



COMMONWEALTH OF AUSTRALIA

Proof Committee Hansard

JOINT STANDING COMMITTEE ON THE NATIONAL DISABILITY
INSURANCE SCHEME

**Services for people with psychosocial disabilities related to a mental health
condition**

(Public)

WEDNESDAY, 17 MAY 2017

SYDNEY

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JOINT STANDING COMMITTEE ON THE NATIONAL DISABILITY INSURANCE SCHEME

Wednesday, 17 May 2017

Members in attendance: Senators Gallacher, Siewert and Mr Andrews, Ms Husar, Ms Macklin.

Terms of Reference for the Inquiry:

To inquire into and report on:

The provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition, with particular reference to:

- a. the eligibility criteria for the NDIS for people with a psychosocial disability;
- b. the transition to the NDIS of all current long and short term mental health Commonwealth Government funded services, including the Personal Helpers and Mentors services (PHaMs) and Partners in Recovery (PIR) programs, and in particular;
 - i. whether these services will continue to be provided for people deemed ineligible for the NDIS;
- c. the transition to the NDIS of all current long and short term mental health state and territory government funded services, and in particular;
 - i. whether these services will continue to be provided for people deemed ineligible for the NDIS;
- d. the scope and level of funding for mental health services under the Information, Linkages and Capacity building framework;
- e. the planning process for people with a psychosocial disability, and the role of primary health networks in that process;
- f. whether spending on services for people with a psychosocial disability is in line with projections;
- g. the role and extent of outreach services to identify potential NDIS participants with a psychosocial disability; and
- h. the provision, and continuation of services for NDIS participants in receipt of forensic disability services;
- i. any related matter.

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FRANKLIN, Mr Greg, Administrator, Mental Health and NDIS Facebook Support Group

Committee met at 10:44

Evidence from Mr Franklin was taken via teleconference—

CHAIR (Mr Andrews): Ladies and gentlemen, I declare open this hearing of the Joint Standing Committee on the National Disability Insurance Scheme for the inquiry into services under the NDIS for people with psychosocial disabilities related to a mental health condition. 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 a contempt. It is also a contempt to give false or misleading evidence to the 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 also be made at any other time. Could 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 this hearing.

I would now like to welcome Ms Jaime Comber, the policy officer of Being, and, via teleconference, Mr Greg Franklin, the administrator of Mental Health and NDIS Facebook Support Group. I invite you both to make an opening statement.

Ms Comber: I am here from Being. We are the peak body representing people with a mental illness in New South Wales, and our vision is for a world in which all people with an experience in mental illness can participate as valued citizens in the communities that they choose. In lots of ways, the NDIS lines up really well with this vision. It gives people the chance to choose the supports that work for them, it gives them more autonomy, and it lets people get services that they have never had access to before. We talked to a person who is able for the first time to see a personal trainer, which they have never been able to do before, and they found a trainer who had their own lived experience of mental illness, and it has had a hugely transformative effect on their life. Those things are really fantastic.

What we have found is that people who have plans in place that align well with their needs are quite happy with how the NDIS has impacted their lives. But we have also found that this was not the case for a lot of people, and that there have been lots of issues around how the NDIS has been implemented, and, also, really high levels of fear and stress among people to do with the NDIS. That has severely affected some people's mental health. We have also heard a lot of concern about people falling through the cracks and losing services, and so we really want to make sure that it is a system that is going to work for everyone.

Some of the big issues that we found were that there was huge variability in a person's experience of the application process and the planning process, and a big part of this seemed to depend on which planner, local area coordinator or NDIA staff person they were working with. We heard that people in very similar situations received very different funding under their plans, and it is unclear why this took place. There also do not appear to be mental health specific assessment tools used in the eligibility process. So people have told us, basically, that they want more consistency and more transparency in the process.

The thing that made the biggest difference to a person's experience in applying was whether they had a support person helping them through the process. People who had a Partners in Recovery person or a Personal Helpers and Mentors person helping them through the process were much more likely to get better services that they were happy with, and they found the process reasonably straightforward, although still quite long and arduous. People without this support found the process time-consuming and confusing, and did not get as good outcomes. We also heard that the support people know the right language to use when they are talking to the planners and when they are talking to the NDIA staff, and that if you are a person who is applying for yourself, you do not know that language, and, as a result, you might not get what you need.

The thing that made the biggest difference to a person's experience with their plan was the NDIA staff planner that they got. What we, basically, heard was that people who got a planner who was trained in mental health had a significantly better experience. They had to do less explaining about their situation, they felt understood and they got plans that were tailored to their goals. It is exhausting for a person with mental illness to explain to people over and over again how their illness is affecting their lives. Some of these people have never had to give such a

detailed explanation of their situation before. For people who have episodic illnesses they might have their planning meeting on a day that they are feeling better and then feel like they have to convince the planner of how sick they are in other time periods.

This kind of links into a concern we have with the overall NDIS process, which is that it is not necessarily strengths based and it is not necessarily in line with the recovery model that is best practice for people with mental illness. It encourages people to focus on what their deficits are and their negatives. We have heard from people that they walk out of these planning meetings sometimes feeling bad about themselves and about where they are at. The thing that we are most worried about is that people with complex mental illnesses who do not qualify for the NDIS might already be accessing services like personal helpers and mentors that are really helping them, keeping them out of hospital, keeping them going and helping them achieve their goals in their lives, and they are now at risk of losing these services.

For some people we talked to PHaMS were the main support that they accessed and it is really helping them achieve their goals. In mental health we are trying to keep people out of hospital, have people live in the community and contribute in the ways that they want to. That means better outcomes for people and it is also more cost effective but it does not work if we are not providing the services in the community. Those are our main concerns.

CHAIR: Thank you very much. Mr Franklin, would you like to make some opening comments?

Mr Franklin: I would like to make a short speech. I heard what Being said. Funnily enough, I am familiar with Being, because I made it into the Facebook group that was setup specifically for Being, one other person and our group.

I would like to thank the committee for the opportunity to present via telephone. I do this because I have a psychosocial disability. My wife also has one. She was rejected by NDIS and it is currently before the ombudsman. My daughter has not received the early intervention that she was promised, so we have had to pull her out of school, which means I have to stay at home as a full-time carer.

As a brief summary, I have a growing additional experience. We, as a group, are consumers—for want of a better word. And our [inaudible] the NDIS. I represent a diverse group of Australians suffering from many different mental health conditions [inaudible]. I also represent the carers of these people who have not been recognised properly in the scope within the NDIS legislation. We have [inaudible] submitted to the inquiry that we have utilised the social media form of groups to provide peer support and established the overly bureaucratic, inconsistent, poorly trained and litigious NDIS.

The NDIS concept was initially reviewed by the group members as a means to finally addressing the complexities of mental health conditions and their management. We were seen as a way out of the fog that prevented many from having more fulfilling lives. [inaudible] get off their disability support pensions, for example, by training or [inaudible] in the workforce, establish small businesses, certain avenues for successful inclusion of a wide range of other benefits that would lead to better management of [inaudible] episodic nature of many mental health conditions. It would enable carers of those with more severe conditions to obtain assistance in building the capacity to cope or being able to once again go to social activities. It also provides a means for them to undertake courses [inaudible] and, just as importantly, their own mental health and physical wellbeing. Sadly, this has been anything but the case. Applying for an assessment is extremely stressful even for those who have used an agency to fill out their application. The NDIS staff have zero understanding of mental health and many are rude and intimidating.

There are cases of retribution or [inaudible] if a person complains. The staff will not acknowledge [inaudible] contempt and even to get results is an [inaudible] I notice that there is no regard for the time it costs required. It is particularly problematic in regional and remote areas, where specialists are only available via stretched public health systems and need hundreds of forms to be channelled to a private specialist, who can charge anything up to \$500 and require booking months in advance. It is well beyond the reach of those on the disability support pension. Even after obtaining the required documentation, many have been rejected with no reasonable alternative to support assistance. The functional aspects of the legislation do not apply in many cases, with rejection being based purely on a diagnostic basis.

[inaudible] is of particular concern. The Ombudsman is investigating one matter which also [inaudible] another person after complaining to their local area coordinator, who threatened to call DOCS and report that the mother was unfit if she did not withdraw the complaint. As you can imagine, many simply give up. It is a sure sign of a growing concern within the group.

In early 2017, I raised an issue with my local federal MP, asking [inaudible] assistant minister promised me amendments to [inaudible] resolution by the end of March. This did not eventuate. [inaudible] go unanswered which is concerning [inaudible] Communication was then commenced with the shadow minister. This was proving helpful [inaudible] investigating the 100 per cent rejection rate for psychosocial applications in our region in southern New South Wales, which began in February-March 2017 when I raised the issue of plans being stalled and planning reviews being [inaudible] by in some cases 80 per cent in other regions, including trial sites. None of my turns have been returned and even emails are not [inaudible] in this matter.

Other issues that have occurred that are not in our submission; an addendum includes [inaudible] of 64 having assets stalled, for want of a better word, so they reached the 55 cut-off age. People with disabilities over 55 no longer able to access support can [inaudible] and they are discontinued due to the NDIS. My Aged Care does not cover disability support.

The NDIA is having to provide funding for one condition, refusing funding for comorbidity, which is in so many cases. Plans that we do get through are not sufficient to meet goals and for the legislation. There is a complete breakdown of the early childhood and early intervention and there are conflicting views between NDIA and the early childhood intervention planners. Some children are going for more than six months without any support.

We are also very concerned about the extremely litigious nature of the NDIA with the upcoming High Court appeal, providing loss of supports [inaudible] upheld NDIA claim [inaudible] no longer viable [inaudible]. We are concerned if the NDIA decision is overturned, the NDIA will only provide supports within its budget. There is a third alternative but that is beyond the scope of this meeting, but I would welcome the opportunity to discuss it.

There is a growing number of self-harm [inaudible] being achieved as a result of NDIA such as Lifeline and headspace et cetera not being able to assist, and they appear to have little knowledge or understanding of people with complex and chronic mental health conditions.

Likewise, state mental health services are steps to turning people away. An increasing sense of despair in the group [inaudible] state failure when you have to cover the psychosocial cohort. The recent increase to the Medicare levy only covers the original \$40 billion that was [inaudible] and large numbers of psychosocial [inaudible] actually in the cohort.

The 64,000 in the region with psychosocial fall so far short of actual government numbers as far as we are concerned is laughable. Recently, we sought the world health authority on the profession as the leading global debilitating condition [inaudible] and the highest [inaudible] shows 64,000. Some [inaudible] extremely inaccurate database or just sheer incompetence. In effect [inaudible] concentration by many NGOs in previous mental health issues, many in the group are dealing with [inaudible] at the moment.

Some NGOs have lobbied for a return to block funding. Basically, we fear that this could result in mental illness being taken out of the NDIS. People with lived experience often feel used by services, as a tick box rather than [inaudible] as equals, looking towards consumer-centred [inaudible] that meet our needs based on our lived experiences. Inability of the psychiatric and clinical psychological professionals to assist patients by struggling to [inaudible] diagnose as a lifelong disability. This may be [inaudible] of the academic mental health practice [inaudible] It is placing patients in an untenable position. The profession's first concern should be their patients.

We believe that supports available to regional and remote Australia are in dire straits in mental health. The way the NDIS at the moment is being rolled out is exacerbating this problem. The NDIA has payment rates that do not reflect the higher costs of supports for those in the psychosocial cohort. Removing listed supports such as PHaMs [inaudible] in the region and to hundreds of rejected applicants without any supports other than the already overstretched public health system. There is a fear that the removal of psychosocial and NDIS supports will place already fragile people under more stress and could lead to an increase of suicide.

In conclusion, the NDIS was never designed to accommodate mental health and this is now even more evident. [inaudible] to undertake proper scoping to allow for sufficient funding and will result in economic and social disaster as far as [inaudible] is concerned. The government needs to engage with actual members of the psychosocial cohort and not the many agencies supposedly representing us if they want to have any chance of averting this disaster.

A bit more background on myself. I was a project manager working with complex and highly-trusted projects. I was known for getting projects that had gone off the rails up and back and going. As far as I am concerned, the NDIA is off the rails. [inaudible] the NDIS. Thank you.

CHAIR: Thank you. It would assist us if you have a—

Mr Franklin: I cannot hear. I am having sound problems.

CHAIR: It would assist if you could email us a copy of your opening statement. That might help us because we are having sound problems at this end as well. We will try to overcome them as best we can.

Mr Franklin: I barely got that. I can barely hear anything that you are saying. I will bring up the phone on the computer. There is a delay, so I do not know how we can get around the sound problem. [inaudible] is that a possibility?

CHAIR: Whilst we are endeavouring to sort out whatever technical difficulties there are, we will start with Ms Comber. One of the things which you highlighted both in your written submission and in what you had to say this morning was the need for people to continue to receive services whilst NDIS plans are put in place. You also make reference to the continued funding for existing mental health services here in New South Wales. Do you have any examples of where that has not happened or has been inadequate in terms of the way in which services have or have not been provided to an individual?

Ms Comber: What we have heard is that a number of services are now not taking on new clients, because they are only taking people who have had NDIS plans in place. So people are having more difficulty in finding services. The other thing that we have heard is that the quality of services that people are getting from PIR and PHaMs has really changed, because it has become much more NDIS-focused, so people are not getting the same kind of holistic support that they were getting before.

CHAIR: In the case where new people are not being taken on by services, what is their experience? What is happening? Anything, or nothing? Are they just being left unserved?

Ms Comber: What we have heard is that people are being left unserved. These are people who are seeking out these services. They are getting in touch with them and being told that they are not taking new people. Some of these have been from regional areas, where there is limited service availability anyway.

Senator GALLACHER: From your organisation's point of view, what range of people will qualify for service in the NDIS, and what will fall outside?

Ms Comber: One of the things that we have heard multiple times is that it seems to be quite unclear why some people get accepted and some do not and why some people get XYZ services in their plan and others do not get the services that they request. I do not think we have a clear idea of who is being accepted and who is not. All we know really, in terms of the numbers, is from the modelling we have seen in the media that has said that there are going to be a large number of people who are going to miss out on accessing the NDIS. We are really not sure what is going to differentiate that.

Senator GALLACHER: What is your view of the services that remain, in that event? Are the state-based services going to be sufficient to meet those needs?

Ms Comber: My understanding from the funding that services have been getting previously and the need and how that is going to change under the NDIS is that probably they will not. There are services like Personal Helpers and Mentors, where part of their design is that people do not necessarily stay with them a long time, but they are still being cut. Under the NDIS we do not know what is going to fill those services and what is going to fill the funding for those services for people who need some help, and getting that help makes a huge difference in their lives, but they do not reach the permanent incapacity requirements for the NDIS. Those are the people that we are concerned about not reaching.

Senator GALLACHER: I think we heard some evidence last week about the avoidable consequences of people failing to get an expectation delivered. Is anybody working in that space to ensure that people who may apply and do not get funding do not suffer unfortunate consequences?

Ms Comber: For example, the NDIA connecting people with services?

Senator GALLACHER: If they apply for a funding package and do not get it, are there sufficient resources to keep them in a supported state?

Ms Comber: If services such as Personal Helpers and Mentors close, and are transitioned into the NDIS, my understanding is that there will not be sufficient services for people who are found ineligible for the NDIS.

Ms MACKLIN: One of the important issues you raised in your submission is the need for outreach services. I agree with you that that is a very important issue, particularly for people with psychosocial concerns. What would help the committee is if you have suggestions about how that could best work. Do you think it should be in the NDIS, or do you think it would be better to have it operate separately? If so, how would that best be constructed?

Ms Comber: Do you mean, should the NDIA be doing that outreach?

Ms MACKLIN: Should they? Or would it be better to do it separately?

Ms Comber: I do not see a problem with the NDIA doing the outreach. I would think they would have best knowledge about who would qualify for the NDIS and how all of that would work. But I think they need to work with health professionals to make sure that that information is getting out there. What we propose in our submission is doing more education with GPs and people who are having the frontline interactions with people.

Ms MACKLIN: Isn't one of the problems that the NDIA do not actually know some of the people who may be eligible? This is the reason we need outreach. They are not necessarily people who are going to be very keen to come into an office and meet with people they do not know and do not trust. They are all very real issues. That is why I am interested to see whether there might not be a better model than expecting people to meet with officials from the NDIA who they do not know. It might be better to have groups of people who are already well connected with people who might be living on the margins of society, who are very hard to reach and who may not be part of PHaMs or PIR, but who need help and may be eligible but nobody knows where they are. It seems to me there is a group of people like that in the community and we have not figured out the best way to contact and interact with them.

Ms Comber: I agree 100 per cent that there are a lot of people who are not being reached and who do not understand the NDIS and do not understand that they may qualify for the NDIS. There is not a huge level of understanding about what psychosocial disability even is, so even when you see it on the news or that kind of thing you do not necessarily know that it applies to you.

If there was better information getting out there to all service providers about what the NDIS is, what it means for people with psychosocial disabilities, who can apply for it and how they can do that, then that would address some of that. Then the kinds of services that you are talking about—for example, homelessness services and that sort of thing—would have the correct information to advise people. At the moment, it seems like there is a lot of confusion and suspicion towards the NDIS.

Ms MACKLIN: That is a good idea too. I do not know—maybe the NDIA is doing this. I think working with homelessness services or something like that would be very helpful—don't you?

Ms Comber: I do. I think working with all of these services—

Ms MACKLIN: Do you know if that is happening?

Ms Comber: There is no outreach that we have heard of to do with psychosocial disability. The only thing that we have seen is the psychosocial disability fact sheet that the NDIA has put out, but apart from that we have not heard about any proactive outreach. I know that the NDIA identified the need for outreach but, as far as we know, it is not happening. The people who contacted us, they had either heard of the NDIS through PIR or PHaMs, or they had heard about it through the media. Of course, if you hear about it through the media then there is much more misinformation.

Ms HUSAR: Thank you for coming today and providing your insight to us. You talked about the NDIS having trained people specifically in mental health training. It is something that has come up repeatedly, not just in the psychosocial area but generally speaking across the NDIA. I have two questions. What do you think would be the adequate mental health qualifications for NDIA planners to assist somebody requiring certain psychosocial supports?

Ms Comber: What qualifications do we think that people would need?

Ms HUSAR: What qualifications do you think would enable somebody who is an NDIA planner coordinating someone or for getting someone into that role? What would be the minimum qualification, in your experience, that would be required for somebody?

Ms Comber: I can start to answer that, but I might need to also take it on notice because I have other people I work with who might have a better answer. The best experience that someone had with the NDIA that we have heard about was with a planner who was a psychologist. Obviously, that is a high level of qualification that the person has. One of the things that would probably be really important for all planners to have—but especially in psychosocial disability—would be some sort of trauma informed care training because that would at least minimise how much they are re-traumatising the people who come to see them in this kind of institutional process. Otherwise, I will take that on notice.

Mr Franklin: I can hardly hear a word that is being said, but I could hear the answer to that question and I can add to the answer. The experience I have had with NDIS planners is that their backgrounds are very diverse. The highest level of training I have had with any NDIS person in a planning role has been a former occupational therapist. The rest of them have come basically from [inaudible] and that type of thing. I have been told by an ex-

NDIS planner that they got two weeks intensive training [inaudible] supervised training. That was it. As far as access people go, they have very minimal training and absolutely none in public health.

Ms Comber: Just to second what I think Greg just said: we have also heard that people have very good experiences with occupational therapists. I think that is what Greg just said. Is that right, Greg?

Mr Franklin: Yes, that is right. It is a very bad line, but, yes, the training in mental health is very, very poor, and the NDIS planners [inaudible] access staff do not have any relevant qualifications whatsoever.

Ms HUSAR: No. 2 on the summary of recommendations that you provided, which is along the same line that I just asked—

Mr Franklin: Sorry; I could not hear that. Can Jaime can relay all of it? I can hear the girl from Being. If she can repeat the question for me, I would appreciate that.

CHAIR: She may be able to summarise the question in her answer.

Ms HUSAR: The NDIS assessments should use assessment tools designed specifically for people with psychosocial disabilities. Do you know of any that exist now or have they been created through your organisation? Yesterday I heard from some people who had taken a problem and designed some things around it specifically to their organisation. Have you got any tools or any kinds of assessment criteria that you would use?

Ms Comber: Greg, the question was: do we have any assessment tools that we would recommend for people with psychosocial disabilities? I think I am going to have to take that on notice. There is none that immediately comes to mind. We certainly have not designed any.

Mr Franklin: No. Obviously we would not have developed any assessment tools, but we would be only too happy to contribute in the design of those tools, because we think the people who suffer from mental health conditions have had very, very little, if any, input into the means of assessment. The closest I can [inaudible] assessment area [inaudible] But if any of those [inaudible] on our worst day, every single question would be answered in the worst possible [inaudible]. [Inaudible] depression, where you physically cannot get out of bed. [Inaudible]

Senator SIEWERT: Apologies if this has been covered, but I wanted to address the issues around foster care. Mr Franklin—and I must admit I am having trouble understanding through the sound system here—I wanted to understand a bit better the comments that you made about foster care and the issues in foster care.

Ms Comber: Greg, did you hear that?

Mr Franklin: I did not understand that question, sorry. This is a really poor audio line.

Ms Comber: Senator Siewert has just asked you to elaborate on what you said about foster care in your submission.

Mr Franklin: There has been a development in that insofar as I have not had [inaudible] I tried to get it. About two months ago, the people got back in touch with me and said that an agreement had been reached where they were not forcing the children [inaudible] They are not children; these are adult mental health sufferers that have been in the family a long time. They are not forcing them out. At this stage, another decision will be made in, I think, July 2018, so that could be an ongoing concern for them in the future.

Senator SIEWERT: Thank you.

CHAIR: Ms Comber, thank you very much for your written submission and for the discussion this morning. The reality is that what you have said tends to reinforce what we have heard in other hearings, so we are not exploring it in further depth, because a lot of the things basically are the same as what we are hearing from various witnesses in different hearings. So thank you very much for that. Can I ask you to relay to Mr Franklin—because you seem to be the only one he can clearly hear—our thanks for his written submission and for today. For both of you, if there are any further matters you would like to forward to the committee, could you do so in the next two weeks. If you could relay that to him, I would appreciate it.

Ms Comber: Sure. Greg, Kevin Andrews has just thanked you for your submission and for what you said today, and he has also said, if there is any other information you would like to give to the committee, to get it to them within the next two weeks.

Mr Franklin: Okay, I will email the speech. That may be easier. If the committee is agreeable, I am only two hours from Canberra, and I can get up there at some stage and sit down with them. That may be a better way to go, because there is a lot to cover. That is another option we have.

CHAIR: The secretariat will be in touch with Mr Franklin.

Ms Comber: Okay, great. The secretariat will be in touch with you. Also, I think Senator Siewert wanted a written copy of what you said about foster care, if you could forward that with the other information.

Senator SIEWERT: Any further details would be really appreciated.

Ms Comber: Any further details about foster care would be great.

Mr Franklin: I am sorry; I did not understand a word of that.

CHAIR: Thank you very much for coming along and for the submission.

Ms Comber: Thanks for giving us the opportunity.

AVERY, Mr Scott, Policy and Research Director, First Peoples Disability Network

DAVEY, Mr Bernard, Member, Australian Services Union

FARRANCE, Ms Harriette, Member, Australian Services Union

FINCH, Mrs Kate, Manager, Systemic Advocacy, People with Disability Australia

FING, Mr Jake, Council Member, Disability Council NSW

JONES, Mr Philip, Member, Australian Services Union

McFARLAND, Mr Angus, Assistant Secretary, ASU NSW and ACT (Services) Branch, Australian Services Union

MILLS, Mr Jon, Member, Australian Services Union

SALIGARI, Ms Janine, Member, Australian Services Union

STUART, Mrs Jodi, Member, Australian Services Union

VILLELLA, Ms Bianca, Member, Australian Services Union

WHITE, Ms Linda, Assistant National Secretary, Australian Services Union

[11:23]

Evidence from Mrs Finch was taken via teleconference—

CHAIR: I welcome representatives of People with Disability Australia, the First Peoples Disability Network, Disability Council NSW and the Australian Services Union. I invite you in turn to make some opening remarks, perhaps starting with you, Mrs Finch.

Mrs Finch: Thank you very much to the committee for inviting People with Disability Australia to appear. I would like to acknowledge the traditional owners of the land on which this meeting is to be held.

I am pleased today to be appearing with Scott Avery from First Peoples Disability Network. First Peoples Disability Network made a separate submission to this inquiry. However, we are both organisational representatives of Disabled Persons Organisations Australia, which is a collective of organisations that are run by and for all people with disability. Our experience and collaboration as DPO Australia ensures that the intersectional issues that many people with disabilities face are brought to light through our contributions to policy and practice. It is this perspective that we hope to bring to this hearing.

How psychosocial disability manifests in different communities is unique—multifaceted in both cause and effect. In addition, how these communities and cultures recognise and respond to psychosocial disability is also unique and brings with it particular strengths and challenges. Our main concern is that the structure of the NDIS does not currently consider the provision of disability and mental health services through this intersectional lens, resulting in both barriers of access and a missed opportunity for the scheme to tailor services to meet the needs of these people.

Finally, I would just like to note that we were pleased to see the funding announced in last week's federal budget for mental health services for those people with psychosocial disability who will not access the scheme. We would like to note here that we feel it is critical that this is not capped but that the NDIS and the Department of Health actively track how people are referred and refused services to ensure that no-one falls through the gaps. Thank you again to the committee.

Mr Avery: Thank you to the committee. I would just like to acknowledge the traditional owners of the land on which we meet.

We put a submission to the committee which was in two parts. It was done with the La Trobe Law School. The first part was really about trauma and psychosocial distress for Aboriginal people with disability. The second part was about the interface with the justice system—those particular issues. We just want to acknowledge the work of the Australian Disability Justice Campaign, which I believe you have spoken to. I want to speak about the trauma, and particularly on that intersectional issue.

It is actually very rare to meet an Aboriginal person, let alone one with disability, who has not had some experience of mental health or psychosocial disability. Either they have experienced that themselves or they have family or friends who have, or know a community member who has. There are many interrelated contributors to this, it is usually traced back to some form of dispossession, ongoing discrimination or social marginalisation.

Within that population there are groups which are at risk. Our expertise is around Aboriginal people with disability, but the concept is that if you are an Aboriginal person and you are a person with disability that these factors combine and the degree of social isolation magnifies.

Our submission referred to some preliminary data. Since our submission, the ABS, with the support of our organisation, has released an occasional paper on the health and wellbeing of Aboriginal people with disability. So we can now quantify the impact on health and wellbeing if you are Aboriginal and you have disability. I will just give a summary of some of this data.

If you are Aboriginal and you have disability, compared to the Aboriginal population as a whole you are 2.5 times more likely to experience higher levels of social distress; 1.4 times more likely to be removed from home; almost twice as likely to live alone; almost twice as likely to be homeless; 1.5 times more likely to experience the recent death of a family member or friend; and 5.2 times more likely to have experienced mental illness. So that is for Aboriginal people with disability, compared to the Aboriginal population. The significance of that is that we can now quantify this intersectional impact, which from a policy perspective—and as sobering as that is—means we can actually start thinking about policies and strategies.

The second point I want to talk about is that whilst these numbers are confronting, even these mask the human impact. We spend a lot of time going to remote communities in particular, and through our research program we come across communities which are almost like trauma hotspots. You need to see trauma and psychosocial illness as a social disease. It is almost like a contagious illness. We have come across many people who have actually undergone personal programs: they might go to a counsellor for an hour and then they come back to this environment. This constant, perpetual re-traumatisation almost undoes that work.

Bringing this back to the terms of reference of the committee, we need to think of these issues as intersectional issues. Firstly, cohorts of our population are seriously affected by this, and it magnifies. Secondly, when psychosocial programs rely on the individual only, they will have limited effectiveness. The phrase that comes to mind is: preach from your scars, not from your wounds. In other words, healing needs to precede resilience, and Aboriginal people need healing first.

Whilst this is heavy reading, there is a glimmer of hope because, when we look at this intersection, there is one aspect where there is no difference in the outcomes for Aboriginal people with disability and Aboriginal people, and that is in their community participation. I am talking about their involvement in ceremony and their involvement in cultural activities. There is no difference in that outcome. We have seen that when we have gone to communities and people say—when we go to places where despair is quite acute—'We know there is something stronger within us.' We just need to find that.

In conclusion, we see community and culture as a way forward. The question for us is: how can we infuse this cultural and community intelligence into how the NDIS operates? Thank you.

Mr Fing: First off, I would like to acknowledge the traditional owners of the land on which the hearing is being conducted today. As an Aboriginal man from Moree, I strongly extend that respect to any other Aboriginal people who may be here today.

I thank the committee for allowing me to come and speak to our submission. Unfortunately, I was not involved in the writing of the submission, but I do have a background in justice issues. I currently work for the New South Wales government in the Department of Justice. As an Aboriginal person, I live with a psychosocial disability, so I can speak to the submission from my own personal standpoint.

I do not really think there is much else to add by way of an opening statement. I can assist through personal experience, my job and as a member of the Disability Council, and I have worked with people with a psychosocial disability. I thank you, and I will leave my opening remarks at that. Perhaps I can assist later.

Ms White: I would also like to acknowledge the traditional owners of the land on which we meet. The ASU thanks the committee for allowing us to appear before the committee to give voice to the workers working in the community mental health sector. I am here from the union. I am Assistant National Secretary of the Australian Services Union. With me is Angus McFarland, who is assistant secretary of the New South Wales branch—he is in the back stalls behind me. Very importantly, we have also brought seven ASU members with us—three from New South Wales, one from South Australia and three from Victoria—from six different employers. Each of them is working at the front line in the sector. They will each make a short statement from their perspective of how the provision of services under the NDIS for people with psychosocial disabilities related to their mental health condition is impacting on the workforce. They are representing the ASU, not their employers, but their employers are all aware that they are here, and they are certainly here with—blessing might be the wrong word; they are aware of it and are happy for them to give their own personal experiences from the front line.

There are seven of them. The first person who will speak is Jodi Stuart, and then we will move to the others. The three from Victoria have literally just walked in the door, having flown in this morning.

Mrs Stuart: I would like to acknowledge the traditional owners on whose land we are meeting today. I am currently employed by One Door Mental Health in a personal helper and mentor role. I have obtained diplomas in both disabilities and counselling, I have been working in the community services sector for 32 years and, over the last seven years, have worked with people with a mental health condition.

The unpredictable nature of mental illness challenges the NDIS criteria. The majority of our participants—practitioners, allied health professionals and support services—do not see a mental health condition as a lifelong impairment, and a recovery, strength based approach to supports and service delivery has proven to be successful in programs like PHaMS.

Our PHaMS participants are reliant on support to address issues that are impacting on their ability to manage their daily lives and to live independently in their community. These issues generally do not have a lifelong functional impairment. However, they have a significant personal impact on recovery and on a person's ability to participate economically and socially within their community, if not addressed. If participants are ineligible for NDIS and services lose Commonwealth funding, significant gaps in services for people living with a mental illness will be created.

CHAIR: Thank you, Mrs Stuart. Mr Jones?

Mr Jones: Thanks very much for the opportunity to present. I too would like to acknowledge the traditional owners of the land on which we meet today. I trained as a registered general and mental health nurse and have 26 years experience in the mental health sector, although I am no longer working in the traditional role of the nurse. The last 20 of my working years have been in psychosocial support services.

Today I welcome the opportunity to raise my concerns and my colleagues' concerns about the Personal Helpers and Mentors service, which is being phased out and somewhat defunded with the implementation of the NDIS. The Commonwealth has invested heavily in the Personal Helpers and Mentors Service, which has enabled thousands of people with a mental illness who could not access psychosocial supports previously to access those types of supports. This has been a national success and a major improvement for mental health services. In South Australia, for example, we have 10 different NGOs delivering these services across 19 regions and we have seen a collaboration that we have never seen in this sector before as a result.

PHaMS is a model that addresses significant service gaps, promotes recovery, and encourages partnership and collaboration among consumers, carers, NGOs and state clinical services. In South Australia we have approximately 1,745 people who received PHaMS services—and that was flexible and responsive support—in 2016. Our state peak body, the Mental Health Coalition of South Australia, did a study last year amongst member organisations and it estimates that 1,200 of these people will not be eligible for NDIS or will face significant difficulties in accessing NDIS. My questions are: Why are we dismantling a service model that is working well and meeting the needs of thousands of consumers and carers across the nation? There is the need for NDIS support for people who experience long-term disability as a consequence of their mental illness, but why should it be at the expense of services that are early intervention and recovery focused, with the capacity to respond to unexpected and immediate needs?

CHAIR: Thank you, Mr Jones. Now I think we are going to have the interchange, so to speak. Mr Davey, it looks like the ball is in your court, if I can mix my metaphors.

Mr Davey: Thank you for inviting me to speak today. I would like to acknowledge the traditional owners of the land on which we meet today. I have a Certificate IV in Disability. I worked in the disability services sector for five years, and in the last three years I have been working in the mental health sector, specifically in the Partners in Recovery program. I work in the Western Sydney region, which is currently transitioning participants over to the NDIS.

I would like to address the uncertainty and anxiety amongst the workforce, and consumers, as a consequence of the potential loss of the Personal Helpers and Mentors program; specifically, the many specialist mental health workers who will be lost to the industry, the considerable uncertainty as to the transferability of their skills into diminishing block funded mental health services, and a National Disability Insurance Scheme that does not have specific mental health focused service delivery. These same workers are relied upon by the consumers they work with and have built an understanding and rapport. They provide mentoring and continuity of support that is a vital component to recovery oriented mental health service provision. Also bear in mind that a large percentage of these workers are acting in a peer worker capacity, which has been recently recognised as having significant benefit in developing positive outcomes for consumers in their recovery journey.

CHAIR: Mr Mills?

Mr Mills: I have worked in the community services sector for the last 15 years. The last nine have been with the Personal Helpers and Mentors program, with after-care, through Western Sydney, the Blue Mountains and also the Central West. I have diplomas in mental health, drug and alcohol and community sector management.

A significant concern regarding the NDIS and mental health is the lack of flexibility that this model entails, especially compared to the PHaMS program. From the new hurdles created by the application and planning process for an NDIS package to the practicalities of service delivery from both clients' and workers' perspectives, it does not appear to be an appropriate fit for the mental health sector.

Mental health issues can be cyclical or episodic, can fluctuate in severity, and can be worsened or have new issues brought on by any number of external factors throughout someone's life. Recovery from the effects of mental illness can be a long and winding road, where the support required is both direct and indirect work. A worker's capacity to meet these flexible needs is vital: capacity for workers to engage with other services, to case manage, to liaise with health services and state funded health services, housing—the list goes on and on, depending on what someone's need is. It does not appear that the NDIS model will allow the roles that we have in supporting people with those needs to have that flexibility that will both meet their needs and our needs to be able to do our jobs.

CHAIR: Thank you. Who is next?

Ms Villella: I work at Neami National in Melbourne, Victoria, as a community mental health support worker. I have a qualification in social work and art therapy, and have been in the social and community services sector for about five years, the last couple of which have been at Neami. The location I work in is part of the northeast metropolitan area, otherwise known as the NEMA, where the NDIS is being rolled out.

One major concern my colleagues and I share is that the change in working conditions due to the transition from bloc funding to the individual packages provided by NDIS is very problematic. In a nutshell, the NDIS limits the way companies such as Neami provide services, which ultimately negatively impacts on the quality of service being provided. There are some specific points of concern. These include the line items available in the NDIS price guide mean significant reductions in resources. This places workers such as me in more high-risk work conditions, whereby our own personal safety and wellbeing is not catered for. And in response to the NDIS, Neami has created a subsidiary company named Me Well that will do NDIS work. The main company of Neami will not do this work at this stage, and workers have not been informed of what will happen to their workplaces other than knowing that their roles will eventually cease to exist.

More specifically, the new type of work offered by the subsidiary company of Me Well will be done by a more mobile workforce. The concern here is that there will be fewer personal development opportunities for staff, less supervision, fewer chances for peer-to-peer support, increased caseloads and unfair pay. All of these things will ultimately negatively impact workplace culture and morale and lead to an increase in burnout and a high turnover of workers, which ultimately will result in low quality of service for consumers.

CHAIR: Ms Farance?

Ms Farance: I have been working in the community mental health sector for about six years. I began as a support worker and now I am managing a program that is transitioning to NDIS. I have a Bachelor of Social Work with honours from RMIT University.

Through my experience, I have seen the benefit of recovery-oriented practice for people living with mental illness. This support model focuses on exploring one's identity outside of their illness, and this is particularly important for people who have been stigmatised by the mental health system in the past and defined by their illness. The NDIS recognises that everyone's needs and goals are different, as well as hope and optimism being integral to recovery. The experience, however, for consumers has not reflected this. Many consumers we support do not identify with having a disability, and for this reason alone do not feel empowered by the NDIS. Feedback through the planning process has been that this is not strength based, as consumers are asked to focus on their impairment. The approach to assessment makes it necessary for consumers to consider a worst-case scenario in order for them to have adequate levels of support in their NDIS package.

Many consumers have spent a fair portion of their lives working really hard to reframe the challenges that they experience in order to build resilience and strength. The concept of a permanent disability within itself contradicts the idea of recovery and relates much more to physical disability rather than to mental illness. Also, due to a lack of rapport between consumer and NDIS planner, many consumers find it really challenging to articulate their needs. It has meant that support workers are needed to speak on their behalf, and this is quite a disempowering experience for many consumers who have been encouraged to self-advocate.

There are also many discrepancies between knowledge base and perspective of individual planners, and this inconsistent message about what support can or cannot be accessed through the NDIS is very anxiety-provoking for consumers. It leaves consumers feeling judged and stigmatised. This experience also takes away from consumers feeling that they do have choice and control, which we understand is intended to be at the heart of the NDIS.

Ms Saligari: I work in Melbourne, Victoria, with an organisation called Prahran Mission. We have MHCSS—mental health community support services—funding, which is state funding, for individual client support packages. We also run PHaMs programs across the Bayside region in the inner east and southeast of Melbourne.

I have been in my current role as a client assessment coordinator, since transition from PDRS, for the last two and a half years. Prior to that, I was a support worker. Overall, I have been in this sector for 10 years. My qualifications include a diploma in community health and development and welfare, and a certificate IV in alcohol and other drugs and non-clinical mental health. I have done 10 years of professional development training—including as a Recovery Star trainer—for our organisation, strengths-based training, supervision, trauma-informed practice, dual diagnosis, suicide assist, first aid certificates, and I could go on and on. Today I want to talk to you about the qualifications and the experience of our workers, and the current pay rate under the SCHADS award compared to current NDIS pricing for working with the same cohort of participants. Thank you.

CHAIR: I will lead off with some questions. I think Mr Jones made mention of the South Australian experience in which there are some 1,745 people currently on the PHaMs program, and the expectation that something like 1,200 of them would be ineligible or would not receive the same level of services. Do you, Mr Jones, or anybody else in this session, have any examples of where people who are currently receiving services will no longer receive services under the change to the NDIS, or are not receiving services at the same level?

Mr Jones: In South Australia, we roll out on 1 July, so we are preparing people for their plans, at the moment, using the eligibility screening tool, which is part of the PHaMs assessment framework. Basically, member organisations, like the mental health council association, have been doing that work. Their estimations are, looking at criteria, that those that are unlikely to get a service will find it difficult. That is what that was based on. It was more work that was done internally—a projection. My interstate colleagues might have something to say on that.

Senator GALLACHER: Mr Jones, I think the South Australian minister has extended funding for 12 months.

Mr Jones: That is in regards to state psychosocial support services. We have two streams of funding, like the other states. Here, in New South Wales, you have HASI funding for disability and psychosocial supports for people with mental illness. In South Australia, we have similar funding, and our state government has extended that for 12 months to see what the impact of the NDIS is on that group of people. That group of people sits outside of that 1,700 people, though, so that is an additional 1,000 people who are receiving services that are state-funded. I am not exactly sure the number of 1,000 is accurate, but it is around that mark.

Senator GALLACHER: Thank you.

CHAIR: Does anybody else want to add to what Mr Jones has said in terms of examples?

Ms Farrance: I have examples of several consumers at Neami who will not receive support. It will be very hard to find support similar to what they have been receiving from that. That is due to their being over 65 or not being a permanent resident.

Ms Saligari: One of my concerns, as we are coming into and preparing to transfer information to the Department of Health and Department of Human Services for NDIA, is the participants who are homeless who we are currently able to work with do not even look like they will be able to go on the list to NDIA because when you are homeless often you lose phones or they get stolen so there is not a contact address and no contact details. Yet where we are in our community we are very prominent on Chapel Street in Melbourne; it is quite iconic. So consumers can come to us and approach us and they do. We have that ability to service them there so it does not matter if there is not an address. We will work with them to try to get housing and to get things happening for them that they need and that they are identifying now. So we are quite concerned about those most vulnerable participants falling through the gaps before they have even reached NDIA.

Ms MACKLIN: I just want to follow that up because a number of people who have come to the committee have really emphasised this issue of outreach. What I am interested to hear from any of you, because I am sure you all share the concern, is: what would be the best way to deliver that outreach? That is the first thing while I have the floor—once you lose it, you are done!

I just want to follow up with Jon Mills's point—I thought that was a really good one, Jon. You talked about the loss of flexibility. Once again, I think the committee has heard a lot about this point. I just want to take this

opportunity to really reinforce what you have all said, which we have heard loud and clear, about the recovery point. We have had some very detailed submissions from the Mental Health Council and so on about how that might be addressed. I just want to make sure you all know that has been heard loud and clear. Coming to you, Jon, the real issue I think you raised which is very important is the point about flexibility. What I would be interested to hear is your view of how that could best be addressed in the NDIS. They are the two issues for both of you.

Mr Mills: My perspective obviously is comparing the early stages of the NDIS with what I have historically worked with under the PHaMs program. In my experience with participants of the program, their needs might fluctuate. Someone might need five hours of support one week, half an hour the next and two hours the week after that. With the NDIS funding model and for organisations providing services, it sort of requires an ongoing, regular, set two hours this week, two hours next week and two hours the week after that.

Ms MACKLIN: Why does it have to be that way? Why can't it be flexible?

Mr Mills: I believe one of the problems with it is the income stream for organisations. A lot of organisations—mine for starters—is booking people into regular appointments in light of preparations for NDIS funding and having a package where the support or the service they get is a regular weekly, fortnightly or what have you type of support.

Ms MACKLIN: So you would suggest that when a person goes to develop their plan with an advocate—that seems to be the message—the NDIA really needs to hear that people need flexible access in their plans.

Mr Mills: The risk that I am seeing is that while we do not have many NDIS clients currently, we do have our existing PhaMs clients. We are trying to operate as we would in an NDIS model. That means booking regular appointments that tend to be fixed. This, I have found, means that people can range from being quite underserved if they are at a crisis point to being overserved if they are doing okay. Under the PhaMs model, we would be taking a step back to allow them to have that growth.

CHAIR: There is a fear, Mr Mills, that under the NDIS there is a kind of set-and-forget-mentality—that is, you put in place a plan and then it is not reviewable. Equally, is it not possible that within the structure of the NDIS there can be flexibility in terms of service provision? That is what I think Ms Macklin was trying to tease out.

Ms MACKLIN: Yes, that is right.

Mr Mills: I guess it overlaps with one of the other comments about the price points of the NDIS hourly rates for particular line items in that we do not have the flexibility and time to meet someone's needs if they need more support in that manner. From an organisational point of view, it makes a lot of sense for hours to be booked ahead of time and to be fixed to minimise the gaps in-between seeing particular clients. What that does not allow for is the time we would otherwise spend allowing an appointment to extend longer if needed and allowing us to liaise with other services. One example I thought of really highlights this issue: sometimes with the work we are involved with we will do case management stuff that the client may not like or may not agree to. I guess the big question would be: who funds that? Who funds us making a child protection report or liaising with a drug and alcohol counsellor or organising for someone to be hospitalised because of their mental health issues when they do not want that to happen? But we have a duty of care to make that happen.

Ms MACKLIN: Yes, it is a good point. Janine, would you mind answering the outreach issue?

Ms Saligari: Yes. With the outreach issue, I think Bianca talked earlier about how the workforce is going to be more mobile to get to clients with the plan they have with the NDIA. But with the homeless, it is points in community that they go to. I can think of places in St Kilda—not-for-profits there that they go to. I can think of other community places scattered around Australia that would have places where those that are homeless, vulnerable and in need of help could say: 'I can go there. I can access something there.' There is no appointment booked and there is no line item. There are just organisations responding to the needs of the community. That is what gets in those who are homeless. You will often work with someone who is homeless and say: 'What do you want to work on? How do you want to work towards your mental health?' And they will say, 'I cannot think about my mental health until I have somewhere to live.' So, then, that is what we address first. Mental health support workers become housing workers. They become finding somewhere for the dog or the cat if someone is fortunate enough to have a pet whilst they are about to go into a hospitalisation they did not expect to occur but that we have noticed and have seen the signs of them becoming unwell. It is definitely that ability to respond and a place to go when you do not have an appointment booked. That is the most crucial part. We have done outreach for years, and we do it well. I think we can continue to do that and it is allowed for in some aspects.

My concern though is that workers are starting to use their own cars. Fleet cars and their ability to transport clients—we talked about this on the way here—and that parallel side-by-side conversation in cars are some of the

most therapeutic conversations we have with our clients. Sometimes it is the time when they can disclose something that is going on that they are worried about that is causing them anxiety and great stress. They can disclose that to us when we are in a car. Somebody providing transport is not going to be a social worker or a psychologist, and there is not going to be the price point for that type of work. They are my concerns.

Senator SIEWERT: I want to tease this out a bit, because some of your evidence suggests that you do not think psychosocial disability going into NDIS is a good idea. Jenny articulated some of the issues about evidence we have received about recovery and how we can address that. It seems to me that the argument you are putting is that there are still huge numbers of people with mental health illness and people who are always going to be outside the system. They will probably miss out on the ILC program as well, so we really need to make sure that we have the strength outside the NDIS system. Is that a correct summary?

Mr Davey: As a frontline worker in a region that is transitioning to the NDIS at the moment, the NDIS leans towards services running as a business model. A business model is not going to help people for the reasons that my colleague said. With the episodic nature of mental health, you cannot book somebody in in a week's time for an hour's appointment and then they become unwell and cannot attend. You cannot run a business that way, if you are subjected to running your organisation based on line items. A support worker would need to have 40 hours per week of line items scheduled for that person to be gainfully employed.

The role of the Partners in Recovery program, which I am involved in, was to help pick up those people that are falling through the gaps. In my opinion, the NDIS would only lead to more people falling through the gaps. The reason is that not everyone is going to be eligible for the NDIS, and a lot of the bulk-funded services are being taken away. Therefore we are going to have a cohort of people who are not receiving any services at all.

The problem with the funding for the NDIS concerning mental health was that a lot of these people experiencing mental health and living in the community were not captured by any service in the first place. Therefore you do not have the numbers of how many people are out there and how much it is going to cost you to service those people.

Senator SIEWERT: Mr Avery, I wanted to ask you to expand on your comments about community healing. How would you recommend we address that issue? I get the concept. The question is: where do we go from here?

Mr Avery: The community-wide trauma aspect?

Senator SIEWERT: Yes, because I think it is very important.

Mr Avery: I think what we are understanding now are the relativities of the barriers to access. There are relatively low barriers to access to the scheme, which might be if you have an advocate. You have very, very high barriers to access, if you have large degrees of co-occurring morbidity, disability or community-wide trauma and you go into these places. We have approached some of these things around personal healing by using things like art to build that sort of esteem. The thing is: in a lot of the communities that we have, with the lives that they have led, people are very distrustful of outsiders. But, as we go into communities, we are finding people and we can encourage them. We have always thought the NDIS could be a bit of a catalyst for community development. And when we start talking and taking the time to actually listen to them on their own terms, and telling them stories—which is a form of healing themselves—they start going, 'How can we start doing things for our community?'

So we are very interested in how we can cultivate this community approach—community mentors, people within the community. At the individual level we use art and those kinds of things to stimulate them. The Aboriginal arts sector is very vibrant. What we are starting to do is look at disadvantaged communities over in America and other places like that. They have started to emphasise the built environment that these people live in. We take that concept of building pride and self-esteem at the personal level and take it up a level: how can we look at the built environment and get the community involved in taking pride and ownership of their community and their physical surrounds? This is something that is a bit different to how the NDIS might operate—

Senator SIEWERT: How do you resource that, because it is outside—

Mr Avery: This is a problem that we face with Aboriginal policy and disability policy. They operate separately; but Aboriginal disability is across everything. We come to this committee, and it might be on disability, and Aboriginal people are one perspective of this disability problem. The reverse applies when we go to Aboriginal policy inquiries. It is a perspective across many, many things. We need to find a way to consolidate these fragmented things and come up with a coherent strategy for Aboriginal people with disability, because it comes across everything. This is the basis for our recommendation on the NDIS: you cannot just see this as an individual thing. There are so many determinants pulling in here. We need a coherent strategy for this, which is not just addressing what the individual needs, because they will focus on things like personal mobility, physical

mobility and sensory things, but they are not touching or even getting their head around this community-wide environment that they are in.

That is the problem that we are seeing: even if you are in the scheme—which is very unlikely, we are hearing—you come back to an environment where you are continually retraumatised. Our supposition is that the NDIS could be a catalyst for this kind of thing. I think we need to bring disability people and Aboriginal people together to think about how we can solve this. What the outcomes are showing is that they are just perspectives of one problem, where it is creating this almost separate class of people who are chronically disadvantaged. The data says that that is happening now. Neither approach is working. We need to bring these approaches together. It will only get worse unless there is some ability to bring these policies together into one Aboriginal disability strategy.

Senator SIEWERT: I am also involved in aged care inquiry at the moment in another committee. One of the things that we have heard in Aboriginal communities with CDC, the consumer-directed care, the new approach to home care and aged care, is that it is not going down well in Aboriginal communities. People are going, 'Good—I've got a package—when do I get resources so I can share them in the community?' The concept of the individual is anathema. Is that the same thing that is happening with the NDIS? I heard what you said about the other issues, that there are not that many packages out there that we have experience with. Is the same sort of concept occurring?

Mr Avery: What we are seeing is that there are people on packages. There are a small number on packages, but it is almost random how they are getting there. These are people with—when I say low barriers to access, I use that term wisely. They may have an advocate to advocate for them. There are people who are very happy. There are a number of people who have plans but they are not suitable and not working. They have something but it is addressing an assumed need, not their real need. They might be getting wheelchairs, but they are housebound because they do not have disabled access housing. It is that kind of concept.

But we are also seeing this large swathe of people who are so far removed from understanding what the NDIS is about. These are the people who are probably most disadvantaged that we are seeing. They are carrying a sense of abandonment. If you go there you can almost feel it. You walk into these places and you feel this sense of abandonment. When you dig under it you think there is a little bit of hope there, but we need to think creatively and innovatively about how we can cultivate the environment that these people are in so they can actually do it.

Ms HUSAR: I just wanted to follow on, Bianca—sorry, I think that is easier than attempting your surname, and that is fine, because I would rather people go with Emma too. You talked about the impact of the turnover of staff on clients, and, as Ms Macklin said—the member for Jagajaga and definitely not part of that Senate—we are hearing about the turnover and the casualisation of the workforce. Can you describe what the impact on a client who receives psychosocial support is and what it is likely to be if the workforce does go through such a transition where there are such casualised people. I ask all of you people who have presented today—highly qualified, highly skilled and very, very experienced—what would that mean for a person who is receiving support?

Ms Vilella: I think it would mean a few things. The first thing that jumps to mind is this complete loss and undervaluing of what it means to have a therapeutic relationship with a worker. I guess a big part of recovery work is forming a collaborative and trustworthy relationship where you build what the work is together. You see the person receiving support as the expert of their own experience. As workers we use our training and skills to hone in on that and cultivate this special therapeutic relationship. A major concern that I have heard from colleagues and consumers is that that is going to be lost. They are going to be interacting with—it might be multiple different people each week or however they structure their care and support, depending on their needs. I think a colleague of mine mentioned the transportation. If there is somebody new driving you to every psychiatrist appointment, or whatever the appointment may be, that can cause a huge amount of anxiety and stress. It is also ripping somebody off of a potential therapeutic interaction that could enable their recovery.

Secondly, replacing skilled, highly trained workers with people that are less experienced is going to disadvantage consumers as well. They are not going to come with the trauma-informed knowledge and the approach of honing in on somebody's strengths and values with the background knowledge of psychosocial disability.

Mrs Stuart: Can I just add that, for someone who we have built a rapport with, in terms of a recovery support worker—they have told us their story. We know that story; we have heard it. They do not need to say it again. But if we have a casualised workforce and we have a high turnover of staff, that person is being re-traumatised by having to tell that story again, because that casual worker does not know that that person cannot walk on that side of the street because of a reason, because of what happened there. Unlike a physical disability, where you go, 'Okay, obviously you cannot get yourself out of bed'—that is easy. A mental illness is not like that, and that is the trauma of this—people do not want to have to tell their story over and over again.

Ms HUSAR: Is there anybody else that wanted to feed back to that? Did any of the workers want to make a contribution on that?

Mr Jones: Just that I think there is a lot of skilled staff as well. At the moment we have some people that will transition to NDIS—and probably quite rightfully so—but they will say: I want Roy to be my worker. Roy is not going to work for \$22 an hour when we have been paying him \$32 an hour under the state's award for his skill level. That person will not have that choice any more about Roy, because Roy will work in a different type of capacity. He will work as a case manager, with the skills that he has, and a person does need that level of skills as well. So Roy will not be working with that person if that person goes under NDIS. It will be a different workforce that we will employ at level 2, which will have basic qualifications. Then we would question the quality of support we would be able to offer that person as well.

Ms HUSAR: Do you think that that change in the workforce and the change in the nature of the line items and how we charge has the ability to cause more harm to the clients? Unanimous nodding?

Ms Farrance: You asked about impact on the consumer in terms of turnover. Absolutely, as Jodi said: re-traumatisation. I would also say potentially complete disengagement from the service.

Mrs Finch: In our submission we raised our concerns around the quality and safeguards framework and the use of restrictive practices, and how a casualised workforce, and perhaps a less-experienced and qualified workforce, will ensure that they are in line with efforts that are being made to reduce the use of restrictive practices and, within an unregistered and mainstream services support area where people access support, how this will ensure that the safety and rights of people with disability are respected. That is something I wanted to add as another risk involved in the transfer of skills and how that reflects the services people receive.

Senator SIEWERT: I want to clarify: you think that the casualisation of the service and re-traumatising will lead to people going: 'I don't want this'?

Ms Farrance: Yes, based on fear.

Senator GALLACHER: Mr Jones, I am looking at a media report which says that disability services will be outsourced in the SA private sector and that there will be up to 10,000 disability clients—of which I think 2,700 are in the mental illness sector. But, 700 staff in the public service will also be asked to either transition to the private sector or find a job somewhere else. Won't there actually be more resources in your sector?

Mr Jones: There possibly could, but whether we would actually be able to pay for them to come across—is that what you are talking about: the transition of the workforce from government to non-government?

Senator GALLACHER: So, basically, 700 public servants will be outsourced?

Mr Jones: Yes, but I do not think that it will be at the same pay levels and conditions that they are working for under their state government contracts.

Senator GALLACHER: No, but won't the private sector have more ability to gain contracts to resource the sector, if there is a transition from public sector employment to private sector employment? Won't there be more contracts, more—

Mr Jones: There will be lots of jobs and more contracts for the individuals or the people you are talking about?

Senator GALLACHER: For the sector.

Mr Jones: There will be more contracts but, again, the payment of those contracts and whether we are able to maintain a workforce to deliver those contracts is our concern. Also, too, in South Australia—and I know that we are talking about mental health care—in the disability sector, there are going to be very skilled case managers within our disability services that will no longer be there anymore because, with the transition to NDIS, their case management role goes as well.

Senator GALLACHER: But the decision has been made that elderly and disability care services will be outsourced. That is affecting, I think, almost 1,080 public servants and 16,000 clients

Mr Jones: Yes.

Senator GALLACHER: That is with domiciliary care as well as disability. Won't there be a huge influx into the private sector to resource that? Will there be much more money in the private sector?

Mr Jones: I do not think that there will be much more money in it, because it is not—we are able to deliver on block funding.

Senator GALLACHER: How are we going to maintain services, if we do not transfer the resources?

Mr Jones: In the NGO sector, the difficulty will be whether we can actually do that. Again, too, I suppose, like in Neami's example, you have another business model where you pay people at a lower level with casualised conditions to be able to make sure that you have a business model that survives the unpredictability or the lower pay rate that you get from delivering a support service per hour.

CHAIR: I think it was you, Mr Avery—but it might have been Mr Fing—who mentioned multifactor differentials in terms of the combination of mental health disability and Aboriginality or Indigenous. Was that an Institute of Health and Welfare study or an ABS study?

Mr Avery: The data that was released in April this year is an occasional paper. It is from the Australian Bureau of Statistics. It is the social and wellbeing indicators for Aboriginal and Torres Strait Islander people with a disability. It is using the National Aboriginal and Torres Strait Islander Social Survey, which is an Aboriginal survey by the ABS. For the first time, working with the FPDN, we have been able to put disability flags on the survey, if you like, so we can actually compare outcomes for Aboriginal people without disability and Aboriginal people with disability. It is quantitatively proving this concept of intersectionality, and it is quite sobering. I am happy to send the paper through to the committee.

CHAIR: We can get it. I just want to know the source because it may be of use to us when we consider recommendations and how we approach it.

Mr Fing: Using such a survey puts Aboriginal people in the same collective body and I think that in order to really address Aboriginal people with a disability you cannot group Aboriginal people together. Ms Macklin, I am sure in your time as the minister for Aboriginal affairs, each community that you visited and every nation of Aboriginal people in Australia were so different. I am from Moree; I am a Gamilaroi man, and my nation is so different compared to the Wiradjuri people down here. That Aboriginal people are seen to be one people needs to stop happening, because we are not.

I understand that a lot of Aboriginal communities are struck with people with a disability. A lot of the transgenerational trauma that has occurred does cause mental illness and has collective effects on the whole community, but I do not think that it can be said that what is good for the people in the Aboriginal community in Moree is good for the people who live in Redfern because they are completely different Aboriginal identities and they are very different social settings. I think that needs to be understood before progressing further.

CHAIR: It is probably true of non-Aboriginal communities as well, Mr Fing. Broadly, the issues and needs in Moree, whether Aboriginal or not, are going to be different to what they are in Redfern, let alone here in Penrith.

Mr Fing: Yes, very much.

CHAIR: I thank you all for your submissions on behalf of your organisations, and I particularly thank you for coming along this morning for the discussion—including you, Ms Finch. If there is anything that you wanted to add to your submissions or what has been discussed this morning could you forward it to the secretariat within the next two weeks, please. Thank you very much again.

Proceedings suspended from 12:22 to 12:52

SCHORER, Ms Janet, Executive Director NDIS Reform Group, Department of Premier and Cabinet, New South Wales

TAYLOR, Ms Samantha, Executive Director NDIS Implementation, Department of Family and Community Services, New South Wales

CHAIR: I welcome representatives of the New South Wales government. I invite you to make an opening statement, if you would like to.

Ms Taylor: Thank you. We thought a little bit about how to open, given the current environment around the NDIS and, as the committee would be well aware, the significant adverse media that is attracting a lot of angst in the community and in the minds of people with disability about the value of the NDIS and government's commitment to it. We as senior bureaucrats charged with implementing reform on scale in New South Wales reflect that it is a very disheartening environment at the moment and we are committed to making sure that, at least in New South Wales, we are able to send positive messages to people with disability to support them to transition into the scheme in the best way possible that gives them confidence in their future participation in the scheme and to do that to the best of our abilities in consultation and collaboration with our colleagues in both the Commonwealth and the National Disability Insurance Agency.

We have in New South Wales 50 per cent of the total participants in the country now within the NDIS—about 54,000 people with access agreed. If the committee peruses the actuary's reports, the national satisfaction rate, which measures whether participants feel their interaction with the agency to be good or very good, is at 88 per cent and the New South Wales participant satisfaction rating is nudging 90 per cent. Whilst we do most certainly get representations from people who need help and feel that their participation experience has not been all they want, we are working very closely with them and with the agency to remediate those issues. I will leave my opening statements at that.

CHAIR: Do you want to add anything, Ms Schorer?

Ms Schorer: No, I am happy.

CHAIR: Good. I will lead off with some discussion then. A series of issues have been raised with us, and undoubtedly you are aware of them. One of them is the efficiency of the whole planning process with the NDIS and, according to the evidence, the apparent inconsistency of plans of outcomes for people in similar situations et cetera. Do you have any observations about that?

Ms Taylor: We share those concerns. The New South Wales position is that we are in transition. We do not have a full scheme in place, nor will we have that until the middle of next year. The manner in which people who have been in state systems move into the scheme should create, unless they desire it, minimum disruption to the supports that they are receiving now and enable them to have access to information that enables them to understand what the scheme could be for them in the future and adjust their supports immediately if they so desire. We are concerned about what I can only describe as over-engineering of that process for planning with people. The human-centricity of that process is not all it could be, so we have been working with the agency to highlight where we think there are opportunities to improve that planning process.

The committee would be aware as well that disability ministers asked for a review of the planning process, which we are aware the board has been undertaking. I participated in a workshop last week with participants and providers about how to improve the planning process and I was very heartened by the ideas and the way in which the agency was really embracing the ideas that were coming from participants, particularly about how to improve that process. So, yes, we do share those concerns. We feel there is a lot of room for improvement.

CHAIR: And specifically in relation to this inquiry, which is a subset of a whole lot of issues, I think there are at least two common themes that have come through the evidence to us. One is the tension between the approach under the mental health regimes around Australia, which tends to be a recovery oriented approach that looks at the functionality of the participants versus what people perceive under the NDIS, which is a diagnostic approach and has less flexibility. I would be interested in any observations you have about that. If, in your view, that tension does exist, are there ways in which this tension can be resolved?

Ms Schorer: We would certainly agree that there is a lot of work to do about the experience for people with psychosocial disability in the planning process, and there are a number of components to that. Partly it is the experience of people being prepared and understanding, as you have rightly said, that this is more a diagnostic process than a recovery. So we have been working closely with the agency and with our sector in New South Wales to understand how we can work with people in understanding how they can approach the planning process differently. We are not at the scale yet in New South Wales with that particular cohort of participants to have a

real momentum behind that experience. Certainly, understanding more where people access systems rather than it being a disability focus—people who have mental health issues and experience psychosocial disability access services differently. The mental health sector is designed differently. So we need to think about where GPs and other aspects of the health system can better assist with that planning. And understanding how disability planning is done versus how that wraps around people's mental health supports is absolutely a work in progress.

CHAIR: I want to ask you about a concern expressed here today and elsewhere around the country about people who are currently in receipt of services for mental health and will not qualify for service, or receive the same level of service, under the NDIS. What will happen to them? Is it a fair assessment from your experience here in New South Wales that there will be people in this situation, and what is the response to that?

Ms Schorer: I want to make it really clear that for New South Wales there is not any change in what we already deliver in mental health services. None of our mental health funding is going into the NDIS. We continue to provide the \$8 billion, or around that figure, that we currently provide for mental health service provision. The question is really about how the boundary works between the scheme and mental health delivery. As I mentioned before, that is most definitely a work in progress. It will change the way mental health services work with people who have ongoing functional disability. That is particularly the case for people who have really complex needs. The NDIA getting an understanding of how to commission and develop a market for people who need episodic care and move into crisis, and the things that come from that in terms of homelessness and other things, is really where we are trying to work at that closer interface. In particular, we want to think about people who are not aware of the extent of the support that wraps around them and how they articulate that in a plan so that there is not gap in service coming about just because of awareness. So it is about addressing information asymmetry in the planning process but also moving into how to wrap the functional supports in an ongoing way with the agency with support planning and other things. That is very much a work in progress, but we are deeply committed to what we already have and working through the applied principles to make sure that our system works very closely with the scheme.

CHAIR: Is there enough emphasis being given to tier 2 of the NDIS compared to the actual provision of services? It seems to me that that is one area where this interface between state and territory services and the NDIS is going to be quite significant.

Ms Schorer: I would agree with that. I think there is significantly more work that we can do around tier 2—information and capacity building—to really understand the role that that more informal range of supports in the community can have for people who are still grappling with the idea of an ongoing disability but also the more community based and inclusion based supports that come from that tier. We would welcome further work—and I think we have made representations along those lines—to encourage how we might use that, as we have with other programs in New South Wales, like Ability Links, to really understand how to wrap that informal support around people before they need it, in terms of an early intervention principle as well, to enable people to not need intensive psychiatric care or the more significant issues that come with complexity of placement breakdown and family breakdown. So really working at that early intervention is what we are very interested in through ILC.

Ms Taylor: We are very happy to share with the committee a recent final evaluation of the program that Janet has just referred to, Ability Links. That program does not form part of ILC per se in terms of the contributions from government but it is an extremely successful program in New South Wales. It has supported upwards of 40,000 people who have disability—not into the scheme or into special supports but to assist them in getting really creative community based solutions that help them participate socially and economically in their communities. The cost-benefit analysis for that particular program showed that for every dollar the New South Wales government spends on it we were returning at least double that, and in the employment space we were getting back \$1.20. In most social programs even getting an economic return in terms of work, employment et cetera on that scale is very modest. It is quite rare.

Ms MACKLIN: Thank you very much for being here today. I want to follow up on your point about the community based mental health services that are going to continue in New South Wales. It would really help the committee if you could give us a note on what they are. The reason I think it would be very helpful is that, as you can imagine, we have heard a lot of submissions from people who are very concerned about the people who are not going to be in the NDIS. As I am sure you are aware, not each state is doing what you are doing. So it would be very helpful for us to have a practical idea of what that means—not just the line items in the budget and the amounts of money. Could you describe what they do and the sorts of people that you help in that regard? That is the first thing.

The second thing is the point you make—which I think is fair—that it is a work in progress to find the way in which, particularly in this area but in other areas as well, the intersection between health and the NDIS will work.

Given the transition in different places in New South Wales, do you have any good examples of where that is working well? Obviously, we hear a lot of bad examples. That is fair enough, because people are experiencing difficulties. Given your breadth across the whole state, I thought you might know where a hospital psychiatric service, for example, is working in well with the local non-government organisation providing support to a person who is in the NDIS.

Ms Taylor: We have quite a number of examples, balancing off with examples that are not ideal, as you reference.

Ms MACKLIN: You can tell both; we have heard a lot of the negative—

CHAIR: You might want to balance it up.

Ms Taylor: Rather than us trying to take up time talking through case studies today, maybe if we were to give you some of those examples and confer with our health colleagues about how some of that is working. There is some really good work being done, particularly in the Hunter. That launch site was chosen because of the very strong and mature mental health service delivery system in that location. There have been some very interesting collaborations done between mental health, the NDIA and the intersection with specialist disability in the transition in that place.

Ms MACKLIN: As you draw out the examples, could you indicate to us what policy decisions have been made by the state and, probably, also the NDIA, that have made it work. What are the things that should be replicated elsewhere?

Ms Taylor: I am happy to do that.

Senator GALLACHER: I am just not clear: if you are the largest group that will have people transition to the NDIS, are you saying that there are no state resources or jobs that are going to transition into the private sector? In South Australia, there are 700 jobs and 10,000 people under Disability Services that will be—as the minister says—outsourced. Are you saying that New South Wales has a different model?

Ms Taylor: No, New South Wales has been transferring its direct service delivery for a couple of years now. In 2016, we completed the transfer of Home Care Service NSW. That service is now delivered by Australian Unity. It is the largest home and community care provider in the country. That means that we transferred 50,000 clients over to the operator. With their clients have gone the care workers, who continue to deliver supports.

Senator GALLACHER: So they have transitioned from public sector employment to private sector employment?

Ms Taylor: Yes.

Senator GALLACHER: Is that case study available? Do you know how many people—

Ms Taylor: Certainly, we are more than happy to provide you with the details of that particular transfer. It was announced by the government in 2015 and concluded at the beginning of last year, and 4,000 staff moved over. We put in place an employment guarantee period to ensure that, through that transfer arrangement, there was continuity of support for the clients of that service. The care workers continued to be the care workers that would go to their house, shower them and clean their house, et cetera. We did not want any adjustments to that. We are more than happy to provide you with that.

Senator GALLACHER: Has there been an evaluation of the success of that program?

Ms Taylor: No—

Senator GALLACHER: But the transition has occurred.

Ms Taylor: But the transition has been relatively—well, very—smooth, actually. In fact, we have seen five per cent growth already in the workforce under Australian Unity, signalling what they had announced when they took the service on: an intent to grow it, both into the aged care space as well as under the disability reform agenda. If you simply look at growth—

Senator GALLACHER: I think it would be useful, because there are states that are transitioning this year, so to speak. It would be instructive for the committee to know that it has been successful at least somewhere.

Ms Taylor: Yes, and we have also just announced the first tranche of transfers of our clinical services—our therapy support coordination services. That is about 800 staff who will transfer to The Benevolent Society. Off the top of my head, there are 7,000 clients of that particular service that will transfer at the beginning of August this year and be closely followed at the end of this year by transfer of a significant number of our group homes. Announcements have also been made on a number of transfers of supported accommodation and centre-based respite. That is upwards of 1,000 clients and 3,000 workers who will move again with their clients under the same

employment conditions that they have had within the state. Those particular transfers will be concluded at the end of this year. We are in the process for the remainder of our direct services.

Senator GALLACHER: And just to complete the circle, so to speak: you have retained enough staff to service those who do not qualify for the NDIS? So your mental health services are still whole, so to speak.

Ms Taylor: Mental health services as a whole. I think it is important that, in turn in terms of the services that I have just described that we are transferring to the non-government sector, those services have been traditionally funded under programs that have eligibility, or gateway criteria, if you like, that are very similar, if not identical, to the criteria for entry into the NDIS.

There are small numbers that we saw in the trial in the Hunter area of New South Wales and are now in transition who are not meeting the eligibility criteria. They are very small numbers. There are, as we described, mechanisms in New South Wales. We hope under the ILC that we will assist in improving the strength of those people's participation in the community. But they are very low consumers of support. We have done a piece of work which assists in looking at what might work to make sure that they continue to get a level of assistance and social engagement that they need, even though they may not participate in the scheme.

Senator SIEWERT: I want to go to the issue of the change in plans in the review process. When we had our hearing in Canberra last week there were a number of people who said their plan had been reviewed and had had their funding cut back. In terms of the Hunter as the area where, as you said, the NDIS was first being rolled out, as they have come up to their plan review have the plans been cut back to a large extent?

Ms Taylor: From a state perspective, we actually cannot see that data. So I just preface my response with that note. However, we have looked at where people have had a number of different iterations of their plan. We had a look at about 8,000 as a sample. Over the number of people who have had more than one plan in their participation in the scheme in New South Wales, out of 8,000 people only 10, from what we could see, had had a financial adjustment downwards in their plans.

Senator SIEWERT: When did you do that review?

Ms Taylor: We do it kind of ongoingly. There is an issue—

Ms MACKLIN: Can you say that again? What was the number?

Ms Taylor: Out of 8,000, 10 people—that we could see. I think there is often an issue from the representations we get with the planned outcomes of the initial point of first plan, which means that people may not be having their support—I am talking about existing clients; people who are new to the scheme are difficult for us to interpret. So if we can stick with the pre-existing. We think there is an interpretation issue. And Janet described how sometimes people do not always know how to articulate the supports they get—whether, in fact, they are funded supports. They certainly do not necessarily know their value. But we think there is a translation issue in the first plan from people's current supports to what they get in their first plan. Some people are deeply distressed about that and seek assistance from New South Wales to help them work with the agency to resolve that, which we do. We have teams of people who work very closely with individuals to negotiate that during the transition phase. We generally get pretty good responses from the agency on that. It might not always be the first review point—it might be the second one—but generally speaking people get on an even keel.

I think there may be some issues about not necessarily the initial plan value but whether or not initial supports before people participate and the level of the plan give them the degree of continuity that they require. But certainly, when we have looked at the data, we have not seen mass financial reductions in plan values at all—if anything, pretty significant increases.

Senator SIEWERT: What about from 1 July 2016?

Ms Taylor: We can only look across the whole set to see whether or not there have been reviews that people have requested since 1 July 2016. I am talking about everything in that.

Ms MACKLIN: In that number you just gave us?

Ms Taylor: Yes. We can certainly provide you with our view on that. It is untested with the agency. We can only look at the high-level data to make that assessment. I can give you another example where we have done some work with some children who are in state voluntary out-of-home care, working with the agency to review their plans to make sure that they have satisfactory resources within their plan to enable a family restoration, for example.

We have had stunning results with that and significant uplifts in plan values through that review process that is going to enable some of those children to not be in that voluntary out-of-home care setting any longer. We are

doing that pilot with a view to sharing the results of that nationally and building up good practice in that cohort of children—and, indeed, adults who are complex cases.

Senator SIEWERT: When does that trial finish, and is it possible to give the committee some more information on it?

Ms Taylor: Certainly. We are more than happy to give the committee that advice in the coming months.

Senator SIEWERT: That would be appreciated. In terms of the comment that you made about not actually seeing the plan and getting the high-level information in terms of the plans being reviewed and their outcomes, can you compare the whole of the package or just the actual dollar value? I am thinking of in-kind supports and things like that.

Ms Taylor: I will have to get back to you about what we can actually provide. I would not like to put a view in the minds of the committee members, given my limited numeric capabilities, but I am happy to provide you with information about what data we do get.

It is an evolving process. We are aware that the scheme actuary has been spending a significant amount of time building up the data warehouse that would enable jurisdictions to get the depth of data that we got in the trial environment, which was basically everything. That is certainly improving, and we are getting a much better view to enable us to do that comparative analysis back against what supports people have had.

Senator SIEWERT: That would be appreciated. On Friday we got information about the use of agency managed funds compared to self-managed funds, and one of the concerns we heard from individuals on Friday was that the agency managed funds, for example, were not necessarily all being spent and that then impacted on their next year's funds. We had a direct comparison when we heard from a lady who self-managed one of her children and whose other child was agency managed. From the information we were given, there was a significant difference between the different types of management. Do you get to look at the self-managed funds and the agency managed funds at the moment?

Ms Taylor: I would have to get back to you on that.

Senator SIEWERT: If you could, that would be really appreciated.

Ms Taylor: We certainly have had representations in the past, which were resolved, about people on New South Wales programs who self-manage and continue that self-management. But that is an interesting issue that I had not heard before.

Ms HUSAR: You mentioned that you are in the process of transferring Home Care to Australian Unity and the clinical support to the Benevolent Society. Can you describe who is taking over the group homes. Is it one provider, or are they going to multiple service providers?

Ms Taylor: Multiple service providers. We put to market groups of our accommodation services, grouped in a way that made sense in terms of the management structures, so we were not breaking too much of the management layer and therefore some of the clinical supervision layers et cetera. In terms of the current announcements that we have, we have five NGOs that are taking on a range of different services. They range from organisations that are taking on just one single geography—in the case of western New South Wales and the group home cluster there, one single service formerly known as CareWest and now known as LiveBetter Community Services, will be taking on those houses. In northern New South Wales, Sydney, New England, Illawarra and southern New South Wales, House with No Steps is taking on a variety of clusters of group homes, for example. We are happy to provide the committee with the other NGOs that are publicly announced, and we are actively working with those organisations at the moment to effect that transfer.

CHAIR: As there are no further questions, can I thank you very much for coming along today and for the discussion. If you could provide the further information that the committee sought—what is available—within the next couple of weeks would help us in terms of the timing of our inquiry. Thank you very much for that. The committee will now proceed to its public discussions.

AYOUB, Mr George, Partner, Lifestyle Directions Pty Ltd; and Private capacity
BALDACCHINO, Ms Sharon, Director, Listening and Spoken Language Services, The Shepherd Centre
CALLAGHAN, Ms Ruth, General Manager, Stakeholder Relations, Northcott
CARPENTER, Ms Aleta, Business Development Project Officer, Northcott
CAVALLETTO, Mr Bart, Director, Services, Royal Institute for Deaf and Blind Children
CUDDIHY, Ms Caroline, Chief Executive Officer, Sunnyfield
CUSACK, Ms Stephanie, Accountant, Autism Advisory and Support Service
DALE, Ms Narelle, Executive Officer, EMPOWERability
FAVA, Ms Grace, Founder and Chief Executive Officer, Autism Advisory and Support Service
HAILES, Ms Casey, Executive Manager – Client Services, Afford
HARPER, Mr David, Strategic Business Analyst, Stakeholder Relations, Northcott
HEATH, Ms Denise, Chief Executive Officer, Nepean Area Disabilities Organisation
HUNGERFORD, Dr Jim, Chief Executive Officer, The Shepherd Centre
INGRAM, Ms Andrea, Private capacity
KARP, Ms Berinda, Founder, Autism STEP Australia
LOWN, Ms Sharon, Government Partnerships and NDIS Manager, Royal Institute of Deaf and Blind Children
MILNE, Ms Cathy, Team Leader, Autism Behavioural Intervention NSW, Assessments and Behaviour Interventions
MOORE, Mr Craig, Chief Executive Officer, Interaction Disability Services
NAING, Ms Cathy, Private capacity
NOPERT, Ms Jessica, Private capacity
PALMER, Dr Damian, Private capacity
PALMER, Mr Ray, Executive Officer, Riverlink Interchange Inc
PATHER, Ms Prithi, Private capacity
RANGI, Mr Kevin, Director, Therapies for Kids
ROBERTSON, Mr Don, Private capacity
ROBERTSON, Mrs Lesley, Private capacity
TAME, Ms Susan, Senior Manager, MS Care, MS Australia
VARGA, Ms Leanne, Systemic Advocate and Leadership Facilitator, Family Advocacy
VINE, Mr Mat, Chief Executive Officer, Plan Management Partners
WAY, Ms Melissa, General Manager, Community Connections Australia
WERNER, Ms Sue, Networks Manager, Community Connections Australia
WICKS, Ms Kylie, General Manager, ParaQuad New South Wales, ParaQuad Northern Territory, BrightSky Australia
WRIGHT, MS Ruby, Early Childhood Intervention Manager, Connect Child and Family Services Inc

[13:27]

CHAIR: Ladies and gentlemen, I will resume the committee's hearing. Can I welcome everybody who has not joined us before today. I remind all that these are official parliamentary proceedings. A *Hansard* record will be prepared and the discussions are being broadcast.

We have roving microphones for the purpose of the discussion this afternoon, so if you would like to contribute to the discussion please raise your hand and one of the staff will bring a microphone to you. Could I ask all those contributing to the discussion to not divulge confidential, personal or identifying information during your contribution. If you wish to supplement anything you say today with written information, that can be forwarded to the secretariat after this hearing. Our session will examine general issues of the NDIS operations and discuss people's experiences or interactions with the scheme.

Can I also say that not all members of the committee can be at every hearing, but all of us cover a variety of hearings and we all get the opportunity to read the *Hansard* record for those we are not at. On that note, I should say in advance that because of another commitment in Melbourne I have to leave at 3.15 pm and I will hand over to the Deputy Chair at that stage. We all will read the *Hansard* record.

This is essentially a listening exercise for us on the committee—listening to your observations and experiences. Because there is a large number of people I suspect will wish to contribute, could I ask you, if you can, to limit your contribution to about three minutes. Even with three minutes it will take us all the time we have plus more than we have available to get through what is being said. You should be mindful of the fact that we heard last Friday from a large number of people in Canberra who are participants or providers in the scheme, and we also heard some people in Melbourne, so I suspect that many of the issues that will be raised this afternoon have been raised with us before. So you do not have to feel like you have to speak at great length. It may well be that the committee has already heard particular matters, and you will be reinforcing them rather than bringing them up for the first time. On that note, if you agree with what somebody else has said and simply say, 'I agree with the previous contribution,' we will take it that that is not limited to the four or five seconds it takes to say that but involves everything else that other person said. I am saying that not to cut down on the discussion but to try to facilitate everybody who may wish to contribute being able to do so this afternoon.

On that note, I ask if someone would lead off and make a contribution. Do not be shy. We do not bite.

Mr Moore: I am the CEO of Interaction Disability Services. Thank you for the opportunity to address the committee. The maturity of a society is often gauged by how well it cares for its most vulnerable, disenfranchised and disadvantaged citizens, and the NDIS demonstrates Australia's commitment to all its citizens. Interaction fully supports the NDIS.

Interaction is a generalist and specialist disability provider, predominantly covering northwestern Sydney. Interaction's specialist support is for people with Prader-Willi syndrome and is internationally recognised, and we are currently expanding interstate. We are a registered NDIS provider and are well prepared for the NDIS. Our governance and systemic processes were ready, and Interaction has now transitioned 95 per cent of its existing clients into the NDIS whilst increasing its market share through supporting new participants into the scheme.

Our most significant concern is that the NDIA has developed non-contextual pricing. In our view, this has happened because of what we believe is a failure to engage wholly with service providers on planning and pricing. This is a misplaced philosophical position based on assumptions that service providers will inflate prices. These assumptions have never been tested. An example of non-contextual pricing is the significant restriction in what is claimable under the NDIS for a psychologist. The funding gap has been borne by providers, which is not sustainable for all parties.

Interaction has a large team of psychologists. They provide assessment, behaviour intervention support plans, skills training and therapeutic support to people who experience challenging and/or other behaviours, their families and our staff. The breadth of their services is needed to enable the participant to interact with the community without significant support. Well planned and funded intervention of these support services facilitates the NDIS's intended insurance outcomes of reducing funded supports in the longer term.

Interaction has a number of clients with very complex needs. The number of hours provided for in plans is now significantly less than needed. For example, a teenage boy that was receiving 300 hours per year is now reduced to 22 hours per year. In addition, the pricing is confusing and mainly limited to face-to-face hours. This limitation means that essential and required tasks—such as report writing, service formatting of behaviour intervention support plans, individualised pre-reading and research, coaching of staff, coaching of families and so on—is not covered. Interaction's psychologists require 44 claimable hours per fortnight to support their role within the organisation. That 44 hours requires another hour or two besides that to actually do the task, which means they do not have enough time per fortnight to actually do the job that they are supposed to do.

I would also submit that non-contextual pricing has other, unintended consequences. For example, the NDIS pricing structure reduces the ability of organisations to attract and induct the expected injection of new staff into the sector. In that regard, skills atrophy has been observed in overseas jurisdictions that have implemented

initiatives similar to the NDIS. Investing early and establishing a system where people can access appropriate training reduces participant risk, staff risk and organisational risk.

Finally, Interaction is investing in its Prader-Willi expertise by bringing out international experts Dr Hodebeck-Stuntebeck, chair of the international Prader-Willi carers board, and Dr Hubert Soyer to train key people in best-practice supports and outcomes for people with Prader-Willi syndrome. These doctors provide training throughout Europe. This is unfunded, and only made possible by the long-term investment of Interaction in the future of the Prader-Willi syndrome community. Solely funded under the NDIS, this would not be possible.

The NDIA must reassess its approach to training and the inclusion of this in pricing and scheme design in future rollouts, for the sustainability and longevity of the NDIS. Thank you.

CHAIR: Thank you, Mr Moore. Who would like to be next?

Dr Hungerford: Good afternoon. I am Jim Hungerford, the CEO of The Shepherd Centre. We are an early-intervention service, providing support for families who have got children with hearing loss and making it possible for those children to learn to speak. Our concern as to the Western Sydney rollout is: we have got our largest centre in this area, and it serves many families who are disadvantaged and who struggle to engage with mainstream services. With the transition provider arrangement in New South Wales, we are required to support those families through their planning process and to then come up with a draft plan which is then enacted by the NDIS. We are required, under the procedures that have been set upon us, to produce a plan that inherently will not enable those children to achieve spoken language, because of restrictions that require us to put forward only plans that are less than what are required by the families, and, as a result of that, unless we find some other way to fund our activities, we will not be able to support those children to achieve spoken language. In addition, the systems of the NDIA do not recognise the challenges that these families are under and the difficulties of engaging them with services and also of things like trying to do planning over the telephone and not face to face, with insufficient cultural support for challenged families. Thank you.

CHAIR: You say you are required to put forward plans that only deliver less than what is required by the families. Can you elaborate on that—as in, by whom and how are you required to restrict those plans?

Dr Hungerford: In New South Wales, the government has contracted a number of early intervention providers to become transition providers and to do the planning for families that are within the early intervention/early childhood process. The planning restrictions that are put onto us limit what we are able to recommend for any child, and we are unable to recommend the support that a child needs within those limitations—we are unable to recommend the support that a child needs to achieve spoken language.

CHAIR: Perhaps not now, but could you forward to the committee an example or two of what, in your assessment, the child requires versus what you are restricted to providing?

Dr Hungerford: Absolutely; we will follow that up.

CHAIR: Thank you. Who is next? Yes, the gentleman right down the back. In what capacity do you appear today?

Dr Palmer: My name is Damian Palmer. I am here in a private capacity. I thank the committee for this opportunity. My 17-year-old daughter, Bethany, has a profound intellectual disability and became a participant in the scheme in early November last year, and I am an academic with research interests in disability. My comments are about the planning process, drawing upon both my personal experience and my research.

We had a planning meeting with a local area coordinator in late October last year. When we received a copy of my daughter's plan in early November, it was full of surprises. It included funding for supports she does not require, and did not request, and it was missing funding for essential supports. For example, she is tube-fed, but there was no funding for the required equipment.

The statement of goals bore little resemblance to anything said in the planning meeting, and there was no clear explanation regarding the decision-making process that had led to the plan we had received. I sought clarification about the decision-making process, but, with no direct access to the planner, this proved to be a fruitless exercise. The absence of funding for tube feeding equipment, underfunding for my daughter's self-care needs, and a number of other problems left us with no choice but to submit a request for a review in February.

I had two phone conversations with the planner responsible for conducting the review. During the first conversation, I believe I was threatened, and, in the second, she terminated the phone call. Her hostility towards me appeared to be a response to my request for clarification on a number of issues. The end result of the review is that the total value of my daughter's plan is now considerably more than it was in the original plan; a somewhat surprising outcome. On the surface, this sounds like a good news story, and we are pleased with the funding made

available in the reviewed plan. However, I have no idea what set of decisions produced the first plan in November, nor any more idea as to how the reviewed plan was produced. Therefore, I do not know how decisions will be made next time my daughter's plan is reviewed.

There is a level of uncertainty in this that is deeply troubling. The inconsistencies and lack of transparency around the planning process lead to significant levels of frustration and anxiety for families such as mine. In fact, I would suggest that the use of the term 'planning process' is itself problematic. When we use the term 'planning process', we need to be clear: are we talking about the process outlined in the NDIS Act and the NDIA's own operational guidelines, or are we talking about the so-called first plan process adopted on 1 July last year before rollout. I would suggest that these two are not the same. The first plan process, with its use of reference packages and other mystical processes, is a truncated version of the legislated planning process, and is:

contrary to the objects and intent of the NDIS.

That is a quote from the Civil Society statement put to COAG and the agency in December of last year. Unfortunately, I do not think this distinction is being properly recognised in the current conversations about the planning process. For example, the Productivity Commission's issues paper for its inquiry into NDIS costs fails to recognise this distinction, and conflates the two planning processes in a confusing manner. It then asks a series of questions about the planning process. The failure to distinguish between the two different planning processes could lead to misleading results, when the submissions made to the Productivity Commission are analysed, and it will be interesting to see if this is the case when they release their position paper later this month.

In addition to this confusion regarding two distinctly different planning processes, the lack of publicly available information on the first plan process and its use of reference packages and assessment tools makes it extremely difficult, if not impossible, for any individual or organisation to make an informed response to questions such as those being asked by the Productivity Commission. We simply do not have access to the necessary information. I would encourage this committee to request that the NDIA make the necessary information available for the sake of participants in the scheme who remain confused and frustrated by vague fact sheets, inconsistent advice, and a bewildering process, and for the sake of those who wish to offer feedback as co-producers in a scheme that offers so much. Thank you.

CHAIR: Thank you, Dr Palmer.

Mr Ayoub: My name is George Ayoub. I am here in a couple of capacities. Firstly, I am a partner in an organisation that manages lifestyle directions—we support people with their plan management—but I am also here in my own capacity as a service user. I have had a disability for a long period of time. I transitioned through Addax to a direct management plan. I manage my own service, and I am really happy with that. I find that it is great because it gives me the freedom to choose what I do and when I do it and to make full access to the community. However—there is always a 'however'—currently I am waiting on equipment. When I put my plan in, the LAC who came out said, 'Well, we will put this equipment down on your plan, like a new wheelchair, a new seat and a new bed.' This is to give me comfort and the ability to move, to be able to function. The delay that I have been facing has not changed—the issue around disability—for the last 40 or 50 years. The delay is significant. What it is actually doing is it puts further pressure on the funding that I have with my services. The delay that we are finding to receive specialised equipment is making it harder for us.

I work in the community. I have lots of friends with disabilities. One of the things that we have in common is that people who are facing a plan by an LAC seem to find a lot of gaps, especially around access to equipment. However, if we went through an NDIA planner—a lot of the people who went through these planners are getting what they need. So there is injustice there at the beginning: the ones who go through an LAC are getting lost in the system—which has not changed in my 40-odd years of being involved in disability—while those who get planners are getting what they need. I hope we can address this, because the NDIS is really for us, for people with disabilities, who want to be a part of this great society and to give back. We need support to give back. I know the support we give back is quite good. So for it to work, we need everything to work, not holding back where they are holding back.

CHAIR: Thanks Mr Ayoub. Yes—down the back?

Ms Tame: My name is Susan Tame. I am from Multiple Sclerosis, and I am representing people with multiple sclerosis and other neurological disabilities. MS supports the introduction of the NDIS as contributing to significant transformation of the disability sector. MS has been involved since 2013 in supporting the application of the NDIS for people with neurological disability. Since 2013, people with multiple sclerosis have been receiving greater access to funded supports under the NDIS, and the lives of individuals and families are changing. But, with the introduction of the full scheme last year, MS has to acknowledge that the experiences of

people have declined—their experiences have not been positive or adequate—and that the application and administration of the scheme has not been friendly or consistent. It has challenged and frustrated many of the participants, their families and our workforce.

Negative experiences range from initial planning through to application of plans from the LAC and review processes, with adverse practices and processes hindering the successful introduction and acceptance of the scheme. Our examples are similar to Mr Palmer's. Many of our families are experiencing confusion, frustration and inconsistency, and we will submit a lot of these examples to the secretariat, as you suggested. But, overall, MS supports the recommendations of the National Disability Services paper of May 2017, *How to get the NDIS on track*.

Mr Cavalletto: I would just like to support Jim's comments about the evidence that exists around early intervention and the outcomes for children with a hearing loss. Jim, that is well acknowledged, as we know, in previous government reports. What we are finding is: the evidence indicates that a transdisciplinary model and a team model are what achieve some of those best results. We are finding that the sessional funding basis is very difficult to apply across that board, as a previous speaker said in a different forum.

What we are finding is that organisations are really having to meet that gap between the packages that are provided, which, again, as Jim said, really do not meet the overall costs that have been identified. This is really placing quite a significant burden on organisations to meet that gap, and we are seeing that with our colleagues across the country who are really struggling—particularly some of the smaller operators—to continue to provide those services as they do not really have any cash reserves in that area.

Mr Rangi: Therapies for Kids is a specialist paediatric allied health practice which advocates strongly for early intervention for young children. I would like to endorse the comments made by the previous speakers and the sentiments that they have expressed. In particular, we have witnessed a number of inconsistencies where client patients who have the same condition and severity grade and who should receive the same intensity and regularity of treatment in fact receive marked differences in funding for the treatment.

We have been able to compare what one participant has had approved for a recommended treatment and frequency of treatment to what another participant who has been approved to achieve the same or substantially similar clinical outcomes, and there are obvious and large variances. With these client patients, the quantum of dollars approved in the participant's plan would appear to be of little relation to the patient's clinical needs. The only other variable factor is that the LAC personnel, the NDIA planner or both have little or no appreciation of the clinical requirements of the participant they are assessing.

When we have questioned the parents or caregivers about the process they experienced which resulted in what they have received in their approval, the answers we received indicate that it is dependent upon who they have allocated to assist them from the LAC pool and who they finally get as their NDIA planner. Where either of these persons have little or no clinical expertise, the ability to competently assess the ongoing and future clinical needs of the child is compromised. An observation has been made that, in the initial stages, the LACs and planners were discouraged from being influenced by clinical reports provided by service providers. Hopefully in more recent times this hard line may have softened. Thank you.

Ms Callaghan: Northcott is a major provider in New South Wales. We work across the lifespan with people with disabilities and their families across a whole range of issues and experiences. What has come out already is something that we want to highlight. There are two elements. One is that, with a major and much needed reform like the NDIA, you are always going to have unintended consequences, and I think some of those are now being experienced as we rollout a much bigger and fuller scheme. I think there is a real opportunity for government, the sector and people with disability to really engage with this stuff and fix it now, because I think long term there is a risk it will undermine the absolute intent of the scheme. Also, if we address some of these pricing and skill issues now, it will in fact save the government money. It is win-win, if you want to put an economic rationalist hat on.

Our experience and that of our many customers is that the pace and complexity of the rollout means that we are having to respond to and navigate, all the time, unintended or unidentified consequences, whether that is around staff resources, our own internal systems or customers getting quite clearly inappropriate and not appropriately priced plans. Some of the major things we are experiencing at the moment are responding to families where LAC support is unavailable or where LACs may not have the knowledge or experience required to respond to customers. I think, with all the best intent in the world, there really is a lot of evidence now that the LAC workforce do not have the skill and capacity, often, or potentially the bureaucratic support from NDIA that they really require to customise plans to meet the needs of the very people the scheme is to benefit. You have heard that today. That is coming across fairly clearly.

One of the other things—and it goes to the Productivity Commission work that our friend up the back mentioned—is some of the issues around pricing. I will not go into great detail but there are clearly emerging issues around economic assumptions that were made that might apply well to efficiency on a railroad, but, when you are dealing with major human service systems and change process, the way some of that is panning out means that providers, out of absolute commitment to and best interest for people with disability and their families, are in a sense absorbing some of those costs. Long term, it will not continue to be possible. Again, people have already raised a couple of very clear issues. We have our own. I am happy to hand over some material. It is a great scheme and a fantastic reform but we really need to start addressing some of these pricing and planning issues right now, because they are going to get away from us really quickly.

CHAIR: Thanks, Ms Callaghan. If there is material that will support what you have been saying, then please forward it to the secretariat. It would be useful. The lady up the back is next.

Ms Fava: I am the founder and CEO of Autism Advisory and Support Service. I am also the proud mother of two boys with autism, so I am here in both capacities. I was very hesitant when the NDIS was originally sold, because I am a bit of a realist. I knew there was no great pot of money, but I embraced it, because I thought, 'Anything has to be better than what is out there at the moment.' Sadly, my fears have been realised. We are based in Liverpool, which is southwest Sydney, which has the highest CALD population in Australia and the lowest socioeconomic economic population in Australia. Most parents of children who we serve have either mental health issues or their own disabilities and English is not their first language. So we have a nice little cocktail of complications out our way. Because of the cultural mix, we have a lot of genetic issues as well.

Our local office is Liverpool, which is wonderful! They are one of the only offices that do not have a phone system, so you cannot actually call in. You can to any other office in the state but not Liverpool, because they are so busy. We were sold my first plan because they found that they had underestimated the need in southwest Sydney. They hugely underestimated the need, so they pushed out my first plan. As a mother, I can tell you we did not get even close to what my children were getting before the NDIS. But I let it go because I thought, 'There are worse off than my kids.' I realise that is the worst attitude to have, because every child is as important as the next. So I put in for a review and I was told, 'If you put in for a review, even though you have evidence of what you had before, you may actually get less than what you are getting now.' All of our parents are being told that, even for administrative anomalies that are part of the NDIS, it is their administrative error. If, on behalf of our families, we say to them, 'We would like a review put in. Please just have this changed. You made the mistake. Change it from self-managed to agency managed,' that needs a full review, and this family may end up with less money.' So it is kind of like a veiled threat: 'Don't even go there. Don't hassle us'—remembering who our prime clients are.

The planning questions are not aimed at those with invisible disabilities like autism, and like intellectual delay, they are primarily aimed at those with physical disabilities. So when a participant goes to answer questions they are not even relevant. And there is nowhere that you can say, 'No.' The only thing that you can say is, 'Sometimes,' and it is not even sometimes. Our children cannot do these things at any time, but you cannot say that. Therefore, the plan starts off to not represent what that participants needs are.

You have little glitches in the plan, so you ring up the NDIS and you say, 'Can you please clarify what this means? Send me and email,' or you email them, 'Can you clarify what this means?' They ring you back. Nobody will give you an official answer. If you speak to 10 people you will get 10 different answers. The rules seem to be changing as we are going along. I can handle that. Send me the guidelines—no-one can send me guidelines—because we at least want some sort of a basis to run off. Again, remembering our clients: they are the most vulnerable in the country.

When our families go in to do their plan they say, 'We're currently receiving music therapy,' planners are saying to them, 'You can't do music therapy. We've run out of money. You can't do that.' First of all, music therapy is an NDIS recognised therapy. They tell a families: 'You can't do that, because we've run out of money.' It is not just one or two families that we have heard. I have been in the office when this has been told to our families.

We have had planners who come from backgrounds in insurance and backgrounds in banking—we have even had a vet do a plan, which is wonderful—but they turn to us and say, 'What is autism?' How on earth can you plan for this person—sorry, I am getting passionate—when you do not even understand what this person's life is about? It is not just one or two. We see that it is like a lotto. You win the lotto if you get a planner who gets what you are going through and who gets what your life is about. Even with us in the room, if you have a local area coordinator with you in the room, it then goes off to a planner. If they do not get the information that they are told then you do not get a meaningful plan.

From my own personal experience, I was given a 45 minute telephone interview to do two plans. Neither of those plans reflected either of my sons' needs. I have a 13-year-old. In the part where it says, 'about my life,' it has five lines, none of which said that I need to wipe this child's bottom, none of which said that I need to shower this boy and none of which said that this boy has no awareness of safety. Nothing of his needs were reflected in this plan. We ended up with a very mediocre plan—a very poor one, in fact. Again, I was very hesitant to appeal that, because if you appeal you could get less. You may get more; but you could get less.

I would like to see this changed for the better. The premise is good. I think it can be better. I would like to see two streams. One for those with a physical disability and one for those with an invisible disability. If we are going to do this, let us do it properly. Let us make it meaningful, because right now all I see is a leaking boat with lots of band aids all over it, if we can make the questions meaningful to reflect the needs of the participant and if we can make sure that the funding is not dictated to us by planners, who have no idea of what they are saying. I will give you an example of this. We have a non-verbal client who is 16 years of age and is always being suspended from school for behaviour issues. He has autism, among other things. He received \$6,000 for therapy. He received \$20,000 for core supports that will enable him to access the community. This child does not have functional behaviour to access the community. What we should have done instead is either get the \$20,000 in therapy to give him those tools, to give him the functional behaviour, or say to the parents, 'You've got \$26,000. What do you want to do with it?' That would be a more meaningful thing, but right now our families are dictated to—'No, you cannot pour any money from one section into another. If you want to do that, it needs a full review.' Even if you do not want any more money, with a full review you may get less money. I can give you countless examples of this. It is a nightmare in our area.

We have a transition rate of 15 per cent. Our funding finishes on 30 June. I see heads nodding. We are told that we have to still support the 85 per cent who have not transitioned on barely any money. This is not sustainable. Thank you for listening.

CHAIR: Ms Fava, thank you for bringing those examples to our attention.

Ms Karp: Good afternoon. My service is Autism STEP Australia. I am a new provider. I will give you a bit of history. Some people in the room know me. I was one of the TAFE cuts, so I reinvented myself. As a new sole trader, I have over 30 years experience of working with people with disabilities. I have four degrees. I am enrolled in a PhD. I wrote most of the courses for the qualifications for support workers and taught those over the last 30 years. I looked at the portal to register myself and followed the little guidelines that went from here to there. One module took me six or seven hours to fight through. I found that, for registration as a behaviour intervention specialist, I needed to register with some people in Melbourne. I sent them my 13-page CV and all the information on my certificates and got a lovely reply saying, 'Thank you very much. You have lots of skills and experience, but you don't qualify to be a behaviour intervention specialist under the NDIS.'

I am really pleased that there is a gatekeeper and I am really pleased that there is registration to keep the shonky people out, but there was no room for me to apply for RPL or to look at how my registration and how my skills and experience could be translated into being a behaviour intervention specialist. I have been employed by ADHC over the last 10 years. I work with people with very challenging behaviours who are on the autism spectrum and have intellectual disability, but there is no room for me to register. Also, with the registration process, the TPV costs went from \$2,000 to about \$8,000 within days because of the changeover in the portal. That is beyond me at the moment because I do not have an income. I found a way around it. My question is, firstly: how can there be movement for the registration and some flexibility by an authority? Also, the TPV costs are prohibitive for me as a sole trader. My way around it is that I encourage people to self-manage and they can directly engage me. I am also in contact with a couple of companies that I am subcontracting through. That is okay for me; I have the nous to do that. There are a lot who do not.

As others have said, the plans for the clients that I have at the moment all require review. I gave the parents and the clients full guidelines of what they needed before they went to their meetings with the LACs and it appears to me that the LACs have little idea of disability support needs, how to read and understand psychometric and psychological reports or what a person may need. I understand they are to take on the additional role of support coordination. I have heard around the traps that there will not be any funding for independent support coordinators; the LACs are going to take this role on. How can they do this when they have no idea about the approach that service providers require?

I have one client who I believe is suicidal. At the moment, his funds have run out for a psychologist, behaviour intervention support and anything else, and I predict that he will follow through with his suicidal tendencies, but there is no support and the family have no money. I have another client who was totally funded, like Grace and others just said, in the wrong section. We have requested a review in the hope that he will not lose any funding.

This client does not need a whole pile of funding in one area; he needs it in the other areas, but we have been told it needs to go through the process.

I am really pleased about the registration process for providers. I am really pleased that there are going to be some qualifications seen. When we wrote the courses 30 years ago, we approached the industry and said, 'This needs to be a minimum qualification,' and, lo and behold, 30 years later it is coming into place. There is a whole lot of catch-up to be done.

I am not going to mention the portal.

Ms MACKLIN: Go on!

Ms Karp: Okay, I will mention the portal. All I can do on the portal is register. I cannot do anything else with it because I cannot register in the categories that I need to as a private provider. As I said, there are people in this room whom I have worked with over the years. They have been my students and they have been my colleagues. It is very disappointing that my skills could go to waste when I have a passion for working with people on the autism spectrum and people with disabilities. Thank you.

CHAIR: Thanks, Ms Karp.

Ms Cuddihy: Good afternoon. I am pleased to contribute today in my capacity as CEO of Sunnyfield. We are a family member based, not-for-profit charitable organisation with a trusted 65-year history of supporting people with moderate to severe intellectual disability. Sunnyfield provides support for over 2,000 clients across New South Wales and the ACT and employs over 1,200 staff. Sunnyfield and I personally are proud to advocate for the rights of people with disability and their families. Sunnyfield actively contributed to the campaign to bring about the National Disability Insurance Scheme and we are a champion of the successful and sustainable introduction of the NDIS throughout Australia.

There are many aspects of the NDIS that are working well. However, if Australians truly want the NDIS to be successful and sustainable for people with disability and their families and to become a best-practice model for other countries to utilise, as a society I believe we need to be mature and constructively critique this new scheme, identify areas for improvement and make improvements for all involved. There are a number of aspects of the NDIS that are not working well, and you have heard a number of them so far. Most clients with a disability and their families do not get to comment or agree on their NDIS plan. It would be nice for them to be able to sign it off and agree to it. It is given to them and it is incorrect, it must be first activated and used and then a review can be requested, and maybe, many months later, the plan may be changed. It was stated by state government representatives in 2015 that no-one would be worse off under the NDIS compared to state based funding. However, there is a large number of people with very complex needs who are getting much less funding and it is insufficient to support their daily living needs and reach their NDIS goals. The amount of additional evidence and hours of work for not-for-profit providers who are prepared to do this, to champion for each of these clients to get their NDIS reviews, is enormous particularly when providers are already overwhelmed assisting and transitioning clients into the NDIS.

NDIS plan goals are inconsistent and in some cases non-existent, making it difficult for participants and providers to know what needs to be done over the duration of the plan. Low NDIS employment participation rates to date are leading to higher unemployment rates for people with disability, in total contrast to the NDIS objectives. This is not a good outcome for society or for people with disability and their families. Australian disability enterprises, which already struggle with financial viability and exist purely to employ 20,000 Australians with disability, are being put at even greater risk, with the NDIS potentially being the catalyst for their demise and significant job losses for people with disability. The NDIS disability support Quality And Safeguarding Framework needs to be introduced urgently to put in place national quality assurance and participation safeguarding to protect this vulnerable group of Australians.

For families, carers and guardians NDIA systems and processes are complex and very difficult for clients particularly with intellectual disability. They are especially difficult for elderly families, new families and those participants with no family or carer or who are receiving guardianship from Trustee and Guardian. There is insufficient or no clarity on what evidence participants need to provide to commence their planning. I agree wholeheartedly with other comments that it would be great to have clear guidelines around that. This again has negatively impacted people's guaranteeing of their maintenance of funding.

There appear to be no specialised facilities of last resort for clients with intellectual disability whose support needs are very complex and so great that their families, in desperation, relinquish their care and where support and professionals are put at risk in delivering health care needs and daily supports. There still remains for many in our society, and especially for those with disability relying on the disability support pension, a significant lack of

affordable housing. The NDIS Specialist Disability Accommodation Initiative is three years too late, with many unknowns and potential risks with little impact on increasing housing to date. Disability support providers are primarily not-for-profit charities that operate with very low margins, if any, and small reserves. These organisations have invested heavily to make the NDIS work, with new organisational systems, processes and resources, and little if any funding for that. This makes a challenge for those organisations.

It is important to note the NDIS pricing. It has been mentioned, and I would like to specifically say that one-to-one supports at \$42.79 per hour for Monday to Friday daytime base rate is too low. It is insufficient. I would compare it with how the state government has been funding the sector, and also, if you have a look at comparisons to the funding of home care, home care has a deregulated pricing regime and the charges there are \$46 to \$50 an hour. People are respectful that this is taxpayers' money, but this also needs to be sustainable and also sufficient to provide quality and safe supports for clients. Many clients are receiving transport allowances of \$2,500 per annum. This is also insufficient. Not all people with disability can utilise public or private transport or subsidised taxi transport. A high number of people with disability do not have the capacity to travel safely independently.

The bilateral agreement between New South Wales and the federal government is very ambitious, with many clients from New South Wales year one, region one, planned transition, still yet to transfer, with only six weeks to go until the end of the financial year. However, state government funding is being cut off on a percentage basis to zero for that region by 30 June. Obviously, good practice is for families to have time to understand and prepare their NDIS transition, to exercise their rights of choice and control, to decide on their support arrangements and also, of course, to be able to sign and agree with their new contracts. Time is running out and it is very ambitious to do this and it could create funding gaps for disability organisations, who then have big gaps in their cash flow.

Sadly, the NDIS portal is cumbersome and clunky. It is a time-consuming and unfriendly system for all involved. Ringing the NDIA is also a challenge. Centrelink has a new rival in waiting times for getting through. I do thank the NDIA for holding the very first provider feedback forum in April in Parramatta.

In conclusion, I ask that the NDIA and state government work collegially and inclusively with organisations that deliver supports for people with disability, like Sunnyfield, to understand the issues and identify a range of options to address and implement improvements, in addition to working closely with and for people with disability, their families and their carers. Sunnyfield, like many other charitable support providers, are committed to collaboratively making the NDIS work because we are absolutely committed to creating good lives, of their choice, for people with disability and their family carers. Thank you.

CHAIR: Thank you, Ms Cuddihy.

Mr Robertson: We are the parents of a 50-year-old man with Prader-Willi syndrome who lives a quality life thank you to two organisations—I know that one of them was here—Interaction Ltd. I believe their CEO spoke earlier and I have just heard the CEO from Sunnyfield. Our son has received accommodation support for 24 years from Interaction and for eight years, I think, in the work field from Sunnyfield. Those two organisations are largely responsible for his quality life, as it is at present. I thought it might be helpful to give some of our experiences, from a parent point of view, with the NDIA. It has been a mostly positive experience. However, one thing that I would like to comment on is that, while it is difficult to expect people who prepare plans to be familiar with the range of categories of disability, there are some cases, in this case Prader-Willi syndrome, where it is most essential that it is taken notice of and it is dominant in the need category for any of the providers—I mentioned two a moment ago—plus any carer. To ignore the diagnosis is sure to bring about a poor quality of life.

Therefore, it would be helpful if the NDIA were aware that in this case that they were going to talk about the plan for a person with Prader-Willi syndrome. It is vital that in preparation they become familiar with what has been published worldwide on this syndrome because, while it does present a great many difficulties, with knowledge and care—specific care, as I have said with our son and I am sure for many others—they can live a quality life. That was one thing that I hope may be a positive comment or a positive suggestion—to have planners somehow become aware beforehand.

Briefly, it becomes very difficult because one of the essential features is restrictive practices. Restrictive practices always raise concerns, as they should, but there are some which are unavoidable if a person with Prader-Willi syndrome is going to live a quality life. Planners who have not heard this may think—as many people would—that this is harkening back to the dark ages, in terms of restrictive practices such as not having access to one's own money directly and not being able to get into a kitchen, having kitchens locked. Those are two examples. Many planners who are faced with this would assume that the person they were listening to was—I do not know—in the dark ages, I suppose. It is very difficult for them to get their head around that. We were lucky in

the sense that our son already had the accommodation and the workplace. For parents of younger people with Prader-Willi syndrome, who are trying to get a plan that would allow their child to live this quality of life, I imagine it would be very, very difficult.

The other thing that I would like to make as a suggestion—and I think Craig Moore, whose talk I missed, probably mentioned it—is that, for our children to have a quality life, it does not matter how long a carer has been working with people with a disability; if they have not worked with people with Prader-Willi or been to courses and trained, they run the risk of producing an unhappy person. Somehow—and I do not know where this fits into the NDIS—training for carers of this particular group of people is highly desirable. In fact, it is essential.

Mrs Robertson: The only other thing I want to put in there is how things will change in time, because our son, as I say, is 50. Do we have to go through this process again? It was quite a difficult process for us. While the people who came to interview him had some knowledge of the syndrome, and others in the house got what was necessary, we had to go through many appeals and so on to get what was needed for his care. We know that these people change and deteriorate over time, and we are wondering what is going to happen then.

Mr Robertson: I hope this will be helpful. Our experience, as you probably gather, was quite a positive one. The planners that we first spoke to were empathetic. Our son received a plan. We felt there were some deficiencies in it. We appealed and, not long after, we received another plan that did have additional funds in it. We have gone along on that.

I think it was a month later, maybe more, when we received a letter from another section of NDIA saying, 'We regret to tell you that your appeal has been denied,' and it gave reasons. I have not contacted them. I just hope that the first one is the one that is going to—whatever caused that confusion has left us somewhat confused, but on the right side, I hope. It would be good if that confusion could be removed. Thank you.

Ms Dale: I am an executive officer of EMPOWERability. We are an organisation that has been providing one-to-one support for high and complex needs in the Nepean Blue Mountains area for the past 25-plus years. There are a couple of things that I would like to raise today. I agree with everything that has been said so far. We are a small-to-medium organisation. We have been in the scheme 18 months now. We are almost 100 per cent transitioned over to the NDIS. We have found that the planning process has some major gaps for people who have high and complex needs, especially people who have intellectual and behavioural needs over people who have high physical needs. We are finding that the plans for the people that have the high complex needs are coming back insufficient. It is not representative of their needs.

There is also a glaringly obvious gap for families of people with high and complex needs with regard to case management and support. People are being given coordination-of-support funds, but those are not supposed to be to provide support for families who have high needs in their family unit. What often happens in the case of a family that is caring for someone with high and complex needs is that they lose a lot of their informal supports as their child or young person gets older. They have a lack of family support, a lack of community support and rely on support services for that. There is absolutely no funding within the hourly rate to provide those services, so services such as ours are providing this out of their own pocket.

The other thing that we are seeing happen on a regular basis to people with high and complex needs is that they are being turned away from support services because their needs are costing too much money. Some people have actually been evicted from their support accommodation because of their high needs. They are being refused access to other services purely because their support is costing too much money and the hourly rate—the 1-to-1 rate of \$42.79—does not cover this. Services like ours have to fund this out of our own coffers, so to speak. Obviously, a small-to-medium organisation like ours cannot sustain those funds. At the moment, as we are 18 months in, we have pretty much used up our reserves and we would really like to see a solution to this soon.

The other thing that is concerning is the reviews and appeals process. As recently as yesterday we had a person ask for a review and be told, 'Do not bother asking for a review, because you'll actually get less than what you have now.' The Administrative Appeals Tribunal process is another concerning avenue. It is actually taking anywhere up to four months to get a review of a reviewable decision, and then the process to get to the tribunal takes seven months plus, so you are looking at 11 months to get to the tribunal, but the plan lasts 12 months. Once it gets to the tribunal, they have no jurisdiction over it anymore because the plan has expired. That process then becomes null and void, so there is actually no real process to do the review of a reviewable decision.

Lastly, I know that a lot of speakers have spoken about this, but there is the increased administrative burden on disability service providers. I know that, for our service in particular as a one-on-one service, the amount of administration has increased by at least 100 per cent. Obviously, our hourly rate has decreased from what was being provided by state funding. That can only lead one way, and that would be to decrease the quality of care.

The only way we could actually continue to fund services at the administrative level we need would be to reduce the quality of care, and I am pretty sure nobody here wants to see that.

CHAIR: Thank you.

Mr Harper: As mentioned before, we are a disability service provider across New South Wales. In addition to the points that have been made, currently there is a lack of financial provision for interpreters for those customers whose main language is not English. They come from culturally and linguistically diverse backgrounds. The second point I wanted to make—and I think this is kind of important in Western Sydney—is that there is a clear need for targeted capacity-building programs that local communities can deliver to to enable families and kinship to provide support, particularly within the Aboriginal community. Recognition is needed, but many Indigenous people only engage in the formal services system such as the NDIS when the quality of family and kinship care has been exhausted. Consequently, information linkages, capacity and funding ultimately need to be strengthened to take account of the unique characteristics of delivering disability support services to Indigenous populations in areas like Western Sydney and remote areas.

CHAIR: Thank you.

Ms Werner: I work in a fairly specialist role, and part of that is looking at language access. I can see a lot of people who look at their plans and go, 'This doesn't make sense to me.' I ran a workshop and I had a father who took a day off from his work. He is a barrister and he said: 'I've come here wearing shorts because I'm not working today. I read really complex documents all day and I cannot make sense of my daughter's plan.' I have looked at plans where we get lots of questions. There are things in there like, 'This will be funded, which is R&N.' What does R&N mean? The person asked me, and this person does not have an intellectual disability. 'Does that mean I have a registered nurse that is going to be coming?' It was the shortening of 'reasonable and necessary'.

People need to understand. When they get a plan, it needs to be in plain English, making it accessible for them so they know how to implement it. People do not understand words like 'core supports' and things. There is jargon being used that everyone has got used to but not the people who are receiving the plans. We do not give them that bit of information. It is not on the website. Accessible language is for people who read. Go down another level for people who have problems with literacy. They cannot access their plans. They cannot access the portal. It is a complex document with complex information. If we are going to do this properly, we need to look at inclusion so that people are able to understand the systems that are around them and their funding.

The second thing is that there are people, particularly in New South Wales, which I can talk about, who have had special arrangements made for them through ministerial arrangements prior. Things were set up for them so that their very individual needs are catered for, which means that they can live in the community with the supports they need and not end up, for instance, in a justice system. As things roll out now, the supports that were put in through those ministerials are not necessarily being honoured, leaving those people extremely vulnerable.

The other thing I would like to bring up is that people do not really know what 'high intensity' means. There are lots of different interpretations of high intensity. If you can get some clarification about what that means, I think these things should be defined really clearly so that people have an understanding of what supports they need and how those can be implemented in their plans.

As people have brought up, I think that there is the level of inconsistency between plan and plan. Two people can be sitting like peas in a pod, with very similar needs. Maybe this is based on early articulation, but one gets a plan that really does support them and gives them what they need, and the other person gets a fraction. There are those inconsistencies.

Thank you for your time in making this session available.

CHAIR: Thanks, Ms Werner. Now—the lady in the blue, up the back?

Ms Cusack: Good afternoon. I am Stephanie Cusack. I am the accountant for the Autism Advisory and Support Service. I also double up in my spare time as the mum of a 10-year-old on the spectrum who has an NDIS plan. I must admit that my experience earlier on in the piece with a LAC, late last year, was actually a very positive experience. I was really very happy with our first plan, so I will just put that in there.

However, working as a service provider—we are a not-for-profit and what I would call a small organisation—my concerns surround the seeming lack of transparency, the lack of information and the lack of accountability within the NDIA in relation to the plans that they are writing for participants and the service providers. I will just bring up a couple of examples today, if that is okay? Just a couple of little examples.

On numerous plans that come through from our clients, they have an allowance of \$1,000 for low-risk equipment. We have used our best judgement and the recommendations of the therapists who work with the

participants to determine what low-risk equipment might be. Within the guidelines there is something that I will not even call a definition; there is a two-line set of examples. There is no definition, and all of the examples for low-risk equipment relate to physical disability equipment. So we have absolutely no written guidance on that. We have approached the NDIA on a number of occasions and have been given very different responses and quite restrictive guidance on it, to the extent where we are almost afraid to advise our clients at all on it in case we do the wrong thing and we are held accountable to it.

The other point I have on this—and on a number of other occasions—is that when we ask for advice from the NDIA, they are more than happy to give their opinions or advice but they are not happy to put it in writing at all. I have a big issue with that. It is the same issue with guidelines for assistive technology; I do not think that they are terribly clear and they are changing all the time. Where perhaps it might have been acceptable to purchase an iPad late last year, apparently that is no longer appropriate. But we are hearing the changes through rumour mills, not through guidelines and official information around those.

I am concerned about the level of risk that the service providers are wearing in trying to interpret plans, to interpret what low-risk equipment is and what assistive technologies are. With the NDIA, we have stumbled across background information that is sitting behind a client's plan, under their core supports or other categories, that we are not aware of. It is not written in the plan that we see from the client, but behind the scenes there is a \$3,000 allowance within core supports for this item and a something allowance for that item, but we have assumed that the core supports are for something else. We are support coordinators, we are not privy to enough information in the background of the plan. The plans seem to be a little vague and not very transparent. This is no good for the participants and is no good for the service provider, which is genuinely trying to help them to implement their plans.

We have had clients come to us and say, 'Can you provide this service under my plan?' We will do our best to interpret the plan that they have. In some cases it is extremely vague and very short. In those cases where we are not sure, we will send them back to their planner to query it—the person who wrote the plan. They have been advised very clearly, in writing, to go to their service provider, because their service provider will tell them if they can do it or not. And so we are in this catch 22 circle where, again, I feel very much like the NDIA is putting the risk and exposure onto the service providers to interpret plans that we did not write. If we get it wrong, what is our exposure there?

Not only that, obviously we are first and foremost trying to do right by our clients and provide really good service for them—service that is reasonable, necessary and needed. Again, every time we ask for advice and are given it, we are time and again told, 'I have to be very careful about what I put in writing, and, no, I am not going to put that in writing.' So it is a hard environment to exist in, and that is outside of the administrative burden which a lot of service providers have already mentioned today. I have spent the better part of six months not as the accountant but I guess as the NDIS administrator and interpreter in our organisation, and that is concerning, because I guess my role is to advise the board and my CEO on financial sustainability and business models and things like that, and that is really difficult to do.

My last point is that we have spent the better part of the last 18 months modelling and changing the business model that we have, obviously to provide evidence based supports for people with autism and their families but also to fit within the constraints of the NDIS, because we anticipate and know that in the future a very large percentage of our funding will be coming via the NDIS. However, then we had a conversation out of the blue with an NDIS person who had called to inquire about an appeal that we assisted a client to put in. I am not going to go into the nitty-gritty of it, but essentially they said, 'Are you aware that this is our funding model—the NDIS's funding model—for children who come out of early intervention phase with autism?' She went on to explain what the funding model was. The funding model is not in line with the evidence based models for kids of that age group with autism. It is not supported by that. Frankly, it is not how we have modelled our business or our organisation and our supports provision going forward. I am just talking about kids with autism, but if there is no transparency around how the NDIS is funding different disabilities, how can service providers be expected to really to model their organisations and be financially sustainable going forward? If we have to adopt the model that we were told about that is the funding model for the NDIS for kids over the age of seven with autism, we are never going to survive. That is the financial perspective, because I guess that is where I come from. But certainly looking at the evidence and what the kids need and the assumptions that are being made under that funding model that the NDIS told us about, it is not supported and it is not sustainable, and it certainly does not support the disabilities and the possible abilities for these children.

CHAIR: Before I go to the next person, I should have said at the outset that there are a number of officials from the NDIA here who people might want to approach after this hearing. At the Canberra hearings I asked them to identify themselves at the outset, and I forgot to do that today. Sorry to do that at this stage; I had overlooked it.

Ms Baldacchino: I am from The Shepherd Centre. I just wanted to add a short adjunct to what my colleague Dr Jim Hungerford said earlier on the individual plan costs. My comments are really around the delays in the system, which I guess a lot of people have commented on today. Just to give some examples, in the Western Sydney region we have just under 15 per cent of approved plans for our cohort. I guess we are very fortunate in that we are a transition provider for early intervention. As you may be aware, transition providers are required to submit their first 10 initial plans to the early childhood early intervention national team for auditing purposes, and only after those first 10 plans are audited can we then submit further plans to the region. Unfortunately, that has resulted in a three-month delay for many of our families, because we have only just received our permission to forward plans to the region. I should take the opportunity to thank some of the local NDIA contacts that we have in helping to expedite that, but I guess it is just exemplifying a delay in the system for families and organisations.

Aside from the early intervention families within the cohort in Western Sydney, we have some children that are school age, and they have been going to the local area coordinators. My comment around that is that, again, we have been fortunate to have the guidance of the national team of auditors in the specificity of our plans for the planners at NDIA, and we are definitely seeing quite a difference between the plans that we asked to produce and the plans that are being produced by the local area coordinators for the older cohort of children that we see.

Just a couple of impacts for families—there is one family, for example, who have had difficulties accessing the portal. That has meant that they have not accessed a service now for two months, because they are unable to sign a service agreement with their service providers. I guess, as other people have said, with under 15 per cent of our children having approved plans and the stepping down of funding from ADHC, that means a funding gap for our organisation.

Ms Lown: I am from the Royal Institute for Deaf and Blind Children. I just wanted to comment further on a point made previously around the assistive technology and the process. I understand that the process changed in November last year and I understand why the NDIA did that, because previously people were just requesting a list of things and the need to ensure that the assistive technology provided related to their goals. What happens now is that they have to have an assistive technology assessment, and a form is filled out which we then send on to the NDIA, and participants can also load it into the portal. We are finding that we have been sending some forms in and we are not getting them back. After chasing up many times, they then say that the forms and the quotes that go with them have expired because they are more than 90 days old, yet they are sitting there for that long. So it would just be helpful if there were some clarity around the process so that people could get their assessments back and get an outcome determined as to whether they can get that technology, because our service providers—we are fielding quite a lot of inquiries from our clients who we provided with an assessment a few months ago and they are still without their technology.

Ms Wicks: I am general manager with ParaQuad New South Wales, ParaQuad Northern Territory and BrightSky Australia. I just have three comments. The first one sits around local area coordinators, and I think we all experience the same thing: if you get a great local area coordinator, you will get a great plan. I tend to think it takes two things though—a good local area coordinator and a client who can really advocate on their own behalf. I have some clients with fantastic plans who are certainly better off than they were under previous funding. But I have many clients who are worse off and many clients who have fewer hours of care, and there has been no consideration for review of the specialised equipment. As I said, I am from ParaQuad, so the people who I deal with are people with traumatic spinal cord injury. Although they have recognised the need for a wheelchair, they may not have recognised in the plan the need to replace the wheelchair and for the specialisation of the wheelchair, the commode chair, that bed, the mattress or whatever. With the threat of autonomic dysreflexia for this group, it is a concern for us.

The other thing I would like to talk about is coordination of supports. We provide coordination of supports. Recently, we have been asked to provide that while the participant is still an inpatient in various spinal units. That is because we are told that the unit is having difficulty dealing with NDIA and the participant's plan. With providing COS—coordination of support—I thought, 'Well, isn't that meant to happen in the community?' Yet I have certainly contacted NDIA to have that explained to me, and I am told there is no framework for this yet. I certainly think it would be a shame that COS is used before the client even gets to the community. I would welcome anyone who can explain to me how I balance between NDIA and Health services, because as a service provider I feel like Health will go, 'That's NDIA,' and NDIA will go, 'That's Health.' The participant and I are

sitting in the community going, 'Right. Where do we go now? How does that balance?' I think those sorts of things need to be addressed.

I am actually clinician, and I have a research background myself as well. I have worked for over 30 years in spinal cord injury. My area of expertise is neurogenic continence management. I often hear—at particular forums and in plans, et cetera—that people with neurological loss do not necessarily require a continence assessment. They say, 'Just bring your list to the planning meeting.' I think I have already said that sometimes the planning meeting does not go to plan. I took it upon myself to survey 1,000 people to actually ask them if they understood their own continence needs and if they understood how to actually ask for an assessment at the plan. I came back with 80.9 per cent who did not. For me, I think that is a bit of a challenge. I do wonder what NDIA is going to do in the future if the continence needs of people with neurological loss are not being addressed now. They are probably all of my questions, thank you very much.

Ms Heath: I am CEO of NADO, a local disabilities service provider in the Nepean region. I echo a lot of comments that have been made in the room. I just wanted to raise an issue about clarity of policy and pricing. Specifically, in regards to the specialist disability accommodation, or the SDA framework. There are variations in what you hear are the rulings. I spoke at the federal members' forum yesterday about this. It has been tabled, and I do have some information coming to me. I also want to have some clarity about eligibility of participants for SDA. That is not clear to me. That is, whether people can get their hopes up to actually have that payment for specialist disability accommodation. The other area is in pricing and in planning as a provider. For example, we decided as a service provider to commence plan management. But after we had actually gone through the process of registering and so on, we realised that the pricing in the price guide was not accurate. In fact, a line item had been deleted. It changed our modelling quite considerably. That was all I wanted to raise today.

Mr Vine: Thank you for your time this afternoon. I am the CEO of Plan Management Partners. Every day we hear from individuals who need support and guidance, such as families who are perhaps daunted and overwhelmed. They might have an NDIS plan or they may not. They may be in the process of getting one. We go through a process of providing support, guidance and taking away the administration and hassle of managing their NDIS plan.

Our comment is about the plan creation and the process, which has been talked about pretty extensively so far today. Particularly, I would like to focus on the participants being made aware of their plan management choices. There are three choices that are available: you can self manage; you can NDIA manage, which is current default option; and you can plan manage. We find that sometimes self managed is offered—but not always—and plan management is offered rarely. When they come to speak to us about their plan, they might be two months into their plan and have not been able to activate their plan—that is, engage service providers and commence receiving services—and so they have not known where to start in kicking off their plan and bringing it to life.

We speak to them about plan management services. There is an enormous sense of relief that they feel when they feel like someone can help them get started with their plan, so get that plan underway. They decide at that point that they would like to use plan management services. To make use of our services, if they do not have plan management in their plan, they need to go through a review process. We have heard bit about that today. It is quite a lengthy process to change their method of managing their plan.

We are finding that the vast majority of participants, had they had the conversation during the planning creation stage of the process, would have made the decision to plan manage at that point. Therefore, that would reduce the onerous task of the review process for the participant, as was reduce the extensive workload of the NDIA in doing the review process and getting what we would say are probably unnecessary reviews through the review process. If they were made aware of that beginning, when they were doing the plan creation process, we feel that it would be a better outcome for the participant, as well as for the NDIA. Thank you for your time.

Ms Hailes: Thanks for having me today. I am from Afford. We have heard a few negative things this afternoon, so I am going to address the positive things that Afford is finding. Some of the things that we are coming across is that our clients are actually getting more services once they have come into the NDIS, prior to them just having ADHC funding. This includes our clients that are accessing our ADEs. Previously, they would just assess the DMI level and they were receiving work in the ADEs. Now, they are receiving core supports and we are able to assist them in their homes. Most of our clients are now getting more services on the weekend and better community participation and integration. Our clients are also getting a lot of allied health services included in their plans. They are getting more than what they would have been offered under the ADHC services. They now able to access who they need to and have ongoing therapy at the rate that they actually require.

We have had a big intake in overnight respite or centre based respite, to the point that we have actually had to go out and purchase more properties to be able to accommodate the need and to be able to sustain carers in the

caring role a lot longer. We have also had to go and purchase more group homes, because there is a massive need for group homes. We have quite a lot of group homes at the moment, but we are heavily investing in more group homes going forward to try to help the people who require it.

We have developed quite a few internal reviews processes that we go through before we contact the NDIA to have a review done regarding where there may be a participant who has underfunded for whatever reason. We are finding that we are trying to simplify things as much as possible before going to the NDIA, hence getting your review done a lot quicker and a lot more effectively as well. That is because you have already got all the documentation that they require.

The one thing that we have spent a lot of time, energy and effort doing is educating our families. The more education that we give to our families prior to them going in and having an NDIS plan done, the better the outcome of the plan is going to be. We go through their whole entire life, their whole week, the routines that they have, the types of supports that they require and what their goals are. We speak to them about what is reasonable and what is necessary prior to them going into the plan meeting as well so that they have an understanding of what is possibly going to be achieved and what is out of reach or not necessary at this point in time.

We have also built relationships with the NDIS and our local area coordinators. Again, if there is an error in the plan, we can contact them directly and have it fixed as quickly as possible. From AFFORD's point of view, we are seeing this as a very positive experience. At the end of the day, it is getting more services to people with a disability and we are very happy that it has come in, and we are happy to support our families going forward. Thank you.

Ms Ingram: I have two children who were participants in the NDIS. I am a foster carer, and my children are long term within the care system. My experience with NDIS has been nothing short of a debacle from the beginning right up until today. I have gone through the process of a review. I have two children who are already marginalised by the disabilities—and they have multiple disabilities—and I know that there are a number of other families that are in the same position that I am in.

I am here today with Ruby from Connect Child and Family Services, and I live in the Blue Mountains. We do not have services in the Blue Mountains to provide for our children. We are on waiting lists that are so long it is ridiculous. By the time they will actually get any services provided to them, they will not need them anymore because they will be past school age. There is one service that has a list that is four years long—that is ridiculous.

When we first went through the process of applying for NDIS, we were told that this would make things much easier for our children. It has not made it easier and, in fact, I went through plan meetings with planners who asked ridiculous questions like, 'Is this a disability or is this something they are going to grow out of?' It is a chromosomal abnormality; I do not think that is something that they are going to grow out of.

We have found dealing with community connectors to be abysmal. They found it quite easy to pass on information about the personal lives of the children within our care and, then, once that had happened and we made a complaint about it, we were told, 'There is really nothing we can do about it now, because the horse has bolted, the gate has closed.' But two years on—because we went through this scheme fairly early on—our children are still suffering because of this disclosure about their personal information from the community connector, who was a local person, who is still there and whom we still see on a regular basis because she is a parent at the school my children attend.

I know of a number of other people who have given up on NDIS. You can spend hours and hours and hours on the phone. They are worse than Centrelink—much worse than Centrelink. I know people whose families' relationships have broken down because they are dealing with the children in the first place and they are not receiving the services. I think that sometimes you need to stop and look at the fact that this plan seemed so wonderful and so great. You were going to provide so much for so many people. But I am sitting here. I have two children, and I have been provided with nothing but grief and heartache for the children, and very few services.

At no point in the beginning was I told that we could use a plan manager. I was told that, because we are foster carers—even though we are long-term foster carers—we could only use the NDIA to access. So that meant that a lot of service providers that we might have been able to go to, we could not go to because they were not going to register with the NDIA: it takes too long; it is too cumbersome; they do not get paid; and anytime anyone mentions the portal, people laugh. So we are forced to not access services, or to actually go and access services and pay directly out of our pockets because we are not going to see our children go without.

I am going to pass over to Ruby, who is actually here as somebody who is a provider. Her organisation provide services for our family and for a number of other families in our position. But, speaking purely as a foster carer, we are treated abysmally.

CHAIR: Thank you, Ms Ingram. We are sorry about the circumstances and hope that, through this process, we may be able to help improve the situation.

Ms Wright: I work for Connect Child and Family Services. We are a not-for-profit early childhood intervention agency. I would like to raise concerns about the implications of the NDIS Early Childhood Early Intervention model—that is, the ECEI model—specifically for children with disabilities and the families in the mid to upper Blue Mountains. The ECEI approach is how the NDIS is working with early childhood providers to deliver early childhood intervention for children aged zero to six years. When families have a concern around their child's development, an ECEI partner will work with the family to identify the child's needs, link the child and the family into mainstream services, provide therapeutic supports and, where appropriate, assist them into the NDIS—that is, not all children accessing supports through the ECI will need to become an NDIS client.

Connect is a strong advocate for this model, which resulted from an acknowledgement of the current statewide effective referral pathways, the existing local connections and the sector's understanding of family centre practice and child development. But Connect was very disappointed to discover that, because the Nepean Blue Mountains was the pilot site for the ECI model, it would be excluded from the rollout of the ECEI New South Wales state transitional arrangements.

For many years, Connect has worked collaboratively with families and service providers and has developed expertise, knowledge and extensive referral pathways to ensure that children that need assistance to receive it in a timely manner. Connect has adopted a holistic and responsive model that enables children and families requiring early intervention to be identified prior to them attending school or be seen through the more formal pathways. With the introduction of the NDIS ECEI pilot in the Nepean Blue Mountains area, we will no longer be funded to do this. Without block funding we can only afford to see children after they have an NDIS plan in place.

Following on from the learnings of the Nepean Blue Mountains pilot, this model transition approach has enabled approximately 60 per cent of New South Wales FaCS-funded ECI service providers to retain a substantial percentage of their block funding to continue delivering these pre-NDIS services under this model, thus enabling families to experience a smooth entry into the NDIS.

Unfortunately, ECI services in the Nepean Blue Mountains pilot region did not have the opportunity to retain any of their family and community services block funding. Instead, two ECI providers based in Penrith were funded to be ECI providers in the Nepean Blue Mountains, leaving significant gaps and delays for children and their families in the mid to upper Blue Mountains. Local evidence at a recent community forum highlighted the geographical gaps in the service delivery to families in the mid to upper Blue Mountains since the model's pilot inception 16 months ago. These gaps included the two ECI-funded providers not responding to referrals in the mid to upper mountains; families waiting for 15 months without assistance; early childhood centres not receiving support for children with developmental delays disabilities; and schools noticing the marked increase of children enrolling in kindergarten without any prior access to early intervention. The transitional arrangements that have been put in place till the NDIS full scheme rollout in 2018 seem inadequate to meet the need, and yet we have services in the Blue Mountains like Connect that have the capacity, the skills and the referral pathways to bridge this gap until the model is in place.

Ms Pather: Good afternoon. I am a hospital social worker in Sydney's southwest. I want to talk about my experiences as a hospital social worker. We refer new patients to the NDIS process. When we started—we rolled out in July last year—we were under the impression that there were some standardised processes, given that it had been rolled out in different areas. The first thing that we found out was: there was no standard process. There was no standardisation. There were no guidelines. There was nothing to inform us on how to go forward with the process. We have subsequently rolled out a process in south-west Sydney, but, again, between the hospitals there is variation. I guess that is the common theme that comes out—there is no standardisation, there are no guidelines, there is no process that says to individuals that are going onto the process for the first time, 'This is your starting point, this is the information you need to be familiar with, this is the information you need to know.' We were fortunate; we got appointed a planner to work with the hospital, so we have one point of call. The good thing about that is that when you have queries, when you have things you want to check out, you have someone you can contact. The difficulty, however, is that when she is on leave or off sick, she is your point of call and you have to wait until she is back. It is a system that can work if structures are put in place, but it is a matter of how you start putting them in place so they are accessible for people who use the system.

The rest of it you have heard, in terms of the delays, the sitting on the phone. We go through that as well within the hospital system. I guess for me it is just getting the message across that we do need guidelines, we do need information, we do need standardisation of processes.

Ms Milne: I am here in an official capacity as a team leader for assessment and behaviour intervention. I manage a team of early intervention behaviour specialists. I am also the program manager for an ADHAC-funded Intensive Family Support Program, which is an early intervention program designed to prevent children from being relinquished from their parents' care, not because of child protection issues but because of the complexity of their disability and the burdens that puts on the family.

I am also here in a personal capacity, as I am a guardian for a gentleman with moderate intellectual disability in his forties who lives in a group home and is non-verbal. To start with something positive, his planning process was amazing. We had a planner—who is from the agency, not an LAC—and it was a planner who had been in the community team at ADHAC for many years and who had a really solid understanding of what it means for a person to have cognitive disability. He could not speak for himself, and she understood that she could rely on those around him to speak for him. He has achieved a goal of his that has been in the planning for more than 10 years—he has got his fourth day at a day program.

For 10 years we have been looking for funding for that, because when he is in an environment where he has space to walk around outside and people who understand him, he does not have behavioural issues; he has a great life. When he does not have those supports, at different times in the past he has assaulted people, he has self-injured—it has been disastrous. The planner understood that putting in funding for an extra day at a specialist day program for people with complex behavioural needs significantly reduced the chances of him being hospitalised; it reduced the need for clinical services, around behaviour support; with these extra services his psychotropic medications have continued to decrease, which means it is costing Medicare less. This is a system that works. The planner understood, because she had met him personally many years before and had been witness to his violent and aggressive behaviour and could see the contrast that good supports made in helping him have a quality of life.

He was lucky. There are not many people in the group home system of that age and older who have people in their lives. A lot of people were relinquished because that is how it was done then. But he has people around him who could advocate articulately for that, had he got it. That has been wonderful. We have families who work with our organisation that have had similar processes, and usually it has been because they have had someone in their life that can articulate well and use the coded language that NDIA uses—parents have learnt not to ask for 'respite' because respite does not exist; you need 'supported access to the community'. It is also dependent on the planner. Some planners get it. Some planners do not. With one of the families we work with the planner actually called a halt to the meeting because the child was there and he was jumping across furniture and pulling light fixtures from the ceiling. The LAC planner felt so insecure at the meeting because of this child's violent and aggressive behaviour that they halted the meeting for their safety. The meeting was rescheduled with the team leader from the LAC and a social worker who was working at the LAC, and this child has received an adequate plan. But I do not believe that would have happened if that child had not been physically in the room. It was the physicality of the fear and the danger that that planner was confronted with that really helped them to understand the lived existence of those parents.

We have had other families with similarly violent and aggressive children who have not had the child in the room. One of my team attended a planning meeting. She is a senior behaviour specialist who is a psychologist. She went to support the family because they were part of our Intensive Family Support program. The planner was more interested in what the child's interests and hobbies were and only agreed to discuss risk and safety when my senior psychologist insisted, at the end of the meeting. When the plan came back, there was no support coordination, there was a very small therapy budget and the description in the plan of this child did not correlate with the child we know. It talked about his passion for bowling. This is a child with ASD who has no hobbies and interests. He is obsessive is over very small things, and a large amount of that is about trying to physically harm his mother. But the LAC planner had refused to talk about risk.

Before the plan was released, I received a call from my senior consultant and another behaviour therapist, who were in the home. We cannot safely allow our team in that home without two staff. I got a call from my team at seven o'clock at night—the session was meant to finish at 5 pm—to say they were still there because the eight-year-old boy was trying to strangle his mother and they were trying to keep the three-year-old sister, who has a severe and degenerative vision problem, safe from the violent incident.

After that incident, when my staff left the house finally confident that the three-year-old was safe and that the seven-year-old brother, who was hiding in his room, was safe and that the mother was not going to be any further physically harmed and that the child had had his PRN medication, I then spent a further two hours with my staff calling DOCS, because this is a mandatory reporting issue. We are legally obliged to report risk of significant harm. So we did this. Even if we were not legally obliged to report risk of significant harm to children, my senior behaviour clinician is a registered psychologist and she has professional obligations. There is a child here who is a

risk of harm to others. He has suicidal ideation. He has been hospitalised in an acute setting three to four times since his NDIS plan has rolled out, and our ability to support that family is less than it was under ADHC block funding.

Fortunately for this family, the three-year-old has not rolled into NDIS yet, so we are still able to provide some support through Intensive Family Support services. However, that ends in under six weeks, and we have to say to this family, 'That's nice but we can't help you anymore.' How do I do that?

I have staff who are immensely dedicated professionals who are highly skilled. You cannot be an effective early intervention clinician and you cannot be an effective behaviour therapist if you have not built a rapport with these people. So I have staff who report directly to me. I have a case management and coordination responsibility directly with these families. I am in the invidious position of having to say to my staff, where families have rolled into the NDIS: 'No, I cannot allow you to do that, because there is nothing to pay for it.' Sometimes I say to them, 'Look, we'll just cop this one,' because I can't in good conscience go home knowing that a family has been left in that situation. Never mind the fact that child protection legislation says we have to; never mind that my staff could be deregistered from their profession if they do not do it; I would not be able to sleep at night knowing that there is a family in this situation.

When we have called DOCS reporting, they refused to acknowledge that family violence can be perpetrated by the child in the family. All modern understandings of family violence are that it can be in any direction. People do not want to acknowledge that an eight- or nine-year-old child can actually be physically dangerous. They can be. It is no intentioned; it is not malicious. But an eight- or nine-year-old child, particularly one with autism spectrum disorder and who has a limited understanding of how people's emotions are being displayed because they cannot interpret what is going on and they become more and more confused, can be incredibly aggressive and incredibly violent. That is not coming from a place of ill intent; that is sheer confusion about what is going on. If these children were in out-of-home care, which is a very real possibility for many of them, they would not be left with one carer. It would not be safe. Any employer who put these children in the care of just one support worker would be negligent and liable under WHS. But parents are expected to cope.

I have a number of single-parent families who have two or more children with this level of disability who are being expected to cope with behaviours that are beyond the understanding of most of the planners and people that they have to deal with. I have a family who have been part of our intensive family support program where we have provided 50 hours of unfunded support. I know that there is a seven-year-old hiding in his bedroom because he is terrified of his nine-year-old brother. This family did not get any support coordination. Under the bilateral agreement, they were guaranteed that there would be no disadvantage and that there would be continuity of support. We, on good faith, said to them, 'No; roll into the NDIS. You are guaranteed continuity of support. You will not be disadvantaged.'

How do I stand by and not provide that continuity of support? And so we are. We are a small organisation. We are a tiny organisation that does very specialised work. My team does a huge number of hours of work for these families, and we cannot claim it under NDIS because NDIS does not recognise that behaviour support plans need formatting, that a child may not be able to buy a standard resource off the shelf but needs someone who has skills, expertise and knowledge of their situation to customise. I have speech pathologists that will spend hours researching just the right way to help that child communicate and then design a tailored resource. If I was to charge for that, that child would have no therapy budget left. If I was to charge my intensive family support families for the family support, case coordination and advocacy that we had been able to provide for them, their child would get no therapy, no respite, nothing.

I cannot go to sleep at night, having abandoned these families after I sold the party line of there being no disadvantage for transferring. But we are a small organisation. We cannot carry 40 to 50 hours per family once ADHC funding is withdrawn from Western Sydney at the end of June. We had funding in Nepean withdrawn at the end of the last financial year, and, after that was withdrawn, again, we delivered 70 to 80 hours of support. This was because case management is not considered to be necessary under the NDIS. That is nice if you have a high-capacity family who know what is going on, it does not account for hidden disability—carer fatigue. Parents are being told that, if a parent does for a developmentally typical child, NDIS will not fund it. But there is no conception of the difference between the support needs of a child with ASD, or intellectual disability or mental health issues and the level of support a developmentally typical child would need. My parents cannot just hire a babysitter. Babysitters will not look after them. I cannot put highly trained allied health and behaviour specialists in a room with this child, unless there are two of them, because it is not safe for anyone. My parents cannot access emergency respite any more, because they have NDIS.

I think the scheme is a wonderful, wonderful concept. I think massive, massive societal change like this is never going to be easy—there were always going to be hiccups. The portal drives me to distraction. I have no funding for all the time I have to spend calling the agency to try to get that bureaucratic stuff dealt with. But I suck that up because this is important. What I cannot suck up is the fact that my staff and I are dedicating enormous amounts of voluntary labour to a scheme where there is non-contextual pricing, to bring it back to the things that the high-level managers have talked about. No-one in private practice would work with the kind of clients that the state government funded schemes work with. It is not viable.

If my organisation is to continue to exist, we are going to have to behave like a private practice and say, 'I am sorry, we are not the right kind of service for you. Yes, my team have incredible skills and expertise, but you are not a financially viable client.' And there is no longer to be a service provider of last resort. ADHC has provided an immeasurably valuable role—even just the knowledge that there is a provider out there who, no matter how hard it gets or no matter how expensive it gets, cannot and will not say no. With the private market model, that has gone.

ACTING CHAIR: You have made some extremely valuable contributions in your submission. I would strongly urge the NDIA or any officials, in their respective areas of responsibility, to make contact with you as you have indicated that there are children and other people who may be in peril, to put it frankly. We have had a very good contribution from you and your organisation. If you would like to conclude in the next couple of minutes. We do have agency officials in the room and they should contact you before you leave this room, so that there is a process in place to address what you have essentially put on the parliamentary record as evidence.

Ms Milne: I can see people from the agency in the room who are absolutely amazing—they really are. In the pilot rollout, in Nepean, the scheme was able to be responsive. It was staffed by people who understood complex disability. You had named people whom you could contact. As it has gone to bigger rollout, it has become very bureaucratic, and there is not the responsiveness for issues that are very real and very dangerous.

ACTING CHAIR: This builds on evidence we received in Canberra last week where people indicated that mental health and dealing with it is not always easy. It can be very aggressive and very dangerous for families, caregivers and all people involved. So we are building a core of evidence in this area.

Ms Milne: In short, I wanted to get this on the record, because these are families that do not have the capacity to get it on the record for themselves, because they are carrying a burden that no paid support worker would ever be asked to carry. If they were adults, it would not be in question, because there would not be that line, 'Parents of developmentally typical children do that, so you should.'

ACTING CHAIR: Thank you very much for your contribution. Who would like to go next?

Ms Way: I am the general manager of services of an organisation called Community Connections Australia. Our organisation has always prided itself on providing individualised support to people to live in their own home in the community, and we have done this successfully for the last 30 years. Recently, with the rollout of NDIA, we have also taken on doing a little bit of support coordination, and that has, I guess, opened the door to look at other organisations and other providers that provide more of a group home style of accommodation service.

What I have found in my experiences and those of my colleagues who also do a bit of support coordination is a lack of consistency from different providers around, particularly, the issue of people who are deemed to be higher intensity or have complex care needs. The agency needs to have further clarification or some sort of guidelines so that providers in general are aware of the delineation between the two. For example, I have a woman who lives in a shared household. She has epilepsy, a moderate to severe intellectual disability, a brain tumour and an acquired brain injury. She has violent and unpredictable behaviours. She has been classed as standard care. I have another person I provide support coordination to who is currently living independently in his own home. He self-transfers. He has an acquired brain injury, but it is not at a significant level. He is able to make his own decisions. He is able to eat his own meals. He lives within his home. He has a ground floor unit and does not have access to any sort of overnight sleepover. He is about to move into a service where he is going to be provided with funding by the agency at the higher intensity rate. So where is the equality in that process?

The next thing I would like to raise is around core supports. Whilst as a provider representing the people we provide services to I truly appreciate flexibility within core supports, I am also struggling with an issue where I have somebody who receives 30 hours a week of personal care or self-care services who wants to convert \$300 a week to cover his transport costs. We ring up the agency, and he is saying, 'Yes, I have been told I can do it.' We are not his support coordinator, but he is insisting that we do that conversion so that he is able to get his extra \$300 to use for his transport costs so that he can access the community. Where is the fairness in this, particularly given other examples we have heard today where people do not have sufficient services?

The next thing I would like to raise is particularly around the group home model of service delivery. A lot of families have had an expectation that they will be provided with reasonable and necessary supports. Part of those reasonable and necessary supports for the people that are residing in the group homes is for families and the people themselves to be able to say, 'We'd like to have access to individualised supports within the group home environment.'

I was privy to a number of earlier plans—say, prior to November last year—where, if there were one-on-one supports approved, these were actually stated in the participant's plans, which gave families, participants and providers very clear guidelines: 'Yes, you may be in a group home but every Saturday and every Sunday you will get six hours of one-on-one support.' Under the way core supports are now operating, a large number of providers within group home accommodation services are saying: 'How much do you have in core supports? It is going to be this amount of money.' Families and individuals are now signing up not being aware of how they can access those individualised supports, which are crucial for everyone to have.

The second last thing I would like to raise is the issue with health and disability. We have one person we provide services to who has motor neurone disease. Under the NDIA that is a disability and he is funded for his supports. He has requested that he have access to a cough assist machine, which will help relieve the congestion and build up of fluid in his lungs, which is a direct result of motor neurone disease. The NDIA have refused to fund this piece of assistive technology, which will keep him alive for longer—he is only in his 30s—because it is health, and health have refused to fund this equipment because it is disability. The poor man will literally be dead—he has rapid onset motor neurone disease—before there will be any decision made by anybody that, 'Yes, he really needs to have this cough assist machine.'

Finally, there needs to be some sort of mechanism or way forward for people who do not want to live in group homes in New South Wales. We have a number of people who are currently living in a group home model of service and they are desperately trying to spread their wings and live independently in the community, as everybody else does, and not be segregated in a house that is shared with other people who just have to be there because they all have disabilities. We have a number of people within our own service at this point in time who were funded through FaCS to have that individualised support. I have been told repeatedly by various people in the agency—none of them are sitting in this room, may I add—I'm sorry your model of service does not fit and we do not know how to account for somebody to be able to live in their own home independently.' Thank you.

ACTING CHAIR: Are there any other contributions?

Ms Carpenter: I want to add that it has been raised a few times that there are inconsistent processes and inconsistent communication of those processes. This is something we have experienced, certainly from the trial site—and I have not been involved in all of the trial sites. The information that is circulated now is significantly better. We have got provider toolkits and we are getting updates and lots of information that we did not have before. I really want to acknowledge the benefit of that. What is still missing from some of that information is some of the step-by-step, how-to processes, particularly around those areas where we need or are required as a provider to have critical interactions with the NDIA—for example, with submitting assessments and submitting quotes. The toolkit will say, 'Submit,' but there is nothing around how to do that. So what we are finding on the ground, particularly as an organisation that works across multiple NDIA regions, is that each region is kind of inventing their own processes around doing that that are not always communicated.

So as an organisation we are getting caught up in how we navigate that space. That really could be easily negated by some of that information being consistent and being published. I will give you some examples. We have been told to email it and there are multiple email addresses to use—some of those bounce and some of those give no response. This all holds up the submission of the assessment and the information going to the family, and there is staff time in doing that. We have continued to try to resolve this. Recently I was at a provider forum where we were told that you can submit via the portal and that you can attach it to the customer's record, which would be wonderful, but the experience of using the portal is that that is not possible. There is an upload evidence section that you can use, which is a very generalised bucket, but there is no way you can do that. I even went as far as logging on to the portal on my tablet and showing that to the people there and saying, 'You tell me how', because we want to do it, but they were not able to do it. That is no criticism of the NDIA staff; it is just that there is not actually a process around this stuff that is clearly defined. I suppose my request is in some of those critical areas. The simple step or the simple addition of some of those how to steps that are consistently followed in every region would make a huge difference to the efficiencies we can gain on the ground and to how quickly we can get information turned around for families. Thank you.

ACTING CHAIR (Senator Gallacher): Are there any other contributions? We have a couple of minutes.

Ms Karp: What I am hearing in the room is that a lot of providers are here for early childhood. I work with youths and adults on the autism spectrum. You need to realise that what is happening in early childhood carries on. These people actually grow up and become adults. The adults that I am seeing were not privy, mostly, to early intervention and they were not privy to supports at school. A lot of them are not diagnosed until I see them and I encourage them to become diagnosed to gain support. These people become adults. The lady at the back was saying about a young eight-year-old's violence; I am dealing with 21-year-olds and 22-year-olds weighing 120 kilos. I am four feet nothing, and I have got these kids who have not had support. To put an NDIS plan in place for a 22-year-old, who looks normal, can drive and at some stage has got through school, that says they can have \$11,000 in incontinence pads ain't appropriate. To put in a plan for somebody who looks normal but does not know how to communicate with adults 'I want to get a job' or 'I want to live with my girlfriend' is not a plan and is not what that person needs. We have the issue of saying that this person needs an advocate and the people at the other end, the LAC and the planner, not understanding the communication needs of people on the autism spectrum who are nonverbal. These people need to be able to use alternative means of communication when they are dealing with the agencies. People are told, 'You must have a phone interview'. They are threatened with, 'If you do not have a phone interview, you are going to wait six months.' A review was mentioned here before. As I said at the beginning, I have a client who is suicidal. I have a client who has not got access to enough therapies. His mother was willing to pay me out of her own funds. She is not coping. She needs interventions. So where is the support for carers? Thank you.

ACTING CHAIR: We are timed to finish at 4 o'clock. Do you have contribution?

Ms Noppert: I am a parent here. I was not going to speak but what I want to say very, very quickly is thank you so much for holding a forum that actually allows us to advocate for our children and to get to know some of the people in the room. I live on coffee and I have good foundations that allow me to look like I can cope because, honestly, without the services that my child gets I would be a crumbling mess. I am an educator and I am not stupid, but I read my NDIS plan and if I did not buy a vowel I would not have had a clue what is going on. I am really, really sorry, but normal people, who do not have massive degrees, do not get it. We do not understand it. I did not understand assistive technology. In my world, technology means anything that has a power pack. I did not know it meant incontinence pad. I did not know it meant consumables. Line items are confusing. We do not understand them. And, to be honest, knowledge is power.

I run a Facebook group. I do things out of my own time to be able to get parents together who are not coping. I look like I am coping, but I am not. If I did not have like-minded people around me to say, 'It's okay, my kid does that; it is okay, don't worry, we get it,' then I would not have anywhere to go.

I have a husband who is in the military who is very hard faced and does not understand my child, but that is because that is what his line of work is. I would love to be able to say to him, 'Let's go to this night; let's go to the support group for parents to be able to help them,' because otherwise, we do not get a chance to help our kids.

What is going to happen when I die? Who is going to look after my boy? To be honest, a lot of these carers, as wonderful as they are, do not have the specialised skills. Let's train them. Let's put some money into educating people. Let's put some money into educating the education system on people with a disability. They are not different and they are not strange; they just need to be heard and they need an advocate. A non-verbal child who bites his LAC because it was a different face coming into his room and she was not up on his chart is very daunting. People with physical disabilities, who cannot get out in and out of places—it is very daunting. I am just asking the government to think about not just now, but what the future holds for a child when their family is gone. Thank you.

Mr Palmer: I am with Riverlink. We have been around for about 30 years. We provide community access and individual in-home support. As a small to medium organisation, I would just like to inform you that a lot of the processes that fall on our organisation as a result of the NDIS mean an increase in staff. They also mean that a lot of our carers and participants—a large number are from non-English-speaking backgrounds—are not able to understand the process and are quite intimidated by the whole thing. Part of the support prior to planning is large, but even after the plans come back and parents have concerns, they constantly ring us because they know us. So we are providing a lot of support that is—I hate this word—non-billable. My concern is that if we continue this way, just like other small organisations, we will just not be able to survive. We will be unsustainable. As a result of that, our carers and participants will have less choice. That is really important for them, and that is one of the important things about the NDIS.

ACTING CHAIR: I would like to say that this is a joint standing committee of the Australian parliament. It is charged with inquiring into the implementation, performance and governance of the NDIS in addition to the administration and expenditure of the NDIS. Clearly, all the evidence that we take formally from witnesses and

the contributions from audiences like yourself form the basis of our deliberations. We can seek the appropriate answers from the government agencies and then recommend, very clearly, evidence-based solutions to many of the issues that have been raised here today. The whole committee is bipartisan and wedded to that outcome—we want to get evidence-based solutions to the many problems that have been raised here. This is a tremendously difficult area of public policy, as we have experienced here today. There are a lot of really difficult issues. We are all completely bipartisan and looking forward to trying to present some evidence-based solutions to the issues that you have raised here today. I commend you for all the work that you do in your communities, representing and caring for people. Thank you very much for your attendance here today. Do we have a final contribution?

Ms Varga: I am representing Family Advocacy. We are not-for-profit organisation that is a disability advocacy organisation. We represent New South Wales, including the Western Sydney area. We have been around for about 25 years. We were formed by families that have a person with a disability. Our overall objectives and aims are very much in alignment with the objectives of the NDIS. Our goal is to advance and protect the right of people with a developmental disability to achieve meaningful lives and enjoy the same opportunities and living conditions as the majority of Australians.

We created Resourcing Families about a decade ago. It is designed to inform and resource families to support their family member with a disability to live a meaningful and typical life, like we all wish for. So it is very much in alignment with the whole concept of self-direction, which we understand is being given a very short uptake at the moment. I think the figure that has been thrown around is about eight per cent of self-direction being taken up nationally. From our perspective, we wanted to look at what barriers are in place at the moment. We welcome the opportunity to give you our input, so thank you for hearing us.

Echoing a lot of the comments today, the bureaucratic nature of the system at the moment is creating issues that are alienating, ultimately wasting time and creating mistrust. Referring to what many people have raised regarding the process from the very beginning, with the preplanning process, the feedback coming from our families is that the LACs are ill-equipped. They have a very superficial knowledge of disability and also what it means to be self-directed. Obviously, that is an issue which we wish could change and that there could be some more in-depth and broader training at that preplanning level. This would ultimately lead to fewer reviews and less work for the agency clogging up the system and further down the track at the Administrative Appeals Tribunal level.

There is the issue of the portal and the practical frustrations that people are going through. One of the ladies mentioned being a registered provider and the onerous process involved. It is quite costly in time for a sole trader just to put a business plan together. It is important, we recognise, to have safeguards in place so that people have qualified assistance and support, but it seems to be too onerous a process for somebody who is a sole trader. We would say that that is creating an unnecessary barrier for people who wish to self-direct. If you choose, say, to self-direct but plan and manage the financial part of it, or the payment of the invoice, you have to have a registered provider and you are subject to the price guide. That cuts that option out for people, so there is no real true choice and control.

ACTING CHAIR: Thank you very much for that final contribution.

Ms Varga: Sorry, I have not finished. The review process that we are experiencing—

ACTING CHAIR: If you have this in writing, you can submit it. We are barely going to—

Ms Varga: I have been waiting patiently today; I would appreciate having the opportunity to speak, if you could—

ACTING CHAIR: Go ahead, please. I was just saying: if you have it in writing, feel free to submit it.

Ms Varga: Thank you, I will. There seems to be little information on what entails support coordination and what the criteria would be, so we would ask for some public information to be provided about that—obviously in plain English and language that is accessible to people from a non-English speaking background.

There seems to be a lack of transparency in terms of the plan itself. It would be wonderful if there could be a draft plan provided to the participants so that they could check that the information was correct, that the goals were correct and that their choices were correct so that they could sign that off and there would at least be agreement. Administrative issues that clog up the system with unnecessary reviews could be avoided.

Finally, the lack of flexibility in the plans, that painful process associated with the price guide—it would be helpful if things were simpler for people to understand. The fact that I am here today representing families also suggests the importance of advocacy being provided. There has been mention from New South Wales government that advocacy will be provided out of participants' NDIS plans. We obviously do not agree with that approach and

would push for the New South Wales government to continue to support advocacy to provide support to these vulnerable people that have a disability. Thank you for your time. I appreciate it.

ACTING CHAIR: Thank you very much.

Ms Varga: I also have one of our family members who has come along with us today who would like to say something very briefly. Would that be okay?

ACTING CHAIR: I am sure it will be okay, but we may lose people as we go through. That is all.

Ms Varga: Thank you.

Ms Naing: This is my daughter, Laura Naing. She has just graduated. We have a success story with our plan-managed NDIS. I set up a plan management for her, and it has been an amazing story. We would like to share the process of it and then the ups and downs of the local area coordinator and some grey areas on this path. Having an insight into the scheme, as I planned my daughter's funding, there are a number of areas where communication, implementation and delivery arrangements need to be improved in order to deliver the scheme fairly, effectively and efficiently. What I have come across is: either you get a good or bad egg. I was fortunate enough—and I strongly advise that, if you are a carer, that you and your family go and get yourself trained if you wish to self-manage or plan manage. There are safeguarding quality measures in place and, when something goes wrong, you can actually navigate them yourself.

I represent my CALD background, a non-English speaking background. If you do not have informal supports, get formal supports like advocacy, family advocacy, Diversity and Disability Alliance, self-advocacy and NSW Council for Intellectual Disability. That is what they are for. If you do not ask in the pre-planning and you do not advocate for yourself, you will have no idea how to meet your goals. If you have a co-existing disability, you will not know the jargon of core supports and improved lifestyle support. Core support is for you to employ a support worker. For improved lifestyle choices, you must state that at the very beginning of your pre-planning. There is a set-up cost and an administration fee. Like the CEO of Plan Management Partners said—and I totally have to agree—it is hassle free and it is transparent. I can look at the invoice from my place, I can estimate how much I have used and I am able to employ two, or possibly three, support workers around Laura's support needs in community participation, civic duties and her social, emotional wellbeing.

It has worked. It is value for money and it is good economic growth. So a system in place is evidence based. She has no dead times. Her five-day program is locked. I am able to employ two or three support workers, negotiate the pay, the hours and the conditions. Get your ABN set up but, most importantly, carers and families, please go and get resources, information, forums, workshops and get yourself trained to be safeguarded. The teachers at TAFE in the community sectors are well equipped. Make sure that you are well equipped because if something were to happen to your loved one you can actually navigate it yourself. If there is sexual exploitation, abuse or neglect, you have the power. This is social revaluation. Value people. My daughter and many thousands—460,000—have valued roles in the society. Treat them with respect and dignity. They have the choice to practice dignity of risk.

Community education is very important. Coming from an education background, I have seen some barriers. I have resigned as a school learning support officer. I have upgraded my skills to be able to set up my daughter's plan. She is doing so well. She is full of energy, she is not isolated, she is not depressed; she just wants to make a difference. She can make a difference. Plan management can work. Get those skills-based goals and the basics right. It is value for money. Cover yourself. Go and get yourself trained. That is what formal supports are. Advocacy groups are here to support and to get what you ask for if reasonable and necessary. It is value for money for the long economic growth.

I strongly advise a lot of carers and families to go down this path. It might not suit every individual; every individual is different. But that is what is great. You have the flexibility and different components. I have a service provider that Laura goes to, Nova Employment, for a two-year program and open employment to train her up. Then she is booked in for community participation at the local gym five days a week. Education is very important. It will start at school, and then at the community and at the workplace. It is everybody's business. Nongovernment and government agencies—it is everybody's business. Local businesses and small businesses—it is everybody's business. We have one vision and one goal.

ACTING CHAIR: Can I just ask you to wind up. There are people with travel plans and we are long way from Sydney Airport and some people would like to get home; that is all.

Senator SIEWERT: Or go to the next committee.

ACTING CHAIR: Or attend the next hearing, yes. Thank you again for your contributions here today. I do reassure you that the *Hansard* will be evaluated and the core issues identified and forwarded to the respective

agencies. Then we will have the agencies giving evidence in the terms of the questioning we have drawn from these sessions we have had. So we are looking forward to getting some positive solutions to these many and varied problems we have evidenced. Thank you very much.

Committee adjourned at 16:09