REPORT ON PROCEEDINGS BEFORE

PORTFOLIO COMMITTEE NO. 2 – HEALTH AND COMMUNITY SERVICES

IMPLEMENTATION OF THE NATIONAL DISABILITY INSURANCE SCHEME AND THE PROVISION OF DISABILITY SERVICES IN NEW SOUTH WALES

CORRECTED

At Jubilee Room, Parliament House, Sydney on Monday 17 September 2018

The Committee met at 9:20 am

PRESENT

The Hon. Greg Donnelly (Chair)

The Hon. Scott Farlow
The Hon. Paul Green
The Hon. Courtney Houssos
The Hon. Shayne Mallard
The Hon. Bronnie Taylor
Ms Dawn Walker

CORRECTED

The CHAIR: Welcome to the first hearing of this inquiry of Portfolio Committee No. 2—Health and Community Services into the implementation of the National Disability Insurance Scheme [NDIS] and the provision of disability services in New South Wales. This broad-ranging inquiry will consider a number of issues centred around the implementation of the NDIS and how disability services are provided to the people of New South Wales, including the effectiveness and impact of privatising government-run disability services, the experience of people with complex care and support needs within the scheme, and the provision of support services for people with disability regardless of their eligibility for the NDIS. It is important to point out that this inquiry is not intended to investigate individual cases; rather to consider broader policy solutions to issues raised in the terms of reference.

Before I commence, I acknowledge the Gadigal clan of the Eora nation who are the traditional custodians of this land. I also pay respect to elders past and present of the Eora nation and extend that respect to other Aboriginal persons present or listening to this broadcast. As I said, today is the first of two hearings to be held as part of this inquiry. Today we will hear from the NSW Government, National Disability Insurance Agency and National Disability Insurance Quality and Safeguards Commission. This afternoon the Committee will also hear from peak organisations in the disability sector as well as a panel of individuals and carers.

I will now make some brief comments about the procedures for today's hearing. Today's hearing is open to the public and is being broadcast live via the parliamentary website. A transcript of today's hearing will be placed on the Committee's website when it becomes available. In accordance with the *Legislative Council's Guidelines for the Broadcast of Proceedings*, while members of the media may film or record Committee members and witnesses, people in the public gallery should not be the primary focus of any filming or photography. I also remind members of the media that they must take responsibility for what they publish about the Committee's proceedings. It is important to remember that parliamentary privilege does not apply to what witnesses may say outside of their evidence at this hearing. I urge witnesses to be careful about comments they may make to the media or to others after they have completed giving their evidence. Such comments would not be protected by parliamentary privilege if another person decided to take defamation action. The guidelines for the broadcast of proceedings are available from the secretariat.

There may be some questions that witnesses could only answer if they had more time or with certain documents to hand. In those circumstances witnesses are advised that they can take a question on notice and provide an answer within 14 days. I remind everyone here today that Committee hearings are not intended to provide a forum for people to make adverse reflections about others under the protection of parliamentary privilege. I request witnesses to focus on the issues raised by the inquiry's terms of reference and avoid naming individuals unnecessarily. Witnesses are advised that any messages should be delivered to the Committee members through the Committee staff. To aid the audibility of this hearing I remind both Committee members and witnesses to speak into the microphones in front of them. In addition, several seats have been reserved near the loudspeakers for persons in the public gallery who may have hearing difficulty. I now welcome our first witnesses from the New South Wales Government.

ELIZABETH KOFF, Secretary, NSW Health, sworn and examined

TIM REARDON, Secretary, Department of Premier and Cabinet, sworn and examined

MICHAEL COUTTS-TROTTER, Secretary, Department of Family and Community Services, sworn and examined

PETER SEVERIN, Acting Secretary, Department of Justice, sworn and examined

The CHAIR: Mr Reardon, I understand that you wish to make a brief opening statement on behalf of the Government. After your opening statement the questions will be shared between the Government, Opposition and crossbench members.

Mr REARDON: Good morning and thank you for the opportunity to make some brief opening remarks to provide context. The NSW Government welcomes the Committee's inquiry into the implementation of the National Disability Insurance Scheme [NDIS] and the provision of disability services in New South Wales. I am here today together with my colleagues: Secretary of the Department of Family and Community Services, Secretary of NSW Health and Acting Secretary, Department of Justice. Together with the Secretary of the Department of Education and the Secretary of NSW Treasury we compromise the New South Wales board of the National Disability Insurance Scheme, which is responsible for overseeing the role of New South Wales in the implementation of the scheme. The NDIS is a once-in-a-generation initiative but in many ways it has also been the culmination of a decade or more of disability reform.

New South Wales first began investing over a decade ago in a more flexible, person-centred, specialist disability services to respond to needs identified by people with disability and the sector more generally. The scheme is often talked about in numbers—dollar figures and the number of people accessing it—and while all of that is important, it is not at the heart of it. The scheme is about supporting people with disability to reach their full potential and to exercise the same right of all Australians to have choice and management over their lives. It is a scheme for people with disability and it is owned by all Australians. This is why the Government is proud to have been the first State to commit to and achieve the full roll-out of the NDIS and there are positive early signs. As at the end of August 2018 more than 997,000 people were accessing the scheme in New South Wales. That is 97,000 people who are now better able to receive support based on their personal goals and aspirations, have choice over from whom they receive support, and live life their way.

All Australian governments have an important stewardship wrong in working together to make sure the scheme delivers on its potential. A distinctive feature of the NDIS is that it is both co-funded and co-governed by every jurisdiction. While funding responsibility is shared, so too is decision-making. The scheme has enabled a robust intergovernmental governance structure including the Council of Australian Governments [COAG] comprised of first Ministers, the Disability Reform Council comprised of disability Ministers and Treasurers, and supporting working groups of government officials. The scheme will reach its full potential only if all governments remain committed to working together to make it happen.

The New South Wales Government takes seriously its stewardship role and it needs to play that role to make the scheme as effective as possible. That is why New South Wales' transition to the NDIS has been guided by the secretary level NDIS Board, which was first established in 2015, supported by a dedicated NDIS reform group in the Department of Premier and Cabinet, which has provided whole-of-government coordination and project management. Our approach, coordinated and whole of government, has been critical to the successful achievement of transition to the full scheme NDIS and, in particular, the transfer of more than 99 per cent of existing disability clients as at the end of August 2018, the transfer of almost all services, and well over 9,000 direct service delivery stone transferred to non-government organisations.

In addition, New South Wales has invested significantly in residual services to support the early years of transition. Eighty-five per cent of New South Wales scheme participants surveyed in the last quarter of 2017-18 rated their satisfaction with the National Disability Insurance Agency [NDIA] as either good or very good. Just as it took us many years to get to this point it will take some years yet for the scheme to reach full maturity and achieve all intended benefits, and even higher customer satisfaction results. We are committed to doing just that. While all governments have a stewardship role in relation to the NDIS, it is the responsibility of the Commonwealth to administer it through the NDIA. To be clear, the NDIA is the administrator of the scheme and works with the NDIS Quality and Safeguards Commission, which is responsible for ensuring the quality of funded services and the safety of participants. Those two organisations are accountable for day-to-day customer service delivery for people with disability using the scheme. The NDIA has New South Wales' support, and that will not change.

Lessons around the ongoing implementation of the National Disability Insurance Scheme will continue to be learnt. The current inquiry will be an important source of those learnings. The Committee can assist the ongoing efforts of all governments to achieve the full benefits of the NDIS by reaffirming its commitment to the scheme and the potential it brings, identifying immediate improvements that can be made to service delivery, reinforcing the lines of responsibility in relation to decision-making and day-to-day administration of the scheme, and supporting the NDIS' focus on improving outcomes for particularly vulnerable and complex clients and resolving mainstream interface issues.

In conclusion, I reiterate the New South Wales Government's ongoing commitment to improving outcomes for people with disability in this new customer-empowered environment. We will work to achieve the successful implementation of the full scheme NDIS and ensure that it is achieving the intended outcomes, fulfil New South Wales' enduring responsibility to provide accessible mainstream services under the Disability Inclusion Act 2014 for all people with disability, and build an inclusive community. New South Wales is the largest State to transition to the scheme. We are also the first. We are committed and indeed proud of where we are at now and will be unwavering in driving further improvements for the scheme across this State.

The CHAIR: Thank you very much, Mr Reardon. We appreciate the opening statement. We will now move to questioning, if that is satisfactory.

Mr COUTTS-TROTTER: Sure.

The Hon. COURTNEY HOUSSOS: Thank you very much for your time. I refer to the New South Wales Government's submission, which states that New South Wales has taken a strong lead in clarifying some of the responsibilities between the State and the Federal Government. How much of that has been left to individual departments?

Mr REARDON: I will begin and then pass across to the Secretary, Department of Family and Community Services. The National Disability Insurance Scheme Board was established in 2015, as I said in my opening remarks, to basically bring us together as a single one-voice New South Wales approach. That coordination has been very important for us. The collegiate role of having six secretaries out of 10 for the New South Wales Government together on a frequent basis, chaired by the Secretary of the Department of Family and Community Services and supported by the remaining secretaries, indeed has been a very collaborative and focused approach. It has really helped us with our Go Live activity leading to 1 July 2018, but it has been going on for some years.

That has been supported by a dedicated project team within the Department of Premier and Cabinet being the central and lead agency. That has worked really effectively. That has worked because we have had very strong alignment between Premier and Cabinet in that coordinating and project management role with each agency to understand what the interface issues are, and to remain very focused on Go Live readiness, likely would for any other project. That has been an effective arrangement. In terms of our interaction with the Federal sphere, the interaction is at several levels: first, on day-to-day management, clearly, Family and Community Services interacts with the NDIA on day-to-day operations, particularly as we have transitioned to Go Live. Within the governance, the Ministerial Council for Disability Services has been important but that also flows into the full COAG agenda and first Ministers.

Our alignment has been good. We will continue to learn lessons. We would be happy for any comments that the Committee might have on that. But from where we sit right at the moment, we put governance in place that has been reasonably enduring for several years now and certainly project management that has been quite strong, and we have treated it in a very methodical manner in terms of the rollout. We continue to manage risks. We continue to manage issues, as you would with any other program, but it has been quite a complex but well-defined and coordinated approach we have taken. That is an overarching view.

Mr COUTTS-TROTTER: I will quickly add that underneath the Disability Reform Council and Disability Ministers there is a senior officers working group, but there are working groups looking at the interaction between the scheme and particular services. There is a group on health. There is a group on justice. There is a group on mental health and there is a group on child protection. That is, at a higher policy level, where these inevitable points of clarity are being worked. But inevitably there will be work that had to happen to get clarity on some of this, and those working groups are the kind of key place where that happens at a high level.

The Hon. COURTNEY HOUSSOS: I am interested not just at a high level but at an individual level. Obviously I appreciate the magnitude of the scale. I would be interested to hear also from the Secretary of Health and the acting Secretary of Justice as well because a lot of these issues obviously are being ironed out on a case-by-case basis. Mr Severin and Ms Koff, do you have individuals within your organisations that are assisting with that for people who are currently within the Health system or currently in the Corrective Services system who are trying to seek support through the NDIS or the NDIA?

Ms KOFF: I can respond in terms of the Health position on that. Under the governance of the health system with the local health districts we established an NDIS coordinator or leadership position within each district because, with the high level governance that is well established at a whole-of-government level, it is the issues on the ground at the operational level that represent the day-to-day challenges. We established the NDIS coordinator leader positions within Health and also have a governance structure at the system-wide level at the State level for NSW Health and NDIS issues management. As described by Mr Reardon earlier, when we have issues that we have trouble resolving at those local areas on a case-by-case issue, we escalate through the normal channels via the NDIS senior officers group and the board. They have been escalated accordingly.

The other part of the governance that I think it is important to understand also is that all the Health secretaries across the country meet as part of the Australian Health Ministers' Advisory Council [AHMAC]. In the recently negotiated Health Reform Agreement, we have identified interface issues between the NDIS and Health systems nationally as an issue that we need to be fully aware of and understand what the challenges of the interface issues are. The response to health occurs at a number of levels to ensure that we are delivering the best service possible for the clients for the NDIS.

The Hon. COURTNEY HOUSSOS: I come back to the specific positions that you referred to, are they the transitional leads?

Ms KOFF: Yes, that is right.

The Hon. COURTNEY HOUSSOS: And the Mental Health Champions?

Ms KOFF: Yes.

The Hon. COURTNEY HOUSSOS: How long have those positions been in place for?

Ms KOFF: They were rolled out sequentially in response. First of all we had the trial sites at Hunter New England and then Nepean Blue Mountains and we understood the requirements of the role through the rollout of those sites. Then they have been rolled out accordingly to when the NDIS is rolled out. The time frames, I could not tell you exactly.

The Hon. COURTNEY HOUSSOS: Could you take that on notice?

Ms KOFF: Yes, certainly.

The Hon. COURTNEY HOUSSOS: Is there a position within NSW Health, not within the local health districts, that is designed to be interacting with the NDIS on a case management system?

Ms KOFF: Yes. Within the government relations department the executive director is the main interface and there is a core team that deals with the issues. It would be fair to say also that Department of Premier and Cabinet [DPC] has been assisting us in having discussions with the National Disability Insurance Agency [NDIA] and the application of the applied principles for criteria for entry into the NDIS.

The Hon. COURTNEY HOUSSOS: Can you tell me the title of that position with the government relations department?

Ms KOFF: The Executive Director of Government Relations Ms Jacqueline Ball is the lead for the NDIS within the ministry and her staff members, the team, sits below that position.

The Hon. COURTNEY HOUSSOS: Is that a new or existing position?

Ms KOFF: No. Because of the importance of getting the implementation of the NDIS right, we created a special team within government relations branch to assist in the delivery of that and there is a guidance committee that does have clinical representatives on it also.

The Hon. COURTNEY HOUSSOS: When was that established?

Ms KOFF: I will take the date on notice if I could.

The Hon. COURTNEY HOUSSOS: Can you give me a general idea? Was it in the last three or four months?

Ms KOFF: No, well before that. We have been on the journey with the rollout since 2015 and as the program has expanded, both in size and scale, we recognised early we needed to have a coherent response, so it was well before the last three or four months.

The Hon. COURTNEY HOUSSOS: I will ask Mr Severin?

Mr SEVERIN: In the Department of Justice the responsibility for the broader policy coordination rests with a division, Justice Services, and within that we have a diversity services group that is particularly focused on that. In the service delivery arms of the Department of Justice, particularly Corrective Services, obviously Juvenile Justice, Trustee & Guardian and the Public Guardian, there are various varied arrangements in place. Talking about corrections, we have a statewide disability service coordination group that very early in the time engaged in the transition from the previous model to the new model. They have very strongly focused on ensuring that those offenders who at the end of their sentence get access to the program.

Nationally, the health administrators of Corrective Services—as have the Ministers—have very actively engaged with the Commonwealth for a number of years. There were a range of issues, as one could understand, to be addressed in that very specific space. That work is currently coming to an end because we consider that in terms of transition we have reached as much as we can collectively, but that is not to say that will not re-emerge. Fundamentally, it is quite obviously a complex process for those that are in custody or are under the guardianship of Trustee & Guardian or the Public Guardian or Juvenile Justice, the complexities are being managed very proactively.

The Hon. COURTNEY HOUSSOS: I understand that there are new positions that have been advertised for new roles within NSW Health and the Department of Justice, amongst others, which are designed to have this case management role since the effective abolition of the Department of Disability Services in New South Wales. Perhaps this is a question for Mr Reardon: Why was the decision taken to put them within existing departments rather than instead to retain a role for the Department of Disability Services?

Mr REARDON: I will either have to take it on notice, or the Chair of the NDIS board might have a comment on it.

Mr COUTTS-TROTTER: I think the important conceptual backdrop to this is inclusion. What we have seen over a long period in New South Wales and other jurisdictions is a terrible lack of clarity in this area and an inability within some of the mainstream service systems for Health or Justice or Education to provide a strong and appropriate response to people with disabilities. The NDIS, much of the focus is drawn to people who have funded packages, but the great bulk of the reform is about equipping the community and universal government services to better meet the needs of people with disabilities. We strongly believe the fact that my colleagues are making, that a priority and building capability inside their own agencies is a really positive step. They are taking responsibility for it.

As I say, we see that as completely congruent with the Disability Inclusion Act 2014, and the responsibilities we all have to make our service systems disability capable. I think the old days of relying on a specialist agency was a necessary reality but it was a rationed system. It was a system where people looked to Ageing, Disability and Home Care NSW [ADHC] and now we have a system that is no longer rationed, that is imbued with a principle of inclusivity and where people with disabilities get to exercise choice and control, which includes making their way through universal service systems as they choose to.

The Hon. COURTNEY HOUSSOS: I stop you there; I appreciate that and I do not think there is anyone on this Committee who disagrees with the important work that the NDIS is doing. I am interested from a New South Wales Government perspective why a decision was made that there would not be an overarching view, that it would not be run out of the Department of Disability Services, instead it would be partly run out of DPC and partly left to individual departments, and why at a time when effectively an entire department was abolished other departments were recruiting to fill the gaps?

Mr COUTTS-TROTTER: I think the approach is a coherent approach. There are issues that fall appropriately to a lead Minister's agency. We are working at a national level on those big system interface issues, but individual agencies in New South Wales are simply reflecting their proper responsibilities to be disability capable and disability inclusive.

Mr REARDON: We are discharging our duties and in terms of the central agency in our Premier and Cabinet. As I noted before, we do have a strong role to play and we are playing that. We have resourced it appropriately and we will stay at that for a transition period that will monitor how the scheme continues to roll out and adjust accordingly if we need to. As Mr Coutts-Trotter pointed out, agencies then play the role that they effectively play. We look at the interface issues as they arise, but we will remain as Premier and Cabinet strongly engaged for some considerable period, both in terms of how we as a coordination group across New South Wales continue to work together and how we advocate our arrangements in governance that we described earlier with the Commonwealth.

The Hon. PAUL GREEN: To make it very clear, people are asking, "Why are we going into the NDIS when it is now a Federal issue?" I make it very clear: "Because we have jurisdiction for the welfare of the people of New South Wales. That is why we are here trying to work towards ensuring that none of them are left behind with this service transition." The Committee has received more than 300 submissions. I will pick out some key points. One is the inadequate funding and inconsistencies. I will paint a picture and ask for comment. The NDIS commissioned report in 2016 regarding support for preschool children with autism recommended 20 hours of intensive intervention for all children with autism regardless of their level of autism. The NDIS is funding this for some children and not for others. It has also been noted by parent advocacy groups that families in Canberra seem to consistently receive funding for 20 hours of therapy, compared with families in New South Wales who receive much smaller sums. Do you have a comment on the inconsistencies and inadequacy of funding for programs? I will then come back to the autism issue. Who is evaluating those benchmarks?

Mr COUTTS-TROTTER: The discussions should be consistent nationally and should be made consistent nationally by the National Disability Insurance Authority planners. I know our NDIA colleagues will soon take the stand, so I will leave the detail to them. We would expect a consistent approach.

The Hon. PAUL GREEN: The NDIA is endorsing best practice for children with autism. What are we doing to ensure best practice is being achieved? What are we doing to evaluate what is happening and who is keeping them accountable? It seems that best practice is not being achieved for children with autism or those on the spectrum.

Mr COUTTS-TROTTER: One of the things we are collectively trying to do in New South Wales is to identify the information we need to know whether or not the aspirations and ambitions for the National Disability Insurance Scheme are being realised. There are obvious areas to look at, such as the proportion of people with disability who are working, increasing their work or taking on study and the proportion of carers who in turn can do that. However, there is a range of indicators that would go to wellbeing and, over time, the kind of trajectory people experience as a result of being participants in the scheme.

By that I mean the whole design of the scheme takes an investment approach; that is, you provide the right supports at the right point to maximise someone's outcomes over life and to reduce the costs over a lifespan, rather than take the approach of the old systems where we focused on one-year, two-year, three-year and four-year budget cycles. We would say it is really important for us in New South Wales to gather that data and to use it to work with our Commonwealth colleagues to ensure that the ambitions of the scheme are being realised. It is about outcome data.

The Hon. PAUL GREEN: Talking about data, it was stated in one of the submissions that a person who has 15 years of specialised medical training is finding it difficult to navigate the NDIS or NDIA systems. Given that, what hope do everyday parents have who do not have a clue about the health system? What are we doing to ensure they are able to understand the new lingo of the NDIS? Many of them are being left behind. If a specialist doctor is finding it hard to manoeuvre through the system, what are we doing to break it down to simple terms for parents who do not have that academic knowledge?

Mr COUTTS-TROTTER: In New South Wales over the past three and half years we have run three communications campaigns—we are about to run a fourth—that attempt to do precisely that. They explain how people can access the scheme and talk in very plain language about what they can expect and what they need to do to prepare themselves for the planning process. You have seen recent announcements from the Commonwealth that the NDIA is investing to develop the skills and capabilities of its planners and to provide specific pathways for children, including of course children on the autism spectrum, for Aboriginal people, culturally and linguistically diverse groups, and people with particularly complex disability where it has been very clear that the existing processes do not work well enough for them. To its great credit, the agency has recognised that and it is investing to change and to make it a better and more helpful process for people with disability and their families and friends.

The Hon. PAUL GREEN: I am concerned about rural and regional parents who are fairly simple and who do not have academic or health training. If there are inconsistencies with funding, they have been told they have received 70 per cent of the early intervention funding to help their child and that they are expected to be the therapist for the other bit. These are mums and dads who are highly strung because they have a child with huge needs. The last thing they need to be told is that they must also cover 30 per cent of the therapist funding. They are being told that they must now take on the additional role of therapist. That is a big concern for me in rural and regional areas. Those people do not have access to the sorts of things city people do. They need an agency that walks beside them that speaks their language and not double Dutch or Chinese. It is like teaching these people Chinese. They simply do not get the system because it is too complex. All they want to do is to help their child.

Mr COUTTS-TROTTER: New South Wales agencies have stuck our hands up early and enthusiastically to say to our colleagues at the NDIA that we want to work with them in partnership as they develop these new pathways. We will bring our expertise to bear in Health and from the Department of Family and Community Services because we recognise it needs to improve. There is no doubt that it needs to improve.

The Hon. PAUL GREEN: That is what this is about.

Mr REARDON: My opening comments were about exactly that—the lessons learnt to date and the next steps we need to take. In terms of communications, we did put in a lot of effort leading up to 1 July in delivering plain English communications across the State. If there is any data, particularly in regional areas, that it is not cutting through, we would be very happy to see it. I mentioned the NDIS board several times simply because we have been together for multiple years and we will be together for some time yet, and so will a group delivering within the Department of Premier and Cabinet. If there are areas where we need to focus further on plain English communications about the scheme and how an individual customer interacts with the scheme, we will take that on board.

As you know we have done a lot of work on customer satisfaction with Service NSW. As a group in New South Wales, our expectations for people with disability accessing the NDIA are that they will get exactly the same customer satisfaction. I mentioned that it is 85 per cent. We clearly all want to see that at a higher rate going forward, and we will stay fairly focused. Our communications campaign was reasonably effective over the transition period on 1 July, and we are more than happy to take on board any further feedback we need if there are pockets where we should increase our efforts, particularly in rural and regional areas.

The Hon. SCOTT FARLOW: Thank you for being here today. I will pick up on the first point that 99 per cent of people have been transitioned to the NDIS in New South Wales. Can you elaborate on what the Government is doing to fund residual functions above and beyond our contribution to the NDIS, particularly for the 1 per cent who have not been transitioned?

Mr REARDON: The Government has focused very heavily on residual functions and transition. There is a range of areas. The comments about changes refer also to changes in agency arrangements. That has been done to ensure we do not see anything fall between the cracks. We have supported and funded a range of activities and home and support services. The board as a group has certainly ensured that it has collated all of those residual functions and put a position to the Government about ongoing residual funding to ensure we get a smooth as possible transition path. They cover Health, Justice, Education and Family and Community Services in particular. I will ask Mr Coutts-Trotter and others to provide comments on the specifics.

Mr COUTTS-TROTTER: The only detail I would add is that we recognise in this period of transition while we are all learning as we go that there is a range of things we need to do to give the NDIS the best chance of delivering on its promise, and also to manage the risks in that transition. For example, the Government has continued funding to Ability Links NSW for a so-called community safety function to ensure that people with cognitive disability moving out of the justice and health systems do not fall between the cracks. They are very vulnerable to being victims of the crime, and some people are also at higher risk of being perpetrators. It is really important that in this transition period we do not drop the ball on those important wraparound supports for people moving between those systems.

We have a cognitive impairment diversionary project being trialled in a couple of areas in the State. We have an integrated service response hosted by Health, that attempts, in this transition period, as we are learning, to make sure that there are wrap-around supports and we do not have people falling between the gaps in new and emerging systems. So there is an awful lot happening, but we remain really optimistic that a lot of this is just issues of transition, and that the scheme is already demonstrating that it offers the prospect of solving problems that have existed in New South Wales and other States for people with disability for a very long period of time. But there is this period of transition, where things are not mature, things are not bedded down and people are still learning. The Government has committed two or three years funding to a range of interventions to manage the risks of that transition.

The Hon. SCOTT FARLOW: What is the quantum of that funding? What are we looking at?

Mr COUTTS-TROTTER: In Family and Community Services it is $150 million over three years. So, actually, from last year to this year, our disability service budget through FACS rose by about 7½ per cent—a very significant increase in funding.

Mr REARDON: You might just add the 2018-19 numbers.

Mr COUTTS-TROTTER: Sure, or if you have them there—

Mr REARDON: As Mr Coutts-Trotter pointed out, for three years there is $150 million. In 2018-19 that was around an $87 million allocation. Michael pointed out a range of those areas already—ability links; sports for children with disability residing outside the family home; restrictive practices; authorisation; community safety, which was mentioned; transitional advocacy grants; and disability administration and oversight. That is just for FACS; there are others across other areas of government agencies, which I went over broadly. They are areas such as the Office of Public Guardian, the NSW Trustee and Guardian, the New South Wales Civil and Administrative Tribunal and support for people in contact with the criminal justice system, community transport, allied health and behavioural intervention in schools. Those areas, and a couple of others, are the areas. As I said, we had quite a long list to take to Government seeking allocation to ensure we had as smooth a transition as possible and that the interfaces were identified and dealt with so we did not have gaps. That is what Government has allocated back to us.

The Hon. SCOTT FARLOW: Mr Coutts-Trotter, picking up on some of your comments before, and reading between the lines—I will use my words, not necessarily attributing them to you—with respect to the disability positions that are now being taken up by agencies, it seems that previously there had been a view within Government that if it fell into the disability bucket, so to speak, it was ADHC's responsibility and not necessarily the department's. Now, with the NDIS being in place, and clients being transitioned across to the NDIS it seems that Government agencies are taking a more proactive role in their responsibilities as part of the disability inclusion plans. Would that be a fair assessment?

Mr COUTTS-TROTTER: Yes, absolutely. We make much of the fact that there is a secretaries' board. I think people outside government may scratch their heads and go, "What's the significance of that?" Every month the heads of agencies are meeting and working through the detail of these issues. Predecessors of mine, who might have headed ADHC would have given their back teeth to have the opportunity to get agency heads together each and every month to work through—

The Hon. BRONNIE TAYLOR: Service coordination!

Mr COUTTS-TROTTER: Yes, service coordination and the disability capability of other, partner agencies. It is a genuine reflection of a focus on inclusion. We know we have a lot of work to do.

The Hon. SCOTT FARLOW: So, New South Wales was the first State to sign up to the NDIS.

Mr COUTTS-TROTTER: Yes.

The Hon. SCOTT FARLOW: How is the New South Wales experience compared to some of the other States? I know, for instance, when it comes to mental health, other States have decided to give up all of their responsibilities and largely invest just in NDIS. New South Wales has continued its mental health funding. Ms Koff might like to speak on that. Are there any other examples of how New South Wales is different to other States, and where you think perhaps we have it right or other States might have it right?

Mr COUTTS-TROTTER: Personal view: firstly, there has been 15 years of disability reform in New South Wales. It has been multi-partisan. It has seen a focus on individualising supports for people with disability. It has seen significant, year on year increases in funding, and the NDIS was the next logical step in that continuum of reform that took place over, as I said, nearly 15 years.

Arguably, if New South Wales had not committed to the NDIS there would not be an NDIS. It was the frisson of a Coalition Government committing to a then Labor Commonwealth Government reform that, I think, locked it in. New South Wales would not have been in a position to do that if it had not been in line with a continuum of reform. Also, New South Wales had the financial ability to make that commitment, in part because we are getting out of the direct delivery of disability services. That has freed up around $200 million a year that was formerly consumed, quite appropriately, inside my agency in management, policy and corporate and administrative support. That has all gone into the National Disability Insurance Scheme. So we were able to commit, without drawing money in from other services, to things like community mental health.

New South Wales—alone, I think—has not taken any money out of the community mental health system and said, "Look, this is disability specific. We are committing that to the National Disability Insurance Scheme." So we have been able to commit to it—the first State to commit to it—with the resources of Family and Community Services, without having to draw resources elsewhere from Government. As I said, I think that was profoundly important in seeing the NDIS delivered. It has also eliminated some of the issues that you see in other jurisdictions about the intersection between the scheme and community mental health services.

Mr REARDON: I just add that I think we will continue to learn lessons, as I said in my opening remarks, but we have gone a long way to understanding how the scheme design and implementation through the NDIA and the interface issues and how other jurisdictions might look at areas such as mental health. I might leave it to

Elizabeth to make a comment on that. What I would say is that being the largest jurisdiction to enter into a national arrangement like this, and being the first, is incredibly important. I support Michael's comment that without New South Wales strongly entering into the NDIS, it may have struggled on the pathway. Us going in early is a significant contributor. Having well over 90,000 people involved in a scheme and ensuring that we get that right—that we get the customer focus and the customer centricity right for those people at that scale—is quite a benefit, I think, for the NDIA as it is implemented further around the country. There will be a lot of lessons learnt for other jurisdictions.

We want to get onto the front foot and keep learning lessons and keep getting the fine-grain detail right here so we do ensure that not just all of the entrants—up to 99 per cent—but any new entrants have a good process, a good customer experience, when they enter the scheme. I think we are long way down the line of doing that. We have pointed out what we said about the NDIS board arrangements. Yes, not only would ADHC really want such an arrangement to be in place for multiple years—because you have the attention of six secretaries out of 10 across the Government—but to have that on a monthly basis. ADHC sat with us right up to the 1 July transition to ensure that they could see how arrangements would be placed into health, education and justice et cetera to ensure that the transition was as smooth as possible. Again, we have still got lessons to learn, but we are a long way down the line. Being the first and the biggest jurisdiction to enter into the arrangement, as I said in my opening statement, we are quite proud of. But we want to ensure that we continue to get it right and we continue to see customer satisfaction rates improve.

The Hon. SHAYNE MALLARD: Thank you for your submission. It was very informative; I appreciate that. In your submission you said:

> As expected, there are some people with disability who were previously receiving disability supports from the NSW Government who are not eligible for the NDIS.

Firstly, could you outline why they are not eligible for the NDIS if they were getting support from State Government. Secondly, what provisions have been put in place to support those people who do not qualify for the NDIS?

Mr COUTTS-TROTTER: There are around 4,000 people in New South Wales who were previously receiving some services from the New South Wales Government who were deemed ineligible to join the NDIS. The overwhelming majority of those people were in the so-called Community Care Supports Program, which provided a range of relatively low-cost supports to people in their homes.

This was identified as an issue back in 2015 when we struck a transition agreement with the Commonwealth and plans were put in place in partnership with the Commonwealth to make sure that anybody in those circumstances deemed ineligible would have some kind of continuity of support. Essentially, that function has done three things for people. For some people who were deemed ineligible it supported them to test that decision and some people have been able to get access to the scheme—the minority of the group. Then there are people, with appropriate supports and the help of family, friends and community organisations, who can manage perfectly well without any additional support.

For example, in one case a person who was receiving cleaning and lawnmowing support through the community care and support scheme got a light-weight vacuum cleaner and a brand new lawnmower and their adult children who were living in the home committed to mowing the lawns instead of having someone come in and do it. Then there were people who were on the brink of being eligible for the Commonwealth aged-care system. Over the past couple of years, around 5,000 people have had that continuity of support provided to them and we extended the funding of that through till the end of September to make sure that the transition was effective. That seems to have worked pretty well.

The Hon. SHAYNE MALLARD: Where do those supports sit within government? Are they in health?

Mr COUTTS-TROTTER: There is a new program in health, safe and supported at home [SASH], which will provide access for some people who may emerge in the future who otherwise would have got access to the community care and support program. They now have an alternative in health. I ask my colleague Elizabeth Koff to add to that.

Ms KOFF: As Mr Coutts-Trotter described, the SASH program is specifically designed for that group of individuals who do not meet the requirement but still need both clinical and non-clinical support in the home setting.

Ms DAWN WALKER: I am interested in the gaps also and I thank you for the information you provided on that particular area. I am interested also in those people who may have transitioned onto the NDIS but have later had the eligibility re-tested and withdrawn. What is the policy and criteria around ensuring that we are aware of those people and what happens to them?

Mr COUTTS-TROTTER: That is fundamentally a question for the National Disability Insurance Agency about the operation of planned reviews. But we know from our experience as a disability service provider that there are people who need episodic supports and who moved in and out of the State disability service system. They have support for some time and then do not need and then possibly need it again—there could be people in that circumstance. But if someone is not eligible for a funded package of reasonable and necessary supports through the NDIA and needs universal services we would hope to progressively build our capability to provide those services to people and to do it well.

Ms DAWN WALKER: One of the other issues that people have to come to me with in regard to the NDIS is around the workforce and the demands on the workforce. The Federal Government has spoken about how the workforce needs to roughly double in size over the next five years to meet the expected demands under the NDIS. Has the New South Wales Government worked to address these workforce challenges in the disability sector?

Mr COUTTS-TROTTER: I give full credit to my predecessors because there has been a long period of working with the disability service sector, industrial partners and training providers to build the industry and workforce capability. For example, since 2011, in New South Wales alone $56 million has been spent by the State Government to build the capacity of providers and the workforce. Most recently, for example, under the Smart and Skilled program, 7,250 students completed a certificate III in individual support. More than $12 million has been spent providing grants for disability businesses to scale up more rapidly, including $4.5 million for Aboriginal businesses. There has been quite a bit of focus from the State Government. In the Commonwealth—and I know my colleagues in the NDIA can talk to this—there is $207 million nationally, including a $110 million sector development fund, a $64 million NDIS jobs and market fund, and a further $33 million to build the capacity of existing providers in both the disability service system and the aged-care service system to expand their operations or come into the NDIS.

In the last year in New South Wales there has been a doubling of the number of registered NDIS providers and there is now 8,500 registered NDIS providers in New South Wales. There is much more to do because, as you say, the challenge of filling all of those roles is really significant. But equally there are opportunities for NDIS participants to, with reasonable and necessary supports, participate more fully in the labour market and for jobs to be created behind this in every nook and cranny of New South Wales. It is a phenomenal opportunity.

Mr REARDON: Could I add to that? First, on the NDIS board and the forecast of where we were up to, 97,000 people with a disability have transitioned into the scheme. We forecast and look at what demand will be going forward and we continue to do readiness checks and will continue to do that for a considerable period. That will include consequential demand on those services. But to what Mr Coutts-Trotter said about supply and opportunity, there is a very big workforce and jobs opportunity within the NDIS. If I go back to one simple example from 2011-12, in the transport sector we looked at the community transport providers—and there is well over 100 of those. There is a few large players and a lot of very, very small players and even back then we started getting them NDIS ready and brought them into the Passenger Transport Act and regulations to ensure that they were considered professional service providers in the transport sector so they could take full advantage of the opportunities that would arise with the NDIS.

It was a six or seven year journey—it was not only in the last year or so—to get them as ready as possible, because we did see that they would have a great deal of opportunity. Opportunity has come out of the NDIS and will continue to come out, notwithstanding the fact that it will have to find a lot more resources and train people differently. Mr Coutts-Trotter has outlined some funding that is going towards that but we see it as an area where there will be a whole range of jobs created that probably were not there before.

Ms DAWN WALKER: I am interested in disability advisory services. We know that funding was withdrawn and then reinstated until 2020. There has been some discussion about whether those advisory services will be encompassed in the NDIS and it seems very clear that they will not be. Other States have picked the funding up. Has anyone got any comments about advisory services and the important role that they play in the community, particular in regional areas, in assisting people with disabilities to access all sorts of systems and be advocated for when they come across issues in every day life?

Mr COUTTS-TROTTER: I will reiterate some of the comments my Minister made during budget estimates. You have described them as "advisory services" but I think in general discussion they are known as "disability advocacy services". We have got the Commonwealth's Information Linkages and Capacity Building program and what we have seen in New South Wales is a $46 million State-specific budget for that program. So far, only $19 million has been expended and the NDIA has signalled that it wants to take a more strategic approach to build the capacity in communities to enable people with disabilities to get access to the services and supports they need outside of the NDIS.

At this point I think the view of government is that so much needs to develop through both the ILC program and the Commonwealth's National Disability Advocacy Program and that some of the concerns we see now may not exist in 12 or 18 month's time. It is a developing set of relationships and the transition funding is there. That gives people an opportunity to make these changes and it gives the Commonwealth a chance to invest through its ILC program to build the capability of its local area coordinators and then for people to take stock in the future.

The Hon. COURTNEY HOUSSOS: Mr Coutts-Trotter, during the budget estimate hearings my colleague who is not here at the moment asked the Minister about young people in nursing homes. Do you remember that?

Mr COUTTS-TROTTER: Yes.

The Hon. COURTNEY HOUSSOS: The number provided was 2,200.

Mr COUTTS-TROTTER: Yes.

The Hon. COURTNEY HOUSSOS: According to the National Disability Insurance Agency's submission there are 1,888.

Mr COUTTS-TROTTER: Yes.

The Hon. COURTNEY HOUSSOS: That seems to imply there are 312 young people under the age of 65 in nursing homes who are not eligible for the NDIS, is that correct?

Mr COUTTS-TROTTER: My assumption about that was that they are not yet participants. I also noticed the discrepancy in those two figures so we are seeking some advice on that, but if you are in a nursing home as a result of your disability I think there is no way known you are not going to be eligible for NDIS support.

The Hon. COURTNEY HOUSSOS: That is right. I am happy for you to take this question on notice but what is the NSW Government doing to ensure that those people do have access to the NDIS as a matter of urgency?

Mr COUTTS-TROTTER: Indeed.

The CHAIR: Thank you all for appearing before the Committee today. On behalf of the Committee I thank you for the most important work that you are doing in overseeing the proper and full implementation of this scheme.

(The witnesses withdrew)

VICKI RUNDLE, Deputy Chief Executive Officer, Government Communications and Stakeholder Engagement, National Disability Insurance Agency, sworn and examined

SCOTT McNAUGHTON, General Manager, Government Relations, National Disability Insurance Agency, sworn and examined

CHRIS FAULKNER, General Manager, Advisory Services, National Disability Insurance Agency, affirmed and examined

STEPHANIE GUNN, General Manager, Critical Services Issues Resolution, National Disability Insurance Agency, affirmed and examined

The CHAIR: Would any of you like to make a brief opening statement?

Ms RUNDLE: Thank you for inviting the National Disability Insurance Agency [NDIA] to appear before the Committee. I appreciate the opportunity of being able to make a few opening comments. I would also like to acknowledge the traditional custodians of the land on which we meet today and pay my respects to elders, both past and present. As I said earlier, my name is Vicki Rundle. I am one of the deputy chief executive officers in the NDIA. I would like to introduce the Committee to my colleagues: Scott McNaughton, Stephanie Gunn and Chris Faulkner. Between us we have quite a lot of experience in the NDIA and a deep understanding of the National Disability Insurance Scheme [NDIS]. We are looking forward to addressing the Committee's questions today. We hope that we can address all questions here but if we cannot then we are very happy to take them on notice.

The NDIA is a world-leading insurance scheme; the first of its kind. This has meant that it has not been without its teething problems. A reform of this significance and complexity is bound to take time. We acknowledge that the roll-out of the NDIS from the start of transition in July 2016 was impacted by a range of process, system and data issues. However, at the end of June this year almost 184,000 participants had entered the NDIS—a 100 per cent increase since June of last year. In New South Wales at the end of June there were 89,600 people benefitting from the scheme and, as Mr Reardon said earlier, in July that number rose to 97,000. The number of registered providers nationally at the end of June was 16,700—an increase of around 93 per cent since the same time last year. In New South Wales there are now around 8,500 registered providers. Nationally more than 50,000 people are receiving support for the first time from the NDIS and almost half are from New South Wales—around 24,000 people.

The NDIA board and management are committed to delivering on the promise that every Australian with a significant and permanent disability, along with their families and carers, can get the support they need to maximise their potential in their communities. The agency is demonstrating this in five key ways. I would like to go through them quite quickly because our submission also picks up some of these things. Firstly, we are demonstrating it through our commitment to the beliefs and principles that underpin the scheme that were mentioned earlier by Mr Reardon and Mr Coutts-Trotter. We recognise that all Australians with a disability have the right to participate fully in and enjoy the benefits of being a member of their community, to have the dignity of being able to find employment to the extent that they can work, and to be respected for who they are as an individual. We are committed to ensuring that we take a whole-of-life view of the person and invest in them early to maximise the benefits they might receive from the scheme.

The NDIS puts the person with a disability at the centre and acknowledges the important role that families, information supports, community and mainstream connections, as well as NDIS supports, equally play in the person's life. This is part of a broader ecosystem that all comes together to give them the lives that we want them to have. Secondly, above all else, we are committed to getting it right for participants. That means we are committed to delivering a scheme that is person-focused and outcomes oriented, a scheme that delivers a quality planning experience. For that reason the NDIA Board embarked on an extensive Pathways work. Our written submission outlines the Pathways work we have undertaken. We can provide further detail if required today.

We are starting to see the payoff of all the work we have been doing, particularly in the last year. I note that our satisfaction rate, which was holding quite steady for each quarter at 84 per cent, rose in the last quarter to 88 per cent. Even more satisfying is the fact that participants are saying that outcomes for them are improving. This is outlined in quite a lot of detail in the quarterly report. We are really proud of this but we are far from complacent. We know that that means that there are still some people who are not having the participant experience that we all aspire them to have. We are intent on fixing that. As we outlined in our submission to you, and can do further today, we have got some significant improvements underway.

Thirdly, we committed the building and marketing of innovative supports and providers. We have a range of initiatives underway in this area including the independent pricing review, changes to our portal and a much greater engagement with our providers. This is essential because, if that is not there, participants will not be able to access quality services in the areas that they need them, and they will not be able to exercise genuine choice diversity; nor will they get the innovation that we are seeking. We also want providers to be able to operate effectively in the NDIS.

Fourthly, we are committed to engaging with other stakeholders, who are the lifeblood of the sector. We can and will do more, but we are making good progress. We have been doing a lot of work with key groups, such as the mental health sector, and people working with complex disability in addition to the mental health sector. More recently we engaged and set up a specialist advisory group in autism. Earlier I heard questions on autism, and we are very happy to address those. We have set up a range of other stakeholder engagement groups, such as our participant reference groups and provider industry forums. They know we are genuinely listening and intent on working with them to get this right. We value and appreciate their support, as we do that of our State and Territory governments, particularly New South Wales with which we work very closely.

Last and certainly not least, we are committed to a financially sustainable scheme. We know that has to be the case if the scheme is to be there for future generations of Australians. Every year to date we have delivered the scheme and we have come under budget. We are committed to ensuring that that is the case always so that the scheme will be there for always. In conclusion, while we continue to have challenges as the scheme matures, as we would expect with a world first of this sort, we are confident that we are making significant progress. We still have some work to do to ensure that new participants in New South Wales get the supports that they need now. We will work very closely with our New South Wales colleagues and other key stakeholders in New South Wales to focus on our issues over the coming year. Chair and Committee members, thank you very much. We are very happy to answer your questions.

The CHAIR: That was a very good and clear opening statement. As you mentioned, your submission has been received and it has been marked submission number 342. Are you okay with moving to questions now?

Ms RUNDLE: Yes.

The Hon. BRONNIE TAYLOR: Thank you very much for your time today and thank you for attending. I suppose I just wanted to start with something to which you alluded in your opening statement: The NDIS really is a world leader and it is once in a generation. I am sure it is a very challenging job but it must also be pretty rewarding to know that you are part of rolling out something that the sector and the community have cried out for for so long. I want to go down to more of a base level where I can offer experience. I spent a lot of time as a nurse. To me it just goes back to the person. I know that where I live, in southern New South Wales, we have had some experiences with people. A fellow in Crookwell had a nasty stroke. He had cancer as a child and had such severe radiation that it affected the capillaries in his brain. The NDIS changed his life because he now has a motorised scooter and he has been able to repair his home. It is just a really fantastic story.

There is another story about a young person in Cooma who also has been really helped recently. I think it is really important to acknowledge that as well. Congratulations to everyone who is involved with that. I suppose my issue and one of the questions I have for you would be about those people for whom the story is not so great or who have found it really hard to navigate the system. I will get around to my question. Earlier we are saying that it is great and that everyone is working at a senior agency level, but really it is how it transpires on the ground that counts. That is really important and it has to happened for governance. What is open to the people of my communities—I represent communities across rural and regional New South Wales—when they do not know how to navigate the NDIS and when it is so hard on the ground? What are we doing for them? You talk about 88 per cent, which is tremendous—absolutely fantastic—but what about the 12 per cent? What are we doing for them? I realise it is a very broad question, I am sorry, but it is such a big issue.

Ms RUNDLE: No, it is actually a very good question and it is one that the board and management exercise themselves about a lot. Unfortunately, we know that for some people, they have not had a good experience. We know that. Often, of course, we see it through the media but we know it anyway through other feedback that we receive. There are a few things I will mention. First, I will pass to Mr McNaughton in a moment to talk about the Pathways work because I think that is really important work. Second, the new chair of the board: Of course, the board has been a new board since January last year, but in about April of last year they recognised that very thing and they said that this is just not okay. If we cannot get the participant experience right, nothing else will really work. They instigated the Pathways work.

We have been working systematically across a range of different sorts of participants and groups to work on what sort of experience needs to be different to enable those people to access the scheme and come through and have a good experience and to get a plan that they understand and that they can then implement. I will defer to Mr McNaughton in a moment, but we have a range of other things that we do for people whom you mentioned before—those who find it hard to navigate and find us hard to get to. We are doing some work with each State and Territory government and the sector on reaching hard-to-find participants. We are doing a lot more work going out more aggressively and looking for participants, particularly people with psychosocial disability in areas. We are using the sector a lot to do that and help us.

But we are also improving our communications and trying to make our communications more accessible by finding different ways. You will know that when we go into a new area and start the NDIS, we move in about six months beforehand. With our Local Area Coordination [LAC] partners, we provide information forums and we try to make it as easy as possible to work out how to find how to get into the NDIS. I will hand over to Mr McNaughton because the Pathways work is probably the key thing that will make the difference.

Mr McNAUGHTON: Thank you. It is a really important observation and lesson we heard through the public consultations because it is a big change of management approach for people as well. Many people are moving from block funded systems to a new system where it is a person-centred model where the participant is in control of their budget. For some people, as Ms Rundle said, 50,000 people never got any support at all. We need to make sure that we are able to get information to people where they naturally get information from—the schools, the general practitioners [GPs], the health clinics, the Aboriginal-controlled health organisations, and Easy English. We have started some work rolling out community connectors. These are locally employed people from Aboriginal and Torres Strait Islander communities. Their role is to translate the NDIS and make it accessible and make it easy for people to understand how to access the scheme.

We are starting to roll this out in communities that are culturally and linguistically diverse [CALD]. We will have CALD community connectors as well. We need to do more of that to make sure that we demystify it and put it into the right language. We also make sure, like we heard earlier, that GPs are aware of the NDIS and what their role is in this. We are doing a lot of work with national peak groups around this as well and also through advocacy. We recognise that this is a big change process. There is more to do, but we have certainly been doing a lot of work to try to help people understand and navigate the NDIS more and more.

The Hon. BRONNIE TAYLOR: You talked about how CALD is in Aboriginal and Torres Strait communities and linguistically different communities. Is that for every community? Would you do that in rural and regional communities or is that specifically for those communities?

Mr McNAUGHTON: Yes, we started with the community connectors in East Arnhem Land as a bit of a trial and we realised then how successful they were. We are starting to export them right around the country. We will see as we move down into other areas where there are big Indigenous populations in urban settings, we will have community connectors there. We will be rolling out some cultural and linguistic diverse connectors in parts of Western Sydney to trial them in certain communities there as well. We will go to those organisations and give them all the training and the resources and they will then go to their local events and be able to pass that message on to their communities.

The Hon. BRONNIE TAYLOR: It is amazing how people appreciate a central point of contact.

Mr McNAUGHTON: And what we learn is people like to get information where they trust to get information from now. Some people come into our offices or a Local Area Command [LAC] office or a New South Wales Government office, but mainly they want to go where they get their information from now, through schools, peer groups are really powerful for us, as we said, general practitioners [GPs]. We are doing a lot of work in our hospitals at the moment as well.

The Hon. BRONNIE TAYLOR: I am conscious that this is not my overwhelming feedback, but I have you here and so I might as well ask it, as I said, I have had some incredible stories about its success. You talked about the IPR review. One of the things that is happening in some of the smaller rural and regional communities that I travel around, particularly rural, is that they have often had services that have done a lot of this before, but now there are new services. Mr Coutts-Trotter alluded to the potential of employment. In our main street there are shops popping up now for providers. But there is also a conversation about some providers who are coming into these communities and charging exorbitant rates, obviously not to the consumer but back to the NDIA, if you are the funder—and please correct me. What are we doing to ensure that that does not happen, the probity for the Government is strong and we do not have situations where people are coming into communities that they are not familiar with, setting up and not doing the right thing?

Ms RUNDLE: A couple of points I will make, others may wish to add. When you talked about people charging the exorbitant rates, there are two aspects of this. One is participants being informed well enough to know what value for money they are getting when they are buying services, and particularly for self-managed participants, all participants. But for participants who are not self-managed, what we pay is according to our price guide. Providers really cannot get paid more than the prices in the price guide. I think that is still correct. Unless there are exceptional circumstance and they might quote for a service, because we know it is a different sort of service, perhaps a bespoke wheelchair, and then we will look at that quote and we will assess value for money and then we will agree to exceed the average price for that item. Or, if it is a self-managed participant, they are not obliged to follow the price guide. What we often find though is that self-managed participants can find things even more cheaply.

The Hon. BRONNIE TAYLOR: Would anyone like to add anything to that?

Ms GUNN: The only thing that I would add is that what we are seeing is that the risk for us is when we have those two issues that you have talked about come together, where the potentially hard to reach or less well connected individuals are approached by new providers offering the world. What we have seen in response to that is a fantastic community response building on the issues that the New South Wales representatives raised, is this does take a holistic community response to understand and respect the role of people with disabilities and their right for inclusion and choice. We have seen lovely examples where the community has basically said, "That is not acceptable. We do not want you in our area, in our town." and protecting those individuals.

The Hon. BRONNIE TAYLOR: That is a good point, and that is why I am hearing about it. The community has said "No". It has said, "Bronnie, can you believe this?"

The CHAIR: That is an interesting response. Would you elucidate on that, without necessarily giving the detail of the organisation of the people involved? What was your point about communities coming together and saying "No"?

Ms GUNN: This for me was from an isolated Aboriginal community where there was a provider coming in and saying, "We can sign you up. We can offer you these services. We can offer you this service. All you need to do is just sign this piece of paper." Most of those individuals were unaware of the risk that that was potentially raising for them around giving consent for that provider then to see their plan.

The CHAIR: I am not asking for the location but what service were they touting?

Ms GUNN: Support coordination. It was very simply a number of the elders within the community saying, "We do not want your service here. We do not need you and we will protect the interests of these individuals in our community."

The Hon. BRONNIE TAYLOR: It is great that you are aware of it too. It is disappointing that there are people out there doing this. That is very reassuring for me.

The Hon. COURTNEY HOUSSOS: I think you heard my last question to the New South Wales Government about the discrepancy between your submission, which talks about 1,888 young people in nursing homes in New South Wales who are currently accessing the NDIS, and questioning in budget estimates a couple of weeks ago here revealed that there are 2,200 young people in nursing homes in New South Wales. That implies that there are 312 young people in nursing homes in New South Wales who are not currently accessing the NDIS, is that correct?

Ms GUNN: I cannot confirm the statistics. I am very happy to look at that for you but I imagine the difference is a combination of those individuals that we have not yet been able to access, have chosen to delay a conversation with us, or some individuals who may not be eligible for the scheme if they are in those nursing home facilities, as we saw with palliative care, for example. We would be very happy to have a look at the statistics for you.

The Hon. COURTNEY HOUSSOS: You can provide on notice what is happening?

Ms GUNN: We can identify where the 300-odd that you are talking about are and what their status is, yes.

Mr McNAUGHTON: The only thing I add to Ms Gunn's response is, we have dedicated teams within our regions who are out there managing, they are more highly skilled planners. We go out to the settings, work with the potential participant, the family, the aged-care facility, do all the planning face-to-face with all those parties involved. It does take a little bit longer. We are not doing any of the access decisions over the telephone, we go and visit each of those settings personally and do a lot of work with them one on one, but we will have to get you the rest of the numbers. I just did a quick check, it is 1,888 who are eligible so far with a plan. The gap would be how many we are still working through that process.

The Hon. COURTNEY HOUSSOS: As you heard, Mr Coutts-Trotter said it seems unbelievable that there would be young people in aged-care facilities who are not eligible for the NDIS.

Mr McNAUGHTON: Yes.

The Hon. COURTNEY HOUSSOS: I appreciate they may be under palliative care.

Ms GUNN: Individuals with palliative care might be, and there are a proportion of individuals in that circumstance that we have found to date.

Ms RUNDLE: But the real difference is that we will be working through them to get them into the system to get them a plan.

The Hon. COURTNEY HOUSSOS: Do you have a time line for when they will be in the system?

Ms FAULKNER: Can I add to that? We are working very actively to try to get them into the scheme. We are having some challenges getting into residential aged-care facilities, of which we are working with the Department of Health, Commonwealth, to get that access into the residential aged-care facilities.

The Hon. COURTNEY HOUSSOS: What are those challenges?

Ms FAULKNER: A lot of the residential aged-care facilities are not familiar with what the NDIA can provide, so they have done a lot of work with peaks now to try and inform them of what we can provide to those residents and now we are in their newsletters being spread throughout their memberships and their peaks to gain access into those residential aged facilities.

The Hon. COURTNEY HOUSSOS: There is not a central register? The New South Wales Government can tell us that there are 2,200 of them. You can tell us there are 1,888 accessing the care. The New South Wales Government cannot say to you: This is where they are?

Ms FAULKNER: We often know where they are. It is making the connection with the residential aged facility to access their facility to work with the participant we have found has been our greatest challenge to date.

The Hon. COURTNEY HOUSSOS: That is a challenge because you do not have enough people to do that?

Ms FAULKNER: No. We have dedicated staff, as Mr McNaughton referred to. It is the facility not understanding who we are and making that access available to us to go to the facility to work with those participants.

The Hon. SCOTT FARLOW: What does that look like? Is that your agency making a phone call to a residential aged-care facility and them saying, "Sorry, you are not welcome here. Sorry, you cannot come."

Ms FAULKNER: It is about us making a phone call to the agency introducing ourselves and explaining how we would like to work with an individual in their residential aged care facility. Often they do not have family members who have had contact with them for a while, so it is the facility that looks after them. It is about trying to make ourselves familiar and making the time to sit down and to talk with those individuals.

Ms RUNDLE: And working out who are their nominees and so on. I make it clear that we are absolutely committed to ensuring that all of those young people get a plan. Sometimes it takes a little while for them to move out of a nursing home. That is another issue that relates more to the availability of suitable accommodation. It takes a little while, nonetheless they have an NDIS plan while they are in the aged care facility.

The Hon. COURTNEY HOUSSOS: This implies that there are 312 who do not have an NDIS plan. Obviously I am concerned about young people in nursing homes, but I am even more concerned that there are young people in them who do not have a plan.

Ms RUNDLE: We are working through them. We will confirm the numbers. We are committed to getting them their plans.

The Hon. COURTNEY HOUSSOS: Great. I refer to Linkages and Capacity Building [ILC] funding, which you refer to in your submission. I am happy for you to take this question on notice. Can you provide a list of the groups and programs funded in the April 2018 round? I think you said there were 55.

Ms RUNDLE: We will need to take that question notice, but we can provide that information.

The Hon. COURTNEY HOUSSOS: Was there a funding round before the April 2018 round?

Ms RUNDLE: I have the ILC funding only for 2018-19.

The Hon. COURTNEY HOUSSOS: I am happy for you to take that question on notice. Have there been previous funding rounds?

Ms RUNDLE: There have.

The Hon. COURTNEY HOUSSOS: Who was funded?

Ms RUNDLE: Can I take that question on notice?

The Hon. COURTNEY HOUSSOS: Yes, that would be great.

Ms RUNDLE: That information is publicly available on our website; there is a list of who receives funding and the amount. However, we are very happy to put together a table.

The Hon. COURTNEY HOUSSOS: I would appreciate that. Your submission refers to the NDIA as adopting a more strategic and programmatic approach to the ILC investment. I am told that the April 2018 round was by invitation only. Is that correct?

Ms RUNDLE: No. There has been a range of approaches during the past financial year. We also advertised open grant rounds so many people could apply. I would like to address your question about the change in our approach. We have been working with our State and Territory colleagues, and we will continue to do that because we still have work to do in that regard. I am thinking about what we want to build for the future. Mr Coutts-Trotter described the broader ecosystem really well. A slide we often use says that it was envisaged that 460,000 people would come into the NDIS. However, around that there are many other people with disability who live in the community and who will need a range of other mainstream supports and also community supports.

One of the things that the ILC was always intended to do was to build that community support system and individual capacity as well for people with disability such that they could find their own way through the systems. They might not have a need for the NDIS when they have a minor requirement for support, as Mr Coutts-Trotter said. But if they are in the NDIS it will help them to connect better with their community supports. They will be more able to negotiate their lives in the community.

The Hon. COURTNEY HOUSSOS: I am familiar with what it is, but I am interested in what "a more strategic and programmatic approach" means.

Ms RUNDLE: It means we will be focusing more on building individual capacity; that is, things like peer support, advocacy, individual advocacy because we know that people do better when we work in that area, and community capacity and helping communities to be more accessible for people with disability. These are just some examples and we will be looking at taking a more direct programmatic approach to building an ILC infrastructure.[1]

The Hon. COURTNEY HOUSSOS: I would like to know what would happen in a particular scenario. A resident in an Ageing, Disability and Home Care NSW [ADHC] group home that has been privatised is allocated a special disability accommodation [SDA] allowance. If that person chose to leave the group home would they keep that SDA?

Ms RUNDLE: Yes.

The Hon. COURTNEY HOUSSOS: Would it be reviewed if they left the group home?

Ms FAULKNER: Yes. If there is a change of circumstances there is a plan review to see what the requirements are going forward. If they had been in a legacy arrangement with an SDA, they would have an assessment to see what level SDA they would require if they wanted to go to a new living arrangement. If they have had an SDA for some time then they would have a baseline allocation. They would not be without an SDA when they moved out of the group home.

The Hon. COURTNEY HOUSSOS: But it may be at a lower level.

Ms FAULKNER: They would have a base level. They may get more if their needs are greater, for example, if they have higher physical needs.

The Hon. COURTNEY HOUSSOS: But if they chose to leave that home there would be a chance they could receive a lower level SDA? If they were eligible and they were receiving an SDA, even after a review would they still receive at least the base level?

Ms FAULKNER: Yes. They would not get a lower SDA if they had gone from an ADHC arrangement; they would not get less than that base SDA rate.

---

[1] See correspondence received from Ms Vicki Rundle on 9 October 2018 regarding clarification on evidence

Ms RUNDLE: A participant chooses the accommodation that suits them. On that basis we will fund that SDA support. I imagine it could move either way. However, it would not be the NDIA making that decision; it would be for the participant to decide where they wanted to live. We would ensure they were funded appropriately.

The Hon. COURTNEY HOUSSOS: I am giving an example of someone who was exercising choice about where they wanted to live and ensuring that they do not receive a lower level of support as a result.

Ms RUNDLE: They should not.

The Hon. COURTNEY HOUSSOS: How often are plans generally reviewed?

Ms FAULKNER: At the moment the legislation stipulates 12 monthly plan reviews. However, if there is a change of circumstances we will review it before then. If a review is requested, we will consider it on merit and do a review if we believe it is appropriate. There can also be a request for a review of a decision and an internal review decision will be made.

The Hon. COURTNEY HOUSSOS: How many plans are undertaken in New South Wales for people who have not had a change of circumstances and who have not requested a review of their plan? I am happy for you to take this question on notice. How many plans in New South Wales have been reviewed within 12 months? I am interested in those instigated by the NDIA.

Ms FAULKNER: I will have to take that question on notice.

The Hon. COURTNEY HOUSSOS: I appreciate that I am asking a lot of specific questions. Of those, how many related to children and how many subsequently received a lower level of support or no support at all from the NDIA?

Mr McNAUGHTON: During the consultations some people asked why their plan was reviewed every 12 months. They were happy with their plan and they wanted us to stop interfering with their life so they could get on with it, so to speak. We are trialling a newer approach to helping participants through the review process in Coffs Harbour and Toowoomba. We think there is an opportunity for a percentage of people to move to longer plans where they have fairly stable environments, good informal supports and they are self-managing. These are people getting on with their life. We think that over time more people will move to longer plans, perhaps to two or three years. We are testing that at the moment. We will review it and look to roll it out nationally.

The Hon. COURTNEY HOUSSOS: If you want to provide anything else to the Committee about that, I am sure that would be useful.

Ms RUNDLE: Would you mind if I picked up on something you said?

The Hon. COURTNEY HOUSSOS: Of course not.

Ms RUNDLE: You mentioned some plans going down. I know this might not have been the reason you mentioned this, but I thought I would take the opportunity to talk about this because the fact that plans will reduce in value has been played out in the media. It is true that sometimes we have had some bad experiences where our planners have unfortunately made a very inconsistent decision; they have made a mistake and we have needed to remedy it. We hope that is fairly rare and that it becomes rarer. However, the insurance part of the NDIS goes to the fact that we want to ensure that the scheme funds are there for all time for anyone who needs them. That means that plans will go up and down depending on people's needs. So, some people will come in and get early supports—for example, capital supports, in the first year of the plan—and probably for another five years or whenever it is that they need a new wheelchair, their plan will go down, considerably probably if it is an expensive wheelchair, for the rest of the four years. Then the plan might get another boost in the subsequent year. That is the nature of the NDIS, and I think it is important that we make that point.

The Hon. COURTNEY HOUSSOS: Absolutely. I appreciate that when there are capital costs involved there will be a lesser amount. The concern—it has been well ventilated in the media and it has certainly been raised with me by individuals in feedback—is that when people are on a plan and they are receiving support, and they feel like they have just been established, for some other reason their plan is being reviewed. I appreciate that that may be a decision that is taken at a higher level than what you are operating at, but I guess the very real concerns about implementation are why we are having this inquiry. So I do not want you to, in any way, think that on this Committee there is anyone but the most vocal supporters of the NDIS in theory. You are tasked with an incredibly difficult job in implementing it, but we want to make sure that everybody who needs support is receiving it.

Ms RUNDLE: Quite so. We agree.

The Hon. COURTNEY HOUSSOS: I have one last question. How long, on average, if someone requests a review as a result of an error or an inadequacy in their plan, do they have to wait to receive that review?

Ms FAULKNER: If it is a change of circumstances and a request of an unscheduled review, we have a timeframe to make a decision for that review to be carried out. That is 28 days or 14 days. I may be corrected.

Ms RUNDLE: We may need to come back.

Ms FAULKNER: Thank you. I have been advised that it is 28 days. If we choose not to continue with that review, participants should be notified to that effect. We do recognise that we have a large backlog of review requests at the moment. Part of that has been addressed with a dedicated team to work through those review requests. We see that decreasing—I can provide the numbers after this—to bring those numbers down. We are seeing great gains. We do recognise that we have had review requests that have not been addressed for a length of time, and longer than we would be satisfied with.

The Hon. COURTNEY HOUSSOS: You said that they have to be addressed within 28 days.

Ms FAULKNER: Yes, as to whether we proceed with a new review plan or not—a decision to be made, not the plan to be done, in that time.

The Hon. COURTNEY HOUSSOS: How long will it take for the review to be done?

Ms GUNN: There is no legislative timetable; it says "when reasonably possible" or "within a reasonable time frame".

The Hon. COURTNEY HOUSSOS: Do you think nine months is a reasonable timeframe?

Ms GUNN: No. We have absolutely accepted that those delays are not acceptable. The establishment of the team to triage and, in a sense, identify those where there is a priority through the nature of the changing circumstance that is being pursued, will have been prioritised. Our teams have been really focused on getting back on top of those scheduled reviews.

The Hon. COURTNEY HOUSSOS: Can I just ask: when will that backlog be cleared?

Ms FAULKNER: We aim to have that backlog cleared by March, but we are still addressing new ones coming in at the point of time that that is occurring.

The Hon. COURTNEY HOUSSOS: I appreciate that. I know that this is obviously the beginning of it—

Ms FAULKNER: It is a significant backlog to be addressed.

The Hon. COURTNEY HOUSSOS: —but there are people who are waiting for their plans to be reviewed, and they really want to know when they are going to be achieved. They are waiting.

Ms FAULKNER: I know, it has not been acceptable. We have, as I said, developed this team to do that triaging and get those priorities organised to get those plans reviewed.

The Hon. COURTNEY HOUSSOS: Did that team have to come from within your existing staff cap?

Ms FAULKNER: Yes. Contractors and our staff with a delegation and experience of those reviews that need to be done.

The Hon. COURTNEY HOUSSOS: So you were not provided with any additional staff to create that new team?

Ms RUNDLE: Not for that one, except in terms of the contractors, but I can talk about our increase in cap, because we have had an increase in our average staffing level [ASL] cap, which the Minister announced last month. Did you want me to—

The Hon. COURTNEY HOUSSOS: That is okay. What is there? Can you discretely tell me what is there?

Ms RUNDLE: Our cap will go up. This particular financial year—this is separate to the cap—we will have another 760 people coming into the agency. That was planned. That will come about through our planned recruitment of about 540. The remainder—up to 760—is made up of the saving in the ASL that we got through outsourcing our call centre. On top of that there will be an ASL increase. It is an increase of around 134—I have the figures—this first year, but then over the three years we will get to a total ASL of 3,400. So it will increase by 400 from the original 3,000. That is right. The other thing I should say is that, overall, our workforce, which is more important, is made up of our own workforce ASL cap and local area coordinator [LAC] partners, early childhood early intervention [ECEI] partners and contractors, as Chris has just said. So it is considerable, and we feel confident that we have the staffing caps to be able to manage.

The Hon. COURTNEY HOUSSOS: I just have one last question. I have had two specific early intervention, wrap-around services that have had their funding cut as a result of the transition to the NDIS. They were previously funded under ADHC. These are very early intervention playgroup services that are interacting with children who have not come into contact with any kind of preschool, organised care or anything, but they are able to provide those services. Do you have any ability, under the NDIA, to fund those groups?

Ms GUNN: We address the needs for early interventions through our early intervention partners, who offer similar services, where they work with children who are identified by a kindergarten or a playgroup, undertake an assessment and provide initial supports for that child. They certainly support the playgroup to engage and deliver the strategies that are required for the intervention for that child as well. So direct funding of a playgroup—no. But ensuring that a child, as you have identified, has appropriate access to early intervention supports—absolutely, through our early childhood partners.

Ms DAWN WALKER: Expanding on the staffing, how many NDIS planners are employed in New South Wales?

Ms RUNDLE: We really need to take that on notice. I am sorry, we do not have that with us.

Ms DAWN WALKER: That is fine. Could you outline the skills and experience and training that is required by the local area coordinators and the planners.

Ms FAULKNER: We used to have an eight-day training course for our planners. We have now changed that with the reviewers to undergo a pathway review to a six- to eight-week, face to face, on-site at their site, online training course to make sure our planners are consistent and skilled in the delivery of what they do. I think it is also reflected with our LAC partners.

Ms DAWN WALKER: Could you walk us through what happens when a client meets with a planner, and, on average, how long that takes. How long would an NDIS local area coordinator meet with a client to coordinate the plan?

Mr McNAUGHTON: One of the things that we have looked at as part of the new pathway review is the improvements to the planning process. That is one of the areas we got a lot of feedback on—that we needed to make that process a bit more consistent for people. One of the things we heard was that people were often having to retell their stories multiple times. What we are doing now is linking the participant with their local area coordinator or their planner, who will become the consistent person in their planning journey. So they will have a pre-planning meeting with them, and we will invite whoever they would like to be with them as part of that meeting—whether they are informal support, advocate, friend, family member or provider. They choose who they bring.

So this preliminary meeting usually goes for an hour or an hour-and-a-half to understand the person, what is important to them in their life, what they do, where they get their local services from, and are they connected to advocates, peers, or whoever else they need. We then have another planning conversation that gets into the detail around what supports they would like from the NDIS, which goes to their goals and aspirations and other things they might want to do. Then there is usually a final meeting to finalise the plans. For some people we can do it in the two sessions, but often it is three. The next thing we have started to do, in response to a lot of feedback is to have a plan implementation meeting.

So after the plan has been approved they will come back and meet with their LAC and go through implementing their plan. They will do all the transactional things, connect to the portals, work out how to find providers, work out how to create service bookings, understand how to use their plan flexibly, go through whether they are going to self-manage the plan or use plan intermediaries or support coordination. We heard quite strongly that we were not doing enough to help people implement their plan so now the LACs will have a face-to-face plan implementation meeting. Some of our partners have been doing some innovative things recently and we are doing workshops around implementation. They can come every second Tuesday afternoon and the LACs and other officers will have their implementation meeting, self-management meeting or a how to manage your plan workshop to help with that change management journey. That is how that strategically works and then the LAC will check in at various points throughout the plan and then move into the review process, as we just mentioned. That is how it will work and we are rolling that model out across the country. We are starting in Victoria and we are rolling it out progressively now.

Ms RUNDLE: You asked before about training and I want to link that with that question. We are also doing a lot of restructuring of our workforce so that we have specialised planners working in particular areas who are more skilled in the more complex cases. It is important to note that point.

Ms DAWN WALKER: What about if there is a change in circumstances? I understand that at the moment if there is a death of a carer or someone is hospitalised, the person has to apply for a formal plan review. Is that still the case?

Mr McNAUGHTON: If there is a significant change in someone's circumstances we definitely need to do something to review that plan to make sure that they have the right supports around them because, for example, the informal supports might have been helping them implement their plan, so we might need to put more funding in for support coordination; or there might have been a change in accommodation settings. We will need to go through a review to make sure we continue to fund all the reasonable and necessary supports that person is receiving. We have made some improvements to our information and communications technology system to make it easier to do a plan review. We do not need to rebuild the whole plan from scratch and can add in additional items or adjust items as we need to. As we mentioned before with the triaging, when someone's informal supports break down because something has happened it is a really important change of circumstances and we would prioritise those plan reviews.

Ms GUNN: The other really important component of that is giving the participant the confidence to understand the flexibility that they currently have in their plan. They can use existing funding to find immediate responses to a lot of those circumstances as well and the funding allows them to address those immediate needs and then we will do the plan review to build the plan going forward to be strong in their new circumstances.

Ms DAWN WALKER: When they are getting the review, are their services suspended?

Ms GUNN: No, a plan has what we call "service bookings" and they have agreed dates. We will always try to do a review before those dates.

Ms DAWN WALKER: Has that been happening?

Ms GUNN: We have unfortunately had a few plans that have expired and there has been a commitment that as long as those service provisions stay the same as what they were prior to the date of the expiry, the agency will honour all of the payments.

The Hon. SHAYNE MALLARD: I thank you for coming in today and I concur with my companion the Hon. Bronnie Taylor's view on the bigger picture of the great story that is happening here. We have received some evidence that people in the community feel that NDIS service providers are exploiting opportunities to make extra money. I am aware of one example where the family has to top up the cost of a carer now because the provider takes a commissioner, whereas before, under the State government system, it was a block service. The lawnmower and gardener issue comes up regularly in the inquiry. Is there an audit process? Can you assure us that there is value for money in terms of the provision of services to the community?

Ms RUNDLE: Later on Commissioner Graeme Head of the Quality and Safeguards Commission is appearing before the Committee and I know this is a really good question that he might also like to address. The thing to understand is that as providers have moved from block funding they have had to price their services so that they do cover the direct cost of the service provision to participants and their overheads. They have had to price differently and some people have taken a while to adjust to that. I mentioned earlier that our price guide does not allow people to charge more than we will pay unless a participant chooses to pay more money themselves, but they should not need to do that. In the case of self-managed participants, the price guide does not apply. I may not have answered that well enough.

Mr McNAUGHTON: The only other thing I would add to that is that recently the Minister announced an approach to managing fraud within the NDIS. It is a $22 billion scheme and we expect that there will be some unscrupulous people trying to get into the market. Every cent that is taken away fraudulently is taken away from someone who really needs it, so we have partnered up with the Australian Federal Police and the Department of Human Services, who are very experienced in this space, and are setting up a 100-strong taskforce that will investigate that with a tip-off line and will look at trends and at people who might have done this in family day care or other settings if they are entering and registering. We will be sending a strong message out there early that we will not tolerate fraud within this scheme.

The CHAIR: This has been very informative. I thank you all for coming along and making time available. I know you are very busy. On behalf of the Committee, I thank you for the great work you are doing in implementing what is an extraordinary program that will benefit many needy people across the country.

(The witnesses withdrew)

MIRANDA BRUYNIKS, Complaints Commissioner, National Disability Insurance Scheme Quality and Safeguards Commission, sworn and examined

GRAEME HEAD, Commissioner, National Disability Insurance Scheme Quality and Safeguards Commission, affirmed and examined

SAMANTHA TAYLOR, Registrar, National Disability Insurance Scheme Quality and Safeguards Commission, affirmed and examined

The CHAIR: Would any of you like to make a brief opening statement?

Mr HEAD: I will begin by clarifying the way our roles work together. The Commission was established by amendments to the National Disability Insurance Scheme [NDIS] legislation that came into force on 1 July this year. The Commissioner is the statutory officeholder across all of the functions of the Commission. The registrar and the Complaints Commissioner report to the Commissioner but are not separate statutory officers. The statutory office is a single statutory office across the entire functional remit.

The CHAIR: Thank you for clarifying that.

Mr HEAD: It is good to be able to talk to the Committee this morning about the establishment of the Commission but I am only going to speak for a couple of minutes in my introductory remarks. The Commission has been operating for 11 weeks today, so we are about to finish our first quarter of activity. We were established as a result of work that had been done through the Disability Reform Council [DRC] of the Council of Australian Governments [COAG] to develop a national quality and safeguarding framework for the NDIS and the need for a new approach to quality and safeguarding was referred to in the original Productivity Commission report. The DRC worked on the framework, which was endorsed by COAG and released in early 2017, and the establishment of the Commission reflects the Commonwealth's major obligation under that framework. The legislation to establish the Commission was introduced and passed late in the spring session last year. As I indicated, it commenced on 1 July this year.

What that effectively means is that the Commission is now fully operational for New South Wales and South Australia and, in the way the statute works, our powers are enlivened at the point that a State or Territory transitions to full scheme. So we are functional for New South Wales and South Australia and all other jurisdictions, other than Western Australia, will come under the Commission's jurisdiction on 1July next year, with Western Australia coming in on 1 July 2020. We have a broad regulatory remit. We register and regulate NDIS providers and we do that using some new tools that were developed as part of the framework, new practice standards and a new code of conduct. We undertake compliance monitoring, investigation and enforcement action. We respond to complaints and reportable incidents, including abuse and neglect of participants. We are involved in national policy development and setting for the screening of workers and, importantly, national oversight and policy in relation to behaviour support and monitoring the use of restrictive practices within the NDIS but also working with the service system to reduce and eliminate the use of those practices.

The CHAIR: Can you explain what "restrictive practices" means?

Mr HEAD: Those practices that are used to restrain or restrict people with complex or challenging behaviours. A very explicit part of the Commission's remit is to do a number of things aimed at reducing and eliminating the use of those practices, including we have a specific responsibility to develop competencies for people in the workforce around the use of restrictive practices. We have a broad suite of regulatory functions but we are also involved in capacity building. So in addition to taking formal regulatory action, the Commission is equipped to work with the sector to build capacity, lift capability to educate participants and consumers about their rights, and how they can use our complaints function to raise issues that they are concerned about in respect of supports they are receiving. We have a broad scope to what we do in the conventional regulatory area, as well as capacity building for both providers and participants.

Importantly, until we commence in a given jurisdiction, the existing regulatory arrangements that apply to date in that jurisdiction continue to apply. So for all other States, other than New South Wales and South Australia, the quality and safeguarding framework in place in those States is what is in place today. For everyone other than Western Australia that will change on 1 July 2019, when the next five jurisdictions come in. With us now operating in New South Wales that means we have coverage of about 108,000 participants and just under 90,000 of those are in New South Wales. In the first two months of our operations we migrated about 9,700 registered providers from the NDIS into our own jurisdiction. We are now looking at roughly 500 new registration applications and we have taken more than 5,000 calls in our contact centre, many of those from providers seeking information about how the changes affect them but we have also been receiving complaints and reportable incidents. Registered providers that transferred to us are required to report certain incidents to us and that system is working well. We have a national office based in Western Sydney at Penrith. When fully staffed, we will have roughly 300 people around the country—about half of those based in the national office in Western Sydney and the rest distributed across regional offices in each State and Territory. Those of our functions that can be performed centrally such as registration will be done out of the National Office. Our people on the ground in States and Territories will be working on complaints resolution, compliance and investigations but also on behaviour support. I will leave it there.

The Hon. COURTNEY HOUSSOS: Thank you very much for your time. I will begin by saying we very much value the important work you are doing and appreciate that you are only 11 weeks in. We are keen to get some feedback on this early operation. Will you be taking on the current role of the NSW Ombudsman? What will be the demarcation between the two organisations?

Mr HEAD: In each jurisdiction there is a set of pre-existing arrangements around the way quality and safeguarding works. For each jurisdiction there is a transition from their existing arrangement to the new set of arrangements. We will be operating a regulatory system that is consistent around the country. In respect of the Ombudsman in New South Wales, part of the transition process involved a detailed discussion with the Ombudsman's Office around where they currently do work in the sector and how we would manage the transition and any residual areas of activity for the Ombudsman. The Commission's regulatory remit in disability is significantly broader than is the remit of the New South Wales Ombudsman's Office at present.

We have identified a series of issues that we have been working with the Ombudsman's Office on, most importantly around initially just being aware of what complaints were already on hand and how many residual matters would be dealt with during the transition phase, and ongoing work in respect of reviewable deaths, et cetera. As part of the regulatory remit for the Commission, I have a broader set of functions in relation to what is required to be reported to my office about the death of a participant. The New South Wales Ombudsman's Office is limited to residential care whereas the Commission has a much broader jurisdiction. If you want further specifics, either I or Ms Bruyniks can follow up.

The Hon. COURTNEY HOUSSOS: That brings me to make second question, which is around reviewable deaths. Does that mean that you will take over all of the existing reviews that are done through the Ombudsman's Office?

Mr HEAD: The Commission has the scope to look more broadly, or has a broader range of issues and service settings in which those deaths occur. The existing reviewable deaths function of the New South Wales Ombudsman's Office has been extended in its current form until the end of the current financial year. The Commission will determine, when the other jurisdictions come in, how it will approach specific reviews. We differ from ombudsman's offices in that we not only have the capacity to undertake reviews but also regulate the providers of services. We are able to take a range of enforcement actions in respect of matters that we identify in reviews—not just enforcement actions, but where there are patterns of conduct that we are concerned about we can raise awareness. There are many useful insights that have been provided in the Ombudsman's reports to date which, because of the character the Commission had, it will be able to take a different rate of actions in respect of.

Ms BRUYNIKS: The Commission has the remit of taking information from providers whenever there is a death of an NDIS participant which occurs or is alleged to have occurred in connection with the delivery of NDIS supports and services. Those particular deaths are notifiable to the Commission and they are different in terms of the scope of deaths that were reported to the Ombudsman in the past. The deaths that are reported to the Commission or notified to the Commission include expected deaths and unexpected deaths. The Commission requires providers to give the initial notification within 24 hours of them becoming aware. The initial information that is then taken by the Commission is about immediate risk and the types of actions that the provider should take.

The Hon. COURTNEY HOUSSOS: Are you aware of the very recent NSW Ombudsman's report into reviewable deaths?

Ms BRUYNIKS: Yes, we are.

The Hon. COURTNEY HOUSSOS: It contains findings about the former Stockton residents who died as a result of being transferred out of that facility and then received lesser care. What is your Commission doing to ensure that this does not happen again?

Mr HEAD: As we have indicated, a registered provider is already required to notify the Commission of any death that has occurred, that occurs, or that is alleged to have occurred in connection with the provision of supports or services by that provider. The registered NDIS providers who were involved in supporting a participant leading up to their hospitalisation or some other significant event would be required to notify the Commission. We have the capacity already with the nearly 10,000 registered providers who have transitioned into our jurisdiction to not only advise registered participants but also, where risks have been identified, make people aware of those risks.

An extremely important feature of the arrangements for the Commission is that when we register people, it is not simply a process of people applying to be registered and quality issues not being addressed up front. For each of the providers that we have already transferred—so transitional rules actually transferred people under our jurisdiction—the Commission, based on the sort of complexity of supports that are provided by a provider, such as recency of audit, history of compliance and a range of different features like that, determined which of the organisations who have transferred are in the highest priority category for auditing under the new practice standards. The practice standards themselves deal with an array of issues to do with complex supports and complex care, some of which have been the subject of commentary in both the current Ombudsman's report and previous reports. Already within the first 11 weeks we have people on an audit timetable—on a reregistration timetable, I should say—that includes the necessary level of auditing against practice standards. The prioritisation of providers around that has been directly linked to a range of factors that relate to risk.

The Hon. COURTNEY HOUSSOS: Are you taking any specific action against any of the providers around what was covered in the Ombudsman's report?

Mr HEAD: The jurisdiction of the Commission commenced on 1 July this year. Our jurisdiction relates to matters going forward from that time. But of course, part of what we have looked at in assessing the prioritisation of that very rigorous audit process against practice standards is past performance. Notwithstanding the fact that our jurisdiction commenced on 1 July, a range of issues relating to past performance has influenced the prioritisation. That audit process is a very rigorous audit process.

The Hon. COURTNEY HOUSSOS: I might leave that topic there but I may have some more questions on notice for you. The 5,000 calls you received in 11 weeks is a fairly high number. You would acknowledge that?

Mr HEAD: Yes, but I might just indicate that in sort of split-up terms, I think about 70 per cent of those calls have come from providers.

The Hon. BRONNIE TAYLOR: I am sorry—how many per cent were from providers?

Mr HEAD: About 70 per cent. I wrote on three separate occasions to providers, two in advance of the transition date, and once to provide their certificates of registration on 1 July. That was to advise people of what they could expect in the transition process. We encouraged providers as part of that process to contact us if they had questions, because in fact they are dealing with quite a new system.

The Hon. COURTNEY HOUSSOS: It was not 5,000 calls lodging complaints, 70 per cent of those were seeking information and 30 per cent were lodging complaints?

Mr HEAD: No, not necessarily lodging complaints.

The Hon. COURTNEY HOUSSOS: Can you tell me of those how many were complaints?

Mr HEAD: I think the number of complaints we have had is about 250.

Ms BRUYNIKS: For the months of July and August for New South Wales and South Australia.

Mr HEAD: Lots of calls are just inquiries, people wanting information, et cetera.

The Hon. COURTNEY HOUSSOS: Can someone make a complaint about the NDIA to you?

Mr HEAD: No. We do not have jurisdiction over the NDIA in respect of its processes. Complaints about the NDIA are typically first responded to by the agency itself, and if somebody is unhappy with that response they could go to the Commonwealth ombudsman. That is also true for the Commission. If people are unhappy with something that we have done in respect of our functions, they might initially make a complaint to us and if they are unhappy with the way we have responded to that, they can take that matter up with the Commonwealth ombudsman. We regulate providers and whether they are registered or unregistered, the code of conduct applies to both registered and unregistered providers. We do not regulate the NDIA.

Ms DAWN WALKER: Apologies if you have already answered this: How many registered NDIS providers are there currently in New South Wales?

Mr HEAD: I think about 8,500 in New South Wales. We have transitioned just over 9,700 but that includes South Australian providers as well. That refers to all providers, not just the subset of providers who have been active since they initially registered.

Ms DAWN WALKER: Are there currently unregistered NDIS providers in the sector?

Mr HEAD: Yes, and the framework explicitly recognises the capacity of some people to use unregistered providers, but of course unregistered providers are not included in those numbers. Those numbers refer to registered providers. They are the people we have a registration relationship with in a regulatory sense. Unregistered providers are subject to the code of conduct but our capacity building and work with participants is going to be extremely important in terms of our reach to unregistered providers, given that by definition they are unregistered and therefore our support to participants who are using unregistered providers depends on the participants feeling confident making complaints to us. Worker screening as it develops nationally will play an important role in respect of unregistered providers as well.

Ms DAWN WALKER: Does the Commission see itself as having a role in registering those unregistered providers? Do you take a proactive role in bringing them on board?

Mr HEAD: We encourage the marketplace to be aware of, as it emerges, the role of the Commission and what registration involves and what registration allows people to do. But the framework itself explicitly acknowledges the right of people with disabilities to exercise choice and control and there are circumstances in which those participants actively choose to use unregistered participants and that is a matter for them. There are some constraints around types of supports that self-managing participants can use unregistered providers in relation to. But choice and control is an underpinning principle of the National Disability Insurance Scheme Act and unregistered providers are part of that service delivery system. For the Commission a big part of our work with unregistered providers is to make those people aware of what their obligations are in respect of the code of conduct and what sanctions attach to a failure to meet those obligations.

Ms DAWN WALKER: How would the participants know that they were dealing with an unregistered provider? Is there a quality control check?

Mr HEAD: I might ask Ms Taylor to outline some of the more detailed processes, but participants are only using unregistered providers in a setting where they have chosen through their planning process, and their planning process permitting that to use unregistered providers. There are checks and balances in the system to do with the complexity of supports

Ms TAYLOR: That is correct. Unregistered providers are generally almost always used by people who are self managing their own plans. They have control over the way in which the moneys that attach to their plans are spent. They can make decisions about the support workers that assist them in their daily living, or if they decide to utilise other businesses, who those businesses might be. An important part of our work, as the Commissioner has said, is to communicate with those self-managed participants to help them understand the new code of conduct that would apply to any worker that they would employ directly or any business that they seek to purchase services and supports from.

Ms DAWN WALKER: I understand the practice standards for the NDIS Commission requires providers to refer participants to advocates for independent support in certain circumstances, is that correct?

Mr HEAD: I will let Ms Taylor talk about the practice standards in detail.

Ms TAYLOR: There are some core practice standards that talk about the way in which an NDIS provider would make sure that an individual had the right level of support, informal support, or if they required it, advocacy support to assist them in the execution of their plan. Those core supports are pretty general, they relate to things like rights and responsibilities, which is where I think you are referring to the link with, where someone requires it, an advocacy support if they do not have other means of getting informal supports or people advocating for them around the services and supports that they might need. There are a number of other modules that relate to different specific aspects of service delivery under the NDIS that put additional requirements on providers in the areas of high intensity support.

For example, where participants in a service might have very complex health needs, how they might make sure that they have the workers and the people with the knowledge and right connections with health practitioners to assist people with those complex needs where they are providing specialist behaviour supports, specialist support coordination, early intervention and so forth. The nature of the supports that an NDIS provider is delivering will determine the level of consideration through an assessment that they will need to undertake, basically the depth of an audit and to satisfy the Commission. If someone is delivering core supports, complex supports, such as accommodation or other skills with daily living or those specialist aspects of delivery that I just described, they will need to undertake what we refer to as a certification audit, which is a full review of all the elements of service delivery, as well as the management and governance within the organisation.

If the provider though is delivering lower level supports and has an existing regulatory frame around their practice—for example, allied health professionals—they go through a more straightforward, simple audit which is to verify the fact that they have the ability to operate the contemporary practice authorisations, insurances and complaints and other incident management systems. The approach that we take is quite proportionate and relates both to risk as well as to the nature of the services and supports and the legal configuration of the provider.

Mr HEAD: In addition to what Ms Taylor has outlined in respect of practice standards and the specific question you asked, the Commission, as part of its setup process, initiated a discussion with advocacy organisations from across the country, with a particular interest in those operating in New South Wales and South Australia. Its purpose was to start to chart the way forward in terms of how the Commission works effectively with people involved in both individual and systemic advocacy. We have just gone back to the participants in that two-day workshop with our response to the questions and answers raised during those discussions. This is an ongoing piece of work for the Commission in terms of setting up the right relationship with that sector and ensuring that that advocacy is working well with the quality and safeguard framework.

The Hon. SHAYNE MALLARD: We heard from NDIS representatives before you that they were working with the Australian Federal Police to address the potential for fraud, and they deferred the question asked about audit to you. What assurances can you give the people of New South Wales that you are proactively addressing the potential of dodgy or fraudulent operators coming into that very lucrative space?

Mr HEAD: It is a really important part of the registration process. Providers are not only required to be audited against the practice standards but an important part of what we do in the registration process—this applies to both the reregistration of people who transition to us from to the NDIA and to new applicants—is a piece of work that is outlined in the rules called "suitability assessment". In the suitability assessment of any provider who we are considering reregistering or any new provider, all of the relevant matters about their fitness, as it were, to operate appropriately in the sector can be considered. We can take quite strong regulatory action, including suspension of registration, revocation of registration, or issue banning orders where we determine there are problems. Of course, we are working with well with the NDIA and the Department of Social Services as the work ramps up on fraud prevention and response. However, we have a very good set of regulatory tools to consider relevant matters at both the front end of the process and to take action were inappropriate activities are identified to us along the way.

The Hon. SHAYNE MALLARD: Is that targeting corporate entities as well as directors?

Mr HEAD: I will let Ms Taylor explain in detail.

Ms TAYLOR: Our rules require suitability assessment at the corporate level as well as of key personnel in any organisation. We look at a range of things in making that suitability assessment, including adverse findings or referrals from other bodies.

The Hon. SHAYNE MALLARD: That is reassuring. You need to be vigilant. What about auditing of value for money?

Mr HEAD: The Commission's remit is very squarely around quality as it applies to the practice standards and safety. Our specific statutory remit does not focus on those things. However, of course, through the NDIS planning process participants articulate outcomes they are seeking. There are other aspects of the system that I think are more within the agency's purview than our own around value for money.

The Hon. SHAYNE MALLARD: I imagine some of the complainants would point to their perception that someone is ripping off the system—not a client but a provider—and you would refer that back to the NDIS.

Mr HEAD: I cannot provide a yes/no answer to that question because there are some matters that a complainant might raise about some area of practice where we might think it does not speak only to value for money but also to some other kind of practice that may touch on those suitability factors that I talked about before. Indeed, it might be something that is squarely within the agency's remit. The good thing about our contact centre is that it is able to spend the necessary amount of time with people who are calling us to understand in depth the nature of their complaint to determine whether it sits squarely within our purview or someone else's. It does not just send people off into the wilderness but works with the complainant to refer them "warmly", as it is described these days. We ensure that they get to the right person to achieve an adequate response to their complaint.

The Hon. SHAYNE MALLARD: I do not envy your job when you get different States and Territories with different systems. Can you assure the Committee that the protections and standards we have in place in New

South Wales for clients have all transitioned to the national body with the same level of protections and guarantees?

Mr HEAD: NDIS providers in New South Wales and South Australia who transitioned on 1 July, when everything kicked in, are subject to a more comprehensive regulatory framework than was in place prior to that. Exactly what is in place differs from State to State. However, the breath of the Commission's remit, its capacity to take action in response to problems it identifies, and its broad regulatory powers mean that as each State transitions there is an uplift in what is available in the system. The fact that registered providers in New South Wales who have transitioned have already been prioritised for audit against new and comprehensive practice standards that touch on many of the issues that have surfaced in reviews and complaints and where people are required to complete that process in a specified timeframe means that the migration and administrative processes are actually pushing the service system into the new quality model straightaway.

The CHAIR: Obviously this is an extraordinary and transformative scheme. I would like to follow on from the Hon. Shayne Mallard's question about the potential for abuse by scurrilous individuals or organisations that might see this as the goose that laid the golden egg. I draw your attention to potential abuse in respect of taking advantage by over-servicing an individual. I refer to a service provider dealing with an individual who clearly needs a particular service or suite of services and the provider suggesting they need far more of a service because they believe that is what the individual needs. However, on a reasonable analysis that is probably an exaggeration of their needs. In the context of our national health scheme, Medicare, we are all familiar as members of Parliament with claims of doctors and specialists over-servicing. Surely the NDIS, the NDIA and yourselves are very aware the need to look at that over time. Does potential over-servicing fall within your remit or would the NDIA deal primarily with that?

Mr HEAD: Principally, the agency, but of course it is the case that every part of this new system—whether it is the agency or ourselves—needs to be alive to what are often now referred to as "sharp practices": the sorts of things you are talking about—

The CHAIR: Sharp practices, yes.

Mr HEAD: —because poor governance or poor behaviour of a provider in one aspect of their interaction with the service system may be a pointer to the Commission that it needs to examine a particular provider more closely in a particular respect. We have very good information-sharing provisions that have been put into the Commission's legislation to allow us to work with other organisations, including the agency, around those things that deliver integrity to the system. Certainly, my appointment was able to start before the legislation commenced, in order to do a number of things to get the organisation up and running. Certainly, I was impressed by the focus from both the Department of Social Services and, in interactions with the agency, around sharp practices and the way the system would need to respond to prevent and respond to those behaviours, where they are occurring.

The CHAIR: Thank you all very much for making your time available. It has been very informative for you to provide such detailed evidence. Thank you for the great work of overseeing what, as I said, is a transformative program for so many needy people in Australia, now and into the future.

(The witnesses withdrew)

TONY POOLEY, Senior Manager, State Operations, National Disability Services, affirmed and examined

KAREN STACE, NSW Sector Operations Manager, National Disability Services, affirmed and examined

THERESE SANDS, Co-Chief Executive Officer, People with Disability Australia, affirmed and examined

ROMOLA HOLLYWOOD, Director, Policy and Advocacy, People with Disability Australia, affirmed and examined

The CHAIR: I welcome our next witnesses from the organisations National Disability Services and People with Disability Australia. It is very important to hear from a new set of witnesses who have this interface with the program—its implementation, its conduct and working with the sector in full. With respect to National Disability Services, we received your submission. It is marked as submission No. 258. With respect to People with Disability Australia, your submission is marked as submission No. 329. There is no need to go into your opening statements, which I am about to invite you to make, in a lot of detail which is contained in your submissions, because clearly they speak for themselves, but it is important to provide you with the opportunity to make an opening statement to set the scene, so to speak. Once that is done we will share the questions between ourselves and work our way through until they are exhausted. Mr Pooley, do you want to make an opening statement?

Mr POOLEY: Thank you for the opportunity to give evidence. National Disability Services [NDS] represents more than 400 not-for-profits disability service providers in New South Wales. NDS advocated strongly for, and remains committed to, the principles of the NDIS, and we acknowledge that when all aspects of the scheme come together—an appropriate plan, adequate funds and functioning administrative systems—there have been some great outcomes for people with a disability. But all too often this has not been the case. Most importantly, the less than optimum national roll-out of the scheme has impacted on people with disability—both participants in the scheme and those who have been found ineligible. This, in turn, has impacted on their families, carers and circles of support. Many of those concerns have been detailed to the Committee in submissions to this inquiry.

It has also impacted on service providers. As we outline in our submission, more than five years after the scheme launched, both providers and participants are faced with poor, inconsistent and inadequate annual plans; a dysfunctional portal and IT interface; lack of communication from the NDIA; inadequate telephone and email support; unacceptable delays in initial plan creation, plan reviews and plan renewals; inadequate prices across a range of supports; and extensive delays in payments to providers. As has already been identified, New South Wales is the second largest shareholder in the national disability scheme, and remains primarily responsible for the delivery of mainstream services that support all citizens, including people with disability such as health, transport, the criminal justice system, housing and continuity of supports.

As we said in our submission, NDS does not support the proposition—nor do we believe it even meets the dictionary definition—that the transfer of Government disability services to not-for-profit disability providers constitutes a privatisation of those services. But without dwelling on the semantics, we believe that the NGO sector has the skill, capacity, commitment and determination to provide the complete breadth of disability service provision, and indeed has been doing so for many decades. But the administrative burden that an inefficient and poorly managed NDIS, combined with the rapid loss of supporting infrastructure in New South Wales, make it a difficult environment in which to operate. Thank you.

The CHAIR: Thank you, Mr Pooley.

Ms SANDS: Thank you for the opportunity to appear before you today. As you may be aware, People with Disability Australia is governed, led by and made up of people with all kinds of disability. We are specifically funded in New South Wales to act as a peak representative organisation and we also provide individual advocacy support across New South Wales. We have a specific advocacy program for people with disability living in boarding houses in New South Wales. So we have direct and first-hand knowledge and understanding of the experiences of people with disability in New South Wales—not just in relation to the NDIS but also in relation to the interface with a whole range of policy areas, including education, justice, health, mental health, transport and other areas.

We note that only 10 per cent of people with disability will be assessed or deemed eligible for the NDIS. This means that 90 per cent of people with disability not eligible for the NDIS, including children and young people, and older people with disability in New South Wales, may still need to receive disability-specific supports. All people with disability in New South Wales will also need accessible and inclusive services, for example in health, justice, education and housing and in regulatory oversight and accountability mechanisms to protect them from violence, abuse and neglect. They will also need access to independent advocacy and ongoing representation through peak representative bodies.

So the New South Wales Government still has an important and strong role to play to represent the interests of people with disability in New South Wales to the Commonwealth, including through the Disability Reform Council. The New South Wales Government must ensure that all service systems in New South Wales are fully accessible for people with disability, that people with disability do not fall through the cracks of service provision, and that those who are not eligible for the NDIS still receive the disability-specific supports they may require.

Our submission outlines what the New South Wales Government can do to realise a vision of being a State of Inclusion. Some of the key or overarching recommendations we have made include establishing a Disability Inclusion Minister with a budget for reform and responsibility for leadership and disability rights and inclusion; commit to implementation and funding for the New South Wales Disability Inclusion Plan; provide robust oversight and regulation of the quality and accessibility of services in New South Wales and the interface with the NDIS; implement measures and programs to address the gaps in services for people with a disability who are not NDIS eligible—this includes those who were promised they would receive continuity and ongoing supports but also all people with a disability in New South Wales who need these supports; and provide ongoing investment in improving the accessibility and inclusion of people with a disability in mainstream services and participation in all aspects of community life. Thank you.

The Hon. COURTNEY HOUSSOS: I thank both the NDS and People with Disability Australia [PWDA] for appearing before us today and also for your very lengthy contributions—they were both very valuable in informing the work of our Committee. I want to start with a basic question, which is: If there is no plan, what happens for an individual? If someone does not have a plan, what happens? I know these are basic questions but I think it is important that we establish this.

Mr POOLEY: I will commence by saying that they are certainly not part of the NDIS, so they are relying on some kind of legacy support. That support may be provided by family, carers, circles of support. But they are certainly not participating in the scheme if they do not have a plan.

Ms SANDS: Yes. They are basically not a NDIS participant. They might be receiving some benefit through a project that is being run through the Information Linkages and Capacity Building area, but in terms of disability-specific supports, they may have lost those supports because it has been transferred through to the NDIS, so there is nowhere else for them to go, or the services are charging for those supports and they do not have the means to pay for them.

The Hon. COURTNEY HOUSSOS: Are you representing organisations that are being faced with people who are in this situation that were previously receiving support and are no longer receiving support?

Ms SANDS: We are providing individual advocacy to many people with disability to support them—many people who are either not eligible for the NDIS or have received what they perceive to be or that may be inadequate NDIS plans that do not meet their needs. But there are many people who are not eligible for the NDIS who are now struggling to find the supports they need to continue to live their lives the way they did before. That could be anything from having the in-home support to enable them to have the personal support they might need, it might be to do housework, it might be to assist them in the home, it could be doing a whole range of issues that they no longer have that support for. They are in quite dire situations in many cases.

The Hon. COURTNEY HOUSSOS: Ms Sands, before I go back to the NDIS I would like to ask a question about an interesting point you made in your opening statement. You said 90 per cent of people with disability are not eligible for the NDIS—why is that?

Ms SANDS: The eligibility for the NDIS is based on having a permanent disability, and a significant and profound level of disability. So there is only a certain number of people that meet that. Currently the estimates are that 10 per cent of people will be eligible based on that criteria and then other people with disability will not be receiving funded packages or a funded plan through the NDIS.

The CHAIR: Sorry, that is 10 per cent of what figure?

Ms HOLLYWOOD: I can answer that. As part of the New South Wales Government's Disability Inclusion Plan it is recognised that it is nearly 20 per cent of people in New South Wales, according to Australian Bureau of Statistics [ABS] statistics, that do identify according to robust criteria determined by the Bureau of Statistics as having some form of disability. When we look at that figure for New South Wales it is roughly 140,000 people who will be eligible for the NDIS when full rollout occurs, but it is actually over a million people in New South Wales that identify as having some form of disability.

The Hon. COURTNEY HOUSSOS: So how are these people receiving support?

Mr POOLEY: There are currently 97,000 people in the scheme in New South Wales, but that was an end August figure. We think it is about 100,000. As has been identified, the original projection for the scheme in New South Wales was 142,000. A more recent Australian National Audit Office figure suggested that figure could be as high as 152,000, so we are about two-thirds of the way in.

The Hon. COURTNEY HOUSSOS: The real reason behind this inquiry is for the people who are missing out, for the gaps. Mr Pooley, in your opening statement you made that very clear. Everyone on this Committee I am sure is a great supporter of the NDIS in theory, but the reality is that it is not living up to its promise for too many people. How are those people who are falling through the gaps currently receiving services and how can we fix it?

Mr POOLEY: The scheme was never designed to support every person with a disability. It replaces the specialist disability service system previously operated by State and Territory governments. Of the 97,000 people who have currently transitioned into the scheme, 90,000 were previously supported by the State government specialist scheme. Your broader question about how we support those people who are not eligible is part of the issues that have already been raised by PWDA today but it is about having an inclusive and engaged broader service system which covers all of those areas—health, education—that everybody engages with. The responsibility is on us all collectively, including the New South Wales Government which manages those service systems, so they can be as accommodating as possible for all people with a disability.

Ms SANDS: I would add to that we are finding there are some people who are not eligible for the scheme who still need disability-specific supports. So either that is something that needs to be built into mainstream service systems in some way or the New South Wales Government must remain responsible for providing those supports, identifying where the gaps are and looking at who still requires disability-specific supports—what are they? How much can the mainstream system be inclusive and develop new ways of perhaps providing supports? And where does the New South Wales Government need to retain a role in the provision of disability support? A "provider of last resort" is often the term used for where people might be falling through the gaps. Previously you would rely on your Government to assist you to receive the supports that you were not receiving or where service systems were failing. Now we do not have that any more. Part of our submission was strongly stating that the New South Wales Government has a responsibility to look at that emerging issue or the issue that exists now as it is emerging through the implementation of the NDIS and what is still their responsibility in relation to that.

The Hon. COURTNEY HOUSSOS: Are you representing the providers that are being forced to be the provider of last resort because the State Government has totally opted out or are these people simply falling through the cracks?

Mr POOLEY: There is no formal provider of last resort. In practical terms what happens is if there is a Friday afternoon crisis or somebody who needs urgent support in the majority of cases if they have engaged with a service provider there are a lot of panicked calls between the service provider and the agency to identify the specific change in circumstances and to come up with an interim ad hoc solution to that person's circumstances. Then over the course of the next few weeks, sometimes months, they engage with the agency about getting a plan review, identifying what service or accommodation options the person needs. That is the practical reality at the moment.

Ms SANDS: I suppose we are not representing providers but we provide advocacy support to those people and we are in a very similar situation. Increasingly we are finding that we are taking on a case management role because there is nowhere else to support those people or no-one who is supporting the person through the service system and connecting them to services. So we are also trying to fill the gaps, working with service systems to try and get the supports around that person, whereas before we may have had the contact within the New South Wales Government to actually talk with them directly about supporting that person and taking on the case management for that person. So we are increasingly stepping outside of our role as independent advocates and having to do case management because there is no other way to support the person.

Ms STACE: I think also under block funding arrangements providers had more flexibility to be able to deal with people who were knocking on their doors in crisis or requiring slightly more supports at one time and less supports at other times, whereas support at the moment, particularly for NDIS participants, is very much dictated by what is in the plan and what they are able to provide. If it is not in the plan then it is very difficult for providers to provide that and when they are they are often doing that unfunded.

Ms HOLLYWOOD: I guess the other point that we raise strongly in the submission is that it does impact on mainstream services as well. So people may end up in the health system in emergency hospital arrangements or something like that simply because there is nowhere else for them to go. It is having an impact on mainstream services and whether those mainstream services have the supports necessary, have the staff training et cetera in a crisis mode again is a question of concern for us.

The Hon. COURTNEY HOUSSOS: Even though the State Government has opted out of providing disability services in effect they are going to have to because they are coming through these other avenues—whether it is Health or Justice or whatever it might be? Is it fair to say that people are in hospital and people are in jail because they cannot access the NDIS right now?

Mr POOLEY: Yes.

Ms STACE: Certainly from reports we are getting from providers and certainly from participants.

Ms SANDS: Yes.

The Hon. BRONNIE TAYLOR: Have you got evidence of that? If that is happening then it is really important that people know. If you have evidence that is actually happening is there a mechanism to report it?

Ms SANDS: So where we—

The Hon. BRONNIE TAYLOR: You just said that you were being told that there were people in hospital because the system was failing them and they had nowhere else to go. I used to be a nurse. If that was happening to one of my patients or to someone I was advocating for then I would report that that was a problem. Are you doing that?

Ms SANDS: We have certainly done it in our submission and we have certainly had conversations with the New South Wales Ombudsman and with other agencies.

The Hon. BRONNIE TAYLOR: About particular clients?

Ms SANDS: About particular issues, that is right. There is only so much taking of individual cases to change systemic areas that need changing. I think what our submission is saying is while we are doing those things there is a responsibility for the New South Wales Government to be looking at—for example, does it have the systems, programs or response in place to assist people so they do not fall through the gaps?

The Hon. BRONNIE TAYLOR: The evidence the Committee heard this morning suggested that they do and now you are saying they do not. There is a discrepancy in what is being said—namely, before you were saying that people are slipping through but in the evidence this morning the Committee heard that they are having multifaceted coordination between all the departments to target the people who are falling through. That is what I am trying to nut out. When one make comments like that it is pretty serious and they want to be able to substantiate them.

Ms STACE: It is and—

The Hon. BRONNIE TAYLOR: Ms Houssos, I have another question following on from your earlier question. Do you mind if I ask it?

The Hon. COURTNEY HOUSSOS: That is fine.

The Hon. BRONNIE TAYLOR: Ms Stace, you spoke about the NDIS plans and basically if it is not in the plan then you do not get the service. I would think if a situation changed with one of my patients then I would have to approach it in a different way. Are you saying there is no ability for the plan to be changed?

Ms STACE: The ability is via review. There is certainly flexibility within certain types of supports that are in someone's plan, so core supports are flexible. That means a participant is able to work with a provider to deliver those that meet their needs. So there is some flexibility within that but I think there was an example this morning if a participant or a child has 20 hours of therapeutic supports in their plan and they actually require more than that, and the participant agrees that is exactly what is needed, the family agrees, the therapists agrees, the doctors agree, then really the capacity for a family to get more than that is either to pay for it themselves or alternatively seek a plan review.

The Hon. COURTNEY HOUSSOS: In your experience on average how long does that plan review take?

Mr POOLEY: Months and months and months. The latest available figures indicate there are currently 14,000 plans under review—that was evidence to the Federal estimates committee earlier this year—and there are 160,000 people in the scheme so it is almost 10 per cent. Two-thirds of people in the scheme are in New South Wales so it is fair to assume that two-thirds of those plan reviews affect New South Wales residents. There is a huge backlog and it takes months to get a plan review back.

The Hon. BRONNIE TAYLOR: So the issue is that the plans are not being reviewed in a timely manner to ensure very good care, not that there is no flexibility. Ms Stace, correct me if I am wrong, when you were answering the earlier question you gave the impression that if a plan is in place then that is that and there is no flexibility but when I have asked you again there is flexibility. I absolutely acknowledge that if those plans are there and they are not being reviewed then that is something that needs to be looked at but for the sake of the record, and just repeating your evidence, there is flexibility. There always has to be a plan and a review of a plan to get that flexibility to cope with people's changing needs. I do not have experience in the disability sector but I imagine needs change and vary sometimes by the hour?

Ms STACE: There is certainly flexibility in how supports are delivered. I guess I was more referring to the fact that if somebody knocks on the door and is asking for a particular support that is not currently in their plan then the provider is not able to deliver that—

The Hon. BRONNIE TAYLOR: Because their situation has changed.

Ms STACE: The situation has changed. There is a review process absolutely.

The Hon. SHAYNE MALLARD: I want to flesh out the statistics and get some clarity around them because I am a bit confused. Page 2 of the Government's submission talks about 96,000 people accessing the NDIS—I think Mr Pooley said 97,000—as of July 2018 and that is 99 per cent of existing New South Wales disability clients who have transitioned. Ms Sands said there is a larger cohort who are not on NDIS but is not the figure of 96,000 or 97,000 the defined figure of people with disabilities who were New South Wales clients that transferred across and it is 99 per cent of the people on the books?

Ms SANDS: I think the issue is that there were many people with disability who were not receiving supports before.

The Hon. SHAYNE MALLARD: From the State?

Ms SANDS: From the State Government.

The Hon. SHAYNE MALLARD: So you are looking at a broad definition?

Ms SANDS: That is right.

The Hon. SHAYNE MALLARD: That did not apply to them before either?

Ms SANDS: That is right. It is a broader definition of the population group of people with disability as opposed to those who were in receipt of services through the Department of Ageing, Disability and Home Care.

The Hon. SHAYNE MALLARD: You would like the inquiry to broaden the definition and expand the services? I accept that that is your position, but we are looking at the performance of the NDIS as it stands today and as it stands in relation to the services the State provided before. What the Government told us this morning is correct: 99 per cent of existing clients from the State have transferred across.

Ms SANDS: That may well be. I do not know those figures.

The Hon. SHAYNE MALLARD: Okay. I just want to make it clear.

Ms SANDS: That may well be the case in terms of existing Ageing, Disability and Home Care [ADHC] clients, but we know there was significant unmet need and there were many people who were not receiving any supports. They are now actually entering or accessing the NDIS.

The Hon. SHAYNE MALLARD: I think it is a broader issue.

The Hon. SCOTT FARLOW: Just on that point, you are saying that there are now more people who are accessing those support services under the NDIS than there were previously under ADHC?

Ms SANDS: We know there are people who are receiving supports now that were not receiving supports through the previous system.

The Hon. SHAYNE MALLARD: There is more money.

Ms HOLLYWOOD: I guess the point is that we are getting anecdotal reports of people, and the case studies are documented in our submission, of people who are receiving less supports than they were formerly receiving. They may be an NDIS participant but put simply their experience is that they are receiving less support. We have the new participants coming in who maybe have not received services before and are now receiving services, so that is great. But there may be people—and it is harder to track that—who were receiving supports and are either getting less or nothing. We are not actually in a position to provide the data on that area, but that might be something to explore.

The Hon. SCOTT FARLOW: In your anecdotal studies, are there any particular areas where there is a concern, or a particular classification where there is a concern that people are receiving less support than they previously did?

Ms HOLLYWOOD: I think an area to look at, which again is in our submission, is where people maybe have chronic health needs. Maybe they were receiving supports through the former system in New South Wales under ADHC but, when they have been assessed, they are seen as having a health issue that needs to be dealt with by the health system as opposed to the disability service system under the NDIS.

The Hon. SCOTT FARLOW: Is that still being met through the health system? This morning we heard evidence from the New South Wales Government that, for instance, departments are picking up their responsibilities whereas before they may have shifted those responsibilities to ADHC and are now implementing them themselves—Health in particular. Are those needs still being met?

Ms HOLLYWOOD: Looking at it from a holistic point of view, it is still really early days. It is a change process. We have examples—again it is anecdotal case studies—where it is a systemic issue and people have actually struggled to get the supports that they need. That may not be the fault of the health system and it may not be the fault of the NDIS system, but we are in a transition process and agencies are trying to work out who is responsible for what. Those jurisdictional lines—and this has been identified by the Productivity Commission as well—need to be clarified. Sometimes that has been worked out at an individual officer or worker level. It is actually also the responsibility of the government agencies as a whole to have those clearer policy settings.

The Hon. SCOTT FARLOW: One of the concerns with hearing anecdotally that people are receiving less support is that we have seen with the transition to the NDIS funding effectively doubled to $6.5 billion for people with a disability through the provision of the NDIS, so that is a concern there. I understand that there are new participants as well who are part of the scheme, but it is a concern, if there are people who are not receiving similar levels of support, as to, effectively, where the money is going. Do you have any insight into that, if that is the contention?

Mr POOLEY: Some people certainly receive more support than they previously did under the State scheme. Just to give you an example of a service type where our members have found people they support are routinely receiving less support than they did, there are those people who can largely live independently but need drop-in support. This is not a 24/7 group home arrangement. These people are often accessing private accommodation and they need support at specific times—often at mealtimes and when getting out of bed, those kind of things, depending on their disability. That is an area in which, it is routinely reported by organisations and in turn individuals, are encouraged to seek a plan review. Whereas previously, for instance, they were getting between 15 and 18 hours of support from ADHC, but they get a plan that comes back and provides them with six hours of support. That decline can make the difference between whether those people can continue to operate in that supported environment as opposed to where that they then tip into the need for a more substantial supported package. That is just an example of a service type.

The Hon. SHAYNE MALLARD: Is there an appeal process?

Mr POOLEY: You can go through that. Once you receive your plan, you can lodge an appeal. The administrative difficulty that people have at the moment is that you wait months for that appeal result. In the intervening period of time, including for those people whose circumstances changed dramatically, you can still only claim up to the value of what is in your plan until you get a successful plan review.

The Hon. SHAYNE MALLARD: There is no bridging?

Mr POOLEY: There is no bridging.

The Hon. COURTNEY HOUSSOS: Is there any backdating?

Mr POOLEY: There is a whole bunch of unofficial arrangements in which organisations—I dare say People with Disability Australia [PWDA] and other advocacy organisations—can have phone communication with the agency which says, "Yes, we'll fix that up." That is the nature of it. There is no formal arrangement. There is no formal provider of last resort. After you manage the ad hoc interim arrangements, you have then got to get a plan review and engage with the agency to be paid. It is not for me to speak on behalf of PWDA, but a lot of the case management services will never be reflected in a plan and so those advocacy organisations will never get their money back.

The Hon. BRONNIE TAYLOR: This morning in evidence the NDIA openly said—I do not know if you were here—

Ms HOLLYWOOD: No.

The Hon. BRONNIE TAYLOR: —that there have been real issues with the plans and that they have to do better.

The Hon. SHAYNE MALLARD: More resources.

Ms SANDS: Yes.

The Hon. COURTNEY HOUSSOS: Is there any backdating of those plans? If there is a situation that comes up where someone previously had 15 hours of support and it has now come down to six and they develop some problems, is there any kind of backdating?

Mr POOLEY: It is rare that in that situation plans would be backdated. What does occur for a major change of circumstances in which, for instance, somebody who was previously living at home or in a partially supported environment goes into full-time care, once that plan review comes back whichever organisation has supported the full-time care will get that support backdated.

The Hon. COURTNEY HOUSSOS: How long are organisations being forced to wait for that backdating?

Mr POOLEY: Months. We have organisations that have got debts that are in excess of 12 months old. The agency is rather good at creating specialist teams to deal with problems and there is a specialist provider payment team, which now includes 82 people, to specifically deal with the backlog in payment issues to registered providers.

The Hon. BRONNIE TAYLOR: Just clarify that: You are saying that the NDIA pays the services. Is that right? Correct me because, as I said, this is not my specialty.

Mr POOLEY: Correct, unless they are self-managing.

The Hon. BRONNIE TAYLOR: You are saying that there are providers out there that are waiting in excess of 12 months for a Federal government agency to pay them.

Mr POOLEY: In excess of 12 months for hundreds of thousands of dollars—in some cases, millions of dollars. With the introduction of the specialist provider payment team, there has been a decline in those outstanding claims, but those claims still exist and there are examples of where they exist for more than 12 months.

The Hon. BRONNIE TAYLOR: Current examples?

Mr POOLEY: Current examples.

The Hon. PAUL GREEN: Mr Pooley, you talked about two-thirds of the people being in New South Wales and the delay in getting the reviews back. You said it was quite significant. Can you walk us through why that is so, and what we can do to speed that up?

Mr POOLEY: If I am deemed eligible for the scheme, I have a meeting with a planner, I get a plan back. That will include supports grouped in various support categories. I can commence accessing those supports if I have got a provider that is able to provide those supports immediately. But if that is not adequate, I or my support or an advocacy group does not believe that support is adequate, then I have to apply for a plan review. It goes back through a different planner, and that can take months to get a plan review back, months and months. In the meantime, I can only access the supports up to the value of the plan, what that person is considering the inadequate value of that plan in the first instance.

The Hon. PAUL GREEN: Those people who need that care which has not been ticked off and has been sent back through the system, how do they get that care if it is not available in a regional or rural area? How are they able to get that care anyway if it does not exist in their area?

Mr POOLEY: I say generally, rural and remote areas suffer from service provision across the range of supports, broader than disability services. Usually in New South Wales almost all service areas are supported by at least one provider—you can argue whether that provides choice and control—or there is an outreach support from a more substantial town. People with a plan can usually access core supports. People with Disability Australia [PWDA] will have views about this—where it becomes difficult is if you have regular need for therapy services but only a visiting therapist, then that becomes a specific problem if you cannot provide the travel yourself to get to the therapist.

The Hon. PAUL GREEN: Or, turn it around, if the client does not appreciate the therapist, or that particular agency, for whatever reason.

Mr POOLEY: Sure, absolutely.

The Hon. PAUL GREEN: They have no further choice either, do they?

Mr POOLEY: Absolutely. The provision of servicing for rural, remote and thin markets is a key issue for this scheme going forward.

The Hon. PAUL GREEN: Basically, your disability services really rely on the post code as to what sort of service you will get.

Mr POOLEY: And in broader terms than the provision of disability services.

The CHAIR: Forecasting is always difficult but we have the 1 July date this year. We have a new national scheme, which is transformative in its nature but contains a particular definition around disability which has some specificity to it which will not cover every person who is identified, perhaps with a broader notion or definition of disability. Is it not likely the case looking ahead that in the main these people who do not, for one reason or another, find themselves eligible for the national scheme, will go off to the respective health department, hospital, whatever it might be, seeking that support through effectively the New South Wales health system, or just muddle along as best they can? It will primarily be the health department, will it not, that will pick up the slack? It will be the portal or the entity which most people will gravitate to, given the nature of their general condition as a disability.

Would that be a fair comment? Or do you believe it is broader than that? The Government in its submission this morning primarily said that we are working now very diligently—I am using my words, not theirs—to make the respective departments far more conscientious and capable of dealing with matters of disability. That being the case, the argument is that there is no need to have a freestanding department. If we can get this right, this will deal with the reality of this difference. I am not quite sure; you obviously do not share that optimism or is it too early to say?

Ms SANDS: What we are saying is certainly, all government agencies have a responsibility to be accessible and inclusive of people with disabilities. In the situation where some people may be requiring support, they are not NDIS eligible, it may also be the case that government departments need to be thinking about specific programs to address issues for people with disabilities. It may not be just in the Health area. It might be in the Justice area, for example, community justice support programs, et cetera, that people might require, which used to be funded or there was some funding through ADHC. Maybe that is something that is funded within the Department of Justice, for example, but there is recognition that people with disabilities, who may not be NDIS eligible, may still need certain supports. We are certainly saying that kind of mapping out, scoping, ensuring that people are able to access a range of supports, is important. But we also know there is a group of people, and it is not just in relation to health, but it could be home and community care type supports that they did receive once before and they are not receiving, and it is not clear how they would get those supports unless they purchased them themselves, and they are unable to do that.

Some people may not have the financial means to do that. Some people might be in situations in very isolated, segregated systems where they really need substantial support to be able to go and access in the mainstream system, or even other kinds of services as well. From our point of view, we are seeing people who still need some kind of specialist disability support, it is not currently in the mainstream system, it would be great if it was. We are saying the New South Wales Government also needs to be really clear about looking at that emerging issue or the issue as it stands in terms of the provider of last resort and how they are going to assist people who may not be able to receive supports through the mainstream system.

The CHAIR: You believe at this point that that consideration is not there? Is that what your submission is? You do not believe they are taking that approach? In other words, they are effectively providing the money to the scheme to support the Commonwealth scheme, but in dealing with this difference that focus is not there. Is that your submission?

Ms SANDS: Yes, we are saying that. We are saying there needs to be more investment. We already have the Disability Inclusion Act, so there is more investment that agencies need to be doing across government to look at how they include people with disabilities. That might be anything from accessible information provision, to having specific programs or supports within their systems. Some agencies are doing that. All agencies are meant to have disability inclusion plans. But that intersection with the NDIS is new and emerging and as it roles out will have different impacts. There needs to be specific focus on that. There needs to be recognition that for some people there is no provider of last resort and there is nowhere for them to go, except for going to advocates or hoping that service providers will provide them with supports unfunded, et cetera. That is what we are seeing currently.

Mr POOLEY: I certainly think the obvious default is the Department of Health, because of a lot of those things. To mention one quick anecdote: A person who became homeless on a Friday night in the Hunter region two weeks ago; urgent attempt to contact the agency; net result was it was after 4.30 on a Friday—I am not really trying to reflect on public servants—but the suggestion was to take the person to the emergency room or the local police station. Cut a long story short, the provider came up with an interim solution and there is some money flowing now. But they are the default mainstream departments that people who cannot generally be supported end up in.

Ms DAWN WALKER: To elaborate on this, because this evidence is really important, I noticed in your submission you gave a practical example of this service provision gap that the NDIS seems to have created. That was the community care supports program, which was funded by ADHC. A large number of those clients are not eligible for the NDIS and the withdrawal of the funding has now created a gap. Would you like to talk a little more about that?

Ms STACE: That is also picking up on the points around the individuals who were receiving those services. We heard this morning that they were predominantly services in people's homes, that is, personal-care services, house maintenance, domestic assistance and so on. They were broadly funded through a number of different providers, including health providers. With the withdrawal of that funding going into the NDIS bucket, those individuals are not eligible for the NDIS. That means some of them are being supported through mainstream services and some are being picked up the Commonwealth Continuity of Support Programme that the Department of Family and Community Services representatives talked about this morning in terms of the Pathways Project.

Our members are still telling us there are individuals facing gaps and that the Commonwealth Continuity of Support Programme is not adequate or that it is not picking up the services they had previously. That is probably one of the biggest areas where people were receiving supports but they are now not eligible and they have to look at other mechanisms to meet their needs. It falls back to the health system and to providers to stretch their limited resources to provide some of those supports. If those individuals are deemed ineligible, they can certainly appeal that decision; that is one of the decisions they can appeal. The pathways/continuity support program has helped individuals to progress. Where they have not had the right information, it has helped them to get it. However, we are still finding that people who are not eligible who were receiving services are still wondering how they will get their needs met.

The Hon. SCOTT FARLOW: A lot of the issues you raised were about linkages. How do your members or clients believe the ILC is operating?

Ms SANDS: I know the ILC is being reviewed by the National Disability Insurance Agency to make it more targeted. The point of the ILC is to look at making mainstream communities et cetera more accessible and inclusive of people with disability. However, the ILC is funded on a project grant basis. There are concerns about the sustainability of those projects after they have finished their deliverables for a particular contract, the life of the projects, and the impact they can have. The design of the ILC is really critical as is the level of investment. It is not only the ILC that plays a role; the New South Wales Government also plays a role in terms of the work it is doing under the inclusion legislation, the inclusion plans and the agency plans. Some of the ILC projects have been really innovative and important. The issue is sustainability when you get a project for one year or two years and how it is maintained.

The Hon. BRONNIE TAYLOR: It is the ongoing question of timing. We should make it all five years.

Mr POOLEY: The ILC was supposed to provide a wraparound set of supports outside the specialist system. Like the scheme itself, we believe it has potential, but it is just not there yet. There has been one funding round in New South Wales. I was surprised that the agency could not identify that. There has been a national round, but there has been only one ILC funding round in New South Wales in April this year. There is not a wraparound suite of measures supporting those people who are not eligible for the NDIS and dealing with a disability of some kind—yet.

The Hon. BRONNIE TAYLOR: I come from a rural community and that motivated me to be here to fight for services. I accept that there are some harrowing stories, but there are also some really good stories. You said there was a lack of services. Many new services have come to my community and have employed local people and there are now more jobs as a result. Although in some areas it is not working, would it be fair to say that in others it has provided that opportunity?

Mr POOLEY: Unquestionably. Employment in the sector has significantly expanded as a result of the scheme.

The CHAIR: Thank you for your submissions, which are very good. They contain a great deal of detail and content, and you have been able to augment them with some precise and detailed responses today. I appreciate the work you are doing in facilitating this scheme, and particularly in pointing out gaps that must be addressed.

(The witnesses withdrew)

(Luncheon adjournment)

MELINDA PATERSON, NDIS participant, affirmed and examined

ALISA COLEMAN, NDIS participant, affirmed and examined

AMBER CURRY, NDIS participant, sworn and examined

The CHAIR: I now welcome to our inquiry a panel of three National Disability Insurance Scheme [NDIS] participants who are our next set of witnesses this afternoon. Before we proceed, the Committee has resolved that there is to be no photography or filming of the witnesses in this session. We ask the media and the public to refrain from taking any photographs or undertaking any filming. I note, Ms Curry, you have your supporter this afternoon. Thank you very much for coming along. I invite each of the witnesses to make an opening statement.

We have received your submissions—thank you very much for those. You do not need to read the submissions to us, we have got those, but I am sure you will have some opening comments you would like to make. Then we would welcome the opportunity to ask you some questions. As I said, we have received your submissions. Ms Curry, your submission is labelled submission 111. Ms Coleman, we have received your submission, which is 104. We have received your submission, Ms Paterson. The next stage is to provide each one of you with a few minutes to make an opening statement to set the scene. Then we can start with our questioning. We will start with Ms Curry.

Ms CURRY: What NDIS stands for is good. It should help me get skills to reach my goals of being part of the community. I am being failed. More time needs to be spent to understand people's individual needs. I felt I was treated like a child and I am a 20-year-old. My plan was written for a four-year-old and not for someone of my age. The person who came over to speak to me had never heard of my disability, dyspraxia. He did not understand how it could affect my daily life and my speech and muscle tone. I had to explain to him what it was and what barriers can occur with this. I had someone spend only 15 minutes with me to talk to me about my plan. They did not understand how this can affect my daily life.

In my own experience, I had a waiting period with the NDIS after I finished school. It took six months for my funding to come through and the plan. I would have preferred to be out doing a placement at Fighting Chance and getting to meet new people and get my skills up in social and work skills. I sat at home for six months. Dad had to stay home and travel train me. We ended up having to go to Paul Fletcher, our local member, to speak to him. I had to talk to him about my plan and other people like me, such as my friends who had already finished school, and they still were waiting on their plans. I only got red-flagged because of my connections with a family member of ours who helps people like me get their plans approved. They helped rewrite my plan with my mum. She talked to me for over an hour about my experience with the NDIS.

The Minister got a copy of my plan and then red-flagged it as urgent for an interview. Other people like me cannot jump up and down and scream and do not have family members like mine who can help them deal with problems like this, and they will be left behind in the system. They will possibly never get the skills for employment. They will be sitting at home and relying on family members and government payments. I want to get a job in the animal care industry and contribute to society. The NDIS focuses on our weaknesses and not on our strengths. This is not what it should stand for.

The CHAIR: Thank you very much. That was a very strong and clear statement of your experience and your feelings in regard to the NDIS.

Ms COLEMAN: Mr Chairman and members of the Committee, if I had been asked 18 months ago what I thought it would mean to be a NDIS participant during the transition phase of the NDIS implementation, I would have said that plan approval meant that I had become a party to a national scheme that would enable me and my individual plan needs to be met by private providers who had become registered, which I would have also assumed meant credentialed and accredited, to deliver programs and services in accordance with the NDIS individual service plan agreements. I would have also said that service agreements had a contractual function that tied participants and providers together under the auspices of the NDIA in accordance with the aims and objectives of the NDIS and in compliance with relevant legislation, standards and terms of business.

Eighteen months on and one ongoing complaint over the use of door keys for service access later, here is what I now know. While as a NDIS participant I am indeed taking part in a national scheme that is meeting my individual needs in accordance with my plan requirements, the three presumptions I had made concerning, one, private provider registration; two, the contractual force and reach of the NDIS individual service agreements; and, three, the role played by the NDIA in ensuring scheme compliance were wrong or, as I prefer to think of it, unrealistically optimistic. Of the three presumptions that I made, potentially the most systemically problematic is, I contend, the first one because private provider registration has the capacity to impact on my other presumptions, as they all directly relate to three of this inquiry's terms of reference, specifically terms (a), (d) and (f).

The reason for my concern is that while the process of registration itself requires private providers to comply with specific requirements, principally outlined in the Provider Registration Guide to Suitability, and the NDIS Terms of Business for Registered Providers, once a private provider signs the declaration of suitability and becomes registered—which, at the moment means being listed—the NDIA's stated position on the matters, as emailed to the Australian Human Rights Commission on my behalf on 19 June 2018 is that, "All providers need to manage their own compliance obligations and ensure that they meet or exceed the relevant requirements of each jurisdiction." In other words, service providers are no longer compelled, post registration, to rigidly adhere to any specific requirements of the NDIS—particularly, I would suggest, when it comes to matters concerning the exercise of choice and control by NDIS participants.

If I only leave one message behind for consideration by this Committee today, I hope the message is this: Private providers, as pivotal components of the NDIS, should not be permitted to continue to self-manage their own compliance requirements under the NDIS. It should not be forgotten that when private providers who choose to participate in the NDIS, and therefore choose to receive the benefits that publicly funded scheme participation confers on them, they must also accept—as must I, as an NDIS participant—the obligations of participation. I thank the Committee for the opportunity being afforded to me today to raise these issues in relation to the NDIS.

The CHAIR: Thank you. That is very insightful, and very useful for our deliberations. We will come back, I am sure, with our questions in a moment.

Ms PATERSON: I am in my second plan under the NDIS, and I have to tell you that it is working really well for me. I work in the community care sector, so I knew all about the NDIS. I had read the Act. I had been to a few information sessions. The State of New South Wales put a lot of money into skilling people up to get into the NDIS. I particularly found a pre-planning session that was funded by ADHC in the south-east Sydney region was very helpful. I did a lot of work myself before I went into the planning process for the NDIS. I sent them a pre-planning document to explain how my day works and what sort of supports I thought I might need. I should note that I was getting virtually no supports under the State system—partially because I do not have an intellectual disability, and the State system tended to focus on younger people with intellectual disability, and also because I work full time and the block funded providers could not give me the flexibility I needed.

So I went into the planning process. I was pleased to find on both occasions of planning that my local area coordinators were excellent. They were both employed by St Vincent de Paul—again, in south-east Sydney. I think they are doing a really good job. They listened to me. They treated me with respect. They explained the process properly and prompted me on a few things that they thought I should be talking to them about. As a result, both my plans have adequately provided funding to cover my needs. I have chosen to use a private service, but I have to say—backing up Alisa's comment—there is a lot of hard work by the individual involved in managing your own service. I have been quite fortunate that my provider is good in terms of quality, but I have had to develop my own systems on a day-to-day basis for the workers. So I guess my message to the Committee is: NDIS can work really well if you have the tools, going into it, that you understand how it works, you understand where the pressure points are and how you need to articulate your needs in a way that gets across to the people putting together the plans, and take advantage of whatever supports are out there to help you on that journey.

Once again, for the Committee, my concern going forward, is that the State of New South Wales has put everything into the NDIS. So I have very serious concerns about people who do not fit into the NDIS—people who are not eligible or who are simply not covered by the NDIS. I am particularly concerned about carers, because block funding has disappeared under the transition, and other ADHC funded programs in New South Wales, including advocacy. So, if I had any problems I am not sure where I would go for help after this financial year, because this financial year, in theory, is the last year that advocacy will be funded in New South Wales. I have made a lot of use of advocacy over the years, despite being fairly articulate and able to argue my point. You need help to do these things. So I would like you guys to please look how New South Wales can support people—whether or not they are in NDIS—and, if we are having problems, how New South Wales can support residents of this State to make sure we get what we need from the new system. Thanks.

The CHAIR: Thank you, Ms Paterson. An equally excellent opening statement, where you have covered a number of points and reflected on your own experience. That is great. Are people okay that we open up for some questioning now? I will ask each member to identify who they wish to ask their questions to, so that it is very clear who the questions are being directed to.

The Hon. COURTNEY HOUSSOS: I reiterate the Chair's thanks to all of you for your excellent opening statements. They were very informative. We obviously have a wealth of lived experience but also professional experience here. I really appreciate that. I have a question for each of you. Ms Curry, I want to ask you about the delays. We heard this morning from the NDIA, and they said, "Yes, we can be doing better," but to be frank I felt they fobbed us off a little bit about the delays. You have given us a real insight into what a delay means for someone like yourself. You left school last year. You want to make a valuable contribution, and you can, but you are not able to through that delay. You talked about how your mum and other support people around you really helped you. What would have happened if you did not have mum or other supports?

Ms CURRY: I probably would have struggled to get the funding through, and get it red-flagged.

The Hon. COURTNEY HOUSSOS: Have you got your plan in place now?

Ms CURRY: Yes.

The Hon. COURTNEY HOUSSOS: What does your plan now give you?

Ms CURRY: I now can go to my SUEZ work placement to learn job skills and social skills.

The Hon. COURTNEY HOUSSOS: Fantastic. How many hours a week is that?

Ms CURRY: Three days a week.

The Hon. COURTNEY HOUSSOS: Fantastic. That has made a huge change in your life. It is very valuable. Is there anything else you wanted to add to that about the delays and what could have happened?

Ms CURRY: Probably just that I could have fallen through the system without the connections.

The Hon. COURTNEY HOUSSOS: Absolutely. Full credit to you, because we are delighted that you are still part of it. Thank you very much.

The CHAIR: Thank you to Mum, too, for the great support and advocacy.

The Hon. COURTNEY HOUSSOS: Ms Coleman, we have heard from the new Quality and Safeguards Commission. In your submission you talked quite a lot about where you have had to appeal to. Do you feel that the commission now addresses some of the concerns that you have raised?

Ms COLEMAN: My problem has been going on for the last 18 months and the new Quality and Safeguards Commission has only been running for a couple of months. It would have been nice if it had been up and running before the rollout of the NDIS started. I am now so far down the complaint process that I have been involved in for the last 18 months—almost the entire length of my time as a NDIS participant—that I think the framework and its arrival is a little bit late for me. I am hoping that it is going to serve others well; I do not think at this point that it is going to serve me.

But I have some problems with the framework itself and what I understand it is going to do because while it is good if you are able to articulate your concerns quite well and put forward arguments and complaints, if you have problems that relate to your disability that do not allow you to be articulate or to put your position forward in a way that you are not going to feel compromised about in terms of your service provision then the framework is going to have some problems. That would be unfortunate because there are many people with disabilities who at the moment would find, for instance, the complaint process I am going through a very onerous thing to do.

The Hon. COURTNEY HOUSSOS: Absolutely, it seems like it is very onerous. I am interested to hear whether you are aware if the Quality and Safeguards Commission would provide for and assist someone who had your issue? If you are not aware of that that is okay.

Ms COLEMAN: It is suggested to me that I could approach them now. How that would fit in with all the other processes that are currently in train to try to resolve my issue I am not sure. I think that I have to let what is happening at the moment play out. It may be something that I look at as an in between measure between having to go, perhaps, to the Federal Circuit Court, which is not something that I really want to do. If I can use them in that way at that point I will do that.

The Hon. COURTNEY HOUSSOS: Obviously the Federal Circuit Court is not the ideal place to be resolving an issue like yours.

Ms COLEMAN: It is the absolute wrong place to be resolving this issue. In fact, my issue seems so trivial in many ways that I cannot believe that I am talking about the possibility of it having to go to court. If it does go to court what I stand to run is a cost that runs somewhere between $30,000 and $100,000.

The Hon. COURTNEY HOUSSOS: That is incredible. Thank you very much for that, Ms Coleman. I have a final question—because I know we have limited time—for Ms Paterson. Ms Paterson, you talked about block funding and the need for block funding and for the State to retain some level of disability services funding, particularly for advocacy. I think everyone has touched on the importance of advocacy services, whether it is within your own families or having access to those. I found it really interesting that despite working in the sector yourself, you still see the need for advocacy.

Ms PATERSON: That is because if you are in the middle of a highly stressful situation—and it is potentially very emotional—you need someone with a cool head who is a bit objective and is highly skilled and has a legal background. I do not so I absolutely need advocates at certain points.

The Hon. COURTNEY HOUSSOS: Do you think that there should be some services that are retained within New South Wales?

Ms PATERSON: Definitely. I would like to remind you that the State of New South Wales has an obligation to people with disabilities. We have a Disability Inclusion Act and we have the international Convention on the Rights of Persons with Disabilities. What was really scary for someone who worked in the sector was watching all the State money go into one bucket. As soon as you put it all in one bucket there are people who are going to be left out. The people who I was working with when I was in community care are the people who are not going to get into the NDIS. Some of the people in the community care supports program use quite low levels of service, but they are crucial services to keep them out and about and keep them at work. Things like community transport need to be funded.

The Hon. PAUL GREEN: Ms Coleman, I just want to come back to some of the things you said. You made some very good observations about how the private provider registrations are basically self managed. Your comment was that it should not be self managed under the NDIS, given that it is publically funded and that it is not unusual to see huge amounts of public funds rorted in other systems, for example vocational education, where we have seen the system absolutely rorted by private self-governing issues. Have you thought about what it would look like and how we can keep accountability?

Ms COLEMAN: Yes, I have thought about it. I think that having registration only mean that somebody's company details got put on a list for the purposes of them being able to take money for services rendered is not sufficient. If you are talking about private providers coming into the service of the NDIS they have to understand what the NDIS is all about and, more than that, they have to build the NDIS and its components into the DNA of the organisations with which they work. It is not enough for providers to cherry pick the provisions that they choose to put into place and leave others undone. If we are going to have a national system of support services for people with a range of disabilities then we have to have a system that can consistently meet the needs of that range of disabilities. If providers are allowed to cherry pick the good and the bad people are going to miss out on services or get poor service and there is not going to be a consistent quality of service given.

I think that the registration process should be in two parts. There should be the registration that there is now, where they are required to go through a process where they look at the NDIS terms of business and look at the quality assurance provisions and so on and be registered after they have signed a declaration of suitability. But then I think there should be a provision that says that for the two years following the registration they have time to bring their organisation up to speed to conform with the needs of the NDIS. Once they have done that after the two-year period—or whatever period you want to nominate—they then get full accreditation as an NDIS service provider. That actually means something that everybody can rely on. Otherwise it is very difficult.

There are many good services providers out there and some of my services are being provided by people who are doing their upmost to make sure that the terms of the NDIS are met. But in the case of my particular home care dispute, my home care provider, who took over from the New South Wales home care service when it was privatised back in 2016, is not particularly interested in running home care in a way that is consistent with the NDIS. They are interested—I think—in running home care like they run their system of private homes and hostels for people in aged care. That system is very different. In that system they own those facilities and the facilities are purpose-built and have call buttons on the walls and staff 24/7. In my home there is no call button on the wall and there is no staff 24/7. It is my home and I should be able to have the staff come in to it that I want to see in it and I should have the means to determine how they access my home.

The Hon. PAUL GREEN: Ms Paterson, would you like to say something?

Ms PATERSON: I guess my experience has been quite different because I was not getting any services before the NDIS, I have come in purely as a consumer. So I looked in the market and I found a provider who would be flexible and who would see me as the boss rather than themselves. I pay them to do what I want them to do and only what I want them to do. That is not to say that it does not involve a bit of work because I have had to put together systems in my home with a diary and ticking off boxes for the workers to come in each day to do what they need to do. The other comment I would make is—and partially this is from my provider background as well—the registration process has the process of locking some really good providers out of the market. Small local providers just will not be able to do all the onerous things that need to be done. I am not so sure that for someone like me it would actually provide any better service than what I have now. I think it is also worth noting that there are three options in regard to how your plan is managed and two of those three options give control to the consumer or the participant—sorry, I am aged care background—rather than service providers.

I have actually gone with plan managed, which is the second option. I could have done self-managed but I did not have the time or energy to deal with finances. I pay a management service that is costed within my plan so it does not cost me any more money and that means I have absolute control over which providers I have. Within my plan I have what they call supervision of self-care—so daily core support funding for which I use a provider. I also have occupational therapy money, physiotherapy money and so on. I use different providers for each of those things and I just ask them to bill the plan manager directly. I am in charge of my care; no-one else is. From people I know in the NDIS that has been some of the problem—that they have actually left control of their package with their old providers. I have to say, a lot of the negative examples that I have heard either in the media or through friends have actually been services that were already funded under the old government system. They are actually not new providers, they are not private services, they are actually long-existing, government-funded services as Australian Unity is.

The Hon. PAUL GREEN: There is no doubt that some of those older services are trying to reinvent themselves to make sure they qualify for the funds.

Ms PATERSON: That is right. I think there is a danger in demonising new providers and private because you get good and bad in every group.

The Hon. PAUL GREEN: You are correct and you have made fantastic point. Certainly in rural and regional areas you do not have a plethora of choices.

Ms PATERSON: That is exactly right.

The Hon. PAUL GREEN: In rural and regional areas there are smaller providers who are really well known in the community and they are doing a great job but if you put all this accreditation over the top of them it will basically kill them. Then the big providers will jump in those spaces and give you the standard McDonald's. Ms Curry, I have a quick question for you. Ms Paterson has told the Committee about her pre-planning session. Were you offered a pre-planning session?

Ms CURRY: We were told that no planning was to be done until after school had finished. When that happened the school was not told about certain things that they should have done to prepare for that. We ended up having to go back to find out what was happening from both of the people.

The Hon. PAUL GREEN: So where the education factor should have been plugging in they left you high and dry?

Ms CURRY: Yes.

The CHAIR: That basically put you at the end of the line and you had to wait a long time to get your services?

Ms CURRY: Yes.

Ms DAWN WALKER: Ms Paterson, I was interested in what you said about advocacy services. Could you elaborate on your own personal experience and your knowledge of the need for those services for other people?

Ms PATERSON: A few years ago I enrolled in a community college program and discovered that it was not properly accessible. So rather than me yelling and screaming down the phone, and getting in a fight with that institution, I had an advocate help me with that and it got sorted out. That is probably the one that sticks in my mind but keep in mind that some of the block-funded advocacy services also have regular newsletters, they have websites, they offer different types of information sessions or training for their members. I am a member of IDEAS NSW, which is an information and advocacy service. I am a member of PWD, which does a bit of everything. Even the ones I am not a member of I keep an eye on their websites. The Council for Intellectual Disability does some really good stuff.

The My Choice Matters program, which was funded by the New South Wales Government out of the Consumer Development Fund, did fabulous work over a three- or four-year period at least in travelling around New South Wales educating people about their rights and then training people in how to be involved in planning and things like that. But once again it comes back to having some time and some energy as a person with disability to keep your ears open and keep involved. The reality is that some people just cannot do that, they do not have the time or the energy, and the carers who are trying to look after the person they care for and come to terms with the new system often just cannot manage it. There is always challenge with the transition as well. This particular transition I have been able to manage quite well but there have been a couple of personal sacrifices along the way. I actually resigned from a board that I was the chair of because I knew I needed to focus some time into this but choices. We all make choices.

The Hon. SCOTT FARLOW: From your evidence there is a bit of a mix as to who you get. Ms Curry, with your planner you had a very unsatisfactory initial plan and a case of advocacy. Ms Paterson, you have had a great story in somebody who has really understood your needs and been able to provide you with a great plan. I guess we have some fundamental challenges with the system and who you get, who is looking after certain regions and the like. Have you seen any improvements at all? Ms Paterson, did you say that this was your second plan?

Ms PATERSON: Second plan, yes.

The Hon. SCOTT FARLOW: Have you seen any improvements?

Ms PATERSON: Both my local area coordinators were really good and they both had appropriate backgrounds. I actually checked them out before they came. They asked me questions before I made the appointment so I very stroppily said, "Well you know about me, now tell me about you." I was fully prepared to refuse that local area coordinator if I found her unskilled and I was going to demand someone else, but luckily they were both fine.

The CHAIR: Have you thought about becoming an advocate? Seriously, I think you would make an excellent advocate.

Ms PATERSON: Absolutely—because this is my life.

The CHAIR: Yes, absolutely.

Ms PATERSON: I did not want someone unskilled coming to help me plan my life. But I recognise that I am fortunate, or unfortunate—depending on which way you look at it—that my disability is clear and obvious. I do not have to justify myself. I do not have to argue. I do not have to explain how it impacts on my life, although I did give them lots of written information to explain how many times I transfer between the chair and the toilet, the chair and the shower chair, and the chair and the bed—things like that—just to emphasise how important supports are. But certainly anecdotally, a lot of my friends, who are carers, tell me that if their children have things on the psychosocial range, particularly autism, they are having difficulty being understood by some of their local area coordinators and planners, and they are not necessarily seeing plans that respond to their needs, or they are finding that from year one to year two that they are being pressured to take a reduction in funding.

There seems to be a lack of understanding that some disabilities impact. Most disabilities do not improve. The insurance model of the NDIS is based on the assumption that you spend a lot of money on someone to begin with and you kind of work towards them needing less support in the future, and becoming productive members of society and paying tax. For a lot of people, that is just not going to happen. That is partially why I personally—and it is very much a personal view—think that there should be two systems. For someone like me with productive capacity, for whom a flexible individualised funding program works, I should be able to choose something like the NDIS. People who through no fault of their own either are not productive or cannot manage the choices should be able to go with a block funded program.

The Hon. SCOTT FARLOW: Ms Curry, to pick up on that point, you are very much somebody who wants a plan that enables you to be productive and seek employment in the future. Do you think your current plan now has those steps in place, effectively, that it caters to those needs of yours?

Ms CURRY: I think it does now.

The Hon. SCOTT FARLOW: But you have travelled a long road to get that.

Ms CURRY: Yes. It has taken a long time to get there.

The Hon. SCOTT FARLOW: That it caters to you now is good to hear and encouraging. Of course, I commend your mum and all of the supporters around you who have enabled you to get to that position.

The CHAIR: I am sure I speak on behalf of all members of the Committee when I thank you all for coming along. Your evidence has been very enlightening for me and others, I am sure. You did not just usefully reflect on your own experiences and speak to that, which was very useful, but I compliment you all for looking ahead to make some suggestions about what could be done better, more effectively and more speedily to enable people to benefit, as we all want them to do, from the scheme. On behalf of the Committee, I thank you all very much for your contribution. Your evidence will be most useful in our deliberations.

(The witnesses withdrew)

JENNIFER CLARKE, Individual, before the Committee via teleconference, sworn and examined

KERRIE TYLER, Individual, before the Committee via teleconference, sworn and examined

KATERINA ATHANASSIOU, Individual, sworn and examined

The CHAIR: I now welcome our next witnesses, who include two witnesses giving evidence via teleconference, Ms Jennifer Clarke and Ms Kerrie Tyler, and a witness at the table, Ms Katerina Athanassiou. The Committee has resolved that there is to be no photography or filming of the witnesses in this session. I ask media representatives and members of the public who are present to refrain from taking photographs and filming. Ms Athanassiou, in which capacity are you appearing before the Committee?

Ms ATHANASSIOU: I am here as a private individual.

Ms CLARKE: I appear as a private person.

Ms TYLER: I am giving evidence on my own behalf today.

The CHAIR: Without nominating the specific numbers, I want to confirm with you that we have received your submissions to this inquiry and we are grateful for those. They are quite detailed and provide us with some insight into your circumstances which will help inform this inquiry. I will ask each one of you whether you would like to make what we call an opening statement, which is to say a few words to give us a bit of context and background. Once each one of you has done that, if you are agreeable, I will open up the hearing to Committee members to ask you questions. It will flow in that way until we exhaust time. Are you okay with that?

Ms CLARKE: Yes.

Ms TYLER: Yes.

The CHAIR: We will proceed firstly with Ms Athanassiou, who is present, then Ms Clarke and then Ms Tyler. Ms Athanassiou, would you like make an opening statement?

Ms ATHANASSIOU: Thank you, the Hon. Greg Donnelly and other members, the public and those at home at teleconference. I would like to acknowledge the traditional owners of the land on which we are, the Gadigal of the Eora nation and elders past, present and emerging, any here today or at home, and acknowledge those with lived experience, carers and supporters of people with disabilities. Regarding myself, a bit of background and context. I have a team around me, a counsellor, a psychiatrist and a general practitioner who have supported me since 2006 on my own journey of self-care and maintaining ongoing recovery. I am not on the National Disability Insurance Scheme. As far as that goes I have my application filled out at home. I have never submitted it because of fear of getting into trouble.

Also, thank you very much to New South Wales Government for my funded spot at the Australian Psychosis Conference over the weekend. I have since learnt that, yes, probably at this stage in my life I am not eligible, which is understandable. Also, with regard to ongoing recovery, art, music, theatre, nature, the beach, exercise, full-time work—I am an early childhood teacher, I am professionally accredited—and family and friends help maintain that ongoing self-care and recovery. Information from a dietician, exercise physiologist, physiotherapist and my own research has also helped me on my journey since a diagnosis in 1999 until today. I do not feel comfortable saying what my diagnosis is.

The CHAIR: That is okay.

Ms ATHANASSIOU: I have a disability. I will go as far as saying I have a mental health disease.

The CHAIR: Leave it at that, that is fine. Thank you, that is very good. That has given us a context and an outline. I move now to Ms Clarke. Would you like to make an opening statement?

Ms CLARKE: I will make a short one. I live in Kempsey on the mid North Coast of New South Wales and I was working as a registered nurse back in August of 2007 when I was injured. Since that day I have lived in constant and often debilitating pain. I had one lot of surgery to try to improve the nerve impingement. This was not successful. In 2013 it was noted by specialists that I had a 19 per cent whole person impairment and at that time it was believed that I was continuing to deteriorate. Present treatments include the use of opiates and non-pharmacological options such as counselling, meditation, massage, et cetera.

The injury has affected every part of my life including my social life. In late 2013 I was medically retired from work as the injury continued to degenerate. I am now living on a disability support pension. I use a walking stick when mobilising short distances, longer distances can increase my pain and it reduces my ability to mobilise. I am also able to attend to my own personal activities of daily living [ADLs]. I am able to attend to my own housework, garden, maintenance, et cetera. I applied for the NDIS in early 2017 as I was led to believe that I would be eligible, but I was informed by them in July of that year that I do not meet the access criteria. I was verbally told that they do not consider my disability substantive enough. Since this time I have not had contact with any other disability services.

The CHAIR: Have you finished?

Ms CLARKE: Yes, thank you.

The CHAIR: Thank you very much. That is very succinct and complete. I move now to Ms Tyler. Would you like to make an opening statement?

Ms TYLER: Yes. I live in Sydney with my son. I have been on a disability pension for the past 10 years. Unfortunately, I have not been well enough. Due to declining health issues I have not been able to work since then. I am basically housebound except for doctors and treatments and things like that, which takes up a lot of time. It tends to be endless amounts of doctors and specialists and treatment and everything else. It affects me, my health affects my sleeping, causes migraines, depression, widespread, severe body pain actually and terrible fatigue and mobility issues. I am just really struggling to get around the house these days. I really ideally need a lot of help but unfortunately because I have been denied the NDIS I do have some help from a provider, because I am Indigenous as well. I do have to pay for that. Unfortunately, I cannot have an unlimited amount of hours. I am entitled to it, I have been with them for a few years but unfortunately I cannot afford to pay for it at common private rates and all these medical bills. Often I cannot even afford to see my specialist. I have got seven different specialists to see because I have got systemic health problems, which is actually neurological, gynaecological, digestive, joints, spine, metabolic, blood disorder and it is now affecting my organs as well from all the different types of medications and things that the doctors have tried and failed on me.

My medication is also not under the Pharmaceutical Benefits Scheme [PBS] because I have multiple allergies and my diseases are not easily treated. They are also rare, so I am not too sure if this is why I have been denied, because there is no cure as well for a lot of these. They are not easily treated. I am having issues with my home care provider on numerous occasions but I cannot afford to try to swap because it will probably cost me more money and there will be a longer waiting list. I am simply dealing with getting two hours a week. That is simply not enough but there is nothing else I can do about it. They are very unprofessional, they often do not turn up or walk out or turn up late, leave early, all sorts of things. It is not a great situation. Because I have rare diseases I need to see private doctors, so paying for all that out of my own pocket is extremely hard as well. Thank you.

The CHAIR: Thank you for opening up and giving the Committee some insights into a number of difficult medical and health challenges. I will open up the hearing to questioning, if you are agreeable to that. We have members from the Government, the Opposition and the crossbench. I will get them to identify themselves so that you know who is asking the question. Members will need to direct their questions to a particular person so that it is clear to whom they are talking. I will then provide you with a chance to respond. We will move around the table. Is that okay?

Ms ATHANASSIOU: Yes, thank you.

The Hon. COURTNEY HOUSSOS: My name is Courtney Houssos. I am member of the Labor Party and the Opposition. I will ask the same question of all three of you. Thank you for giving us your time and sharing your experiences and personal stories. I am sure it is not easy and we appreciate it because it will inform our discussions and deliberations as a committee. Part of the challenge we are hearing about is the absence of support from the National Disability Insurance Scheme [NDIS] increasing the burden on State services, the most obvious being the health sector. There might be other support services you are utilising because you are not being supported through the NDIS. Can you each explain what services you are utilising to obtain those supports? You all touched on it in your opening statement, but I am keen for you to elucidate.

Ms ATHANASSIOU: I am not accessing any. I would like to clarify the question. I see a psychiatrist and a psychologist privately and my general practitioner treats me privately. That is it.

The Hon. COURTNEY HOUSSOS: So you are not accessing other State services; the cost is coming out of your pockets?

Ms ATHANASSIOU: I am a full-time professional. I am here today—thank you for the invitation—because I have a big question mark. I am beginning to understand on my journey that I am probably not eligible at this stage. But in the future I will not be able to work full time as I do today. Like the two ladies who have spoken via teleconference, I will not be able to afford to have that ongoing support. No, I am not accessing anything out there.

The Hon. COURTNEY HOUSSOS: Thank you for that.

The CHAIR: Ms Clarke, would you like to respond to the question?

Ms CLARKE: Certainly. The only services I am getting that would be paid for by government would be general practitioner services. I see a counsellor once every six weeks because I feel it is very important for the control of my pain. My injury in 2007 was a workers compensation injury. As such, I got a very small payout. I have been using that to pay for my home-care services, like gardening, maintenance, some shopping, house cleaning and stuff like that. Everything else apart from the counselling, I pay for privately.

The CHAIR: Ms Tyler, would you care to respond to the question?

Ms TYLER: I am using home care and part of that has been funded. I have seven different private specialists and I receive some of that money back. But it is a struggle for me to get to my Medicare levy cap so I can get a lot more money back, and I am not at that. I sometimes do not even get half back. My general practitioner does bulk bill me. Other than that, I am paying the rest myself as far as physio and massage are concerned. I have to get someone to come to the house because I cannot travel. I am paying for a naturopath and so on. I need meal replacements because I have an oesophageal disease.

The CHAIR: Did you say "meal replacements"?

Ms TYLER: I have a disease of the oesophagus that affects my eating and drinking.

Ms ATHANASSIOU: I would like to clarify "lack of knowledge". I sometimes get Medicare bulk billed by my general practitioner. I also have a mental health plan through my general practitioner. I get that again every year. I have learnt about it only in the past five years even though I was seeing a counsellor. Some of the psychiatrist's fee also comes back from Medicare.

The Hon. COURTNEY HOUSSOS: Ms Clarke and Ms Tyler, you were refused access to the NDIS. How did that play out and how long did it take? What was the application process like and how long did it take for your cases to be evaluated and for you to hear back?

Ms CLARKE: I sent my application probably in March or April 2017, and I got a response in about July. I cannot remember how they told me I was not eligible. I think I may have got a standard letter saying I was not eligible. I immediately started writing a letter asking for a review. Then I got a phone call before I sent the letter saying that in their opinion I did not have a hope in hell—they were their words.

The Hon. COURTNEY HOUSSOS: That is really helpful.

Ms TYLER: I have the letter declining my application here and there is no date on it. I think there was a few months between my application being lodged and getting the rejection letter. That was about three years ago. Do you want the reasons they gave me?

The CHAIR: Yes.

Ms TYLER: It says that I do not meet their requirements as in (c) and (e). The letter says that (c) means the impairment or impairments result in substantial reduced functional capacity to undertake social functions under one or more of the following activities: communication, social interaction, learning, mobility, self-care or self-management. It also says that (e) is that you are likely to require NDIS support throughout your life.

The CHAIR: Thank you for that.

The Hon. BRONNIE TAYLOR: I think it was the last person who spoke who said their letter stated they had no hope in hell of receiving—

Ms CLARKE: No, the letter did not say that. I got a phone call afterwards to say—

The Hon. BRONNIE TAYLOR: Do you know who made the phone call and said that?

Ms CLARKE: No idea. I must admit that I was furious.

The Hon. BRONNIE TAYLOR: I bet you were.

Ms CLARKE: They basically said that my issues are chronic, that the help I needed would be met by general health services, and that there was no way in hell I would be eligible for any other service at this point.

Ms DAWN WALKER: My question is to Ms Tyler and Ms Clarke. I am interested if there are any services that you have been accessing that are no longer available since the NDIS has come on.

Ms CLARKE: The only thing that would be eligible for me would have been—if ADHC had been around when I applied for NDIS, I probably would have gone straight to them and maybe talked to them about getting access to an occupational therapy or an occupational assessment so that I could actually prove that I had a disability. But seeing that ADHC is no longer around, I have no access to that kind of service. If I wanted to get an assessment, I would have to find money out of my own personal account. I have not accessed home disability services because, after being told that I did not have a hope in hell of that, I did not think I wanted to apply to anybody else because it is a very—you spend so much time applying for stuff and to just get knocked in the face like that is really hard. I have just been through insurance problems and then to be knocked back because they reckon you do not have a disability, it just sort of gets you in the gut. Pardon the expression.

The CHAIR: No, feel free. Ms Tyler, do you want to add a response?

Ms TYLER: Can I have the question again?

Ms DAWN WALKER: I was interested in whether there were any services that you are currently accessing or have accessed in the past that are no longer available since the NDIS has come into effect.

Ms TYLER: No, I do not think so.

The CHAIR: Ms Walker, do you want to pose that same question to Ms Athanassiou?

Ms DAWN WALKER: I think we have had a very comprehensive answer from that witness in that regard.

The CHAIR: That is right. I think that point has been covered.

The Hon. SHAYNE MALLARD: Thank you for coming in today and for participating on the phone. It is not easy to tell your personal story, and we really appreciate hearing it. It helps inform and fill out the whole picture for us. Each of you can answer this, and you partially have answered it: Prior to NDIS were any of you receiving benefits from the State Government's disability services system? Obviously, each of you has been rejected for benefits under the NDIS for a different reason, but essentially for not meeting the criteria that it has in place at the moment. I was wondering if you are getting benefits under the State. I think one or two of you mentioned that you were, but could you go through those for us?

The CHAIR: We will start with Ms Ath—athan—

Ms ATHANASSIOU: It is like you are going to sneeze—Athanassiou. I am happy with Katerina.

The CHAIR: I normally take instructions about pronunciation before the Committee commences. My phonics are dreadful.

Ms ATHANASSIOU: Thank you for the question, the Hon. Shayne Mallard. I need to clarify: I am not or have never been rejected by the National Disability Insurance Agency or NDIS. I still have my application, signed by a psychologist, a psychiatrist, a GP and myself, filled out, in the envelope, ready to hand in, but because of fear of the whole process and the fact that the eligibility criteria online were very wishy-washy and unclear about persons such as myself—and then they came up with the label "psychosocial disorder" and even that is still unclear with regard to myself—I still have not applied. To answer your question: No, I have not received any benefits other than Medicare rebates and the dietician, which was on a plan with my GP—the exercise physiologist which was on a plan because back then I was 30 kilograms heavier.

The Hon. SHAYNE MALLARD: Were they all covered by Medicare?

Ms ATHANASSIOU: I paid some out of pocket.

The Hon. SHAYNE MALLARD: But not the State, not the New South Wales Government.

Ms ATHANASSIOU: I am sorry—I am showing my lack of knowledge. Is the Medicare a State—

The CHAIR: No, that is Federal.

The Hon. SHAYNE MALLARD: It is Federal.

Ms ATHANASSIOU: Right. I beg your pardon.

The CHAIR: No, it is quite complicated.

The Hon. BRONNIE TAYLOR: We get confused, so do not worry.

The Hon. SHAYNE MALLARD: That is okay. There are three layers of government and probably one or two too many.

The CHAIR: Ms Clarke and Ms Tyler, it is the same question from the Hon. Shayne Mallard to both of you. Ms Clarke, do you need the question repeated?

Ms CLARKE: No, it is okay. I only get the Federal stuff. I get nothing from the State, but feel free to get together and organise to send me a package of anything you like.

The Hon. SHAYNE MALLARD: We will take that on board.

The CHAIR: We will take that as a very clear position you put. Thank you for that. Ms Tyler?

Ms TYLER: Sorry, can you repeat the question? Just give me one example. My brain fog has really kicked in.

The Hon. SHAYNE MALLARD: I essentially wanted to know whether before NDIS came along, you were receiving State benefits for disability, which obviously are discontinued now. I think Ms Dawn Walker asked a similar question. Were you receiving any benefits from the State before the NDIS came along?

Ms TYLER: Would that mean disability pension?

The Hon. SHAYNE MALLARD: That is Federal.

Ms TYLER: Oh, that is Federal.

The CHAIR: Any payments or services that were provided by the New South Wales State—in other words, the relevant State agency? Were you receiving any of that before the NDIS commenced for you?

Ms TYLER: Would that be my home care provider?

The CHAIR: Possibly so, yes.

Ms TYLER: Yes, home care provider.

The CHAIR: What did the home care provider do for you?

Ms TYLER: Shopping, cleaning, cooking, gardening—whatever you wanted to do. And transport.

The Hon. SHAYNE MALLARD: Is that home care provider still provided to you?

Ms TYLER: Yes.

The Hon. SHAYNE MALLARD: Under the NDIS?

Ms TYLER: No.

The Hon. SHAYNE MALLARD: Under the State?

Ms TYLER: No, I am paying for it myself now. I mean, I pay a part payment and the Government picks up the rest.

The Hon. SHAYNE MALLARD: The State. Thank you very much, all of you.

Ms ATHANASSIOU: A side note: When I was unemployed—2007, prior to that—I was on unemployment benefits and rental assistance.

The Hon. SHAYNE MALLARD: That is Canberra again.

Ms ATHANASSIOU: Sorry.

The Hon. SHAYNE MALLARD: No, it is good.

The CHAIR: Thank you. That helps us understand the scope of services you have received, so that is good. Are there any final questions for the witnesses? If not, on behalf of the Committee, I thank all three of you for participating. I know it is a bit awkward doing it over the telephone, but you provided invaluable insights into your own lived experiences about dealing with matters of disability and how you have managed with them and dealt with them, both prior to and after the introduction of the NDIS. It will be valuable evidence that we will be using in our deliberations. Once again, on behalf of the Committee, thank you for participating in the inquiry.

Ms ATHANASSIOU: Thank you.

Ms TYLER: Good luck.

Ms CLARKE: Have a nice day.

(The witnesses withdrew)

(Short adjournment)

SCOTT RAND, National Disability Insurance Scheme Carer, sworn and examined

KAREN WAKELY, National Disability Insurance Scheme Carer, sworn and examined

SANTHI CHALASANI, National Disability Insurance Scheme Carer, sworn and examined

ANN RIDD, National Disability Insurance Scheme Carer, before the Committee via teleconference, sworn and examined

The CHAIR: I will invite each of you to make an opening statement to set the scene, so to speak. I inform you all that your submissions have been received by the inquiry and we have had the opportunity to review them. You do not need to read them per se but you can refer to their content for the purpose of elucidating answers to questions, et cetera. We will start with Mr Rand and work our way through.

Mr RAND: I am a carer for a disabled granddaughter. I am just an ordinary bloke. I am married. I have three kids. By the end of the year I will have seven grandkids.

The CHAIR: Congratulations.

Mr RAND: The eldest of the grandchildren lives with me full-time. My wife and I have full-time care. She has Pitt-Hopkin syndrome. It is fairly rare. I think there are only eight or nine in Australia that have been diagnosed with it. There is about 500 worldwide. It is characterised by severe global development delay. She is non-verbal. She cannot walk without assistance. She cannot talk. She cannot feed herself. All aspects of her life require care. We have lived the transition from Ageing, Disability and Home Care where my disabled daughter originally had the ADHC intervention which then transferred over to us when we took over the care of our granddaughter and we have then transitioned into the National Disability Insurance Scheme [NDIS]. We are pretty competent, confident people.

We have found that the NDIS for us has been a very, very confusing, complex system. We have concerns. We have concerns about the future of our child. For most people their goals for their children is to be a doctor, a lawyer, an engineer or to travel the world. Ours are pretty simple. We would like her to be able to get a glass of water from the tap by herself, to be able to change her clothes, to be able to have a bath. Going forward with the NDIS, we are concerned for the future of our children.

The CHAIR: That has been very clear and concise. It adds nicely to your written submission. Ms Wakely, would you like to make an opening statement?

Ms WAKELY: I am a carer for a son with autism. Thank you very much for inviting me here. It is a privilege to be here. My purpose with making a submission was I know that everyone has heard a lot of stuff about the NDIS and its shortcomings and that is well founded, but what I wanted was to give you a good story and explain how it has been such a positive thing for me and my family. It has resulted in probably the most significant support that my family has had. We really got no effective support at all before the NDIS. Therapy was very ineffective because it was not affordable.

Now we have actually got access to affordable therapy and it has come at a critical time in the life of the family. It has made a big difference and that was the message I wanted to get across. Despite some of the negatives that we have all heard, it really has made a big difference in our life and it has given us the first meaningful support that we have had. I would like to see some of the language changed. When we hear stories about cost blowouts in the NDIS it tends to make you feel very burdensome. It makes you feel a bit guilty that you are a burden on the country. I would like to see more positive stories come out.

Dr CHALASANI: My son was diagnosed with autism at the age of 22 months and he presented in a fairly classic way with deficits in communication, social skills, play skills and some mild motor deficits. He has actually done remarkably well with intensive therapy over the last two years, which has largely been self-funded. I agree with both Karen Wakely and Scott Rand. I think there are many positives to the NDIS but we have also experienced some problems. We previously received the Helping Children with Autism package before being switched over to the NDIS, and we have clearly benefited from it. However, the problems that I see with the overall process have been, firstly, massive time delays. I think that is of critical importance in the early intervention space where time is really of the essence. I think there is really a lack of training and understanding in NDIS staff about autism and we have certainly encountered that personally. I think there are inconsistencies in funding between States and between families, despite clear evidence to show efficacy of therapy. I think there is a lack of standardisation of assessments as well as—

The CHAIR: Are you talking about autism here or more broadly?

Dr CHALASANI: I am talking specifically about autism in relation to my personal experience as well as other families that I have been involved in advocacy groups with. I was talking about a lack of standardisation of assessments and documentation necessary for funding decisions. It is very confusing for parents to know what we need to provide. We often spend a lot of money on different reports and many of them may not be relevant or may not be actually looked at.

So I think there need to be clear guidelines for that. I think we have run into an expectation from the NDIS that we, as parents, should be the primary deliverers of therapy again, which I do not think is evidence based or a reasonable expectation when families are struggling to come to terms with the diagnosis itself. Finally I think there is misrepresentation of the medical evidence for best practice treatment in children with autism, especially with generalisation of models used in children with other disabilities and then generalising that to children with autism where there has been no clear evidence in that space. I think for me those are the main points.

The CHAIR: Ms Ridd, would you like to make an opening statement?

Ms RIDD: Thank you. My son was 32 years of age when he was diagnosed with motor neurone disease. He was up until that time what I would call very much a sportsperson. He surfed, he played rugby union, first grade, for Penrith and he also represented Australia in the Old Boys. He played for Illawarra representing and he also spent two years in England playing for Newcastle upon Tyne. At that stage he was also a self-employed carpenter. He was what I would call pretty well fit. In December 2011 his whole world fell apart when he found out he had motor neurone disease. At that stage he was given one to two years to live which was a bit of a shock at such a young age and at that stage he had a five-year-old daughter. I am very pleased to say that through his stubbornness and determination he had made seven years. He turned 40 this year which is something we never expected to be able to celebrate with him. However, he does not what I would call have a quality of life at all from what he had in the past. He is 100 per cent dependent. The only things that he can move are his eyes and his head. Everything else has to be moved for him, including a finger to scratch his neck or whatever he has to do.

In regard to NDIS, as I said in my statement, a couple of good things came out of NDIS, one of them being an increase in carer hours and also an allocation of carer hours that then enabled him to be able to attend his daughter's sporting events, or a school event, et cetera. They upgraded his laptop computer where he is now able to converse with the outside world. Although he cannot use his hands, he uses a little silver disc, that people may be aware of, that does all the typing for him on the computer which allows him then to send SMSs, Facebook, turn the air conditioning on and off, turn the television on and off and change the channel. So it gave him back that little bit of independence that he so badly needed.

But having said the good, there is one hell of a lot of bad by NDIS, frustratingly so for me who has for over 12 months an ongoing argument with them in regard to many items. You may be asking more questions down the road so I will not go much further with it, but just to say that he has recently had to move out of our house where he had been living with my husband and I looking after him. We have been waiting for over 12 months for the bathroom to be made paid suitable for a wheelchair so he has now moved into a granny flat that has the availability for him to get in and out of the bathroom and be showered with a bit of dignity. He has also waited, I think it is 16 months now, for a new chair to sit in.

So you have got to say at the end of the day that NDIS staff, I do not know whether they are not trained properly or whether they have a big changeover in staff but it was evident from the time I started working with the NDIS from day one that it looked like it had been rushed. There was no real process or procedures put in place. Nobody really knew what was right and what was wrong. The rules had been changed on the run which is very frustrating. A lot of people I speak to all seem to have very similar complaints. There is a little bit of good out of the NDIS but a hell of a lot of bad.

The CHAIR: Thank you for explaining those difficult details associated with your son's deteriorating condition and his experience. We will commence now with the questioning. As I said, members of the Government, the Opposition and the crossbench are in the room and we will share the questions around. Each person who asks the question will identify themselves Ms Ridd but we will follow the same rotation with witnesses in order to get through it in an organised fashion.

The Hon. SCOTT FARLOW: I thank everybody for being here today, for being so open with the Committee and for all the work that they do as carers. I know it is a great challenge at times and so rewarding as well to be able to see that progress and improvement, which is what we all want to see from the NDIS, where possible. Mr Rand, you outlined your concerns for the future. In many ways the NDIS is supposed to be there so that when there is a future and you are no longer there you might have some comfort. We have heard that from some people before the inquiry today. I just want to understand your concern for the future. How have your interactions with the National Disability Insurance Agency made you feel so concerned?

Mr RAND: When you have a child that cannot talk and cannot communicate, the whole focus seems to be shifting people into self-managed plans. When we look to the future when we are not here, who is going to be responsible for that person? She cannot manage a plan on her own. She will never have that capacity to be able to do that. Currently, if we start looking at obtaining the services of a plan manager that they can provide through the NDIS, how do we guarantee their integrity? What sort of people are we going to be putting in charge of her for her future? Secondly, those costs also come out of the plan.

When we have discussed starting to try to build those relationships for the future, they say, "Well we can decrease your funding in other areas and allocate that money across for that particular thing." When I am looking to the future, what are the provisions for her for assisted living? We are still 10, 15 or 20 years down the track. If something happens to us in the interim somebody has to try to pick up that plan and try to assist her with her growth. I find the term that they use that NDIS is the informal support really offensive because there is nothing informal about what we do. When you are asking me about what the future looks like, I do not know what the future looks like because all I can see is constant change going on. The community housing sector has all changed and everything is constantly changing. When I put out feelers to see what is potentially solutions for the future nobody seems to know.

The Hon. SCOTT FARLOW: In terms of that plan management, when you have been talking to people about the cost for those services, what sort of cost are you looking at in terms of managing plans?

Mr RAND: If I am looking at the hours that we put in currently and just through the coordination, that is a full day a week—a minimum of eight hours a week reconciling, submitting invoices, coordinating services. That is just for the plan alone; that is not for every other aspect of life that requires full-time attention.

The Hon. SCOTT FARLOW: So they are significant costs that would go into all the service provision that is required.

Mr RAND: Yes.

The Hon. SCOTT FARLOW: Ms Wakely, you have got a brighter story in terms of the NDIS and how that has changed things for you and your family and your role as a carer. You mentioned the question about cost blowouts and how that has been marketed in the media and the like. Have you gone through a review of your plan under the NDIS or is it just the first plan?

Ms WAKELY: No, this would be our fourth year that we have been on it. We are essentially on the same plan now that we were. He was 15 when we started and he is now 18, so you can imagine the changes that have happened in that time. The way the plans are crafted are very poor. We started off with three goals and strategies, to implement two of them. From a strategic planning point of view you would expect to have some goals and then some activities. They are not crafted in that way at all. There was just so much duplication in the goals that we could have done just about anything with it. My way of dealing with that is just being anytime I want to do something I will just phone up and say, "Are you happy for me to do this?" so I have then got a record if there was any problem. But otherwise they are so broad that you could put just about anything under them.

The Hon. SCOTT FARLOW: Your funding under the plan has stayed fairly consistent over that four-year period then?

Ms WAKELY: It has dropped a little bit, but I was happy with that. I think our first plan we got something like $18,000—our care needs are not anything like Mr Rand's—and they tended to meet our requirements. We have got an application for review in at the moment because my son is leaving school this year and we wanted to start a supported employment program next year, but nobody knows what they are doing with that because the process is changing this year. Obviously they have known about that since the start of the year but here we are September and they still do not know how they are dealing with it. It will be interesting to see what happens in a couple of weeks' time because we have got two weeks of school left and do not have a clear plan yet.

The Hon. SCOTT FARLOW: Dr Chalasani, in terms of your experience with somebody with an autism diagnosis, early intervention is so key, and having those delays in the process, while it is very concerning to hear that, have you seen any improvements or any signs of improvements through the NDIA and how they are able to adapt and be able to provide those services when they are needed?

Dr CHALASANI: My contact with the NDIS started in late 2016, shortly after my son's diagnosis, and because that was so close to the rollout of the NDIS in certain areas there was a lot of confusion. When I called the NDIS phone line the staff could not answer my questions, they could not direct me to appropriate people. I ended up leaving that conversation after about two hours on the phone with a number for the Northcott Society in Bendigo. I just find that very frustrating. That was very close to the time of the diagnosis and I think at a time when you are struggling to cope with the diagnosis to then just have to try and meander through the system it is very difficult.

Following that I just did my own research and realised that at that point in time the NDIS was going through a transition with early intervention so you could no longer get an access form directly from them, you then had to go through secondary bodies such as the Northcott Society, Lifestyle, Plumtree. So then I just put my son's name on the waiting list for all of them because I was told it was going to be months just to get an access form to the NDIS. By the time that whole process finished it was 12 months between the time I initially made contact with the NDIS and the time we got an initial planning meeting, and that is critical time in early intervention. If I had not just gone ahead and done intensive therapy my son would probably still be non-verbal. Because he has been getting such intensive therapy we have every expectation he will be able to attend mainstream schooling with no supports and not be an NDIS participant, which is exactly the outcome that we want.

It benefits the community to invest in early intervention because after two or three years if a child can avoid special schooling and achieve mainstream schooling the community has made up that money. So I think the time delays have been a really problematic part of the whole process. Even though we got our initial plan at the end of 2017 it was not enough funding and so we immediately put in for a review and we are currently in the tribunal process. So almost all of my son's therapy has been self-funded.

The Hon. SCOTT FARLOW: And, Dr Chalasani, of course there are many people who would not be in the same position as you to be able to provide that sort of assistance, which is concerning.

Dr CHALASANI: Exactly. Through these battles I have become involved in a lot of parent advocacy groups and it is really upsetting to see children who could be verbal and could be speaking and could be achieving such different goals not being able to do that because they are still waiting for the NDIS. It is a scheme that has the capacity to impact millions of lives for the better; it is a wonderful scheme with potentially wonderful outcomes for people, but the time delays in the early intervention space are really critical.

The Hon. SCOTT FARLOW: Dr Chalasani, we have heard a few instances so far of differences in terms of the LACs and how they are able to assess individuals. You yourself raised in your opening statement the problems of inconsistency of the assessment process as well. Do you think that in particular with those with an autism diagnosis assessors do not really get them as much as they do perhaps other disabilities?

Dr CHALASANI: Just to clarify the question: Do I think that NDIS assessors—

The Hon. SCOTT FARLOW: Yes, in terms of the assessments and that when it comes to an autism diagnosis there is not perhaps the understanding of some of the assessors of that?

Dr CHALASANI: Definitely. I think there is a clear lack of understanding with NDIS staff and assessors. I think that is demonstrated through multiple means; firstly, the use of an assessment tool called the PEDI-CAT, which is used in initial planning meetings. That is not a clinically validated tool.

The CHAIR: Sorry, what is a PEDI-CAT?

Dr CHALASANI: It is called the Pediatric Evaluation of Disability Inventory Computer Adaptive Test [PEDI-CAT] and it asks you a series of questions about the functional capacity of your child. It is not a clinically validated tool for use in autism. I am not sure why it is even being used in that capacity. That is one example. Other examples are that NDIS often cite a document which contains guidelines for early intervention in Australia, which of the 94 references only one is in relation to autism, and that study is a very small study which is not adequately powered to form any firm conclusions. That guideline is constantly used and applied to children with autism, when it has no relevance.

The Hon. SCOTT FARLOW: I think you inferred in your answer before that in terms of your plan it has reduced in value over the years. Is that correct?

Dr CHALASANI: We are still in our initial plan getting that reviewed at the tribunal. So we have not progressed—

The Hon. SCOTT FARLOW: From the initial plan?

Dr CHALASANI: —at all.

The Hon. SHAYNE MALLARD: Thank you everyone for coming in and sharing your experiences. I am aware of families of children on the autism spectrum and how diverse that is and the problems that they are having as well with navigating and slotting into the NDIS. I think in the NDIS's submission today, which you may have read, they are sort of acknowledging that there is a bit of a problem there for them and they have set up an autism advisory group—it is on page three of their submission, if you have not read it—with some objectives, but it does not pick up on early intervention nor the type of medical approach. Nonetheless, I would encourage you to look at that and certainly contact them at a high level and share your experience because it is very valid. They are saying that in their submission, so they have clearly picked up on it.

The CHAIR: There is an awareness that this is an issue. They certainly have commenced taking steps in the right direction. There is some way to go, but they are aware of it.

The Hon. SHAYNE MALLARD: I just wanted to make that observation.

Dr CHALASANI: I will do that. Thank you.

Ms WAKELY: The issue with type 1 and type 2 is a real worry.

The Hon. COURTNEY HOUSSOS: I am going to ask a couple of different questions of different participants. I will start with Dr Chalasani. I thank all of you for taking the time to share your experiences. It is valuable for us to hear firsthand experiences. We were painted a particular picture this morning from the New South Wales Government and the NDIA that there are some teething problems, but there is no doubt that the feedback that you are giving us is the reason we created this inquiry in the first place.

Dr Chalasani, you talked about the importance of early intervention, particularly for children, but how difficult it can be at the same time as you are navigating through that process yourself with a diagnosis and a new system. It came across in everyone's opening statement that there is a need for advocacy support through that process. Do you want to talk a little bit about why that is so important, even if you are, as I think everyone has said, relatively educated or able to engage in a proactive way? Why is there still a need for outside support?

Dr CHALASANI: I am medically trained. I trained in the New South Wales health system. I did internship, residency, physician training. I have had 20 years in the health system, so I am very used to navigating that system. If I found it so confusing and so difficult to navigate, I can only imagine what other families, who perhaps do not have English as their first language or do not have that experience, have found it. It is incredibly important to have an advocate who is able to go through the steps with you. At the time that I tried to access the scheme, it was rolling out in different areas, so nobody really had much experience. That was a real problem that I ran into. Now it is a lot better because the scheme has been functioning for a few years and people can approach other families. For example, people will call me up and say, "What are the steps?" But I did not know of anyone at the time that I was trying to access the scheme that I could do that with.

I thought the previous system, the Helping Children With Autism package, was very well organised. I did not really have to do too much to access that. My developmental paediatrician gave me information on that. I was contacted. I received that funding within two weeks of diagnosis. It was all very straightforward. Having said that, as I said, I think the scheme is a wonderful chance to benefit people with disability. I agree with Ms Wakely in that I do not just want to paint a negative picture. Although we have run into these problems, we have been the beneficiaries of the scheme and we are much better off for having it. We receive more funding than we would otherwise have received, having already gone through Helping Children With Autism funding.

We are better off for having that and I want to make that very clear, but obviously it is very important to have an advocate, someone who can guide you through the steps. You are not thinking clearly when you get the diagnosis. You are devastated by what this means for your daily life, for the rest of your family, for the future. You are contemplating dreams you had for your child that may not be possible. I was 27 weeks pregnant at the time of the diagnosis. I had to contemplate the possibility of a second diagnosis in my unborn child, the risks being 10 per cent for a female sibling and 25 per cent for a male sibling. It was a very difficult and emotional time.

The Hon. COURTNEY HOUSSOS: I will ask the others to reflect upon the role of an advocate and how that helped you or would help someone in your situation?

Ms WAKELY: Advocacy is really important because you do not know what you do not know. You are there with your limited experience of the system. Sometimes you are hearing stuff that does not sound quite right, but you do not necessarily know how that is fitting within a policy context. I certainly know that I had to stand my ground in the first plan. I was putting together what I thought was a fairly simple plan. My son was overweight because of the medication he was taking, so I really wanted to focus on health. I thought something that would be quite simple is to have someone take him to the gym and it was, "Oh, no, we cannot do that." How could his health needs not be a priority? I just did not understand that. I had to stand my ground and say, "Well, yes, of course I could take him to the gym, but I am trying to work and stay in the workforce. In order to do what you are suggesting, I will have to give up work and go on Centrelink. Is that the outcome you want?"

I think you said it beautifully, sir, when you said autism is not understood. They see a child who can walk and talk and they can hold a conversation with them, but they were there not last week when he got into a fight at

Darling Harbour and had to have a couple of community members break it up because he was not being cared for adequately. You come from a background of understanding that when you try to approach risk managing your child, you learn pretty quickly that that does not work. You have to be really careful about who is in charge of your child, where they go and what they take part in, because you know what the triggers are going to be and you know what the outcome is going to be if it is mishandled. In this case, I had to stand up to the planner and say, "I will not take part in this if he is not adequately supervised." I had to draw a firm line and I should not have had to. It comes back to the training issue that they did not understand what they were dealing with.

The Hon. COURTNEY HOUSSOS: Mr Rand?

Mr RAND: The advocacy role is key for good outcomes. Our experience has been that when we transferred over with the early intervention scheme, they did not explain to us the roles of the LACs and the local area coordinators did not understand their own roles. The advice that we got for our initial plan was incorrect. We have been with the NDIS for 18 months and we are on our third plan review in that time. My wife is a very, very strong advocate. When things are not working, she is down to the NDIS, then we are back to the local area coordinator and they are saying, "You cannot do that." She is saying, "Yes, you can. I have gone down there and got all the information. This is what I've got, it's in writing. This is where we go to."

The challenge with dealing with the NDIS is that there is never a return phone number. It is always from a private line. The staff hot desk; they are continually moving around, they have no permanent phone lines. You can never get to speak to the same person twice. We have insisted on that in our dealings with them. For people that would be time poor, not used to dealing with bureaucracies, or challenging authority, or standing up for their children, it is an absolute minefield. Our expectations from our LAC—their service has been terminated by the NDIS and a company that is spaced 100 and something kilometres away on the Central Coast that has no staff is now our LAC. We have tried to get into contact with them. They said their books are full. It is the same issues that we had when we were part of the early intervention transition. Their books were full. They had no capacity to take on anymore people. When we are talking about advocacy, we are looking to those organisations to provide that advocacy. They are not resourced, they are unable to do it. We are doing it ourselves.

The Hon. COURTNEY HOUSSOS: Ms Ridd, would you like to talk about the importance of advocacy services within what you have been through with your son?

Ms RIDD: I agree with what Mr Rand just said in regard to trying to get someone to answer a phone when you want to make an inquiry. I will use my bathroom as an example. We started, in about April of last year, wanting to change our bathroom to make it accessible for the wheelchair to get in there. I think the least amount of time I ever waited on the phone for the customer service centre to answer was 40 minutes. I did hang on one day for a phone call for well over an hour because I needed to get some answers as to what was happening.

Although we had a coordinator supposedly looking after my son's interests and supposedly being able to get things done, I do not know whether she was doing everything correctly. I am not going to call that, but she was getting absolutely nowhere as well, so I took it on myself to try and get to the bottom of it. Here we are today; we never, ever got it resolved. That is because they kept on changing the rules and the way in which they wanted to do things. I never got a person who could give me a straight answer or anything in regard to what more we should do to get things moving.

I had a conversation with a guy one day in regard to the plan that they had sent us to change the bathroom. This was a little thing. They had railings on the wall, the toilet and the shower room. I have a 150 centimetre vanity at the moment, with storage under it. Part of doing this alteration was to take out my linen cupboard in the hallway, which meant I needed storage for the bathrooms for my husband and myself, because we live in the house as well. I was told that I had to have a 60 centimetre basin with no storage underneath so my son could put his wheelchair under that basin and that he needed the rails to get himself up and down. When I explained to the person that it is not beneficial to him at all because he cannot use his arms or legs or anything else, he was 100 per cent dependent, they told me that he was disabled and that is part of the disabled rules and therefore we have to have them. I said to the guy at the time, "You don't put disabled people under one umbrella. Every case is different." Obviously, they were not bothering to look into that.

It was very frustrating when you spoke to people because all you ever got was, "I don't know; I can't help you. I'll put you through to somebody else." You wait for another five or 10 minutes to get that person to basically get the same sort of answer. Since 2013 my son, on his own bat, was having massages done to his body. It is pretty important because, up until very recently he could supposedly—I use the word lightly—walk, but that was with the aid of us hanging onto his hands as a balance for him. To have weekly deep massages was very important for him to keep the muscle tone and to keep the muscles in his legs going, and also in his neck. Massaging his back made him more comfortable, considering he is sitting in a chair not able to move for at least 12 hours a day. He had to pay for that all on his own, although it was added to his plan but never taken. They actually took it off his plan this year. He can have physiotherapy, but the physiotherapy he has had does nothing for him. His massages were the things that made him more comfortable. But they will not accept him having massages; they will only accept him having physiotherapy. We cannot work out why they cannot accept him having massages.

He was also in need of a new chair to sit in. Now, at 16 months down the line, he is still waiting for this chair. As I said, he is a very independent person. He had gone on line and found a chair that he wanted. It was $1,600. Currently, given the costs for getting the occupational therapist's report, paying the coordinator that is supposedly helping him get this chair, we are up to $20,000 and we still have not got a chair. So, again, we cannot work out why we did not just get the $1,600 chair in the first place. We would not have wasted all that other money.

His carers, because he cannot move, have to pull him out of bed into the wheelchair. His caring company is saying that if this continues any longer they are going to cease sending carers. A bed was ordered probably in about February or March this year, and we are still waiting on that bed to be done. When we ask the question as to why this bed has not been approved, why we are not getting it done, they just keep on saying, "We are still processing this." That is the same sort of answer we get in regard to the chair. So you cannot help but, at the end of the day, say that there is a no-care factor. They do not really care. They have their rules in front of them. They do not treat you as a person; they treat you as a number, and it becomes very frustrating.

The Hon. COURTNEY HOUSSOS: That feedback, particularly about the massages is very compelling when this is supposed to be an exercise about individual choice and individualised planning. That is not actually being allowed through the process. The feedback, as well, was about the reports and the bureaucracy exceeding the cost of the item. The thing that I have taken away from all of the evidence—particularly from Dr Chalasani, but also Ms Ridd—is that the delays are not just taking time but are so expensive in so many other ways. Whether that is the end result because someone has limited time or because those interventions can only be made, there are so many flow-on effects that these delays just have to be addressed. I think that is going to be a crucial part of it, as is the need for trained staff and specialised staff at a planning level and at the later levels as well.

I just wanted to ask all of you about the NDIS Quality and Safeguards Commission who we spoke to us this morning, and the way that they could potentially be addressing some of these issues. I do not know if they would be helpful for you, Ms Ridd. Your challenge is really with the NDIA actually funding the bathroom, not necessarily the provider. Is that correct?

Ms RIDD: Yes, But also we had to use an NDIS provider. When we originally started it there were only three people that NDIS would allow us to use. I think after three or four months they put one more person on in our area. So they came out and did the quote and did everything else, but again I do not know where it went. No-one could ever answer any of our questions as to updates—just that it was being processed. As I said, my son was a carpenter. All his mates had said, "Nathan, we'll do the bathroom for you," but they were not allowed to do it because they had not—I think it was "passed"—the NDIS qualifications. They had to go in and do some sort of qualifications check on them. These guys are all registered. They have all been carpenters, plumbers, gyprockers and everything all their lives but they are looked at as being inferior.

The Hon. COURTNEY HOUSSOS: Thank you very much.

Ms DAWN WALKER: I just wanted to follow on from my colleague's question about advocacy. It was actually very telling that your answer really showed how much work you are doing yourselves, as individuals. In terms of advocacy, there is a concern that advocacy services in New South Wales will not receive ongoing funding. I was wondering if each of you could outline specifically if you have accessed, in the past, support from advocacy services.

Mr RAND: Not at this stage. I am not aware of any that fit in. I accessed the New South Wales carers' website and their resources, and spoke to people there. But apart from that, no.

Ms WAKELY: Yes, I have, but not within the timeframe of the NDIS per se. I did take a service provider with me to our first planning meeting, because that is somebody who we had been accessing anyway. That was very helpful. Otherwise, I have not used an advocacy service since then.

Dr CHALASANI: When we started the tribunal process I initiated access to Intellectual Disability Rights Service [IDRS] and got an advocate through that society. She has been wonderful and invaluable in negotiating us through the whole legal process.

Ms DAWN WALKER: Ms Ridd, have you accessed any support from an advocacy service in New South Wales?

Ms RIDD: No, we have not. I was not aware of it, actually.

Mr RAND: It was my understanding that our LACs were part of our advocacy process and that they were assisting us with the transition and the plan development. But what we found was that because of the lack of knowledge and lack of understanding of the NDIS and the constantly changing rules the information we were often getting through the LAC was inaccurate and incorrect. It was not until we went and directly advocated for ourselves at the NDIS and went through the reviews and kept turning up on their doorstep that things got pushed through. As Ms Ridd was saying about the delays and the complexity that is involved, some of the modifications we are talking about are straight off the shelf. I am waiting on vehicle modifications that do not have to be manufactured; you buy them off the shelf and bolt them in.

We have spent thousands of dollars on OT assessments and reports to get them through to the assistive technology assessment stage at the NDIS. Now we are waiting on an answer for whether they are going to accept them. We are talking about a bolted-on step, a hand rail and a little davit crane in the back of the vehicle to pick up the wheelchair and put it in. Our goal is that the granddaughter will be able to climb into a car. That is part of our physio and OT and our goal in a plan is to focus on her being able to transition into the van by herself. Currently, she is lifted in; she is 35 kilograms. That is a lot of weight to be lifting, especially when it is a living, moving person.

Ms DAWN WALKER: Mr Rand, you mentioned in your submission that you are on your third NDIS plan in 15 months and that you have had to apply for multiple plan reviews. Could you tell us why there has been this need to keep reviewing?

Mr RAND: The initial goals that were drawn up in our initial planning meeting with the LAC were very vague. In the first plan that received the money was allocated to the wrong areas and we could not access it for the things that we needed. We were told that we had approval for complex home modifications—a ramp out the front, hand rails and bathroom modifications—but when we got part of the way through the first process of trying to get the reports in we were constantly being told, "Oh no, you need a different type of OT, here is another nine month waiting list to get on to see somebody who can do complex home modifications." The information in our first plan was wrong and the funding was allocated wrongly. Both the area coordinator and the NDIS, despite the discussions, had allocated money to the wrong areas.

When we hit our second plan we suddenly found that there were additional issues: things had dropped off. She had grown and we needed wheelchair modifications to widen the wheelchair from a child's wheelchair to an adult's or larger person's. Once again, we are not talking about complex modifications; they are straight off the shelf, bolt in, Meccano set type components. But that took from December last year to July, with thousands of dollars spent on OT reports and it going backwards and forwards to the NDIS. Then the funding was not there and the service providers could not access the funding. They have not been paid. The components had been sitting on the shelf since March, waiting to be installed. In the end they installed them but I still do not know if they have been paid.

The Hon. COURTNEY HOUSSOS: When you said that there are thousands of dollars being spent on reports, are those reports being paid for solely by yourselves?

Mr RAND: They come out of the plan. This is money that is not being spent on therapy; these are the on-costs.

The CHAIR: It is drawing down the amount in the plan.

The Hon. COURTNEY HOUSSOS: For reports that might not actually be relevant in the first place.

Mr RAND: Yes.

The Hon. COURTNEY HOUSSOS: Dr Chalasani, you said that is part of the problem as well.

Dr CHALASANI: Yes, every time you submit a review, put in the initial request for a plan or even access the scheme you have to have a lot of reports. We have funded most of our reports and to give you an idea of how much that would cost, a developmental paediatrician's report is about $650 and OT and speech pathology reports are another $100 each. Essentially, every time you submit something to the NDIS it is a minimum of $1,000 in reports.

The Hon. COURTNEY HOUSSOS: Dr Chalasani, I have heard that children under the age of six who have been diagnosed with autism need another diagnosis after they turn six. Is it your experience that they have to go through this whole reporting process again at six in order to continue receiving support?

Dr CHALASANI: I am probably not the best person to answer that because my son is only four so I have not run into the problem yet. From talking to other families I have not run into that specific problem about re-diagnosis. I think the conception that you can lose a diagnosis of autism is actually wrong. You can teach a child to cope so that perhaps their autism is not evident, but that does not mean that they are cured.

Ms WAKELY: They cannot grow another brain.

Dr CHALASANI: Exactly. They still think in different ways and process things in different ways—the way they process emotions and social situations is different. But you can teach them how to cope in different situations.

The Hon. PAUL GREEN: Unfortunately you cannot teach other people how to respond to them because they look and sound normal and, as you said, can have an episode that is misunderstood by the general public. That is really complicated. Dr Chalasani, I did raise some of the issues that you mentioned today with the secretary this morning, so I encourage you to read the transcript when it comes out for this hearing to see some of the issues that you brought up about autism and the inequity of some of the treatments between States and so on. The other thing I want to say is that it sounds to me that there are issues with these sorts of services being prolonged when trying to access services. I have a disabled brother who was hit by a car and is living in a hospital and institution situation. I remember when we were trying to get his bed and chair approved and it went on for ages. There is just no accountability.

If you put in a development application for a house these days you can follow through with council which step it is up to, who is accountable for it, whether it is being dealt with and why it has or has not been moved to the next level. One would think that would be very helpful in these situations. At least you know it is not being progressed, why and who is responsible. There is accountability because person A has not pulled their weight and done their job while your child or loved one is incapacitated. Sitting in a chair all day has a lot of physical challenges that come with it—never mind trying to go to the toilet and the sores and everything else. It is alright for those people who are unaccountable not to tick off on these infrastructure needs because they are not living it. Would it be helpful if we had a recommendation that says there has to be a system where there is open and transparent processing accountability?

Dr CHALASANI: Definitely.

Ms RIDD: It would be very helpful. The most frustrating part of it is that no-one takes responsibility. While I am doing my job, I speak to people who say, "I can't do anything more for you." It is just not on. As I said, given that my son sits in a chair and cannot move for 12 hours, to want a more comfortable chair and the cost is blown way out to $20,000, which is because they want a report from the coordinator and occupational person and all this sort of stuff, I just cannot fathom that people are treated this way.

The Hon. PAUL GREEN: That is why we are having this inquiry.

Ms WAKELY: You do tend to just give up in the end. I think what Dr Chalasani was saying was important: Often you just end up paying for it yourself because it is easier.

The Hon. PAUL GREEN: Because that is what a parent does.

Ms WAKELY: Yes.

Dr CHALASANI: And I think in the early intervention space you have to do that because otherwise your time window is reducing and you are not going to be able to achieve mainstream schooling.

The Hon. PAUL GREEN: In children with autism it is crucial in the development of the brain to make behavioural changes from birth to six years of age so that they can be the best they possibly can.

Ms RIDD: Can I just add that I really want to emphasise the bit about him and the home massages. He has had the same lady since 2013, she does the full body and he gets the relief out of it. If he misses a week he can notice a difference in himself. She knows how to treat him and what to do but it costs him $180 a week. She is charging him less than what she would normally charge but for him not being able to get this—the problem we have also got is: What are the stipulations on this lady doing it? If she does not fit under their criteria, which I do not even know what that would be, then he has to go and get someone that NDIS says he has to use; that is not on. We should be able to pick the people that we want to look after us in our last days. Who knows, he may have another year left or he may only have six months left? For God sake let him have some sort of dignity, be comfortable and things like that. The NDIS makes it so hard to be able to do that.

The Hon. COURTNEY HOUSSOS: There have been reports in the media that we should be trying to get people with level 1 autism off the NDIS because there are other means of supporting them. Can you give the Committee any final points about why it is really important to provide support for all children with autism?

Dr CHALASANI: I completely disagree with taking children with level 1 autism off the scheme. All children with autism have deficits in three major domains: communication, social skills and play skills to varying degrees and they may also have additional motor deficits again to varying degrees, but all of them struggle in those three domains. You can imagine how difficult it is to function as a meaningful member of society with difficulties in those domains if you cannot communicate, if you cannot engage in a social situation or you cannot engage in basic play skills, which are actually quite complex—things like imitation, imagination, pretend play. Those things are very important and form the basis for ongoing learning opportunities and developing skills. Regardless of the level of autism I think it is very important that they continue to be on the scheme.

The other thing I will say is that it is very difficult at the point of diagnosis for a doctor to ascertain exactly what level of autism it is. Firstly, the level of autism is actually determined by how quickly the child picks up skills and you cannot see that in one point of contact. You may see a child who has the same deficits as another child, give each of those children the same six months of intensive therapy. One child may do remarkably well—actually their severity may probably be a bit less than the other child who may struggle more with picking up new skills. I do not think you can make a call as to the level of autism or the severity of autism just based on one point of contact assessment. I think it has to be done in an ongoing therapeutic relationship. That is why it is very important not to exclude people just based on that initial diagnosis.

Ms WAKELY: Can I add to that too? We do know that people with autism experience extremely high anxiety so by the time they get to 13 or 14 years that is when they are likely to develop co-occurring diagnosis. In the case of my son he developed oppositional defiant disorder and that is every bit as charming as it sounds. I often wonder would he have developed that had he got appropriate early intervention, which he did not get. So if you spend a buck now and get those kids the support they need early they may not—do not wait for them to get worse. Get into it, get them therapy, get them strong in the early instance and then they will not develop these co- occurring conditions as well. The other thing is that conditions like these put an enormous pressure on families.

I have to say I have seen the impact on my daughter and I am now seeing the impact on myself—I am now receiving therapy and I am on medication as well as a result of stress. It also leads to family breakdowns. If you look at those other outcomes and roll that in, I think very often the sense that I get is that people are looking at me and my son but they are forgetting the picture of the other family members. They are forgetting what it is like for my daughter who now has significant depression and anxiety as well. She may not have experienced that had my son got that early support.

Dr CHALASANI: I totally agree with all of those points but the other thing I would like to add is that studies have also shown that children with lesser degrees of autism—level 1 and level 2—actually do the best with therapy. It is really important to give all children regardless of their level of diagnosis that opportunity.

The CHAIR: This has been a very enlightening session. Your submissions in the first instance were very informative in setting the scene but I wish to thank you all for opening up your hearts in giving the Committee significant details about the challenges of very close loved ones, family members and their experiences as well as yours in dealing with the NDIS scheme. You have also enlightened the Committee as to the impacts on the whole family. I can assure you that the Committee will use the rich information we have received this afternoon in our deliberations in putting together our report and final recommendations. Finally, I thank you for the outstanding work you are doing every day of your life in supporting your family members.

(The witnesses withdrew)

(The Committee adjourned at 16:53)