your submission that you think the local area coordinator function should be reviewed. What sorts of changes would you like to see in that role?

Mr Fox: We believe that the local area coordinator role has tended to focus very strongly on planning, and planning reviews. Therefore, there has not been enough attention given to the actual role of coordination. We do not see that represented in the way in which there is engagement with our members. Our members report that their clients do not necessarily feel that they have been able to access services by reference to information or work that has been undertaken by the local area coordinators in linking them to appropriate services.

THE CHAIR: Your member services do not feel that they are being coordinated by that body and they are not connected with one another. Do they make those connections themselves with one another?

Mr Fox: Yes, they do. I think the more significant issue is about what we would call service connection. When a person first engages with the NDIS system, they do not necessarily understand who provides services, what those services entail, what the construct of those services is and what their choices are.

The role of the local area coordinator is to assist people to navigate through that system in relation to those needing specialised services—not just those people within the NDIS but also those people who are not necessarily in the NDIS and who may need some assistance. The local area coordinator is meant to provide signposts, directions and guidance to those individuals as well, as to where to find additional information or support to enable them to appropriately address the particular issue that they are dealing with. In those areas we do not see much in the way of performance from the local area coordinator, either here in the ACT or indeed nationally. But we are focused on the ACT here.

THE CHAIR: Has any mapping been done, that you are aware of, of disability services in the ACT so that it is easier to navigate that system and understand where the gaps in service provision are?

Mr Fox: The mapping that we have undertaken—as I suspect is the case with everybody else—has been about who is a registered NDIS provider and where they may be operating, whether they are operating, whether they are a sole trader or a larger entity and what their field of delivery is. We are not aware of any real data, other than that held by the NDIA, which could in fact do more work in that space to make that clearer, about what the full shape of the sector really is. For example, in the quarterly reports issued by the agency, they are able to identify that about 90 per cent of the services are still delivered by around 25 per cent of the registered providers. But getting beyond that is quite difficult. They spell out a range of other details around services to particular age cohorts or particular types of disability, but who is delivering those services is not very clear at all.

MRS KIKKERT: You manage the planners; is that correct?

Mr Fox: No, not at all.

MRS KIKKERT: I do not have your submission with me.

Mr Fox: I will take a step back and explain. National Disability Services is the peak body for disability service providers. We have about 1,100 members around Australia. Most of those are in the not-for-profit sector, but we do have a number of for-profit associate organisations. We are, in shorthand form, the chamber of commerce for specialised disability providers.

MRS KIKKERT: I have heard a couple of times that they just do not know what services to provide. Why is that? Why is there such confusion?

Mr Fox: There are a number of reasons.

MRS KIKKERT: And how can it be addressed and fixed?

Mr Fox: Going firstly to why, under the block funding arrangements it was clear who was delivering specialised disability services because those were the organisations that were funded. With the advent of the NDIS, the whole point of the scheme is to put the money in the hands of the person receiving the support—therefore, where they are self-managing at least, to be able to buy those services effectively from anybody in the community who has the capacity to deliver that support. You do not necessarily know who they are, other than by reference to the fact that they may be claiming money from the National Disability Insurance Agency.

The second dimension is that that group of people has been widened quite considerably so that it is not simply those delivering everyday living support; it includes people who do, for example, home modification, car modification—a whole range of allied health supports and a range of other kinds of services. People are being assisted, for example, in education, with access to education or development of their educational capabilities.

The range of providers has increased. You could have registered providers who are on a list determined by the agency and released by the agency. You could also have a significant number of non-registered providers for which there is no visibility as to who they are. As such, you have a sense of the scale from the number of registered providers and the types of people with disability who are claiming, but you do not have a comprehensive understanding at this point as to how large the sector is.

As the peak body for the services sector, our membership has been comprised largely of those existing providers under the old block funding arrangements. It is growing but quite slowly, as many new people are entering as both registered and unregistered providers. They do not see the necessity to link with us as a peak body at this point.

MS LE COUTEUR: You have quite a list of recommendations in your submission to us. I do not have enough time to ask about them all. I was particularly shocked to see some of them as recommendations because I thought surely this is actually going to happen. Your second one is to retain the Office for Disability. It did not occur to me for one instant that that was an issue. I have not counted the number of recommendations, but there is more than a page of them.

Mr Fox: Yes; there are 27.

MS LE COUTEUR: Of your 27 recommendations, which ones are the most important? I am referring particularly to ones that are likely not to happen, if you know what I mean. Maybe I am wrong in thinking that the Office for Disability is likely to continue, but what are your priority recommendations out of the 27?

Mr Fox: You are right; I think the Office for Disability is likely to be retained. There is not perhaps a question about that. But we did want to make the point that there was not going to be an Office for Disability until the minister decided there should be. That is a decision that could have been made differently or was in fact going to be made differently. The government then changed course. So it is an important thing to have a specialised area retained in the government.

I would say, though, that one of the key issues is about housing advice for people with disability and addressing issues of housing—independent living for people with disability. That is an area of enormous complexity, as people need to find both suitable accommodation in terms of location but also the kind of support that they can get in that location and what they can afford and, if they are going to the private market, what is suitable in terms of design, if they need that. Then, of course, there are the issues around the people who it may be necessary to have live in, depending on the amount of support they have.

I think the whole advice around housing and the government supporting the provision of that kind of advice is a very important. I believe that the support within the hospital system for a specialised person to undertake navigation for people with disability in and out of the hospital system is also a very significant issue. Health interface generally is a complex one and still evolving with the NDIS, which reaches beyond the hospital system. But the hospital system is a particularly complex interface.

MS LE COUTEUR: I thought there was some support for that in the hospital system already.

MRS DUNNE: There was money in the last budget for navigators.

MS LE COUTEUR: Thank you.

MRS DUNNE: But I do not know whether they have been rolled out yet.

Mr Fox: We would strongly support that. There is always a risk that those kinds of initiatives are piloted and then ceased. We think that they would need a strong emphasis on piloting. The third area I would nominate is the area of those information and linkages services. We specifically instanced, I think, TADACT and Pegasus in our submission—

MS LE COUTEUR: Yes, you did.

Mr Fox: but there are a number of others: the Deafness Resource Centre, Epilepsy

ACT, Arthritis ACT, Alzheimer's ACT. There are a range of those kinds of organisations delivering value in our community for which ACT government funding has been withdrawn. They do not easily fit, or at least their whole operations do not fit, within the current structure of the information linkages and capacity building grants system. I believe that is a very significant area of continued engagement by the ACT government, and also some redesign.

The one last one I would mention is the issue of research and data collection. We would like to see the ACT Long Service Leave Authority give us more detailed information around the disability workforce. On workforce generally, we think that it would be really valuable to have easier access for people with disability to school-based apprenticeships. I will stop. I think those are the key ones.

MRS DUNNE: I want to follow up on the last one about the ACT Long Service Leave Authority. Is that because that is a useful repository of information about people who work in disability?

Mr Fox: Yes; exactly.

MRS DUNNE: It is not definitive, but it would be moderately comprehensive.

Mr Fox: Unusually, I can give you a brief answer to that. The answer is yes.

MR PETTERSSON: In your submission you talk about location-specific pricing for the ACT. Why is that?

Mr Fox: We believe that there are a range of pressures on prices, not so much prices as wages—wage costs, effectively—to employ people within the ACT. Those pressures include the cost of workers compensation. They include competition from government, both the ACT and commonwealth, and they also include some issues around the way in which our industrial relations arrangements have been traditionally developed within the community sector so that there are quite a lot of enterprise agreements and so on that still have a legacy impact. In consequence, the conditions often are perhaps well in advance of those in other jurisdictions. Those are some specific cost pressures. I must say that we are not optimistic of any specific pricing outcome.

MR PETTERSSON: Are there any jurisdictions or locations in Australia that have specific pricing schemes or is it a national pricing scheme?

Mr Fox: There are effectively two regions for prices. The Productivity Commission has pretty much said that there is no logic to the dividing line between them. The ACT is in the higher pricing group of the two, but we just believe that prices more generally, specifically for personal care, domestic support and community access, are too low. We believe, in a sense, that the design features that the agency has put into its pricing are insufficiently comprehensive.

MR PETTERSSON: Do you think the solution is for the tier that we are currently in to be raised and for everyone in that tier to get a raise in the prices that they work within? Or is it a case that they need to create a new tier with particular locations—

Canberra, inner city Sydney, Melbourne?

Mr Fox: We think that perhaps you will never get that level of granularity, but there are potentially a couple of ways of dividing between densities—your high density cities, regional locations and remote locations. There is a remote allowance within the scheme, but the ACT does not qualify for a regional top-up in the pricing. It stands between both city and regional, but it certainly has some cost pressures. We think that perhaps the better solution is to be able to get a better price for those key deliveries of domestic support, community access and personal care at the hourly rate. If we are going to have price control, then those prices need to be higher.

THE CHAIR: Thank you. We have to wrap up there. On behalf of the committee, thank you for attending today. We will be providing you with a proof transcript so that you can make any corrections you need to.

Mr Fox: Thank you.

Hearing suspended from 12.42 to 1.32 pm.

COCKING, MR GLENN, President, LEAD
NEVILLE, MS KERYL, Chief Executive Officer, LEAD

THE CHAIR: On behalf of the committee, I thank you for attending today. I remind you of the protections and obligations afforded by parliamentary privilege and draw your attention to the coloured privilege statement on the table. Could you confirm for the record that you understand the privilege implications of this statement.

Mr Cocking: Yes.

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

Mr Cocking: Thank you. I am here as the president of LEAD, a not-for-profit organisation which is led by a board of parents and a couple of business professionals to support 500 ACT people with a disability. I am also here as a parent of an adult son with a disability. Lots of good things have come from the NDIS, particularly the provision of support funding for people who previously did not have any or did not have enough. But some things have not worked well. That is what my submission concentrates on. I have three points in particular to make.

Firstly, there is the failure of people to get employment support into their NDIS plans; a similar failure to get one-to-one capacity-building support into their plans; and the price that is paid for one-to-one capacity-building support. There are NDIS clients who want to work and whom LEAD knows they would employ but who cannot get work into their NDIS plans. The opportunity to work is an important thing that we believe should always be supported but that is not happening consistently. We estimate that LEAD could have placed 25 to 30 more people in jobs in its businesses during 2017 if NDIS funding had provided for supported employment.

This is unique. I have been president of LEAD for 20-odd years. Last year was the first year with everyone scrambling for jobs. It has just reversed. LEAD has provided the community with case studies that demonstrate the blockages clients encounter when they try to get employment into their plans. As I reread them last night, I was still astonished that these blockages happen.

There are other important concerns, in the written submission, with NDIA's treatment of supported employment. I do not think it is getting attention. The article in the front page of the *Australian* last week made no mention of employment issues. There was a mention of it in this morning's *Canberra Times* article. The Productivity Commission review of a year or more ago said a lot about the planning process but had hardly anything and nothing significant to say about employment.

Secondly, many ACT people with a substantial disability received ongoing block funded, one-to-one skills development support from LEAD before the NDIS. There were 180 such clients. To continue this support within the NDIS, clients have to receive "CB social community and civic participation" funding in their NDIS plans. In most cases, NDIA simply is not doing this. The number of clients receiving this support from LEAD has fallen to 54, and some of this is only short term. It seems that NDIA has decided to reduce the long-term learning support for people with substantial disabilities to a small fraction of its former level. I think that should change.

LEAD board members ask each other, “Where have these former skills development clients gone?” We can only know anecdotally, because NDIS has the data, not us. It seems obvious that some have gone to lower priced, group-based community access activities and some have had their daytime community access program absorbed into their accommodation support, both of which are provided in plans at lower prices. There is no one-to-one support there. I feel particularly for the clients of the former Disability ACT ACE program, whom LEAD took over from Disability ACT and who were provided with one-to-one skills development support. But I think that is now largely gone.

Thirdly, there is currently an insurmountable problem for LEAD with the NDIS price paid for CB social community and civic participation. It is about $55 an hour. Before the introduction of the NDIS, LEAD conducted a financial modelling exercise, which indicated it would cost us approximately $75 per hour to deliver this service. We knew there was a problem and raised it in the consultations. But there was a suggestion at the time that NDIA would quickly move to a deregulated marketplace. We continued to provide skills development services while waiting for deregulation to occur and in the hope that NDIA would make changes to adequately fund skills development. This has not happened and there is no sign that it is going to.

So LEAD has made a loss in their service ever since a significant proportion of the clients moved to the NDIS. We covered this for several years by the use of reserves, but that cannot continue. It is inevitable that LEAD will have to stop this service, probably by stepping it down during 2018-19.

NDIS pricing is forcing the casualisation of the disability support workforce, apparently deliberately, which is bad for the quality of service to clients with complex needs. Clients need stable, well-trained and committed staff. Casualisation runs counter to the initiatives to raise the confidence of staff in the disability sector, for example, through the government’s equal remuneration order to deliver equitable wages for disability workers.

There are other issues in our written submission. I appeal to the ACT government to forcefully take these issues up with NDIA. A community organisation like us has no influence whatsoever with NDIA. Some clients, mostly high needs clients, are worse off in the NDIS than they were under previous ACT funding. Please do not let budget pressures cast people with complex needs into inappropriate group services with little help for skills development. I believe that none of the NDIS reviews conducted so far, including that one by the Productivity Commission, have addressed the issues that I have talked about here.

THE CHAIR: Thank you for your submission. I just want to kick off with a question. One of the issues you have raised is around the structure of plans. You have suggested that, while capacity building can be funded from the core budget of a self-managed plan, it cannot be funded under the core funding of a non-self-managed plan. You are suggesting that is a change that should be considered. Why is that important?

Mr Cocking: It was important when I wrote this because people had the experience of having adequate funding in core but no provision for one-to-one skills development support. When there was enough money in that core and they were self-managed, then they could buy skills development support, which is a good thing. But it only works if there is enough money in core. What we are hearing from people who have got back to us as things have moved on is that that excess money in core is being eroded, disappearing.

Ms Neville: Can I respond? The thing that we thought would happen with the NDIS was much more flexibility for people and the ability for them to get support in a way that met their needs flexibly, and by categorising things into particular bands like capacity building, core supports and employment. What it in fact has done has restricted people’s ability to get their needs met and to be flexible in the way that they address their support needs.

It is not necessarily saying that agency-managed people should be able to use their core support funding to use capacity building. It is a bigger issue, which is that people should be able to use their bucket of money in a way that flexibly meets their needs, whether that is using core support for employment or whether it does not get defined in those very rigid budget areas.

THE CHAIR: Thank you.

MRS KIKKERT: Thank you so much for being here. To what extent does having no skills development have an impact on the person with disability and also their carer? I understand the lack of job opportunities but what about emotional wellbeing?

Mr Cocking: A lot of the people who receive skills development support are struggling in their lives, and they need to learn and they need to keep on learning. Sometimes they have setbacks in their life which put that on hold for a while and they have to come back and recover. But it is very much a long-term process. It is not something that you just fix, put in short-term funding to teach people a few things and everything is all right. These people with those emotional, autistic and intellectual disabilities need to have ongoing assistance to manage their lives better.

Ms Neville: And I guess, again, it fits with that normalisation principle around lifelong learning. All of us have an option to continue lifelong learning opportunities. Glenn’s point is that people with complex needs should also have that opportunity to really have their support targeted in a way that is about building skills.

Part of the struggle with the NDIS is that you get caught up between the notion of what is about support and what is about building people’s skills. And sometimes people with complex needs will need support forever, whilst they still are able to build skills. It is not that they cannot build skills because their support needs are too high; it is that they might be able to be build skills but they still might require support forever.

What we hear in the capacity-building line items is that it is time limited: “They should be able to build a skill; it should take them three months and then that should stop.” But for all of us building skills is a continual thing. For us it is that difficulty around getting a clearer definition of what capacity building actually relates to, because even the people with the most support requirements still have the opportunity to build skills, whether they just be tiny, incremental skills. It is a philosophical thing, I think, that makes it more normal.

MS LE COUTEUR: You talked about the casualisation of the workforce being one of the outcomes of the NDIS. I wonder if you can talk about that more, particularly in terms of your role as a service provider and supporter. You said it was bad for the clients. Is it also making it harder for you?

Mr Cocking: It is all the same thing, really. That is why we are here, to look after the clients. If we cannot have appropriately trained and skilled people with some experience to provide the one-to-one support for clients, it is the client who suffers and of course it is a problem for running the organisation.

Ms Neville: As Glenn hinted, we took over an ACT government program that had a large number of clients in it. We took that over in 2008. As part of that we were asked to maintain it in its current form for two years. At the end of those two years we took it out of its current form and went down the line of one-on-one skills development programming.

Prior to that we had used a lot of casualised university students in a way that allowed us to have lots of people running around, and we ran a very strong roster system. The roster really drove what we did. In 2010 we went, “Oh my God, if we could get rid of this roster and work more with people and relationships, and work harder on building relationships, we would get a better service.” And we saw that. We saw really great outcomes.

One of the things that stand out mostly for me in answering your question is that we went from having incident reports of about 200 a year—they might be little things like someone burned themselves on steam from a kettle or something; little incident reports—to, when we built a stronger relationship between a support worker and a client, about 15 a year. We saw a significant drop in our incidents and part of that was because the client and the staff member had a better relationship, knew one another. You did not have that same level of risk that we have associated with putting casual staff with people that they may not have that level of knowledge about.

It is not just the casualisation. I think the other thing to understand is that the pricing is really an interesting point, because people go, “You say it costs you $75 an hour to deliver services?” But that $75 includes things like the cancellation processes, the annual leave, the portable long service leave that we have. It is really important to understand that that price is not just about a support worker’s wage but it is all the rules that the NDIS includes within its system that impact on that pricing—the travel arrangements when people are travelling between one client and another client and who absorbs that cost. There are a whole range of things that are in that price that are not just about a support worker’s wage. The casualisation is to drive you back to just looking at the support worker’s wage, and that just negates all those additional things that are in there.

MS LE COUTEUR: Do you think the casualisation is inherent in the NDIS model, or could we have the NDIS model and not lead to a casual workforce?

Ms Neville: For instance, our financial modelling had, at the point where we moved into the NDIS, our billable hours for staff. We had all full-time workers, and our billable hours for those full-time workers sat at around 68 per cent. That, again, has all their leave, all their training, all their staff meetings, all their administration tasks in it. We are sitting at about 68 per cent. We did feel that we would be able to drive that up to between 75 and 80 per cent. We thought we would be able to get our staff billable time to that. We did manage to do some of that and we have dropped our hourly rate down to $66 an hour, I think. The NDIS has modelled in its pricing formula between 85 and 95 per cent billable time on staff. There is no way to get there. In all our modelling, there is no way for you to get your service to that level.

Mr Cocking: I do not think that NDIS would say that casualisation is their objective, but it is the inevitable consequence of their pricing.

MS LE COUTEUR: One of the things I am thinking about is not just the pricing but the structure of how it is. The pricing would have to be a bit higher because of the structure, but still with compensation. Is that what you are saying?

Ms Neville: Yes.

MR PETTERSSON: Bear with me as I try to get to this. When people have a plan they get allocated funding to do employment activities. Do they need to pre-identify the place they are going to be working?

Ms Neville: Yes. It is a chicken and an egg situation because we are saying we need people with employment in their plan but, under the current way that the NDIA is structured, it is difficult for the NDIA to put employment in someone's plan unless they have an already identified connection with an agency. And some of that is because they are yet to determine an appropriate way of funding employment in the new system.

In the old system it was determined by a computer algorithm that led to something called DMI levels, and in the new system there is not that computer system to create DMI levels. They are struggling around: "How do we determine new people's levels?" They have given what they call an averaged outlet rate. Now, instead of getting different levels or people determined by their support needs, we get one level determined by us as an agency and our averaged previous history.

Our average is different to Koomarri's average. They are the other employment service in town. Unless people have identified when they turn up to the NDIA whether they are going to come to LEAD or Koomarri, it is actually very difficult for planners to put in there because it is a different amount of money. There are some structural things that make putting it in the plan difficult, and we are saying it is difficult for us to say to someone, "We can give you a job," until we know that they have got support. It is a bit chicken and egg. It is crazy and there needs to be a way that that can work.

MR PETTERSSON: Moving past the chicken and egg situation, do the different rates that you and Koomarri attract change who works for you?

Ms Neville: It does not work for us. What it does create is a disincentive for us to not consider, necessarily, those people with higher support needs. I do not know what Koomarri's is, but our average outlet rate sits between a DMI level 2 and a DMI level 3. There are currently four DMI levels. As a DMI level 4, you would—

MRS DUNNE: Sorry, DMI?

Ms Neville: Disability maintenance instrument. It is just a tool name. At a level 4 you would have previously received $15,000 a year for employment support. At a level 2 I think you receive about $7,000 a year support. Ours sits somewhere in between seven and nine. For us, if we see people who typically we would have thought needed a level 4, at $15,000, we are less inclined to want to work with those people at the lower rate that we are attracting under the NDIA. It does mean that possibly that group of people will end up being streamed out at some point, despite our work numbers that we have.

MR PETTERSSON: What opportunities would be available to someone at that DMI level 4 in the ACT?

Ms Neville: We currently open all our ADE employment opportunities up to anyone. We do not currently stream out people. There is a level of wanting people to be in a job that they like or enjoy—some of it is about that—but their support level has never stopped us working with people before. But, as I said, because of the current structure and the averaged outlet rate we are more likely to think about that as an impediment to working with someone.

Mr Cocking: We are a parent-run organisation, rather than a commercial one. We do our darnedest to provide work for anyone who comes along under these arrangements.

MRS DUNNE: Just to follow up on that, in a sense the funding for employment is not attached to the client; it is attached to the service?

Ms Neville: It used to be attached to the client. It was based on—

MRS DUNNE: That undermines or goes against the spirit of the NDIS?

Ms Neville: That is right.

MRS DUNNE: It does not give the client autonomy?

Ms Neville: That is right.

Mr Cocking: And the fact that they get employment support is still tied to the client. But the money that gets paid is determined by which organisation you are talking to, yes.

MRS DUNNE: Rather than by client need?

Ms Neville: And their needs, yes.

THE CHAIR: We are out of time. Thank you for coming along to present to the committee today. When available, a proof transcript will be provided to you to make any corrections. Thanks a lot.

Ms Neville: Thanks.

REDMOND, MR CHRIS, Chief Executive Officer, Woden Community Service

THE CHAIR: Thank you for attending today. I remind you of the protections and obligations afforded by parliamentary privilege, and I draw your attention to the pink-coloured privilege statement that is before you. Could you confirm for the record that you understand the privilege implications of the statement.

Mr Redmond: Yes, I understand.

THE CHAIR: Would you like to make an opening statement?

Mr Redmond: Yes, please. Thank you for the opportunity to speak with you today. NDIS, the NDIA, has been a topic of great interest to Woden Community Service. We have been in the transition to NDIS since its inception in 2014. Prior to that we prepared ourselves for the transition by offering families opportunities to test out the things that they would like to do with their children in our service, to see how it would work for them once the system started operating in 2014.

Woden Community Service is a multiservice organisation insofar as disability and psychosocial support is not the only thing that we do. We provide fee-for-service children's services which make up almost half of our revenue. We provide a range of child, youth and family support services, and tenancy support. We run OneLink, the human services gateway. We offer the commonwealth home support program. We deliver a range of health services on behalf of Health—mostly mental health services. We deliver the commonwealth home support program and community transport. We auspice *The Big Issue* here in the ACT. There are probably a couple of other things that we do—volunteer coordination and a range of other things.

I mention it because we have the luxury of being a multiservice organisation that has a revenue stream rather than direct-funded, government-funded programs. As we go through, I would like you to remember that—what impact it has had on us and what impact it would have on services such as LEAD, who rely solely on the NDIS for their activities in delivering their services.

The ACT went to full-scheme rollout, as you know, in 2014, and the transition finished in 2017. The ACT had a full-scheme rollout while other states trialled client segments in regions. As the larger states are now transitioning, you can expect to see the ACT experiences writ large, and the pushback to the NDIA that you will see in those larger states will be really more pronounced. Not many providers, unfortunately, have looked to the ACT as a whole-of-jurisdiction rollout to learn from us, their counterparts.

Woden Community Service provides support coordination, capacity building, and core supports in ability services and psychosocial services. WCS specialises in recovery-oriented psychosocial services. In our ability service area, in our service delivery, we have between 38 and 40 participants. In our support coordination service we currently have 59 participants. In our psychosocial services we have 63 participants, using both service delivery and support coordination. And four are just receiving service delivery.

From 1 July 2017 to 31 March 2018 the NDIS contributed 12.51 per cent of our total revenue. Total year-to-date NDIS revenue is $1.643 million, of our total revenue year to date of $13.1 million.

The NDIA has introduced a new funding environment. The work that is undertaken by services under the NDIA should only be funded through individual funded plans. Any activity that is not funded as per the pricing schedule should not be undertaken. NDIS funding does not account for service overheads and administration, recruitment, training, supervision, leave and back-office functions, or quality. Any activity that is not funded cannot be justified, yet there are critical pieces of work that need to be done to ensure appropriate support for participants, support for staff and service viability. These sometimes are not funded, and the cost is borne by the provider.

WCS is wearing the cost of the NDIS through cross-subsidisation from other revenue sources. Our fee-for-service children's services, for instance, from where we derive half of our revenue, are essentially covering the cost of the NDIS service delivery for Woden Community Service. We as an organisation are not in a break-even position as at this financial year, and far from it, through our provision of NDIS services. We are running at a significant deficit for the year, and this has become more pronounced in this financial year than in any other previous years.

Until the end of the last financial year, we were travelling okay. We had managed to transition really well. But at that point significant changes occurred within the NDIS-NDIA environment that had a significant impact on our service delivery, the most important one being the introduction of Feros Care, the LAC provider, into the ACT. As a result of their introduction into the ACT, we lost half of our support coordination that we delivered under ability services almost overnight. They came here in around June-July last year.

The other thing that occurred was the beginning of the reviews of psychosocial plans. Psychosocial disability was the last tranche of work brought into the NDIA, so they were going through the first annual reviews in June-July last year. It was when we were seeing plans coming back with incredibly reduced support coordination and capacity building funding, although the core component was significantly increased.

The issue for us was that we believed the NDIS was a great scheme. The intention was good. We believe there should be a strength-based approach to service delivery which is about enabling people to increase their independence. We believe that that is done particularly through the capacity-building activities within plans. The core parts are those bits that we see as being residual services that could in some way increase dependency or people not being able to build the skills to do it themselves. We saw an incredible reduction in support coordination and capacity building when we saw the first reviews going through, and an increase in the core parts, around what I would call not the skills-based activities that you would like to see developed.

The point that I want to make is about the lack of a provider of last resort in the NDIS service. All that is available to people in the delivery of services is what is in their plan. Disability ACT used to be the provider of last resort in the ACT. There is no longer a provider of last resort. When people have extenuating circumstances or their needs are greater than those that you find in their plans, unless there is a service that says, “We will pick those up or support the individual,” there is no other service available to support that individual. Woden Community Service believes that that function and responsibility have been pushed back onto the service provider through their relationship with the recipient or participant.

With respect to continuity of supports, there was an undertaking by the commonwealth to ensure that no individual would be worse off as a result of the introduction of the NDIS. There has been a bunfight between the Department of Health and the Department of Social Services about who is responsible for the delivery of continuity of supports.

It was great to see in the budget this week that next year DSS will pick up one year’s responsibility for continuity of supports, at around $30 million, and for the next three outyears it will go to Health, who will deliver, I think, about $30 million. We do not know what that will look like. All I can say is that for the ACT the opportunity has been lost. The programs that provided continuity of supports, especially in the area of psychosocial services, such as personal helpers and mentors, partners in recovery and the respite service for carers, have all been cashed out. They will be cashed out by the end of next year. We get $20,000 a year now for the delivery of family services. They have all gone. The continuity of services here in the ACT has disappeared.

Of great concern to us is the paradox that the LAC provider, Feros Care, in this case also does plan connection, planning of individual funding plans, and reviews. They enjoy the privilege of being a block-funded service, in an environment in which all providers of services to the NDIA are fee for service only. We get paid on a per hour basis. They are paid a block-funded amount by which to deliver their service. The biggest contradiction, I believe, in this whole scheme is that they call them a partner. I am not being critical of Feros Care; I am critical of the process by which this has occurred.

In deleting a block-funded environment and having a fee-for-service environment, they have actually contradicted themselves by block funding their partner to deliver services. There is an extension by offering them a long, expensive contract to deliver services on their behalf, which is what we thought we were doing. As I said before, we lost half of our support coordination under ability services to Feros Care within the first month of their operation. I find it hard to believe.

As market stewards, the NDIA are responsible for managing the market. The providers are the market. We are the investors, apparently—we were told quite recently by the NDIA—in the service. We believe that the NDIA have poorly performed their job of market steward. In creating a new market as they have under the NDIS, it is their responsibility to ensure that there is some certainty for providers in that market. There has been no certainty for providers in this market in the ACT over the last four years.

We were a trial site, so everything within the NDIS was trialled; it was a demonstration. They told us to build a business model around our service delivery. For us, service delivery has always come first, so our service model came first and our business model came second. It is not to say we do not operate on business principles, but our concern has been that we have not been given any clear and stable market conditions within which to deliver our service. There were constant changes over the first three years of introduction of the things that they were trialling. As a result, what we got to deliver changed all the time. And the conditions of our delivery have changed all the time.

THE CHAIR: I am cognisant that we have only a few minutes remaining and we need to ask some questions as well.

Mr Redmond: Okay, sure.

THE CHAIR: Is there something you want to conclude with?

Mr Redmond: I want to mention a couple more things. In respect of the issue of choice and control versus reasonable and necessary supports, choice and control seem to have taken a back seat now to reasonable and necessary supports. In respect of casualisation of the workforce, we had to make redundant all of our disability service workers at the introduction of the NDIS because we paid them at level 4 and the NDIA only pays at level 2.

Obviously, having a casualised workforce means that your quality and support for staff goes out the window. I have talked about changing models and changing rules. I have also talked about workforce. I will really quickly address the future of our recovery practice. Woden Community Service delivers a recovery approach to psychosocial services. This means that we assist people to live with their conditions. It is not to say that they will ever get better, but they will learn to live with their conditions and live full and meaningful lives.

With the cashing out of block-funded supports or services for people, the NDIA has shifted the financial burden of ongoing assistance to people living with a disability on to service providers, whether they have an NDIS plan or not. The practice is unsustainable, and I believe we will see an increase in services withdrawing from the market, an increased risk of market failure and a degradation of the quality of service provision. Lastly, it is going to push a whole lot of service back down on to those services provided by the ACT, such as your health services system, your justice system particularly and your community services system.

THE CHAIR: Does any committee member have a burning question? We are short of time?

MS LE COUTEUR: Basically, as a summary, it all sounds appalling. What would be the most important thing the NDIS could do to improve things?

Mr Redmond: The McKinsey report recently reviewed the pricing. They made a number of recommendations. The NDIA taking this to the board to approve those recommendations would be good. However, I talk about it from a service provider perspective and the viability is not there for service providers. What the NDIA needs to consider is what makes it possible for the service providers such as us to remain viable, in consideration of the things that support us to deliver our quality service. Those things just are not there in terms of recruitment, retention, training and quality.

Next year, with the introduction of the disability commission, we will be required to meet the national standards for disability and for psychosocial services. With the process you need to go through, it does not happen in a vacuum. It is about ensuring that we have the appropriate level of funding to support the level of quality services, and for organisations to be able to sustain and support staff to do that.

MRS DUNNE: I want to follow up on the viability of the organisation. At one stage, Mr Redmond, you said—if I am paraphrasing you too loosely, do correct me—that essentially you were cross-subsidising out of child care into disability support. One interpretation of that is that people who are paying for childcare services are paying more than they need to so that disability support can be funded through Woden Community Service.

Mr Redmond: No, it actually means that we are making a loss as an organisation.

MRS DUNNE: You are making a loss as an organisation.

Mr Redmond: What we used to do was to use our surplus. We have had a modest surplus every year—$80,000 to $200,000 a year. What we used to do with that money was fund services that were underfunded by government. For example, we have been running for the last two years a hoarding service that works with the hoarding case management group.

We have been running a youth wraparound service for eight to 12-year-olds as they transition from primary school to high school. We run a little pantry, which is an essential food service for people who have not got enough to make ends meet. We have retained the little pantry, but we have let go of the other services that we used to fund ourselves. We can no longer afford to do that.

MRS DUNNE: Does Woden Community Service have a view about its long-term viability in this space? If nothing changes, how long can you last?

Mr Redmond: We have an exit strategy already developed for the delivery of NDIA services. It is not something that we would wish to do. But it is something that we might be forced to do as a result of the fact that we cannot make ends meet.

The bigger issue for us is what happens to people who have complex needs in the current environment who will not be supported by providers. I think there are a number of those people we are working with that will not get the supports they need to live quality and meaningful lives. But, yes, our viability is at stake, and it is work that we have been working on over the last six months.

MR PETTERSSON: You have mentioned Feros Care and what its current role is. It has not been particularly kind. What services do you think they should have been providing that are currently not being provided?

Mr Redmond: It is our understanding that they have actually been brought into the territory to deliver primarily the local area coordination services. I have not seen any great evidence of that being the case. It may well be occurring. But it was then thought that they would be doing plan activation because there is a whole issue around people having plans but not being able to activate them. But it is my understanding now that they have actually expanded their role in taking on the work that is actually being done by the NDIA, which is the planning and plan reviews. The work it has also taken on is the support connection, which is the lower level coordination support, which is what we were doing prior to it coming into the market.

MR PETTERSSON: This is a very rudimentary question but, based on your position, would you know if they were doing these things?

Mr Redmond: I know that they are doing support connection. I know they are doing planning and plan reviews because the plans we put up are actually being done by them. They are reviewed by Feros Care. We provided training to Feros Care and the NDIA in December last year on a recovery-oriented approach to service delivery for people living with a psychosocial disability. So we know that they are doing both those things.

MR PETTERSSON: In terms of local area coordinators, though.

Mr Redmond: I have no idea.

MR PETTERSSON: The question is, and this is a very rudimentary one: you are in a position where you would know if they were doing it?

Mr Redmond: I would expect to know.

THE CHAIR: We are running over time. I ask that all other questions be placed on notice. Thank you again for coming in, Mr Redmond.

Mr Redmond: Sorry if I have spoken too much.

MRS KIKKERT: No, you actually answered some of my questions.

MS LE COUTEUR: Very interesting, Chris.

THE CHAIR: We will forward the proof transcript for you for any corrections.

Mr Redmond: Thank you.

GRIFFITHS-COOK, MS JODIE, Public Advocate and Children and Young People Commissioner, ACT Human Rights Commission
ROGERS, MS LEE-ANNE, ACT Human Rights Commission
VIEIRA, MS MARIA, ACT Human Rights Commission

THE CHAIR: Thank you, and welcome. I remind you of the protections and obligations afforded under parliamentary privilege and draw your attention to the privilege statement before you on the table. Could you confirm for the record that you have read and understand the implications of the statement.

Ms Griffiths-Cook: Yes, I do.

THE CHAIR: Would you like to make an opening statement?

Ms Griffiths-Cook: I begin by acknowledging the traditional custodians of the land on which we gather today, the Ngunnawal and Ngambri people. I pay my respects to elders past, present and emerging, for they hold the memories, traditions, culture and hopes of Aboriginal and Torres Strait Islander people across the nation.

Thank you for the opportunity to appear today. I am speaking both in my own role as Public Advocate and Children and Young People Commissioner and also on behalf of Ms Karen Toohey, the Discrimination, Health Services, Disability and Community Services Commissioner.

The HRC is strongly supportive of the intent of the NDIS but appreciates that we still have some way to go before its benefits are fully realised. We recognise the scheme is still under development, and it is both timely and critical to address issues with ongoing design and implementation that negatively impact on ACT participants. Today I will speak to four key points. The first of these is the experience of people with disability, and their families and carers.

While some people indicate positive experiences with the NDIS, many report that the processes have placed an ongoing and significant burden on them. Participants and families report delays in NDIA processes, including in relation to seeking eligibility, getting their first plan, obtaining approval for assistive technologies and home modifications, and in plan reviews due to changed circumstances. Many people report a lack of assistance to access and navigate the system, placing pressure on informal supports and other service systems and resulting in some people not accessing the scheme. For many people the provision of information alone has not been sufficient and more personalised assistance has been required. While some of the support may be provided in an individual’s plan, a broader strategy of capacity building is central to the NDIS and not yet adequately engaged.

The second issue of note is the difficulty experienced by participants in accessing supports. The disability services market in the ACT is not yet fully able to meet participant need and deliver the necessary quality and quantity of supports across the sector. Notably, we believe there is a market failure for people with high and complex needs, particularly those who require therapeutic supports. The specialised training, skills and experience required to support people with complex needs is higher than for other consumer groups, and participants are finding it difficult to engage providers with staff with these capabilities.

Further, participants with complex needs are less able to exercise consumer power to change providers when they are not satisfied with the quality of services and often have extended periods of time with no funded supports, requiring family and informal carers to bridge that gap. Previously, Disability ACT provided case management for people with complex needs and people with limited or no social or family support. Within the NDIS this may be available through supports coordination; however, there are significant limits to the quantity of this provided for in the plans and in the availability of experienced and skilled staff to undertake this critical role.

There are some levers that could be used within the NDIS to address this issue. The higher hourly cost of providing support to a person with complex needs could be reflected in the prices set by the NDIA. In addition, the amount of support included in plans could reflect the higher needs of this group, rather than the standardised approach that appears to be currently used.

The complex bureaucratic processes and standardised funding practices of the NDIA are my third point. By the end of the ACT's two-year trial period the NDIA had addressed concerns associated with planning reviews and the need for supports coordination. However, since the commencement of the full scheme in the ACT in July 2016, ACT participants have recorded poor planning processes, changes to processes resulting in increasing delays and, most concerning, significant reductions in the amount of support in their plans.

The current approach to planning appears to apply the standardised or benchmark levels of support rather than consideration of the reasonable and necessary supports required by individual participants. As an example, NDIS plans needs to be able to respond to the variable pattern of need experienced by people with psychosocial disability. I know my colleague Chris spoke at length about psychosocial disability. Participants should not need to have frequent reviews to address these fluctuations in need. Although NDIS plans can include high levels of supports for estimated time periods, based on past patterns of need, in practice the focus on planned funding levels not exceeding benchmarks means that funding allocations may not be sufficient for people with episodic high support needs.

Further, at times the language used by the NDIA to explain decisions about the level of funding in plans is not consistent with the application of "reasonable and necessary" as set out in legislation. The statements made by some NDIA staff about possible process outcomes associated with actions such as requesting a review have me concerned about the potential mismatch between the culture of the NDIA and the intent of the scheme as articulated in the legislation and its family philosophies.

The final area I am addressing is in relation to complaints. The HRC is concerned that the right of redress for ACT NDIS participants is negatively impacted by the pathways for complaints about the NDIA—that is, going through the legal processes of the AAT or commonwealth agencies with limited scope. These pathways are not sufficiently accessible for many people and risk losing sight of the person with the complaint, which can further disadvantage people with disability.

The HRC can take complaints about disability services in the ACT and has received numerous inquiries and complaints about the NDIA. We have attempted to seek a response from the NDIA in relation to concerns raised with us. However, the NDIA has refused to participate in the HRC's complaint process. It has disputed the HRC's jurisdiction over the NDIA, arguing the NDIA is simply a funding body and does not provide disability services.

The NDIA's refusal in these matters would appear to be inconsistent with our obligations under the UNCRPD and also appears at odds with undertakings made in the quality assurance and safeguards working arrangements for the ACT NDIS trial, in force until 30 June 2019. The NDIA's response is also contrary to the guiding protocol for the NDIA and the ACT Discrimination, Health Services and Disability and Community Services commissioners in relation to complaint handling, signed in May 2015.

Ultimately the HRC seeks to engage collaboratively with the NDIA, ideally before a matter reaches complaints stage, by facilitating alternative dispute resolution between the NDIA and its participants. The HRC can provide a range of options to support NDIA participants to resolve concerns, including through individual advocacy and having an independent, flexible, quick and confidential conciliation process and an alternative to legal proceedings. I will leave my initial comments there. I welcome questions from the committee.

THE CHAIR: I want to go to your point in relation to your alternative dispute resolution role. Can you comment on how that worked prior to the NDIS coming in and what the contrast has been since?

Ms Griffiths-Cook: That is a challenge for me to comment on directly. As you would probably be aware, within the Human Rights Commission Karen Toohey is the responsible commissioner for all complaints that are taken. Maria Vieira works within that business unit.

Ms Vieira: My understanding is that the HRC was able to receive complaints from/or against Disability ACT. I was not at the commission prior to the NDIS rollout, but my understanding is that the previous process was much smoother. I am happy to provide further information on that.

THE CHAIR: Yes, I think that would be helpful. I get a sense from your submission that it was a much easier process and that disputes could be resolved before they needed to be escalated.

Ms Griffiths-Cook: Yes. The experience I am aware of is that, although disability service providers themselves certainly have a willingness to engage with us, should something come up, in many respects it is the issue of engaging the NDIA directly in those processes as opposed to the providers themselves.

THE CHAIR: Are the NDIA refusing to deal with you at all or are they just refusing to deal with you on certain matters? What is the extent of the relationship?

Ms Griffiths-Cook: In terms of complaints, my understanding is that there has been a fairly firm statement indicating that they do not believe themselves to be a provider of disability services and therefore they do not engage on that basis. Given that the jurisdiction for complaints covers disability services, we have had some willingness to engage in our advocacy area. I think my concern within that space is that that seems to be person dependent as opposed to system dependent. That is a particular concern for me. If the system itself does not have an overarching perspective or stance that says, “We are happy to work with you to effect outcomes for people,” then we are potentially placing people in significant disadvantage where we are relying on the goodwill of a person in a particular position to be willing to engage on individual matters.

THE CHAIR: Would you be involved in planning on behalf of a client or assisting a person who has come to you for help?

Ms Griffiths-Cook: Not necessarily. Our role in the area of statutory advocacy is different and distinct, in some ways, from a community advocate in that space. However, having said that, if someone has approached us, talking about the challenges that they are having engaging with that system in terms of getting a plan developed or getting the plan to reflect their circumstances, there have certainly been times when we have engaged in individual advocacy and equally have taken on some of those matters through our management assessment panel as well.

THE CHAIR: The Public Advocate’s role, is that—

Ms Griffiths-Cook: As Public Advocate, our role is within the space of statutory advocacy, which primarily is about ensuring that systems do what they are supposed to do in the way that they are supposed to do them, in the time frames that they are supposed to follow. Quite often in that space there is obviously blurring of lines. We are usually engaged by people when they have attempted to get situations resolved in other ways but they are still falling through the gaps or there are still gaps in the system. They are usually the times when people approach the Public Advocate for assistance.

THE CHAIR: There is no federal commissioner role that would have taken up the gap with you leaving the system?

Ms Griffiths-Cook: Not that I am aware of. Certainly, the Australian Human Rights Commission have a level of jurisdiction within their ability to negotiate the NDIA operations, but it is by no means at the level that we have previously been involved in the past. I think that is the challenge. The shifting from a state-territory level jurisdiction to a commonwealth jurisdiction, and their perspective in that space that they are not bound by or accountable to local level statutory processes, has been where some of those challenges lie.

THE CHAIR: Thank you.

MRS KIKKERT: I am very mindful of the time. I will put my questions on notice, if that is okay, but I would love to hear from Ms Rogers. Do you have anything to add to the discussion?

Ms Rogers: I am Lee-Anne Rogers. I work in the Public Advocate's office. I work as an advocate for people with mental health. I assisted my commissioner to prepare this submission. We work on individual cases. We have worked with quite a number of people and advocated about 328 times in the last financial year. A large amount of that advocacy for people with a disability relates to issues with the NDIS.

MRS KIKKERT: Wow, okay. Thank you.

MRS DUNNE: I have a sort of high-level question, I suppose. The Human Rights Commission here has a human rights remit. In your opening remarks you spoke about the international covenant. Do you see that the NDIS is failing to meet the expectations that the people had in that space? If so, what do they need to do to bridge the credibility gap?

Ms Griffiths-Cook: Good question. As I see it, part of the inherent challenge is that the rights obligations that we have as a state party to the convention, for instance, are well embedded within the legislation that the NDIA and NDIS, as a scheme, operate under. I think some of the concerns that we see relate to the inconsistent application of the provisions that exist within that legislation, in terms of the way that people on the ground are running the show and the extent that they are involved in access to determinations, the planning process or whatever it may be. That inconsistency alone speaks to a system that is not fully upholding its obligations. It is great if one person is, but if another is not then the system as a whole is not meeting the expectations that are laid upon it, both by its own legislation and equally by the participants that are involved.

MRS DUNNE: I suppose there is the other part to this. A lot of the evidence we have heard is that the processes have changed a multitude of times. Do you have any sense that, before those processes changed, there was any evaluation? Do the NDIA know why they changed their processes?

Ms Griffiths-Cook: I am not sure that is a question I can answer. The NDIA probably could. I would like to think that there is some evidence to support the changes that have been made. If I look at the responsiveness of the NDIA during the trial period here in the ACT—while I was not in the ACT at that time, my role as the Public Advocate in Queensland certainly had me talking with the existing Public Advocate here—I see there was a willingness. Indeed, we saw the outcomes of that in change processes here, around hearing what people were saying, responding to that and seeking to make sure the scheme was being and doing the best it could.

In some instances, it is hard to see the where the evidence lies for the changes now taking place. That is what is concerning. Previously a concern or an issue was raised and that effected a change in a process or system. Here we are seeing changes made that are actually negatively impacting people. It is difficult for me to see how they could be using evidence to support those changes if they are having a negative impact.

MRS DUNNE: Thank you.

MR PETTERSSON: Your submission details delays in processing in various applications for those detained at AMC. Can you expand on that for me? Do you know why that has occurred?

Ms Griffiths-Cook: The why is again probably something I cannot answer. I think it speaks to the NDIA and the way that they perhaps prioritise some of those processes. I can say that the processes within AMC have improved, in terms of their identification of people with disability who may be potentially eligible for the NDIS.

We see a challenge. My guess as to why those things do not happen in a timely manner—people are housed, they are accommodated, they are getting support through corrections at that point in time—is that there is no urgency to the NDIA acting for those individuals, despite the fact that often there is uncertainty associated with release. Sometimes a release is dependent on there being the existence of supports.

That is certainly one of our biggest concerns. Sometimes a person's conditions or potential conditions for release rely on there being supports available for them so that they can comfortably be supported and some of the risk matters can be attended to within a community setting. If those supports are not in place then that means a person may be detained for longer than might otherwise be necessary.

MR PETTERSSON: Are you aware of that happening?

Ms Griffiths-Cook: I would be happy to take that on notice and see whether we can provide any examples about that happening. It is certainly a concern where there is a need and has been a need for us to advocate strongly to try to get those assessments taking place in a timely manner.

MR PETTERSSON: Thank you.

THE CHAIR: Thank you. I would like to thank you for coming along today and for your submission, which was very concise and very clear. I remind you that the proof of the transcript will be forwarded to you so that you can make any corrections that may be necessary.

Ms Griffiths-Cook: Thank you.

ROWLAND, MS CAMILLA, Chief Executive Officer, Marymead Child and Family Centre

THE CHAIR: Thank you for attending today. I remind you of the protections and obligations afforded by parliamentary privilege. I draw your attention to the pink privilege statement before you on the table. Can you confirm for the record that you understand the privilege implications of the statement?

Ms Rowland: Yes, I do, thank you.

THE CHAIR: Thank you. If you would like to provide an opening statement, we would be happy to hear it.

Ms Rowland: Thank you for the opportunity to provide a submission to the committee. We are very appreciative of that. I would like to make a few opening statements. I know that you will have read our submission. A great deal of the content of this submission was actually presented at a national conference of providers for clients with disabilities. We also had present Kevin Andrews from the Australian parliament. He was on a panel of which I was the facilitator. There was certainly recognition that the comments that I made were relevant not just to the ACT but also to other parts of Australia.

I would also like to pay tribute to some of the NDIA regional management staff and also the staff from the ACT Office for Disability. Particularly in the last 12 months, they have worked really closely with us on some really complex cases. There are still some systemic issues that remain. But I think that their engaging attitude should be complemented in that process that we have been through.

From Marymead's perspective, we have a few hundred clients we work regularly with on NDIS plans and we have over 2,000 different clients and people that we work with who are engaged in a disability space in the ACT. A majority of those are children, young people and their families. While we feel that the NDIS design is aspirational and many clients feel that the aspirations of the scheme are positive, we have a long way to go in terms of transforming this concept into something that is going to work in reality longer term, for long-term outcomes for families.

I keep saying "families" because one of the major issues that is put to us time and again is how the focus is on the individual child or young person and not on the family context in which they live. Many of the families we work with have more than one child or one person in the family with a health diagnosis and with a condition. Often it is very difficult to coordinate the needs of that family with the NDIS, not just the individual. We still feel that the scheme sits within a tightly controlled NDIA bureaucratic structure. It is not flexible and responsive as needs change. If you are looking at a family context, those needs can change sometimes daily, if not weekly and monthly.

In the submission itself, I also drew on the Marymead Autism Centre advisory group, which consists of around 12 people. All have someone living with autism in their family. But we have people like the head of ACT P&C on the group. We have a researcher into disability needs and we also have somebody who is the head of a major peak body in education on that group. So we have some people who are fairly well connected. We also have a member of a special school board on that group. We have people with wide-ranging networks and they have provided input into this submission.

In addition to the family construct needs not really being taken care of, we are also still concerned that there are what I would consider emergency or critical situations where families are falling through the gaps. Even as recently as in the last few months we had a family who decided to informally relinquish care of their child. That child was in Queanbeyan but had been accessing services in the ACT. The child came to stay with us for a very short time. It was still around the interface between New South Wales family and community services, the official visitors of the ACT and the support coordination agency that was in the ACT.

After a month of that child being relinquished from care, they were unable to coordinate a long-term or even a medium-term response to meet the needs of that child under the NDIS and under the government as a whole. As little as only a few weeks ago I was told that children in the surrounding area of New South Wales are still in a situation where New South Wales FACS is unable to understand what its interface is with the NDIS in relation to children who fall into crisis.

I think we often see that reflected here in the ACT as well, for ACT children. Where a child or a family has not been a previous client of the Community Services Directorate but the family is failing—when I say “failing” I mean functionally failing—because there is an emergency situation that has arisen, it is very difficult to manoeuvre quickly to respond to that situation if they are not already an ACT government-registered client. That is one of the other major issues.

The other one is around NDIS planners not being fully trained or not fully understanding the situations of the whole family context in which they need to work. Another thing we are deeply concerned about is that families seem to be getting less in their second to third plans coming around than in their first plans—sometimes without explanation, true explanation.

Families who are what we consider to be really high needs, meaning their children or young people need on-on-one support or one-on-two support, are getting substantially less than they did previously. The interventions they have for their family on an ongoing basis that help maintain the family are becoming less and less, and they are starting to get more and more stressed. That is one of our other major concerns.

We are also concerned about some of the providers that are coming in for early intervention for children. Their systems that they have in place are not responsive in a timely manner and that interface with the NDIS is not happening in a timely manner. Those are the major concerns that we have articulated. I am open to questions.

MRS DUNNE: Ms Rowland, much of what you touched on was touched on by Carers ACT this morning. The point they made is that often there are multiple clients of NDIS in the one family. They have quite delineated and strictly separated programs, to the extent that one of the examples this morning was that there are three children who all have different plans, which means that they have a different person who picks them up after school and takes them to care, provides that care and then takes them home, whereas a normal family has probably one person who provides that care. It would be cheaper, better and more like real life if that were the case, but they cannot do it because there is not even an option of having an integrated family plan.

Ms Rowland: Correct, and we would support that.

MRS DUNNE: You would support that?

Ms Rowland: We support that comment. We would see many examples of that. If there had been a brokerage component of the NDIS for families with what we call complex needs, that would have made it much more efficient and effective to work with families where you have multiple clients, and we have a number of those families. As you mentioned that particular case, I am working through my mind and I can think of at least 25 families, straight off the top of my head, that are in that situation.

MRS DUNNE: It seems to me to defy belief that an organisation could not, even from a self-interest point of view, say that it would be cheaper if we treated this group as a whole rather than as a set of individuals.

Ms Rowland: Yes, and in actual fact is not even just siblings; it is the parents. We have a significant number of parents with mental health issues. If we look in the autism space, there are a significant number of children whose parents also have autism. As I said, if we were able to do services for complex families and work with both the parent and the child together at the same time, with the same plan, it would be a much better use of resources.

MS LE COUTEUR: We have just heard evidence from another service provider who said, in summary, that it was very hard financially to be a service provider for the NDIS. Is it your impression that for the service providers the NDIS model is long-term sustainable? Can this work long term?

Ms Rowland: We had some independent financial modelling done by RSM when we were doing some work around a short-term accommodation issue we had. So did other providers. We were concerned about market failure. One of the things that came out of that, for example, was that the new rate for short-term accommodation is sufficient to cover service delivery costs but there is no extra build in that for training, for ongoing staff development, for any of the back office corporate services, other than the most basic finance and administration.

We are finding at Marymead that although some of the services are now financially sustainable in relation to covering those specific costs for that service, it does not cover the back office services. We are using other funds to cover back office services. So long-term, yes, I think there are going to be financial issues. For us, the NDIS is only about 20 per cent of our total funding.

For example, in respect of the autism centre, we have almost 2,000 clients in the ACT that could access our service at any time. We run an enormous number of group programs. We have only been given a one-year funding extension by the NDIA under the ILC grants. But this is an ongoing concern. So what happens after that? In actual fact, they gave us less than what we asked for and we provided a well-thought-through, factored, costed proposal for the minimum that was required, and they gave us less than we asked for.

Of course we are going to accept that, because we need to. But, because of the number of people diagnosed with autism who require support, that is not going to be sustainable. So we now need to look at what other funding is going to make that sustainable. In a small jurisdiction like the ACT, where we do have people from the surrounding regions who move into Canberra, we have an expanding population and statistically we are going to have a lot more people with autism in the ACT than we have had previously.

There is no forward thinking by the NDIA around, "Well, there is going to be some service that cannot come under NDIS but that will require ILC or block grant funding to maintain those intervention services"—what I call critical services.

MS LE COUTEUR: You said that NDIS is only 20 per cent of your funding. Does that mean your other 80 per cent is subsidising NDIS or—

Ms Rowland: The other services are other counselling, out-of-home care services. But we do have a small percentage of philanthropic funding. Some of that is going in to underpin some of our NDIS services as well—for the back office services.

MRS KIKKERT: I do not have any questions, but I wanted to say thank you for all that you do. Is there something that you want to add, finally?

Ms Rowland: I think that the aspirations of the NDIS are good. I do not think we should be throwing the baby out with the bathwater. But I definitely think there is space for a separate component, which is block grant funding for brokerage or for keeping baseline services for non-NDIS clients, for clients with disabilities—people who have not yet been diagnosed. I am talking about families where there is not the attention to their complex needs.

There seems to be nothing there in the ACT to cover that section. As you are aware, we also operate in New South Wales. They have left some funding to be able to support issues that emerge. I think that that would be critical for the NDIS to understand. There needs to be some sort of outlining and commitment of funds to an area that is more than ILC grants.

MRS KIKKERT: That is very interesting. There is a model like that happening in New South Wales?

Ms Rowland: I think it is short term. It is short term and it is during their transition. They are rolling out their transition over a much longer period of time and they are ensuring that there are some funds available for the next year to two years where there are situations emerging that NDIS does not cover. That is what we have been told.

THE CHAIR: I have a final question before we break. It is around the planning process. You have highlighted in the submission that there is a real focus on the individual—

Ms Rowland: Yes.

THE CHAIR: and that they will involve the individual in the planning process but that the NDIA, or whoever is developing the plan, is often reluctant to involve other people in that process.

Ms Rowland: Yes.

THE CHAIR: Who do you think they are currently excluding?

Ms Rowland: When we have children who are under age, we certainly have parents involved. But when there are complex situations where you have a number of agencies involved, or even another agency that can provide a perspective, we have asked a number of times whether there could be a worker present, obviously in full knowledge of the family, to provide information that would assist in the planning.

I can think of a few complex situations we have had where it would have been good to have had contingencies built into that plan. This is where we had multiple members of a family with issues. It may not be disabilities but there might be a parent with drug and alcohol issues. I am just thinking of a particular family who had a chronic disease. It would have been great to have had a worker present to provide a perspective on what the needs were of that child in that context of the family. At this stage, that is not part of what is allowable.

THE CHAIR: So it is just not allowed at all? There is no process to be able to nominate a person that should be there?

Ms Rowland: I think that it is often dependent on the NDIA planner whom you are dealing with as to how that is interpreted. But we have had situations where planners have said no, that is not appropriate or who have not allowed that to happen.

MRS DUNNE: I have a quick question. Ms Rowland, with your sort of cross-border remit, do you see a difference in experience between residents of the ACT and residents of New South Wales in their dealing with NDIA?

Ms Rowland: I think there has been a lot more preparation because, of course, that state has learnt from other jurisdictions. There has been significant preparation in how they collaborate. There is a lot more involvement of the New South Wales government department—their Department of Family and Community Services—in families where there are identified issues. Certainly, their case managers, their workers, are a lot more involved where there is a family with complex needs—from the beginning.

MRS DUNNE: When you say “with identified issues” is that a care and protection type issue?

Ms Rowland: Yes.

MRS DUNNE: Rather than just a family with complex needs?

Ms Rowland: Yes. In terms of families with complex needs, no. It has been the same process. Even if they have not been a previous client, they are quite happy to try to get involved to work out the best solution for that child or family in that situation. I think they have probably learnt from some of the other states. Time will tell. It is fairly new. I am actually a carer of a sibling in Sydney who has been part of the disability system for 40 years. She is now on to her second plan. She has received less in her second plan than what was asked for, without explanation. We are appealing that. There are still those same NDIS issues that are happening in New South Wales. But in terms of government involvement, there seems to have been more preparedness.

THE CHAIR: Thank you for your testimony today. I remind you that a proof transcript will be provided if you need to make any corrections.

Ms Rowland: Thank you.

Hearing suspended from 2.50 to 3.08 pm.

CORLEY, MR BRIAN, Chief Executive Officer, Community Options
HALL, MS PENELOPE, Executive Director, Client Services, Community Options

THE CHAIR: We will resume the public hearing with testimony from Community Options. I remind witnesses of the protections and obligations afforded by parliamentary privilege and draw your attention to the pink privilege card on the table. Could you please confirm for the record that you understand the implications of the privilege statement.

Mr Corley: I confirm.

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

Mr Corley: Just very briefly, yes. Community Options is an ACT-based community agency. We have been in existence for about 28 years, operating solely in the ACT. We operate across the disability, aged care and community services area. We are funded by multiple sources—commonwealth and ACT government and now the NDIA. We currently have about 70 NDIA clients. Our primary role in working with those clients is in plan management and support coordination, and the expertise that we provide as an organisation is primarily through service coordination and case management services. We also work closely with the ACT health system in providing post-hospital support services for people leaving ACT hospitals.

We have a small NDIS unit, currently three staff. It was four staff but we reduced it recently after a flush of clients in the first year of the scheme. Funding in the last 12 months of our role with the NDIS has reduced quite significantly and we are looking at making further changes to our staffing profile. The primary reason around that is that, since the introduction of the LAC in the ACT, we have seen a significant reduction in the support coordination in plans and for clients whom we are working with. We can go into some more detail about that, but that has seen a significant reduction in our role in working with our clients. Our concerns are that some of these decisions appear to be arbitrary and in some cases quite detrimental to clients. We have had to, in a few cases, advise clients that we can no longer support them because of the reduction support coordination.

As we have detailed in our submission—and thank you for inviting us and thank you for having a look at our submission—there are a number of areas that we have issues with in relation to the NDIS. We could talk for a long time about the scheme as a whole, but it is probably not appropriate at this point in time. From a personal point of view there are still some significant flaws in the design of the scheme and some significant assumptions that underpin the scheme that have not really been tested. One can argue that providing services to highly vulnerable people as a marketplace raises questions, I think, which do not sit comfortably with many people. But some of that cannot really be changed in the short term.

Our major issues around the scheme—and we have identified them in our submission—relate to the quality of planning. As a provider we have seen wildly inconsistent outcomes for people through the planning process. As you would have heard, we have seen plans changed dramatically, often with no explanation to the client or the person as to why those plans have changed. When I say “changed” I mean reduced, and often with no understanding of the consequences and sometimes the devastating consequences that dramatic reductions in service to people can have and the impact that has on families.

Again, as you have probably heard earlier, it concerns us that the planning processes around the NDIA and the NDIA services are what I call hyper-individualised in the sense that they focus on the participant, and often at the exclusion of what else might be happening in that family dynamic. You may be aware that often families have multiple dysfunctions or multiple issues—it is not always just the impact of disability—but the NDIS has this process of seeing the participant and not considering what the impact has on other family members and the family dynamic.

We have grave concerns as an organisation about the varying skills of planners that have come and gone in the ACT. I do not have the figures, but we would be of the view that there has been a massive changeover since the start of the scheme in the ACT in the number of planners and the personnel. It has been very hard to get a consistent relationship, not just for us as a service provider but, I am sure, for the participants, given the turnover in the number of planners. There have been huge variations of the quality of the plans and the outcomes and I think that has had a detrimental effect for many people, and certainly for us as a provider it has made it very difficult.

We have noted in our submission the concerning trends which claw back to many the old idea of institutionalisation. We have worked with a number of people over a number of years who have successfully lived in their own houses in the ACT, on their own independently, but have been told through the planning that, no, that cannot happen now; they have got to go and look for shared accommodation. And we see it. We are concerned that that seems to be an escalating trend. As I have mentioned, we have been concerned about the significant reduction in the amount of support coordination allocated in people’s plans.

To us the NDIA fails to recognise the important role of skilled support coordination in delivering the outcomes that they are seeking in the plans, ensuring that the money in the plans is actually spent and appropriate services delivered and also in safeguarding people. Skilled, independent support coordination is one of the best primary safeguards for people as an extra set of eyes on what is happening in that person’s life, and often in this current environment people are at the mercy of service providers without a third set of eyes on what is going on in those people’s houses.

As you see in our submission, we have provided a number of case studies. Most of those case studies relate to people who were seeking access at the time of the case study to the NDIS, to the scheme. We have seen significant roadblocks particularly in the last 12 months to people accessing the scheme—often people with quite complex and difficult support needs. And that has caused us as a provider agency a high degree of concern but nowhere near as much as it concerns those individuals.

Finally, it is not all bad. The NDIS is a brave and massive social change in this country. But not everyone is a winner. As an organisation we are happy for people to do well out of the NDIA, and there are many people who do well out of the NDIA.

The concern we have is that there is a group of people who are doing quite poorly and those people are the ones that usually you know will do poorly—the people who need support, who need what I would call good old-fashioned case management or support coordination.

It concerns us as a provider when Feros Care, as the LAC, identify a client whose support needs are too complex for them to do their role and the NDIA come to us and say, "We will give you support coordination." But it is at $2,600 a year, which equates to 20 minutes a week. We cannot do our job in 20 minutes a week, supporting someone with complex and difficult support needs who needs all sorts of linkages and connections with the community. I am hopeful that at some point in time the NDIA will realise that skilled and appropriate support coordination will actually save them money in the long term. But at the moment my fear is that they see it as the easiest thing to cut and it will have devastating consequences for some people.

Going forward, there are huge issues for the ACT in the interface with ACT systems. There are huge issues that are emerging with the interface with the health system, and again our case studies relate to many of those instances where people are at that interface point. But there will be huge issues with the criminal justice system, with the family services system and with the education system. We have moved from a system in the ACT where multiple players came together and solved problems to a new system now where every player is saying, "It is not my responsibility." And the major thing that has changed is the NDIA and the NDIS and the move to a market-based system.

I am happy to take any questions.

THE CHAIR: I will kick off. You have mentioned that there are some people who have been made ineligible for the NDIS after a plan review. In what circumstances would that be, that you have come across?

Mr Corley: To be fair, when the trial started in the ACT we were surprised that some people got accepted. In the early days virtually everyone got accepted. I suppose it was the euphoria of a new scheme. But what we have seen recently is that a number of people have been made ineligible. I do not know the exact numbers. We can just talk about our case, and Penny might have some more details.

As I am aware, the reasons are not made clear to the person other than that the delegate has made a determination that they are no longer eligible for the scheme and the person has a letter that basically says that. There is no other statement of reasons. They are invited, if they so choose, to have that decision reviewed. Why those decisions are made would be a question for the NDIA.

THE CHAIR: Are they coming to you to seek support around that review?

Mr Corley: A lot of people are being referred to us, from various agencies, who had their plans either ended or severely cut. The trouble for organisations like us and other ACT-based services is that large swathes of our funds which we previously had have to be cashed out and sent to the NDIA. We do have some residual ACT funding under the community assistance and support program, which you may be aware of. We are rapidly reaching capacity in that program. That program was originally intended to be a low-level, short-term program for people who might be leaving hospital or in other situations. Our program is rapidly filling up with people with complex, long-term support needs who are either waiting for, as our case studies identify, or who increasingly cannot get access to the NDIA.

MRS DUNNE: Mr Corley, could you give us a little bit more background about your organisation?

Mr Corley: Yes. We are ACT based. We were established in 1989.

MRS DUNNE: So you are as old as the ACT Assembly.

Mr Corley: Just about. We were established under a commonwealth government initiative, under the old home and community care program. They introduced what was called a community options model into this country. The community options model came from what was often called the Wisconsin community option model, out of the States. The community options model is slightly different in that we hold funds for people. In all of our programs we hold funds.

As an organisation, we do not directly employ support workers. We have a staff of 30 who are basically service coordinators. We hold funds either via NDIS packages, home-care packages from the commonwealth or other sources, then we purchase services with those funds. We purchase highly individualised and tailored services to meet people’s support needs. We are flexible. We are creative. We can use those funds within the broad funding framework of whichever program we are operating under to do whatever we need to do to meet the person’s support needs. Ideally, the NDIS should be a perfect model for us.

MRS DUNNE: Isn’t that what the NDIS is supposed to do?

Mr Corley: The NDIS should have come to us and said, “How do you do it?” because we do it well. What we have found is that, of all of our programs, the NDIS is the least rewarding program we have in terms of our staff being able to meet the objectives and the needs of our clients. We have a highly skilled small group of staff working with our NDIS clients. Those staff are feeling tired and they are feeling frustrated. Their primary role is just managing people’s plans, trying to find out why something has been cut, why they cannot get support coordination and why this is happening. All the good work that they would like to do, in terms of working with people to achieve their goals, to achieve better lives in the community, to interact and live the good life, if you like, they feel they cannot do. They feel they have an endless battle with the NDIA and through the planning processes, and it is wearing them out.

MRS DUNNE: Would it be fair to say that your organisation is a case management organisation?

Mr Corley: Our organisation is a specialised case management organisation.

MRS DUNNE: How many clients do you have and how do they come to you?

Mr Corley: Across the course of 12 months we would have approximately 1,000 clients. The majority of our clients come to us via the ACT health system, on discharge from hospital. We do a lot of work with the major hospitals, the hospitals in the ACT, about providing short-term support to people following discharge from hospital. Largely, people aged over 65 are eligible for aged-care funding, but we have other programs where we work more intensively with people who might be transiting into the NDIS from hospital.

MRS DUNNE: I noticed that one of your case studies was somebody who was really in need of aged-care-type dementia facilities but they were not 65. Do people like that fall between the cracks, to some extent?

Ms Hall: The person in that case study certainly did at some point fall between the cracks and spent about a year—

MRS DUNNE: Fourteen months.

Ms Hall: or fourteen months in hospital. That person did manage to go home but subsequently passed away. He ended up living with another person. That was really due to the funding constraints under the plans. Yes, people do fall between the cracks.

MS LE COUTEUR: You said that you thought you should be an ideal match for NDIS-NDIA and you are not. Do you think the major reason for that is the bureaucracy of the system, the funding of the system or both?

Mr Corley: It is a very bureaucratic system. Prior to the establishment of the NDIS, as you would be aware, they had the individual support package program for disability funding. We used to manage a number of those packages for people. There were certainly issues with the old system. There are issues with every system. They were markedly more flexible. In fact, with respect to the choice and control compared to the flexibility and choice people had under the ACT ISP system, it is chalk and cheese, largely. People are being constrained. I know there have been efforts in the NDIS system to make things more flexible. I sit in a different level of the organisation but the feedback from staff is that they feel constrained by the bureaucracy.

The frustrating things for organisations came about right from the start of the ACT trial. I think every provider in the ACT welcomed the establishment of this scheme. I know that back before it started we were all gung-ho to work with the NDIA to make this the best scheme it could possibly be. Right from the beginning we found no pathway in. There was very little capacity for organisations. We were probably naive in that sense, but we learnt very quickly that the NDIA saw us as the problem, I think it would be fair to say. As a sector, we still struggle to see a pathway in. There are huge amounts of knowledge and experience in the ACT community service sector. People have done amazing things in this community in supporting people with disabilities, but there seems to be no pathway for those people to actually influence policy.

In fact, I am not sure what the policy is. There is very little policy development that we can see in the NDIA. There are rules and guidelines, but I cannot see any innovation. We are confused by seeing a funding source as innovation. At the moment

NDIA is just a funds transfer system. That is all it is. I have been doing this for far too long. I see no innovation. The only innovation you do see is where a family gets a spark and does it themselves, but that is not systemic innovation because the next family who does not get that spark does not do it.

MRS DUNNE: Maybe I just had a light bulb moment; maybe I did not. You are saying that, in a sense, your organisation has been doing what NDIS is supposed to be doing on a local scale.

Mr Corley: Yes.

MRS DUNNE: Actually, what you have described is a failure to implement at a local level. You have high-level implementation. There is no what you might classically call subsidiarity. You do not actually get the benefits of local knowledge on the ground.

Mr Corley: That is what I alluded to at the start. Personally, I have fundamental concerns about this whole model. I believe that services are best planned, delivered and funded as close as possible to their delivery. At the moment we have a system that is being planned somewhere. You may know where it is being planned—Geelong or Woden; I do not know where it is being planned. There is no linking there. With these decisions, Penny has been invited to high-level meetings in Geelong to talk about support coordination, capping and this sort of stuff. We see none of that filtering down to local decision-making. We are frustrated that we see no pathway to influence policy.

MRS DUNNE: Also, you cannot create best practice and say that regional health service boundaries might be an appropriate boundary, the boundary of the ACT or a municipal boundary, if it is a large-enough municipality. That may be the right size to deliver those services, but what we actually have is a national organisation which obviously has this cookie-cutter approach because it is too difficult not to have a cookie-cutter approach.

Mr Corley: Yes. Again it is a perspective issue. Some people believe everything has to be uniform across the nation. It is a pretty common commonwealth view. Other people believe that innovation and creativity happen at the local level, where people do not just get plans but can actually interact, create and innovate at a local level with their local community. When we move to these big schemes, that is what we risk losing.

In the bad old days of disability services, there were lots of problems, but you would hear, “Some region in New South Wales is doing it this way. That’s interesting. Let’s look at that,” or “The ACT is doing it this way.” In the ACT there were a whole range of really brilliant individualised funding models that were being operated prior to the NDIA. There was the ACT ISP scheme; there were schemes in New South Wales and Victoria—in every state. The NDIA took notice of none of that. They drew on none of that, and developed a scheme based on an insurance model—I am not sure what they are insuring against—that requires people to go to the AAT to dispute decisions about funding for their core support scheme. I cannot believe it. But it forces people into court systems.

Some people do that, and some people have wins. Other people just get too tired and drop out. We have had clients who, when it is presented to them, have to appeal the decision and it has been reviewed. Your next pathway is a quasi-legal system. They just drop out: “We’re not interested. We can’t do that. We can’t do that as a family.” It is a strange system.

MR PETTERSSON: In your submission you say that a large number of your clients with high support needs are increasingly being denied the support they need to live independently in their homes. What happens when they are denied that support?

Ms Hall: That is getting back to the fact that some people, either as they age or as their disabling condition continues to deteriorate, are often faced with a situation under the model where they have to move, to live with somebody else, in a group type of setting. There is really not a lot we can do about that at the moment.

MRS DUNNE: Is there anything essentially wrong with a group setting?

Ms Hall: No, there is not anything essentially wrong with it. It is just that some people would rather not. I can give the example of a person who lives alone and whose main support is an ageing mother who has her own health issues. There is no contingency anywhere in his plan for what happens when she goes, but we know he will need significant amounts of support—maybe a bit more than what he is getting, but we do not know how that will pan out into the future. That is obviously uncertain for that person and for his mother.

We anticipate that that may be something they will look at, because he will not get the plan and the money he needs to support him at home as he is now. However, some of the plans should be more flexible. We have looked at the plan. If you actually look at the totality of the money in the plan, you could probably make it work. But when it is broken up into different sections you have to seek permission to pull out of this one and move to another one.

MRS DUNNE: The money is not fungible across the categories?

Ms Hall: Not always, no.

MRS DUNNE: I have lots of constituents like that; they are ageing, they have disabled children and they are the principal providers. It makes their declining years a nightmare because they are terrified about what will happen to their kids. Is there not the capacity to have an aged-care assessment-type process for those individuals?

Ms Hall: We are starting to see that, when people are getting to the 63-64 mark, they may, if they have been rejected from the NDIA, apply for My Aged Care early, as long as they have a letter to say they have either been made ineligible or they are not eligible for the scheme.

MRS DUNNE: But sometimes those adult disabled children do not fit in that grey area. They might be 40—

Ms Hall: Sure.

MRS DUNNE: and their parents are 80, and they might need to go into care. I suppose this requires flexibility at a government level to say, “This is a package for people who need assistance.” If mum or dad gets an aged-care assessment package, why doesn’t the disabled son or daughter get one as well? Maybe they can move together or the appropriate arrangements can be made. Is that beyond the wit of people?

Ms Hall: I do not think it is beyond the wit, no. You almost have two separate schemes there. Aged care and disability somehow have to come together.

Mr Corley: And schemes are moving; they are diametrically opposed. If anyone around this table is going to have a catastrophic injury, have it when you are 64. Do not have it when you are 66. Again, in this country it is bizarre. If you are going to get a catastrophic injury, get it before 65 because then you get free services. You get your equipment purchased. If you have it at 65, you cannot get a wheelchair or a hoist; you have to end up in a nursing home. Then you are paying huge fees.

THE CHAIR: We are going to have to end there, unfortunately. Thank you for attending today. We will provide you with a copy of the proof transcript. You have the opportunity to check it for any corrections that need to be made.

HOGG, MS DEBRA, Acting Executive Director, Community Connections
LUCAS, MS YVONNE, Acting Manager Support Services, Community Connections

THE CHAIR: Thank you for attending, and welcome to our inquiry. I remind you of the protections and obligations afforded by parliamentary privilege and draw your attention to the privilege statement on the table. Could you acknowledge that you understand the privilege implications of the statement.

Ms Hogg: Yes.

THE CHAIR: Would you like to make an opening statement?

Ms Hogg: As described in our submission, we are a provider of specialist coordination services, and we just heard about those. We also provide plan management under the NDIS. We work with people to build better lives and for them to become valued and included members of our community. We use people's NDIS plans to facilitate this.

The NDIS has created a huge change, and I would like to give some feedback on the impact of the introduction of this scheme for the people who use our service, all of whom are ACT residents. These people appreciate the extra individualised funding that has been provided and they understand the NDIS is a huge and complex project. Nevertheless, almost without exception they feel highly stressed and under pressure to meet the administrative requirements of the scheme to gain access and to justify their needs. They feel they have to tell their story many times and that no-one listens. Their requests and inquiries are not answered.

Many hours are spent worrying about funding and reviews, collecting evidence to justify their support, juggling multiple budgets for the different categories previously described, working out what service fits in what category and what fits within the NDIS guidelines. Almost all believe the scheme is great in principle but excessively complicated in the way it operates. They know things will get better as the scheme matures, but in the meantime they want to get on with their life and do what works for them.

Community Connections wants to see people with disabilities included in our community, having valued roles and not being seen as disabled. We want them to participate in every activity and event our community offers. So how has the NDIS implementation supported people in this way? Funding: thanks to the NDIS, this can be the easy part. There are often adequate funds, except the funds are not always in the right category. You might know what you want to do, but you cannot buy that service because the funds are in a separate category. The rates are fixed. You cannot buy a service that you value because it costs above the NDIS rate. In fact, the options for developing the right kind of support are limited. We highly recommend more flexibility in plans, particularly for people who do not currently manage their own funds.

Services: we have seen an increase in disability-specific services and group programs, and this has been welcomed. But many people want to step beyond this and forge the path to inclusion. The sky is the limit, but it can be pretty tricky to try new things and step beyond the disability service provider you know. It is harder to go to the local CIT, the local dance group, apply for a job, and it can be difficult to break into a new group, find transport and know if you are in the right level of a class. You need someone to assist and to guide the process and walk alongside you at the right pace.

Anything is possible, but it takes time, energy and skills, and this is the role of a support coordinator. As a coordination of supports provider, we believe coordinators can be the critical link to helping people do what they have often only dreamt about—to look beyond the obvious, to try the new, to challenge stereotypes, to move forward step by step, to make changes when things go wrong and to get back on the horse. But to do this takes time: time to build a relationship, time to be there or walk alongside bridging the gaps, trying again.

Unfortunately, at the time of the introduction of the LAC service the NDIS reduced the number of people who receive any coordination of supports in their plan and also significantly reduced the coordination of supports for people to a level where it is simply not possible to provide a high quality intensive form of coordination that will result in positive outcomes and minimise the risks for some of the most vulnerable people who will fall through the cracks in support and service provision. Safeguarding and supporting these people is an important role of coordinators.

Community Connections strongly recommends that coordination of supports be provided to all people who request this type of assistance and that it be viewed as a support in its own right and not just a few hours that allow a couple of meetings, some phone calls and preparation of a report for a review meeting. An investment in coordination of support funds can bring long-term gains for individuals, and our submission provides further information about the need for coordination of supports for people with psychosocial disabilities. We strongly believe this type of disability will gain more benefit from 100 hours of coordination than from 1,000 hours of support worker time. We welcome any questions about this or our submission.

THE CHAIR: In your submission you talk about in-kind services provided by state governments, including the health system. How are those in-kind services reflected in NDIS planning at the moment?

Ms Hogg: That is a good question. I would say there has been complete confusion about how the in-kind system, particularly with Health, is working. Sometimes it is mentioned in plans; sometimes it is not, more so in current times. In terms of whether people are then receiving those services through ACT Health, it is very hit and miss. It seems to be a little clearer in Education, in terms of transport and the personal care assistance that children at school can receive. But the complete confusion has resulted in our coordinators having to spend a huge amount of time trying to sort it out for each individual. There really is not a clear description of how it works anywhere that we have been able to obtain. We have sought advice from both the NDIA and ACT Health and still do not understand it properly.

THE CHAIR: So it is not written into the plan, necessarily? It is a support that exists outside of that?

Ms Hogg: No. We often have in-depth discussions about particular people and circumstances, and ACT Health do not seem to be very clear about it either, or at least the people with whom I am able to speak.

MRS KIKKERT: You mentioned how people with disability would like to join in community events. Are there any networks that you are a part of that could make it easier for people with disability to reach out and be participants of community events, or do you have to wait for other people to come to you? How does that work?

Ms Lucas: Just because a person has a disability should not mean they have to be a part of a specific group to be able to just go out to an event. If they want to go to the movies or a gig or whatever, it would be good for them to just be able to do it and not have to be part of a big network or whatever. What I keep hearing is how we can make this happen for free for people like that and how we can join them in with volunteers or this or that. I wonder why they cannot have a support worker and then go where they want to go, when they want to go and be a part of the community like everybody else.

Ms Hogg: A lot of people have adequate funds if they choose to engage a support worker who is able to attend events one to one. But it may be that they do not have funds in that part of the NDIS package available for use for that. They might have funds they can use for an occupational therapist or physiotherapist, but that is not who they need to be able to get to the pub and be with them while they are there. And how are they going to get home? Where is the transport? If you have to pay for that, that can be the difficulty.

MRS KIKKERT: It is social interactions within the community.

Ms Hogg: Yes.

Ms Lucas: In the same way that the rest of us integrate into the community rather than being sectioned off.

MRS DUNNE: So spontaneously, rather than as part of a big exercise?

Ms Lucas: Yes, or not separately with a group of people with disability. Not everybody wants to go to the same thing, and it gets messy.

MS LE COUTEUR: I am interested in the interface between Health and NDIS. You have got an example in your submission of someone who was NDIS funded but then had a medical condition—I am not sure that I understand—lymphedema, which restricted walking, but their NDIS money could not be used for physiotherapy. This seems—

MRS DUNNE: That is a big problem for people that have lymphedema.

Ms Hogg: I guess one of the difficulties that we are experiencing particularly now is that in no part of the NDIS plan is there any indication of the type of disability that the person has been assessed as being eligible for the scheme.

MS LE COUTEUR: If I got a plan, it would not say, “You have got a plan because you are autistic," or whatever, just, "You have got a plan."

Ms Hogg: And it would not say that you have a disability. Sometimes as a support coordination agency we meet people that we do not know and we do not know very much about, and they may choose not to tell us very much about it. It is difficult to know what disability the NDIS has accepted for part of their scheme.

Getting down more specifically to your question, many people have multiple medical and disability conditions. The example of lymphedema is that that person has a medical condition but the disability is that their mobility is severely impacted by what is a problem with their legs and they are not able to walk very well. That person wanted to use physiotherapy, a specialist physiotherapist, to improve her lymphedema so that she could walk better. The planner told her she was not permitted to do that because lymphedema is a medical condition.

When funds are put in the plan for therapy, the person has choice and control about which therapist they attend, and I understand the therapist has the choice about which treatment modality to use. That lady chose to go to a specialist, registered physiotherapist who was going to use a treatment appropriate for lymphedema, and the outcome would have been better walking.

But, as with respiratory or cardiac conditions or a whole range of conditions, it is really difficult to know where the medical condition or the health condition ends, where the disability finishes and what restrictions are going to be placed on individuals through their plan. Currently, very rarely is there any written description of how those funds can be used, but we do get these verbal discussions where planners give direction about how the funds can or cannot be used and what type of therapy—and this happens in psychology a lot—where the planner tries to tell the person how they can use those therapy funds.

MS LE COUTEUR: They cannot use a specific therapist, for example?

MRS KIKKERT: Is that right?

Ms Lucas: Yes.

MS LE COUTEUR: I am totally intrigued at the concept that they do not record what the disability is. Surely they must record in their paperwork, "You have been accepted because of," whatever. "You are whatever." If you are claiming for something else which is—

Ms Hogg: We currently have one happening at the moment where the person has, after being accepted for a psychosocial disability—we have determined that after many long hours on the phone to the NDIA—a mobility issue. They wear a complicated orthosis, a complicated device to help them walk properly. That condition has not been accepted. However, ACT Health are insisting that because they are part of the NDIS then everything should be covered, and they will not repair that item. It is not that they are in the NDIS but really that one condition has been accepted and one has not because it is not severe enough. This is a scheme for people with severe disabilities.

I come from a background in health and I probably have some more understanding than some people in the disability area. I have more personal contacts that I try to obtain information from.

MR PETTERSSON: When those conflicts do arise, what is the process to resolve them? I know you said that you try and intervene, but is there another mechanism that helps resolve conflict?

Ms Hogg: On any occasion, if you want to contact the NDIA you phone them. Strictly speaking, you are not supposed to email individuals, so you phone a call centre. The call centre is not able to contact individuals within the NDIA. They are physically unable, as we understand, to put calls through. It becomes a case of trying to deal with it via the information they have on electronic record-keeping or what they call "escalate" the inquiry.

You are now told when you ring what the waiting time is. We have resorted to headphones so that we can multitask while we wait. And it takes some time. Then you have to wait for that person to call you back. The other option is, for example, to go through Health or Education or whichever other department you are trying to deal with to find clarification. The NDIA is incredibly reluctant to put anything in writing. We ask for decisions in writing.

MR PETTERSSON: That is never a good sign.

Ms Hogg: But it is very difficult to get anything in writing.

THE CHAIR: We are going to have to wrap up, unfortunately. Thank you for coming in today. A proof transcript will be forwarded to you to make any corrections.

Ms Hogg: Thank you.

STOKES, MS KYLIE, Executive Director, Sharing Places
KAL, MS MARY-ANN, Program Manager, Sharing Places

THE CHAIR: Thank you and welcome to the committee's inquiry. I would like to remind you of the protections and obligations afforded by parliamentary privilege and draw your attention to the pink privilege statement. Could you just confirm for the record that you understand the privilege implications of the statement.

Ms Stokes: Yes.

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

Ms Stokes: I want to start by just talking a bit about what Sharing Places does and the people we support. We are a not-for-profit provider, providing community access and social participation support for adults aged 18 years and above who have severe to profound disability. The people who access Sharing Places have high and complex needs and require full-time support and intervention. All clients accessing Sharing Places have a primary intellectual disability requiring 24/7 intensive support. Clients present with high and complex needs in the areas of mobility, challenging behaviour, communication, personal care, PEG feeding, seizures, self-injuries, behaviour, sensory disorders and dual disability disorders.

Sharing Places recognises that each of our clients is an individual with different needs and desires. Sharing Places works closely with our clients, their families and other agencies in developing and delivering individualised supports within a variety of community settings. Individual plans are developed between our clients, staff, families, and carers and other disability service providers, and these plans include specific and detailed strategies and skills development against goals from a range of learning domains. Sharing Places works to see individuals achieve self-determination in all those matters important to them and strives to remove barriers that prevent people participating fully in our community.

We currently support around 160 people across 12 support teams in the ACT, with each support team having access to a team base and wheelchair accessible vehicles. We employ permanent staff members, both full time and part time. This is due to the complexities of the people we support and the need for specialist knowledge management across the organisation. This is also essential for workers to build relationships based on trust, as people with high and complex needs can only achieve their goals when they are in environments where they feel comfortable to take on new challenges.

That is what we do and whom we support. We are happy to take questions or we can raise some of the main issues that the people we support face at the moment.

MRS DUNNE: I am kicking off. I go to local area coordination. It seems to be a—

THE CHAIR: Recurring theme.

MRS DUNNE: Thank you, a recurring theme, that there has been significant impact by the appointment of an out-of-town local area coordinator and that most of the established agencies have lost access to funding as a result. Can you comment on that from your own experience?

Ms Stokes: With the LACs?

MRS DUNNE: Yes.

Ms Stokes: A lot of the people that we support are very confused by the LAC and what their role is, and we do not see—

MRS DUNNE: Can I say, they are not alone.

Ms Stokes. Yes. A lot of the time families do not know if they are being contacted by the agency or by Feros Care. It does cause confusion. Because they have been around for some time now it is getting better. But, yes, the LACs do not provide a lot of linking to community or to businesses for people with disabilities. And there have been occasions where families have not known what to do. Their support coordination is now out of their plan and they are left with their plan and not understanding how to implement it.

MRS DUNNE: You see that as a direct result of the implementation of the LAC structure that we have here?

Ms Stokes: Yes.

MRS DUNNE: Is Feros Care providing support coordination?

Ms Stokes: We do not see a lot of support coordination in the same way as we see it when there is support coordination in their plans. There are a lot of service providers like Community Connections, who were just here. We have a much closer relationship with those coordinators of support, rather than the LACs. We do have contacts with the LACs, but it is not as close a relationship. And I do not think the participants have the same sorts of outcomes as they do with private support.

Ms Kal: Once the person has got their plan and the LAC has finished their role, the person can no longer contact the LAC except going through the 1300 number. And they have not been able to get that ongoing support that they used to get with the support coordinators.

MRS DUNNE: It boils down to the fact that the changes have meant that, in a sense, people do not have a contact point; they do not have a case manager—

Ms Stokes: That is right.

MRS DUNNE: In a sense then, they do not have continuity of service?

Ms Stokes: No. It is like a call centre number that they need to ring. They cannot ring their own coordinator.

MRS DUNNE: But they are ringing someone in Geelong, if you like?

Ms Stokes: No. This is for Feros, their call centre.

Ms Kal: In Queensland.

Ms Stokes: I think it is Queensland actually, yes.

MRS DUNNE: So there are two call centres, one in Geelong and one in—

Ms Stokes: The Feros one—

Ms Kal: We do not know.

MS LE COUTEUR: The Feros Care call centre is separate from the NDIA.

MRS DUNNE: That is right. That is as clear as mud.

MR PETTERSSON: This is a new one to me. I did not realise that transport costs were not covered by the NDIA. Are certain transport costs covered?

Ms Stokes: The mobility allowance was then moved to the NDIS. People have transport in their plans but it is based on the mobility allowance. There are three rates and I think most of the people that we support have $2½ thousand in their plans for a year's worth of transport.

MS LE COUTEUR: And your clients would all be people who are not travelling independently?

Ms Stokes: No. No-one travels independently.

Ms Kal: No.

Ms Stokes: And many cannot use public transport. They need specialised transport, vehicles that have been modified specially.

MS LE COUTEUR: You would not get a lot for $2½ thousand a year.

Ms Stokes: No. Their core supports can be used flexibly, but it does not necessarily mean that they get money in there for transport. They may have to forgo supports to cover extra transport costs.

MR PETTERSSON: What are the uses that are not covered?

Ms Stokes: I think the transport can be used for any kind of transport, but it is the high cost of specialised transport that people find difficult to cover.

Ms Kal: Can I explain a day? A person may be picked up from their home and if they are in a wheelchair they are using a modified vehicle. So we send out a fleet of vehicles to people's homes to pick them up from the family home. If they are in supported accommodation we do not do that. The people who are in supported accommodation will bring them in. They use their transport allowance also for that. So we need to pass on the cost to the client to go and pick up the person from their home. They come back to the centre and then the programs are worked out. They are all going off in different directions.

Interruption in sound recording from 4.05 to 4.08—

THE CHAIR: Could you continue from where you left off?

MR PETTERSSON: I will jump back in. There is a specific line here that is confusing me. It says:

> There is currently extreme financial pressure on the organisation's overheads to cover the absences that are not claimable under the NDIS …

It is talking about transport. What is not covered for transport?

Ms Stokes: I think the point there was that organisations would love to cover the cost of transport. Especially for Sharing Places, under the block funding model, transport was covered. Everything that we did was covered under that funding. When it moved to the NDIS, one of the pressures on our finances was that we could not claim for over eight days of non-attendance. Because our people have severe health issues, it is a big cost to us. Unfortunately, we could no longer cover the cost of transport and we had to pass on all of those costs to participants.

MRS KIKKERT: What happens when the cost of funding transportation is finished? Do you just not provide any more service to those clients—

Ms Kal: Quite possibly.

MRS KIKKERT: or does it come out of your own personal pocket?

Ms Kal: User pays.

Ms Stokes: When the NDIS came in, we had to pass all of our transport costs on to the service users. Because of the other pressures, the organisation could not cover those costs. It passed them along. It is absolutely the case that some people who cannot afford the transport miss out. They usually come with a budget and they cannot go over that budget. We work with families to work out other ways for them to have some community access that does not require transport or they do it in a different way.

Ms Kal: We are very aware that we do not have a case of the haves and have-nots—those who can afford to have the extra transport and activity costs and those who cannot. We are constantly working with the families so that we do not have a case of those who can afford it and those who cannot.

MRS KIKKERT: Are there any other issues that you wanted to raise? You mentioned at the beginning that there were some main issues that some of your clients were facing.

Ms Stokes: A big issue for our families is that there is more and more pressure on them. We hear from a lot of our parents that their own health is deteriorating because of the stress of the NDIS. We have been in the trial phase for three years and we are now into the transition to full scheme, and there is no relief regarding that stress and pressure. Every year, with the reviews coming up, it is an extra pressure for families. That is something that concerns us greatly.

THE CHAIR: You have committed to the professional development of your own staff but I understand that you do not get funded for that?

Ms Stokes: No.

THE CHAIR: How do you fund that? Where does it come from, and can you pass on the cost of that to clients as part of a user fee?

Ms Stokes: We used to have eight training days for all of our staff every year. We had to stop those and we have employed a full-time trainer on our staff. He trains on the job. We do a thorough induction process because of the high needs of the people we support. No-one goes out alone until they have passed all of what we call the competencies. They have a three-month induction, and that is very comprehensive. He is employed full time to train the staff and we have also been able to reintroduce two training days per year. One of the things that the staff really missed about not having the training days is that they could bounce ideas off each other. Those training days were extremely important, so we have introduced two days back.

THE CHAIR: Can you get funding by increasing the fees that you charge the user?

Ms Stokes: No.

THE CHAIR: Is that banned under the scheme?

Ms Stokes: Yes. There is no training. There is training for individuals—for people who have specific training needs. There is provision for that, but we have only seen that once, in one person's plan. Although the training was covered, the staff time was not covered. We as an organisation have seen the desperate need for that training to continue, so we have found that funding.

Ms Kal: We need to organise training in things like PEG feeding, when people are fed through a tube. We need to organise training for staff to administer midazolam, epilepsy management and all those sorts of things that come with high and complex needs, as well as the positive behaviour support plans implemented with psychologists and whatever. We welcome therapists to come in and work with our staff where possible, but there are extra costs involved with people with high and complex needs. Unfortunately, instead of maintaining people's budgets, their budgets are gradually being cut, and that is putting pressure on the families as well.

Ms Stokes: There are different rates of support needs. There is a standard rate and an intensive support rate. That is part of that intensive rate whereby we are able to find that money for training and for the essentials that people need to support people.

THE CHAIR: Thank you very much for attending today. We will be sending you a copy of the proof transcript so that you can make any corrections that need to be made.

BUCKLEY, MR BOB, Chair, Speaking Out for Autism Spectrum Disorder

THE CHAIR: Welcome to the committee inquiry. I draw your attention to the protections and obligations supported by parliamentary privilege and the privilege statement before you. Could you confirm for the record that you understand the privilege implications.

Mr Buckley: Yes, I do.

THE CHAIR: Would you like to make an opening statement?

Mr Buckley: I am chair of Speaking Out for Autism Spectrum Disorder in the ACT, which is the local advocacy group, and I also am the convenor of Autism Aspergers Advocacy Australia, which is the national grassroots advocacy organisation. In terms of an opening statement I should say that my son has severe autism and he has been a participant in the NDIS since very soon after it started. Out experience so far has been that it is a significant improvement over what came before. He is 26 years old, and his needs and the response to his needs have been significantly improved by the NDIS.

On the other hand, I speak to a lot of families of children with autism who are either preschool age or school age and their needs are not being met very well at all by the NDIS. The whole autism sector is experiencing substantial difficulty having any kind of dialogue or conversation with the NDIA and its organisation. This is a consistent complaint not only from our organisation but from across the autism sector nationally.

The response to autism has been pretty disappointing, and that is very concerning. The last figures I saw showed that 28 per cent of NDIS participants listed autism as their primary disability and in the early intervention sector it was over 50 per cent, and yet their needs are not being not listened to and the evidence presented has been disregarded by the NDIA. That is all I have to say to start with.

MRS DUNNE: You said that the treatment you and your family have received through the NDIS phase was better than what came before. Would you elaborate on that?

Mr Buckley: Sure. The big thing that has made a difference for us is that before the NDIS we had to scrabble around to find services from all over the place. He left school, and both of us work. So to get services in the day we could go to one place until 3 o'clock, but that service then had to switch over to providing after-school care for people with disabilities who could not be handled in the conventional after-school system, so he had to move. When that happened a transition had to occur every day and we basically had to check that that happened effectively every single day. Other services were fairly random. We had to scrabble around. We were dealing with a plethora of service organisations just so that we could maintain our jobs and he could be supported during the day.

Under the NDIS we have control of the funding and therefore we can actually go out and negotiate with the service provider about the service we can get. We do not have to choose from what is available. We still spend a fair bit of time talking to service providers about how these needs are going to be met. In particular, if we did not have skills in behaviour support, we would be in a lot more trouble than we are. But primarily dealing with one organisation makes this a lot easier. So that is the main change we have had.

MRS DUNNE: So you have not had difficulty having money in one pot that cannot be used elsewhere? You have got a pot of money which is sufficiently flexible to provide the services that you need?

Mr Buckley: I suspect we are probably better at doing that than most people. Not everybody has the ability to reword things, to describe things appropriately and to make things fit in in the way that a family with our personal resources can. I do not think everybody is in that situation. In fact, I would say we are probably the exception in that regard.

MRS DUNNE: But you think that is because of your capacity for advocacy?

Mr Buckley: I think so. I think also they would be a bit worried about coming after us; they know we can deal with the media better than most. At the personal level things worked for us because of our personal situation, and it really concerns me that that is the situation. I do not think people like us should be the ones who experience this when other people are having enormous difficulty, and some of the difficulty I am seeing is quite substantial.

MRS DUNNE: In the autism community?

Mr Buckley: I mostly deal with autism, yes.

MRS DUNNE: You said in your opening remarks that your situation was fine but that people with younger children struggle.

Mr Buckley: We have been doing this for a long time, so we have learnt that you have to fight and there are no holds barred. When your child is first diagnosed with autism and you believe the world is still a happy place it is much harder to come to terms with the fact that that is not the case and that bureaucracy is not your friend.

MRS KIKKERT: Why are families with preschool and primary school children being turned away and their evidence disregarded?

Mr Buckley: Because the people who are running the NDIA are not nice people. They often do not look at the evidence. They reject evidence. We have bureaucrats with no skills and no qualifications rejecting evidence from very experienced clinicians and overruling them, and they will try this on as much as possible. Some of the things I have seen happening, in terms of the lawyers and the AAT are truly disgusting. What is going on in that sector and the complaints and review process is appalling.

MRS KIKKERT: Is there a way for families who have been rejected to ask for an extra review?

Mr Buckley: The process is that you ask for a review. I have seen families ask for a review and that review has not happened after nine months. In the case of early intervention, let us be clear that the best advice for early intervention for children with autism is that they need intensive, individualised early intervention for two years. Only 30 percent of children with autism are diagnosed in time to get any intervention; a very small percentage are diagnosed in time to get two years of it, given that there is a cut-off at age six years. So the longer that they can drag out a review process, the more money they are going to save on spending on early intervention.

This is not a long-term saving because cutting cost in early intervention is a massive long-term cost to the community—massive. So we are seeing them dragging out this review process and they then reject them with no reason. Half the time they do not even read the evidence put in front of them; we have clear demonstrations of that. Then the families have to go to the AAT, which many are reluctant to do. Getting through the AAT process is going to take you 12 months at least. So now you are talking about 18 months or up to 24 months to get a review done. So most of the opportunity for early intervention has been squandered in the review process.

MRS KIKKERT: And then they have to ask for extra evidence during the review process?

Mr Buckley: We do not know; it has never got to that point. I have not seen the cases in the ACT. I know that Legal Aid in New South Wales are more interested in getting a conciliation. They will tell families to just accept what they offer. And that is what has happened—we have lawyers that have told us to just accept it. The lawyers do not actually understand the law; they do not understand the case; they have never looked at the evidence. They have been resistant to looking at evidence.

MRS KIKKERT: Are families given a reason why they are being rejected in the first place?

Mr Buckley: There are three clauses in the act that they often say. One is that it is not value for money. So the thing that has been advised to them as being best practice they are saying does not have evidence.

MS LE COUTEUR: Value for money is such a bizarre concept in what we are talking about. I do not know how you work out what is or is not value for money.

Mr Buckley: It is quite easy to do; it is just that they do not do it. They have never actually done a cost-benefit analysis on the value for money for early intervention for children with autism, and yet they reject on that basis.

MRS KIKKERT: You mentioned three clauses. That was the first one, what are the other two?

Mr Buckley: Sorry?

MRS DUNNE: The other two options in the legislation apart from value for money?

Mr Buckley: I can probably get back to you on that and let you know what those three items are.

MRS KIKKERT: Yes, that would be good. You can take that on notice.

MS LE COUTEUR: You said there was a cut-off of six for early intervention. Is that a cut-off from a clinical point of view or from an NDIS point of view?

Mr Buckley: There is no scientific evidence why that cut-off should be there. But that cut-off was introduced in the helping children with autism package and nobody has questioned it since. The helping children with autism package, the federal package, had a cut-off because they had a finite amount of money that they had to deal with. They set it up that there was a cut-off at that age point. That should not apply, but that is what the NDIA has applied.

MRS DUNNE: There are still a large number of children with autism who do not even get diagnosed.

Mr Buckley: That is right. The average age of children who are diagnosed by the time they are 15 is nine or over. I can tell you that from the data that we have nationally on the number of children with autism. It could be worse in the ACT, I think. I make some comments about that in the submission.

THE CHAIR: To follow on, I think one of the issues you raise in your submission is the lack of data coming from the NDIA around children with autism, or clients with autism. Do they draw out any data that you are aware of, or any data about the clients?

Mr Buckley: There is a quarterly report that gives a few breakdowns. They sort of give the average cost for each thing. The average cost for autism that is in there averages it for adults as well as for early intervention children. So it is pretty meaningless. It is not really hard to—

THE CHAIR: Does it provide a further breakdown of—

Mr Buckley: They really ought to be breaking it down. Originally, they did not provide any. It was only after we asked them that they started to provide this information. But they really ought—it would be really good if you guys could encourage them to do this—to break it down to preschool and school age at least and then post school. Then they should break it up a bit by the different disabilities.

MS LE COUTEUR: We earlier heard some evidence from, I think, Marymead. I get confused because we have actually spoken to quite a few groups. They were running groups for autistic people. I think they said that—

MRS DUNNE: Marymead, yes.

MS LE COUTEUR: Okay. I think they said that they had about 2,000 people involved in that. They understood that in the fairly near future that would not be funded anymore because NDIS was not going to do it and they have been using old funding from the ACT government. Have you any comment on that?

Mr Buckley: I am guessing that these are really HCWA funding things—

MS LE COUTEUR: We did not go into where the funding was. The point was that it was not continuing the funding. The NDIS was not going to fund it.

Mr Buckley: That would be my understanding.

MS LE COUTEUR: Is it a problem that it is not going to be funded?

Mr Buckley: It is a massive problem. You see, the NDIA wants you to believe that everything that happened before the NDIA was appalling and that everything that is happening since is absolutely fantastic. You can understand why they want you to believe that.

The interesting thing with autism is that the Howard government introduced the helping children with autism package. Then Bill Shorten implemented it. It is recognised that autism had transitioned from being a rare disorder to being one of the most common. At now 30 per cent of the NDIA, I think we have to sort of say that this is a significant disorder. But there has never been any effort whatsoever—any planning or anything—to actually bring services in line with that increase in the number of people, to recognise that autism is a distinct disability from other disabilities and that there are services these people need, especially in the behavioural area.

I think that is what the Howard government tried to do by introducing healthy children with autism. They introduced a number of things. One of the things that they introduced was autism advisers and those were much better than I expected, actually. The outcomes from those were really hugely regarded in the autism sector. There is no replacement for that under the NDIA. Yet it is an absolutely essential service.

When your child is first diagnosed with autism, basically you have to do a six-year degree in autism. Every parent, if they are going to get anywhere, has to do the equivalent of a six-year degree because when they go out to the health professionals and elsewhere, they do not know anything. They have never been trained. They can read in DSM-5 a few words about it, but it does not tell you what happens, what the needs are, how the services are going to be met, what is going to be really the prognosis and such things. The only way you can find this out is to get on the internet and chase it down, and that is not a very reliable process.

The autism advisers actually filled that gap much better than I ever anticipated. But now it is gone. It was abolished very quickly in the ACT and it will be soon gone nationally. Families now turn up to a bunch of people who really do not understand autism at all. They are getting advice that is just wrong and often very bad. There is no requirement for the access partners to have knowledge of autism and they certainly do not demonstrate any from what I have seen.

We are losing significant services. The ACT is the only jurisdiction where the autism association has collapsed so far. We are the only state or territory that now does not have an autism association as a direct result of the NDIS. Yet that has always been an essential service.

MS LE COUTEUR: Why did the autism society collapse in the ACT? I assume that it was not government funded. It was people like yourself getting together—

Mr Buckley: There was a little bit of government funding. It is a bit of a complicated story.

THE CHAIR: Can you provide that on notice because we have to wrap up.

Mr Buckley: Okay.

THE CHAIR: If it is a complicated story, we want to—

Mr Buckley: I am sort of reluctant actually to—

THE CHAIR: That is okay.

MS LE COUTEUR: Okay.

THE CHAIR: Thank you very much for coming forward to the inquiry today and for providing your testimony. A proof transcript will be provided to you to make any corrections. The committee will adjourn for the day.

The committee adjourned at 4.33 pm.