COMMONWEALTH OF AUSTRALIA

Proof Committee Hansard

JOINT STANDING COMMITTEE ON THE NATIONAL DISABILITY INSURANCE SCHEME

NDIS participant experience in rural, regional and remote Australia

(Public)

TUESDAY, 16 APRIL 2024

DARWIN

CONDITIONS OF DISTRIBUTION

BY AUTHORITY OF THE HOUSE OF REPRESENTATIVES

[PROOF COPY]

JOINT STANDING COMMITTEE ON THE NATIONAL DISABILITY INSURANCE SCHEME

Tuesday, 16 April 2024

Members in attendance: Senators Steele-John and Urquhart and Ms Coker and Mr Conaghan

Terms of Reference for the Inquiry:

As part of the committee's role to inquire into the implementation, performance and governance of the National Disability Insurance Scheme (NDIS), the committee will inquire into and report on the NDIS participant experience in rural, regional and remote Australia, with particular reference to:

a. the experience of applicants and participants at all stages of the NDIS, including application, plan design and implementation, and plan reviews;

b. the availability, responsiveness, consistency, and effectiveness of the National Disability Insurance Agency in serving rural, regional and remote participants;

c. participants' choice and control over NDIS services and supports including the availability, accessibility, cost and durability of those services;

d. the particular experience of Aboriginal and Torres Strait Islander participants, participants from culturally and linguistically diverse backgrounds, and participants from low socio-economic backgrounds, with the NDIS; and

e. any other related matters.

WITNESSES

AH KIT, Ms Ngaree, Minister for Disabilities, Northern Territory Legislative Assembly

BREE, Ms Bryony, Executive Director, Social Inclusion, Department of Territory Families, Housing and Communities, Northern Territory

LIVESLEY, Ms Samantha, General Manager, Community Participation and Inclusion, Department of Territory Families, Housing and Communities, Northern Territory

Committee met at 08:39

CHAIR (Ms Coker): I would like to declare this public hearing open. In doing so, I would like to acknowledge our First Nations traditional custodians of the land where we meet and pay respects to their elders past and present, and I extend that respect to Aboriginal and Torres Strait Islander peoples who are with us today. This is the first hearing for the Joint Standing Committee on the National Disability Insurance Scheme into our inquiry into the NDIS participant experience in rural, regional and remote Australia. I'd really like to thank you particularly, Minister, for your attendance and wisdom here today. I would like to give a shout-out to our secretariat, who do a great job in supporting us here today. These are public proceedings being audio streamed live with open captions via the parliament's website, and a *Hansard* transcript is being made.

I remind all witnesses that in giving evidence to the committee they are protected by parliamentary privilege. It's unlawful for anyone to threaten or disadvantage a witness on account of evidence given to a committee, and such action may be treated by the Senate as a contempt. It is also a contempt to give false or misleading evidence. Witnesses also have a right to request to be heard in camera. The Senate has resolved that an officer of a department of the Commonwealth or of a state shall not be asked to give opinions on matters of policy and shall be given reasonable opportunity to refer questions asked of the officer to superior officers or to a minister. This resolution does not preclude questions asked for explanations of policies or factual questions about when and how policies were adopted.

If a witness objects to answering a question, they should state the grounds upon which the objection is made, and the committee will determine whether it will insist on an answer, having regard to the ground which is claimed—which has not happened previously, I must say. If the committee determines to insist on an answer, a witness may request that the answer be given in camera. I remind those contributing that you cannot divulge confidential, personal or identifying information when you speak. If you wish to supplement your evidence with written information, you can forward it to the secretariat after the hearing.

I'd like to welcome the Hon. Ngaree Ah Kit, the Northern Territory Minister for Disabilities. It is really great that you've made time in your day to come and speak with us. I also welcome Ms Livesley and Ms Bree from the Department of Territory Families, Housing and Communities. I understand that information on parliamentary privilege and the protection of witnesses giving evidence to Senate committees has been provided to you. We're looking forward to a very good discussion. I now invite you, if you would like, to make an opening statement.

Ms Ah Kit: Thank you again for coming to the Northern Territory to kick off these important discussions with your important standing committee. I'd like to also start by acknowledging that this public hearing is being held on the beautiful lands of the Larrakia people, and I too pay my respects to Larrakia elders past, present and emerging.

I want to acknowledge the incredibly important work of your standing committee looking into the National Disability Insurance Scheme. We here in the Northern Territory have thousands of current participants, and we have almost three times as many Territorians living with disability who aren't in the scheme. My responsibility as the Northern Territory Minister for Disabilities is to help look after every single one of those Territorians. We have around 20,000 Territorians living with disability today.

I acknowledge all of those who have provided submissions to your inquiry, and I want to congratulate and thank them for retelling their stories and for all of their efforts to ensure that every single person who is captured under the NDIS gets to receive the support they need to live their best life. It'll give people an opportunity to discuss and reflect upon their experiences as well as the experiences of others, and I know that these discussions will provide a genuine opportunity to learn about their lived experience with the NDIS and the barriers faced every day, which include: challenges for people with disability to stay on country and with family; challenges to ensure consistent support and appropriate treatment when many services are fly in, fly out or—a new one that I learnt—drive in, drive out; barriers to family members who provide informal supports, often without respite or financial recognition—that's a big one up here; and barriers and limits to choice, particularly in thin or non-existent markets.

It's no surprise to anyone that the Northern Territory context is complex and unique. Through my visits to remote communities in my role as Minister for Disabilities, it has been repeated to me time and time again by people with disability that I meet that positive engagement and real communication, particularly in our remote communities, must be conducted in a culturally safe and appropriate manner. It is critical that communication is in language and includes not only people with a disability but also their carers, their families, the wider community representatives and, where possible, the providers who deliver services in those communities.

The Territory is culturally diverse, with a dispersed population over a large, remote geographic footprint. In early 2023 I initiated a deep dive into NDIS access and utilisation in the remote communities of Maningrida and Yuendumu. I wanted to pick two communities, one in the Top End and one in Central Australia. I did this with the intent of bringing to the attention of the Commonwealth and the NDIS Independent Review Panel the lived experience of people with disability in our most vulnerable communities. It was important to highlight that, while the NDIS has been a game changer for many people with a disability right across Australia, service delivery gaps remain in regional and remote areas. This has a significant impact on people with disability, on their ability to remain on country and on their ability to fully participate in community life. It was clear that all sectors of government needed to respond to this issue in new and innovative ways and with a community and cultural lens to ensure that disability services would be provided in collaboration and partnership with local community members and community controlled organisations.

In August 2023 it was my pleasure to join the Minister for the NDIS, the Hon. Bill Shorten, to announce Maningrida as the first trial site for the Commonwealth's alternative commissioning pilot program. The announcement was a response to the feedback received as part of the Maningrida deep dive we undertook. The trial site is expected to strengthen the access and utilisation of NDIS in remote communities and attract investment into Maningrida. The pilot program will enable the community to identify new and innovative ways to bring disability services to communities where historically there have not been enough services available to meet participant needs. This project is being led by the National Disability Insurance Agency, in collaboration and partnership with the Northern Territory government as well as other Commonwealth agencies, local community members and community controlled organisations. It is hoped that the locally based solutions identified through this pilot will be transferable to service delivery across other remote communities in the future.

Again, I want to say thank you to everyone who will be attending today to share their story and their lived experience. Your voices are essential to effect change and necessary improvements to the way the NDIS is delivered in our beautiful Northern Territory.

CHAIR: Thank you very much. I understand that you don't have a lot of time with us today, so I want to cut to the chase with you. As a pilot program, the Maningrida deep dive is very good in terms of looking at regional, remote and rural locations, the impacts of being in those locations and what we need to do within the NDIS to ensure that people in those communities who have a disability are well served. I know it's still ongoing, but what has it uncovered so far? What do you think are some of the key solutions that we need to be looking at to improve the lives of people with disability in remote areas?

Ms Ah Kit: I'll speak about the Maningrida experience first. I am a proud Aboriginal and Torres Strait Islander woman, so it was really important in regard to working with our remote communities that we worked through that cultural lens. When asking and tasking my department to engage with community members, we first had to seek the permission of the community to work with us in partnership. I promised from the get-go that this would be community driven and supported. It was a four-way partnership between the Northern Territory government, the National Disability Insurance Agency, the community and service providers. It's important to make sure that all four lots of people are on the same page and invested.

What we need to do is understand that Maningrida is not like any other community. It is completely unique. So going out and working with the people and hearing from them firsthand was a focal point and a starting point and really important. With Maningrida, we actually sent our teams out to do a bit of the groundwork—to explain to people what a deep dive is, because it's not a well-used term with a lot of people. So we were explaining that this was a way that we wanted to operate to get the best out of the local voices and ensure that they were leading the plan just as much as government, going forward.

With Maningrida, we learned certain things loudly and clearly, and I'm happy to give you some stats—and my team can correct them if I'm a little bit off. I believe we have just over 73 NDIS participants in Maningrida. We had around 48 service providers. We had around $4 million worth of NDIS packages, and just over $1 million was being drawn down. Out of that comparison, a quarter of the money being allocated for NDIS disability supports was being used, while $3 million was not. Again, that's part of the reason why I chose Maningrida as a Top End community. It is a large community that has a fluctuation of between 2½ thousand and 3½ thousand people. It is very, very big. That was our baseline: how do we ensure that we work with community, the providers and the NDIA to help local residents on a package draw down more support to live their best life? That was the starting point we had.

We went out there and met with all the organisations. We spoke to them face to face in the community about the NDIS, how it is working, what they think is valuable and what sorts of solutions existed. It's always really important to encourage them to have their voices heard. We have a great Aboriginal health service out there, and they have the majority of the participants that they provide support to. So, again, my department and the NDIA worked with the community through that lens as well, so we can support the community in a way that they find very helpful. And, again, always with my lens is the question 'How do we do ourselves out of a job?' How do we help the community to strengthen themselves? Can we develop a bit of a community plan and blueprint so that they can continue to ensure that their local residents who are on the NDIS today and those who may need it in the future have a way where they can be safeguarded at that Maningrida local community level?

Very clearly, a lot of services are fly-in fly-out. Or if it's good weather and all the roads are accessible—there's no water on them—you can drive-in drive-out. But what we heard loudly and clearly when we spent time with people in the community was that the language and the communication aren't always exactly the way in which they need them. We need to make sure that we have messages that are translated, that we speak in their local language and that we use words that they're comfortable with. Here's a key example. On my visit back to Maningrida I spoke to the people and, when I used the term 'NDIS participant', a lot of people had strange looks on their faces. I asked them, 'Do you use the word "participant" out here?' They said, 'We don't know "participant".' So I said, 'Do you still use the word "client"?' They said, 'Yes,' and the whole room nodded their heads. I looked around the room, and I said to all of those that we had brought in from Darwin, 'Please note that the Maningrida community would like to have their participants referred to as clients.' Simple changes like that show respect to the community. It engages with them through communication, which they have advised us is really important. And it makes sure that, when we're saying clients, they're on the same page. Again, it's looking at those—I wouldn't really call it innovative—practical and realistic community led ways of doing the business that we all want. That was really important as well.

We will continue to work with the NDIA for the rollout of the pilot program. Again, what's very clear from the statistics I shared with you all is that there was $3 million worth of value going unrecognised and unaccessed. The way I looked at it in my head as the Minister for Disabilities was that clients out there were living a quarter of the wonderful life they should be accessing.

With the community, we heard loudly and clearly—and we saw it through our data—that the fly-in fly-out, drive-in drive-out model is very expensive and very difficult to manage. So working closely with the federal minister and my other ministers around the country, talking about alternative commissioning, was really important to make sure that Maningrida had the opportunity for consideration as well. The idea is that local people will be able to pretty much control the way forward, because this is about that self-determination and independence in that community. They're going to be the people who are there tomorrow and next year, and their families will be there next generation. People in our jobs will change, and people in the service provision will change, but they are the constant. Again, working with the community through that long-term vision was really important from the get-go.

What I'm really looking forward to seeing now, going forward with the alternative commissioning model, is the value directly to the people, the regular communication in their first language and making sure everybody in the community is aware of what this pilot is, how it operates, the benefits that are there and, more importantly, if something goes wrong, where to go to actually raise that as a focal point. We need to make sure that people aren't just accessing services and drawing down the $3 million that isn't being used. It's making sure that they are living their best life, that they are getting the best service provision and that the entire community has an uplift through that as well. Again, I've looked at the Maningrida deep dive and alternative commissioning pilot as an entire community uplift exercise. It's not just about looking at the 73 participants and how they can draw down their package.

CHAIR: Thank you. Have we got time for a couple of questions to you?

Ms Ah Kit: I've actually got to head off—my apologies—but I have two fantastic staff who know the way that I work and the agenda that I've set. I'm really sorry that I wasn't able to stay a bit longer. If there's anything else I can take on notice or follow up, I'd be happy to come back to you all, because I think you're doing an amazing job, and this is a really important public hearing.

CHAIR: Thank you very much, Minister.

Ms Ah Kit: Thank you again. It was nice meeting you.

CHAIR: I have a question, and I'll leave it to you as to who will answer. That $3 million not used is concerning. Why isn't that being used? What are the key things that need to be done to ensure that people with a disability in remote areas are able to utilise that funding to improve their lives?

Ms Livesley: The key thing that can be done is some of that market stewardship and developing a market response as well as a local workforce. It comes down to the plans being built, but then you need to back that in with identifying where those gaps are in those plans to work out: What are the service provision items not being delivered? How do you activate and build that market and get those providers and other services into those remote areas? It's not just a set-and-forget plan; you really have to look at the whole-of-community approach as well to work out how you can build a sustainable market that is building on all the participants in the community. I think that market viability is some of those issues for providers as well. But, for some communities with small populations, there needs to be more of a hands-on approach to support providers and participants around that. Since the beginning of the Barkly trial, we could see across the board in remote areas—not just in the Northern Territory—what we'd call low utilisation rates.

CHAIR: Did you want to add anything, Ms Bree?

Ms Bree: I would only just add one thing to that, and it's to do with building that local market. It's about how you build local capacity as well to deliver services. I think that will be key, going forward, for the communities.

CHAIR: From our perspective, each community is different; their needs are different. But I think we're also perhaps looking at that higher level. What are the key things we can do that will help remote communities across the board? Is there anything that you would like to suggest here—this is your moment in the sun—that would be a key improvement?

Ms Livesley: I think the Maningrida alternative commissioning site—the NDIA and Department of Social Services have framed up some of those approaches that we've been working with them on, and I think we really need to implement them. Some of those are about different ways to purchase or commission those services.

We know the NDIS is an individualised person-centred approach, but when you have a small population and small community, like I said, there's more of that hands-on approach. It may look like returning to a block funded model, but it's not the old ways of block funded where you just got what was provided by the provider; it's more about having an informed discussion with participants and their families about what services they want and how they want those delivered.

It may mean different commissioning approaches to purchasing those services. It may be through direct purchasing like a block funded model or more about working with a group of participants to identify if there's a collective, joint need across their plans and then identifying a provider that can draw down on their plans. The National Disability Insurance Agency can speak further to that, but it's more about being more involved with the participants and assisting them, their families and communities to do that.

The other key thing we think is really important is to build the local workforce and use those employment programs there to move local community members into that care and support workforce. There are other opportunities around repairs and maintenance of equipment on community, instead of having to send it into a regional centre. It's those kinds of things, where you're supporting the participants in the community, you're supporting local community members and you're building that circular economy within that community as well.

Ms Bree: I'd only just add infrastructure and providers coming out that don't necessarily have somewhere that they're based, because they are coming in and out of the community at the moment. So how they operate in community can be a bit challenging when trying to have confidential conversations—where they might talk with a participant. That's probably one of the challenges, and I'm sure that other providers will talk to that to you today. It's how they can base themselves in community and have those sorts of facilities to work well with the community while they're there.

Senator URQUHART: I've had a look through the submission and I may have missed it, but what is the time frame for the pilot?

Ms Livesley: There's been a bit of work happening. I know it was announced in August. We are working with the Department of Social Services and the NDIA to confirm when they will be officially starting the work. We can come back—

Senator URQUHART: What about the length of the pilot? How long will it be?

Ms Livesley: They haven't set a time frame on that. I think it's probably hard to set a time frame. It's probably around meeting outcomes and when we're starting to see those improvements in utilisation and increased choice and control.

Senator URQUHART: I presume there will be markers along the way to establish how well it's going or what needs to be done to actually change what's happening.

Ms Livesley: I understand the Department of Social Services are procuring an evaluation component for the alternative commissioning sites.

Senator URQUHART: I had a smile about drive-in drive-out because I deal with that in Tasmania all the time. We have remote communities—nothing like what's remote up here. A remote community for us is 2½ hours from a major centre. It's a very short period of time, but, for people living in those communities that I look after, it's still a lot because there's difficulty in transportation and a whole range of things similar to what you have here.

One of the experiences that I find in north-west Tasmania and down the west coast of Tasmania is specifically around that drive-in drive-out component and providers of NDIS services who are then unable to be utilised in other areas of the health system. As an example, we might have an occupational therapist who drives for 2½ hours from Burnie down to Queenstown—or across from Hobart to Queenstown, which takes a bit longer—and who provides an occupational therapy service to an NDIS client. They are not able, under a pricing mechanism, to then be utilised under what we call the Tasmanian health service. So they will drive over, see maybe two or three clients and then drive out again, when, in fact, there are probably six or seven people in that community that could utilise them. Do you see that same sort of scenario here in the Northern Territory, particularly in those regions that are more outlying?

Ms Livesley: Is that in terms of providing allied health services to non-NDIS participants?

Senator URQUHART: Yes—non-NDIS participants, particularly.

Ms Livesley: I think that is the approach. We have NDIS participants who have funded supports in their plans, and those providers will go out to do that. What's provided through our mainstream health service is done through a different service system.

Senator URQUHART: The two don't interlink, so you may have someone going six hours to provide a service to an NDIS client and then driving back but not actually being utilised in other areas of the community—is that right?

Ms Livesley: Yes. The community might then also have a visiting team from a health service.

Senator URQUHART: It's interesting. It's a frustration for me and for that community, absolutely. In your submission you talked about remote community connectors and how they play a critical role in identifying and engaging. Can you elaborate on what the role of those community connectors is and the problems that their work looks at trying to address.

Ms Livesley: I can give some general information, but they're employees of the National Disability Insurance Agency; they have a role under that.

Senator URQUHART: Okay.

Ms Livesley: I think the focus for them is to be community based members who support NDIS participants in the community or identify people who may be eligible and support them to put in access requests and other paperwork to the NDIA. As I understand it, they don't coordinate plans.

Senator URQUHART: So they will connect someone to—

Ms Livesley: The NDIS.

Senator URQUHART: a provider, or just to the NDIS?

Ms Livesley: Just to the NDIS.

Senator URQUHART: So it's not about connecting to services; it's somebody who can identify—

Ms Livesley: That's my understanding. I think it's probably more of a coordinator or support role, connecting to the service. The NDIA should be able to give further detail on those positions.

Senator URQUHART: I know this is a big issue in Tasmania particularly; it's exacerbated here because of distance, I presume. Can you talk to me about how participants living in rural, regional and remote areas are affected by transport costs.

Ms Livesley: It's considerable, especially if you look at the Top End during the wet season. The only option, to get in and out of a community, is to fly. Charter costs are prohibitive. Even to drive, there are long distances and you need access to a vehicle. Those costs are prohibitive for a lot of people.

Senator URQUHART: Are there any local initiatives in place to assist with the challenges of that geographic distance and transport?

Ms Livesley: If you're somebody who requires health treatment, there is the Patient Assistance Travel Scheme. Outside of that, I'm not aware, but we can follow that up.

Senator URQUHART: If you could take that on notice, that would be useful. What is that assisted travel service?

Ms Livesley: It's delivered through our department of health. It's for patients who need to be brought in for health treatment. It's a subsidy—

Senator URQUHART: So it's a subsidy, but it's a very small subsidy compared to the cost—is that fair? We have a similar situation for people on King Island.

Ms Livesley: I think that's across the board.

Senator URQUHART: The only way they can get off the island is to fly. Sorry, Chair; I'm taking up a bit of time, but I've got one more thing I want to talk about, particularly around those transport costs. I know that's a big burden for people who are participants of the NDIS. What do you think the NDIS could do to help participants with transport costs?

Ms Livesley: I think that transport across the board and the way it's funded in NDIS plans is still an outstanding piece of work. There needs to be a flexible approach, especially looking at where someone lives and what their needs are. A flat funding line in a plan is not necessarily suitable for all participants, noting that in the Northern Territory we also generally have very limited public transport, even in Darwin and Alice Springs. We probably need a regional lens on what the actual gaps and needs are and what the service system is.

Senator URQUHART: So on an individual client basis as opposed to a general catch-all?

Ms Livesley: Yes—knowing that there need to be some parameters around that as well and what some of those other service systems are that we can build upon.

Senator URQUHART: Okay. Thank you. I'm happy to pass the call, but I'm happy to come back if we've got time.

CHAIR: Yes, fine. Mr Conaghan.

Mr CONAGHAN: Thank you for coming along today. I'm interested in the alternative commissioning. Is that a description for building community capacity? Is that what it means? I'm trying to get my head around it.

Ms Livesley: It is a way to build community capacity as well as participant capacity and provider capacity—so it's across the board. It's about having a really focused look—and I know Maningrida's been announced and we're waiting for a second site to be announced—at what the flexible approaches are that we need to consider and implement to ensure the NDIS is accessible and equitable for all participants and that there's not a one-size-fits-all to NDIS service delivery. We do need levels of flexibility and different approaches for different participant cohort groups and different regional and remote areas.

Mr CONAGHAN: The difficulty the NDIS has at the moment is service providers. I'm not from a big electorate, but I've got a place called Bellbrook, which is only 60 kilometres from one of the main centres. They can't get providers out there because they already have their books full. They don't have capacity; they can't take on any more clients. So in remote communities such as yours, where you're travelling thousands of kilometres, we have to be honest with ourselves. You're not going to get service providers out there, as much as you advertise, as much as you say you need to go to remote communities. What can you do within those communities without draining other sectors, such as aged care, to fill these services, or is it pie-in-the-sky stuff?

Ms Livesley: No, I don't think we can accept that it's pie in the sky. We need to look at the outcomes for the NDIS participants. In a remote community we also need to start looking at the surrounding human services sectors and not just think, 'This is the NDIS; this is a health service; this is aged care,' because there are similarities in what service provision is needed across all of those in the care and support sector. It's about how we are all linking in to not to be competing with one another. If you've got an OT going in to do NDIS work, can that same OT be doing, as Senator Urquhart said, health work or aged-care work? What does that look like in terms of a joined-up approach? That's part of the alternative commissioning. I think that's part of the work we really need to consider: how are we joining up those different care and support sectors to make it sustainable?

Mr CONAGHAN: What we're seeing, and tell me if you see the same thing, is that a nurse who's on $35 an hour will leave nursing and go and become an NDIS provider on $65 an hour. So you have a drain there. Have you seen or heard those anecdotes?

Ms Livesley: I haven't, but I could ask my department of health colleagues if they've seen that.

Mr CONAGHAN: Do you think there's an avenue for that same nurse, if we use that example, to be able to also become a provider in remote communities without having to leave her or his sector?

Ms Livesley: Possibly, but I think the thing we'd need to look at [inaudible] to the service providers, and around conflict of interest as well—ensuring that what they're doing for one job is not conflicting with their other job and that they're not accessing information that someone doing the NDIS service provision job wouldn't necessarily have access to. So there would just be those considerations, like if someone's working in a health clinic, and also then making sure there aren't sharp practices around that.

Mr CONAGHAN: But isn't that exactly what we should be looking at to get rid of the bureaucratic tape to open up services to these communities? I'm not being critical of you.

Ms Livesley: I probably would need to come back to you on that one—take that one on notice—and talk to the National Disability Insurance Agency around some of those matters. I think, for us, pushing forward with the alternative commissioning site is probably to test a lot of those scenarios to see what really does work and what is feasible.

Mr CONAGHAN: Thank you.

CHAIR: Just before I throw to Senator Steele-John, who is with us online, I have a question for you around participants on country. On page 11 of your submission you mentioned that participants in remote communities want to stay in their community on country, which makes absolute sense, but that's not well understood or accommodated in the NDIS plans. To what extent is this a challenge brought about by limited awareness on the part of the NDIA, and how do we better accommodate this need?

Ms Livesley: I think the awareness has increased over the last 10 years of operation of the NDIS. We acknowledge there are a number of participants who live in major regional centres due to their disability support needs, and it's predominantly around what we would call supported accommodation or those SIL or SDA services. But it's really important to acknowledge that connection to country and culture and to be able to support those participants to return to community, even if it's not permanent—to go back for what we used to call, before the NDIS, respite—and to support people to go back to community to make those connections to family, culture and country and to have them supported there. Those are some of the key things that we'd really like to see considered as part of the Maningrida alternative commissioning side. Who are the NDIS participants from Maningrida who may live, say, in Darwin, and what does being supported to be able to go home at some times in the year look like for them? None of us want to be away from family. It's just really important.

CHAIR: Thank you. I'll now hand over to Senator Steele-John.

Senator STEELE-JOHN: Thank you so much for your time today, and I really apologise for not being able to be there in person. I'm recovering from COVID, so I couldn't make the trip. I want to start by asking you a question about the Applied Principles and Tables of Support document, which sets out the division of responsibilities between the NDIS and the Northern Territory government. Do you feel that this provides adequate guidance for the NT government to base its provisions upon?

Ms Livesley: The APTOS was developed a number of years ago, and I think it's something that we all need to review in light of the NDIS review recommendations. But it has provided that guidance and reference point for the Northern Territory, and other states and territories, around what is an NDIA responsibility and what should be a mainstream service response responsibility. It has guided a lot of that work for us at this point.

Senator STEELE-JOHN: The NDIS review recommended it be replaced. Do you support that recommendation?

Ms Livesley: I'd probably need to consider that further. In terms of it not being a static document, I think it's probably timely for it to be reviewed. It hasn't been reviewed for quite a number of years, and I think there are different approaches in the service systems. That, just in terms of the overall NDIS review recommendations, is something that we're all still considering.

Senator STEELE-JOHN: Are there any particular areas of the APTOS that you think should be reviewed with a priority? Are there particular challenges that you're seeing that the document in its current form creates for the NT?

Ms Livesley: Not immediately, off the top of my head. Maybe there are, looking at the health interface, around incorporating what were some of the agreed disability related health supports more formally into the APTOS, but nothing comes immediately to mind.

Senator STEELE-JOHN: Does the NT government provide funding to ACCHOs to deliver disability related support?

Ms Livesley: My department doesn't, but we could take that on notice and seek advice from our Department of Health.

Senator STEELE-JOHN: Thank you. If so, would you be able to provide us with an outline of those services and whether there is a framework or plan for those partnerships that is currently in place?

Ms Livesley: I can seek that advice, yes.

Senator STEELE-JOHN: Thanks very much.

CHAIR: I would like to now pass back to Senator Urquhart.

Senator URQUHART: In your submission, you talk about the interface between health, education, justice and the disability services system. Can you elaborate more on those observations and what sort of a role they play?

Ms Livesley: Particularly for health and education, they play rather critical roles. In terms of health, especially in a remote context, the one place most people will be attending is a health clinic. It's that kind of initial service that may be able to identify someone who could be supported to apply for the NDIS.

Senator URQUHART: I think the minister spoke about an Aboriginal health service in one of the areas—

Ms Livesley: Maningrida. It's Mala'la.

Senator URQUHART: Yes. Are there people that are—I hate to use this word—qualified to identify people who may be possible recipients of the NDIS within those structures already?

Ms Livesley: I'm not aware of them being identified positions, but they would be your clinic nurse or a visiting medical professional or maybe an allied health team visiting, and, as part of their training and qualifications, they would maybe identify someone.

Senator URQUHART: Where do housing and justice, particularly, knit together in operating those sorts of services?

Ms Livesley: For housing, it's part of our broader department as well. All new builds are now to the silver standard, trying to increase that stock of accessible housing. I know our housing colleagues have done a program over the last few years where they've released blocks of land to providers in Darwin and Alice Springs to build dedicated SDA properties for NDIS participants. For justice, it's probably ensuring that, as prisoners are coming up for release, there is that planning in place should that person be NDIS eligible, and what does that NDIS related support look like for that person post release?

Senator URQUHART: I don't think I have any questions that I've missed, Chair, so I'm happy to hand back.

CHAIR: I wanted to focus on the challenges around language. The minister mentioned the need for the right language, appropriate language, to be used so that there is better communication. I'm interested in understanding whether there are any local initiatives taking place that address this and support CALD people when they access the NDIS.

Ms Livesley: I'm not aware of any particular one, but we do, obviously, have our Aboriginal Interpreter Service and we also have our Interpreting and Translating Service of the Northern Territory for all non-Indigenous languages. There are those existing services should someone need an interpreter, should someone need documentation translated.

CHAIR: In previous hearings I've heard that it can be very challenging to get an interpreter and there is a cost associated with that. Is that the case in the NT?

Ms Livesley: I can't speak to the cost, but sometimes the availability of interpreters, for a range of reasons, can be an issue that we're aware of.

CHAIR: Ms Bree, have you got anything to add to that?

Ms Bree: I'm just aware that, through the alternative commissioning, training is going to be undertaken with the organisation—NDIA—to do their cultural awareness program. Hopefully, that will help increase the awareness and their understanding, when they're going out into remote communities, about how they can better interact and improve outcomes.

Senator URQUHART: At the end of your submission you have possible reform opportunities, which I love—I love it when organisations get together and provide possible ways to make things better. There's quite a long list there about a number of areas. Is there anything in particular that you'd like to raise? It's on page 14, in the last pages of your submission. There are a number of areas around the themes of the NDIA and then possible reform opportunities. I guess my question would be on whether you want to expand on any of them but also: are most of those pointed in the direction of the NDIA, the NDIS at a national level, or is it a collaborative approach between different levels of government that you've aimed at there?

Ms Livesley: These are some of the key findings for the NT. When the NDIS Review panel was undertaking its work we advocated—and they actually spent a week last year—visiting remote communities in the Northern Territory. These are some of their reflections on their experience in terms of remote service provision and what communities told them. Some of these have been incorporated into the final report of the review of the NDIS as well. We supported the key themes and some of their reflections on what they experienced, and what they took away from that, around further work needing to be done for the successful implementation of the NDIS, especially in the remote context, and work that is culturally appropriate as well.

Senator URQUHART: Have any of these been implemented since then, or is it all just forming part of the overall review?

Ms Livesley: It is forming part of the overall review, but, alongside that, there was that commitment to the Maningrida alternative commissioning, which we're hoping will begin to achieve some of these and set a bit of a framework around how it works in Maningrida and how that can be uplifted to other communities, noting again that it's not one-size-fits-all.

Senator URQUHART: There's a difference, yes.

Ms Livesley: All communities will have different requirements.

Senator URQUHART: This was done in collaboration with the communities?

Ms Livesley: Yes.

Senator URQUHART: Great. Thank you.

CHAIR: On that note, I'd like to thank you, Ms Livesley and Ms Bree, for your time today. I think you may have a little bit of homework, to send through answers to some of the queries. If you could send those through to the secretariat that would be greatly appreciated. Thank you very much for your time today.

HARRISON, Ms Judy, Co-convenor, National Regional, Rural, Remote and Very Remote Community Legal Network (4Rs Network)

HARRISON, Ms Ros, Managing Solicitor, Darwin Community Legal Service

KAY, Mrs Denise, Senior Disability Advocate, Great Southern Community Legal Services [by audio link]

LEWIS, Mr Brodie, Business Manager, Great Southern Community Legal Services [by audio link]

McKINSTRAY, Ms Anne, Acting Senior Disability Advocate, Darwin Community Legal Service

ROSALES, Ms Cheryll, Solicitor, Disability Advocacy Service, Uniting Communities Law Centre

[09:29]

CHAIR: I would now like to invite representatives from the Darwin Community Legal Service and the National Regional, Rural, Remote and Very Remote Community Legal Network to come forward. While you're being seated, I'll just remind you that I understand information on parliamentary privilege and the protection of witnesses giving evidence to Senate committees has been provided to you. It's lovely to have you. Thank you. I know your work is very busy and we appreciate your time. Would you like to make an opening statement?

Ms R Harrison: Yes, thank you. The NDIS is a system designed to provide for every Australian, not just those living in a well-serviced urban area. The Darwin Community Legal Service is a combined service, being a community legal service as well as hosting the Seniors and Disability Rights Service, which is our only advocacy service for people with disability, NDIS participants and their families in the Top End of northern Australia. In crude geographical terms, our disability advocacy service covers Katherine and everything north, including remote, regional and very remote communities.

Now, of course, these communities have their unique cultural identity, and we need to acknowledge the differences between the needs and culture between rural, regional, remote communities and the participants within them. We also need to acknowledge that there's a real need for specialised legal and advocacy assistance arising from NDIS provision for participants and their families, ranging from NDIS access, planning reviews and appeals assistance to employment and consumer law issues that arise directly from the functioning of the NDIS within communities—such as employment law, for example, if a participant is employing a support worker.

In our experience, geographical location alone determines a participant's outcomes and their access to the NDIS. Our service tries as best we can to provide access to justice for NDIS participants living in the Top End. However, we've got limited funds and note the increasing cost of service delivery to rural and remote communities.

Living in a rural and remote or regional area in Australia is a double-edged sword for most Australians. Benefits include a lifestyle of freeness, easy access to nature, connection to country and family, and unique community and cultural identities. However, the foundational supports and infrastructure—such as education, health care, recreational facilities and suitable accommodation—can also be limited by geographical location in these places. For the less-abled population, particularly those with a disability, in these areas, the isolation can be compounded in terms of access to appropriate services and justice, the ability to access services in a timely manner, and of course the ability to access the support of an advocate or legal service. There are, of course, the issues of the ability to access culturally appropriate educational information, accommodation and therapies in these areas. Now, while most people can choose where they live, living with a disability, and when and how that disability arises, is not a choice that is made either by the participant or by their family.

Focusing on the NDIS as a legislative scheme has been the past experience, and we're very pleased that this committee is focusing on the experiences of our clients, as participants of the NDIS, and also their families. The committee will no doubt find the outcomes for participants and their families are significantly different to those in urban areas. We acknowledge the experiences of the Maningrida trial, and particularly the issues with recruitment for service providers, but also note the lack of community and independent advocacy consultation within that area during the pilot program. In our opinion, this is symptomatic of some of the broader issues that are faced in implementing the NDIS in rural, remote and very remote communities. We're also very aware of the delay in getting this project started.

Thank you for publishing our submission and for inviting us to appear today. I refer you to page 5 of our submission, where you'll find our recommendations. These recommendations can be essentially divided into four broad themes that relate to access, availability and protection for NDIS participants and their families. Our first theme, regarding the access to advocacy and legal services, essentially is access to justice should there be any misunderstandings, issues, barriers or changes that are required regarding any of the relevant aspects of the NDIS, referred to in this committee's terms of reference, for participants or their families. Second, in our experience, is the role of and need for a safeguarding commissioner to protect participants and their families from unruly providers, practices and misadventure. The third main theme is culturally appropriate education and information to ensure that remote, rural and regional participants are able to effectively participate within the scheme. Our final theme, and probably one of the most important, is the ability to access adequate service provision. Of course, this relates to both the availability and the suitability of that service.

I've prepared a table that links the recommendations to the committee's terms of reference and also to other themes. I can either hand it up or email it at the end, whichever suits best.

CHAIR: Please hand it out.

Ms R Harrison: Sure. I've got seven copies. I might just keep one to refer to. Thank you.

Finally, I should also disclose at this point that I am in fact the primary carer of an NDIS participant: a lovely seven-year-old boy who's got a rare genetic diagnosis and has benefited from the NDIS since it's been rolled out in the Northern Territory. While we're not clients of the Darwin Community Legal Service, our personal story differs significantly from that of most participants in the Northern Territory in terms of the entry pathway to the NDIS and our ability to self-advocate. I have exceptional familial support from a family of interstate medicos who all have opinions. Indeed, when we travel interstate to be able to access the specialist therapy that my son requires, we have access to free accommodation, the use of a car and the ability to travel easily to the specialist therapy centre. I also have enjoyed flexible workplaces where those arrangements have enabled me to continue working in a career despite having a disabled child, for which I'm very grateful. But, again, note that my personal experiences are significantly different to those of most in the Northern Territory. Thank you.

CHAIR: Thank you. Just before we continue, I'd just like to ask our committee to formally accept the tabling of this document. Thank you very much for putting that together for us. I'm interested in talking to you about page 2 of your submission. You noted, as did the previous presenters, the experience of participants, their low plan utilisation and the fact that it is challenging to be able to fulfill the needs, which I think is very concerning to the committee. So I'm wondering if you can elaborate on this observation and explain how you believe this situation could be improved.

Ms McKinstray: That's an enormous question.

CHAIR: Yes. We're here to hear your potential solutions.

Ms McKinstray: Okay, you asked. I think it's a really complex onion, and one layer affects the next and the next and the next. For me, in our advocacy space, I feel that actually digging down, starting to think about what is the root cause of why this is occurring, and working out from there is our best chance at having success. I have been involved with the scheme since literally as a child in Tasmania, so I've been involved right from the get go and seen it in various shades of grey. The scheme was introduced really quickly in lots of ways. I think that's been compounded by providers reading things into NDIS rules and guidelines and whatnot and interpreting them in different ways. I think we've got a situation of not understanding how the regional and remote, particularly in the NT, understand the NDIS and understand what it means for them, let alone finding out what they need.

CHAIR: So the first thing you're suggesting is that there needs to be better awareness and education in remote communities about what the NDIS is and what it isn't able to provide.

Ms McKinstray: Yes. And what it can't provide.

CHAIR: So that's one. What else would you suggest?

Ms McKinstray: You also need to tie in the need for really considered cultural awareness about that particular community and provide that information in the way that it needs to be delivered. In many communities people still hold quite a lot of shame around having a family member with a disability. So it needs to be taken into consideration. There are situations where people don't want to have to share their story with their neighbour. You're looking at small communities. There needs to be consideration of that.

CHAIR: So you're saying that the disability workers and providers need to be very cognisant of the culture and linguistic needs of that community. But also there need to be spaces that are set up—this was mentioned in the last presentation as well—where people can speak confidentially. And that doesn't always happen.

Ms McKinstray: From my experience I probably don't see that as as big an issue, to be honest. You can sit down on a concrete veranda out in the community somewhere and have that conversation with someone. I've done that myself, sitting with family and just having that conversation with them. Many community members feel okay about going to their clinic. But again, they're still going to the clinic. Other members of the community are going to see me going to the clinic. I might be taking my person with a disability to the clinic. So there's that sort of stuff.

So I probably wouldn't put as much emphasis on that. I think that's doable. I think we can achieve that with—I'm just thinking of a couple of communities that I've worked in where it probably would be okay. I think more about understanding the cultural specifics of that family and that group.

CHAIR: Anyone can answer this question. You also mentioned about providers. Obviously having the type of providers with the right skills and the number of providers to offer choice is challenging in remote areas. But you do say in your submission that there needs to be greater oversight of the NDIS providers in remote communities. I'm interested to know why you make that recommendation.

Ms McKinstray: There are probably a number of reasons for that as well. In terms of the advocacy space, we've come across, unfortunately, multiple cases of very sharp practices occurring, where providers will go to a community on the weekend. They've managed to find out where people who are on the scheme live, and they've literally door knocked. They've had a sheet of paper that basically says sign here, sign here, we can be your provider, give consent; but people don't really know what they're signing. They've ended up being transferred from one provider to another unknown to them. I think we've had the offers of fishing lures, respite in Darwin, laptops, iPads, cash, to make that change. I spoke to a provider recently who was in that situation. In one day they lost nine participants to an alternative provider who came in exactly like that on the weekend. They managed to talk through the situation with those nine people, and seven of those people returned back to that provider. They were long-standing and had been around for some time pre-NDIS in the disability space, and they have a permanent presence in that community as well.

That was damaging. When we talk about the provider issue, you've got people who are hesitant. They don't trust people. When anybody mentions NDIS, often people in communities think, 'You're an NDIS representative. You're from the NDIA'. There's not a lot of distinction about whether they're from this provider or that provider.

CHAIR: That is very concerning. I know that would be very concerning to the minister and to the NDIA. Have you any suggestions about how we do this better in terms of monitoring? I know that's a tough question.

Ms McKinstray: It is. I would go back to looking at people in the community but also the long-standing, mainstream services, potentially NDIS and foundational support providers that are already there and have been there, and upskilling them in terms of their understanding of the scheme, what is good practice and not good practice. They don't need to know the fine details of how the scheme runs, but they need to know some good solid basic information. We almost need to have champions in those spaces. Then we need to be able to start working with community members to get them to understand what might be a sharp practice, what might be an okay thing and what's not okay. They need to understand their rights in terms of that stuff. I guess, coming from advocacy bent, we're ridiculously funded. There are not enough boots on the ground at this point of time.

CHAIR: By ridiculously funded, do you mean underfunded?

Ms McKinstray: Yes. Sorry.

CHAIR: We hear you.

Ms McKinstray: There are 96 communities in the NT. We are probably managing six or seven. We want to be able to provide support to more, but you have your travel costs as well. We have a regular outreach program where we're going out. We recently restarted going out to the Tiwi Islands and we're finding all sorts of issues. We are trying to bring back a presence so people think, this is an independent group of people that you can contact if you are concerned about something, or you can ask somebody at the clinic to contact us and we can have that conversation with you. We're really worried about the level of advocacy or lack of advocacy within communities and our capacity to get out to those communities.

CHAIR: We hear you on that. There have been discussions on this issue of community legal services and support you have or don't have. I have one final question before I throw it to Mr Conaghan. It's about early intervention. It's something that I really feel is so important. In your advocacy and discussions with people in remote communities, do you see this as an issue?

Ms McKinstray: Yes, absolutely. When you're talking about early intervention, I'm assuming you're talking about early intervention not just with people going into the scheme—youngsters going into the early childhood side of things—but also catching people early in terms of their understanding of the scheme, in terms of them feeling comfortable with the scheme and having a positive experience with the scheme. We have to go back to all of those things. It's almost like we have to go backwards to go forwards. That's how it feels to me. I was talking to somebody yesterday, and I said, 'It's almost like you want to have a blank canvas. Put the NDIS here for a minute, have a blank canvas and think a bit more critically about saying to people, 'Tell us what you need in your community. Do you need an OT?' 'No.' 'Do you need a physiotherapist?' 'Yes, we need that.' Let's work a little harder on how potentially this alternative commissioning stuff is—

CHAIR: And the balance between what the states and territories and the NDIS federally provide to ensure that young children with disability have early diagnosis and the supports that go with that in terms of the communities and families.

Ms McKinstray: Yes. And it's not like you can prioritise a group of people, but when you've got youngsters who are waiting at least 12 months for a therapy, that's 12 months you've lost in the most vital period.

CHAIR: Twelve months for?

Ms McKinstray: An OT, a speech therapist, an assessment, let alone the actual therapy commencing and taking place on a regular basis. Unfortunately, that's the norm not the exception in the Northern Territory.

Senator URQUHART: Is that because of the remoteness or is it because of the lack of a number of those providers or is it both?

Ms McKinstray: You can probably speak to that one, Ros.

Ms R Harrison: I think it's both. In the regional centre of Darwin there's about a 12-month wait in order to get an assessment and the plan process. Then you're back on the waitlist in order to access those services. So, it's essentially it's two years.

CHAIR: Ms Harrison or Ms Rosales, would you like to add to this, because you're here and I'd love to hear your thoughts.

Ms J Harrison: We were hoping to give a short opening statement, if that is possible.

CHAIR: My apologies. We should have offered that opportunity, so do it now.

Ms Rosales: Before Judy goes on with that, I'd like to answer Senator Urquhart's question about the waiting times. In South Australia, I would suggest it's 12 to 18 months for an assessment positive behaviour support practitioner is probably the norm, even in the metropolitan area, so there is a shortage of qualified and well-regarded practitioners.

CHAIR: Thank you. That is noted.

Senator URQUHART: That's a concept that I hear constantly in Tasmania, whether you're based in Hobart or in a more regional area.

CHAIR: Ms Harrison.

Ms J Harrison: I should have also mentioned that four of us are appearing today, two are by telephone. They're from Great Southern Community Legal Services in Albany in Western Australia.

By way of opening, I want to introduce the 4Rs network. When I say 4Rs, the fourth R is 'very remote'. We're accustomed to speaking about three Rs, but we don't quite get there in terms of very remote. The 4Rs Network has been a network for about two years. It consists of community based non-profit legal services, which means community legal centres, Aboriginal and Torres Strait Islander Legal Services and Family Violence Prevention Legal Services.

One of the distinctive factors about those legal services—and Darwin Community Legal Service has given you an example—is that a high proportion of these services are based in regional, rural, remote and very remote locations. It's very hard to be based in some of those locations, so just by that fact these are important services in their communities. In many locations they have originated through community effort. In the Kimberley, for example, the Kimberley Community Legal Service is the outcome of community effort across the Kimberley about 25 years ago, and being able to sustain that hasn't been easy.

The submission that the 4Rs network made has been endorsed by almost 40 organisations. I've given the secretariat a copy of the list of endorsements. They include community based services, statewide services and some national services. What that speaks to is the amount of concern around the NDIS implementation in 4Rs areas and the amount of contact that this whole service sector has with people with disability in 4Rs communities, including people who need to access the NDIS. The national networks that endorsed the submission include Economic Justice Australia, which used to be called the National Social Security Rights Network. Their endorsement indicates and cues us to lack of access to social security legal assistance throughout 4Rs areas. There are exceptions, but from Tasmania, the Launceston Community Legal Service does not have funding to provide social security legal assistance. And, as you know, Tasmania is one of the most regional, rural areas in Australia. I think it's second only to the Northern Territory.

Our submission focuses on two things. We've tried to bring forward themes and tried to add value in issues that the committee may not otherwise hear about. One central point is the lack of participation of most of the services that participate in the 4Rs Network in being able to provide advocacy assistance and levels of legal assistance in relation to NDIS, even where they are the only potential services—certainly the only potential legal services—in their remote and very remote communities. Some examples of that would be the Kimberley Community Legal Services, the Pilbara Community Legal Service and many others.

Cheryll, who will be speaking shortly, will give the example of her service as an exemption. DCLS is also an exception compared to what I'm talking about. These services need more funding, but they're examples of receiving funding when there are so many other similar services that have been excluded from access to advocacy funding relating to the NDIS and provision of levels of legal help. Brodie and Denise's, speaking from Albany, service is an example of receiving funding and what can be done with that, which is amazing, heroic and important but also overstretched and insufficient. We want to paint the picture that it is not okay for Aboriginal and Torres Strait Islander legal services to be excluded from providing advocacy support of the kind that you've just heard—that DCLS is providing. The same applies to family violence prevention legal services, which are located in some of the most remote communities in Australia and service those communities on outreach.

The majority of community legal centres in 4Rs areas should not be excluded either. They're currently excluded in two ways. The first is that the funding pool is totally inadequate for the existing services and others are just not going to participate while it's like that. The second is that there's been no thought about the relevance of these services, even though they're often the key face-to-face trusted services, providing direct advocacy support and legal assistance in remote areas. Our submission uses a rights based lens. That doesn't mean being abrasive. It means reflecting the rights based approach of the NDIS Act and the rights based approach to the human rights of people with disability in Australia.

We also think that there's a major force operating against people with disability in 4Rs areas, in addition to others which are talked about. That is discrimination against the 4Rs. We think that the NDIS has fallen into a metro trap and that it hasn't overcome that to balance the access to the NDIS in 4Rs areas. We're suggesting a strong systemic approach that tries to get at some of the discriminatory attitudes and systems relating to the 4Rs and people with disability in the 4Rs. I will hand over the Cheryll.

Ms Rosales: Thank you very much for having me here today. I come to you with the perspective of an applicant solicitor working in the NDIS space. My program is a statewide service, and, different from other NDAP funded services, we're actually funded by the state government of South Australia. It came out of the Ann Marie Smith inquiry, and the formation of our service was one of those recommendations made by Kelly Vincent and Dr David Caudrey.

It is no surprise to any of us that the NDIS appeals process can be daunting and time consuming. When a regional or rural location is added into the mix, then that appeals process becomes even more challenging. As we've heard, there are limited services and providers, fewer resources and a scarcity of people to provide that advocacy, information and legal advice. Today, I will speak about three clients that we have helped in rural and regional South Australia.

The first person I'd like to speak about is a woman of Aboriginal background who needed help to appeal an NDIS access decision. She was born in the APY Lands, approximately 1,800 kilometres from Adelaide. This woman was awaiting surgery, and the NDIA was unable to determine whether or not she met the criterion of permanence until her surgery was completed. Our client was highly respected and truly connected to her culture and her country, but supports, services and specialists that could help her were all in Adelaide. There were no equivalent practitioners she could see while she was on country, and during the course of the appeals process she had to return to country. This delayed her surgery significantly and delayed the appeals process. All in all, that appeals process just at the AAT took about 18 months. If there were services and support while she was on country or in close proximity, this process might have taken a significantly shorter amount of time.

The second example is a family who attended a regional legal outreach session on the Yorke Peninsula, which is about 230 kilometres from Adelaide, to get advice on future planning. They had a child on the NDIS with significant behaviours of concern, and this family had trouble finding people able to provide them with respite. The family had not found a good fit from the two organisations that were available in the area, and they had not had a break from the care of their child in over two years. They were considering a multitude of options, but they didn't know where to start. We assisted by providing initial advice on future planning, but this family waited over a month for our legal outreach session. While the family's need was not urgent, there should be advocacy and legal assistance available to them when they have the capacity, both mentally and emotionally, to seek that information and advice.

Finally, the third participant I want to speak about lives in regional South Australia on the Yorke Peninsula, 150 kilometres from Adelaide. He presented often to hospitals and medical clinics due to significant and serious self-harming behaviours. He had lived in his own home for many years. His NDIS plan funding was reduced, so much so that his elderly parents, in their 80s, were providing over 50 hours per week of support to keep him safe. His parents were experiencing carer burnout, and they had their own health issues. All three of them wanted support so they could just be a family. So we were able to provide that legal support, and they were able to negotiate that appropriate funding during the external merits review process. It took months to find an OT who could undertake those appropriate assessments, while his parents had to continue to provide that support. The family had to wait months for supported independent-living housing to be built and to be approved by the NDIA, and then they had to wait many more months to find suitable roommates so that his planned budget could fit within what was expected for his SIL accommodation.

We are based in the Adelaide CBD and we've had to get creative about how we meet people. We are the first to admit that we are limited in the regional outreaches that we are able to provide. Our dream scenario—I'm going to throw this out there—is that we would be able to establish offices in the regions or collaborate with the offices that are already out there so that we could recruit local staff and meet clients face to face so that we are able to meet them where they are. Thank you.

CHAIR: Thank you so much for giving us those case studies. It makes a difference to hear those personal experiences. Before we go on, you have presented us with the 4Rs Network NDIS submission endorsements, and I'm just wanting us to accept the tabling of that document. We have the Great Southern Community Legal Services with us as well. Did you want to add anything to that or make a brief statement?

Mr Lewis: We would love to. Thank you for the invitation to speak. I'll keep my comments brief. Denise is going to provide another illustrative case study of one of our client stories to explore the fact that these issues are absolutely relevant across the country and are similar in both the Northern Territory and Western Australia. Our service provides a range of legal and advocacy services, and, as Judy mentioned, we're one of the exceptions of on-the-ground integrated legal and disability advocacy services. Our services are funded through the National Disability Advocacy Program—the core program, not the NDIS-specific funding—as well as some state-specific funding from the WA Department of Communities. We provide a range of help to NDIS participants, including—crucially, for this conversation—assistance in both the internal and external review processes. Where it's available, we work alongside legal assistance colleagues at Legal Aid Western Australia.

As I mentioned, we don't do this work through the specialised NDIS funding, and it's an add-on to what we do. Last year, our advocates helped over 50 people with NDIS related issues, including changes to their plans, helping them understand the complaints process and helping them through the internal and external review program. This work was among a total of around 150 people that we assisted through the general disability advocacy group. However, the 150 we helped were the fortunate ones we were able to assist. Across our whole service—that's including our legal services as well—we're turning away more than two in every three people who seek our help. In the same period that we assisted those 150 people with disability advocacy service, we referred or otherwise turned away more than 200. Where possible, we connect them with colleagues at other services, including some of the services you'd been talking to through this inquiry. But due to a general lack of adequate funding for NDIS appeals and just generally, this isn't always possible, meaning that people with disability and their families are left to fend for themselves in the scheme. Sometimes it doesn't necessarily have the information or the guidance to help them through it.

As Judy mentioned, we're one of a very small number of community-owned legal services in regional Australia that provide both legal and disability advocacy. It's through that joined-up service delivery model that we're best able to assist people navigating the NDIS, both walking alongside them as advocates and representing them through the appeals process—both the internal and through the AAT. Face-to-face services for both individual advocacy and legal advocacy, both for access and review, as well as for related matters—such as discrimination and social security, which our colleagues at Darwin feel and have put most eloquently, 'are related critically to NDIS access and support'—must be the cornerstone of the NDIS.

We'll introduce my colleague Denise shortly, and she's prepared a short case study which will really highlight the importance of ongoing support of state place-based services to help people navigate the scheme. But we note that the lack of funding through the NDAP, through the NDIS appeals stream and through broader legal assistance not only allows ongoing injustice to be perpetrated against some of the most vulnerable in our society but also undermines the NDIS itself by silencing the voices of scheme participants across regional, rural, remote and very remote Australia. Those voices—and we'll hear one shortly—would otherwise be able to really build up and develop the scheme to fulfil its potential. Denise, over to you.

Mrs Kay: Good morning. Thank you for the opportunity to speak to you today. I'm the senior disability advocate at the Great Southern Community Legal Services, and I've been in this role for 18 years. Since the rollout of the NDIS in the Great Southern region in 2019, it's been one of the most challenging matters we assist with. As mentioned, I'd like to provide a short example of the impacts of the NDIS in our region, the necessity of place based support, and the barriers that are faced by those seeking to access the scheme without such support.

Five years ago, a family sought our assistance relating to NDIS planning for their son. At the time, we were not able to take on new clients, as we were at capacity. We provided basic information and suggested they try to self-navigate and come back if it got worse. Sadly, this is something we see more than we would like. While they managed to get onto the scheme, after five planners and more plan changes, they needed urgent help. The now teenage son's profound disability was increasingly raising safety concerns both for him and for the family. Despite these safety concerns, funding only permitted single-person care part of the time—continuing to put lives at risk. This was exacerbated by a lack of allowance for their regional location, which increased costs, which then, therefore, decreased hours of care. Both parents gave up work to support their son full time. The scheme simply gave them no option. They came to us for assistance with the complaint process. We were able to assist with this and help them navigate yet another plan review, following support to speak with senior leadership at the agency. However, the resulting plan still did not allow for two-person care nor sufficient funding for travel. We then also assisted the family through the external review process. We were able to assist, walking alongside the family through the AAT process. Despite no specific funding, our legal service provided oversight and support to the advocate to do this. As we progressed through this process, we also partnered with Legal Aid WA to assist with the AAT representation.

The litany of errors from the NDIS in dealing with this family has been nothing short of a farce. Countless planners and plans, and parents and support workers harmed through careless or negligent decision-making, all added to the emotional trauma for the family. The only saving grace at this time is that nobody has been killed through this display of utter incompetence. Without our ongoing face-to-face help, the clients tell us, they would have given up at multiple points. It's quite probable that the poor plans would have resulted in significant injury or worse. Fortunately, the resulting AAT plan was adequate, long term and sustainable—all sorted after 3½ years and in excess of 300 hours of advocacy time. Well, it was all sorted until a couple of months ago. Our service has recently been contacted by this family again. After a couple of years of reasonable operation, the plan has again been reduced by the NDIS. Sadly, our assistance at this time is limited to helping them seek external NDIS appeals advocacy, as our own capacity has been reduced through limited funding.

We noted in the submission the desperate need to increase funding for NDIS appeals, both legal and advocacy, and broader NDAP funding. This simply must go to regionally targeted advocacy and legal services to prevent location being a further barrier to scheme access, entrenching and exacerbating existing postcode inequality. Services like ours are turning away more people seeking NDIS help than ever, and there are large areas of regional, rural and remote Australia without services at all.

CHAIR: Thank you, Ms Kay and Mr Lewis, for your presentation and thank you for the support you have provided to families. Obviously there is great need. At this point I'd like to ask Mr Conaghan if he has any questions.

Mr CONAGHAN: Firstly, thank you all for the work you do in the community legal services or centres. I couldn't agree with you more that you don't get enough funding. I met with your peak bodies down in Canberra recently. You do just a wonderful job, on the smell of an oily rag. I'm fairly confident that we're bipartisan in that approach—we know what you do and we do everything we can to assist community legal centres to do their work. Ms McKinstray, I think you described it best: we have to go backwards before we can go forwards. I should recognise that when a participant gets the right package and it is delivered by the right service provider, it is life-changing. We all agree with that. But you described some providers as 'sharp' services. I call them dodgy.

Ms McKinstray: I was being nice.

Mr CONAGHAN: Yes. Do you think that properly funded advocacy would weed out a lot of those sharp service providers?

Ms McKinstray: I do, yes. The reason I think that is that we have seen that in some ways. I can anecdotally say that. Recently, in a local community up here, we've just restarted having much more of a presence. I feel like it seems to put some providers a bit on notice when they think there are advocates sniffing around a bit. If we can build that relationship and build the rapport with the local community too, and they have a trusted person that they know is on their side—we're not here to make money for our own business or anything like that or whatever—I think that that has a very strong link in. If we can get a community member to say, 'I just need to talk to the advocacy service about that,' when a provider knocks on their door, for example, I think that's a massively empowering thing for that community member, and it gives them a place to go to get that safe, independent advice that will look out for them. I think it's superimportant. So, in short, yes, I do feel like it would have an impact.

Mr CONAGHAN: We've all heard the horror stories about people abusing the system, abusing the funding—effectively, cases of fraud. Do you think there's enough oversight, particularly with unregistered service providers? That's a question to anyone.

Ms McKinstray: That's a very difficult question. I go back to the Quality and Safeguards Commission. As an advocacy service, potentially as legal counterparts, we've seen it pretty much as a toothless tiger for a lengthy period of time. When we do support people to make a report to either the fraud team or the commission there's a lengthy process in getting anything back, so people are left hanging, asking, 'And what happened?' That's even with other providers—to actually report another provider. They kind of say, 'Nothing really happens, so what's the point of making my sixth complaint about this particular provider?'

I'm loath to go to registered versus unregistered. I have a personal opinion, which I won't raise. I think you get good and bad whichever barrel you're choosing from. Personally, I think there needs to be some kind of greater oversight with an unregistered provider. The swing from registered providers to unregistered providers now is huge. We're looking at a very small percentage being registered providers. That's often because the registration process is onerous—and so it should be—but it's also because it's very lengthy; there are lengthy delays with it as well. I don't think there is the robust oversight of unregistered providers, in my professional opinion.

Ms J Harrison: I might just add to that and go a lot broader. Everything that can go wrong does go wrong in 4Rs Australia in relation to the NDIS. What you're talking about is one of the areas, but there are many others. There's been discussion about underutilisation of plans, workforce issues, lack of access to advocacy—which we're all talking about. Advocacy really is one of the magic bullets; it's one of the things that can be very correcting in multiple domains. That includes issues about abuse of NDIS participants and a range of other things. The implementation and design of the NDIS for 4Rs Australia imagines things work okay and the wheels should not fall off anything. Well, the wheels fall off everything all the time. In terms of the suggestion by Anne about going back, that is one of the things: the perspective needs to shift to being realistic. People are not going to get their rights otherwise. They're not going to be able to self-advocate without assistance. They're not going to come to committees like this. They need conduits. Multiple forms of advocacy are needed.

Mr CONAGHAN: Could I go to a point that you made, Ms Harrison, in relation to the advocacy for the prevention of family violence. I have a shadow portfolio responsibility on the prevention of family violence. This is a question for all of you: how much of your time is spent helping or advocating for domestic violence victims or survivors?

Ms J Harrison: Across community based legal services, domestic and family violence appears in multiple ways. In terms of the safety of victims and survivors, including children, I would say that all community based legal services are aware of those issues. Many are providing direct assistance or are referring to other legal services, other support services or safe houses, where they are available, et cetera.

There are also contextual issues. In many 4Rs communities, there are no domestic and family violence safety plans. The community itself doesn't have a plan. Nothing has been facilitated. Everything's being delivered from the city. It also comes up with Aboriginal and Torres Strait Islander legal services in a different way. Their service provision is strongly focused on criminal defence work. It's strongly flavoured there, and we're very aware of that in the Northern Territory with the number of deaths due to domestic and family violence. That particular point in the 4Rs submission was strongly emphasised by the National Family Violence Prevention and Legal Services Forum, which had input into the submission and asked for that to be strongly highlighted.

CHAIR: I'd like to now invite Senator Steele-John to ask his questions.

Senator STEELE-JOHN: I want to ask a question, first of all, to the community legal services. If there's anybody else who wants to jump in on this, please do. Have you been able to, as a service, pioneer ways of providing your service to the community in a way that is culturally safe? If so, what are the practices you've implemented that you would recommend that we, as a committee, recommend to the agency that they implement across the board?

Ms McKinstray: Maybe one of the best ways to explain that is through a case study. We did some work with the Maningrida community some time back, 12 months or so ago, where we had a number of people on the scheme that required medical attention in Darwin. The only way to get out of the community through the wet season is to fly. There was no accessible lift for them to get onto the plane. So for however long, those people were not able to access things. They would either have to wait until the dry season and see whether there was a vehicle transport that they could use, or they would just wait. Our advocacy service spent quite a bit of time in the community and worked with members of the community to put together a submission and fight for an accessible wheelchair lift. We were successful in getting that, and we've now got people from Maningrida being able to fly into Darwin when they need to fly into Darwin; they can actually access the plane.

Going to your point, in terms of how I think that's been successful, I think that when we're working in communities it's incredibly important to build rapport and trust with the people in the community. If we don't have that, it's really obvious that things don't move. It's like you hit a brick wall. Having the opportunity to be present and for people to see you—that can be the simplest of ways. We could put up something in a clinic that says: 'As an advocate, I'm here on "this day". If you want to have a quiet chat, we can do that.' Being present, speaking with people, getting some wins, and building the rapport and trust is the most powerful tool that we have in our back pocket, to be really honest.

I could tell you that we could develop all sorts of tools. I have recently been looking at developing a tool around how we can culturally and appropriately provide information regarding the NDIS to people. I've gone back to the drawing board and thought: 'Do you know what? I can develop the best learning tool in the world, but, if people don't come to me to sit and listen to that, what's the point?' I have to do that, and I have to build some relationships before that.

Ms J Harrison: I could add a little to that, and then I think Great Southern Community Legal Services might have something to say as well. It really doesn't help things along that the Aboriginal and Torres Strait Islander legal services and the family violence prevention legal services are excluded from the advocacy and appeals program funding. Closing the Gap priorities say that should not be happening, so something needs to be adjusted. The funding needs to increase dramatically, there needs to be an application of Closing the Gap principles to who can participate in that funding, and legal services which are trusted by Aboriginal and Torres Strait Islander people need to be recognised and supported. I think Brodie and Denise might have something to add.

Mr Lewis: On this particular question, our general answer would be to endorse the message in our submission, which is, as Judy said, that there is a network of existing myplace providers through our legal sector on the ground across Australia, including our colleagues in the ACCO sector—our ATSILs and FVPLSs. As a local, place based provider in the Great Southern, we work in partnership with our ACCO colleagues and Aboriginal-specific service providers wherever we can, where appropriate. We have dedicated team members, local Noongar staff who work in community. But, in terms of a specific answer to the senator's question, it's going to be different in every part of the country and that's why a local, place based response—place based in the sense of both location and Indigenous community—is critical here.

Senator STEELE-JOHN: Thanks so much for those responses. Can I also ask you to briefly share with us any challenges that you've experienced or supported people through in relation to providing NDIS services to those within the NT justice system. Are there any recommendations you would like us to make to ensure that the NDIS plays the maximum role it can in diverting people from coming into contact with the justice system?

Ms McKinstray: Probably the best way I can respond to that is to give you an example of a gentleman in the justice system, currently incarcerated, who is in his 50s and has a history of an acquired brain injury, which he got as a young child. Most of his life would have been spent in the justice system. I think there was about a four-year period where he wasn't in some way incarcerated or part of the community corrections system. We received a referral for him because he was requiring supports when he was released. We were asked to assist him with an application for access to the scheme. This is potentially something that we haven't touched on. He had a very strong report from a psychologist that confirmed that this gentleman did, in fact, have a diagnosis of an acquired brain injury and therefore a disability. The report provided great detail about how that affected his life and so on and so forth.

I contacted the NDIS justice liaison officer and talked through this person's situation to work together on getting access for this gentleman. I was basically told: 'Just submit that report. It is so well written and so detailed that it should cover everything off.' That was great; that meant we didn't have to go hunting for evidence, which was going to be very difficult as he'd lived in multiple rural and remote communities.

I put in the submission. It was rejected by the NDIS. It came back as, 'No, he doesn't meet the criteria.' I pulled that apart in multiple ways, trying to find what they wanted. The bottom line was this: he requires further assessment. He's incarcerated, so an assessment of his daily living skills is going to be quite skewed because of the environment he's living in. Not only that, but there is nobody that would fund that assessment for that gentleman. We went everywhere to see whether that was possible. There's been no luck in that. What I have done is go back to the liaison officer. We basically had to look at the reason behind the ineligibility. What they narrowed it down to was, 'This person hasn't participated,' pretty much. 'There's not enough evidence to say that he's participated in programs that could assist him with his disability and improve his life,' or whatever.

There's a waitlist for any particular programs in the justice system to actually access any therapeutic program. He's been on the waitlist for about 2½ years just to get into the program. It's only since I got involved and got the justice liaison person involved that that gentleman is now on there. I still have to wait. We still have to do a resubmission. I have no idea what that outcome is going to be for that gentleman. We still don't have a way to fund his assessments.

Senator URQUHART: I have a very quick follow-up. In terms of the application then being rejected, you were told that it didn't meet the criteria, but you weren't told the reasons?

Ms McKinstray: They do send you a letter. It's quite convoluted, unless there are some reasons it's fairly black and white which are quite easily discernible. One of the criteria for eligibility is that your condition is stable because you're undertaking whatever medication might stabilise things or you're undertaking regular sessions with a mental health professional or some other program that assists that. This gentleman is incarcerated and couldn't access them, so he didn't meet that criteria.

Senator URQUHART: But I guess my question is: are the criteria normally laid out as to why something has been rejected?

Ms McKinstray: Yes. It does explain it in the ineligibility letter. It will state it.

Senator URQUHART: I'm looking at some others on the panel who are going, 'Hmm, I'm not sure.'

Ms Rosales: From our experience, when somebody applies for access to the NDIS and they don't meet eligibility, I would suggest that, at the first instance, that rejection letter is not as—

Senator URQUHART: Clear?

Ms Rosales: clear or thorough as it could be. From our experience, it's not until somebody reaches the explanation from the internal review outcome report that that's clear. Sometimes it even has to come from the first statement of issues at the AAT in order to determine what the agency thinks is missing from that application.

Senator URQUHART: So you'd have to go through a whole process, quite often, before you actually find out what the rejection is about, which actually I think should be at the front.

Ms Rosales: Yes. I'm hopeful that, with this NDIS review, that transparency and that clarity and the consistent decision-making are going to come to the forefront.

Ms McKinstray: I think that it might be worthwhile noting that potentially there are discrepancies between information between one site and another site around that. In our experience, generally in that ineligibility letter it will say: 'You've met this criteria. You've met this criteria. However, we don't believe you've met this criteria.' Then that's that decision of—what they're saying is: 'You haven't met this. You've got X amount of days to actually gather more evidence to put that in.' If the time goes past or if you're not able to get that information, then, yes, it goes to that internal review stuff. I think we have to say, in all honesty, that there is a lot of inconsistency in the information you get from the NDIS no matter where.

Senator URQUHART: That's useful. Thank you.

CHAIR: Senator Steele-John, we are running over time. You did have one more question that you wanted to put to the community legal service representatives.

Senator STEELE-JOHN: Yes. I'll ask them to take it on notice, if that's okay. It is a question partly for all of you and partly for the 4Rs alliance. The one for all of you is: would you be able to provide the committee with any data or case studies that you are aware of or possess in relation to the wait times that people experience to access assessments or specialists in relation to NDIS applications? I want to get a clear idea of what people are facing at the moment in relation to accessing those services that are necessary to be able to make a successful application or engage in a successful review. And then, specifically for the 4Rs alliance, in your submission, at recommendation 3, you talk about the need for the rights of folks in 4Rs communities to be explicitly mentioned within a disability rights act. I'd be really interested to know what kind of specific language or clauses within that proposed act you would like to see.

CHAIR: You've given our panel some homework as well, so thank you very much, Senator Steele-John.

Senator STEELE-JOHN: Thanks, Chair. Thanks to the witnesses as well.

CHAIR: At this point, we'll wrap up. I'd like to thank you all for your time today. It has been very useful and, I think, quite eye-opening. Thank you very much for your time.

Proceedings suspended from 10:35 to 10:48

BROWN, Ms Julie, NDIS Support Officer, Danila Dilba Health Service

FINEGAN, Ms Kate, Senior Manager, Chronic Disease, Danila Dilba Health Service

PATERSON, Dr John, Chief Executive Officer, Aboriginal Medical Services Alliance Northern Territory

SUMMERVILLE, Dr Jenny, Policy, Research and Advocacy Manager, Aboriginal Medical Services Alliance Northern Territory

CHAIR: I'd like to welcome representatives from the Aboriginal Medical Services Alliance Northern Territory, AMSANT, and Danila Dilba Health Service. I understand that information on parliamentary privilege and the protection of witnesses giving evidence to Senate committees has been provided to you. Do you have any comments to make on the capacity in which you appear?

Dr Paterson: Welcome to Darwin, Larrakia land. As per our custom and tradition, I just want to acknowledge the traditional owners, the Larrakia people, and their elders past, present and emerging, and thank them for allowing us to come back for this very important hearing on their country today. We've put in submissions along with one of our member services, Danila Dilba, who are present with us today. They are one of AMSANT's members. We thought it would be appropriate for the peak Aboriginal community controlled health service of the Northern Territory to provide a submission to the inquiry, and we'll elaborate further. I'll make a short statement and then we'll be happy to take questions.

Ms Finegan: Our Aboriginal disability liaison officers come under my role. We came here to represent some of our clients and some of the stories they've told us.

CHAIR: Thank you. I would like to invite each organisation to make an opening statement.

Dr Paterson: Thank you, Chair. AMSANT is the peak body for Aboriginal community controlled health services in the Northern Territory. Our members deliver almost three-quarters of comprehensive primary health care contacts for Aboriginal people in the Northern Territory. The model of comprehensive primary health care adopted by our members reflects a holistic understanding of health embraced by Aboriginal people. As such, comprehensive primary health care is inclusive of a broad range of integrated services, such as medical, allied health, services for children, families and young people, disability support services and age care.

Of our 12 full members and 14 associate members, seven are registered NDIS providers. Several have representatives providing evidence at this hearing, and AMSANT acknowledges that they are better placed to provide specific examples of participant experiences at the grassroots level, noting that evidence AMSANT representatives provide today is informed by consultation and input from our member services over several years and speaks to the systemic issues that impact NDIS participants' experience in the Northern Territory, particularly for Aboriginal people. These views have informed the recommendations put forward by the National Aboriginal Community Controlled Health Organisation, otherwise known as NACCHO—that's our national peak—in their submission to this inquiry and AMSANT's previous submissions, including, firstly, the 2023 submission to the NDIS review panel of a future model for NDIS that meets the needs of Aboriginal people with disabilities in the Northern Territory and, secondly, the 2019 submission in response to the *NDIS Thin markets project* discussion paper.

There are three key points AMSANT would like to emphasise. Firstly, the NDIS has created a fragmenting force in the Northern Territory, with participants having to navigate a complex and culturally unsafe system, frequently relying on our member services to support this process. Secondly, the introduction of external competition has created duplication and fragmentation as opposed to an integrated approach to supporting participants. For example, the fly-in fly-out supports coordinators—who'd previously had no relationship with communities—have leveraged the commercial opportunity, yet then rely on our member services in the Aboriginal community controlled health sector to actually carry out the true work of supports coordination. Thirdly, participants are charged more than necessary in addition to the NDIS price guide, underestimating the true cost of remote service delivery. The fly-in fly-out model the scheme has promoted in the Northern Territory results in NDIS participants being charged excessively for transport for providers and equipment.

For these key reasons, AMSANT supports the recommendations of the National Aboriginal Community Controlled Health Organisation. Those recommendations are:

1. A long-term, stable block funding agreement (with the Commonwealth and State governments) should be in place to ensure the ACCHO sector can build its capacity to sustainably deliver NDIS services in thin and culturally thin markets.

2. ACCHOs and ACCOs being funded to deliver navigation services, including Remote Community Connector, Evidence, Access, Coordination of Planning Officers and Aboriginal Disability Liaison Officers, and national coordination of these programs being transferred from the NDIA to NACCHO.

3. All Aboriginal and Torres Strait Islander participants receiving as default, funding in their plans for support coordination, including Return to Country.

Thank you.

CHAIR: Thanks. I'd now like to invite Danila Dilba to make a presentation.

Ms Brown: Good morning, everyone. I'd like to thank you for the opportunity to speak today in relation to the inquiry into NDIS participants' experience in rural, regional and remote Australia. I'd like to acknowledge the Larrakia people, the traditional custodians of the land we're on today, and pay my respects to all elders past, present and emerging. I am a Larrakia woman. I was born in Darwin and still live here. I currently work at Danila Dilba Health Service as an Aboriginal Disability Liaison Officer, otherwise known as an ADLO.

Danila Dilba is an Aboriginal community controlled health service that delivers primary health care in the Darwin region, which is an outer regional area of Australia although it's a capital city. We are currently funded until December 2024 for two ADLO positions at Danila Dilba. The main purpose of our role is to support Danila Dilba clients throughout the application process to access NDIS services. We also provide education to internal teams on the NDIS and create connections in the community with various NDIS programs and services. Once clients receive NDIS funding, we are not funded to support them. However, to ensure our clients continue to receive culturally safe support that meets their needs, we continue to check in on a six-monthly basis and advocate when the need arises.

The current short-term funding arrangements and lack of funding to support clients once they gain NDIS limits our capacity in service delivery. In supporting clients through this NDIS process, the most obvious barrier to clients accessing and engaging with the NDIS is the cultural safety of the process and services being engaged. There is often an obvious lack of cultural understanding and awareness among staff within the system. An example of this is when an LAC, local area coordinator, was talking to a client. The client didn't understand. The LAC began raising their voice at the client as if they were not hearing or were incapable. The client walked out on this discussion and reported feeling upset and not wanting to engage any more in the process. English was not this client's first language or second or third. The client didn't understand due to the language barrier and for no other reason.

This lack of awareness around language differences creates many barriers within the NDIS. These language barriers are not considered during assessment and access to the NDIS. Clients are unable to do their NDIS funding to access language interpretation services. They can only use funds to support disability related communication barriers. This creates multiple barriers and disempowers individuals to access the support they need with complete comprehension.

Many clients from Danila Dilba often speak about feeling uncomfortable in confined, clean, white spaces. However, these are often the spaces where conversations with NDIS services occur. If more cultural awareness was embedded in the system, services and organisations might be more likely to yarn the clients in community settings outside or even in someone's front yard.

When considering health and social outcomes for Aboriginal people, especially in regional, rural and remote areas, social and cultural determinants such as overcrowding, intergenerational trauma, systematic racism, discrimination and food insecurity all impact on an individual's ability to live a healthy life with or without a disability. These factors are unable to be improved or even considered through the NDIS, putting many Aboriginal regional, rural and remote participants at a disadvantage. The pricing for NDIS services given to participants doesn't take these factors into account. This can influence the capacity of services being able to deliver the intended outcomes.

Other frustrations that our clients discuss with us include timelines for applications. Clients are currently waiting over eight months for an application to be assessed, sometimes even longer, especially if their application doesn't get approved. We have to get more evidence, and that takes longer. Potential participants reported a lack of trust in the system if it takes so long to find out if they can even use the system. Planning meetings that occur over the phone with clients disempower individuals through a lack of understanding of local situations, especially if an ADLO is not involved. Clients often get confused with the introduced community connectors meetings. There are no free services that clients can access in the interim in regional and remote areas, and clients think they are being moved back to community.

Other than embedding cultural safety and responsiveness within the NDIS system, improving communication, information-sharing and integrated care is essential for our clients. Many Top End Aboriginal people may live not only in Darwin but also in remote areas of the Top End at different times of the year or different times in their lives. This type of individual mobility makes it essential for different providers, with the client's consent, to have access to the individual's NDIS plan to allow appropriate supports and resources to be mobilised.

Finally, once clients are able to access the NDIS, it is not uncommon to have clients not accessing any of their NDIS funding, as they have not been allocated a coordinator of supports, or COS, and they do not understand the system. There is also limited access to culturally safe NDIS service delivery in Darwin, impacting on the supporting structure that our population can access. To better enable support for clients throughout the NDIS, all Aboriginal and Torres Strait Islanders should receive, as a default, funding for support coordination. A block funded sustainable long-term funding model is essential to enable ACCHOs to build capacity and deliver culturally safe services in the disability sector in both navigation and delivery of NDIS services.

CHAIR: Thank you very much for that statement. Dr Paterson—actually, you could both answer this question—you talk about the need for block funding. Could you expand on that?

Dr Paterson: Sure. Our experience working in the comprehensive primary health care sector and with the funding that we receive from the Commonwealth department of health is that it has become a bit more flexible, if you like. The funding comes from Commonwealth health through NACCHO. NACCHO then funds the peaks. The Commonwealth directly funds our member services, the Aboriginal community controlled health services, on the ground. So that doesn't come through NACCHO apart from some other specific program funding. Our experience is that when we do have the flexibility of block funding, rather than what we call body part funding—that just doesn't work. It's not suitable. It doesn't fit with the funding flexibility that we need.

CHAIR: Why doesn't it? Can you explain why it doesn't?

Dr Paterson: It's too restrictive. It doesn't give us the flexibility. If our member services can get block funding for delivering NDIS—using NDIS as an example—providing all those services and support services that Ms Brown articulated, I think that would be a better way of getting better outcomes for those clients who need those disparate disability services. If they're restrictive we have barriers of transferring funding and not enough funding. But if we can get the block funding allocated to our member services, that gives them flexibility when they do get some of those unanticipated consequences that might arise, requests that aren't part of the funding agreement that government gives us. That's our preferred model of funding. We've been advocating for decades for governments to fund us like that. We're strong on accountability. We're strong on compliance processes and reporting back to governments. But in terms of the funding arrangements, we find that body parts just does not work for us.

Senator URQUHART: You say that you've been asking for a number of years for governments to provide the block funding rather than sectional funding.

Dr Paterson: Yes.

Senator URQUHART: What's been the rationale or the feedback that you've received as to why that can't happen?

Dr Summerville: The rationale around the NDIS is that there has been a very strong dedication to the notion of individual funding.

Senator URQUHART: You mean individual to the person?

Dr Summerville: Yes. I can show two perspectives here. I can speak as a person with a brother with disability, which is what, as an advocate, we've campaigned for for years and years. However, the flipside is that in remote communities and for Aboriginal people it's a model that has its issues. For Aboriginal people even the notion of an individual outside of family, community, country, does not necessarily align. Secondly, for Aboriginal people in the Northern Territory, particularly in remote communities, there's not enough in terms of clientele for NDIS to really make a sustainable foundation for running the service.

With individual funding, just to give an example, let's say we've got 10 people. There's not enough in that to even hire a coordinator for a team. This is where, in remote communities, it's so important that we have some foundation funding so we can get the team, ensure that there is the management and ensure that we can build the policies and build the system. It's a whole different billing arrangement to the way Aboriginal community controlled health services have run. It requires quite a different system.

CHAIR: In order to run that system—I mean I can see it gives you greater flexibility—I suppose there's that level of trust in you knowing best, but also ensuring that the money that is provided is well spent. How do you suggest that if that was to go ahead that there are checks and balances on the use of dollars?

Dr Summerville: Our services have hundreds of funding agreements. The checks and balances have been there for years and years. We report to KPIs in terms of health and other services. I think that's a system around policies and practices. The other thing to point out at the moment is that many of the services to people with disabilities are provided by our members and supported by our members whether or not they're charging the NDIA. Our services have allied health teams who will do therapy support. They have public health and population health teams who are frequently supporting people with disabilities out in the community. This is where, to have the foundation funding to support that provides them with another income stream. What's currently happening is they're using health funding to do the work of the NDIS.

I can give you an example of one of our member services. Before I worked for AMSANT I did a consultancy for this particular member service and they've given me permission to tell the story. Essentially, they had $20,000 from one of the NDIS readiness grants. It was one of the grants for organisations to get a consultant to do the work to see whether it was feasible and, if so, what it would take to establish an NDIS business. I did that work. They were already doing the job. They had a public health team that were already supporting people with disabilities. It was quite feasible in terms of how many clients they might have et cetera. What they didn't have was the money to initially hire a coordinator, let's say for a year, to establish the processes, the policies and the systems in order to become an NDIS provider. That barrier right there means that they're still doing the same work, but they're still not an NDIS provider. The second thing that was happening to this service was a supports coordinator from Darwin would fly in. The service would pick up the supports coordinator, go and locate the clients for the supports coordinator, sit with the clients and facilitate the conversation with the supports coordinator, and yet the supports coordinator was the one making the money.

CHAIR: Do you think that there is a difference between what the metropolitan areas need and what the rural and remote areas need in terms of the way funding is allocated?

Dr Summerville: Definitely. The thin markets in remote communities is a very big question there. I'd also note that even for Darwin, because there's so much transience in the Northern Territory, people will come into Darwin from all of the different remote communities and also from Alice Springs and regional centres. Hence, services like Danila Dilba also service the remote population. I'd say it's a more complex question than just Darwin versus remote in the Northern Territory.

CHAIR: Ms Brown, did you want to add anything?

Ms Brown: No, I think Jenny covered it all.

CHAIR: There are obviously challenges and obstacles for you servicing regional and remote. I'd really like to understand from you if you can give me a couple of those key challenges and whether you have any suggestions about how we overcome those challenges in supporting people with disability in remote locations. I know that's a big question.

Dr Paterson: You would have heard this at other locations. Workforce generally is our No. 1 challenge in the Northern Territory. I think that's nationwide in all different sectors and industries. We're progressing that through our own advocacy work and meetings with the Commonwealth's Territory-relevant agencies and departments to see how we can potentially look at solutions to fill that workforce gap.

CHAIR: What is the extent of the workforce gap at the moment?

Dr Summerville: Substantial. It's a hard one to tell. Aboriginal community controlled health services have a very broad workforce—everything from disability support roles through to doctors, nurses and Aboriginal health practitioners. It's very diverse, and we don't have a great dataset to look at that. The best one is the OSR. I couldn't tell you off the top of my head, but I can certainly provide that in terms of some of those things.

Dr Paterson: We can take that on notice and get back to you on that one.

Dr Summerville: Just anecdotally, from the last conversation we had—most of our CEOs can, off the top of their head, talk about how many GPs they have—we had about a 50 per cent vacancy rate.

CHAIR: There's the problem; now we need the solution.

Dr Paterson: Back to your earlier question about the cost to deliver services in some of the most remote parts of not just the Northern Territory but other parts around the country: it comes at a cost. I don't think there is appropriate weighting from governments. For example, previously there was a model of funding that would take into consideration a weighting around language, the high cost of fuel and getting from A to B, and the additional cost to deliver services if you have to bring in additional resourcing to explain something. The service provider may have to bring in appropriate experts and specialists to assist them in dealing with their client's request. Previously there was a weighting, and recently you would have heard the Chief Minister of the Northern Territory advocating that the Commonwealth needed to consider this additional weighting to deliver services right across the board to remote communities. The further out you go, the more expensive it becomes to deliver those services.

It's something that, again, we advocate for and raise at various forums, like this. We understand the national economy and the state that's in, but if we're going to make—and I should just say that I also sit on the Joint Council on Closing the Gap, co-chaired by Minister Burney and Pat Turner. I get to see the nationwide view and perspective and then look at it from a Territory perspective, because I sit on all these other committees. I get representation from a number of people, including remote communities, and the one message they're saying is: 'We've got to reinvest in the bush.' About the Alice Springs situation they're saying, 'If we're going to alleviate some of those problems and issues, we've got to invest back in the bush.'

CHAIR: Thank you. Over to you, Senator Urquhart.

Senator URQUHART: To both organisations, could you give me an overview of the size of your services, including how many NDIS participants you have—I think it was Danila Dilba who said you assist with funding but you don't provide funding for support, so I'm not sure how you can answer that—and how many staff you have. You have two, I believe?

Ms Brown: Yes.

Ms Finegan: We have two, yes. Because we currently only have ADLOs, we assist in the assessment process; theoretically, once they're on the NDIS, we're not funded to support them anymore. However, because of our understanding of the thin markets, the lack of culturally safe services within Darwin and our clients' understanding of the systems, our staff continue to support them. They keep in touch with them, make sure they're happy with the service provision and support them if they need that changed.

Senator URQUHART: So that's all done at the side of a desk.

Ms Finegan: Yes, that's all done off to the side. At the moment, there are about 80 people—in terms of client numbers, obviously it's a bit different. In terms of the two ADLOs that we have, we've got 80 people within our waitlist, but they can take on five clients at a time and it takes up to 20 months to get them onto the system.

Senator URQUHART: Eighty on the waitlist?

Ms Finegan: Yes, and that list is going up. So that's only people within Danila Dilba who have been referred within our service because they might need help to get on the NDIS. Often there will be other times where they might visit somewhere else, see someone going to another service provider to access it and then realise they need to step in and support them as well.

Senator URQUHART: And you cover across the entire Territory?

Ms Finegan: No. We're Darwin only.

Senator URQUHART: Only Darwin?

Ms Finegan: Danila Dilba is basically Darwin out to Humpty Doo—if you know that geographic area.

Senator URQUHART: And you've got 80 people on the waitlist just in that area?

Ms Finegan: Just to access the ACCHS, yes.

Dr Summerville: At AMSANT, we're actually the peak body for Aboriginal community controlled health services, so we don't deliver services to the community directly. Danila Dilba is one of our members. Our members cover Darwin and every regional centre, plus about half of the remote communities in the Northern Territory. In terms of the question of who and how many, seven of our member and associate member services are registered for the NDIS. I can tell you that in 2022 at least two were delivering as unregistered NDIS providers.

In terms of the number of participants, I can't give you that for the Territory, in terms of our particular members. I can tell you, however, that all of them are definitely delivering therapy. All of them are actually facilitating the process of getting onto the NDIS in some way or another. Trying to coordinate assessments to get the diagnosis of a disability is a massive challenge in the Northern Territory. We don't have the workforce. There are potentially so many people out there who should be on the NDIS and haven't even got a look into the system.

Senator URQUHART: Is that purely because there aren't the services there for people to access, or is it about the reach of where you can get to?

Dr Summerville: Sorry; I'm unclear on the question.

Senator URQUHART: What is the reason that there are a lot of people out there who you're saying should be on the NDIS but aren't?

Dr Summerville: They haven't had a diagnosis, because of the access to specialists, and also culturally safe services just aren't here in the Northern Territory.

Dr Paterson: Going back to the block funding question that you asked, I think the other issue to understand is that, when clients come to our member services, they don't have just one issue. Usually, there are a number of chronic illnesses that require attention. Someone might come in who is recovering from a stroke; they could have diabetes, which will perhaps require the amputation of a limb, or other chronic illnesses. This is another advantage of that block funding—so we can have the flexibility and get the appropriate experts while we've got the client in the clinic so that we can do that whole health check.

CHAIR: The challenge with the NDIS, which is why we're here today, is that some of those things are related and some of them aren't. To suggest that it should be more broad-based—that's a challenge, because the NDIS is specifically funding people with a disability.

Dr Paterson: As an example, because I want to drill down a bit more on that, if somebody has a stroke they might need speech therapy support. Is that an NDIS—

Ms Finegan: It depends on the definition—how it's defined and who defines it.

Dr Paterson: If there is an amputation, we're going to be looking for the appropriate supports to assist the client to get their mobility back.

Senator URQUHART: Dr Paterson, one of the recommendations that you talked about was the block funding, but you also talked about an Aboriginal community controlled organisation being funded to deliver services. The chair asked about workforce issues and you said they were huge, as they are, I think, right across the country, but that's exacerbated in rural and regional areas. How do you think you could do that better if you controlled the funding to deliver the services and the workforce?

Dr Summerville: It's growing a local Aboriginal workforce, and the NDIS has huge potential around that. Many of our member services have actually chosen not to get into it, because of the complexities with billing and things like that, so there hasn't really been the foundation to provide the training, the wraparound support and the coordination. All of those issues come back to the way it's funded and the fact that there's no foundation funding for them. If there was, for the training of a local Aboriginal workforce, it could be a massive employment opportunity for local people in the Northern Territory. The potential is huge. It's getting that off the ground, and the complex funding model, that's actually the barrier in many respects. I want to emphasise the issue with the block funded model. Ultimately the preference is for block funding, but it could also be blended—and we actually do this in health care—with Medicare. You could still have an individual participant plan that meets the needs of that individual, but you could have funding that enabled the employment, for example, of allied health on the ground in communities to get continuity, rather than the FIFO model. It opens up all of those opportunities to really have a community based model.

Senator URQUHART: When you talk about growing your local workforce within communities, what does the job look like within the NDIS? What sort of things would you look at growing that local workforce to provide?

Dr Summerville: The NDIS is quite broad, as is the nature of disability, so it would have tangents. Allied health and therapy is an obvious one, but also allied health assistance can be really important. These could be locally employed and have pathways into allied health for Aboriginal people. More broadly, obviously the disability support workforce is quite diverse, but that could definitely be a foundation workforce. I think looking locally on community based, it's also a blend of what our services might deliver, keeping in mind that there's one service per region. Those communities own that service. But there also may be other providers of things that don't necessarily—like cleaning services. That might be a council. That does happen. Councils do support that workforce. So it would be a blend at a community based level, but if we had that kind of foundation so we know we can employ people X number of times without having to worry about whether someone has left town and then you're not getting paid. If that were there, I think there's huge potential to grow that local workforce.

Senator URQUHART: Thank you. Do you want to add anything to that?

Ms Finegan: My other thought around that is that at Danila Dilba we have a workforce that is called Indigenous outreach workers. Their role is quite varied, but they do a lot of that coordination that's very culturally appropriate with a lot of our clients. That workforce would definitely roll into some NDIS coordination and supports. They don't have the clinical understanding, but they know the people, they know the networks and they are great at working with our clients. That's a workforce that there's no specific funding for.

Senator STEELE-JOHN: Thanks so much for your evidence so far today. In your submission to the disability royal commission, you made a number of recommendations around the including of culturally appropriate services into the NDIS. The agency has been sharing with us that they've achieved some of these goals. I'm often referred to the particular way they approach the Community Connectors Program in relation to more regional and remote communities. I'm wondering about your experience with the agency in the last couple of years. Do you feel like they've improved in relation to the delivery of culturally appropriate services or the support of those services? If there's more work to do—and I bet there is—how might we best recommend it?

Ms Finegan: I can reference one of the statements that Julie made, that the Community Connectors Program has actually got a lot of our clients confused. A lot of our clients think it's around sending them back to community. They're not really sure. Also, because there are such limited services, that's around accessing free services in the interim until they get onto the NDIS. However, none of those services are available, so everyone gets confused in those meetings. They aren't sure what it is for and why they're having that meeting before they get access. That's probably one comment on that aspect. In terms of any other improvements, do you have any other thoughts, Julie?

Ms Brown: None that I can think of.

Dr Paterson: Thanks for your question, Senator. Something we thought might be a good CQI—continuous quality improvement—process in ensuring major funders and service providers at a national and jurisdictional level are hopefully all on the same page and all have a shared understanding of the challenges and issues that we face here in the territory, is we have a forum called the Northern Territory Aboriginal Health Forum. Members of the Northern Territory Aboriginal Health Forum comprise AMSANT—we have the secretariat—the Commonwealth Department of Health, the Northern Territory Department of Health, NIAA. Why NIAA? Because NIAA has funding for our population and communities around alcohol and other drugs and social and emotional wellbeing. We have the NTPHN. Fortunately we only have the one public health network here in the Northern Territory, so it's easier to establish that relationship and do work with them. The more recent one is that we've extended an invitation and asked NDIA to become a member here in the Northern Territory.

I must say that when the NDIA and NDIS first came about we struggled in terms of getting on the same page and having a shared understanding, establishing the relationship. We requested meetings and we were unable to get any traction there, until in recent times there have obviously been some changes in management and other bureaucratic structures. We're starting to feel that we're starting to get some traction. I think it was a wise strategic decision to get them onto the Aboriginal health forum, because this is a high-level policy and planning forum where they can get a shared understanding of where the challenges and issues are, who is responsible and trying to bring some coordination into delivering those sorts of things. We've seen that as a strength here in the Northern Territory.

Senator STEELE-JOHN: We've heard at the committee today and previously in our work that wait times to access allied health professionals and specialists who are required to produce reports or assessments in relation to participants' access or maintenance of access on the scheme are a real challenge in the Northern Territory. Could you share with us your experience of some of the wait times that people have to go through to access those specialists and services, and also the additional costs that that places on them that are not covered by the NDIS?

Ms Brown: I think wait times is one of the biggest things. Being in the territory, the reason for the wait time is usually OT assessments and speech pathologists and stuff like that, because there are none in the territory, or there is only one, and they're completely booked out. Sometimes we have to wait three months for an appointment. That also pushes out the wait time as well. NDIS says that an application takes 21 days to assess, but at the moment we've got a client who's been waiting eight months to be assessed. So there's that to deal with.

CHAIR: You're saying that there is one speech pathologist?

Ms Brown: Sometimes there's none. OTs as well.

Ms Finegan: Who will complete the assessment. A government employed speech pathologist. It's not part of their role to do some of these assessments.

Ms Brown: Sometimes the payment for the OT is not covered.

Dr Summerville: The other layer of complexity, if you look at our remote services and the fact that allied health for those remote services is often funded, some within flexible, but a program called MOICD, which stands for Medical Outreach Indigenous Chronic Disease, funds that program. But it creates a tension, because it's effectively funded for chronic conditions. When the allied health that are visiting their scope to do work around disability is limited. This comes back to that point that we have a workforce that's travelling remotely, and that's under this funding bucket, not under that funding bucket, so the capacity to do those assessments is limited. Not to mention that they're not there a lot of the time. It's outreach.

Ms Brown: Even one of our speech therapists is actually based in London. She gets up at four o'clock in the morning to do our assessments.

Senator STEELE-JOHN: So that I understand your evidence properly, did you just say that in the entire NT there is only one practising speech pathologist? Did I hear that right?

Ms Finegan: There's one that we can access to do the assessments. Is that correct?

Ms Brown: Yes.

Ms Finegan: There's more than one speech pathologist in the Northern Territory. However, in terms of doing assessments to access NDIS, it's the availability. Obviously speech pathologists do many things, not just assess to access the NDIS. They have a very diverse role, and only certain people will choose to do that.

Senator STEELE-JOHN: Of course. In terms of their capacity to do assessments, are there other speech pathologists who practice privately who are available to provide those services, or does nobody in the territory do access assessments other than that one person?

Ms Brown: They do private as well, but as there are only one or two of them and they're in such high demand, they don't have the capacity to see so many people. That's why the waitlist is so long. It's up to three months, at least, sometimes longer.

Senator STEELE-JOHN: What kind of cost is borne by people who need the assessment. How much are people having to fork out to pay for those assessments?

Ms Finegan: I don't have the exact figures. I'm happy to take that on notice and send them to you.

Senator STEELE-JOHN: Absolutely. That would be really useful. And the same for any other specialist services as well. You mentioned occupational therapy. If you have information on wait times and cost barriers, that would be really useful. You can take that on notice and get back to us. It helps us fill in the picture of the additional barriers in the way of people even being assessed for access or provide additional evidence for support that they might need.

Mr CONAGHAN: Thank you all for coming along and giving evidence today. We hear you that you're all asking for additional funding. I think we could find that in the waste and fraud are that we're seeing. We heard an example this morning of unscrupulous service providers enticing people off successful plans onto other plans with gifts of fishing gear and laptops and computers. Probably to you, Ms Brown: is that something that that you see in your part of the world?

Ms Brown: Yes. For the coordinator of supports, there are only a handful that we trust that won't take advantage of our clients. We've heard stories that over on the Tiwi Islands there's a company there that says that they take the clients on fishing trips. They don't, but they still collect the money. They get the clients to sign the paper for it. The clients think that they're signing for the meal, the lunch. But it's not; they're signing to say that they went on a fishing trip that they didn't go on. It's definitely happening.

Mr CONAGHAN: To the whole panel: are you all experiencing that or hearing anecdotal stories of that?

Ms Finegan: Definitely. It comes regularly from the team that there hearing the stories.

CHAIR: How long has that been going on for? Is it just a recent occurrence?

Ms Brown: This has been going on for many years. It's been going on for as long as I've worked for NDIS. My colleague Jason Bonner worked for three years on his own, and he's the one who told me all the stories that he's been hearing from clients.

Mr CONAGHAN: So do you think there's enough oversight, particularly of unregistered service providers? I don't want to pick on them, but I'm going to. Do you think there's enough oversight generally as to the way they operate?

Ms Brown: Definitely not. Even with registered ones, they're the ones who are being unscrupulous as well. It's not just the unregistered ones. I definitely think they need to be checked on. There needs to definitely be more oversight.

Mr CONAGHAN: With those examples, have you or are you aware of your colleagues reporting that to the Commissioner?

Ms Brown: No, I don't believe we have. I think because we feel like it's hearsay, and we don't have any proof or facts, so it's not worth reporting it.

CHAIR: I wanted to mention that, as I'm sure you're aware, there has been a review of the NDIS, and the minister has come out very strongly talking about the need to crack down on fraudulent practices. There will be significant action in this space. We are aware of it, and I think it's crucial that the money that funds the NDIS goes to the participant. I wanted to make sure that everyone is aware that that is an absolute priority for us. It's so unfortunate that this has occurred for so many years. We need to take action, and I'm very pleased that the minister is doing so.

Mr CONAGHAN: This was happening under the coalition, there's no doubt about that. It's not a criticism of governance, but it's happening and we just need to clean it up.

CHAIR: I understand that, and I think that government has a very clear role to play in policing these unscrupulous actions of certain providers. That is something we can talk about with you separately offline. We would be interested to have further conversations with you.

Before we wrap up, I want to thank AMSANT for your submission and ask members of the committee if we can put that on the public record?

Mr CONAGHAN: Yes.

CHAIR: Thank you very much for your time today. It has really been a very interesting discussion.

McRAE, Ms Kim, Tjungu Team Manager, Ngaanyatjarra Pitjantjatjara Yankunytjara Women's Council

POUTU, Mr Tom, NDIS Team Leader, Miwatj Health Aboriginal Corporation

ROSSINGH, Mr Steve, Chief Executive Officer, Miwatj Health Aboriginal Corporation

SOLOMAN, Ms Dianne, NDIS Coordinator, Mala'la Health Service Aboriginal Corporation

WOOLF, Ms Lesley, Executive Health Manager, Mala'la Health Service Aboriginal Corporation

[11:37]

CHAIR: I welcome the Miwatj Health Aboriginal Corporation, the NPY Women's Council, and the Mala'la Health Service Aboriginal Corporation. Thank you very much for your time today. I understand that information parliamentary privilege and the protection of witnesses giving evidence to Senate committees has been provided to you. I now invite you to make an opening statement.

Mr Rossingh: I'd like to start by acknowledging the Larrakia people of Darwin and the Yolngu people of East Arnhem Land, and I pay my respects to their elders past, present and emerging. We've already had an introduction from my colleague Mr Tom Poutu, who is acting NDIS manager at Miwatj Health. Magnolia Yunupingu is unable to make it today due to illness and sends her apologies.

Thank you to the joint standing committee for the opportunity for the opportunity to appear at this public hearing. By way of background, Miwatj Health Aboriginal Corporation is an Aboriginal community controlled health care organisation which has provided acute and comprehensive primary health care services across East Arnhem Land in the Northern Territory since 1992. The fact that we're an Aboriginal community controlled organisation is very important to us and it's very important to our service delivery, because there is worldwide evidence, particularly from the USA, Canada and New Zealand, that when community control is implemented effectively and authentically the outcomes for First Nations peoples are so much better. That applies in other sectors as much as health.

In terms of Miwatj Health, we are a comprehensive health and welfare service. We are anchored by seven clinics across the seven communities across East Arnhem Land. They're all remote, but two of them are particularly remote and on islands. Our services include services within the clinic setting, within other buildings, and also lots of outreach services where we go out to our clients. This extensive service footprint is aided by our knowledge and our buy-in that community control provides us with. It gives us tremendous credibility and reach across the whole of mainland East Arnhem Land.

We've operated as an NDIS provider since 2016, becoming the first nationally appointed trial site for the NDIS Remote Community Connector program in 2017. Through this program, remote community connectors, who are locally based indigenous staff, provide cultural brokerage to NDIS participants along every stage of their NDIS journey. This includes NDIS education and access support, plan implementation, meetings and reviews. We currently employ five staff, of which four are part time, to carry out this program.

Further to this, Miwatj Health offers NDIS support coordination to assist NDIS participants to build capacity in understanding and implementing their NDIS plans. We currently have seven staff in this area, who support 213 participants across East Arnhem Land, and also Yolngu who happen to be in Darwin at any point in time.

Through our daily interactions with First Nations people living with disability, Miwatj Health has listened to the participants we support and strongly advocate on behalf of the communities we represent. Our submission highlights the stories we have heard and the consistent themes which impact remote communities. Further to our submission to this inquiry, we would like to highlight three key insights.

Firstly, the NDIS does not accommodate cultural and linguistic complexities for rural, regional and remote participants, particularly First Nations people, and particularly First Nations people who do not have English as their first language, which is the vast majority of our clientele.

Secondly, support coordination offers a case management function which supports not only the NDIS participant but their family unit. That's a really important concept to wrap around to be an effective service provider in this space in communities.

Thirdly, NDIS participants in remote contexts face limitations to fully exercise choice control. I'm sure you've heard already, and you'll continue to hear, about thin markets, staffing and service delivery barriers, including availability of premises to operate out of, other infrastructure and risk management areas.

That's my opening statement in relation to Miwatj Health. Mr Poutu will be happy to field any questions you may have, and he can also elaborate on these three insights.

CHAIR: Thank you very much. I'd now like to invite the NPY Women's Council to make an opening statement, if you would like to, Ms McRae.

Ms McRae: I'd like to start by saying that we've always been very enthusiastically engaged with the National Disability Insurance Agency. We were a trial site in 2013 on the APY lands for children. We've spent a lot of energy on putting in submissions and taking every possible opportunity to advise the agency about how to work in remote communities. Our experience has been that there has been some goodwill at times, but that gets overtaken by other considerations. We work with 140 NDIS participants across 25 remote communities. There are some positive stories and good outcomes for some of our participants, there's no doubt about that. But there are also many people who are not getting the benefit of the scheme because of inflexibility and lack of services and lack of culturally appropriate ways of working with remote Indigenous participants. We're very keen to keep engaging with the scheme. We've given lots and lots of advice—they're probably sick of hearing from us—but we will continue to do so, because it's imperative that it works.

There's so much more money available now, and that's a huge positive, but people are not seeing the benefit of that money because the NDIA has not been flexible enough and culturally appropriate enough, and they're unable to listen to good advice. There is a whole pile of barriers to people being able to get the services and supports that they need provided in the way that they need them to be provided.

CHAIR: Thank you very much. We look forward to further discussion on what you raise there. Finally the Mala'la Health Service. Would you like to make an introductory statement?

Ms Woolf: Mala'la Health Service is an Aboriginal community controlled organisation. We're managed by a board of directors, who are all local senior people in the community. We provide services to Maningrida and the approximately 30 outstations in the areas of health, aged care, community services, NDIS and family and community wellness. That's provided across the community.

It's a remote community in West Arnhem Land, approximately 500 kilometres from Darwin. It's accessible by road during the dry season, between about May and October. We've got an air service from Darwin at least once a day, which is great. There are several providers in Maningrida. We're told that there are over 40 providers. We probably see four or five. We don't know who they are. It's not uncommon for someone to produce a card to one of the staff and say, 'Do you know who this person is?' and it will be the NDIS provider or their COS, and they've perhaps signed up with them but never met them. But I'm confident that those who are providing service are providing very good service.

Mala'la works very closely on a regular basis with those that have a presence in the community. We interact and sometimes share clients and activities, that sort of thing. An outcome that Mala'la would like to see is that all providers of NDIS services work together to get the best outcomes for the community members and the participants. It's not a competition. It's about providing the best service possible. That's certainly an outcome that we'd like to see. I'm very confident in saying that Di works very hard at doing that.

CHAIR: I think it would be worthwhile to get an understanding from each organisation around the number of clients you have and the key challenges that you see relating to regional and remote supports and services. McRae, would you like to give us an overview of how many clients or participants you work with?

Ms McRae: Currently we have around 140 NDIS participants. They're spread across 25 remote communities. That a 350,000 square kilometre area of very remote central Australia. The other part of your question was—

CHAIR: One thing we've heard about is the wait list for people to get onto the NDIS.

Ms McRae: It's very challenging for our clients. That's 140 people who've got NDIS plans. There are a lot of people still who don't have NDIS plans, for whatever reason, and it's very difficult for those people to provide all the necessary reports and paperwork. Who pays for that? Getting people in and out of town, because they have to basically come to Alice Springs or Kalgoorlie or Adelaide or somewhere to get those reports done. Those specialists aren't necessarily going out to communities regularly. And people just not understanding—for Aboriginal people in our region, not understanding the importance of getting those reports done. Not turning up for appointments, having other priorities. For us the biggest barrier to people being able to engage with the NDIS is poverty. The people that we work with every day are struggling for food and shelter and safety. So often you make an appointment for someone and you try and put in place everything to make sure that they're going to get there, and that day something else comes up. It might be a family member passes away. It might be that don't have enough money for food for the family that day. It might be that there's been some trouble in the community or domestic violence overnight. There are all sorts of issues to do with poverty that impact on people and stop them from engaging with the services and supports that are available.

CHAIR: It shows the complexity of this whole challenge. It's not just NDIS; it's bigger than that.

Ms McRae: Definitely.

CHAIR: Mr Poutu, would you like to give us your perspective?

Mr Poutu: I think very much of Ms McRae's comments around the socio-economic barriers that we face in East Arnhem Land. In my team of support coordinators I have seven full-time staff, and we currently support 213 participants. Some of them reside in Darwin having travelled here from community for whatever reason, and likely are transitioning back into community.

The reality for the participants that we support is that the NDIS isn't their priority on a day-to-day basis, when they don't have a home to live in, when they face conflicts, other challenges like the logistics of travel to or from Darwin or from the regional hub of Nhulunbuy, which smaller homelands in community. The role that we play as support coordinators when we come in to support a participant is broader than just that individual. We offer the first case management support to a family unit to connect them to other mainstream services which they may not have connected with prior, for example housing. My team are frequently writing housing support letters to support an individual on the NDIS to live independently with the actual asset or infrastructure that they may need.

I think that's consistent across a majority of our participants for all of East Arnhem Land. An allied health therapist can't exactly implement recommendations if there isn't somewhere for those recommendations to be implemented.

CHAIR: You would have a wait list, do you? You've got the number of participants you're currently working with. But do you have a wait list for your organisation?

Mr Poutu: We don't necessarily have a wait list. We identify referrals that we receive based on the relevance to our service and whether we are best placed. It's a hard measure to quantify a caseload, simply because each participant can be funded a different amount of support coordination hours as a fee for service model. So it's very hard to measure someone's need for support coordination against another. Hence our case sizes vary. We don't necessarily decline based on our capacity, in that we work through a fee-for-service model. Each day there are particular numbers in the day, and for some participants their funding may include one hour per month of support coordination funding. It's very different.

CHAIR: Thank you. Ms Soloman and Ms Woolf, would you like to mention a little bit about your number of participants and waiting?

Ms Soloman: You're in a very remote Aboriginal community. I want to say first something that the head of AMSANT said. For some reason NDIS had always been very separate, didn't want to talk to COSs, didn't want to know you. Then all of a sudden they've actually started. I get emails: 'Dianne, can you find this person? Can you find this person in the community? This person has been lost to us for a year.' You go out and find family, whatever. We've probably build a relationship in the last six months. Obviously they're wanting to work closer, and planners are actually getting back to you. That's what I've noticed. But what NDIS don't understand is the whole language thing. We're in Maningrida. There are 14 different languages. There are 23 different dialects. They should not be coming out without an interpreter or having a family member with that person explaining it.

I want to use an example of a young man who had been lost to them for a long time. I was there to help facilitate his plan the other day with his father. I got a community member to come to do the language thing. She was talking in language to this family. I have no idea what she said, which was naughty of me; I should have learned language a long time ago. We were talking about behavioural support plans and independence for this young man, because he had mental health issues, and there were all these big words that they may not necessarily understand. They probably get to school level and learn the first hundred words, and unless they go to university, they're not used to independence, they're not used to behaviour support. As we were walking out of the car this woman said, 'Dianne, did you see me writing all these words down? I've written all those big words down because I'm going to go out to my community now and tell them what it means.'

That's what you're dealing with. When you're talking to people about their behaviour support or their emotional wellbeing, they don't necessarily understand. I've been out there for years. I talk to my clients, and I'll say, 'What did I say?' And they'll just look at me, or they'll tell me something completely different. Sometimes we have to go around it three different times. But you should always have some community member that's attached to that family and has good English skills and can understand. When you're dealing with communities, it would be very fair to say that that's what we're dealing with. They don't understand.

That one part of it. I deal with mental health; I deal with children; I deal with people with intellectual and physical disabilities, whatever. It's very varied. But who gets the assessments done? I had these mental health people years ago. They were saying 'You need to have a psychology report' or whatever. I'm saying, 'But I don't have the money and the plan to do that.' So I was having to go to the OTs. I'm saying, 'I really need to get this done for this person. Can we do it? Can we just work out some money?'

We shouldn't have to do that. I'm dealing with children at the school now. The special ed at the school is ringing me and saying, 'Dianne, probably half our children should be on an NDIS plan.' So they've actually paid for the psychologist to go in there and do the report. It's just a tragic, what happens. Who pays? Does the education department pay? I've got a boy who's just gone to school after four years in a wheelchair, so he needs all this support. The education department is saying, 'We can't put a funding in until whatever, and he needs to be here for 12 weeks.' So who pays? I'm lucky. He was at outstation for five or six months for his grandfather's funeral, and I had this bucket of money that I can use. Otherwise it wouldn't happen.

CHAIR: The review has really focused on how we assess people, and putting less onus on these very expensive consultations, when we often already know.

Ms Soloman: Yes. There's so much infrastructure. Where we are in Maningrida, we are so lucky. We have amazing OTs. We have amazing physios that go out there. As a coordinator, I've been out there a long time. I don't know all the other coordinators, but I know a few and we keep in touch and share. But it's the travel. When you're asking OTs and speechies to go out there, their organisation is here. There are the airfares. Their accommodation has to be paid for. There's the car hire. There's everything. It's a lot of money. That's extra money apart from their hours, and it's just not covered. You ask for it and you say 'travel time', and they manage to do it, but it's very hard. You can't get them out there as regularly as you would like. At Maningrida we are very lucky. The people before were talking about—

CHAIR: Why are you lucky? What's the difference?

Ms Soloman: Because we've really worked hard and we've tapped into the Ots and speechies from years ago, right from the beginning.

CHAIR: Before NDIS?

Ms Soloman: Yes. Even from the Office of Disability. You've had people who've gone out to the community. Probably because of the Maningrida health clinic. It's all connected. It's hard, but we do have the services. When they were talking before about the adult speech pathologist, I haven't had one for months out there. I just found one this week and I've just put in nine referrals. They will come out because they do other communities. I'm just so lucky, because otherwise there's nothing, because that's NT. There's a shortage Australia-wide, they tell me, but it's really hard here.

Ms Woolf: It's a big community with quite a bit of support in the community. There are plenty of cars to transport people, for instance. There's a daily air service. There's a lot more support in a big community compared to a very small community, even though we're very remote.

Ms Soloman: But we don't have the infrastructure. The physios come out, and they'd like a gym. They found one at the lodge. I don't know whether they're supposed to. We make do with what we have, but there's so much more. We all need to be working together. As Lesley said, there's the providers we need. You need to be doing the absolute best you can for the participants.

Mr CONAGHAN: Thank you, everyone, for attending today and giving evidence. Could we stay with the theme of language and cultural appropriateness. I'll direct question to you, Ms McRae, and anyone can answer afterwards. You said that a very early on you dealt with the NDIA, made submissions, tried to work closely with them. I detected an underlying sense of frustration. Would that be fair to say?

Ms McRae: Yes, that would be fair to say.

Mr CONAGHAN: That's because they're not listening to you in terms of your experience on the ground in implementing culturally appropriate measures and dealing with the language factor—is that right?

Ms McRae: Yes, that's correct. They originally came to us in 2012. I've been with NPY Women's Council since 2004, so I've seen before and after the NDIS. They came to us saying they wanted our advice on how to work in those remote communities on the APY lands. We did a project with them around children, identifying children with disability and developmental concerns and how to get those children into the scheme. We wrote a report for them about how to work with those children. We have an established model of service provision. We work malparara way. As a non-Indigenous person, if I go out to a community I work with my malpa, who is a local Aboriginal woman who knows that community, knows the language, knows all those families and who's who, and knows about culture. My background in community development and education is useless without her understanding of language and culture and knowledge of who's who and how I should behave out there. I had to work malparara way for five years before I could start going out and working independently.

So we gave them all this advice along time ago. In 2014 we wrote the first report for them, and we've continually been giving that same advice about how to work in communities. We feel like it doesn't get listened to, or if it does get listened to do it's not being acted on. We're established. NPY Women's Council started in 1980. All the women got together and decided that there were services needed for children, for people with disabilities, for old people out in communities. So we're a long established service. Our directors are all Aboriginal women from the NPY region. We have a really good model for how to work, and we've openly and actively shared that model with the NDIS, yet we still feel like a lot of the information that we've given them hasn't been taken on board and hasn't been acted on.

Mr CONAGHAN: Have you raised that with personnel from the agency?

Ms McRae: Every day.

Mr CONAGHAN: Have they indicated to you a reason why they're not taking your program or your advice, considering your experience and Indigenous peoples experience?

Ms McRae: No, I don't think they have, really.

Mr CONAGHAN: You said in your evidence earlier that despite the fact that you've given all this information the recommendations have been overtaken by other considerations. What did you mean by that?

Ms McRae: In the evolution of the NDIS there have been changes. At the start it was much more open, then it started narrowing down in terms of policies and procedures and the capacity to be flexible. That seems to have changed. I think that's changed as governments have changed, as senior people in the agency itself have changed. There have been some people previously that have been very open and willing and wanting to engage with us. Then you get others who are much more business focused. They're looking at the bottom line, the cost of things. I think all of that has impacted.

Mr CONAGHAN: Do you think that if the agency took up your recommendations that would be a step in the right direction in terms of closing the gap?

Ms McRae: Absolutely it would, yes.

Mr CONAGHAN: Would anyone else like to comment in response to my questions on the cultural appropriateness and language issues?

Ms Woolf: We've had the NDIS since 2018. Number one, we've all grown with it, so we all have a much better understanding. We're stable and so we see progress, but there's been a lot of turnover in NDIS staff, as there is in a lot of government agencies. Some seem warmer in their approach and want to work with you. With others it's like you're the enemy and they really don't want to have anything to do with you. Also, very often they think they know. They may have visited one or two communities, they may have worked in Alice Springs, they may have worked anywhere in remote Northern Territory, but they shouldn't think that they know. Picking up on what Kim said, she's always gone out with a local person. They think they can walk around the community on their own. They think they don't need an interpreter. It's almost like sometimes people can't be told. I'll often refer to our board members if I'm in a meeting and say, 'Would you like me to explain that?' or 'Do you know what I mean?' to try and bounce off them to make sure that whatever I'm saying is being understood, and they're all very literate. But very often when you have people coming out, they don't do that. Correct me if I'm wrong, Dianne, but participants don't see the NDIS staff as anything to do with them. If we talk about NDIS, they immediately think of Dianne or one of the service providers who provide home help or whatever from aged care. It's like 'NDIS' is just another word for them; they're not engaged in anyway. Would you agree?

Ms Soloman: Yes. I'll just give another example of NDIS planners coming out and talking to a young mum. You know it's an urban model. 'Can your child dress itself?' 'Yes.' 'Can your child put its shorts on?' 'Yes.' And I'm going: 'Can you just please read the occupational therapy report. Make sure you read that report.' They don't understand. There's real shame. Even if you've got an interpreter, the family aren't going to say that. If I happen to be in those meetings, I say, 'Please read the occupational therapy report.' It happens all the time. When they leave, I'm saying to those people: 'You shouldn't be asking these questions. They are never going to shame themselves by saying, "My child can't do that." Never.'

Mr CONAGHAN: Do you try and explain that to them on the way out?

Ms Soloman: With the NDIS, but not with the client there. They say: 'But this is what we have to do. These are our questions.'

Ms Woolf: There's got to be flexibility.

Ms Soloman: This is a community. Communities are different. This is something that I wanted to say. They're a very small percentage of the population, so it's a bit like the attitude is, 'Who cares?' They're a very small percentage of the population, but for us that are working out there they are so grateful for absolutely every little bit they get and they deserve more. They do. They just deserve so much more.

Mr Rossingh: Can I just say something for a moment from a Miwatj perspective. I won't reiterate any further on what's already been discussed because it's all very powerful, but I just want to make the point that language is much more than words. Language goes to concepts. In East Arnhem Land the language is Yolngu Matha. There's actually no direct translation for the word 'disability' in Yolngu Matha, so you're not only dealing with what the words mean but you're explaining concepts as well from scratch. It just makes that interpretation even more complex. That's just one point. I'm not sure how that applies to other languages, but certainly in Yolngu Matha there's no word for disabilit I think the critical lever that could be pulled is funding language interpreting services under the NDIS. It's such a critical linchpin to effective service, and yet it can't be funded. If that one thing could be changed, that would open up [inaudible].

CHAIR: I was under the impression that interpretive services were funded via the NDIS. Is that not correct?

Ms McRae: My understanding is that there is some funding for accredited interpreters. The difficulty for us as an organisation is that we are using local community people who are not necessarily accredited. To get onto the accredited interpreters, we would have to use the telephone. We would have to have the interpreter available. Working in communities is very opportunistic; when you see someone, you go for it right then. You can't have rung up the interpreter three days before to book them, so we use local people when we're out there who are not accredited. That's one of the reasons why we lose money in terms of our NDIS coordination of supports—two people are doing that work. There's the non-Indigenous person who has qualifications, and there's the local person who has that critical knowledge of language and culture, understands families and understands who can do what—all of that. We have to send two people.

CHAIR: You employ them, do you?

Ms McRae: We do. We employ and pay those people to do that work with us. We can't use an accredited interpreter for all those reasons I spoke about before.

Ms Soloman: It's not just language; it is culture. It's everything. I go on about language, but it's so much more.

Ms McRae: Local knowledge is really important as well. You might have someone sitting in Alice Springs who speaks Pitjantjatjara, but they may have never been to that community before and they don't necessarily know the people in that community or the way that community works, so it's really important to have someone from that community who can give you all that really local relevant advice.

Senator URQUHART: I was actually going to ask that question about the funding. Where does that funding come from if you pay that person—

Ms McRae: When we claim for COS hours, our COS hours include those hours. Women's Council made the decision a long time ago that we're going to have two people working, even though we're funded for one COS. For us, that has had financial implications, but it has been critically important to the success of our coordination of support. Without those local people, it just won't work.

Senator URQUHART: I get that. But I'm wondering: does the funding come out of the organisation, or does it come out of the NDIS participant's package?

Ms McRae: No, it doesn't come out of the NDIS. We don't charge for two COS every time. It comes out of the organisation.

Senator URQUHART: You find it within your budgets.

Ms McRae: Yes, we internally fund that.

Senator URQUHART: Okay. And you're not actually funded for that, but you find it somewhere.

Ms McRae: Yes.

Senator URQUHART: I understand. You're very resourceful in terms of where you find stuff.

Ms McRae: That's it.

Senator URQUHART: I think most of you have mentioned people coming out to community, and I think you're referring to NDIS staff. I'm not sure who those people are, what jobs they hold and what they're doing in community, such that they don't understand and they don't listen to you as the experts in that community. Who are these people? Can you paint a bit of a picture of what they do? Are they service providers? What are they?

Ms Soloman: Actually, I don't even get to hear when the local NDIS people are coming out—

Senator URQUHART: What are they doing out there though?

Ms Soloman: Maybe accessing people to get on a plan. They'll be at the Centrelink office—but they've stopped doing it. I don't think we've had anybody out here for six months now to do whatever.

Senator URQUHART: So they're employed through the NDIS, and they are local planners—

Ms Soloman: They're coming out to see about plans or renewing plans. It's quite hard to say because they've sort of changed. Just recently, they've been a lot more communicative with me, probably because I'm out there and have been out there for years. That is if they're missing people, they want to know people or they can't get a person on a plan.

I think it would be fair to say—well, in our community, we know this—with our population and the percentage of people that are on NDIS per head of population, that we're missing hundreds. We're missing probably a couple of hundred people. But that's just because there's nobody out there. We're out in very remote communities, and it's hard.

CHAIR: When you say there's not one out there, do you mean that there isn't a place based in community where people can come to get support, or do you mean there's no NDIS presence out there at all in terms of someone coming out?

Ms Soloman: You would think they would contact you and say, 'NDIS are coming out,' and you would probably get all the providers you could get together and all of the people that went out to outstations or whatever and try and get all these people in so they could see them. But there's never been anything like that. We all need to pull together. We just all need to pull together. How can we do this the best way to look after people?

Senator URQUHART: That's what I'm trying to unpack so that I get a picture in my head about what you're actually saying. If an NDIS employee comes out—a local area coordinator or whatever—are you saying that they should talk to organisations such as yours because you work in that community and you know that community and seek advice as to what other services they should take and what providers they should take? I'm just trying to unpack exactly what you're saying and asking.

Ms Soloman: What I'm saying is that, if they're going to come out, they need to say, 'Are there people that have been identified that we need to talk to, and do we need to bring some specialists out here to get some idea of things?' Who's paying? The education department? The Mala'la health service have a mental health team. They actually do a lot of the work. Mala'la pays for that, just like your organisation pays for things, and Miwatj probably does too. You're all just trying to do the best that you can, but there's so much more because there's no communication. It's almost like: 'We work in our own silo, and we don't want to have anything to do with you.'

Senator URQUHART: So if I were to say, 'Let's draw up a flow chart of what should happen when NDIS employees are going out to a community,' what would that look like? Would the next box down on the flow chart say, 'Contact local health services, local aboriginal corporations or the local women's council'?

Ms Soloman: Yes, local providers.

Senator URQUHART: Then, under that, they contact you guys and get advice about what's required, and then you can talk about what's required on community. Is that the sort of thing? I'm just trying to understand.

Ms Soloman: I'm talking about the school as well.

Senator URQUHART: I'm actually trying to understand the message that you want us to take back to say, 'This is a better way of doing it to reach more people and to provide those services.' I'm actually trying to unpack it.

Ms Woolf: I think that it would be ideal if they contacted providers.

Mr Poutu: I can only speak to East Arnhem and Nhulunbuy, but one of the positive changes recently was the regionalisation and bringing planners back to sit in Nhulunbuy as a remote hub. In our experience, we've always had more positive outcomes from planners that are located remotely or with that contextual language understanding. I think a shopfront to allow people of the community, whether you are from a school or an individual who is on or not on the NDIS, to actually speak to someone from the NDIA would be helpful. The NDIA have pulled staff back into Nhulunbuy recently, so we do have people based there, but there isn't a shopfront function to allow any sort of interaction or engagement.

Ms Woolf: That would allow people, if they come to Maningrida, to go to the NDIS office. Currently, there is not an NDIS office.

Mr Poutu: When we look at things like housing and Centrelink, we know that participants are often engaging with these services with an integrated model or a single touchpoint for people to be able to speak to someone.

Senator URQUHART: That makes sense to me.

CHAIR: Obviously, in very remote communities, you can't have one of these shopfronts in every location. However, if there's one in the larger communities then perhaps that is an option. Picking up on your point, Ms Soloman, about the fact that there are hundreds of people out there with disability that you're not aware of, our role is actually to support those people—that's the role of government and the NDIS. How do we find out who those people are and how do we deliver that support? Building on what Senator Urquhart has said about some type of a gathering of the different entities that can administer support coming out to community once every six months or every year to identify how people can be better supported, to bring out specialists and to have interpreters there who can actually understand the local community—what do you think of that concept?

Ms Soloman: I think the local health services know a lot. The point in hand at the moment about talking to the NDIS is that my mental health nurse at the Mala'la clinic had four or five pending applications. He had sent them off and said, 'Dianne, I've got another 20 to do.' Now, he's working in the mental health field; it's pretty full-on, and he has another 20 applications. I just said to the NDIS, 'Come on; there are five pending and there are another

20 in the pipeline, and this person can't do it.' Do you know how that started? They emailed me and they said: 'We've got this person; does he still want NDIS? Because the clinic mental health nurse stuffed up his application 12 months ago.' That's how that conversation started. I thought, 'Of course they still want it!'

Ms Woolf: And he's got a heavy workload as well because there are quite a lot of mental illness—

Ms Soloman: Yes. That's the sort of thing that we're dealing with. At least we've opened that conversation out and they do know; hopefully, they will be coming out and we can address some of it. But this has taken years.

CHAIR: Having the NDIS staff out on the ground is important.

Ms Woolf: Yes.

CHAIR: And there are not enough, in your opinion?

Ms Woolf: No there are not.

Ms Soloman: It's just the planners. The coordinators that work out there do everything. You don't just coordinate—you do the housing applications, you refer them to alcohol and drug help. You do everything because that's what you have to do. Also, that's how you build up the rapport and trust with your community so they will come to you and say, 'Dianne, can you help us?' Sometimes I can't, but I can point them in the right direction. That's how communities work.

Ms Woolf: Similarly—on bringing in the assessor—the school observe kids who aren't travelling so well and will refer them.

Ms Soloman: But, again, who funds it? Who has the money? Does the health service fund it? Does the education department? Does Maningrida School, which has no money? Or will the NDIS fund it?

Ms Woolf: The Territory has a role to play, too.

Ms Soloman: You have these buckets of government money, but it's knowing which one.

Ms McRae: Before the NDIS came in, we used to get block funding for supporting people with disabilities out on the lands. The way we'd identify those people with disabilities was through informants from the community—family members, the clinic. If anyone was worried about someone and thought that they needed some help, they would refer them to us to get that help. Now that we have to have all this verification of the disability, we have to have so much information. Someone can be going without a service for a long time while they're waiting for us to be able to drag all that information from somewhere.

CHAIR: The review has actually acknowledged that that is an issue and that it's causing a lot of problems.

Ms McRae: Yes, it's a huge issue.

CHAIR: There is an alternative pathway now, which does not involve getting every health provider to write up. It's costly to the participant and their family. It's been a really eye-opening discussion, and I think it's been really valuable for us.

Ms Woolf: We'd love you to come and visit.

CHAIR: We would love to come and visit. This is the challenge, isn't it? The remoteness of community means coming to Darwin too. I arrived last night at 12.30 at night. That's when the flight comes through. We have to overcome these challenges if we want to care for people who are on country.

Ms McRae: I've brought along some research that NPY Women's Council did. You may have seen it before, but it's called *To live a good life*. It's what people with disabilities have told us that they want and need to live a good life out on communities. I've brought that along for the committee.

CHAIR: Thank you very much. There are some questions that were asked. If there's any information that you can provide to us to help us with our deliberations and with the recommendations that we will make, we'd greatly appreciate you providing us with that information. Thank you very much for being with us today.

Proceedings suspended from 12:31 to 13:34

DAVIS, Ms Judith (Judy), General Manager, CatholicCare Northern Territory

CHAIR: As we are on time, I'd like to reconvene our hearing into the disability insurance scheme in relation to rural, regional and remote communities. I'd like to thank CatholicCare Northern Territory for attending this afternoon. Judy Davis, would you like to state the purpose of your being here today?

Ms Davis: I oversee the NDIS program. CatholicCare is an organisation that provides broad social supports across the whole of the Northern Territory and also NDIS supports into the remote APY Lands in South Australia. We have about 17 office locations. We are a place based model of service delivery, which means that our staff live and work in the communities in which they serve.

CHAIR: Would you like to make an opening statement?

Ms Davis: I would. I've given you a little bit of background about CatholicCare. We are fairly broad. Our involvement in the NDIS program stemmed from previous programs that were Commonwealth funded, such as the PHaMs program, the Personal Helpers and Mentors program. We delivered that program in Tennant Creek and also across the APY Lands. That particular program transitioned into NDIS, so participants in the PHaMs program then became eligible to apply for NDIS packages. It recognised that severe and persistent mental health issues were a disability. There was a disability component for those participants. That started our involvement, transitioning. We have broadened the scope of our NDIS service provision to also include the Tiwi Islands, so we're based in the Top End in Darwin. We provide some coordination of support. We provide NDIS supports in Tennant Creek and across the APY Lands. So, in opening, I'd probably just like to say that our comments with regard to this standing committee are based on a service provider perspective, but that perspective is based on information, knowledge and feedback we've gained from participants who live in rural and remote locations across the NT and the top end of SA.

I'd like to open in terms of talking about the experience of applicants. We mainly provide services to Aboriginal participants who are in rural and remote locations. For participants in those locations, having access to place based services is really important. I'm not sure that the definition of 'place based' is understood in the same way by everybody. For us, that means living and working in community and being there for participants. We feel that that is really important for participants, having access to infrastructure that's there and available all of the time for participants seems to be important.

The other aspect of that is around employing local Aboriginal people to deliver supports. Mob looking after mob in their communities seems to be really important. There are some barriers around that, of course, but the building of relationships with communities so that the service provision is through someone that participants trust and is community based is important.

In terms of the development of plans—the application, plan, design and implementation, and plan reviews—quite often, particularly in some of the remote sites, it's driven by the health clinics, which is fine. However, quite often we feel and have had feedback from participants that they don't really understand the plan design phase, because there are barriers of language and literacy and the plans that are initially developed are plans that are a little bit standard. Then the coordinator of supports needs to work over a period of time. It takes time for participants to have a plan that actually addresses the needs of that particular participant.

In terms of our experience with the NDIA, we feel that some of the support mechanisms, as indicated in feedback from participants, are not appropriate for remote participants who have barriers around language and literacy and may not have access to the types of infrastructure that they need to access those supports. The 1800 number for participants is quite often talked about with regard to trying to access support or information, and it takes a long time. They won't sit and wait for that call to be answered, and then they're asked to identify themselves and quite often don't have the documents that they need to identify themselves. That is feedback that we have had from our remote participants.

We also deal a lot with NDIA in those locations. In fact, Christina Gordon was supposed to be here today. She is in the APY Lands at the moment in a community called Amata, so she wasn't able to attend. She is our NDIS manager. I've said to her that, if there are any questions I can't answer today, I might take them on notice, and she can provide a response to them. She has gone out to the APY Lands. It's a whole week to travel out there. She's based in Darwin and travelled down to Alice Springs. A drive out to the land takes a day, and then there is getting across all of the communities in that location, which run from the Stuart Highway in the middle out to the WA border. It's a week out of the office. So she's there at the moment. She had been told that an NDIA representative would be there. They were to be there for two weeks. She arrived today, and they've left. So they were there and have left. She can catch up with them in Alice Springs, and she will; however, the opportunity to be on the ground and talk to them about some of the barriers that participants are facing in those communities is lost.

We feel that the NDIA officers have a lack of understanding of the complexity of remote participants. We do acknowledge that they do try to visit and get out there and do those things. We've seen a bit of improvement in that space, but there's a lack of time spent to really understand.

They have also done some work around implementing the Community Connector Program. There is a community connector in the APY Lands that is attached to the health service. One of the issues that participants have brought to our attention is that, because of the complexity of the nature of the disability that is often faced in those communities, there is a tendency to remove participants from community into a major centre. In the past few months in the APY Lands, there have been a number of participants who we were providing support to who have been moved into a major centre in South Australia. Some of that is because they can't access the supports that they might need, so it is well intentioned; however, the participants—and we have some case notes from participants who have said that is not their desire. We have some concerns there about whether or not choice and control are actually being exercised.

Senator URQUHART: Is that a long-term process or for them to get an assessment?

Ms Davis: It's a move into supported independent living. It's a move into a residential—

Senator URQUHART: So it's forever.

Ms Davis: Yes.

Senator URQUHART: Wow. So that's a really big concern if they want to live in their community and they get moved into independent living in a centre where they don't have support networks. Is that because there isn't that opportunity in their communities?

Ms Davis: Yes. I think it is well intentioned in that the community connectors see that they can't access the supports that are in their plan and they have complex needs, but it's a matter of whether or not the participant is comfortable with that. They will probably agree to it; however, the feedback we've had is as I mentioned. We have some case notes about that that we can provide.

CHAIR: How do you overcome that? If someone wants to live in their community and yet they have a real need that can be met only by going elsewhere, because there are not the services there, is there an alternative? Have you thought about what can be done?

Ms Davis: There are definitely thin markets. I think we could give some thought to how some of that support is better delivered. In our submission, we've talked particularly about allied health supports. Quite often there will be allied health providers based in major centres. I mean, you can't have allied health providers sitting out on the APY Lands, really. You might get someone, and there are some good providers that have regular trips into the lands. It takes time to build relationships with participants, and participants will quite often not want to see an allied health provider who's just landed in community, because they don't know them and don't have a relationship with them. Some of our thinking is about having some place based cultural brokers who are community members that could help facilitate the support to participants in place. We've included that in our submission as well because participants have expressed that they're not comfortable. We deliver coordination of support, and participants have expressed that they're not comfortable having an allied health provider fly in or drive in and then come to their home to deliver a support in their home. The opportunity to have a community based brokerage model might be something to look at.

CHAIR: This would be someone who is trusted by the community to facilitate the process.

Ms Davis: That's right.

CHAIR: That in itself is quite an interesting proposal. You talked about the language and cultural issues; those have come up today. Have you got any thoughts about how we do it better in terms of NDIS support delivery?

Ms Davis: I think the employment of local community members is really important in a remote setting.

CHAIR: Is there desire amongst communities for that? Are there people who want those sorts of roles and are prepared to undertake the study and educational uptake to take on those roles?

Ms Davis: I think that's the complexity of it. We have quite a number of Aboriginal local community members working for us. We provide services on the Tiwi Islands, just north of Darwin. Most of our staff are casual; they're local community members. We have had some barriers around passing the NDIS screening, and it also takes a long time to work through that process. I guess community people will wait. In Darwin, people aren't going to wait months to see whether or not they can come and work for you, but we have some staff members who have waited, over time, to come and work because they do want to work with their communities. So it hasn't really been a big problem. There is a lot of complexity in terms of community members having lots of other roles in community and obligations to community, but I think if you've got a flexible service that can work around that. You need that flexibility in your service.

You also need a place based service, and you need the infrastructure. I think that's a big issue because the infrastructure that you need to deliver a place based service isn't funded under the NDIS model.

CHAIR: What you mean by 'infrastructure'?

Ms Davis: We have an office, and we have hubs. We've got a hub in the community of Amata in the APY lands, and we have a hub on the Tiwi Islands. They are hubs where NDIS participants can drop in. They can come in at any time and spend some time there. They can talk to the coordinator of the supports. They can just access a place to be. I was talking to Christina this morning and she said, 'We have got this little video from a participant on the Tiwi Islands who was accessing our hub.' That hub is not funded through any NDIS funds. It sits under our office that provides other social services there. The NDIS team leader had asked, 'What do you like about coming here?' The participant said: 'I like being able to access food.' So that participant is in the kitchen, making themselves a toastie or something. They said: 'I like being able to just sit and watch TV. I like to be able to relax and I like that this is a safe place for me.' So that sort of infrastructure is important for NDIS participants in some of these communities where their homes might be overcrowded and there is a lot going on. They are looking for a place where they can access the support that they need and also have that cultural safety. Our workers in that hub are local community members.

Senator URQUHART: Is that entirely a CatholicCare hub, or does it have other services?

Ms Davis: It's just an NDIS hub.

Senator URQUHART: But it is funded by CatholicCare?

Ms Davis: We provide the infrastructure. We're not making money. We're actually running out NDIS services at a loss, and it's very difficult in terms of viability. We are propping our NDIS services up through reserves at the moment, and we do that because we feel that it's really important. We know there are thin markets. It's really important for participants to have access to quality NDIS support. We provide daily living support, coordination of supports and community connection support. We need somewhere to be able to do that, so we provide that service.

Senator URQUHART: Where are your hubs?

Ms Davis: There are two hubs. One is in Wurrumiyanga on Bathurst Island, which is the largest community on the Tiwi Islands, and the other is in Amata, which is one of the largest communities in the APY Lands in South Australia. The APY Lands hub does provide services to other community based participants, because we get some funding from SA Health to provide support to community members who are not eligible for or who've chosen not to apply for NDIS packages. So it's more of a community based hub where we have NDIS participants, and we have other community members also attending that hub. It's a very similar model, and we would say that that is our most viable service. It's interesting that, out of all of our services, because we've got some other funds, it's more of a viable service. It would probably be the last one we would pull out of.

CHAIR: Mr Conaghan, do you have any questions?

Mr CONAGHAN: I do. We heard evidence earlier today that the language and the cultural appropriateness of the NDIS don't suit remote communities, particularly Indigenous remote communities. Would you agree with that?

Ms Davis: Yes, particularly remote communities.

Mr CONAGHAN: Has CatholicCare engaged the NDIA in terms of any submissions or trying to change that approach?

Ms Davis: We are constantly talking to the NDIA and advocating. When we've had the opportunity, we have responded to the opportunity to put in submissions. We've put in submissions around the reform process, and we're waiting to hear. We would probably support a commissioned model of service provision in remote settings in particular. We think that it's very important. We would be competing with others in a commissioned model of NDIS service provision. However, we think that it is important that is a commissioned model of a place based model of service delivery, where you have a service that is available in community at all times, not sporadically delivered. There might be an office there. That's been the feedback that we've had from participants.

What did Christina say to me this morning? She said that it was really important for service providers to be there when things go wrong and also when they go right. When services are coming in and things are going really well and can be coordinated on the ground in the community, that's really important for participants, but a place for participants to go when everything is going wrong is also important so that there is support in community. Services that know the participants—know where they are, know if they've gone into Darwin or Alice Springs for respite—are also important. Trusted relationships—she talked about the importance of NDIS service provision being community led but participant driven in the remote context.

Mr CONAGHAN: The other piece of evidence which struck me was that advocates today are saying they don't think it's appropriate that service providers go out onto country without a local or a community member being there translating and explaining everything. Let's use the example of your colleague who's gone to the APY Lands. Is she out there with somebody from country who speaks the dialect and who can explain these things? Do you always have somebody, or is it a bit hit and miss?

Ms Davis: She's our NDIS manager, and we have permits to be in community. Any of our staff have to have a permit to be in community. We wouldn't be going out on country. Any activities where participants are taken out of the community and onto country would be with a community elder. That certainly wouldn't be something that we would do without having the correct permission and the right protocols in place, so we would support that submission by advocates.

We've got staff in community; they've got permits and they live in the community. They'll know when the NDIS manager is coming out and they'll advise whoever needs to be advised. I don't go out that often, but if I go out I will ask one of our locally based staff to put me in contact with the elder that I might need to go and see and introduce myself to. We operate from that perspective.

On the Tiwi Islands, our staff are very connected to the local traditional owner groups and the elders in the community. We have an in-house process in CatholicCare where there's communication around anybody who's coming over onto the islands or out into the community to visit—that is advised. Cultural safety is a major issue.

Mr CONAGHAN: You mentioned that on occasion you move participants to major centres off country. What are the criteria for doing that? What are the circumstances where you would move them?

Ms Davis: We don't.

Mr CONAGHAN: You don't?

Ms Davis: No. The only circumstance in which we would do that is when a participant has identified that they want some respite from community. Some things have changed in that respite space. Christina was talking to me this morning about how at the end of last year it changed from participants being able to come into Alice Springs on their own and get respite from community. We'd help them find a culturally safe respite provider in Alice Springs. Quite often, participants know where they prefer to go, or they might have family in a particular area. The respite component of it seems to have moved to being something that's offered to carers. We're now being told that, when a participant puts in a request to access respite, they're told they can't come unless they're coming with a carer, which is a new barrier in terms of participants being able to access respite from community.

Quite often, we ask participants if they would like to access respite over holiday periods, particularly Christmas. Quite often participants will come in at Christmas time. They often have family in Alice Springs. Alice Springs is the closest centre for the APY Lands. In those cases, participants will choose to come in. We quite often have staff who are taking some leave around that time, so participants are given the choice of whether or not they would like to come in and access respite at that time, or we look at who can provide the support in the community if we've got a depleted staffing team there. Quite often community members come in as well, so our local community based staff may not be there either. They would be the circumstances in which we would ask participants whether or not they—

Mr CONAGHAN: Let's just go back one step. You said it's a new thing where a participant, if they want respite from country, now has to take their carer with them?

Ms Davis: Yeah.

Mr CONAGHAN: Who made that decision?

Ms Davis: That's coming from the community connector, that that needs to happen. A request goes in—

Mr CONAGHAN: Sorry, who's the community connector?

Ms Davis: It's an NDIA position.

Mr CONAGHAN: So it's a decision by the NDIA. For respite they've got to take their carer—who needs respite—with them.

Ms Davis: Yes. The participants don't seem to have choice and control over that. I can take that on notice and get some more information from Christina around what's happening and what has changed in that space.

CHAIR: We haven't heard that before, so it would be good to confirm that. You mentioned an NDIS person on site, on country. Then your colleague arrived, and the NDIS worker had gone.

Ms Davis: Yes.

CHAIR: What I'm wondering is: for people to get that consistency of support and communication, what do we need to do better in terms of coordinating when different groups arrive? It sounds very much like this often happens in siloes, and you get different groups turning up at different times, but there's no overarching planning.

You've got the expertise coming into a remote location. We all know that that's challenging in terms of transport, time and cost. Have you got any suggestions for how we can do that better to maximise when people come and how they work together?

Ms Davis: We're in contact with NDIA. That's how we knew. We are talking to them fairly regularly. However, that plan changed after we coordinated—or thought we'd coordinated. Maybe there is a schedule of when the director is visiting community, but that can change. You've probably had people talk to you today about the nature of community and how, when there's sorry business going on, plans change. They can change quickly. A planned trip might not go ahead, because you need to be respectful of community protocols, as well.

However, if there is a schedule of trips, and you've got the providers there are the same time, we work pretty well with providers in community, particularly the place based providers. We've got good relationships with Nganampa Health and NPY. NPY are the other major place based provider, even though they're based in Alice Springs. We coordinate pretty well with them on service provision, because it is a thin market. We probably need some schedule. Maybe there are some NDIA coordination meetings held in community. You might do that twice a year, and you get the managers who are travelling out. We would have staff based there anyway who could attend the meetings—

CHAIR: What do you see the benefit of that being?

Ms Davis: I think it would be a great opportunity to talk about the barriers facing participants in those communities and the issues that participants are telling us about. 'We're being moved into supported independent living in an urban setting, and we don't really want to go. We would rather be able to access the support we need in community.' I think some of those issues could be raised in a meeting held in community. That would probably be my suggestion.

I think it would also address some of the issues around unscrupulous providers, which I know we hear a lot about. They are out there. I don't like to talk too much about it because we all feel tainted by that. The reality is that 60 per cent of NDIS providers are not breaking even, and that's all we want to do. We want to continue to provide supports. There are unscrupulous providers that take advantage of those remote settings. They will turn up and they will offer incentives to participants—

CHAIR: We heard that yesterday, yes.

Ms Davis: to sign up with them. This happens regularly. I came back from leave at the end of January, and a provider had turned up on Bathurst Island, which is very easy to get to, and had signed up 10 of our participants because incentives had been offered. There's offering of money; there's offering of tobacco. We agree with the whole notion of choice and control, and it's up to participants to choose the providers that they would like to have provide service to them, but what happens then is that that provider disappears, never to be seen again, or they come in sporadically or they will try to provide supports from a remote setting. They might try to provide a telehealth service or do that type of thing.

Mr CONAGHAN: So, as a reputable provider, do you report them?

Ms Davis: Sorry?

Mr CONAGHAN: When you hear these anecdotes, do you report them to the—

Ms Davis: We do.

Mr CONAGHAN: Good.

Ms Davis: We're a bit of a serial reporter to the commission.

CHAIR: If no-one actually does report these things, then we don't know. And it is important because we need the money that is spent to be spent in the best way to support the participant. That's the great thing of having you up here on the ground.

Ms Davis: Absolutely.

CHAIR: You can see when that happens.

Ms Davis: Yes. The burden on the providers who've lost participants is that the participants then turn up and say that they want to access our support. Then we're like: 'You're not with us anymore. You're getting your support through XYZ.' So then—

CHAIR: So what happens when someone's signed up and they're regretting their decision?

Ms Davis: We spend a lot of time supporting them to change back, and to do that we have to find that provider, who is quite often unwilling to change that participant's plan over. So that's when we do engage the commission; we will engage NDIA in those processes. But it's a lot of time spent that we're not funded for, so it does impact, and that's a common scenario. That happens a lot, so there is a lot of time spent on unravelling those situations for participants in community, and it's because we're a place-based service provider that is accessible that it will often land on our doorstep. We don't ever say no, but we do spend time explaining to participants that this is what's happened when that person turned up and you signed your plan over.

CHAIR: I really need to hand over to Senator Urquhart, but how do you overcome that? Is it to do with education of people with disability and their families in regional and remote areas? How do we overcome this? It sounds like, as you just said, it's unfortunately quite a common practice.

Ms Davis: I think the way to overcome it is to commission services in community—services that are trusted by the community—so that the community has some say.

CHAIR: So you lock those services in.

Ms Davis: Yes. And it doesn't mean that you can't have other reputable services that come in, because you do need them. You need to bring your allied health providers in. You need to be able to do that, but the coordination of support in the community—and it might not just be one service. You still want participants to have some choice and control over who they're with, but communities would be best placed to identify who the trusted services would be—those they know participants are going to be able to go to when they need support.

CHAIR: Senator Urquhart.

Senator URQUHART: I'm sure we could dig a lot deeper in that sort of area. It is horrific, and it's usually the individual who misses out, which is not fair I'm interested in going back to the issue of the hubs, and whether or not you can provide us a bit more information about that on notice. A lot of the time, when we have hearings like this, we hear about all the bad news and the things that aren't working, but it's nice to hear about things that are working really well. If you're able to provide us with some more information—all of us probably speak to a lot of people in our communities about the NDIS, and the number of people who tell us how it's transformed and changed their lives is incredible. But there are always stories on the other side. It's really nice to hear that balance, so thank you for bringing up the issue of the hubs. It'd be really useful for us as a committee to have some more information, if you can provide that on notice, about how they operate and that sort of stuff.

Ms Davis: Absolutely. We've got some great case studies in terms of some of our participants. There's one in particular on the Tiwi Islands who we've developed a case study around—someone who didn't want to access any support and who is now a very engaged participant through the hub.

Senator URQUHART: That's because of the hub?

Ms Davis: Yes.

Senator URQUHART: That's great.

Ms Davis: And also accessing support from another male community member.

Senator URQUHART: If you can provide that on notice, that'd be great. I want to go back to your opening statement. You talked about having place based people living and working in community. We've heard a lot throughout today—and I know it's an issue everywhere—about the workforce issues; there are just not enough people to do the work. I'm assuming you have a similar issue. How have you come to get staff to live and work in the communities? How did that evolve?

Ms Davis: We've got some pretty amazing people. It's work that I don't know I could do. I'm very grateful to some of our staff who live and work in community. We've done a lot of work around attraction and retention of staff, particularly for our remote staff. Ideally you want to employ local community members—so mob looking after mob. I think there's a great opportunity with the CDP at the moment, with the changes in the CDP. We also deliver the CDP in Central Australia, so I'm aware of what's going on there. The CDP model is moving to more of a real-jobs focus, and I think the NDIS could take advantage of—

Senator URQUHART: Those opportunities.

Ms Davis: Absolutely—training local community to deliver NDIS supports. That's one thing, and that would be my No. 1 priority.

With staff that we employ to go out into community and live in community, we provide them the opportunity for respite—the opportunity to come into town once a month, to come in on the Friday and go back out on the Monday, if they can. We'll put them up in a hotel, they can do all their shopping, they might have some family that might come in—just the local hub; people in the APY Lands come into Alice Springs or people on the Tiwi Islands come into Darwin, and they'll have a weekend out of community to access the things that help them—

Senator URQUHART: A bit of self-care.

Ms Davis: Self-care, yes.

CHAIR: Even finding them accommodation on country could be challenging.

Ms Davis: It's incredibly challenging. It's also expensive.

CHAIR: Who pays for that?

Ms Davis: We do. The biggest deficit in our NDIS budget is salary because we have to employ people full time if they're going to be in community and providing support full time. You can't have a casual model of service delivery when you're bringing people into community.

CHAIR: In terms of budgeting, your organisation is big enough that it can manage this.

Ms Davis: Yes.

CHAIR: Do you think that it is a successful model that the NDIA and the scheme should consider? It is an issue that we've heard today, about not having enough face-to-face support and that level of trust—and just familiarity, actually.

Ms Davis: Yes.

CHAIR: Is it a model that you think could be rolled out and funded?

Ms Davis: Absolutely—properly funded.

CHAIR: What would be the benefit that you would see from that?

Ms Davis: You would have place based services. We look at the budgets and there's only so long we can continue to run a program at a loss. We've got about 30 funded programs across the whole of CatholicCare. There are actually two programs at the moment, but the NDIS program is the one that is of most concern in terms of financially viability.

CHAIR: Right.

Ms Davis: I did actually bring our budgets.

CHAIR: Well, it is—

Ms Davis: This year we're looking at a loss of about $228,000 to date. Last year, we had a deficit of nearly $500,000. It was $496,000—

CHAIR: That is a lot for an organisation.

Ms Davis: on our NDIS services.

CHAIR: Is that made up of the types of things that we've just spoken about, like providing accommodation for people on country and then respite for that worker as well?

Ms Davis: Yes.

CHAIR: And transport costs?

Ms Davis: Transport—so we've got vehicles out there. Most of the costs were staffing costs last year. We had a total income of $1,553,000 for the financial year last year, and our staffing costs were $1,557,000. We've spent about $106,000 on travel. The rest of it would be around providing property and fleet access to all of the infrastructure that people need. Last year, we also didn't factor in our pooling costs there; this year, we have. So our staffing costs this year have gone up to about $880,000 so far.

CHAIR: How many staff members do you have?

Ms Davis: I'd have to take that on notice. For across all of our NDIS programs, I'll have to take that on notice.

CHAIR: Okay. Thank you for actually showing us the costs and where you're at financially, because we need providers to remain in—

Ms Davis: Absolutely.

CHAIR: remote locations.

Ms Davis: Yes.

Senator URQUHART: Good, reputable providers.

CHAIR: Yes, good providers.

Senator URQUHART: I'll just ask one final question. That is the issue, particularly, around the NDIA, and you talked about support mechanisms not being sufficient. You talked about the 1800 number, and a lot of that is outlined in your submission. There are a whole range of things in there that you talk about. There's the issue of people going out and not coordinating with services. Are there any other areas that jump out in terms of how you think the agency could be more responsive? What's your view about how they could be more responsive to you as an organisation that's providing a service but also to people with disability living in those areas?

Ms Davis: Yes. I might just clarify. The situation in the APY Lands is that the planners have gone out with the director. They were going to be there for two weeks. The director has gone back into town. Our NDIS manager there is out there now coordinating the planners, so there's a little bit of coordination happening by the service provider that's on the ground there.

Senator URQUHART: But that would normally be the NDIA person that's gone out of the town?

Ms Davis: You'd like to think that the director spent the time to actually oversee the process over that time frame. That would be important. It's really important for people in the high-level positions to really understand the complexity of service delivery and make sure the planners are getting it right. Our experience has been that some get it and understand the remote context; for others, it will take time because it's not something that you can just learn over one trip. We've worked with some planners that are great and then some who are really very early in their learning journey of remote delivery. That's one thing.

The other issue that we've found is that quite often, when a plan's reviewed, because some of the supports haven't been utilised because of the thin market the plan's reduced—but it doesn't mean that that participant doesn't still need access to that support. Christina talks a lot about a step-up step-down model of NDIS plans for participants so, when a COS can access a support that a participant might need, there is money in the budget to bring that provider in to be able to provide that support. That's important.

CHAIR: That's something that has been picked up over a number of years—the concern of families and the person with the disability that, 'If we don't use it, we're going to lose it.' I think there has been acknowledgment by the minister that that is an issue and that we shouldn't allow that to happen if they have the need. It's unmet, but that doesn't mean it's not needed. So it's an important point. Thank you. It's been a very enlightening conversation. We appreciate your time. If there's any information or answers to questions that you could provide to us, that would be very much appreciated.

Ms Davis: Absolutely. I'll send through some information around our hub model and anything else that's come up today. We will provide that to you.

CHAIR: Terrific. Thank you very much, Ms Davis.

MUNAMATI, Ms Mandinyara, Clinical Manager, Outback Disability Services

[14:28]

CHAIR: Welcome, and thank you very much for being with us today.

Ms Munamati: To make it easier for you, I am Mandi. Our company, Outback Disability Services, hasn't started operating; we are waiting for our certification. We decided not to start before the certification. We discussed it as a family and we said that we think it's good to just to incur the costs whilst we are waiting for our certificate to come out, to avoid complications.

I am here because I work with people with NDIS packages, with different organisations providing care. So I just took this opportunity—we haven't started operating—because I have quite a few things of concern that I have seen over the years that I want to highlight. I started working with the NDIS in 2019. Disability was initially more about physical disability. Now disability includes mental health. When we go to non-restrictive practices, physical disability and mental health are different. There are things that need to be considered when we talk about non-restrictive practices when it comes to people with mental health issues. They don't have the capacity to process things. Some of them are very impulsive.

When I was working as a support worker initially I was working with physical disability. We used to not lock doors. We used to leave everything. Mental health patients wander around. They end up in very vulnerable situations in the community and exposed to drugs and alcohol, which complicates their situation. I don't know what can be done, because if you start to ask if there is anything that can be done to try and contain them it is considered restrictive under the NDIS. So I think it is a process that is just prolonging a process to service people, especially in Darwin where there are pockets of areas which are known for drugs. That's where they are going. Some of them are assaulted. I don't know what can be done with regard to looking at the non-restrictive practices in that situation, considering mental illnesses or disabilities, with the challenges that come with insight and the ability to process and see risk as well.

The other thing I want to talk about—while working with the NDIS I have done applications. I'll give an example. I worked with a family, and in November 2022 I started an application. It was very difficult, because Indigenous people change their phone numbers every day, to try and contact them to complete their forms. NDIS application forms take a long time to process. By the time I finished it was maybe six months before I had everything together. I took everything to the APM. That's what we use here in Darwin. Unfortunately the forms had changed. They had new forms. So I had to start again. This time it took four months before I had everything together.

The other thing is that the person I'm talking about has schizophrenia and ABI. They still want me to provide evidence of psychosocial disability for someone who is always pacing, who can't even sit still. It's all good. We managed to write down everything. Then I heard some people talking about those community engagement meetings. I think the local area coordinators should go out into the communities to sit with these participants in their homes and do these processes. So I ended up putting this person in the car to come to the office. It's often very cold here. It's freezing. So if you've got Indigenous people it's too much for them. They can't sit. This person is always responding. He hears voices. So I'm sitting with this person, and he's talking to the participant. I am trying to say that he can't really hear what you are saying. He's talking to and smiling at him. It didn't really mean what he found, because he's smiling because he's responding to something. That's his best line.

So I have been waiting for close to two years now. I haven't done anything constructive to support this person. His mother has got this person with a mental illness. He's got challenging behaviours with a younger brother. He is always in and out of court. This person with mental illness is very vulnerable in terms of drugs and alcohol. The mother is showing carer fatigue. At this stage I'm still waiting for the application. I finally submitted everything that was required, including doing the community engagement meeting in February. It's such a long process to find supports for people who really need it.

CHAIR: In these individual instances they can be escalated if there is a significant risk to the individual or if there's been some sort of barrier which has been going on for some time. We can talk to you offline about particular situations where there is a desperate need for discussion, and hopefully a way through to getting more help for this individual.

Ms Munamati: That would be really good.

CHAIR: That's something that we can do. In terms of where you've come from, where have you been working and are you moving into working with Outback Disability Service? Is that correct?

Ms Munamati: Yes.

CHAIR: Where were you prior to working with outback? What's your background?

Ms Munamati: My background is that I'm a mental health nurse and I've been a disability support work and worked with people with disability in terms of mental illness. Now it is considered a disability most of the clients are with NDIS.

CHAIR: Have you been working for another provider or independently?

Ms Munamati: For another provider.

CHAIR: Were you involved in establishing the Outback Disability Service.

Ms Munamati: Yes.

CHAIR: Is there anything unique about the service, and why did you decide to start up?

Ms Munamati: With my experience and knowledge, I think I'll make a difference in the community. I have been in Darwin since 2005. My connections in the community through our church the Galiwinku community, so I have a connection and the ability to offer more cultural insight. Talking about that, there was this thing about language and culture. In the community I have done a plain English course to try and help me communicate, and it has helped me so much, even in my work, communicating with the Aboriginal people.

CHAIR: This inquiry is focusing on how we can better support people with disability and their families in remote communities. Do you have any topline suggestions about how we can do it better?

Ms Munamati: If there are services that can be implemented on the ground in communities. There was the DSA accommodation project that started last year that supported accommodation living in houses built in communities—I think it's more here in Darwin. If that project is done in the communities so that their house is out there in community and we don't take people away from their families, I think it would be really good.

I'll give an example of where people are being taken away from their communities. Someone needing a depot injection doesn't really need to be in Darwin. It can be given at a clinic, so if supports when he's with his family it's much better because when they are here in Darwin some of them miss home and they tend to run away. I have got an example of a client from Tiwi Islands who ran away from their support worker and took a ferry back to Tiwi Islands, which is quite risky for someone with a mental illness to do. If initiatives like DSA are implemented in the communities where there will be SIL houses right on the ground with family support, I think it will be much better than removing them from their families.

CHAIR: Thank you. We'll have to follow that up. If you have any further information about the housing option, it would be good to send it through. Mr Conaghan, do you have any questions?

Mr CONAGHAN: Just to follow on, the supported independent living in community sounds like the TSA model. In that circumstance, where that person with mental health issues was removed from the Tiwi Islands, who makes the decision to remove them from their home?

Ms Munamati: With my experience, the people are called 'frequent flyers' because they go back to the community, engage with drugs and alcohol and then become unwell. They come to Darwin for treatment and go back again, so it would be like a burden for the service with the cost of transport back and forth. If there are good supports in terms of accommodation, people to take them to the clinic for the Depo. I really like the idea that Mission Australia has for the community because it is way of taking them away from the drugs and doing something productive.

Mr CONAGHAN: It sounds like in the case of this person it was the decision by Northern Territory Health for support services for rehabilitation?

Ms Munamati: Yes.

Mr CONAGHAN: So it was not through the NDIA?

Ms Munamati: It will all come together with NDIA support coordinators. Because if there are enough supports in the community, I wouldn't think that anybody would be getting moved to come and live in Darwin for things like something a Depo injection because it can be done in the community, unless there are specific special needs.

Mr CONAGHAN: Did I understand correctly that Outback Disability Services, which is your operation, is an independent operation, or are you working for another service?

Ms Munamati: At the moment I am working for another service provider while waiting for our certificate. Once it's out—

Mr CONAGHAN: Did I hear you correctly that some of your clients are coming to you through your church?

Ms Munamati: No, it is only that I am connected. I do volunteer work through churches also, just to help me understand the culture.

Mr CONAGHAN: We heard evidence today from a number of advocates about how service providers reach their clients. It sounds to me like you are someone in the community so you will be able to reach clients that way. The person you're working for now, how do they access new clients?

Ms Munamati: Mostly the clients we access are complex mental health clients, so it is through the hospital. We have some forensic clients through the prison as well.

Mr CONAGHAN: So they are referred to you from government organisations?

Ms Munamati: Yes.

Mr CONAGHAN: Who is that organisation?

Ms Munamati: It is Options Health Services.

CHAIR: From what I gather, servicing complex mental health participants is complex for the provider as well. There seems to be a challenge with that field of getting sufficient providers to provide services for complex mental health needs. If you then add remote on top of that it becomes very challenging. Would you agree with that?

Ms Munamati: Yes.

CHAIR: As far as you are aware, are there many providers in remote areas that provide complex mental health needs support?

Ms Munamati: In the remote areas, I am not quite sure, because we are based in Darwin. But I know that Miwatj work with and support some of the complex clients.

Senator URQUHART: Obviously, you are awaiting your certification. Do you know what that time frame for that is?

Ms Munamati: I am not sure. Initially we were told 60 days. We have passed that, so maybe anytime from now.

Senator URQUHART: How many staff do you have? I am having a look at your website. You have a lot of services on there. How many how many staff do you have?

Ms Munamati: At the moment, it is only the four of us directors.

Senator URQUHART: What would be the staff numbers you would be looking at, and what level of skill?

Ms Munamati: With what we are going to provide—we are going to provide SIL. It will just depend on how our workload is going to be. Once we start to get more clients, we will start to employ. We will be starting ourselves. It is my profession. My husband is a disability support worker. The other two directors are social workers, so most of the things we will start by doing ourselves and then we will start to employ others.

Senator URQUHART: I think you've been here for most of the day; I've seen sitting you in the back listening. A lot of the evidence that has come forward today has been about the workforce issues and the number the people needed to provide the assistance and services, particularly out on country but also in the regional and rural areas. Do you think that will be an issue for you as an organisation moving forward, in terms of having enough workers to be able to stretch yourself out, given that there are already issues around that with other organisations at the moment?

Ms Munamati: It will be an issue, yes.

Senator URQUHART: And what are your thoughts about how you would resolve that issue?

Ms Munamati: Sometimes it's working on staff retention—what you can offer and the supports you provide to your staff as well—because it will also depend on the type of clients. Some issues will come out if you've got complex clients. If staff feel unsupported they'll just leave. So it all depends on the staff and the supports that are in place to work with your staff.

Senator URQUHART: Will you be based in Darwin and have outreach services? What does the model look like?

Ms Munamati: That's what we are planning to do.

Senator URQUHART: Okay, great. I don't think I have any other questions, Chair.

CHAIR: So the ultimate plan is to go into outreach on a regular basis? Which communities would you go to? Have you got any thoughts about where you would go remotely?

Ms Munamati: The community I will be going to, with which I have good connections, is Galiwin'ku. Our plan will be to link with Miwatj because they are in that area.

CHAIR: Right. And then, with the NDIS and your relationship, you will coordinate with them in delivering services?

Ms Munamati: Yes. We'll aim to work with NDIS. I have heard lots of evidence today of the complications. Having been in this space as well, I know there are challenges. It was a really good learning curve today, to hear that and also some suggestions that have come up today.

CHAIR: Congratulations to you for starting up a business as a provider. You are obviously someone who cares deeply about delivering services that support people. We need more of this, so we wish you well with your endeavours. Do you have any other questions, Mr Conaghan?

Mr CONAGHAN: No. All the best.

Ms Munamati: Thank you.

CHAIR: Keep in touch with us. It will be interesting to see how you go on the ground. Thank you very much for your time today.

Proceedings suspended from 14:49 to 15:42

COX, Ms Merrilee, General Manager, Disability Advocacy Service [by audio link]

WRIGHT, Ms Janet, Chief Executive Officer, Integrated disAbility Action

CHAIR: Just before we begin, the committee understands that SBS would like to film this session. I would like to ask witnesses if they are happy to be filmed. If you have no objection, we'll welcome SBS in. You're okay? Alright, thank you. I would like to welcome representatives from Disability Advocacy Service and Integrated disAbility Action. I understand that information regarding parliamentary privilege and protection of witnesses giving evidence to Senate committees has been provided to you. Do you have any comments to make on the capacity in which you appear?

Ms Wright: We're the peak body for people with disability in the Northern Territory. We do advocacy, systemic advocacy, training and events primarily. I'm here today to bring forward some information from members and clients.

Ms Cox: Disability Advocacy Service services the Alice Springs and Tennant Creek areas. We did a consultation with our clients to inform this submission.

CHAIR: Thank you very much. I now invite you, Ms Wright, to make an opening statement.

Ms Wright: First, we'd like to acknowledge the Larrakia people on the lands on which we're having this meeting. We pay our respects to their elders past, present and emerging.

As an organisation that empowers people with disability, improves the quality of their lives and advocates for positive change, we are committed to working with First Nations peoples and communities to achieve equitable outcomes for all.

We welcome this opportunity to have this conversation. We often feel that remote areas get forgotten about in the process of things. It's essential for people with disability to be at the centre of policies and solutions, especially remote and extremely disadvantaged groups. We are hoping for a wonderful outcome of these hearings and really actionable solutions that happen quickly.

CHAIR: Thank you very much. Ms Cox, would you like to make an opening statement?

Ms Cox: I can echo the sentiments that Janet has raised today about wanting to be able to bring forward the voice of people from remote settings, people who often are not heard and who have a quite unique perspective on NDIS service delivery. That's the perspective we want to bring. I'm talking to you today from Warumungu land, which is in Tennant Creek.

CHAIR: Thank you very much. It's good to hear that you're on country. I should just remind everybody who is listening in today that this is a fantastic opportunity for anyone to attend a public hearing in which to offer views on how to improve delivery of the NDIS services and supports into remote, rural and regional areas. That is the purpose of this inquiry. Thank you very much for being here today. I just want to know a little bit from you. You work in remote locations. Can you tell us about your experiences in terms of the things that are being done, that are happening, that are of value? How can we improve delivery? What are the key challenges you see?

Ms Wright: I think the first key challenge in the region is that often English is not a person's first language. Even to apply for the NDIS, you have to have a reasonable level of documentation, an availability to contact the internet, use a phone and any sorts of electronic services, and those simply do not exist, for the most part, in a lot of places, or they're intermittent or inconsistent. One of my examples is that we had a person who had a skin name, he had a name that was given to him by a whitefella, and he had two separate birthdates. Because of that system of documentation—he didn't have a birth certificate and he never did have a drivers licence. All the things that you would need to have to apply were not easily accessible to him or even understandable in any particular way.

CHAIR: Do you think this occurs more in remote communities?

Ms Wright: This person was referred to us in Katherine. Most of his life, he had resided in a remote community, but, when he was referred to us, he was living in an aged-care facility in Katherine.

CHAIR: What would be a solution there so that people like this particular fellow can get the support they need?

Ms Wright: The solution he came up with—he didn't understand why all you whitefellas don't talk to each other. He said, 'I have Medicare, I have Centrelink,' and he had other services that come and go—at that point he was living in an aged-care facility. 'Why don't you speak to each other? Why do I have to re-prove my disability,' which is quite a complex disability. 'Why do I keep having to do that?' And he keeps having to do that every time his plan is reviewed. So, every year, he has to re-prove what his disability is, and he feels it never changes. He just wants us all to talk to each other.

CHAIR: That's interesting. We are actually looking at plans so that you do not have to redo a plan every year. Are you aware of that?

Ms Wright: Yes, I have heard that that's a potential solution. The only thing about that that might be problematic in a couple of examples that I have is that the process of just rolling over a person's plan is not consultative. The problem is that if the person's plan gets rolled over and they haven't utilised it—I think 40 per cent of remote plans aren't utilised—their plan gets reduced.

CHAIR: That's not necessarily the case. These are issues that it's important to look at. But, in relation to the inquiry, what, specifically, do you think we can do to improve the services and supports into remote locations?

Ms Wright: It needs to be person centred.

CHAIR: We've heard this.

Ms Wright: Yes. It needs to be delivered by people that the person trusts and who have a complete understanding of the system, because what happens sometimes is that one person will get assistance from a phone service or from the health service, and another person is lucky enough to have a family member who understands the NDIS or has a connection to an advocacy service, and they just get a better plan because the information is more complete. They understand what the ins and outs of the very complex process are. But, if it was person centred and consistent, then everybody would get the same assistance.

CHAIR: How would that look on the ground, from your perspective? How would something like that be rolled out?

Ms Wright: I think in the very early stages they had local area coordinators, who didn't actually do that work. That's what we thought they were going to do. The communities used to call them 'the purple shirts'. What we'd like to see is for existing services, either the health centre—not always the health centre; sometimes that's a problem in Maningrida. We'd like to see somebody who is not partisan to any particular group—so, not a government agency—so that the person trusts them and knows that they're not trying to railroad them or get them to sign on the dotted line when they don't fully comprehend what they're signing, which is what happens with some of the service agreements now.

Maybe one day a month somebody goes to a community, or they have a community region, and they physically meet with the people who have plans. But they shouldn't be the person who's problem-solving that. So, if they meet with a person who has a plan and the person's wheelchair isn't functioning, because the person providing the service to that wheelchair hasn't been able to get out, there should be a process for triaging that—for assisting that person to get actionable assistance. And in those visits, if you do a risk assessment on a person and you think they're at risk, then that should be moved up the line. If a person's wheelchair isn't working and they are also on dialysis and they live 20 kays out at Soapy Bore and they have to go into Urupuntja for their dialysis, they need that wheelchair access. Fixing that wheelchair should be a priority.

But right now there's no way of escalating the assistance or improving their condition depending on the change, and I think those things need to be addressed.

CHAIR: I have one more question and then I'll pass over to Senator Urquhart. Much of the evidence we have heard today has been about the need for communication to be better and about the barriers around language. There have been a few different suggestions made about how we do this better. I'm interested to get your feedback.

Ms Wright: Yes; definitely there are barriers around language, including in the CALD community. Darwin has quite an extensive cultural and linguistically diverse community, and they also have a difficult time understanding what the process is or a fear—there's like an endemic fear around paperwork or somebody from a government agency asking you questions. If you provided it in language from people who are from their community, I think that would be better. That would build trust. It would be in a language that they understand, where they are not translating translations. For some people English is their third language, so there'd be multiple translating of that being done. And clarity, so when you say a thing it's a clear, simple statement versus some of the really long stuff that goes on. And even when that's translated, there might not be a word for that in that person's particular language. It needs to be simplified.

CHAIR: Yes, and appropriate and understandable to those who are seeking support.

Ms Wright: Yes; that's correct.

Senator URQUHART: I'll go to Ms Cox on the line first. Could you give the committee an overview of your services: how many people benefit from the services that you provide, but also where are they located? And can you estimate how many people you work with are NDIS participants or applicants?

Ms Cox: The area that we work in is Central Australia, including the Barkly region. It's all of the NT below Elliott, if you know where Elliott is. It's a bit south of Katherine. We work on about 500 advocacy matters every six months. About 70 per cent to 80 per cent of our clients are Aboriginal people, and many of those either live in remote communities or travel in and out of the main population centres. Two-thirds of our work now is around the NDIS.

Senator URQUHART: Right, so when you say 500 advocacy matters, can people have more than one issue that you're dealing with at any given time?

Ms Cox: That's correct. We've got up to about 100 clients at any one time. Some matters get resolved really quickly and some matters take a really long time.

Senator URQUHART: What are the primary challenges in relation to your organisation? What are those challenges that you face in working across that area that you do, which is very vast and, I would say, very remote in some areas. What are the challenges in that?

Ms Cox: Partly it's resourcing. We're funded through the National Disability Advocacy Program, and we've got two staff to cover that area at the present time. That in itself is a challenge because the area is huge and we've got limited capacity to travel. Some of the work we do is through other organisations or we do it on the phone or we do it remotely, but, wherever possible, we travel out to where people are. There are a lot of challenges in doing that, particularly with the limited funds that we have available to us.

Senator URQUHART: It's very difficult with only two people too, I imagine.

Ms Cox: Yes; it is. One of the things is that the NDIS is so complex and so difficult to navigate. There are ways in which the scheme is no longer as accessible as it used to be at the beginning of the rollout, when we had NDIS officers. You have to wait for up to an hour now just to speak to somebody on the phone. And even though there is some NDIS presence, it's usually hidden away and no-one actually knows where it is. Like in Tennant Creek—I recently mentioned to someone that there is an NDIS person in Tennant Creek, and none of the disability providers even knew they were there. They're just tucked away inside the Centrelink offices. I think it's a really big problem that people whose preference is for a face-to-face, sit down together kind of contact don't have the capacity to do that. As Janet mentioned, a reliance on telephone or internet based mechanisms for communication with the NDIS does not work in very remote communities. It means then that people are really reliant on services like us to do that navigation for them.

Senator URQUHART: I'll throw this open to both of you, and I don't mind who starts first. Can you talk about what your engagement is with the NDIA and how responsive the agency is to the issues that are faced by the people with disability that you advocate on behalf of. Ms Wright, would you like to kick off? Then we'll come to Ms Cox.

Ms Wright: Our interaction with the NDIA has been problematic. It's very difficult to get a hold of anyone. When you do get a hold of someone, often they have changed positions, so that new person is different. One of the examples that I have is a gentleman who's had a plan for five years and has not drawn down any of it for five years.

Senator URQUHART: Why is that?

Ms Wright: He's on the complex team because he's very unwell. There is no support system for him because of his level of complexity, thus he is on the complex support team. And on the complex support team there is no human being to send out to build a rapport with him or to understand his particular disability, which is an acquired brain injury, so he just gives up. One of the things we've been supporting him on—and this is a good example—is that we've just been trying to get the 'about me' section of his application changed, and we still haven't achieved that. It's that little thing.

Senator URQUHART: Why has that not been achieved?

Ms Wright: Because they just simply don't do it. We tried to get it changed. He came to IDA three years ago trying to get that 'about me' section changed. This was before I was there. They wrote letters. They didn't understand how they could change it back then, so they asked for a review of the decision that had been made. In that process, they said that part of the information in the 'about me' section is incorrect. That didn't get fixed. His behaviour has escalated, and he just stopped engaging with anything with the NDIS because of his opinions of the NDIS. He's come back again, and I've been trying to support him for the last three months to get that one thing changed. We finally got a human being on the phone, who was from Queensland and part of the complex support team, who apologised and said that the three previous complex support people had moved on to something else and that they would absolutely get it changed. I've emailed them three times now, and all I want to know is what they've changed it to or what the next process is.

Senator URQUHART: So no feedback?

Ms Wright: No feedback. Can he review it before they put it in stone? Nothing. If a person doesn't have an advocate, it would be like he was before. They would just simply give up.

Senator URQUHART: Ms Cox?

Ms Cox: I'd love to give you another example, because I think we all have these. One of the things that happens is that if you ring the call centre, those people are not authorised to do anything. You ring them up; it's taking weeks and weeks to process everything there at the moment, and you just get nowhere in your interaction with the NDIS. But I want to give you a particular example. We were contacted by a social worker from a very remote setting—it's about seven-hour drive from Alice Springs—saying that there was a four-year-old child with severe autism who was not on the NDIS, and they were really concerned that everybody in the family was breaking down as a result. They asked for our help in putting together an application because they'd been unable to get the community connector team involved in doing it.

We helped to put together the application because there had been a paediatric assessment of this child about 2½ years previously. We submitted the application, and the NDIS initially said that they wouldn't consider it because the assessment which had been done—and which had identified the child as having level 4 autism—was more than two years old. We put a bit of pressure on them to consider it anyway. It's so impossible to get someone to come out to a remote setting like that to do the assessment, because nobody is getting paid for doing those assessments. Then they considered it, and what we found out afterwards was that this child had been accepted onto the scheme 2½ years previously, but a plan had never been completed because NDIS hadn't been assertive in following up—they'd had trouble getting in touch with the family and then hadn't been assertive in finding other ways to make contact with that family to ensure that child had a plan and had services in place. What that means is we've missed a really critical developmental period for that child where they should have had services but didn't have services.

That's just an example of where I think the NDIS need to be much more active in making sure that people who qualify for their services actually get the services they need. I could give you some other, similar kinds of examples of the way in which I feel that the NDIS are remiss. Another example is a client in Tenant Creek who has been applying for home modification. This is a person with a very severe physical disability who has been applying for eight years for home modifications, and the NDIS have quibbled on the specifics of the home modifications requested on every occasion it has gone to them. What they're failing to get is that the person with a severe physical disability has waited eight years. They've quibbled on money because it costs a lot more to do anything up here. They've quibbled on whether it should be this sort of cupboard or that sort of cupboard. They haven't stayed focused on the fact that here is a person living alone with a severe physical disability who cannot use their bathroom adequately and cannot use their kitchen properly.

These are the kinds of things where I feel like there needs to be an oversight at times where the NDIS [inaudible] we're committed to service delivery occurring. It shouldn't have to be that we're all fighting on the outside for the ins and outs of things.

Senator URQUHART: I totally agree. What is the status of that claim from eight years ago?

Ms Cox: It's still happening now. My client jokes that he's one of the most photographed people in Australia because people are always coming out and getting him to bend over, show how he can't access his toilet and various kinds of things like that. He's had photographs sent to the NDIS so many times. But it's so hard to get past the particular planner, and—

Senator URQUHART: Are you able to provide us privately with details of that? We will follow that up, because that is unacceptable.

Ms Cox: Yes, absolutely. I totally agree. I think there needs to be an internal process of escalation where the NDIS has its own way of flagging when things aren't working properly and, particularly where a plan isn't used—picking up this issue of where, if a plan isn't used, which I think Janet raised—that they take a more proactive approach to that. Sometimes what that will mean is there are some structural issues that are preventing that happening.

The other thing that is really difficult is that a lot of clients in our very remote settings have no idea who their support coordinator is. It is virtually impossible to find out, unless you can be in the same room with that client at the same time, and they're prepared to wait an hour on the phone with you to find out who their support coordinator is so that they can assist them. So there are some blocking mechanisms, which are partly about privacy. But there needs to be a way to think about, 'How can we problem-solve some of these issues so that the NDIS itself is not blocking service delivery?'

CHAIR: Ms Cox, I just want to let you know that we do have, in the room with us, representatives from the NDIS who are listening to what you have said. We would be very pleased to pass on that particular case to the NDIS, because, as Senator Urquhart has said, it is unacceptable, and I'm sure that the representatives from the NDIS would totally agree with this, so thank you for raising it. Senator Urquhart, did you have any further questions?

Senator URQUHART: No, I'm happy to share and come back if I need to.

CHAIR: Okay. I'll just let you know that we have the ABC here in the room. Are you okay, Ms Wright, to be filmed? You're becoming very popular today! Mr Conaghan.

Mr CONAGHAN: This is a question for both of you, Ms Cox and Ms Wright. We've just listened to you expressing your frustration as to dealing with the NDIS and also the NDIA. Have you ever come across anybody in either of those organisations who has lived experience with people with disabilities?

Ms Wright: There are some people in the—I want to call it the 'events and marketing team', but I don't know if that's what it's really called; they're the people who can come out and give you brochures and stuff; I think some of them identify as people with disability.

Mr CONAGHAN: Sorry; perhaps I'll make my question clearer. I'll put it this way. Do you think it would help you on the ground if there were people in the departments who had lived experience, through either having a family member with a disability or having worked in the disability industry? Do you think it would streamline the decisions? Take, for example, Ms Cox, the person that you described as having waited for eight years to get modifications to his house. Do you think somebody who has actually been on the ground and seen how it works should be in a position where they have oversight of these decisions?

Ms Wright: There were people with disability when I was in Alice Springs, which was at DAS. But it's the systems that stop them. It's not the human being who has the disability who doesn't—I mean, they want to help. It's not even that. It's that the systems seem to stop them: 'Oh, that report's two years old, so we can't do that.' It's not that person on the ground making that decision; it's the systems that have told them that they can't do that. I would, a hundred per cent, want more people with disability in every service.

Mr CONAGHAN: I'll come back to the systems. I'll go to you, Ms Cox. It was not the systems that were preventing the modification to the house, in your example—would you agree with that?

Ms Cox: It's hard to know what stops it. The NDIA is a mystery box. We don't really know how it works, from the outside, but it seems that people have a certain level of authorisation and they can't make a decision. And how you take it up to the next level, to the person who could make the decision, is not transparent at all. I tend to agree with Janet that it is actually the system. It's something about the way authorisations happen. But we're not really privy to how it works. It really does feel, from the outside, like a black box, and you have to keep trying to guess how to navigate it.

For example, we found out that there's an escalation team the other day, but we don't know anything about that team. What is the escalation team? How does something get escalated? What are the ways in which you can trigger an escalation? So we've heard there is such a thing, but there's nothing coming out from the NDIS that tells us how to effectively use the system.

I agree with Janet. I completely agree that we need people with disability in employment. And, regardless of whether people have a disability, they need to know and understand disability. I had a very frustrating discussion the other day on the phone with someone who kept talking about sending out letters to my client, and my client is blind and cannot read letters and doesn't really have anyone around them who can read those letters. They were saying, 'They can go on the website.' Well, they can't go on the website. The person I was talking to just didn't seem to get what having a vision impairment might feel like.

Mr CONAGHAN: I'll go back to you, Ms Wright. When you first started, your opening comments were that the infrastructure is not there even at the most basic level—no internet, no phone, no identification. Is this something that the NDIA, the NDIS, actually look at and address? Do they take that into account when you're advocating on behalf of your clients?

Ms Wright: Let's give the example of the gentleman who had multiple names and a couple of different dates of birth. You have to put your Medicare number on the form, which we did. He didn't realise that it didn't match. That went, and we didn't hear anything, so we made an application. He is profoundly unwell, profoundly disabled. We didn't hear anything. We didn't hear anything. We didn't hear anything. We followed it up. We followed it up. We followed it up through the 1800 number. Eventually, he got a letter that said he didn't meet access because the information he had provided was incorrect. That took months.

Ms Cox: That's happened for us as well, I would have to say. The other thing I want to mention is, with the introduction of PACE, people now have to provide a birth certificate, and that is providing a barrier to access the scheme, because people don't have the money to pay for a birth certificate.

Mr CONAGHAN: We know there are nearly 700,000 Indigenous people across Australia that don't have birth certificates, which is a whole other issue. That is something that needs to be addressed and recognised by the NDIS and the NDIA. That is putting barriers, brick walls, in front of people who desperately need help.

Ms Wright: I will go back to the gentleman in Katherine. He was in aged care. He had been in care, in aged care, for more than 10 years. He had Medicare. He had Centrelink. He was on the disability support pension. But none of that mattered. None of that paperwork and none of that already approved, already seen stuff mattered when it came to applying for the NDIS. They didn't care that he had already proved that stuff, that all that stuff had already been taken care of for years. So he then had to re-prove that. It makes it super hard, so they just give up; people just give up.

CHAIR: Within the review, there has been acknowledgement of a number of things you've spoken about. We do need to ensure that we do not put barriers up against people being able to take part in the scheme if they are obviously eligible to do so, and birth certificates are a barrier, particularly going back to the fact that this inquiry is about remote communities and providing services and support to those people. It's something that we as a committee certainly acknowledge.

I would like to give Senator Steele-John, who is on the line, an opportunity to ask some questions.

Senator STEELE-JOHN: Thank you so much for taking the time to give evidence today. We really appreciate it. I must apologise for not being there with you in person. I'm recovering from COVID-19 and couldn't quite make the trip. My first question goes to the Disability Advocacy Service. In your annual report, you discussed working with the NDIS justice liaison team, NAAJA Throughcare and Community Corrections to support NDIS participants who are in prison. What do you needs to be improved in this space? What can the NDIS do better?

Ms Cox: In assisting people in justice settings?

Senator STEELE-JOHN: Absolutely, yes.

Ms Cox: In some ways, I think some of the things that would make that better are Territory responsibilities. The really big difficulty, I think, that we've experienced, in trying to assist people who are in justice settings to get onto the NDIS, is that often people have a disability that was never adequately identified and responded to when they were children. There are often unidentified developmental kinds of disabilities, and that might be accompanied by hearing loss and might be accompanied by cognitive disability. Then we have no capacity within the prison settings to get access to assessments, to provide the evidence base that will get people onto the NDIS. That's been one of the really tricky things.

People in prison, as you would be aware, don't receive Centrelink payments. They've got no capacity to pay for assessments. The Territory government provides minimal support to people with disability, in those settings, unless they're forensic clients. That's the biggest barrier, having access to assessment, contemporary assessment, that will support those people to access the scheme. That could be something that the federal government could support, making sure that there is a diagnostic capacity within the prison setting that would facilitate people accessing the scheme.

Senator STEELE-JOHN: If we look at the general population, people who are not exclusively within carceral settings, we've heard a lot today about the challenges people face accessing assessments anywhere in the Northern Territory, additional assessments or access to specialists for additional evidence to back up certain supports they might be advocating for. With the people that you support, do you also see them experiencing long wait times and significant out-of-pocket costs to access those specialist services and allied health professionals?

Ms Cox: Definitely. The biggest thing is that we've got no brain injury-specific services at all in the Northern Territory, despite probably having the highest level of brain injury in the country. We just don't have any of those services at all. In remote settings, it's impossible to get a neurological assessment. It's just impossible to do.

Senator STEELE-JOHN: So when you say brain injury services, what do you not have that you would find in other jurisdictions?

Ms Cox: In the past, I've worked in Victoria and we had state funded, and also through TAC and WorkCover, specialist acquired brain injury assessment, treatment and support services, and rehabilitation services. We don't have those. We have nothing of that kind in the Northern Territory.

Senator STEELE-JOHN: So if a participant who has a severe acquired brain injury that would make them very eligible for the NDIS lives in the Northern Territory, what do they do?

Ms Cox: There are various ways in which we try and solve those problems. At the moment, in Alice Springs, congress does have neuropsychologists on staff, so for some members of the population now there is some capacity for assessment, but we've had years where we haven't had access to those services. If people live remotely, they just don't get an assessment.

Senator STEELE-JOHN: Wow. So there's no way into the NDIS at that point because there's no way to demonstrate that you have such a condition?

Ms Cox: Well, you try to find other avenues to demonstrate the disability more through the functional impairment side of things, but without the diagnostic thing sitting behind it. Or it might be that you access the memory clinic at the hospital. We do try and problem-solve in all sorts of ways.

Senator STEELE-JOHN: Absolutely.

Ms Cox: Sometimes we try and pull funds. There are various ways that we try and problem-solve. That's part of the advocacy role—to be a problem solver—but it's extraordinarily difficult.

Senator STEELE-JOHN: Of course, yes.

Ms Cox: It contributes to a lot of issues which I won't go into, but behaviour support plans is one of the issues—where often those behaviour support plans that get funded are not actually informed by a level of assessment that would provide something that is appropriate to the client. That's a whole other area of discussion.

Senator STEELE-JOHN: I'm just thinking about a situation where, say, somebody with an acquired brain injury currently has access to the scheme and they'd been able to have access because they had completed a functional capacity assessment that had been accepted by the agency. If the agency subsequently requested that they undergo a more rigorous, specific assessment in relation to acquired brain injury to prove that it was a permanent condition that wouldn't improve over time through rehabilitation, for instance, there's no way to actually obtain that assessment in the NT?

Ms Cox: You can actually get an assessment, but you have to have a really strong rationale to get a neuropsychological assessment.

Senator STEELE-JOHN: Right. So there is the capacity to obtain one in the NT?

Ms Cox: If they're on the scheme, you may be able to argue for that. One of the things that often happen is that people talk about global developmental delay—the doctors might say they've got global developmental delay as the way of justifying that person coming on the scheme because it's clear there's a problem but it's unclear what the genesis of it is. It's a really complex space because generally people haven't been appropriately diagnosed early enough in their life, and then all sorts of other social factors and experience factors can contribute to clouding what the actual issues are for the person.

Senator STEELE-JOHN: Absolutely. I think your evidence speaks so clearly to the need for us to look beyond the NDIS to building the capacity of the allied health system and services necessary to even access the NDIS in the first place. Thank you so much for your evidence. I'll stop there, Chair, as I'm aware that we've got to get a move on. If you've got anything additional, please share it with us, but that was my last question.

CHAIR: I just wanted to ask a question regarding the issue of fraud. Ms Cox, you mentioned in your annual report:

> … many NDIS participants have a very poor understanding of the scheme and are vulnerable to unethical provider practice and fraud.

This is something that has been picked up by the minister in the review. I'm just wondering if you can expand on that, please.

Ms Cox: I'm happy to expand on that. I think there are a few things. One of the things about understanding the cultural context that we work in is that Aboriginal people are generally reluctant to complain. In our experience, people can be being charged for services that they're not receiving, and the client may well not raise the flag on that particular situation. It can take a long time or something going really astray before we find out that the person hasn't been receiving the services that they are entitled to.

In recent times we became aware of a service provider—they were a sole provider—that was booking out that they were doing support work to, we think, about a hundred hours a week. We came across this accidentally because four separate clients happened to be using this support worker. None of those clients raised with us that they weren't receiving the services, but we noticed that all of these people were supposed to be receiving services, some of them at the same time on the same day, so we started our own inquiry into that situation and what we discovered was that people weren't receiving the services. We also discovered—and this speaks to the issue of registration—that this particular sole provider had been twice jailed for fraud in other settings, two different settings, not related to the NDIS. It was clear that this person was charging for services that were not being delivered. That's an example where—

CHAIR: That is exceptionally concerning. As we've heard before, when this happens, those dollars are not going to the participant. That's why there is now a focus on the issue of fraud. When you discover these cases, do report them?

Ms Cox: Yes, we do, and we put in other strategies. For example, we always alert the support coordinators if we've got those sorts of concerns, and we encourage them to put in place practices to make sure that people sign off on service delivery or that there's a process of regular investigation to make sure that those services are being delivered. We look at those things.

We do report to the NDIS Quality and Safeguards Commission, but I did want to speak to that as well because, as an example, I made a report of serious neglect a month ago, and I've had no response from it. I'm concerned that that is not an adequate safeguard for clients. We can't rely on that as the strategy for ensuring that people's rights are being protected. We need to take action in our own ways to follow those things up.

CHAIR: We can take things offline if there is a need to support an individual when a complaint is not addressed in a timely manner. There has been the introduction of the Fraud Fusion Taskforce. Have you found that it has had any impact out there, particularly in remote communities, where it sounds like there is more vulnerability to these types of fraudulent activities?

Ms Cox: I wasn't aware that they were doing anything in remote communities. I've not had any contact or interaction with them. I did hear today from the NDIA that they're saving the taxpayer a million dollars a day, but I'm not aware of how that's being achieved.

The other thing I wanted to speak to is inducements for support clients. There's basically bribery going on at the present time. There are providers who encourage people to transfer from one provider to another, particularly in the area of support coordination and supported independent living, using inducements. I'd really encourage some thinking about how the NDIS flags if there are those sorts of transfers where people are transferring from one provider to another—which it is obviously their right to do, but it can be severely disruptive to their service delivery—and there's unscrupulous practice. It might be where a provider says, 'We'll give you, rent free, a 50-inch television in your room and Kentucky Fried every Saturday night if you come across to live in our facility.'

CHAIR: Thank you, Ms Cox, for that example. We have heard other examples today. I'm very pleased that we are looking into these types of practices. There will be ramifications, because this is not looking after the participant, and that should be our focus. Thank you, Ms Wright and Ms Cox, for your time today. It's been very revealing, and we really do appreciate you taking the time to give us your views and experiences. The aim is that we improve our delivery to remote communities, and the report is really valued.

Ms Wright: Is there a time frame for your final report and when anything will change?

CHAIR: For our recommendations, we will undertake a number of hearings. We will come back together and have hearings in Canberra, as well, and we will put together a report. We haven't got a specific time frame, but my view is that we will very likely complete the inquiry before the end of the year. Thank you for your input.

PACHOS, Ms Christina, Private capacity

PACHOS, Mrs Helen, Private capacity

[16:36]

CHAIR: We now have an opportunity to invite people with lived experience of disability and the NDIS to make statements. We would like to invite Mrs Helen and Ms Christina Pachos to come and share their experiences. Good afternoon. Thank you so much for giving your time to come and share your experience. I would like to ask if you could please state why you have come to share your views today. I now invite you to make an opening statement.

Mrs Pachos: I'm Christina's mum and legal guardian. Christina is my daughter and has an acquired hypoxic brain injury. The reason I wanted to come today—it's been a long, uphill journey. We had no idea about anything to do with the NDIS. I looked after Christina by myself for the first five years. We got six hours a day of support, just to assist me with showering. We were told Christina was going to be in a vegetative state and not to expect anything even if she survived. As a mother, that wasn't going well with the grain, so we decided we were going to do everything for her. She had three old assistants who were very supportive; there was a huge age gap, so they were like her second mums. She got a lot of home support.

We soldiered on for five years, but it took its toll on my health. It took its toll on my right hand, which I've injured in several places; it's never really recovered. I got six hours of support and thought I'd been blessed. When I went to our rehab doctor, he suggested we go onto the NDIS. I tried to navigate and find information about it, but I couldn't find anything. I was very, very fearful that, if I went on the NDIS, I would lose the six hours support that I had, so I strongly resisted every three months when we went for our appointment, even though he kept trying very, very hard to persuade me to get an assessment. Eventually, after 18 months, we did, and it was the best thing we did; it was life changing. When she was assessed, the assessors were horrified that I'd done this by myself for five years. She was deemed to need two people, not one person, to do the manual handling I had done. We were very grateful. Because I've been very grateful, I've put some photos in the submission to show you where she's come from—a 'before' and 'after'. It's only since we've had the NDIS that she's made those gains and improvements.

She was on a PEG; she was PEG fed. We were told she would never eat. Christina, before her brain injury, was an amazing cook, even at the age of 18. She was the best cook in the family; we miss her cooking. Every time I would eat something in front of her, I would get what we as a family call the death stare from her; she wanted some. We spoke to our speech therapist, and we kept getting the same response. We changed speech therapists several times and kept getting the same response—that she would choke, that she's not able to eat solids or any fluid or anything orally, that she is just to be PEG fed. Having that little bit of rebel in me, I gave her what I was eating. I started with ice cream and different fluids—just giving her a taste, like you would with a baby. Three years later Christina got her PEG removed and ate, and is eating everything we eat. She is now starting to drink fluids through a straw. We were told after the eighth or 10th speech therapist that, once she starts to use her mouth and starts to suck, she will start to get control of her mouth and her tongue, and that will help with her voice and her oral side of things. There's actually a picture in there where the only communication she had—she absolutely destroyed the blinds in her bedroom, but that was the only way she could get attention. If I left the room when I was on my own to get something or to get her medication and she wanted me, she would kick, scrunch up the metal blinds and make as much noise as she could so I knew she was either awake or wanted my attention to go back into the room. She thinks that's very funny, but I've had to replace the blinds twice.

Senator URQUHART: Your blinds have now survived!

Mrs Pachos: Now we're at the stage where Christina is using her voice to call out. We know what she wants. She's not speaking it, but she's using her voice to attract attention. Her different cries tell us, like a baby, whether she's in pain or just wanting attention. We've just had an eye gaze trial. Through the NDIS, we got funding, and she's got the eye gaze, and she's given me a three for my cooking.

Senator URQUHART: Only a three!

Mrs Pachos: Yes, only a three. But it's the beginning of getting Christina's communication skills up, which is my biggest worry. I worry that if I'm not going to be around and people don't know her as well as I do that they won't know what her needs are and how to meet her needs. Currently we're going through a rough patch where she's been unwell. We had a similar patch last year, and it proved to be Ross River. We didn't know what it was, and it meant going from one doctor to another—trial of elimination—until we found out what the issue was. This time, we're going through the same sort of process purely and simply because she can't express. I can't predict everything, and I'm not a medical person, so I don't know what questions to ask her, so we're back and forth from the doctor, eliminating things until we get to the bottom of it.

I really want to say that more information would have been great. Meaningful stuff, like someone that I could have rung and said, 'What will the NDIS do for me?' I guess that will still be relevant for people that don't know what the NDIS is—a hotline or something that I could have rung and said—

CHAIR: There is a hotline, but you weren't aware of it?

Mrs Pachos: That's what I mean. I still didn't know there was a hotline. Christina has made huge gains, and we were really pleased to see these gains continue. Then we got a letter that her funding had been cut. That caused us a lot of stress. It caused Christina stress. It caused the family stress. It caused me stress, because I knew that I couldn't step back into that role again. They wanted to cut from two carers to one support worker. I knew there was no way they could handle it. I knew what would happen is they'd get injured, they'd leave, and I'd be left with no-one again.

CHAIR: Do you know what the rationale was for the change in the plan?

Mrs Pachos: That is why I've got this on here for the review. We never got a reason. We never spoke to anyone. We never got feedback. I never had anyone that I could speak to about it. Every time we would get in contact, someone would ring me and I would say: 'Who can we talk to? Who can we appeal this to?' It went on for six months, and I got a different letter every month. One said that they would make an appointment for the appeal process to go through. A month later I got a letter—and I should have found them and brought them with me—saying that the funding decision stands. It was conflicting information and a different person all the time. Then I ended up going to the IdA advocates and saying: 'I really need help here. I can't navigate this review. I don't know what's going on. I don't know what was behind the cuts in the funding. She was doing so well. Maybe I shouldn't have told them she was doing so well.' I was even second-guessing what I had said. I said: 'She's doing well, but she's still not there. She's still not bathing or eating by herself.' We're actually at the stage with the OT where we're getting her to bring the spoon up to her mouth. To this very day, I don't know why it was cut. Eventually, IdA managed to get hold of someone; I don't know who. Then we got a face-to-face review—with a person that's in this room, actually.

Senator URQUHART: How long did that take?

Mrs Pachos: Six months, and her funding had run out.

Senator URQUHART: So what happened in that six months?

Mrs Pachos: They were pulling money out of all the other pools of money that were there and that hadn't been used. There were times when we had blocks in the day where I sat with her, but we made sure they were times when she had been fed and bathed and was just sitting—

Senator URQUHART: That must have been terrifying for you, to think that—

Mrs Pachos: I actually got ulcers from it, and I'm on medication for it.

CHAIR: That's very stressful for you. To have been the sole carer, then to finally get the level of support that you needed and then to think that it would be taken away—that must have been very difficult. What happened in the end?

Mrs Pachos: In the end, I can only just thank the lady present in this room.

Senator URQUHART: You can name her if you want to.

Mrs Pachos: Yvette. She was a godsend. When she came it was the first time that anyone from the NDIS had met Christina. She observed her. She saw her program. She saw all the notes from the therapist and the gains she had made. Christina gave her, I think, a zero for her outfit at the time!

Ms Pachos: I didn't.

Mrs Pachos: What did you give her?

Ms Pachos: A three.

Mrs Pachos: Oh, a three.

Mr CONAGHAN: Same as your cooking!

Mrs Pachos: Well, the OT got a minus for her outfit.

Senator URQUHART: So all that could have been avoided had you had that face-to-face at the start, right?

Mrs Pachos: And a person to speak to, not a hundred people telling me something different. Even with our costs, someone who was across it, who knew that Christina was making gains and who could see the reports from the therapist and had contact with her would be able to make a much more informed decision about what her funding needs are. Initially we needed a lot of equipment and now we don't. We just need some money for therapy and support workers to carry out those programs.

CHAIR: I think one of the points that you're making is about the importance of face-to-face meetings.

Mrs Pachos: Absolutely.

Senator URQUHART: And timely.

CHAIR: Yes, and timely as well, as Senator Urquhart has said. Yvette and another representative of the NDIS are here and obviously very aware of your situation. It's good to have them here, because they can hear these statements. It's good from our perspective, as well. We are here to actually look at how we can improve the system, and we will make recommendations. We have a regional and remote inquiry occurring now, but we also run, parallel with that, a general inquiry where your views can be noted and contribute to recommendations within that inquiry. So thank you very much. Did you want to ask a question or make a statement, Mr Conaghan?

Mr CONAGHAN: Thank you both for coming along, Christina and Helen. We have heard you. There's a definite need for greater advocacy so people know what's out there and where to go when they face that situation.

In terms of the reviews, I think it's cruel and unusual punishment, in many cases, to review people's funding when there's no evidence to support that review, but I do know that that's something that the government and the committee are looking into. Thank you both for coming along. Christina, you're a hard marker if you're just giving everyone threes! I appreciate it.

CHAIR: At this point, I'd like to thank you, Helen—if I can call you Helen—and Christina. Thank you so much for being with us today, and congratulations on the progress you've made. It's just amazing. Helen, as a mother you must be thrilled—and the family as well. Thank you very much for your time today. We greatly appreciate it.

Mrs Pachos: And she's walking. She wanted me to tell you that she's walking.

CHAIR: Really?

Mrs Pachos: Yes. With a walker, she did 30 laps at the gym.

Senator URQUHART: Wow, that's amazing.

CHAIR: That is amazing. It just shows you that, with the will and the level of support, there is a way.

Mrs Pachos: And the funding.

Senator URQUHART: Good on you for fighting, Helen.

Mrs Pachos: Thank you.

Mr CONAGHAN: And thank you, Yvette.

CHAIR: That concludes the committee's hearing for today. I'd like to thank all witnesses who've given evidence to the committee today. As mentioned earlier, where witnesses have taken questions on notice the committee requests that information be provided within two weeks, by 30 April this year. However, please liaise with the secretariat if additional time is required. Thank you also to Hansard and Broadcasting for ensuring that this session is recorded. The committee intends to hold its next meeting on Thursday this week in Broome. I would also like to thank the secretariat for their role in supporting us.

Committee adjourned at 16:57