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JOINT STANDING COMMITTEE ON THE NATIONAL DISABILITY
INSURANCE SCHEME

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JOINT STANDING COMMITTEE ON THE NATIONAL DISABILITY INSURANCE SCHEME

Tuesday, 30 June 2020

Members in attendance: Senators Askew, Carol Brown, Hughes, Steele-John and Mr Andrews, Ms Coker, Ms Payne, Mr Wallace.

WITNESSES

COATES, Mr Paul, Chief Executive Officer, Carers WA	8
CROCK, Ms Sue, Consultant, Sexuality Education Counselling and Consultancy Agency	21
JENKINSON, Ms Samantha, Executive Director, People with Disabilities Western Australia	14
MITCHELL, Ms Felicity, Systemic Policy Officer, Carers WA.....	8
RASHID, Ms Shabnum, Solicitor, Sussex Street Community Law Service Inc.....	1
TERPOU, Ms Juana, Manager, Senior Psychotherapist and Forensic Sexologist, Sexuality Education Counselling and Consultancy Agency.....	21
THOMPSON, Mrs Lana, Co-design Group Member, People with Disabilities Western Australia.....	14
TIMMERMANIS, Ms Jane, General Manager and Principal Solicitor, Sussex Street Community Law Service Inc.....	1
WIKITERA, Ms Isobelle, Disability Advocate, Sussex Street Community Law Service Inc.	1

RASHID, Ms Shabnum, Solicitor, Sussex Street Community Law Service Inc.

TIMMERMANIS, Ms Jane, General Manager and Principal Solicitor, Sussex Street Community Law Service Inc.

WIKITERA, Ms Isobelle, Disability Advocate, Sussex Street Community Law Service Inc.

Evidence was taken via teleconference—

Committee met at 12:03

CHAIR (Mr Andrews): Welcome. I declare open this hearing of the Joint Standing Committee on the National Disability Insurance Scheme inquiries into NDIS planning, NDIS workforce and general issues around the implementation and performance of the NDIS. These are public proceedings, although the committee may determine or agree to a request to have evidence heard in camera. I remind all witnesses that in giving evidence to the committee they are protected by parliamentary privilege. It is 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 contempt. It is also contempt to give false or misleading evidence to a committee. If a witness objects to answering a question the witness should state the ground upon which the objection is taken, and the committee will determine whether it will insist on an answer, having regard to the ground which is claimed. If the committee determines to insist on an answer a witness may request that the answer be given in camera. Such a request may be made at any other time. 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, please forward it to the secretariat after the hearing. Information on procedural rules governing public hearings has been provided to witnesses and is also available from the secretariat. Ms Timmermanis, or your colleagues, I invite you to make some opening comments if you would like to do so.

Ms Timmermanis: Would you like a brief overview of our service so you've got a context?

CHAIR: Yes, thank you, and any comments about the NDIS that you would like to make.

Ms Timmermanis: I have only two issues that I would like to raise on that point. I will start with a brief overview. We're a not-for-profit community legal centre. We've been providing legal and social services since 1978. We're based in the Perth east metropolitan area. We do have a strong focus on advocacy and legal assistance to people with disabilities. Since 2003, we've delivered disability advocacy in regional and remote Western Australia and the Perth metropolitan area. We have advocates in the Mid West, Gascoyne, Goldfields-Esperance and Great Southern areas of WA. We provide the only state-wide disability discrimination legal unit and, more recently, have had NDIS appeals and disability royal commission advocacy services as well.

As to the couple of points I was going to raise this morning, those two issues are drawn from our experience and feedback from regional and remote WA as a focus, and from the advocacy needs of people with disabilities, and they touch just slightly on the Quality and Safeguards Commission, which gets rolled out here in WA in December. Are there any questions?

CHAIR: Do you want to expand on those issues that you have touched on?

Ms Timmermanis: Yes. The first issue is about the zone changes that have recently occurred and are going to occur, their implementation systemically and their effects on NDIS participants, families and carers, as we experience them with the feedback from the remote and regional locations.

CHAIR: Can you explain a bit more what those zone changes are and what the effects are that you are concerned about?

Ms Timmermanis: Yes. The zone change, as it's out on the NDIS website, is anticipating, with the geographic classification, a change from 1 October 2020, when they'll be moving from the 2015 modified Monash model, as zoning, to the 2019 model, as to how it classifies remote and very remote locations. That change on the website isn't due to take effect until 1 October 2020. It also says that how it may affect participants is that, if you receive services in a location that has increased in classification, your plan budget will automatically increase to account for the additional charge.

The experience that we've had, from our advocates based in the remote and regional locations where this zone change is probably most likely to have an effect, is that there's a great deal of confusion and a lot of worry arising from that, and that, in general, good information is very hard to find. As to the main contributors to that: we see that it starts initially from the planning meetings with the NDIS, as planners are often not available in regions. When participants are meeting with planners from the NDIS, the feedback that we're receiving is that the level of remoteness is not properly accounted for in those planning meetings. So participants believe they are going to

receive a certain number of hours of service of a certain type—whenever that may be, whether it's weekends or whatever—including travel. However, when their support coordinator, if they have one, looks at the plan, or when they have direct conversations with the service providers themselves and they attempt to arrange those supports, a whole other conversation and set of figures emerges from the providers, usually resulting in significantly fewer hours—sometimes, up to 50 or 80 per cent less time or service than they thought they were going to receive from the planning meeting.

Despite—and as the intended consequence, perhaps—those zone changes and increases to hourly rates, which are significant increases, about 80 per cent in some cases, not being meant to occur until 1 October, and the intention for participants to have their money increased commensurate with that, the feedback we're getting is that there is some confusion, and some providers are already charging that higher rate. So what participants are being told and what the families have been advised is that their funding is not enough to last to the end of the plan and it may result in a reduction of service hours. We've then queried what they're being told is an option to fix this, and our feedback is that they're being told to discuss reduction of service hours weekly so that they do last the full term, or to file for a plan review.

CHAIR: Before we come to questions, what was the second issue?

Ms Timmermanis: The second issue was that, as an advocacy service generally that's independent of the NDIS, we assist people with any issues they may have that may arise from their plans and their implementation of those plans. What we are receiving as feedback is that, in cases where people feel that they've not had the number of hours delivered in the service that they thought they were paying for, it's difficult for us to make those referrals as to, if they've suffered a potential financial loss or funding impact, what their remedy might be to have that dealt with but also to have any possible funding restored. Coming from, I suppose, a more legalistic side of it, you may look first to the service agreement and any service plan that goes with the service agreement. However, the status of both of those documents is difficult, and what we see is perhaps a gap there, or at least some confusion for us and participants, as to any contractual remedies that may arise, that may be available to the participants, and whether those are accessible and available, and how that works within having the Quality and Safeguards Commission—things like the fraud hotline and Consumer Law remedies. It's not clear for us, and I think for us to advise participants, and for them themselves to find out, how they might navigate through to a remedy.

CHAIR: Let me lead off with a question before I come to my colleagues, just to understand the issue about the zoned changes. As I understood what you were saying, it was that the providers are charging a higher fee, even though the funding increase doesn't occur until October this year.

Ms Timmermanis: That is our feedback. I'm not saying that's being done with any malfeasance or any intent, other than: it is confusing. We suggest that—as it may start with the NDIS planners, the NDIS staff, as they are where a lot of this starts in the regions—better information of systemic change be more proactively and actively distributed and made available to NDIS staff, to start with that information. But we'd also suggest that the portal is more regularly updated so that participants themselves, who maybe don't have planners and don't have support coordinators, have a place that they can go where they can get some accurate information, and that providers, however they receive their information, are able to access information or to ask questions where they feel that there's a confusion. The pricing guide that is out there as the latest one still only refers to the 2015 zoning for its pricing. I think the 2019 zoning isn't meant to kick in until 1 October, so that's another looming disparity or confusion that we don't want systemically affecting people in regions who already basically suffer from a lack of information and support to help them make some of those decisions.

CHAIR: Listening to you, it seems like there's a breakdown in adequate communication by the NDIA.

Ms Timmermanis: I might ask Isabel—she's our advocate in the Kalgoorlie office and has had some experience on the side of being an NDIS provider—to make a comment on her impression of that experience on the ground. I'm more than happy for her to do so.

CHAIR: Ms Wikitera?

Ms Wikitera: I work hands-on with the people that are impacted by the planning. What's coming through from the clients is they do not understand a lot of the changes that are coming through. Their providers don't have enough information to inform them correctly or give them as much information as they can before they sign on the dotted line. The clients are getting frustrated because the services that they thought they were going to get are significantly less because of the charges they're getting from their provider. They're thinking that they're paying this rate and are being told, 'No, your specific zone pays this rate.' That hasn't been explained to them fully before they've gone into their service agreement meeting. The result is I've got families coming back almost in tears

because, for funding they thought would last through to May next year, they've been told by their provider it will only last until September of this year.

To even reduce the hours of service they're receiving or to request a new—in one case that I had she was successful in having her plan reviewed, but it took a long time to request her review, and they weren't able to speak with her until mid-May. It's only because she connected to an advocate that I was able to advocate on her behalf the importance of what was happening, and she had a successful outcome there.

But I'm also being questioned by other people in the community on how this is going to impact their child's services. I've got a lot of families that are worried that this is going to happen to them and there's not going to be enough money to last through the services that they've got at the moment. There's not enough staffing for those people to get the services, so they have to wait longer periods, which isn't helping the children and their progress with their support therapy.

CHAIR: Ms Timmermanis, have these problems been communicated to the NDIA state office in Western Australia?

Ms Timmermanis: I think I did send it through. As part of the disability coalition group that we belong to with other advocacy agencies we have meetings with a couple of the policy people from the WA NDIA here, say, every six months or something. I did foreshadow that to the NDIA. I haven't had a response; otherwise I would have included that and referred to it. I think it was on this point; I can't be a hundred per cent sure, but I know I sent something last week to Helen.

Senator CAROL BROWN: Thank you for your evidence. Firstly, I want to clarify the issue around pricing. Your evidence is that the increase in pricing in people's plans that is due to come in with the changes in zones is being charged by providers now.

Ms Timmermanis: At the moment, if plans are being properly put together, the pricing guide refers to the 2015 zoning. In one case, a particular town is a zone 5, and I can only assume—because I wouldn't be saying otherwise on this with any evidence—that correct pricing is being included. We understand that a conversation has been had that soon that pricing will be going up as it should be on the 2019 model in October. However there appears to be a gap in the information being provided to participants about how that's meant to happen and the reassurance, I suppose, given that there's meant to be a mechanism by which they won't be disadvantaged. For us, we need better communication or better information distribution so that everyone is consistent around the understanding of what zone changes are, when they're coming, how they're aligned and the impact that will have on participants and providers themselves.

Senator CAROL BROWN: So it's about the communication. The increases in pricing may well be taken into account in a plan, but there's no communication or there's confusion around exactly what pricing is included in the plan—is that what you're saying?

Ms Timmermanis: Yes. I would go to Isabel if she wanted to comment on whether our understanding is that those 2019 zone prices are being charged incorrectly at this present moment in time.

Senator CAROL BROWN: Okay. Do you find that the confusion is across the board, or do those participants that have an advocate with them do better in terms of getting a plan that actually is tailored towards their needs?

Ms Timmermanis: I also have feedback from our advocates in the Mid West and Gascoyne that there's the same type and level of confusion, and from feedback from a planner themselves and a support coordinator, in that they're trying to work their way through what may be happening with zone changes and finding it very difficult to do that themselves. I could perhaps provide some of their evidence later, because I couldn't for sure say that anything had been incorrectly charged, other than there was confusion and having to re-do a plan.

Senator CAROL BROWN: The evidence that you're giving today is that there's a lack of information and there's an issue around communication with planners and the NDIA getting information out, and even the providers don't know the answers to the questions?

Ms Timmermanis: Yes.

Senator CAROL BROWN: Are you able to give us an understanding of how that information is provided to participants? Is it done in written form?

Ms Wikitera: Jane, I can comment—

Ms Timmermanis: On the process, yes.

Ms Wikitera: as an advocate. Before I was an advocate, I worked for a service provider, and it was my job to sit down with the clients and do the onboarding paperwork for service agreements, setting up service bookings. What I'm finding now as an advocate is that my families are coming to me and saying that, in the conversations

they're having with the providers, the information the providers have is not enough either. So there appears to be a gap between the provider's understanding of how to read those price guides and how to have that conversation with the participant when they go in for those meetings, understanding that the price guides change throughout the year and to let the participant know: 'There's been a price change. I need you to come in and we will sit down and tell you how this is going to impact your current plan and whether we need to re-do your service agreement to make up for those adjustments.' Those conversations aren't happening.

I'm finding a lot of the clients are very overwhelmed by the whole NDIA process, from the planning, from trying to register, right through to having their meeting—how to have that conversation with their planner so that the planner understands fully what the needs are for the family and has that implemented into the plan that they're sitting down to do the service agreement on. It's like a breakdown of communication. There needs to be more community education from NDIA to come out and speak with providers, separate to the participants, and explain, 'As providers, this is what you must do,' and then sit down and have that same conversation with the families but in a language the families can understand. A lot of the families don't understand the processes with NDIA. They go into the meeting and come out knowing less about what they were supposed to find out about. It just whirls around in their head.

Senator CAROL BROWN: It's not good that people are going into meetings and coming out knowing less. That certainly is not very good. But we have heard before about issues around the need for greater education and the need for that community education and participant education to be delivered in a way that is easy for people to understand. Do you have any recommendations you'd like to talk to us about as to what can help participants and providers? What can we recommend that will make it easier for participants to go through the planning process?

Ms Wikitera: From my point of view I think there needs to be more concentration on community education for participants, and I'd say workshops and information sessions for providers, so that they're fully aware of the impact that these changes are going to have. I also think that the NDIS portal for participants needs to be a little bit easier for them to navigate. I've had a few comments come back that they've been to the portal and it just flows over their head; they don't understand when they're looking at their service bookings what it actually means. They see the service booking for the service, but, again, they don't understand it. So maybe there needs to be a little bit of education about how to read the portal so that they can see firsthand where their money is going, how it's being utilised, who's utilising it, who's making claims, when the claims are being made. I have been assisting one client to look at her portal, and it appears in her portal that no claims have been made against her funding. She's confused because she thought that that's all been taken care of by the powers that be.

Senator CAROL BROWN: Had the person that didn't have any claims against her plans been receiving supports and services?

Ms Wikitera: Yes, and now she's concerned that she may have used up all her money, but she can't see that effect in the portal. It's just got the service booking and who's providing the service and whether they've made any claims for that period. It appears on her portal that no claims have been made, and she's worried they're going to make all these claims at once and the funding's going to be depleted. We said to her to sit down with her provider and go through it point to point and then ask that important question: 'Why have there been no claims made on my funding?'

Senator CAROL BROWN: When people have questions, has there been a timely response if they are able to find somebody to ask the question to?

Ms Wikitera: I had one client who came in. They had put in a review request in February, and they hadn't had a response by April, when they were told by the NDIA call centre to call them back. It was a very curt response. It wasn't until I had connected to the client and written an email, with her consent, to explain the gravity of the situation. From there, it took maybe 10 days, and she was able to sit down and have the meeting. The client didn't have the language to use in asking, so they were just being told, 'Well, we've got a backlog; we've got a backlog.' Once the importance of what was happening and how it was impacting the client was explained in an email, they were able to get that meeting fast-tracked.

Senator CAROL BROWN: I have one last quick question. You talked about a community education program. Who do you think should deliver that community education program?

Ms Wikitera: I think that, when it comes to the planning price guides and things like that, it should come through NDIA, through community workshops and sessions. There are also groups that I know of that are led by families that utilise NDIA-managed plans, plan-managed plans and self-managed plans. They will sit down with families and explain what those differences are, how effective they are and what it will do for each of the families. We've only had one of those training sessions in the last three years, and that was absolutely the best thing that

we've had up to now for helping families who are trying to decide how their plan should be managed. I'd like to see more of those come here. I'd like to see the NDIA come in and do some workshops with families and providers so that everybody is on the same page when the families go and meet with the providers and they're not overwhelmed by all this organisational speak, which just confuses them. What I don't want to happen is for the families to sign on the dotted line, not fully understanding what they're signing away their rights to.

Ms COKER: Thank you for the opportunity to ask a few questions. I'm interested to know how widespread the issue of participants' funding running out prior to the conclusion of their plans is. Is this a widespread issue impacting all participants across WA, or is it happening occasionally?

Ms Timmermanis: What I learned from our advocates was not only with Ms Wikitera in the Goldfields-Esperance area but also in the Mid West Gascoyne, which is where the issue originally arose for me as an alert, because that is also a region that is probably affected disproportionately by zone changes, compounded by the fact that, in regional and remote locations, there isn't the access to planning services. In the Mid West Gascoyne there aren't any planners, so the NDIA, by default, has responsibility for that role. It is also compounded by the fact that, even when participants may have a plan, not everyone has the support coordination that can then assist them to make that connection or have those conversations with the providers, and providers themselves can be quite remote and can be smaller and less able to have the time to find that information proactively for themselves. They do their best, but they may be giving out information that's incorrect.

I have an example from the Mid West Gascoyne area where a participant was fortunate enough to have a support coordinator but, even so, that support coordinator then, looking at the original plan and giving some information to the participant about how much money there was going to be, said that, of that plan, there would be a figure in the \$30,000s left over for the rest of that period that they could more discretionarily spend or incorporate into travel. When the support coordinator made a further query, having noticed that maybe there was a discrepancy because of the remoteness of the region in which that was going to be delivered, they had to go to the provider and redo the plan based on what the provider's understanding was, and they're still not quite sure that the provider's understanding is correct. But the result of that was that there was then going to be a significant shortfall in the plan, because the hourly rate had increased—I'll give an example; it wouldn't be exactly this—from, say, \$54 an hour for a service in zone 5 to \$90 an hour in zone 6. For the region in which that was located, that zone change happened between two towns 20 kilometres apart. There was a town that was in zone 5 and there was a town that had gone to zone 6. It was 20 kilometres, and the price difference is of that order of magnitude. The bizarre reality of life in the regions is that that service that was delivered 20 kilometres away is actually still delivered from the zone 5 region.

Ms COKER: Yes, it does sound very confusing, and there is a real concern that it is resulting in people losing services and support and being increasingly anxious. I'm interested if, for participants, the NDIA is offering to review and adjust plans in accordance with this new price scheme? That is being offered from what you've said.

Ms Timmermanis: Yes, it appears that's the information on the website and is probably the intention.

Ms COKER: Are participants taking that up and going in and getting their plans adjusted across Western Australia or in these areas that are affected?

Ms Timmermanis: My understanding of reading on the website is that the zone changes aren't meant to occur until 1 October 2020. Then by an automatic operation, if you're affected by that as a zone change, the prices that providers can charge increases and your plan is meant to increase commensurate with that. However, because there's confusion in the providers in the regions of how, when and what rate it is they apply and that the pricing guide still only applies to the 2015 MMI for plans done quite correctly right now, it is resulting perhaps in some prices being overcharged at a rate that they shouldn't be. This is where I think Isobelle has mentioned that there may have been clients who have already been impacted by increase costs perhaps where they shouldn't have been, but the options that they've been told are either: reduce your weekly hours to manage that funding within a limit or have a plan review.

On one occasion it sounds like the client's undergone a plan review and had a successful outcome as an increase in the funding; however, we're concerned about the impact on the taxpayer, if providers are prematurely charging amounts, and that there is a remedy when they go to a plan review of amounts increasing in their plan to cover that. That's happening in a way that wasn't intended and has an impact on all the parties concerned, including the Commonwealth, of money being paid perhaps when it shouldn't do to provide justice. However, it appears that it's not meant to operate that way.

Ms COKER: It sounds to me that it's up to individuals to go and—

Ms Timmermanis: Find out the information and then do a plan review.

Ms COKER: To me it sounds like perhaps, Chair, that this is an area where we need to be saying, as a committee, that there needs to be more of a process across the board which doesn't leave it up to an individual to have to make these changes. If there's a change in the costings, it shouldn't be disadvantaging people and leaving them with less, unless they have the ability to go and advocate for themselves. It seems to me that we need to be able to put something forward to help. It sounds like it's been very confusing. Have you got a recommendation that you think would help to stop this confusion and make it more streamlined?

Ms Timmermanis: Yes. My thoughts, or our thoughts, are that zone changes and systemic changes of this magnitude don't happen very often. However, where that is going to occur, we'd like to see the NDIA more proactively provide that education not only for participants but also for providers, and for their own staff in particular in regional and remote areas which are more likely to be affected and have fewer services and less access to finding that information out themselves. The NDIS, who end up being the planners in the first place, should feel confident, have that information and proactively distribute that and be a source so that when there are queries they're confident to answer them from providers and participants alike. Where there is systemic change, there perhaps could be some more proactive recognition in regional and remote areas and concentration on the efforts to ensure some communication.

Ms COKER: It seems odd to me that providers are actually charging pre-emptively. That doesn't seem to be right. It's something I would question: why would they be able to increase fees prior to October?

Ms Timmermanis: That's my feedback. I've attempted to really nut that out and clarify it. I haven't been able to absolutely pin that down, but that it is my understanding. Unless I can defer to Isobelle to say that with hand on heart, that's what the feedback is coming from the participants.

Ms COKER: I think that's something that needs to be looked into in more detail, because that is a concern. By flagging that it's happening in October, you would presume the intent of the NDIA is to alert participants and run an awareness campaign. It's not to actually be a flag to providers to change their fees early. That's something that is a concern if that is actually happening; a real concern if it is. I'll leave it there, Chair, and let someone else ask some questions. Thank you.

Senator STEELE-JOHN: I'd just like to take you all to a slightly different question of the impact, first of all, that you've felt in terms of the transition here in Western Australia and the complexities that have been inherent in that process. Have you seen as an organisation a significant increase in demands for your services? I presume you have.

Ms Timmermanis: Yes. The demand hasn't decreased. I don't think we noticed any significant decrease in demand because of COVID. With changes that happen, say, annually with the price guide but compounded with changes to zoning on top compounded with COVID changes as well, there has been a consistent increase, I think—and I'll defer to Isobelle—across the regions, and we do deliver around the Perth metro as well, and just how all of that is going to impact and affect them with varying information and us trying to get varying information back that is of good quality to be able to answer those queries as advocates for our clients. That's been a challenge in itself. And some of this is a moving feast, as far as COVID, so it's been difficult to make sure we've got that information accurately. But the level is, and the feedback we get is, when the responsibility then falls onto families and carers to do something like a planned review—or to go and check the portal again, or to go and do another review, or to do an NDIS appeal or review—they're just giving up. It's just too hard.

Senator STEELE-JOHN: Absolutely. Obviously, we have the different timeline now around the introduction of the quality and safeguards commission, but do you feel that state based funding has kept pace with the increasing demand for your services?

Ms Timmermanis: The advocacy services are partly funded by the state and partly funded by the Commonwealth, as you know, Senator. There's ongoing funding that's been promised but not at an increased rate, so we're looking to try and deliver within what we've got. We can always do more if there's increased funding. And part of our advocacy is individual advocacy and part of it's systemic. So part of it is trying to make some systemic change, to make sure that there isn't an increased demand for our services. But there is an increased demand, and I can't see that going away. With advocacy, even in the planning process, agencies paid to plan actually refer to advocates, even at that early stage, because they want advocates to assist the participants to do the running around—to get the medical reports, to actually do the appointments—rather than be taken by the planning agency. So, even at that early stage, advocacy agencies are having that demand put on them, and then throughout the process, and as they're independent to the NDIS, there's a lot of queries [inaudible] there and how we try and resolve those.

Senator STEELE-JOHN: And do you have any thoughts on the recent announcement to delay the introduction of the quality and safeguards commission purview in WA? Has that had an impact, or do you see that having an impact on the people you support or the processes that you work with?

Ms Timmermanis: Yes. Whilst none of us are sure how that will actually roll out and play out in WA, we can look to other states for some guidance as to what matters can be dealt with, and the wide powers that the quality and safeguards commission has, ultimately, to take licences away from providers where they've been found to do something at the level that requires that. HaDSCO is our state-based agency. It's not an agency that every person who engages with it gets a satisfactory outcome for them; it has its pluses and its limitations.

My second point to raise was we're finding that frustration from participants as to where they feel that they've [inaudible] funding loss. Where do they go?

Senator STEELE-JOHN: Yes, absolutely. On the broader question—and I'm particularly interested in the view from a regional perspective—is it still the case that you seem to be finding that interactions with planners seem to display a lower level than would be optimally desired, in terms of understanding of disability or various related contexts?

Ms Timmermanis: This is just an opinion? Yes.

Ms Wikitera: Is that from the planner's point of view?

Senator STEELE-JOHN: From a participant's point of view, in terms of their experience of interacting with planners.

Ms Wikitera: Yes. Sometimes our clients aren't able to see a planner that's local. So they've been given planners that are not in our geographical area. What those planners are struggling with is they don't know the dynamics of our local community, they don't know what's available in regards to supports and therapies, and a lot of them are using the internet to research, when it comes to providers, supports and therapies in our area. Unfortunately, the internet is what it is—websites aren't updated and some of those services don't exist any more, which is making it frustrating for the client, because the client tries to access those services but the company no longer exists. They would prefer to interact with a local NDIS person, because if they live locally they know what's available in our communities. They're very [inaudible]. Most of our organisations and agencies know each other, not only on a professional level but a social level as well. We can have those conversations with the planners and say, 'Yes, well, these services are available. This is what you could promote to the clients when you're having your meetings.' Instead of the client finding out that services aren't available here, and they're going off and trying to find their own services and not getting very far.

Ms Timmermanis: Perhaps could I just add one more comment on that. I did an audit of our service in the Mid West-Gascoyne in January to get a sense of what the work was that we were doing and what the demand was. My finding from that is that about 70 per cent of the work that was coming to our advocate I would class as planning queries. They were people who were at the very early stage of trying to be assessed for eligibility and be taken on. They'd be given their booklet to work their way through as to what their goals were. That's all they'd been given. There are no planning services or agencies in the Mid West-Gascoyne—I was in Geraldton. So people were totally confused. What few public sessions I understand there have been, they didn't gain much valuable information from them, in that they still went away confused. So they sought a personal, one-to-one contact, which was through our advocate. We're funded outside of the NDIS to be independent of the NDIS, to assist with any queries around advocating for people with disabilities to the NDIS. And, from a funding perspective, I didn't feel comfortable that we were spending 70 per cent of our time as an advocate, really, planning. We were sitting down saying, 'What would you like with your goals: what would you like to do? What services? How many pads do you need?'

I thought, 'That is not what we're funded to do. It's unfortunate that it appears to be a gap, and we'll try and advocate for that, but I don't think that's what we're here to do as advocates.'

Senator STEELE-JOHN: Yes, absolutely. Thank you for providing that evidence. That'll do me, Chair.

CHAIR: Ms Timmermanis, Ms Rashid and Ms Wikitera, thank you for coming online and discussing these issues with us today. It's been most informative and helpful to our inquiry, so thank you very much for your participation.

COATES, Mr Paul, Chief Executive Officer, Carers WA

MITCHELL, Ms Felicity, Systemic Policy Officer, Carers WA

Evidence was taken via teleconference—

[12:52]

CHAIR: I welcome Mr Coates and Ms Mitchell from Carers WA to this teleconference today. Information on procedural rules governing public hearings has been provided to you and is also available from the secretariat. In addition to me, Kevin Andrews, we also have online the deputy chair, Senator Brown; Ms Coker; Mr Wallace; Senators Hughes and Askew; Ms Payne; and Senator Steele-John. I invite you to make some opening comments.

Mr Coates: I'm going to pass over to Felicity to make the comments. Felicity's done some quite detailed work in this area. I think it's appropriate that she makes the opening comments. Over to you, Felicity.

Ms Mitchell: Thanks, Paul. And thank you for the opportunity to give evidence to this committee. Carers WA supports and advocates for unpaid carers in Western Australia. We believe WA carers welcome the NDIS principles of choice and control, individualised planning and lifelong support. The scheme has the potential to improve the lives of people with disability and to further facilitate their inclusion in their communities, and it has already done so. WA is in a unique position, as you know, as the last state to transition to the NDIS, and, while the transition was due to be completed in 2020, we've had several delays. It's expected that there will be 43,000 participants in WA at full scheme; at the moment, we're at 27,000 participants.

Our comments today concentrate specifically on the main concerns of carers from their experience with the NDIS system. The first issue is around access. The process to gain access to the NDIS requires significant time, knowledge and cost. This work often falls to carers and is in addition to the work they already undertake to assist the person they care for. Carers report there is very little support to prepare the documentation needed for an access request, and the process can be confusing and stressful, as I think your last witness mentioned. The LAC partners in the community have a role in supporting people with access requests, but in practice they're merely providing web links and booklets rather than advice and guidance. So further one-on-one support is required.

The second issue is around the planning cycle, and I think it's been well canvassed in other submissions. Once an access request has been successful, the participant and/or their carer enters the NDIS planning cycle. This cycle is intensive and requires considerable preparation. Carers report that there's little support for preplanning for the initial planning meeting with the NDIA. In order to obtain the funding required, the person with disability and/or their carer needs to present a clear picture of ongoing needs for daily care, therapy, community participation, assistive technology and home modifications, along with draft goals—in the correct language—to fit these needs. And then they need to back these up with assessments and reports from health professionals. A lack of extensive preplanning may result in an inadequate plan. Again, the LAC partners have a role in assisting with preplanning, but carers report that this is not being delivered adequately. And this process happens for carers and people with disability every year, as you know.

The third issue is that carers report that, if a child or adult lives at home with parent carers, the NDIS tends to rely on informal support. Often, plans don't provide the allocation of funding required for people with disability to spend time in the community, independent of their families, and therefore carers can't access a break from their caring role. The consequence of this reliance on informal support can be that carers become burnt out and, in some cases, aren't able to provide care any longer. The NDIA has acknowledged this issue and reintroduced the term 'respite' into the NDIS price guide, but we think more needs to be done to ensure that carers are supported, along with participants.

An issue of specific relevance to Western Australia is the thin markets in service provision. The NDIS is predicated on choice and control, but this can't be utilised if service providers are not available to provide specific and relevant supports. There is a lack of personal care workers, allied health professionals and support coordinators in the metro area but particularly in regional areas. For example, carers have reported that there's only one support coordinator working in the Northam area, and other people have told us that it's difficult to find personal care workers just outside of Bunbury, which is a large regional hub. We acknowledge the work already done on this issue by the NDIA, but it's still a significant issue for WA and, obviously, is further exacerbated in remote regional communities in our north.

The last issue we wish to raise is one that's been discussed frequently by the committee, and that's the review process for plans. It's a significant area of stress for carers. The review process can go on for many months, and this puts an enormous amount of pressure on carers while they wait for outcomes. During the time taken to review plans, the person with disability can be left without funding support. We note that this committee has made a

number of recommendations around the review process, including the provision of draft plans to participants and families to minimise the incidence of a review being required, but, unfortunately, people are still not seeing draft plans.

Carers WA works closely with many disability advocacy groups in WA. Along with them, we appreciate the continued work of the Joint Standing Committee on the NDIS and the efforts taken to consult in WA. We'd be happy to take questions on the points raised or any other issues relevant to carers. Thank you.

CHAIR: Thanks, Ms Mitchell. Have these issues been exacerbated or remained similar with the COVID-19 challenges?

Mr Coates: It's hard to tell. You can make judgements, but there's no real research or evaluation being undertaken at the moment. All we can go by is what we hear from phone calls and hearsay. It has increased anxiety. The groups that are vulnerable continue to be vulnerable, and a bit more so, in the COVID environment. I don't think we can blame the COVID environment for some of the issues we need to address in the system itself.

Senator CAROL BROWN: Thanks, Mr Coates and Ms Mitchell, for appearing here today. I just wanted to go back to a point Ms Mitchell made about the lack of support for access requests and subsequent lack of support for pre-planning. What recommendations would Carers WA like to make to support participants?

Mr Coates: I think there needs to be a real focus and understanding on pre-planning. I've been dealing with a family living in the south of the state who actually had assistance set up for a number of years like the NDIS, with their own company and their own management of the position of the son in the family. There's obviously anxiety about these changes. They were fully expecting, having been quite long established in this sort of process pre the NDIS system, that they were in a good position. But they felt that they didn't have any pre-planning at all; they went straight into a draft plan in answer. I think it's all about making sure the process of pre-planning is fully followed through, particularly where there are complex cases. I don't know if you've got anything else you want to add, Felicity?

Ms Mitchell: I would just say that many carers have told us that they think they require one-on-one support for that pre-planning rather than generic information sessions provided.

Senator CAROL BROWN: Have there been any reports where carers or participants want somebody to come along with them and it hasn't been accommodated?

Ms Mitchell: No, I don't think so. I think the system of nominees is working reasonably well.

Senator CAROL BROWN: You also talked about services. How are services and support being accessed? By that I mean: are there services and supports that people have in their plans that are not available?

Mr Coates: I think once you get outside Perth and the main regional centres the market gets thinner and thinner. WA, as you know, is an extremely large geographical area with a spread of regional and remote communities. So once you get beyond the regional centres and Perth availability does get less and less.

Senator CAROL BROWN: In terms of thin markets, as I understand it, we still haven't got a clear direction as to how those issues are going to be resolved. Is there also an issue around adequate communication with participants?

Mr Coates: I think there is, but it's easy to talk about thin markets and regional and remote areas and lack of availability of services; that's no news. The question is: what can you do about it? Perhaps the system could relax its processes more and maybe make use of service providers who are out there already. There may be an aged-care service provider or a mental health service provider quite active in the area who is not a registered NDIS provider. Perhaps there could be some bringing together and utilising of those sorts of organisations as a mechanism in the process. I don't think a lot of that has been thought about and done. If you're in a remote area and there happens to be an organisation that happens to be a mental health organisation, perhaps it's engaging more significantly with the organisation and trying to bring them into the process, allowing for the fact that the process may not be quite as rigorous or following the procedures as it would be if it's in a main city.

Ms COKER: I'm interested to ask about respite for carers. In Victoria, even today, I've heard complaints about lack of opportunity for respite. Is that an issue for carers in WA? If so, what is being done to support carers?

Mr Coates: Respite is one of the most valued services of carers, particularly when there's a significantly challenging caring role. Once again, it depends on whether you're talking about respite as in somebody coming to the home or the person being cared for going into some sort of facility that is actually providing replacement care. That is provided for in the new Carers Gateway program, certainly—both emergency respite and planned care respite, to a certain level, depending on what the funding rules allow. With the COVID environment, respite facilities at residential homes were locking down. And, with in-home support, people are reluctant to bring a

stranger into their home because of the risk of cross-infection. That is all beginning to ease a bit now. But, as with other services, the availability of respite services gets harder and harder as you get to more regional and remote areas. Once again, it's the same issue.

Ms COKER: Is the NDIS adequately supporting carers by giving participants opportunities to take respite on a regular basis, and are there the respite facilities to enable it to occur?

Mr Coates: Whether there are respite facilities to enable it to occur depends on where you live. But I do not think the program itself has that much of a focus on carers and providing respite for carers, in all honesty. So if carers want respite they would have to engage with the new system, the Carer Gateway program. I think a lot more could be done to bring carers to the fore and recognise that the scheme is about independence, choice and control—the quality of life for the person with disability. I think there has been a lesson right from the beginning of the development of the NDIS and those early days of campaigning, where it was all about having a new system which was going to improve the lives of people with disability. In a way, some of the early thinking was that carers and family members would become almost redundant. But then the reality kicked in that the extent of the role that families play, particularly with people with severe intellectual disability, isn't going to abate at all with this new system. There has been a growing recognition that carers are an integral part of the NDIS, and need to be because they're a significant form of support. Even if one has a great plan and is well funded, that often can have an impact on creating more tasks and work for the family members to support that life. So there needs to be far greater recognition so that carers and things like respite do get included in the plan. Understandably, with a system that is predicated on the individual and choice and control, that issue is much less likely to come up in the processes that we have at the moment.

Mr WALLACE: Thank you for your evidence today and also for the work that you do. I am the parent of a child who lives with a disability, but my wife understands respite much better than I do. I get to come to work; that's my respite. Following on from what Ms Coker said, I'd like to talk to you in a little bit more detail about the respite issue. What specific things do you think the NDIA could provide in its system to better provide respite for families? And could you please be specific rather than general.

Mr Coates: I think the planning process itself could have more emphasis and definite flags to ask the question. With the greatest of respect, if a plan has been prepared for somebody with a severe intellectual disability, it is unlikely that the topic of giving respite and a break to the parents or whoever the carer might be—unless someone raises that as a topic—so it is down to the planner or the family speaking up for themselves. Often the family won't speak up for themselves because, understandably and rightly, they are focusing on their family member to get the supports for them. So I think it's got to be a fixed question, and an encouragement for the planners and the family to think that through during the planning process.

Mr WALLACE: With WA being so late to the party, you may not be able to answer this question. In the experience of the committee, early on, respite was almost a dirty word. The NDIA didn't want to know about respite, because respite is for the family not for the participant. Do you want to comment on that at all?

Mr Coates: You're right. There are lots of words that are used in different sectors which are acceptable in some sectors but not in others. Respite is a dirty word—it was used in that way—because the connotation was that it was an opportunity for the person to escape, to get away from the person they are caring for. Sometimes we need to look beyond the words and meanings and political correctness on these things and just look at the situation of the family. It has gone full circle: it is becoming more and more accepted now that it's a necessary reality, and whatever you label it shouldn't matter.

Mr WALLACE: The experience of Carers Queensland is that NDIA will entertain funding for respite for families. But what I have seen in the past is that if you use the word 'respite' there is almost a guaranteed no; but if you use another descriptor for it then they would entertain it.

Mr Coates: That's right, and that's what I mean: we need to get beyond the political correctness of words. In Queensland, you're actually lucky because the LAC process is run by Carers Queensland to a fair old extent. You've actually got people in the know there, who are a bit more aware of that as an issue.

Senator HUGHES: I wanted to cover a couple of things with you. Some of the things you've said from a WA perspective really aren't that unique to WA, in the sense that rural and regional communities have pre-existing markets across the country, and looking for support workers even in areas such as Sydney is not particularly easy. Could you cover off for us what you think are the barriers to entry to the workforce, and why we experience this shortage of workers. Some of the roles need to be undertaken. Like Mr Wallace, I'm also the parent of a child with a disability. Some of the assistance can be funded through the NDIS is not high-skilled, yet even trying to find

those sorts of workers is very, very difficult. What do you think some of the barriers to entry are with this workforce?

Mr Coates: I get what you're saying—that they might not be high technical skills—but there are certainly skills that are needed which people don't automatically have, although you'd they would. Those are empathy and a desire to work in that sector. It is challenging. It's not quite nine-to-five type work, because you're dealing with a lot of emotional issues which, with the best will in the world, you can potentially take home with you and think about through the night. I guess the barriers are pay, availability of staff on those regional areas anyway, and it probably needs some form of campaign and some training and recognition and respect for these roles, even if they are not highly technical roles, to make it a more popular, acceptable and understandable profession. In WA—again, we claim to be a unique but I don't think we're always that unique—we do have quite a strong mining community. When people go out to work in the regions, fly-in fly-out, they get paid a hell of a lot more money for doing actually quite low-skill tasks in some cases. They get a lot more money than they would in a caring role for a disability organisation.

Senator HUGHES: Does WA have access to disability employment platforms like Hireup and Mable that are opening up the marketplace and allowing people to enter the marketplace as workers?

Ms Mitchell: Yes, we do. I believe Mable is quite a popular one in WA.

Senator HUGHES: There are some things you find that not everyone within the disability community is aware of them. Ms Mitchell, I think you mentioned something with regards to people not having funding when they're going through reviews?

Ms Mitchell: Yes, if there is a gap in plans and one plan finishes during the review—

Senator HUGHES: So you mean when there's a gap?

Ms Mitchell: Yes.

Senator HUGHES: That's fine. Obviously if you have a plan and you're going for a review, even though you might be having a look at your plan being redone, the money that is allocated can still be accessed during that review period. We wouldn't want people to not be using the plan that they're given, even if it is under review.

Ms Mitchell: No. The other thing is that we've heard of situations where, if you're reviewing the first plan, there is no funding in that period of time.

Senator HUGHES: We need to be careful with some of that, because sometimes I think we hear anecdotes and hypotheticals that aren't actually what should be happening. When we talk about utilising non-registered providers—and I agree with you that that is actually a very good way of expanding some of the markets in rural and regional areas—what are the sorts of volumes of people and what is your engagement with carers, particularly with families that have the ability to self-manage their plans or use a plan manager? Because, obviously, if they self-manage or they use a plan manager, they have the ability to use non-registered providers. Are you finding that there's a pushback from the NDIA about using self-management or plan management, and that they are trying to encourage agency management? Because it's only agency managed people that have to use registered providers.

Mr Coates: I don't know whether there is a pushback or not, to be honest. I'm not sure we have the evidence to say that categorically. But, certainly, I know they would encourage people to use registered providers for all sorts of reasons—governance reasons and even for family reasons as well. You find a lot of families where the carers who are getting aged, quite significantly aged, and the person they're carrying for is getting into their 20s and 30s and even 40s. So the NDIA is concerned about them—their ability to help in that management process is becoming less and less. So, in those sorts of cases, I'm sure there would be a push to encourage them to utilise registered providers and have the plans managed by a service provider. I know families in that situation, and it is a bit of a tear for them; they've spent a lot of their life managing the process and all of a sudden they realise the reality is that they can't. But we've got no evidence and we've done no study of it to say that this is a common trait.

Senator HUGHES: As I said, I'm in Sydney and I self-manage, and I wouldn't be able to hire the people that I've got if I only used registered providers. The therapist that we've had for seven or eight years is the sole provider and is unregistered. We used to live in a very remote area, so I am very familiar with thin markets in remote areas. I want to make sure that families are at least encouraged or given the right information, because a lot of families, particularly with young children with a disability, are in a position where they can self-manage and work with a plan manager. They can get a little bit more creative with accessing services and providers outside the big providers, who do tend to be very prescriptive in what they deliver and do tend to have much higher

administrative overheads so, therefore, their fees tend to be at the higher end. What their workers get paid tends to be at the lower end. It certainly gives you more scope, using some of these other smaller providers.

Mr Coates: I certainly think the LACs and those are probably more reticent when people want to go down there than with a registered provider.

Senator HUGHES: That is enough for me. Thank you.

Ms PAYNE: Thank you for your evidence today. I just want to ask about young carers, in particular, and how they are faring at the moment with the NDIS in WA.

Mr Coates: I actually don't have a lot of information on that, to be honest. The majority of people we are dealing with tend to be older and have direct issues which are brought to our attention. On young carers' issues, the sorts of things they're facing include managing the care involved and managing the live education aspects of it—keeping that up. There's not a lot more I can say on that.

Ms PAYNE: No worries. That's all from me.

Senator STEELE-JOHN: Thank you for your evidence to this point. I just want to take you to the broader financial context that carers have been experiencing, particularly with COVID-19. How would you describe the financial struggles that carers are facing at the moment? Do you hear reports of it being quite a challenge at this moment in time?

Mr Coates: Yes, we do. The thing about carers is that it's a large and diverse population so there are obviously a whole range of issues. You can categorise them. Carers are struggling with it no more than other members of the community are, to be honest, because they're the same issues, such as job loss and that sort of thing where there's a working member in the family.

In the new Carer Gateway, we negotiated with the DSS who will fund that program. They have been pretty good and allowed a degree of flexibility in things like the carer directed packages, which will give a bit more flexibility on what the money can be spent on to support carers. Obviously, those sorts of things are relatively small and don't resolve the issue of employment and loss of income and that sort of thing.

It's typically a family experience, like many other families that are not in a caring role. It's loss of employment. There are all the additional costs of caring, which are added on and you've got to find and cover them, which is getting harder and harder to address. Plus, in some cases, it's even the availability of some things that carers need, being able to access the sorts of things that they need in the early days of COVID. Obviously, in WA at the moment we're probably in a far better position than a lot of other places, and things are a bit more normal than in other states and territories.

Senator STEELE-JOHN: What have the reactions been like among the community to things like not receiving the COVID supplement and those other issues?

Ms Mitchell: We have had some comments from carers about that. I'm not sure if you're aware, but there has been a survey done by Caring Fairly. There are some stats in there. They are national stats, not WA stats. Apparently 37 per cent of carers have lost some or all of their regular income, and 37 per cent of carers worked fewer hours to provide extra support for the person they care for. Most of the comments we've had from carers is that they struggle in finding services for the person they care for.

Senator STEELE-JOHN: I hear quite often that it is still the case that many carers still feel totally bamboozled by the complexity of the NDIS and really struggle to access the information that they need to understand the implications of the scheme for either themselves or the people they care for. Is that still a lot of what you hear from the people who talk with you?

Mr Coates: Again, it's a diverse and wide population. What comes with that is a whole range of abilities and understanding and ability to understand things like government systems. We still certainly hear this about the NDIS. We also hear it about aged care, for that matter, in working with the aged-care packages there. Agencies and government will rightly say, 'We've got lots of information on our website [inaudible]' and this sort of thing, and that's true, but a lot of people who are engaging in these systems, and the NDIS is one of them, really need to be handheld and carried through it. Yes, I know there are written words on a website, but they need more to understand what a plan is and what its implications are. How many people before this system have engaged in developing a care and life plan for an individual, understanding what it is, what it contains and what they can and can't ask for within that plan?

Senator STEELE-JOHN: Absolutely.

Mr Coates: It's not a simple process. I'm not sure how much simpler you can make it, because it is quite complex in people's lives and with the range of supports and circumstances. You just need somebody with experience to do a lot more handholding.

Senator STEELE-JOHN: I hear that. Finally, you guys have been on the frontline, supporting carers through what has been a pretty complex transition in WA for a while now. In terms of recommendations that we could take back as a committee and implement, is there anything that you don't feel you have been able to covers so far and that you would like to flag with us?

Ms Mitchell: I think just reiterating that point about one-on-one support. We have an individual advocate at Carers WA who has reported that she is spending a lot of time hand-holding people through planning processes, the recommendations around further one-on-one support for pre-planning and annual planning.

Mr Coates: And I think what you've got to realise is there is a tension here. You'll get these companies, organisations or LACs and they are under pressure to deliver volumes. They want to go through a process and churn out plan after plan so they can meet their contractual requirements and volumes. Taking one gently through one-on-one support will not get you those volumes. So I guess my recommendation, added to that, would be to rethink the expectation of volumes.

It's as I've said to departments during COVID, when they've said: 'What can we do to help?' Perhaps they should remove less of the pressure in bureaucracy on achieving contractual volumes, less attention on that for the time being, during that COVID period. Perhaps it's the same attitude we could adopt here, that contracting agencies and offices within the contracting sections be not so focused on doing 4,000 plans under the contractual obligations. If they've only done 2,000 but they've done 2,000 quality plans and there's a bit of a waitlist, maybe that's a change in mentality and approach that the agency and government need to adopt.

Senator STEELE-JOHN: I suppose that comes back to the issue of the staffing cap and the impact that's had on the agency. Do you think it would improve your experience with the scheme, and the experience with the scheme of the people you speak for, if there were the capacity to employ more people in the agency to do this work, instead of LACs and the various ways that we do it at the moment?

Mr Coates: Absolutely. If you get more people into it you're going to end up getting better results, providing they're of a good quality and they're properly trained. But it is a mentality thing. If organisations are not worried about being penalised for lower volumes of output and that sort of thing, and there's trust between the contractor and the service provider, that might help the situation as well. That's something that shouldn't be a high-cost thing at all. It will change that contractor relationship in trust and understanding.

CHAIR: Thank you, Mr Coates and Ms Mitchell. We appreciate you coming online today to discuss the NDIS with us. It's been helpful in our ongoing inquiry, so thank you very much for your contributions.

Ms Mitchell: Thank you.

Mr Coates: Thank you very much for the opportunity.

JENKINSON, Ms Samantha, Executive Director, People with Disabilities Western Australia

THOMPSON, Mrs Lana, Co-design Group Member, People with Disabilities Western Australia

Evidence was taken via teleconference—

[13:32]

CHAIR: Welcome to this hearing today. Do you have any comments about the capacity in which you appear?

Mrs Thompson: I would add that I've been, for the last nine months, on a co-design committee working out how we can improve things for the NDIS, with recommendations and reflections on what we think is working and not working and some things that we think they could develop for the future.

CHAIR: We have your submission to the inquiry. Could I ask you to make some opening comments?

Ms Jenkinson: I'll start off. I guess I want to point out a couple of things from the 18-month project we've been doing around the NDIS and the experiences of people in WA. I want to highlight a couple of particular things. One of the things that we've noted as an organisation, and I think this is shown particularly in the case studies we've put in our report, is that even when people had some good outcomes in the case studies of being on the NDIS—and people have had good outcomes—there was still a very high anxiety about the process of the planning, about the language used in the NDIS and how we understand that language and about the onus being put on the individual. So it's about the bureaucratic nature of the language, the process and anxiety that people have, coming into that planning process, every time they have to go and feel they have to justify themselves, justify their disability, justify their need for funding support again.

The other part of it that I wanted to highlight was, I guess, the onus on the individual. I think this comes back to some of the stuff that I believe I heard Paul Coates talking about, in relation to the levels of support available to people who need support, the fact that diversity of disability is not necessarily well catered for, in terms of the amount of support and expertise that you can get if you need it. There's very much a feeling people have of going through the planning process, essentially, and then it's up to them to get everything started, to make the first move, so to speak. There's an expectation, almost, from the bureaucracy that people will know how to navigate or know what the language means, when people are not necessarily in that position.

The other part I'd like to point out, in terms of that, is that as an advocacy organisation we are seeing lots of people come to us for advocacy on the NDIS. Probably about 35 per cent of our advocacy is related to NDIS, not just appeals and reviews. But we often have the LACs or support coordinators contacting us, as an advocacy organisation, asking us for support to do things which are their job. We had one just yesterday where an LAC contacted us asking for our support with a grandmother with children on the NDIS, to help support her to implement her plan. That's what the LAC's job should be. I think Paul previously noted where some of those issues might be, but we certainly see a large number of support coordinators as well as LACs essentially coming to other people for the expertise and knowledge to do what really should be their job. In some ways, that does come back to where that onus is on the individual to try and get things happening and get things started. If that support is not there, it doesn't happen.

On some of the things that we put as recommendations, I will just quickly highlight the high-level ones from our report. We would point out that, in the NDIS legislation, the actual principles in the objects of the legislation, right at the very beginning, are really good. They actually highlight many of the things that we think need to be in the NDIS all the time. But then it's not actually happening in practice. We think it would be really useful to use those principles in the legislation as a tool to do continuous improvement reviews by the NDIS on the practicalities and the policies and procedures at the next levels down, because we're not seeing that there is actually a connection between them all the time.

We would also talk about co-design. Lana can talk a little bit about the co-design process we've used as a way of trying to use the lived experience of people with disabilities to help make the decisions of what's important. We think that there needs to be a broad focus on increasing flexibility for individual complexity and diversity. This is—again, I think Paul raised it—coming away from a check-box response to something that's a more relationship based response and simplifying the language. I myself have an NDIS plan, and I'm the Executive Director of People with Disabilities WA, and I don't understand all the language in my own plan. But I self-manage, so I just ignore some of that language and just do what I think I know is the right thing to do and what I need. But not everyone has that opportunity.

Mrs Thompson: That's what I do.

Ms Jenkinson: And Lana has just said that's what she does as well. We think that some of that expertise needs to come back to providing people with disabilities and families and local community groups the assistance so that

they can support people with preplanning. Again, we find that, if preplanning hasn't occurred, then there is not as good an outcome as where preplanning has occurred. People are doing preplanning because either there is some state government funding, there is a little bit of leftover ILC grant money or people are getting supported from peer groups to do preplanning. It's not actually factored into anything apart from through those ways. We think people with disabilities need to be training the planners and support coordinators as well as more people with disabilities being the planners and being the support coordinators.

We also would like to see an increase in the role for individual and systemic advocacy. We've also noted that the co-design group from our systemic project came up with a number of recommendations which we think would be good for the joint committee on the NDIS to have a look at in detail. We also had a specific part of our project that focused on CALD communities, and there are some specific recommendations on those as well. I will hand over to Lana now.

Mrs Thompson: Thank you for the opportunity. Sam has covered much of what we discussed in the co-design report. In particular, it related to being listened to by the planners, by the NDIS structure, on what we actually need and not being pigeonholed in the sense that, because one particular person with your same disability didn't want this, then you don't need that either. There were five or six different disabilities on the committee. I am vision impaired but I had no idea what it would be like to be in a wheelchair or to be caring for autistic children, and it really opened up my eyes and made me realise that the processes that the NDIS go through for people who need help quickly and simply are just too cumbersome. I've got issues with them myself at the moment. I have been vision impaired my whole life and I can cope with my own affairs, but I've been waiting six months for particular systems to be implemented, for plan reviews. The people on the NDIS committee that I was on are all very stressed because they might need daily supports with washing and caring for them, and their carers don't come, and how do they get another one?

The whole process, when it works well, is wonderful, but, when it doesn't, it leaves people feeling very vulnerable, very unsafe as to where their next support is going to come from. If you do have an LAC or one of these other support coordinators, it takes many phone calls to get anything from them to then report to the NDIS, because the NDIS's communications are not well structured. Then they get back to you and you've sucked up all your funding using a support coordinator or a liaison officer, and then there is not any for the real daily living things—like caring, taking you out in the community or making you feel mentally well. The mental aspect of that is very severe for some people, and a lot of them just give up.

In saying that, the scheme when it works well gives you freedom to do new things that you didn't have the opportunity to do before, like keeping fit and going to a gym, and it makes you capable of doing new experiential things, giving you equipment that you might not be able to purchase out of your own pocket. So there are many wonderful things about the NDIS, but it is a very cumbersome process, and, even if you know what you're doing, it's very hard to navigate. The departments don't communicate with each other properly. It's also stressful when you have to keep calling them back all of the time. That underpins so many other aspects of the NDIS as a whole.

CHAIR: Thank you for those comments. Much of your submission and indeed many of your recommendations go to the planning process. I was wondering if you have had the opportunity to read the committee's previous report and suggestions to improve the planning process. If so, would those recommendations address most of the matters that you have made recommendations about or are there other matters that would still be outstanding?

Ms Jenkinson: Unfortunately, I haven't had a chance to look in detail at the previous report. I believe some of them talk about increasing flexibility and training; is that correct?

CHAIR: Things like face-to-face meetings, draft plans, opportunities to review plans et cetera, which are some of the things you go to. But if you haven't looked at it, that's fine. I just wanted to know, with those matters that we have addressed before, if there are still some outstanding matters. That was really my question. I'll go to my colleagues.

Ms COKER: Thank you very much for your very detailed submission. During your presentation today you used the words 'stress' and 'anxiety' a lot. You talked about how participants in the scheme are feeling stressed and anxious. This is a concern. Is this to do with COVID-19? Is that having more of an impact on participants? If so, how? What are the key things we need to do to reduce stress and anxiety for participants? I know that's a big question. Your submission is very thorough. If you could respond to that question, that would be great. I'm interested to hear your thoughts.

Mrs Thompson: COVID has had a significant effect on some people's vulnerability. They have not been able to do the activities that they used to be able to do and have not been able to have support workers come and help

them with their daily needs, so, yes, that is a major factor. From my own personal point of view, the stress comes when you contact the NDIS or someone contacts them for you and you're concerned whether you're going to be listened to or your needs are going to be met and then six months later you still haven't had a resolution of the problem you had, so you're making more phone calls or whoever is doing it for you is making more phone calls. It's just this constant having to push and pressure to get answers to queries that should have been resolved and getting finances paid so that you can have your supports continued. If you have an outstanding amount not finalised from the NDIS accounting team then you can't have support workers come and help you because they decide, 'You're not paying me or your LACs haven't sorted it out properly so I'm not going to support you.' Where are you going to get your next lot of support from? I have individual evidence of that myself, but I managed because I kept some funds back in case of these emergencies. Because I'm self-managed I can work things in that way, but it wasn't a lot of fun waiting for large amounts of resources to be refunded to me, which happened after my next plan was introduced, so I didn't even get to spend the money. Then what happens is it gets taken off you because you didn't spend it due to issues relating to the communication between departments of the NDIS.

Ms Jenkinson: I would add that the majority of the findings from our report were done pre-COVID. The majority of the work that our project officer did gathering information was done leading up to around March, so that probably has impacted in terms of our final report findings.

I think what Lana pointed out there is that the biggest stress is that everybody came to the NDIA thinking that once you're in the system you're in and you've got support for your lifetime, and that's what the legislation talks about. Yet at every planning meeting people are fearful that they're going to get things cut because it doesn't seem to be so much about social insurance but rather about insurance in terms of trying to build people's capacity—and what sits under capacity is very unclear at times. Recognition of someone's ongoing needs is not always there. People are anxious because they go into a planning meeting and what they get in the plan doesn't represent what they've said. Also they go into a planning meeting and they have said what they've done previously or why funding hasn't been spent—maybe because they've had issues with implementing the plan—and that still leads to the funding being cut.

There's the idea that this sort of foundational scheme is there to back you up over your lifetime for your needs. You would think that would engender confidence and a feeling that there's a safety net there for you, but it's not engendering that at all. What we're hearing is that it's engendering a lot of stress because people feel that, instead of telling your story that one time, you're still having to tell your story every time and you're still having to bring in the documents every time. And the documents aren't getting read, so then you tell it all in the planning meeting, but the planning meeting's only 90 minutes long, and then the plan doesn't meet what you said. So it's actually the process, and 'reasonable and necessary' has almost become this overhanging foreshadowing of what's going to be cut this time for a lot of people, particularly where the disability or the individual situation is not straightforward. And diversity doesn't seem to get in there. The guidelines that the NDIA are using for their behind the scenes information—'Oh, here's someone with a vision impairment. Because of our data, they're likely to have a package about this size'—don't really take into account individual circumstances. Then, what we find is that even though someone has explained the individual circumstances in a meeting with the NDIS, a delegate goes back to the reference package and just cuts it and puts it on whatever the reference package was. Those are the things that are leading to anxiety and stress.

Mrs Thompson: You wouldn't see plan reviews if things were done properly in the first place and you then didn't have to go through it all again. I've got a plan review in at the moment and there are too many layers of people that you have to talk to—six or seven people to get something done that should take two people to deal with it. You could use those people on a different structure within the NDIS. They could perform a different function. And all the planners need to have the same understanding. You can have a plan in three times and it will get accepted the last time yet you didn't change one word. So it has gone to a different member of the team, one who sees things in a different light. This has happened to quite a few people, so somewhere or other people are interpreting what is reasonable and necessary for someone before they get on the scheme in the first place. All those things are pretty frustrating, and they wouldn't be necessary if they had the right training.

Ms COKER: I will ask one quick follow-up question. I note that in your submission you talk about feedback from individuals and families regarding the quality, experience, expertise and qualifications of planners, saying that those things can vary significantly and that planners may turn up not prepared or not having read the documentation and that there's a tight time schedule for these meetings. That is very concerning. I know in your submission you talk about recommendations regarding planners. In our previous report we have addressed that, saying that planners need to have the right qualifications and expertise. What would be your key

recommendations in relation to planners? What would you like to see to enable consistent quality, experience, expertise and qualifications?

Ms Jenkinson: I would suggest that one of the things we would like to see is that more of the training of planners be done by some diverse people with disability so that there's a greater understanding there. We haven't necessarily put this in our report, but I think there are some fundamental things about the system, such as who's doing planning and whether the planners are actually doing planning or whether they are just signing off on a plan. I think that's one of those fundamental things that is not really addressed but that we see coming up. In fact, when people have preplanning support—they've actually developed their own plan, whether it's with the help of peer groups or with the help of some other people who they know have some expertise in planning—and they're coming to that meeting with their plan essentially already written because they've had support that has taken the time to do it well, they're getting some better outcomes. So I think that underlying this is the question of whether the NDIA planners actually are planners or whether they are just delegates signing off on a funding proposal, because it feels like that's what they are doing. If that's what they are doing, then do you actually need other people to support people to do planning properly?

Ms COKER: So maybe it is about the definition of the role and making sure that planners are very clear about what their role is and that the system understands it as well. Thank you very much for your thoughtful responses. That's all from me.

Mr WALLACE: Thank you both for your detailed submissions. Having read those submissions—and I don't mean this in a disparaging way; I'm just trying to get some context around this—it looks as though you haven't met anybody who has been happy with the NDIS, and I just want to make sure that that's not right.

Mrs Thompson: Sorry, that's not true. I said in my opening statement that you can be 75 per cent or 80 per cent happy with your plan but there may just be things that need to be ironed out that make it better for people coming on, for your own future and for the development of the NDIS. In my own particular case, I am mostly happy with my plan, but the things that I am a little unhappy with would affect many other people as well—those who are struggling with other mental capacity issues or multiple disabilities. It's not that we're unhappy at all; it's just that every person's life, whether they have a disability or not, is an ongoing feat to improve their life. All we're trying to do is make things better for the NDIS and the community as a whole. That's what we were asked to do. So I just want to let you know that it's not that people are unhappy totally; it's just that they need improvements. Sam did say she's not totally unhappy either. It's just about improving the language.

Mr WALLACE: Fair enough. That's fine. I've been corrected.

Ms Jenkinson: The analogy, for me, is a bit like going to the dentist. At the moment, some of the planning and dealing with the NDIA feels like when we have to go to the dentist; we go through this painful process to get to the good outcome. That is why some people then disengage.

Mr WALLACE: It's an interesting analogy!

Mrs Thompson: I became part of this committee for the betterment of the community, not to have a gripe about what I don't get, and I'm extremely grateful. I don't want that to be reflected.

Mr WALLACE: Thank you very much.

Senator ASKEW: Thank you very much for your evidence and also for those thoughts, particularly around the planners and the training and recruitment of them. I have a question in that area: what would be the area of recruitment? Did many of them come in from existing services within the state government services or were they recruited from external services?

Ms Jenkinson: My understanding is it's a bit of a mix here in WA. We had a number of people that came across from the state government and some that came across from other DSS services—so it wasn't necessarily a large number within the NDIA that were recruited. The LAC partners have a bit of a mix. Where people had existing relationships with LACs that stayed in the system, that made a difference for them. To me, it comes back to diversity. People with disability, even in those roles, are still going to have the same issues if they haven't got an understanding of diversity. There is such a huge range of types of people with disability. When you add in socioeconomic and other factors, the diversity is many layered. I think that flexibility around understanding diversity is a big issue. Where it's only a physical disability and nothing else, it seems to get through quite easy and the NDIA seems quite happy about giving people equipment. When it comes to those more nuanced things around supports for behaviours and communications and things that are a bit harder, because they're not as well known amongst a wider group of planners, there seem to be more issues.

Senator ASKEW: You mentioned in your earlier evidence that your thought would be that people with disability should be the ones training the planners or should be the planners. Some of the planners and LACs have

come through from earlier services that were provided through the state government. I would assume that a certain percentage of them already were in that field or had that sort of understanding, training and background. What would be the benefit, and how would you see that progressing? People with disability would obviously specialise in their area of disability, but in being able to understand the greater picture, as you say, there are a whole lot of different areas of disability, both physical and developmental. I am just wondering what your thoughts are in that area.

Ms Jenkinson: I don't know what training the LACs or the planners currently go through. My thought would be that there would need to be, in the training provided to planners, some sessions that might be around specific disabilities where there are high numbers, and that that training would include some people who have those disabilities. I'm not sure that that happens, or to what degree that happens, at the moment.

Mrs Thompson: They also know where to go if they have a particular disability. They may go to an agency and there will be no questions to ask that can relate to somebody's plan; they will know how to dig out the important issues because they have a knowledge of that disability, because they have lived with it and they know how to get extra resources. So they're not just there for a job; they're there because they have a better understanding, so they get a better outcome for the participant.

Ms Jenkinson: I think this is where the idea of the LAC partners is great, but in practice it's not tending to be—in WA, the LAC partners are Mission Australia and APM. They're not necessarily organisations known for being steeped in their disability experience. One of the things we talk about is people with disability's families, the local community groups and the peer groups being assisted to make those connections to assist with the training, whether that's across different areas—so that there's a mix of people with disability. I don't think you're going to get a good outcome if all your training is being run by someone who's vision impaired or someone with a physical disability who might have a good understanding of other areas. If they're not bringing in some people from those other areas to be part of that training as well, you're not going to really get that diversity covered in there. I do think that getting the support systems of the peer groups, the community members and the local community organisations to do that pre-planning work—that is going to have that expertise and relationship. The NDIA really needs to put a lot more money and effort into that building of the relationship between the LACs and the people they're supporting, or the planner and the people they're supporting, through that planning process. At the moment, it's basically once a year. That's great for some people. Even just once every two years is great for some people. But the sorts of people who have the most issues with the NDIS, the people with complex situations or complex disabilities, are really struggling to get the type of support that they need to make the NDIS successful.

Senator CAROL BROWN: Thank you. I'm conscious of time, Chair, so I'll hand back to you.

CHAIR: Ms Payne.

Ms PAYNE: Thank you very much for your evidence today. I must say that a lot of the things that you've raised are, sadly, the things that we have heard from many witnesses in regard to their experience with the NDIA and funding. I just want to flesh this out: draft plans have been a concurrent issue. How much of a difference do you think it would make to people if they could see a fully costed draft plan and have the opportunity to comment on that before their plan is finalised?

Ms Jenkinson: I think draft plans would make a difference, but they'll only make a difference if they're easy to understand. If the language and the ability to understand what's in it don't change, having seen the draft plan won't necessarily change anything unless someone has independent or external support that's going to help them to understand it. For example, my plan has core supports and capacity-building supports. It has some bits about assistive technology et cetera. I'm still struggling. When I go to see the OT to get advice on assistive technology, do I stick that under 'assistive technology', or is that a capacity-building thing? I have no idea, so I just stick it under whichever one I think might be the right one, and you know what? I'm self-managing. The whole thing is there. Hopefully, the flexibility of working between these buckets will be fine anyway.

You said 'fully costed'. That would also be important. People often see a big number and think: 'Oh, wow! That's great. I've got all this funding.' But then they don't know what that translates to or how many hours of support a week that actually provides. So the language really needs to change as well for those draft plans to actually be useful and for people to know if they have been heard.

Mrs Thompson: My comment on that is: do you mean the plan before it's accepted? In my recent plan, I was phoned the day after it was activated, so I didn't see it. I didn't see it in review. I just looked at it and said, 'When can I start using this?' He said, 'Oh, it's already activated, so you can't change it unless you go for a review.' If they only give you half a day's notice, which is usual, or an hour's notice, and they say, 'Well, it's already done,' you don't get a chance to look at it, to review it, to be happy or not happy with it or even to sign off on it. So the

whole power is taken by the NDIS. They're busy. You get all of that, but it would be nice to be able to at least review what is in it and see whether it compares with what you were suggesting that your requirements were and whether they were even going to be met, and to be able to discuss it.

Ms PAYNE: Yes, absolutely.

Mrs Thompson: It makes you feel like it's, 'Oh, well, it's done; let's move on.' Then you've got the whole review process, which takes many months, with many phone calls, which would be unnecessary if you could have had a short conversation to say, 'Yes, I am happy,' or, 'What does this mean?' or, 'What does that mean?'

Ms PAYNE: Yes, absolutely. Our previous report recommended that what we mean by 'draft plan' be something that people see that they have a chance to actually change before a plan is locked in, which seems like an obvious thing, I would have thought, in such a process. Then there have been various trials of things that seem to be called draft plans. I forget the term that it was, but it's not a plan that you can actually change, in which case what's the point? I take it from that that people—you or others—aren't seeing draft plans in your experience.

Mrs Thompson: I haven't in five years.

Ms Jenkinson: No. Some of the most recent case studies were from this year.

Ms PAYNE: Yes, it's very disappointing. In the interests of time, I'll just ask one more question. You were talking a bit about people's experience with reviews. With this sort of push towards reviews ending up with people being on the amount that you get for a certain disability or something like that, would you say that it seems that there is a direction within the NDIA to reduce people's plans through reviews?

Ms Jenkinson: Do you mean reviews of decisions or just general annual reviews that come about?

Ms PAYNE: Both, possibly.

Ms Jenkinson: Certainly what we've heard from people is that that's the feeling they have, particularly with their annual reviews, and that's what they get worried about. I would point out that, although we probably don't have enough data across the diversity of disability types, that is more prevalent for adults with autism, intellectual disability or psychosocial disability. The stress levels for those people are higher because of that. When someone has a permanent physical or sensory disability, there doesn't seem to be as much of a push, but people are still very stressed about that. Certainly as an advocacy organisation we are very cognisant that, when people get a review of decision, sometimes they will then get other parts of their plan looked at which they weren't concerned about, and those areas will get cut instead. So, with the thing that was getting reviewed, they might say, 'Yes, that's fine, we'll give you that, but we've noticed this over here, so we're going to cut that instead.' We do see that happening in those types of reviews. I guess it's concerning because there's an element of natural justice which doesn't seem to be in play. You're reviewing the decision for the approval of the whole plan, not the particular bit that you're not happy with, even though your review and your documentation will be about that bit, but they do look at the whole plan.

Mrs Thompson: Yes, that's because they ask you certain questions when you ring up and ask for a review. They've got about six or seven questions and you've got to tick the boxes to say, 'Is it about this?' or 'Is it about that?' so that you don't get much room for an explanation. That's what they're basing their review on as to whether they'll even give you one, because you've got to find out when you're going to get one before you get one—it's not automatic.

Ms PAYNE: This is where something isn't quite right with the plan and you request a review?

Mrs Thompson: Yes, that's correct.

Ms PAYNE: And you may not get one, even if you've asked for one?

Mrs Thompson: Yes, they have to decide whether they're going to give it to you or not.

Ms Jenkinson: And I think this is the difficulty—it needs to meet the legislative criteria for review of a reviewable decision and that light-touch tweaking, which we did see happening a bit in COVID. These are some of the things which we think need to stay in place.

Ms PAYNE: Do you want to expand a bit on the tweaks?

Ms Jenkinson: During the main part of COVID, we were seeing that, if people were requesting reviews for things which were quite small, they were actually getting through very quickly. It was much better. There was a much clearer understanding of the need to be flexible about those things, which we hadn't seen previously.

Ms PAYNE: It's good to hear a positive. I'd better leave it there, in the interests of time. Thank you.

Senator STEELE-JOHN: I want to drill down in a bit more detail. It seems to be that you've experienced little value being given to disabled people in this NDIS process by the presence of LACs in the system. Would that be a correct characterisation and, if so, what would the alternative to the LAC system look like to you?

Ms Jenkinson: Did you want to talk about that, Lana?

Mrs Thompson: No, because I actually don't have an LAC, because I just do it myself and I don't need all the extra layers. I can't speak about that.

Ms Jenkinson: We've seen a mix, and this is not dissimilar to the previous system in WA, which did have LACs, in that it really depends on what you get. What we're seeing is that the pressure on the LAC system is that, if you don't have support coordination, then you're reliant on the LACs. Because the LACs are doing the majority of the planning here, whether it's time pressure or enough people, they are not building a relationship with people to help people implement their plans, which is what we would expect given our previous experience of LACs. Instead it's been as bureaucratic as the NDIA planner. It's not any different. Whereas the hope is that the LAC model would not just be an extension of the NDIA but a more relationship based system. In some ways it doesn't even matter whether it's people hired by the agency or they're outsourcing to other people; it's about being clear what the role is and doing the role to its fullest, which is what we're not seeing. What we're seeing is someone that's still doing a tick-a-box for a plan rather than someone that's building a relationship to build a plan and support someone to implement their plan.

Senator STEELE-JOHN: Of the challenges that you've observed and detailed in the report, what is your view on the extent to which the staffing cap is driving a lot of these issues?

Ms Jenkinson: We don't know the details of that in terms of how many staff would or wouldn't be there, but certainly we're seeing that the impact of the lack of available staff is that it's getting pushed back onto organisations such as advocacy organisations, organisations like WA's Individualised Services, like Carers WA and service providers themselves, where we don't have the capacity to do that role either but are being expected to. So that preplanning, that supporting people to implement their plans—we would highlight that there's a massive conflict of interest that happens with service providers doing this, but we also understand that the reason service providers are doing it is that, for people who've been in the system for a long time, that's where people have built a relationship, and the NDIA planners and LACs simply don't have the time to support people in that way, so service providers are taking up the slack. Then the service providers complain about not getting paid well enough, because they're essentially doing for some people way more than they're paid for and the other people are essentially—the rate that other people are paying is paying for the extra support that the service provider is giving to someone else because the LAC is not doing their job.

Senator STEELE-JOHN: Thank you, very much. I'm very aware of the time, Chair, so I'll leave it there. Thank you for the evidence that you've given. It's been really useful.

CHAIR: Ms Jenkinson and Ms Thompson, thank you very much for your submission and also for coming on to the teleconference today to discuss it with us. We appreciate that very much.

Mrs Thompson: Thank you for the opportunity. It's very much appreciated.

Ms Jenkinson: Yes, thank you very much. We appreciate that.

Mrs Thompson: We hope that we can all work together.

CROCK, Ms Sue, Consultant, Sexuality Education Counselling and Consultancy Agency**TERPOU, Ms Juana, Manager, Senior Psychotherapist and Forensic Sexologist, Sexuality Education Counselling and Consultancy Agency**

Evidence was taken via teleconference—

[14:24]

CHAIR: Welcome, and thank you for appearing before the committee today. Do you have any comments to make on the capacity in which you appear?

Ms Crock: I am a social worker and teacher who has worked with SECCA on and off in various capacities for 25 years.

CHAIR: We have your submission to the committee. I invite one or both of you to make some opening comments.

Ms Crock: Thank you. I'd like to give you an outline of the agency and what we do and some of the challenges that would like to share with you today, and then Juana and I will be very happy to answer any of your questions. SECCA is the only specialist therapeutic and education service in WA for people with disability, their families and carers and also those who work with them. We focus on working with people with disability in the area of respectful relationships, sexuality education, counselling and consultancy. How we do that—we've been doing it for nearly 30 years; we'll be 30 next year—is we provide direct education and counselling to people with disability. Many of our clients have complex needs—in fact, Juana, as our senior therapist at SECCA, works with some of the most complex cases in WA. That's reflected in the case study, which I hope you've got attached to our submission, as an example of the sorts of people we are working with. Many of our clients have experienced sexual abuse and assault. We estimate that's over 80 per cent—between 85 and 87 per cent of our clients. So we are working at the pointy end supporting other agencies who don't have the specialist expertise to work with these clients. We also provide education, training and consultancy services to teachers, disability support workers and many others in WA who are supporting people with disabilities.

One of our challenges is the high demand for our services—currently we have 200 on our waiting list—but the other challenge is to provide services across this big state, as you'd all understand. One way we've attempted to address that challenge is by developing innovative resources that are accessible to people with disabilities in regional and remote parts of WA. That includes a sexuality app, a SECCA app, and a booklet called *Sexuality and Your Rights*, which is also now being developed nationally as a resource across the country. We'd really like to expand on our resources and our services to people from Aboriginal and Torres Strait Islander backgrounds and also to the CALD community. They're a group that we would like to be able to support more. Of course, we want to acknowledge that in the COVID pandemic the stress on people with disabilities and their families has significantly increased. That also has provided us with some challenges.

People have transitioned really well to the NDIS. In principle, we share the ideals of the NDIS. We support the human rights to independence, access, and choice and control for people with disability. However, as our submission shows and outlines, we do have some challenges and concerns. These include procedures within the NDIS that we believe compromise the privacy of people with disability and a level of administration required under the NDIS that's put a lot of strain on SECCA's limited resources and has also reduced our client contact and our direct service provision. So it is kind of counterproductive.

The NDIS model is also not suitable for some very important services for people with disabilities. This is been impacting both our clients and our agency. An example of this is urgent crisis support. For example, if a person with a disability has been sexually assaulted or abused the model does not suit support for those people. It's not something people include in their plan, for example, because it's often unexpected, or it might be historic and doesn't come to light until they're maybe displaying behaviour that is problematic in the workplace or in school or in their home where they live that brings them to SECCA. Often, once counselling begins and we work with that client, they will disclose that they have been sexually abused or there's a historical circumstance behind the behaviour.

The other thing that the NDIS model doesn't address is the need for preventive education around protective behaviours and respectful relationships education, which of course is the focus of what we do. Another example here is teaching people with, for example, an intellectual disability how to stay safe, what's appropriate public and private behaviour, and how to avoid contact with the criminal justice system. We know that people with intellectual disability are over-represented for sexual and relationship offences—often due to their lack of understanding and the fact that they haven't had education in these areas. This is at enormous social and economic

cost. It's estimated, in WA, for example, that a person with a disability in prison costs the taxpayer \$355,000 per year. So this is an enormous economic cost. And that's not really putting a measure on the human cost.

The other thing that the NDIS model is not addressing well is support for people with complex needs and trauma. Many of our clients, for example, have a disability, but they may also have mental health issues; they may be living in insecure housing or even be homeless; they may experience family and domestic violence or family breakdown, or they may have very little support from family. Some have been in the child protection system and have the out-of-care issues that come from that. An increasing number of our clients are presenting with suicidal thoughts and ideation, which is a serious concern to us.

Without alternative funding pathways, we know that, at SECCA, we can't continue to provide the important services that we have been providing. That's why we've made the recommendations that are listed in the submission to you. We've made seven recommendations covering privacy, systemic gaps, administration loads, counselling requirements, the need for psychoeducation in NDIS plans, planner training for workforce issues, and targeted programs to reduce the contact of people with disability with the criminal justice system. We know on that, for example, that 18 per cent of the population, it's estimated, has a disability in Australia, and that 50 per cent entering prison has a disability. So it's a serious issue.

Thank you. I hope that introduction gives you some background as to who we are and what we do.

CHAIR: Thank you very much. In your submission you say that people with disability are at significantly higher risk of sexual assault and abuse. Is there any data on the prevalence of that?

Ms Crock: Yes, there is. The Australian Institute of Family Studies has done some work on this, which is the reference we've got, that people with disability are at about 11 times greater risk than people who live without a disability. That's the reference on page 1.

CHAIR: I see that, yes. In terms of your recommendation to ensure that people with disability have the same access to crisis counselling services as other Australians enjoy, what modification or changes to the NDIS would you envisage to better achieve that?

Ms Terpou: As to the amount of paperwork that the therapists are required to do: there'd be 200 people on the wait list, for example, and each requires a report, and there's a lot more administrative stuff that takes us away from direct service. As to the supportive reports that we do, we're having to justify why someone needs a service like ours, and that takes up a lot of the counsellor's time. Then we send that information to the NDIS—enquiries@ndis—and we don't know who that's going to. I guess a reduction in that admin would allow us to do direct service.

Ms Crock: I would add that people who are sexually abused or assaulted, either historically—if it happened sometime earlier in their lives, as a child—or even some months ago, are not likely to disclose that, unless they have a sense of trust and safety in being able to do so, particularly if it's abuse that's happening within their family or with carers that they're reliant on for their care. One of the challenges with the NDIS is that people aren't going to write it in their plan unless they really feel safe to do so. Many of them won't disclose it to their NDIS planner. So they come to SECCA, often in crisis over some other issue, and, once we start working with them in counselling, the sexual abuse or assault is often disclosed, once that trust is established.

The NDIS planning process is very rarely likely to be an effective way to get help for people who've been sexually assaulted or abused. So there needs to be some other mechanism. In WA there is the Sexual Assault Resource Centre for people in the mainstream to access, but they don't have specialist expertise for working with people with disability, particularly those with complex needs. SECCA fills that gap; that's our role and our specialisation. So we get referrals from the police and from SARC and from many other organisations to do that work, but we don't have reliable, secure funding to continue it. Under the NDIS model, we're reliant on short-term state government funding. We see the need for secure funding.

CHAIR: Thank you. I'll go to Ms Coker.

Ms COKER: Thank you very much for your submission. You obviously do very good work and it's a very sensitive area. I must admit I don't have a lot of expertise in this field. I note what you say about funding for your organisation and that there is a need for more funding so that you can do the work you do. I'm interested in a couple of things. Firstly, what would you like to see in terms of funding and how it's embedded within the NDIS? Secondly, I'd like to talk to you a little bit about the training of planners in order to deal with this very sensitive area. Firstly, on the funding issue, what would you like to see occur?

Mr Crock: In an ideal world, we would like to see secure, long-term funding that's sustainable for organisations like ours. A lot of the time of staff and members of the board, who are volunteers, is spent applying for funding just to keep us going. That's been an ongoing issue for many years. There seems to be more

uncertainty around whose responsibility organisations like ours are—is it a federal responsibility to fund it under the NDIS or is it a state responsibility? That doesn't seem clear, which we mentioned in our submission. We would like to have guaranteed funding so that we can plan to be providing this service—in particular, crisis services for people with disability for whom we know the rates of abuse and sexual assault, and vulnerability in incidents of family violence, are much greater. In principle, that's what we'd like to see. How might that work in the NDIS model? Sorry, but I don't have enough information or expertise in that to say.

As for the training of planners, I really appreciate you raising that. It's a concern that we've had among our staff at SECCA and it's also from other service providers. I do a lot of work in the mental health space, as well as at SECCA, and I know that understanding the needs of people with mental health issues, as well as the sexuality and relationship issues that SECCA deals with, is a widespread problem. A lot of people who are now participants in the NDIS have not had the capacity to build a relationship with their planners whereby they can trust them to talk to about what their real needs are. I don't know what planners' training is, but we would like to see a lot more training—understanding disability, what it is and the different ways it might manifest—and also intersectionality between disability, mental health, drug and alcohol use and the other complex areas. These things don't happen in isolation. People with disabilities are like everybody else. The intersectionality issues, I think, are really important for planners to understand—and that doesn't seem to be reflected in some of the plans we've seen with clients.

Ms COKER: Thank you. It is quite a complex area. You were talking about the need to have some preventative workshops for people who have a disability so that they can understand more about sexuality and when something is wrong or inappropriate. This is a tough one for me: how do you implement that sort of support for people who have disability. Do you have any thoughts about that?

Mr Crock: We do, and that's the core of our work. I'll leave it to Juana to tell you about it.

Ms Terpou: We have produced some great resources at SECCA. One of them is the SECCA app, which we have spent five years building. It's a great resource. We do training for teachers, carers and parents of people with disabilities. It has 3,000 images that are designed to teach protective behaviours, healthy relationships and puberty—private and public. We run those training sessions regularly. That's our way of empowering the message of protective behaviours to the wider community. And our one-on-one counselling is working with individuals to get the message across about how they can be safe. But it is really through our workshops that we try to get the message out on protective behaviours and healthy relationships.

Ms COKER: Thank you. You're doing great work. There is probably more that we can do to support this area. Chair, in the interests of time, I'll leave it there.

CHAIR: Ms Payne?

Ms PAYNE: Thank you for your evidence today and for your submission. You've explained that it doesn't fit very well with the NDIS model—and I can see that. But where an NDIS patient has indicated that they would like to access support with you, how exactly does the NDIS model accommodate that?

Mr Crock: Good question. We have a triage process for referrals but, with 200 people on the waitlist, it is a challenge. We only have five counsellors in the agency. The NDIS prohibits the natural therapeutic alliance and relationship flow when you are working with counselling. They might have got funding for six sessions, but disclosure might occur halfway through that time and obviously your ethical duty of care is to continue working with that individual. Meanwhile, the waitlist is building up. We also see that sometimes we're not touching on those individuals until their plan is halfway through and that their plan hasn't been serviced by us just because of our limited capacity. It's not a model that is aligned to therapy of this nature. It's an unpredictable experience, so it doesn't really work. It would be ideal to have a similar process to that if you or I or mainstream individuals were seeking counselling. There are some sessions, and you're working with that individual therapist to find better ground.

Ms Terpou: Can I add to that?

Ms PAYNE: Yes.

Ms Terpou: Psychoeducation and preventive protective behaviours in relationship education is something that planners could raise with NDIS participants as a possibility. I'm not even sure many would recognise that it's possible to access that under the NDIS, so even asking the question and asking whether there's any support that that person would like in this regard would be a big help. I'm not sure that that happens very frequently, because I think there are so many other needs that have priority—daily care needs and so on—that often this is an area that can easily be neglected or not addressed in the planning process. I'd really like to see NDIS planners trained up in the importance of relationships and building people's understanding about what protective behaviours are. This

would be about keeping people them safe but also about how they can link in to their communities and build relationships that support their independence more broadly.

Ms PAYNE: Yes, absolutely. Is the situation where you've got 200 people on your waiting list a result of the transition to the NDIS? Has your funding moved to—

Ms Crock: That is a really good question. It's difficult to say whether there has been a hold-up as a result of just having to remodel our whole business approach or whether, throughout the transition, there are other services where people would once have sought—maybe crisis suicide ideation or something different. There have been a lot more individuals that are coming in off the streets who might have presented to a hospital and might not have found acceptance or might have been turned away. We've also got a lot more schools phoning us needing support because there are individuals who are falling through the gaps, and organisations like CAMS have their own waiting lists. It could be that there are just more people out there experiencing more issues at the moment, and there could be a whole lot of systemic reasons why we have an increase in those numbers. As well, there are our own internal challenges that have set us back.

Ms PAYNE: Thank you very much for the work that you do. It does sound like a very important and challenging area.

Ms Crock: Yes, but we're passionate.

Senator STEELE-JOHN: Thank you for the evidence you've given so far. In my experience, there's still quite a lot of stigma. In your experience, does there still seem to be a bit of work that we need to do to make sure that the agency and the planners are free of the stigma around the intersection of sexuality and disability and are able to either actively prompt a participant to request or be comfortable with a participant requesting your kind of service as part of their plan?

Ms Crock: I think that's a really good point, absolutely, and it is one we didn't mention earlier. We often say that we are working in the area of disability and sexuality, so it's a double challenge. However, we also say that it's a basic human right. We're all sexual beings, and sexuality is much more than the first three letters of the word 'sexuality'. It incorporates our relationships and how we feel about ourselves. It's all of our health and wellbeing. So, yes, there is a lot of stigma and fear around people with disabilities and their sexuality that we need to work on, and we do. That's one of the things that our education program always focuses on. Going back to the question we had earlier about the training of planners, at the heart of addressing that stigma is the need for people who work with people with disabilities to think about the values behind it. We need to think about what values we as workers—as planners or as support works, or as counsellors, in our case—bring to our work with people with disability. Often, I think, our values can get in the way. If we think that people with disability don't have a right to a sexual life and don't have the same rights as we do, then we can very easily ignore them. More importantly, if we're not comfortable with our own sexuality, we can very easily not ask those difficult or more sensitive questions. So I think there's a lot of work to do around addressing stigma in this area.

Senator STEELE-JOHN: From a federal perspective, would addressing that stigma look like more specific planner and agency-wide training around these things to actually try to address it before it impacts on people?

Ms Crock: Absolutely. Yes, I think that would be one very, very beneficial approach to addressing the stigma. There's also support for teachers in schools, particularly those who work with children with special needs and disability. A lot of teachers aren't comfortable teaching relationships and sexuality education at that level, and it's very open to attack from parents, who may not see it as the teacher's role. We have a national curriculum and teachers are expected to do this, but often without a lot of supports. So I think it needs to start with young children and what we do in schools, right through to service providers working with older adults who have a disability.

Ms Terpou: And there is the right to confidentiality. On any given day, an individual with a disability has many different people providing support—whether it be personal care or someone to arrange appointments. We have had individuals who had funding for counselling but they haven't had funding for transport. And whether someone is self-managed or NDIS-managed can have a real impact on the process. So that really takes away their choice and control; it takes away their autonomy. If you've been funded for, say, 12 sessions but, for whatever reason, we serve our purpose in six sessions, we then get parents and carers phoning saying that we've got to keep seeing their daughter because they won't get counselling in their plan next year if we don't keep seeing them. So that really is an external demand and pressure on our own expertise and the therapeutic relationship.

Senator STEELE-JOHN: What would you need to see—from the federal level, anyway—to make a meaningful dent in that 200-person waiting list that you have got as an organisation?

Ms Terpou: The same model that is applied to able-bodied people—where it's very much about the clients, the experts; and the therapists support that kind of change but don't have to justify why they need support if they've been sexually assaulted.

Senator STEELE-JOHN: Should there be more funding or administrative changes to facilitate that happening?

Ms Terpou: Yes. Recurring funding would be ideal. The previous model we worked under was a great success because we were able to adapt operationally to demand as it came in—and preserve everyone's confidentiality as well.

Senator STEELE-JOHN: When you say 'previous model', do you mean the previous block funding?

Ms Terpou: Yes, in WA—Disability Services Commission block funding.

Senator STEELE-JOHN: Thank you so much. Is there anything else you wish we had raised that you would like to raise now?

Ms Terpou: With the work that we do, this is the one thing that is really disability led. Across the board, there are no services like we do, even in mainstream services. So I consider all the individuals who see us to be incredibly brave human beings. They know it is really gutsy work. They are there to move in the right direction—where able-bodied people are not doing the same. And there is our app, a great resource which can be applied to the mainstream and broken up to perform all sorts of great things. It can be the first disability led positive thing.

Senator STEELE-JOHN: Fantastic. Thank you so much for your evidence once again. That will do me, Chair.

CHAIR: Thank you, Ms Terpou and Ms Crock. That concludes our questions. I thank you for SECCA's submission and also for discussing it with us today. We appreciate that very much. That concludes today's public hearing of the National Disability Insurance Scheme Joint Standing Committee in relation to the committee's inquiry into NDIS planning, NDIS workforce and general issues around the implementation and performance of the NDIS. I thank you for appearing via teleconference today. I remind participants that supplementary material may be forwarded to the committee secretariat. I remind witnesses that answers to questions given or notice are due in 10 working days. I think the secretariat, Hansard and Broadcasting for their assistance today. On that note, I declare this hearing adjourned.

Committee adjourned at 14:57