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 Macquarie Room, Parliament House, Sydney on Tuesday, 2 October 2018

The Committee met at 9:00 am

PRESENT

The Hon. Greg Donnelly (Chair)

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

The CHAIR: Welcome to the second hearing of the Portfolio Committee No. 2—Health and Community Services' inquiry 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 important issues centred around the implementation of the NDIS and how disability services are provided to the people of New South Wales. These include 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. Today is the second and last hearing to be held as part of this inquiry. Today we will hear from the NSW Ombudsman and a range of organisations in the disability sector, including service providers and advocacy organisations, as well as a panel of health professionals and unions. At the end of the day we will be hearing again from the New South Wales Government. 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 a witness 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. Finally, I ask everyone to turn their mobile phones to silent for the duration of the hearing. I now welcome our first witnesses from the Office of the NSW Ombudsman.

STEPHEN JOHN KINMOND, Deputy Ombudsman, and Community and Disability Services Commissioner, NSW Ombudsman, sworn and examined

KATHRYN McKENZIE, Director, Disability, NSW Ombudsman, affirmed and examined:

The CHAIR: I note that the Committee has received a very detailed submission from the NSW Ombudsman, submission No. 347. I am sure the Committee will use its valuable content in our deliberations. Before we proceed to questions, would either of you like to make an opening statement?

Mr KINMOND: We are pleased to report that since the commencement of the NDIS Quality and Safeguards Commission many of our disability-related functions have moved to the commission. The reason why we are pleased is because the commission is an agency that has an even broader range of functions than those we currently perform. However, it is worth noting that the NSW Ombudsman will continue to finalise its existing matters involving National Disability Insurance Scheme [NDIS] providers. We will continue to have jurisdiction over services operated, funded or licensed by the Department of Family and Community Services [FACS], including FACS-operated disability accommodation and assisted boarding houses. The nature of future oversight in this area will need to be settled in due course. There is currently no change in relation to the work of the Ombudsman's office in coordinating the official Community Visitors Scheme, which involves the visiting of disability accommodation environments and also assisted boarding houses. However, the future of various community visitor schemes across Australia, including our own, is about to be reviewed. That will be an important exercise.

Our standing inquiry into the abuse and neglect of adults with disability in community settings will continue until what we hope will be the establishment of a public advocate—some might call the position a public representative or a public defender—who can take forward and broaden the work that we are currently doing of ensuring that this State can respond to all vulnerable adults who are being neglected or abused within their family and broader community settings. Let me make this point: About 80 per cent of the 200 matters we received in the past two years involved abuse within family or community settings; they did not involve abuse at the hands of disability service providers. I have been in this business for a long time, and some of the worst matters I have seen I have witnessed over the last two years. So there is an absolute need for this State to move on the issue of a public advocate or a public representative so that abuse and neglect matters within community settings can be responded to.

We continue to review the deaths of people with disability in residential care through a joint approach with the NDIS Commission. The commission looks at the disability service provider quality issues and we look at the responsibilities of the State's service system—for example, in the health, justice and other service spheres. As is evident from our last report on the deaths of people with disability in residential care, many of the findings from our disability death review work are highly relevant to the ongoing responsibilities of the State of New South Wales in providing an accessible and responsive health system to all people with disability and not just people with disability who live in residential care. That is an important joint venture between the NDIS Quality and Safeguards Commission and our office.

In their evidence the secretaries and National Disability Insurance Agency [NDIA] representatives have referred to critical work which has been carried out by various working groups and via other arrangements. It is important to recognise that in New South Wales there is recognition of the need to provide a sophisticated and well-calibrated multiagency response to certain groups and to fill some of the gaps, especially for people with complex needs. However, from our work we can confirm that there are still significant challenges and concerns, and many of the witnesses who have appeared before this Committee have outlined some of those concerns. It is clear that the disability reforms associated with the NDIS are, at this point in time, resulting in greater strain on community services such as justice and health services. These strains are not always because of inadequate supports by disability services. Let me stress that: These strains are not always because of inadequate supports by disability services. Instead they can be related to a critical part of the current reforms which involve appropriately repositioning the provision of community services for people with disability to mainstream services.

While we agree that the shifts are necessary, we also note that they present significant risk to people with disability in the short term. Therefore, it is vital that there is a comprehensive approach to addressing these heightened risks, particularly while mainstream services are building their expertise and capacity. Hence the importance of the evidence that the secretaries gave on that issue and the importance of that work landing and delivering the outcomes that are desired. In addition, some but not all of the issues affecting supports for people with disability relate to the intersection between the NDIS and the mainstream New South Wales service systems, such as the health and justice systems, including ongoing debates about Commonwealth versus State responsibilities.

What is critical is that the coalface experience and outcomes for people with disability deliver what they should. In practical terms the tests will be, firstly, whether individual matters are resolved in a timely manner that minimises the adverse impact on the person with disability and often their family members as well. At the moment, while parties are often escalating matters and seeking to resolve issues, we need to solve things faster. Secondly, we need to use the data and embed the lessons from the test cases to ensure that ongoing system reform is taking place to drive less problems, more solutions and better outcomes over time. This process is relevant to both discrete NDIS system reform as well as the reforms that are taking place and that need to take place in relation to the mainstream New South Wales service system. Finally, the system performance outcome measures need to be robust and publicly reported. The New South Wales and the Commonwealth role of effective independent review and monitoring activity also requires more detailed consideration. Thank you for allowing me the opportunity to make an opening statement.

The CHAIR: Thank you, Mr Kinmond, that augments very nicely the detailed material contained in the Ombudsman's submission. We will share questions around between the Opposition and the Government. There is no-one here from the crossbench at the moment but there will be shortly. There is someone on a plane about to land and someone on the way in a taxi not far away. We will commence with the Hon. Courtney Houssos.

The Hon. COURTNEY HOUSSOS: Thank you very much for your time this morning and thank you for your very detailed submission, that was excellent, and of course for the important work that you are doing every day. I should say from the outset, I do not want to speak for the Government, but definitely my Labor colleague and I are great supporters of the NDIS and its promise, but we want to make sure that it delivers on the iconic Labor reform program that it should be. The questions today are very much framed in that way. In your opening statement you talked about the significant risks to people in the short term. I just wanted to refer to a previous report that you have only recently released around the deaths of the former Stockton residents as part of the reviewable deaths report. I think it is useful if we place on the record here just a few of those key findings. What did you investigate in that particular instance?

Mr KINMOND: That related to the deaths of two clients who moved from a large residential centre into a community-based accommodation setting. In addition, there was a third resident who had to be admitted to hospital around the same time. Let me acknowledge the fact that the department did not shirk its responsibility in reviewing this matter. It engaged an independent person to conduct a thorough review and we separately analysed the information and came to similar conclusions. There was a failure to address health risks for residents over an extended period of time ahead of the transition. There was a failure to ensure a safe and informed transition of the residents with known complex health needs. One could say if you are transferring the same staff across those health risks should have been known. The difficulty in this case is that many of the staff had not worked with those clients before—in fact, they had not worked in a disability accommodation setting before—so they were not acutely aware of what were very significant health risks.

The third issue—and these are matters that are common, unfortunately, to a number of the deaths that were reviewed over the years—was inadequate response by staff to provide appropriate and timely support to residents, including actions to identify and effectively respond to critical health issues. So they were observing issues in relation to people not consuming significant amounts of food and obviously significant related nutrition risks. They were, in fact, documenting their concerns. They were raising matters internally, but what they should have done was to escalate these matters quickly to external medical professionals and to take more comprehensive action. So yes, the results were tragic.

The Hon. COURTNEY HOUSSOS: It really was, and I thank you very much for that. Are you aware of the issues in the Summer Hill centre?

Mr KINMOND: Yes.

The Hon. COURTNEY HOUSSOS: Are there any lessons that we can learn to ensure that the same thing does not occur again?

Ms McKENZIE: The difference that you have with the transfer of Summerhill group homes is that the staff are not moving. Part of the complicating factor that you had with the transition of the residents from the Stockton Centre to the community group home in the Hunter was that they were moving out of long-term accommodation to a different setting supported largely by different staff. The transfer process though for Summerhill group homes, as it has been for transfer more broadly of Ageing, Disability and Home Care [ADHC] accommodation is that the staff, in the majority, do not change.

Mr KINMOND: We should also add that the department, following on from the matter that we have referred to in terms of the transfer from the Stockton Centre, has not simply looked at the circumstances of that case and moved on; instead, it has sought to learn lessons from that matter and to have quite rigorous procedures in place in relation to ensuring that staff who go across are aware of the needs—there is the transfer of the information, there is the transfer of the knowledge, there is a comprehensive induction program. So they are the plans. As we know, plans are one thing, the execution of the plans is another thing. One of the points that we have made publicly is that we will continue to monitor not only in broad terms how those plans are applied, but we will look in detail if there are matters that arise that require a detailed examination.

The Hon. COURTNEY HOUSSOS: That is valuable. I appreciate that there are slightly different circumstances. The issue when I talk about similarity is that there were families. I am not sure if you are allowed to tell us this, were the deaths in Stockton covered by the public guardian?

Ms McKENZIE: No, they were not.

The Hon. COURTNEY HOUSSOS: I can say then that there were concerns by family members raised before the transition from Stockton and obviously there are concerns being raised by families of Summer Hill residents. They are the similarities I should be talking about in terms of a lesser service that is being received after the NDIS.

Mr KINMOND: You are making a very good point. There is understandable concern by family members that the service that has been delivered will continue to be delivered. We are conducting a detailed review of the transfer process. We should have an interim report out on that review by the end of the calendar year. The issue of the importance of parents and representatives being involved early and listening to their concerns as well as obviously the involvement of clients, the importance particularly where there is differences in staff of an understanding of those clients and a detailed understanding of their health needs, are critical issues. As well as when you are dealing with clients with high health needs the need to make sure those clinical supports are not something you are going to do in the future but they are addressed as early as possible so the strong clinical connections are drawn and the relationships are built so we get a smooth transition process.

Let me also say, what has been encouraging from what we have heard from parents we have consulted with is their level of confidence in the staff coming across. One of the major concerns that parents have raised is the fear that staff member Jones may not still be on the scene because staff member Jones has done such a wonderful job. I want to publicly acknowledge the very consistent feedback that we have received about the fantastic work that disability service providers have been delivering and the care and commitment they are showing to clients. It is important for me to balance my comments with those observations, given that is evidence we have heard from parents.

The Hon. BRONNIE TAYLOR: Well said.

The Hon. COURTNEY HOUSSOS: Absolutely. Obviously the broader gaps within the policy is not necessarily reflected in the continued care provided by these excellent workers. One final question, I wholeheartedly support the submission around disability advocates. Your submission makes an important distinction between the role of community advocates and the role of a public advocate. Can you explain, that is a Law Reform Commission proposal, but why do you support such a proposal for a public advocate or a public representative, as you referred to?

Mr KINMOND: Or a public defender. Essentially because one needs a body with power and authority. We are a body with certain powers and certain authority. For example, we have direct access to the police system, we have direct access to the child protection system. If we pick up the telephone and indicate to any government agency or the police or a funded disability service provider that there is a problem then we get listened to and there is a response. What we have been struck by with the 200 matters we have dealt with is that in a lot of cases the way of improving the circumstances for the person with disability is relatively straight forward provided one puts all of the pieces of the puzzle together and you have the right people in the room at the right time to have the right discussion, then you can come up with the right plans.

There are often simple ways forward in terms of improving the outcomes for people whose circumstances can be fundamentally compromised. We have had cases of people living in essentially a hovel separate from the family home and the food is served separately to them. They have been separated from family. We have had matters that have involved a father who sexually assaulted his daughter and was incarcerated for the assault. He is on the child sex offender register. He then later on, once she is an adult, so the fact that he is on the child sex offender register is no longer relevant, then seeks to resume a relationship with her and her friends with intellectual disability. These are matters of critical importance.

What we have been encouraged by is the preparedness of government agencies and non-government agencies to bring these matters to our attention, to sit around the table and do something about it. In that case that I referred to the offending father was brought back before the courts with consent orders in terms of him not associating with her or with any of her friends; fantastic work by the police and support by the police in that matter. There are very practical things that can be done. The levels of abuse in this wonderful State of New South Wales that are taking place I have to say has shocked me.

Ms McKENZIE: The only thing I would add, and part of the reason the commissioner refers to the body as potentially "public representative" or "public defender" instead of advocate is we are very clear in saying that the public advocate is not a replacement for community or individual advocates, it is a very different role.

The Hon. SCOTT FARLOW: To pick up on this public advocate defender body that you have outlined and advocated for: Where do you think it should lie? You mentioned the issue in terms of having authority, do you think that should be a federally vested body or a State vested body?

Mr KINMOND: The issues are to do with the rights of citizens within New South Wales, so it should be a State body. We also believe it should have the necessary degree of independence. The only question in my mind is do we create yet another independent body or do we look at the question of where are the areas of vulnerability across the community: We have public guardians, we perform a particular role and there is a potential public advocate role. It might seem a strange thing for someone from the Ombudsman's office to say, but from where we sit we do not have a vested interest in terms of this is not about more power to the Ombudsman's office, in fact, to the contrary.

We think probably in the State of New South Wales, I noticed for example Parliament passed legislation in terms of an anti-slavery commissioner recently. The question for me, do we continue to establish a range of independent bodies in the human services area or do we say, no, we are going to get greater efficiency, we are going to get greater economy of scale, we are going to get greater competency, are we going to build better relationships if we actually combine it within one human services commission? The State needs to take responsibility for the issue because it is a matter pertaining to the rights of citizens within the State of New South Wales.

The Hon. SCOTT FARLOW: I notice you said before about the great work of disability workers throughout New South Wales and paying respect to that. I notice in your submission that you have been working on a project in terms of the transfer of ADHC accommodation services for people with complex support needs to external service providers as well. I believe that was continued until the end of September. It has probably just come to an end now. Is there anything you can report on that project now it has come to an end or if it is still ongoing and provide an update to the Committee on that?

Ms McKENZIE: The project is still ongoing. There is a range of ADHC operated services that are yet to transfer. It is still in play and those are services providing support to people with more complex support needs. We are still running that project and will continue to do so until they have transferred across. There is nothing really that I can provide additional to what we have in the submission before the Committee other than as Mr Kinmond flagged, we will put out a snapshot report on where things are at and the key issues coming out of that work in the next couple of months.

The Hon. SCOTT FARLOW: With respect to some of that work, you outlined before the role of FACS in terms of making an independent inquiry when it came to Stockton. I see the role of FACS here as well working hand in glove with the Ombudsman in ensuring those safeguards are in place in terms of the transition to non-government providers. How much of the Ombudsman's work is done on a real-time basis, and how much is done post fact when it comes to this sector?

Mr KINMOND: That is a very important point. In discussions with government concerning us reviewing the transfer process, we were aware—and government supported our view—that there is not much point in preparing a report several years after the event in relation to matters that have already taken place that needed action. What we have done from day one with this transfer process is to prepare a schedule of issues that we have presented to the department. That has allowed the department then to factor in those issues in terms of the ongoing transfer process. Your point goes to a very significant issue in terms of independent oversight. I talk about twenty-first century oversight. Twenty-first century oversight is not just about identifying problems, it is also about being part of the solution. That action learning business relationship where you are feeding matters back and affecting the trajectory of matters, so that in fact we do not continue to repeat problems unnecessarily, is critical to oversight, particularly when the oversight relates to vulnerable people.

The royal commission has just finished reviewing the child-related employment, the reportable conduct scheme that we conduct. The reason why it recommended the rollout of our scheme across the country is because we take an interventionist approach. Our direct access to child protection systems, police systems, our extensive business relationships that go back many years, enable us to pick up the phone and get things done. That has to be done, both in terms of individual cases and at the systems level. My argument would be that if we are going to achieve effective change in terms of dealing with the gaps in the system, dealing with the Commonwealth responsibilities, understanding and responding to the State's responsibilities, we need an action learning approach. This includes if there is—and I think there should be—enhanced independent oversight of this process, whichever body or bodies play an independent oversight role need to take an approach of not just preparing reports and delivering them from on high, but if there is a problem, being on the front foot, identifying the problems and working with the agencies concerning the solutions.

The CHAIR: I will conclude with a question, which is one that has been troubling me during the inquiry in trying to reconcile some numbers. You are probably familiar with the numbers. I will read from submission 298 from Mission Australia. On page eight it states:

> In NSW, the NDIS is expected to benefit up to 140,000 people with disability.

We have heard that figure many times during this inquiry.

> According to the ABS Survey of Disability, Ageing and Carers 2015, there are over 1.3 million people with a reported disability in NSW and close to 450,000 people have a profound or severe core activity limitation.

I presume that is 450,000 as a subset of that total. Whether we are talking about the 140,000 up to the 1.3, or the 140,000 up to the smaller subset, the 450,000, there is a variance. There is the NDIS definition versus the Australian Bureau of Statistics [ABS] definition, which obviously is a broader, more generic definition. Trying to understand gaps or deficiencies in terms of cover reach is a key part of the inquiry. The situation in New South Wales is—and the government policy which has been enunciated and implemented—that from 1 July 2018 the Government effectively has stepped back from disability matters. You would have read in *Hansard* the earlier comments of the secretaries who gave evidence at the last hearing—and who will give further evidence this afternoon—that the department has been abolished. But there is a drive to enhance the capacity inside the respective portfolio areas and departments in relation to—I use the phrase—the sensitivity of matters disability, which is the mainstreaming that you have referred to. That beggars the question: Is that capable of dealing with the variance? Can you comment on that?

Mr KINMOND: The honourable member could not have asked a better final question, so thank you for the question.

The Hon. COURTNEY HOUSSOS: That is why he is the Chair.

Mr KINMOND: At this important time in our history, it is essential for us all to recognise that advancing the rights of citizens in new South Wales with disability, and as you correctly point out, many, many people with disability will not be covered by the NDIS. The only game in town is not the NDIS. And in this regard the Disability Inclusion Act 2014 introduced enhanced requirements relating to whole-of-government disability inclusion planning, including the development of the State Disability Inclusion Plan, as well as aligned individual agency disability inclusion plans. While this provides an important legislative articulation of the desire for transformational change for all people with disability in New South Wales, it has not resulted in the fundamental and widespread changes that are needed to make critical and lasting gains in the outcomes for and the genuine community inclusion of people with disability in New South Wales.

Therefore—and with this I will conclude—it will be important to ensure that the review of the Disability Inclusion Act results in a renewed focus on the National Disability Strategy and enhanced governance arrangements, including, I would argue, independent review of the implementation of each agency's disability inclusion action plans and the implementation of those plans in terms of whether they are delivering substantial and ongoing outcomes for members of the community with disability. While we acknowledge the important role of the Disability Council in the existing governance arrangements—and particularly in ensuring that people with disability are directly involved in the desired change process—we note that the Disability Council sits within Family and Community Services [FACS], rather than playing an advisory role to both government, and we would argue, an independent body. We are at an interesting point in time in our history.

If we think the only game in town is the National Disability Insurance Scheme, then we have got it wrong. Your point is well made. There are many people with disability who need to have full and inclusive lives in our community. We would argue that when the review of the Disability Inclusion Plan comes up next year, it will be critical to get right those governance arrangements so that we can drive real reform.

The CHAIR: Thank you both for giving evidence today. The Committee appreciates the opportunity to be able to quiz you and drill down into some of the details in your submission.

(The witnesses withdrew)

TOM McCLEAN, Head of Uniting Centre for Research, Innovation and Advocacy, Uniting, affirmed and examined

KATHERINE STONE, Practice Lead Disability, Uniting, affirmed and examined

ANITA LE LAY, Head of Disability, Uniting, affirmed and examined

LUKE BUTCHER, Area Manager, Western NSW and Special Projects, Mission Australia, sworn and examined

JO-ANNE HEWITT, Executive Director Disability, the Benevolent Society, sworn and examined

The CHAIR: With respect to submissions, we have received a document from Uniting this morning. Thank you. That will be given a formal number and incorporated as a submission to the inquiry in due course. We have received a submission from Mission Australia, and that is submission No. 298. We have received a submission from the Benevolent Society, and that is submission No. 299. The last two have formally been incorporated into evidence in this inquiry. I will invite each of the three organisations to make an opening statement. Bear in mind you do not need to go over in detail material that is in your submission. You can take that as read, except for Uniting, because we have just received that submission. Secondly, we are on a reasonably tight time schedule. We are looking to maximise our opportunity to ask questions. With that in mind, we will start with Uniting. Ms Le Lay, you have been delegated with the task?

Ms LE LAY: I have. Thank you for the opportunity to give evidence at this inquiry. I am Anita Le Lay, head of Disability. We appear today in a unique position as a registered National Disability Insurance Scheme [NDIS] provider, New South Wales funded Ability Links provider and, separate to this, an National Disability Insurance Agency [NDIA] local area coordinator, noting that our evidence today is predominantly provided from our perspective as an NDIS registered provider and an Ability Links provider. Our submission contains more detailed information. However, I take this opportunity to emphasise four key points that emerged from our experience. The NDIS transition appears to be having a two-tiered impact on people with disability. It seems to us that the benefits are mostly accruing to those people and their families who can strongly advocate for themselves and who can understand and navigate the complexities of the scheme. People with more complex needs, those who cannot advocate for themselves or navigate the system, in our opinion, risk receiving lower levels of service and poorer NDIS plan outcomes.

In this way, Uniting urges the NDIA to release the new complex participant pathway in the hope that this may go some way to addressing this inequity of experience. There are unresolved issues in coordination between NDIS supports and mainstream New South Wales services. A lack of defined clarity of role and responsibility, coupled with an immature NDIS planning process is certainly resulting at present in a less than acceptable experience for participants and their families. This is particularly impacting on people who require a seamless report. Uniting remain concerned about the ability of the scheme to respond to changing situations and crises in participants' lives.

We have had parents who have experienced lower levels of support post-NDIS transition and subsequently have been unable to resume care of their children, either threatening to relinquish or actually relinquishing them while in our short-term accommodation. We have worked with people of high levels of complexity with limited or no support coordination who are simply unable to activate their plans. We are often supporting customers through plan reviews when plan funds have been expended and they can no longer afford to pay us. We are a well-established and very large organisation but absorbing these costs is not sustainable for us in the long term. Like many providers, we are assessing our place in the market.

Lastly, a word on service gaps for eligible and ineligible New South Wales citizens. Ability Links is an evidence-based program focusing on supporting people with disability to build their capacity and partnering to build the capacity of mainstream and community providers and sometimes entire communities to welcome and include people with disability. Funded by New South Wales Family and Community Services [FACS], it is already delivering on the NDIS information linkages and capacity-building framework and works really, really hard to keep people supported outside of the scheme. Ability Links will cease in June 2019.

As we have just heard, almost 90 per cent of people with disability will be ineligible to access the scheme. Current gaps in service provision, even for those who are eligible, and the absence of Ability Links from July 2019 mean it is critical that stakeholders in New South Wales insist that the NDIA provides people with access to information, linkages and capacity-building [ILC] services that genuinely promote the social and economic inclusion of people with disabilities in the long term. Uniting strongly sports the NDIS. It embodies a critical change in the way that we as a society support people with disability. When fully mature, it will support them to genuinely live a life of their own choosing. In the interim, we are committed to working collaboratively across the sector to ensure that these gaps can be closed as soon as possible.

The CHAIR: Within Uniting's submission there are specific references to individuals.

Ms STONE: It is all de-identified.

The CHAIR: Thank you. We wanted to check to be sure.

Mr BUTCHER: Mission Australia is a large non-government agency that provides a range of consumer-centred evidence-based programs. In New South Wales in the 2016-17 financial year, we supported over 88,000 individuals across 237 programs. In the context of this submission, Mission Australia is an early childhood, early learning provider in New South Wales, Queensland and Tasmania, and a local area coordinator in Queensland, Tasmania and South Australia. We acknowledge that although the NDIS is in its early stages and while it has great potential to provide consumer-centred care to people with disability, there have been some challenges in the rollout of the program. As outlined in our submission, we note particular challenges for people with psychosocial disability access in the program. A concerning number of our clients with psychosocial disability transitioning from block-funded support to NDIS services have been deemed ineligible or have chosen not to go through the NDIS application process, leaving them without essential supports.

The markets and demand to provide choice and control for consumers are expected to grow over time. However, in New South Wales the choices of service providers are limited in some areas, particularly in regional and rural New South Wales. There are simply not the number of participants or an economy of scale for services to operate financially viable business models within the rural communities. For example, in a particular rural community, we were working with a client who had severe mental health and behavioural concerns who required supported accommodation to live successfully in the community.

The person was required to stay in acute and subacute hospital-based care and in his short periods of illness was required to use crisis accommodation services while his NDIS package was obtained. He was declined an NDIS package three times, meaning that he was in this revolving door of accommodation for six months. Once he received his NDIS package, there were simply no specialist providers in place with the resources to effectively meet his needs. This meant that he is currently facing a choice of either leaving his community or remaining in hospital until an appropriate provider can be drawn to this regional community. The inability to access NDIS-related services adds further strain on health, justice and other community services. We advocate for the Government to implement a provider of last resort strategy in instances when there are no support providers to support NDIS participants in particular locations or NDIS participants who have particular issues.

There are also challenges with access and equity of the scheme. Some people whose applications were rejected refused to appeal NDIA's determination to overturn its decision. This process can be particularly challenging as people are expected to appeal the decision within three months, and in some areas there are long waiting periods to see professionals, such as psychiatrists, to gather additional evidence. This initial rejection also puts people off applying or appealing the determination. We note that though NDIS aspirations and intentions are to support people with disability through a strength based approach some practises of the implementation, including the evidence required reflect a deficit-based model. As a consumer with two sons accessing the scheme I can personally attest to this and the disappointment in reading a report focusing on what my children cannot do rather than their strengths, needs and uniqueness.

However, we do note and applaud the New South Wales State Government for retaining the Housing and Accommodation Support Initiative [HASI] and Enhanced Adult Community Living Supports [EACLS] psychosocial support programs that provide case management, coordination and support to consumers with complex needs. However, there is still a noticeable service and system gap that has emerged in the mental health recovery sector, particularly with more services required to support people with high and medium needs. As we heard, we would also advocate for other services apart from the NDIS to be factored into our disability support model.

Ms HEWITT: I thank the Committee for the opportunity of representing the Benevolent Society today at this inquiry. We speak of course from the unique perspective of having taken over the government services previously provided as in the community support team for all the clinical and allied health services that were previously provided under Family and Community Services or Ageing, Disability and Home Care. Given the statements that have been made this morning that reflect our submission and we have the same kind of experience, I do not see the need to repeat that and provide an opening statement.

The Hon. BRONNIE TAYLOR: Ms Le Lay, I spent 20 years as a nurse before I was elected to Parliament so I know a little bit about health and not very much about your sector. I am a very big supporter of the NDIS and I find the transformational change in policy exciting and something which the sector cried out for. They wanted it and I commend the Federal Labor Government for devising and implementing it. But in this inquiry we have heard about many things that are not working and are not happening.

Ms Le Lay, in your opening statement you talked about a lack of defined clarity, an immature planning system and the inability of the planning system to respond to crisis. You conclude by saying that you strongly support it and it needs to mature. You say it would be wonderful because it will allow people with a disability to have a life of their choosing. I do not think anyone would ever want any more than that. As a big provider and in an agency that does that, what are you doing about talking to the NDIA to tell it where the failings are so that we can make it better and we can make this once-in-a-generation reform work? I apologise if I get the acronym wrong because there are quite a few.

Ms LE LAY: There are many forums in which that happens and we play a number of different roles. So there are different ways that we advocate for either individuals or we talk to the agency about some of the systemic problems. We also talk to NSW Family and Community Services around some of the gaps that I mentioned in terms of the connectivity between people who have NDIS plans and still need to access a range of New South Wales services. There are a multitude of points in which we advocate. We have those conversations. I think to be fair, in all of those conversations the agency has recognised that this is a plane that we are flying and building at the same time—I cannot think who originally said that but it is very real for us.

Typically they are open to understanding further where the blockages are, listening to providers, listening to partners in the community if that is the hat that we are wearing from a local area coordination point perspective around what could be done better. I have to counter some of the negativity because we really are sitting inside a transitional period. I think originally in New South Wales with the end of the bilaterals, we were thinking conceptually as the transition period being 2018 and we kind of get to where we needed to be. I think the whole sector is realising now it is more likely to be 2020-21 before actually we are in full transition and we are sitting inside a nicely mature scheme.

The CHAIR: What do you mean by the "bilaterals" from 1 July 2018? Is it from State to Federal?

Ms LE LAY: That was the transition of all of the current recipients of New South Wales and other services, not just State funded services, from 2016 to 2018. I have those numbers from my esteemed colleagues. That was really the very large movement or transition of people from State funded services.

The Hon. BRONNIE TAYLOR: You also said that as the Head of Disability, for Uniting, a fairly big organisation, you are reassessing its ability to be in the market. Are you reassessing to be a part of the NDIS?

Ms LE LAY: Yes, that is what it means.

The Hon. BRONNIE TAYLOR: It is a bold statement.

Ms LE LAY: Our position as a NDIS registered provider has us working with people who have more intensive and super intensive needs so upper complex range of participants. At the moment, reflective of the NDIS price guide it would be fair to say Uniting has concerns and is doing a whole range of things to look at how it can make its future sustainable. In order to work and support people of complexity you need a workforce that is skilled, experienced, who have professional development opportunities, have some semblance of a career path and who are able to paid appropriately.

One of things that we are trying to work through, and I know we are not alone in that, is our workforce strategy. These are the sorts of things we think about. Being a large provider probably has some additional cost imposts into our model—I have to be upfront and say that. Certainly if we want to stay in the market supporting people with complex needs we have to have a workforce that can do that safely and at a really high quality service delivery, and we have to be able to fund that.

The Hon. BRONNIE TAYLOR: That would be your responsibility to make sure you have the workforce that can meet the needs.

Ms LE LAY: Absolutely, yes.

The Hon. BRONNIE TAYLOR: Mr Butcher, I thank you for sharing your personal story. It makes you a powerful advocate both professional and personally.

Mr BUTCHER: Yes.

The Hon. BRONNIE TAYLOR: It is amazing what a little bit of insight into real life can do and when you work in an organisation. Mr Butcher, you talked about regional communities. This morning the Committee heard a lot of what is wrong with the NDIS. However, I have talked to a lot of people in my communities. I have given an example of someone in Crookwell whose life has completely changed because of the NDIS. He has got things that he never thought were possible. He has a high level of independence and his is a magnificent story and he is not alone. Earlier the Ombudsman said that there is some really good information coming out of this as well and that is important. Will you elaborate further on what you thought for the regions. Was it because you think there is not access to services? One issue that has arisen is that there were a lot of smaller services in our rural and regional communities and the big guns have come in and are now operating in the space because it is worthwhile in which to operate but they are struggling. Will you elaborate on that and focus on comments about regional and rural areas?

Mr BUTCHER: Obviously, the cost of doing business in regional and rural communities is quite expensive—we have travel, office infrastructure, attracting a workforce. We have just heard about some issues with workforce. In the particular community where the case example came from out of my evidence there is one psychosocial disability service provider in that town and no other disability providers have moved into that space, given the cost of setting up with an office, with a management structure and with a staffing infrastructure in those communities. This person whose case I used to highlight that story requires some fairly intensive support to remain living in the community. Obviously, being in a hospital is very—

The Hon. BRONNIE TAYLOR: But they have been living in the community so far?

Mr BUTCHER: He has been living in the community with some issues. He has come to the attention of police for some behavioural issues. He is requiring some support to help him remain in the community. The model that his treatment team are proposing is a 24/7 live-in based support with some behavioural strategies. In this particular community there are no providers that have the capacity to do that so we are looking at advocating for a provider to come to town to provide him with that level of support that he needs.

The Hon. BRONNIE TAYLOR: As some of the bigger service providers for people with a disability you are saying when you are coming into places you have to set up and do all that sort of stuff. What about the local smaller services that are there already? What is your commitment as the larger providers to make sure that you check if those people can provide those services first? The person you used as an example has been living somewhere for quite a while.

Mr BUTCHER: This person that I am using as the example has been getting support from the State-based program, the Housing and Accommodation Support Initiative. As an agency Mission Australia is in the process of deregistering as a registered provider of support. That is due to picking up the local area coordinator [LAC] contract in South Australia. The NDIA indicate you are either a LAC provider or a registered provider of support and you cannot be both. Our approach to servicing this particular person and our approach to servicing people in rural communities is to really connect people with the services that need to be there.

The Hon. SCOTT FARLOW: I understand a lot of the complexities that exist in terms of the NDIA's assessment of the psychosocial support services for an individual. As you mentioned, New South Wales has maintained its mental health funding support for HASI and the like. How are you finding the experience in other States that have not maintained that support?

Mr BUTCHER: The evidence from other States has been that the other States look to New South Wales with envy that we have maintained those programs and the State Government has maintained those programs. Given the cyclical nature of mental ill health and psychosocial disability, we know people with mental ill health have issues attracting an NDIS package. There has been a Federal Government inquiry into that. The HASI and Community Living Supports [CLS] programs are really held up as examples of good practice. Our partner agencies in other States look to New South Wales with envy.

The Hon. COURTNEY HOUSSOS: Historically there has been a range of smaller providers who did provide services, particularly in regional areas, but there is no doubt that they are facing increased pressure under the NDIS not just in terms of paperwork but also because of the financial risks that are associated with it. I should begin by saying thank you so much to the Benevolent Society and Mission Australia. They are excellent submissions and the clear recommendations are really useful for us in informing our discussions. I have no doubt that once we get to Uniting's it will be equally useful. I wanted to ask you all to talk about the financial risks that you are taking on as a result of the NDIS. I say this in the context that we are great supporters of the NDIS and all the promise that it offers, but the feedback we are getting is that a lot of the financial risk is being put on to providers. If such a large-scale provider as Uniting is re-evaluating its involvement I think that is very serious for the ongoing viability of the NDIS. If you could all provide a reflection on that I would really appreciate that.

Ms HEWITT: If I could start by saying that the Benevolent Society is absolutely committed to maintaining our registration and continuing to provide services to people across New South Wales. We have grown into South Australia and continue to provide services to people in Queensland under the NDIS. There is no doubt though that from a financial perspective it is incredibly challenging, partly to do with the price point and issues like travel. Travel is not just challenging in a rural and regional environment, although certainly that is a major issue. You can get someone who even if you get a 45-minute each way travel arrangement—you can get a long way in a rural environment in 45 minutes—there might only be one client in that particular district and sometimes you are travelling for hours at a time and having to send someone overnight to see that person. But in Sydney I defy anybody to even find their car let alone a parking spot in 20 minutes worth of travel time. Travel is certainly an issue when providing services to very complex clients who require that therapeutic input in their natural environment.

Having said that, I guess there are cultural and systemic issues that organisations have to work through to make the price point work for us. There is no doubt that the therapy price point is adequate to provide an hour-by-hour service, travel aside. However, when you are dealing with a workforce who are accustomed to providing whatever it takes to support a person with a disability and they suddenly need to provide services within a finite framework of an NDIS plan, so they need to stick to particular billable hours and get used to charging for things like writing their case notes and preparation and those kinds of things—making that cultural change with the workforce and recording everything that they do to ensure that we are billing cannot be underestimated in the challenge to get this pricing right.

In the Benevolent Society we have had the double whammy of taking over the government services and that has been, I must say, an incredibly costly exercise. We opened 35 new centres on one weekend. That was obviously an investment we chose to make. But moving the business model and moving the culture and practice of the staff that we have into an NDIS environment has been painstaking and slow. We currently are at a rate of 42 per cent billable hours and we need to get to 78 per cent in order to break even on our salaries budget.

The CHAIR: Could you break that down and explain what that means?

Ms HEWITT: We have worked out in our business model that people need to see in the available hours that they have, apart from the time that we take out for their training, for their supervision, for their leave, those types of things—that they really need to be providing a client service that is billable for between 78 and 80 per cent of their available time. That is either seeing a client face to face or writing a report or a case note or something that can bill back to the NDIS. It has taken us the better part of 15 months to get to a point where our staff are working at 42 per cent capacity. Some of that is about cultural change. Some of it is about building our client base because we have doubled the number of clients that we have worked with since we went through the transition and we need to double that again in order to be viable.

The Hon. BRONNIE TAYLOR: When I was a community nurse I would have to do an A, B, C, D.

Ms HEWITT: Yes.

The Hon. BRONNIE TAYLOR: Then they would know how many people I had seen and approximately what I was doing. When you say that there was a lot coming out about the financial disincentive for some organisations with the NDIS, it is not that the amount of money for the final consult is any different—perhaps it could be increased, because people tell me it is a higher billable—but you have to account for everything that you are doing when you see a client. That means your case notes, your initial assessment—

Ms HEWITT: Yes.

The Hon. BRONNIE TAYLOR: And that is something your staff have to get used to because they are not used to that because they have never had to do it.

Ms HEWITT: Yes, it is a big cultural change.

The Hon. BRONNIE TAYLOR: But it is not actually that the financial incentive is less than prior to the NDIS, or it is?

Ms HEWITT: No, the custom and practice is different and I think that is really the significant thing that we all need to own.

The Hon. BRONNIE TAYLOR: We are all accountable, are we not? Gone are the days where you can just go in. Everyone has to say who they are seeing, how long it takes and what they are doing.

Ms HEWITT: It has to be said that in some areas some of the price points are inadequate. I will not speak to some of the personal care price points because that is not the space that we are working in but certainly from the therapy perspective, there is no reason why in the best of worlds—and you are right, nurses are very accustomed to working in that kind of framework, as are aged care providers—we need to make those cultural changes in order for us—

The Hon. BRONNIE TAYLOR: Do not get me wrong; it is easier when you could just go in and knock, but it gave everybody a really good idea of what was happening on a shift and how many people. It is really interesting and has really helped me.

Ms LE LAY: Can I just add one thing to that? Would that be okay, just to go back to the question?

The CHAIR: Yes.

Ms LE LAY: I concur with Ms Hewitt's commentary around billable hours. Ours are 85 per cent so even higher. In terms of the rolled up financial effect, if you like, of a regulated pricing structure at the moment, other things that come into what it costs you to operate in the environment now and the things I am thinking of there are obviously the typical things like back of house but in a more commercialised application of disability services you have human resources [HR] services, which need to be restructured to manage very large workforces of casualised folk who need to be nurtured, valued and engaged and all the rest of it in the same way as anybody working full time and part time. You have finance structures which have taken us all of 2½ years to move towards our billing and claiming structures. You have all of the cultural stuff in terms of a workforce being used to using a customer relationship management system on a daily basis to make sure they are recording what they are doing, but beyond that there are parts of the scheme that we are hoping over time will become more efficient.

I am sure you have heard about supported independent living quoting in your time in this inquiry. That is still onerous and still very expensive and those costs are unrecoverable for providers. We have a very small number of accommodation services but we have spent probably in excess of $50,000 just preparing quotes for 26 people and that is unrecoverable. The last point is that we now have a Quality and Safeguards Commission, which is terrific and we are really looking forward to working within that jurisdiction but for us, working with complexity and making sure that everybody is safe and is as skilled and as experienced as they can be. Working inside that quality and safeguarding framework has costs attached to it, which we are happy to pay. It is really important that we are compliant and that we operate as a best-practice provider but, again, I just wanted to build a picture of the rolled-upness of it all.

Ms HEWITT: Absolutely, and if I could just make another comment: I was by no means saying that this is fixed and that all we need to do is get our act together because one of the key challenges when you are dealing people with very complex needs—and of course our organisation, given our staff have come from government so they are typically working with people with incredibly complex needs—that where people have the right NDIS plan, and there are many of those people, you are absolutely right, for many people it has been an amazing advantage in their life, that works really well, but where people are missing out or where the planner has not got it right or the NDIS has kicked back on a certain area that may be seen as the responsibility of a mainstream agency, that is where our staff are really struggling to stick to their billable hours so they are tending to jump in and support a person where they just have not got the right amount in their plan, and rightly so.

I am certainly working with our staff around where that happens, making sure that, "Are you telling someone who can do something about it?", so you are reporting that back to the local planners and reporting it up so we can be telling the NDIA at the highest levels what is going on? They are very responsive when we outline these issues but sometimes there is a lag so we are bearing the costs of some of that extra servicing that is required.

The Hon. COURTNEY HOUSSOS: Yes, and I think that is the point, Ms Hewitt, that I am really trying to get to. I want to hear what Mr Butcher has to contribute to this conversation as well because I have no doubt that he will be very well informed. I think this idea that it is not just about billable hours but that there are additional costs you are being forced to bear—

Ms HEWITT: Absolutely.

The Hon. COURTNEY HOUSSOS: —that are non-recoverable through the NDIS system.

Ms HEWITT: Yes.

The Hon. COURTNEY HOUSSOS: Mr Butcher, sorry, I have cut you off.

Mr BUTCHER: No, I would agree with my colleagues in that summation of the conversation. Obviously the therapy-based supports are very well funded whereas the other disability-based support is quite inadequately funded and the organisations need to bare the cost, particularly when we are looking at not only how do we provide a service but how do we provide a safe and quality service for people on the ground.

The CHAIR: Can you give a non-therapy example of one or two of those for our elucidation?

Mr BUTCHER: Sure. For argument's sake, that is your personal care, your Transport Today program or your activities of daily living which are funded—correct me if I am wrong—about $22 or $23 an hour.

Ms LE LAY: It is $48. And if you look at the distribution of where the funding is sitting in terms of plans, it is 80 per cent nationally pretty much—please check that number—but it is the bulk of the money and it is typically around $48 an hour. Core supports is the rolled up group.

The Hon. COURTNEY HOUSSOS: Mr Butcher, did you want to add something more?

Mr BUTCHER: No.

The CHAIR: I apologise; I cut you off.

The Hon. COURTNEY HOUSSOS: I might put some further questions on notice.

Ms DAWN WALKER: Thank you all for coming today. I wanted to pick up on your point, Ms Le Lay, about advocacy services. You mentioned Ability Links and the fact that they are looking down the barrel of losing funding. Could you elaborate on what that service provides, what you see happening with its tenure and what that will mean in the sector?

Ms LE LAY: I am sorry if I confused things by talking about Ability Links as an advocacy service. It is actually not. Ability Links has been funded by New South Wales since 2014 and was always part of the transition plan to New South Wales moving into the NDIS environment. It was slated to finish at 30 June this year and was given a year's extension for a range of reasons but also recognising that New South Wales and the transition to the scheme was still really in flux and to have an infrastructure like the linkers on the ground for another year would be of benefit.

We are one of many providers of Ability Links in New South Wales. There are linkers in almost every part of the State. The role of a linker really is twofold. One is to work with individuals and their families, and that is an important distinction to make because we are really sitting in a scheme at the moment which focuses very much on the individual and at times families and carers can sit peripheral to that. Linkers work with individuals, their families and their carers to build their capacity to access the community whatever that looks like for them, whatever their goals are. It could be about volunteering; it could be about work; it could be about building social circles, learning new skills, whatever it is. Secondary to that, they work with communities and mainstream services to look at access, to look at inclusion and to build capacity of those organisations to be more inclusive and more welcoming.

A really quick example is a child in Corrimal with cerebral palsy who wanted to be a nipper. Mum and dad really did not know how to approach the surf club. The little boy was in a wheelchair. Everybody looked at that scenario and went, "Oh, my goodness. How are we going to do this?" The role of the linker at that point was to work with mum, with dad, with the participant themselves to understand what it is that they wanted to do and then to work with the surf club about how they could be more welcoming and more inclusive and how all the safety parameters and anything else that needed to happen was put in place. That all happened and that is just an example.

So the linkers will cease in June next year and technically the work that they do should be absorbed within the NDIA's information, linkages and capacity-building framework. We have some ILC grants on the ground now in 2018 in New South Wales. We would love to see them more clearly and more systemically represent the five pillars of the ILC framework. It is terrific that they are on the ground and that those grants have been awarded but going forward into the future what we want to build is a really solid safety net for both people who are eligible and, most importantly, people who are not eligible. So linkers this year are focusing very heavily on people who are not eligible for the NDIS and continuing the work they have been doing.

Ms DAWN WALKER: The Committee has received evidence that there is a common frustration on the part of NDIS clients, their parents and providers in dealings with a range of NDIS staff. I am interested in whether you individually felt there are some gaps in clients getting consistency, rather than having to continually explain their stories to different personnel and staff?

Ms HEWITT: We are seeing once again a really inconsistent application of what is called support coordination in the NDIS. The NDIA do not talk in terms of case management, and support coordination really is a piece of what we would think of as case management. So it is an element of case management but it really does not go nearly as far as actually pulling everyone together. Support coordination links people to the right services and liaises with other services but there is no capacity within the price point to bring professionals together with participants or families to coordinate a case in any meaningful way. That at the moment is typically falling down.

Some organisations are privileging that for some people and actually bearing the cost of that kind of work but, given that it is an individually-based scheme, unless someone has what is called specialist support coordination in their plan, typically that is not occurring at all. It is a huge gap. The other thing is that the NDA, we think—well, the experience is that they see support coordination as a capacity building mechanism. Often people will have support coordination for 12 months and then not get it again. Particularly people with more complex needs are going to require that kind of input for their lives, not just for a 12-month period while they get their services in order.

The Hon. COURTNEY HOUSSOS: So if it is not in their plan, who is providing it? Obviously this is a service that needs to be provided. Is it falling back on you as the provider or is it falling on families? Who is picking up the slack here?

Ms LE LAY: If you do not have support coordination in your plan you are provided with a service through the local area coordinator. You have one or the other.

The Hon. COURTNEY HOUSSOS: But what is happening in practice?

Mr BUTCHER: If I could talk to my experience as a consumer?

The Hon. COURTNEY HOUSSOS: Please do.

Mr BUTCHER: I have two boys. Both are on the NDIS packages; one is seven and one is six. I was really disappointed, when our plan was coming up for review, that the particular registered provider for support came to our house after school to do their occupational therapy [OT], and after the OT left the teacher from the provider came in and said, "You've got $1,500 left on your plan. Your plan is about to expire so you need to use it. Can I go see your son?" I said, "He has just finished a day at school and he has just finished OT. It is about boys wanting to play—that is what boys do. Let him go play out the back. He has got the sprinkler and is having a good old time."

To me I was really disappointed because it started to become not what was best for my boy; it was what is best for an invoice getting generated. So I was talking to my wife about it. He has two NDIS providers and he goes to a school. We had to arrange with the school to get the NDIS providers and the schools together. I called a case conference because he did not have any case management capacity there. So as a parent I am in a position where I can self-advocate; I know the system, I kind of know it a bit.

The CHAIR: Most do not.

Mr BUTCHER: So I can imagine how confusing that could be for parents of children who are not necessarily in this space. If I put my professional hat back on, I think the particular benefit of the Housing and Accommodation Support Initiative and the Community Living Supports [CLS] programs that the State has retained is that those services can provide case management and have a broad brush to say, "We can meet a need that is there because we do not have to map it to a plan, to map it to an invoice. We can provide support where support is needed."

The CHAIR: We have gone over time. I am sure there will be additional questions and you will have 14 days to respond to any questions taken on notice. I thank you for the wonderful work you are all doing in helping individuals come to terms with the scheme and its capacity to change their lives.

(The witnesses withdrew)

YVONNE KEANE, Chief Executive Officer, Early Childhood Intervention Australia, sworn and examined

ENIS JUSUFSPAHIC, National Manager, Sector Development, Early Childhood Intervention Australia, affirmed and examined

The CHAIR: The Committee has received a submission from Early Childhood Intervention Australia, submission No. 261. I invite one or both of you to make an opening statement but please take the content of your submission as having been read so you do not need to refer to it again in detail.

Ms KEANE: Thank you for inviting Early Childhood Intervention Australia [ECIA] to present to the Committee today. I begin by acknowledging the traditional owners of the land on which we meet today and to pay my respects to elders past and present. I acknowledge also any Aboriginal people who are here with us today. ECIA is the peak body for early childhood intervention professionals. We represent members at a State, Territory and national level in advocating for the rights of young children with a development delay or disability and their families to have access to high-quality early childhood intervention and supports.

ECIA enjoys a collaborative relationship with the NDIA and with other relevant government departments and organisations. We endeavour to be the bridge of advocacy and professional development to ensure that we are all working together to build capacity and to improve services and, ultimately, to achieve extraordinary outcomes for vulnerable children and their families. ECIA over the last 12 months has transitioned from a federated State and Territory-based organisation consisting of four member chapters, as we call them, into a single national entity company limited by guarantee. So we are a newly formed national peak organisation and I have only been in place as a CEO for a handful of weeks, which is why I am grateful to have by my side Enis Jusufspahic, who is our national sector development manager, who can provide the granular detail when required today.

As you may know, ECIA designed the national guidelines for best practice in early childhood intervention, which is the foundation on which NDIA have designed their early childhood early intervention, or ECEI, approach in rolling out the NDIS for children aged 0 to 6 nationally. These best practice guidelines provide a framework for universal and equitable high-quality early childhood intervention based on best practice for children with a disability or a developmental delay and, as mentioned, they are the national guidelines for best practice that the NDIA is seeking to ensure are consistently applied in all States and Territories.

We are thankful for the opportunity to appear today as we share with our members significant concern regarding the implementation of NDIS in New South Wales. The two major issues that seem to be facing us right now that we believe should be immediately addressed are the current enormous backlog of children and families waiting for NDIS plans who are currently not accessing vital services and supports. This backlog, or waiting list as it is known, is a symptom of both the nature of the transition across New South Wales, higher than expected demand for ECIA services and the time that it is taking for the early childhood partners across New South Wales to scale up and stand up their business models and also for service providers to overcome the significant workforce issues that they are facing. As you can imagine, a delay of between six and 12 months for access to vital and life-changing early intervention treatment can have a devastating and arresting impact on the future of the child and that of their family.

The second critical issue facing us in the sector is where once New South Wales enjoyed, I guess you would describe, an integrated approach to access for best practice early intervention for children and children without a diagnosis, ECIA has identified a significant cohort of children who have fallen through the gaps. These are the children who are at risk, who do not fit the ECIA model under NDIS, and our gaps paper, which we referred to in our submission, identifies a significant number of children who are not eligible for the NDIS plan but who are caught up in, I guess, limbo as the sector has shifted suddenly to a model focused not primarily on outcomes but focused on NDIS plans and diagnosis. These are at-risk children who face long waiting lists to access services and supports, where once access was more readily available. Without an integrated approach from government, from the agency and from the sector, these children might continue to fall through the gaps until they become a critical problem.

We would also like to note that the ongoing ability for bodies such as ECIA in our advocacy role is critical to the long-term success of the scheme and the sector and the outcomes for children and their families and we hope that the Committee will in turn advocate for ongoing funding for organisations such as ECIA, who currently receive no recurrent funding but who may struggle to remain viable over the short and long term without any support. Without consistent and equitable access to early intervention under the best practice model, children missing vital support and intervention in their early formative years will be faced with a much greater need for support as they get older, significantly impacting on both the child and the family's quality of life and, indeed, placing a greater need on government-funded services and supports into the future.

As you know, the early childhood years lay the foundation for all future development, so it is critical that we ensure every possibility and every pathway is open to children to access the right supports and services as soon as they possibly can. As a mother of a child with a hearing impairment, I know how critically important it is to have access to consistent and high-quality and best practice services and supports. I know firsthand just how life-changing early childhood intervention can be. I am grateful for the opportunity to appear today on behalf of ECIA. We are ready for questions.

The Hon. COURTNEY HOUSSOS: Thank you very much for your time and for your submission. I wanted to begin by touching on something that you raise both in your submission and in your opening statement, and that is about the timeliness of early intervention for children. You said "A six to 12 months delay for children can be devastating and even arresting". I think that comes to the heart of when we are talking about the implementation of the NDIS what we need to be fixing, what are the gaps that we need to be fixing, and these children requiring early intervention, I think, is a key part of that. We heard during our last hearing some evidence to highlight this but I just wanted you to expand on it. You said in your submission, "There are concerns in the sector that the children are missing out on supports now enter the scheme at a later stage with significantly more complex needs". Is there something that the New South Wales Government could be providing to ensure that children who may be missing out on the NDIS, how we can be providing that early intervention to prevent them requiring to enter the scheme? Because, in effect, if you look at it purely at a financial level, we are going to be saving some money but we are also going to be making a life-changing effect on these particular individuals.

Mr JUSUFSPAHIC: I will preface everything by saying that I came from the New South Wales/ACT chapter of ECIA and I have worked on the ground with transition providers delivering the ECIA transitional approach. So I have good insight into that. Currently I have got six networks connecting with ECIA service providers, who we are in touch with all the time, from Central West, Nepean Blue Mountains, Sydney Metro, North Coast, South Coast and so on. Essentially, the issue is that for those children, as it is identified in the gaps paper, who are not covered by the NDIS and it is because they have a very mild delay or they do not necessarily fit the eligibility criteria because it is primarily trauma-related issues or behavioural issues which cannot be related to the disability or developmental delay, those families would be referred to services that are existent in their local community, and depending on the local community and the capacity within that local community and the capacity within the local community services and community health and other children's support services such as playgroups, they will be able to access something.

A lot of providers tell me that they are seeing much larger numbers of children seeking supports from ECIA services. So there are more children coming and there are more children attempting to access services in their local community, and in some communities there is not a great deal available, so those children would go on waiting lists. It is different for different regions, based on resourcing. In some regions the waitlists for playgroups that have a therapeutic-type element to them, it could be six to 12 months, and that is a very long time for a child to wait. So families are looking at all other possible solutions to try and access services. The other issue that runs alongside that is access to other government services for families that have a plan or do not have a plan. Those families are also finding very long waiting lists.

The Hon. COURTNEY HOUSSOS: That is an excellent point. So even people who have a plan are not necessarily being able to access the early intervention services that they need?

Mr JUSUFSPAHIC: They are not necessarily early intervention services because the early childhood intervention services were funded by the New South Wales Government, block funded, and those services have not transitioned to the NDIS and they can work with a certain cohort that has an NDIS plan. In New South Wales it used to operate on a universal model and that universal model would accept everyone and work with everyone based on their needs, but now there is a very clear eligibility criteria about who is able to gain access to a package and who is not. It is not 100 per cent clear all the time because children's needs change over time and families can seek access at another time when they have better insight, better evidence about the child's development.

The onus is not on the parents. The ECEI service provider would work with the family to get a deeper understanding of what their needs are. They would refer them to the community and provide them some interim supports, and it does work. But for the short to medium term they do need to access something from the community. That community component is largely dependent on what is available in that particular community.

One of the recommendations in the "Gaps" position paper is we recommend that we need a mapping exercise to understand what exists in various communities and what families can have access to. It is not entirely clear. It is very different for different communities and different children and based on their needs. If it is a mental health service for a child zero to six there are limited services of that kind that are available across New South Wales if that is required. Depending on the needs of the child and where they sit and where they live they are able to access different things.

The Hon. COURTNEY HOUSSOS: You talked about the block funding that used to be provided and those block funded ADHC groups, many of whom have been defunded. Do you know where those families are going?

Mr JUSUFSPAHIC: They are going to general community services; they are going to playgroups that exist. There are general playgroups and general community health services. They are accessing things. But overall we are getting feedback that there are significant waiting lists for many services.

Ms KEANE: There are navigation issues from a parents' perspective. There are navigation issues of finding their way through. That casework element that used to be in place is no longer there. It is hard to find your way through and to work out where you should be going to get those supports.

The Hon. COURTNEY HOUSSOS: That is a key thing that has come through this inquiry, not knowing where to begin. Even someone informed, such as yourself, still can find it difficult.

Ms KEANE: As a parent I still struggle and I struggled when my child was diagnosed nine years ago. For me that is part of the missing link, whether you are part of an NDIS package or not. There is a missing link in terms of that middle man, that concierge process to take parents through and make sure you are accessing everything that the community has to offer, and if you are in a plan that you are utilising your plan to maximise the outcomes for your child. That is what we want at the end of the day: we want the best outcomes for our children so they can live the best possible lives they can.

The Hon. SCOTT FARLOW: Ms Keane, can you potentially map out for us what it used to look like and what it looks like now? From your own experience, from receiving that diagnosis, what was the support surrounding you then and what the situation is at present?

Ms KEANE: The diagnosis, from my perspective, nine years ago I started a service to teach hearing-impaired children to speak like you or I, called Hear the Children. To come into our service you did not need a diagnosis; we just needed evidence that that child had an impairment and had a speech issue. We would take any children. We were fortunate, we did not have a waiting list and did not have government funding. We just fundraised to support the amount of enrolments we needed to take. You did not need the diagnosis, we did not need a plan, we just needed a child and a parent to find us and come to us. Then we would put into place individual plans with those children and work through all the milestones.

It was positioned around best practice where we would always do the therapy with the parents in the room or we would go into the home and we would teach the parents, give the parents objectives and milestones to hit. We would chunk those down into weekly objectives and show the parents how to work with their child in the natural environment so their child learnt to speak like you or I. Now you need a plan to access that service and it is much more difficult to access that service without a plan.[1]

The Hon. COURTNEY HOUSSOS: If you do not have a plan, have you found prices have gone up?

Ms KEANE: I cannot speak to that. I would have to take that on notice and do some research because my child now goes to school, he does not have early intervention any more. I am not in that space. Where once we were focused on taking the children and working with them to achieve outcomes, now we are very much focused with working within the confines of that environment. What we are seeing right now is teething problems. You have a brand new incredible policy being breathed to life which will have transformative outcomes for children and families into the future. What we are seeing now is teething problems, and what we think we need to find is agile ways to work together to overcome these in the very short term so that we can make sure those outcomes in the long term are as spectacular as they can be.

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[1] See correspondence received from Ms Yvonne Keane on 18 October 2018 regarding clarification on evidence

The Hon. COURTNEY HOUSSOS: A previous witness said it is like trying to build an aeroplane and having it take off at the same time, which is clearly an issue. That is obviously what the inquiry is about. There were various different playgroups that were previously block funded around the State to provide really early intervention supports for children who would not necessarily be visible through preschools or long day care; they were off the grid. I cannot think of a better way to explain it. What supports are in place for children who do not have a plan, who are not currently in preschool or long day care or these early intervention identifying activities? Is there anything available for them?

Ms KEANE: There are supports in the community. Mr Jusufspahic will elaborate.

Mr JUSUFSPAHIC: There are supports. There are supports in the local community services and there are some Commonwealth-funded playgroups and some playgroups run by the local community health services. It depends on the local community and what is actually available there. In the remote communities it is a real challenge because there needs to be a relationship built with those communities and there needs to be outreach. This is notionally the area that the early childhood partner will work on and work with, and currently the rollout has been somewhat delayed. It was supposed to be rolled out three months early but it was rolled out one month early and the partners are scaling up.

Because of the complex nature of the transition there are lots of children on waiting lists, so the partners are focusing on those. We have identified around the State certain pockets in certain communities where there are significant numbers of children who do need assistance who have not had access to any early childhood intervention before. There are all of those issues that need to be addressed before the system stabilises. The partner needs time to work through all the children on the waiting lists and they need time to engage with the more vulnerable communities.

Ms KEANE: Again, the issue is how do parents navigate their way through to finding these services that may or may not be available in their communities for them.

The Hon. BRONNIE TAYLOR: I understand because I was a nurse and one of my biggest jobs was coordinating all the services, but I took that responsibility on as a clinician. That is what I did because it was what my patients needed. Sorry to use your personal story, but it is always really powerful. Hearing loss, non-hearing loss—it is a definitive diagnosis so you can get the supports you need.

Ms KEANE: Sometimes with the milder children, no. In New South Wales we pioneered the Statewide Infant Screening—Hearing [SWISH] system where you pick up hearing impairment at birth. Those children could often fall through the cracks and not be identified until they are seven, eight, nine, 10, when the situation is almost hopeless for them in terms of spoken language.

The Hon. BRONNIE TAYLOR: In my community, my children could go to preschool as soon as they were toilet trained. So if they were 2½ they could access the preschool, which has probably 10, sometimes 30 kids, depending on the year. If my daughters went up to preschool and there was something not quite right then my early childhood education teacher in Nimmitabel—she was a legend—would have picked up something. She would refer on to someone. Mr Jusufspahic, surely we need to map? I would expect that if my first point of contact was my early childhood teacher they would need to know what services are available that my child could access. You are saying we do not know what services exist wherever they are?

Mr JUSUFSPAHIC: People in the local communities definitely do. The people who I work with, the ECEI service providers who have been in these communities for 35 years or longer, they understand, they know the referral pathways. The partners are new, so they are coming into the space and they are learning and they are building their capacity. The referral pathway now is if you have a concern about a child's development you need to go to an early childhood partner. Then the partner will refer you to the particular services that are necessary. I think I need to explain the Early Childhood Intervention Australia approach. The ECIA approach, the way that I see it, it is the interface to the NDIS for children and families aged zero to six. The department has several functions. The first function is the profile development; getting an understanding of the child and the family, linking them in with community supports, whatever is available in their local community, because we want to include children in the community and have them access other government services as early as possible to build inclusion. Then the department will provide some strategies around how to support the child in the home and in the community, and they are built a basic plan. If the family is going along well, then that is great. But if they need ongoing support, they will start the NDIS access process.

Then once they have been deemed eligible, they start the planning process. The plan comes back, they support the family with implementation of the plan, then they would eventually do the plan review. Those initial three functions, anyone can access. There is no eligibility criteria. They can get some supports, referral to community services and some, we call them soft supports, interim supports. Those do include some playgroups, but they can include some one-to-one services. It is dependent on the needs of the child and the family, and it is delivered in that best practice approach, which is based on building the capacity of the family to support the child, generalising the supports within the child's natural environment.

The Hon. BRONNIE TAYLOR: Which is all very positive, and the way it should be in that early intervention phase.

Mr JUSUFSPAHIC: That is right.

The Hon. BRONNIE TAYLOR: That is great. Ms Keane, you mentioned earlier that it shifted suddenly. We have known it has been coming for quite a while. Tell me if I am wrong—I likely am—but the issue in early childhood is getting the diagnosis to be able to access the NDIS?

Ms KEANE: No. You do not need a diagnosis to get help, and this is a message that has not translated into the marketplace. You do not need a diagnosis to get access to those supports that you need, whereas once upon a time parents would chase a diagnosis like you would not believe. You do not need that under the best practice model. I am going to go back to your last point; we should have a framework that works, whether you have an awesome early childhood educator or not. The missing part of this puzzle is that information getting through to those people who deal with children at a grass roots level knowing where to go and what the steps are, and it is not always about the diagnosis. A diagnosis is helpful, but you do not need a diagnosis to start getting early intervention support.

The Hon. BRONNIE TAYLOR: You are the peak for the sector, you said?

Ms KEANE: Yes.

The Hon. BRONNIE TAYLOR: You are providing a lot of that information?

Ms KEANE: To our membership. And we are looking at how do we expand our cohort of members, or how do we expand our messaging to reach out beyond our membership, which are the service providers who understand this.

The Hon. BRONNIE TAYLOR: What percentage of the sector is your membership?

Mr JUSUFSPAHIC: We are a national organisation. All the members are coming on board in different jurisdictions, and that is taking some time. In New South Wales, the vast majority of New South Wales early childhood intervention [ECI] providers are members of ECIA.

The Hon. BRONNIE TAYLOR: Would that be 80 per cent?

Ms KEANE: I am not sure. We can take that on notice and come back to you.

The Hon. BRONNIE TAYLOR: That gives you a great responsibility.

Ms KEANE: Yes. The membership is a moving feast at the moment. There are a lot of sole traders coming into the marketplace, then we need to look at early childhood educators as part of the marketing cohort that we need to target.

The Hon. SCOTT FARLOW: I imagine that is quite difficult—speech pathologists, for instance—being able to track them all across the State?

Ms KEANE: Yes.

Ms DAWN WALKER: Delving a little bit more into your internal experience of the NDIS, what has the transition meant for your organisation, and perhaps particularly in rural and remote New South Wales, are those smaller early childhood intervention services having any issues, particularly with the financial aspect of the NDIS?

Ms KEANE: The transition for a large part of our membership has been very difficult. You are going from one business model to a completely different business model. Ultimately, for consumers this is great because what will happen is you will be making a choice and you will be picking the best services for you. But that transition from block funding to choice by the client, has been very difficult, not just because they might not select your service again, but largely because the financial model has changed. In order to sustain yourself through this transition period you would have to have put away a sum of money so that your business can survive and you can pay your overheads through this transitionary time. The problem with that is a lot of the services do not have any fat and the transitionary time seems to be spinning out.

We are seeing some services in quite critical condition at the moment, and we are doing our best to work with them and the National Disability Insurance Agency [NDIA] to find some agile interim solutions for those members. They always say that nothing worth doing is easy, and this transition is not easy. It is not impossible, we just need to find ways that we can work together, as I said, in an agile fashion to address the problems in the short term. They are real and they can be quite critical, particularly in those remote areas, we are finding that access to services can be difficult. We have some members who are coming up with really innovative ways to make sure that we are providing our clients in regional communities with high-quality, early intervention that will have real lasting outcomes for them. Do you want to add something, Mr Jusufspahic?

Mr JUSUFSPAHIC: Yes. Probably the single largest issue is uncertainty of demand. For a lot of our members it is unclear what the demand looks like in their communities. When they were transition providers they knew that there were significant numbers of people coming to their service, much greater numbers than they have previously experienced with block funding. There is that high demand, and at the moment the demand seems to have dropped off. Going forward, some of the issues that are universal for a lot of we members are low plan utilisation. Many families are not using all the funding in their plan, and that could be because they are learning how to work within the NDIS framework and it takes a number of months to get up and running and families can be quite conservative in terms of using their funds, which is understandable.

The other issue is that services are looking at different ways of bringing in income. They are looking at the next age group up, the seven- to 13-year-olds, which really affects the specialised nature of our sector. They are building their workforce capacity because they know that there are going to be many families looking for services, maybe not right now, but into the near future, and they are looking at innovation. For a lot of the more remote and rural service providers, they are relatively small ones that employ less than 20 staff, they do a lot of work together. They do a plot of planning together, some of them even share staff. They have the more collaborative models. They are looking at tele-services, they are looking at peer-led support services, they are looking at different ways of planning and outreaching to families.

But it is really difficult to be planning and building an organisation in this time of significant transition. For this last financial year many organisations have lost significant money during the transition, and that has had a significant financial impact on them. In terms of their planning for the future, it is very challenging because they do not really know what the market looks like, what the demand is and it is a guessing game. I have spoken to so many who are seeking advice and support, and more than happy to give it, but one person's guess is as good as another's, because we do not have the data.

The Hon. COURTNEY HOUSSOS: I am happy if you want to take this question on notice. You mentioned children on waiting lists. Do you know how many there are?

Mr JUSUFSPAHIC: We do not know.

The Hon. COURTNEY HOUSSOS: Who is holding the waiting lists?

Mr JUSUFSPAHIC: They are currently with the partners.

The Hon. COURTNEY HOUSSOS: Do you know where they are? You spoke about there being long waiting lists in specific areas. Do you know where?

Mr JUSUFSPAHIC: There are areas which have traditionally large numbers of children accessing ECI support, so traditionally it is south-west Sydney, Western Sydney, Nepean, Blue Mountains, mid North Coast, Central Coast. Those which tend to be the significant areas, but each area is significant in its own right. You need a plan for each jurisdiction because each one has different challenges, be it distance or different culture groups that require a slightly different approach or modified approach. Each region is as important as another. One might have the numbers, but the other has groups which require a different model.

The Hon. COURTNEY HOUSSOS: More complex needs?

Mr JUSUFSPAHIC: Yes.

The CHAIR: Your evidence has been enlightening. You have taken some questions on notice. After reading the transcript, there may be some additional questions from members. You have presented well on behalf of the organisation. Thank you both for coming along.

Ms KEANE: I thank the Committee for its work. This is an important piece of transitional work to do right now. Anything we can do to help and assist, please call us. Use us for anything.

The CHAIR: Thank you.

(The witnesses withdrew)

(Short adjournment)

SARAH JUDD-LAM, Manager, Policy and Research, Carers NSW, sworn and examined

ELENA KATRAKIS, Chief Executive Officer, Carers NSW, sworn and examined

JONATHAN HARMS, Chief Executive Officer, Mental Health Carers NSW, affirmed and examined

PETA SMIT-COLBRAN, Quality Support Officer, Mental Health Carers NSW, affirmed and examined

The CHAIR: We have submissions from your respective organisations. They are detailed and comprehensive. They have useful references and footnotes. Thank you. Carers NSW submission is No. 275 in this inquiry. Mental Health Care NSW submission is No. 291. I invite both organisations to make an opening statement. There is no need to go into a lot of detail about what is in your submissions because you can take them as read. We welcome the opportunity to ask you questions about what is in your submission and get you to elucidate on some other matters. I will ask each organisation, if you wish to do so, to make an opening statement first.

Ms KATRAKIS: I will kick off. Carers NSW, as you know, is the peak non-government organisation for family and friend carers in New South Wales. Through our policy analysis, research, our delivery of education and training to carers and to service providers, and our provision of a range of services to carers across New South Wales, including the National Disability Insurance Scheme [NDIS] support coordination, we have been able to closely monitor carers' experiences at the NDIS since it began rollout in the Hunter a few years ago. We support the vision and goals of the NDIS and believe that the scheme has great potential to improve the lives of people with disability, their families and carers.

However, our work with carers in the sector has consistently shown us that while many families are experiencing positive outcomes from the NDIS many are not. We know that the NDIS obviously focuses on a person with a disability and we support that, but it impacts across the whole family. Our perspective is coming from that carer perspective, just to put that into context. Our written submission to this inquiry highlighted our particular concerns about the disappearance of carers' supports, specific carer programs, that the funding has transitioned to the NDIS. Over the past few years Carers NSW specifically, but a range of other providers across the State, has delivered an older parent carers support coordination program. We have also delivered together, a carers support program that has assisted carers support groups across the State. That funding is no longer available for carers.

That funding that was focused on carers has now transitioned to support the NDIS. We also highlighted the lack of alternative supports that are available to people with disability, their families and carers who are not eligible for the NDIS and where the gaps in services are. We have also highlighted the lack of choice and control and inadequate resulting supports that many people with disability, their families and carers are experiencing in planning and plan review processes within the NDIS. We see these barriers to inclusion and adequate support that they need to be addressed or else other systems, in particular the health system, will be faced with many additional costs.

Many of the gains that New South Wales has made in carer legislation that was introduced in 2010 and the NSW Carers Strategy that the New South Wales Government has supported are at risk if these things are not addressed. In line with the terms of reference for this inquiry, Carers NSW is also concerned about the particular challenges experienced by families with younger children which I know you heard about earlier today and people with disability with complex care and support needs in accessing adequate NDIS support. A provider of last resort, ongoing direct services for people ineligible for the NDIS and continued State-funded advocacy support will be critical in ensuring good outcomes for these families.

Carers NSW also wishes to highlight its concerns about the major challenges that service providers are experiencing in maintaining a skill base network of employers to deliver services. With the change from block funding to individualised support it means that there is not that funding to enable education and training of staff. When you are on a fee-for-service model those other things cannot occur easily. We are concerned about some of those issues and that affects then the skill base of the staff that are delivering the NDIS. Government representatives also often point to the availability of the information linkages and capacity building component of the NDIS which is there to support the families and carers, regardless of the their status in relation to the NDIS.

Carers NSW welcomes this inquiry as an important opportunity to identify the key ongoing challenges experienced by people with disability, carers and service providers in New South Wales in order to look at workable solutions. This is a time of great transition for carers, not only with the implementation of the NDIS but also with the forthcoming implementation of the Integrated Carer Support Service, of which there will be a tender grant opportunity announced later this year. While government representatives are quick to point to the Integrated

Carer Support Service and ILC component of the NDIS as the solution to the gaps in disability in carers support, we have identified that both systems rely on linkages to existing services and supports which are rapidly decreasing or non-existent. Both of those service systems rely on referral to local service networks which are fast disappearing. We thank the Committee for inviting us to present today and recommend that carer recognition, inclusion and support be a priority in its deliberations regarding the implementation of the NDIS in New South Wales.

Mr HARMS: I thank the Committee for the opportunity to provide evidence today. Mental Health Carers NSW is the peak body recognised by NSW Health for systemic advocacy on behalf of mental health carers in this State. Mental Health Carers NSW [MHCN] works to ensure that the voices of mental health carers are represented and heard in policy, deliberations, service provision and reform processes. We also generally support the NDIS and think that it is fantastic that Australia has finally got around to a comprehensive model to meet the needs at the population level of everyone who requires significant disability support in this country.

We also appreciate the model that has been trialled at this rollout stage of individual package funding because the intention is to empower people. This is particularly important for people who have experience of psychosocial disability whose views are so often disregarded, along with those of their families and carers. However, we also want to make the point that no single solution for such complex problems is often going to be suitable to meet the whole population's needs. There is a case for government to continue funding services of last resort that the market is not capable of delivering, as well as offering more block funded services that provide different kinds of support for people in the community, which is going to be the kind that is more suitable for some people.

As I like to say, some people are quite happy to sit at the table and order a meal off a menu; other people are going to need to take their plate to the buffet and pick a bit off as they need it. I think in the NDIS there are people who can definitely seek and manage a package of funding, particularly if they do not have cognitive impairment or mental illness, but other people require a different model of support for them to be able to access and have all their needs met. The Partners in Recovery model that had been funded by the Commonwealth actually met the needs of a very significant portion of those people very well. We consider that it probably needs to continue into the future and not be completely rolled into the NDIS for package funding.

The potential of the NDIS is significant and we have heard many stories from carers who have told us that receiving a package has been life changing for their loved ones and has allowed the carer time to pursue personal goals or employment for the first time in many years. On the other hand, many carers are now struggling to access much-needed carer supports, which as we have heard, many of which have been defunded and their funding repurposed for the NDIS. This is especially so for respite and, in particular, mental health carer respite that had been funded by the Commonwealth is now 100 per cent rolled into the NDIS.

Respite for carers is more than a person looking after their loved one for a few hours. There are specific needs that carers have as individuals and human beings, as well as the need for spare time that need to be and are addressed by carer respite programs when they are well designed and appropriately resourced. We think that those services need to be continued. As they have been stopped and all of the funding put into a different purpose, that decision needs to be reconsidered as a matter of urgency. The implementation of the NDIS which is participant focused has been accompanied by the withdrawal of funding from the ADHC and other carer supports, as I have just mentioned. We consider that the integrated carer support services, although they do offer to meet some of the needs of this cohort of carers, actually have a limited scope to provide the comprehensive support required by many people in this population.

Furthermore, as outlined in our submission, mental health carers of scheme participants have reported a number of difficulties when the loved one is developing their plan in not being identified and engaged in that planning process. This can be particularly difficult for people who have never had the opportunity to articulate goals before being deprived of the support person who has traditionally helped them with many of these activities. We think that the NDIS planning process should, as a matter of course, identify and engage carers with the appropriate consent of the person being supported.

We also consider that overwhelming feedback from carers and the people they support is that some of the barriers in identifying the course of action you need to undertake in order to be recognised and accepted into the scheme is quite difficult and challenging for people with psychosocial disability and their families and carers. If the person with psychosocial disability does not receive a lot of support they often will not undertake that process at all. If they are refused or experience any difficulties they will often want to stop. That support for the advocacy for access needs to be better resourced and this is something that carers need to be recognised as wanting to do without necessarily being resourced to do it if they are given the opportunity to support their loved one in that way.

Just to touch on a couple of issues which are outlined in our submission before we go on, there are not service providers of last resort, and that is a particular issue in regional areas where some complex needs cannot be met by the market. The funding for the workers in this area is so low that there is not adequate resources provided for their employers to supervise and manage them. Also many of them lack specific training in dealing with people with psychosocial disability, which can be very challenging. Very bad results can be achieved if you do not go about it in the right way. It is quite skilful work. Funding for training needs to be provided so that we have a skilful workforce delivering these services in the home where there is a lack of scrutiny which would otherwise be available if they were taking place in a facility. We do believe that some block funded services will need to be provided on an ongoing basis, particularly for people with complex needs who need to be supported by a team, as often this will not be suitable for individual funding packages.

Finally, I will just note that one particular class of service that we felt was being done quite badly by the NDIS is social services or community centres. A number of these sorts of community services for people with disability have had their funding withdrawn so it can be repurposed into individual block funding. The trouble is if you have a community centre that only people with packages can access, the rest of the community is not coming. That deprives that service of a lot of its point, because it is meant to be building connections between people. We think that particular kind of service needs to be taken out of scope for the NDIS. The packages should be providing the extra support that people need to get to those services, not providing the core funding to have those community services operated in the first place.

The CHAIR: That was a very comprehensive opening statement. Thank you both.

Ms DAWN WALKER: I was interested in broad terms about how carers have been impacted by the transition to the NDIS. More specifically, you mentioned respite. Could you perhaps tease that out and elaborate on it for us so we have a clear understanding of where it has gone, what has happened to it and what that will mean?

Ms JUDD-LAM: Respite is something that Carers NSW has been really concerned about and has been tracking nationally in partnership with the national Network of Carers Associations. Also we have a committee or a working group that we started last year which includes Mental Health Carers NSW and a number of other stakeholders to track this in terms of both disability support and aged care support—so there are big changes happening to respite across the board—and mental health support as well. I guess the difficulty is that respite used to be a funded support both through ADHC and also through Commonwealth programs such as the Mental Health Respite: Carer Support program. These were dedicated supports that were aiming to give carers a break from their caring role while also aiming to create activities that were meaningful and enjoyable for the people with disability that they care for.

In the move to person-centredness under the NDIS, which is a positive move in most respects, the understanding now is that the activities that a person with disability participates in should be primarily about their interests. That is not necessarily a bad thing, but when the programs that previously provided respite support with the carer as a client if not the client have been transitioned to that NDIS through funding. So the ADHC funding that previously provided respite has been transitioned and the Commonwealth programs that previously provided respite have been transitioned. Within the NDIS itself there is no opportunity for carers to say, "I need a break," and have it guaranteed that that need is met for themselves. They might have what is often referred to as a respite effect from the support that is provided to the participant through an NDIS package, but there is no guarantee that that respite effect is the respite effect that the carer wants or needs and that that effect is adequate in order for them to maintain their health and wellbeing.

We recently did a survey of around 1,800 carers across New South Wales and we had over 700 responses from people that were caring for NDIS participants. We asked whether their needs had been considered in the planning process. We included some of these findings in the submission but have also done some more number crunching since that time because the data is very new. Of the 700 carers that were caring for someone accessing the NDIS, while most of them agreed that they had been included in the planning process, only 40 per cent indicated that they had been asked about their needs in the planning process. While a reasonable amount had said that NDIS supports had enabled them to take a break, the findings around whether NDIS supports had enabled carers to look after their own health and wellbeing or to go back to work were low. I guess what we are seeing is that you might be lucky and get a break to do what you want to do but there is no kind of mandatory assessment or even just question to see whether the carer needs a break and how that break would best suit them as well as the person with disability.

Ms KATRAKIS: I think there is still the reliance on the need for informal family carers within the NDIS. Not for everybody, and we are talking about the broad range of people with disabilities, but there is still a reliance for family carers. I think the rhetoric in the early days was that all carers can now go back to work because there will not be a need for them to do what they are doing within the family. That is not the case. A part of this issue around respite is there are families that prior to the NDIS had not accessed services, so they find it very positive. They are getting their needs met and the needs of the person that they are caring for and they are getting services they never got before. But for many other families, and where these other things were traditionally funded in different ways and accessible with different eligibility criteria and things like that, those things have now disappeared. Yes, we needed to do things differently and, yes, the system was fractured, but where there was a reliance on services and the ability to have a break to be able to look after yourself to continue to care is now no longer available. That is what the issue is that we have been focusing on and advocating about.

Mr HARMS: With mental health carers in particular, I believe the experience from the United Kingdom where self-directed funding was introduced was that they actually found that carers were spending on average an extra eight hours a week in their caring role, but instead of actually delivering the care themselves it was about identifying and managing the other providers of that care. The caring role changed rather than being eliminated. In fact, some of that work is more stressful and challenging than just looking after someone might be.

The CHAIR: Did you say eight additional hours?

Mr HARMS: Eight additional hours, although the reviewer had the cheek to say they did not find that statistically significant. Although if they had been a paid worker who got asked to do an extra day a week they might have found that more statistically significant, you tend to suspect. But for mental health carers often it is about being available to support a person or to prompt a person to help them do something rather than doing it all for them, depending on the severity of the disability and where they are at that point in their illness, because mental illness fluctuates. People can be very well for a long time but then if they get into a stressful situation like attempting to go back to work, which can be very stressful, that can change things rapidly. Being a mental health carer is often not consistent with employment for that reason.

It is stressful and it does still require support for the person to be able to continue in that role. That means respite; the chance to do something else which is not all about someone else looking after your loved one necessarily, although that can obviously be part of it. It can also be about doing things for yourself to recharge your own batteries. That is a class of service that has just passed away into history at the moment because it is not actually being provided by the State or Federal governments and that is an oversight that we think needs to be addressed. Ultimately it is not possible or desirable to replace all the family or carers' support for someone in their family but giving them enough support so they can do it in a way that does not damage their own health and which is consistent with their own participation in the community in the way that they wish to, that is something that I think we need to re-examine.

Ms JUDD-LAM: I support Mr Harms' points on that as well. The other finding we had in our survey that really supports that idea of the caring role changing and increasing with the NDIS is that 61 per cent of the 713 people who were caring for an NDIS participant said that there was an increase in the amount of time they spent per week organising support for the people they care for, so that was a really strong finding. We also know from delivering coordination of support under the NDIS that a lot of the people we have previously supported in other programs where the funding has ceased have not been given support coordination funding with an NDIS plan, even though from our perspective as service providers they very much need it.

We know that is across the sector; we have heard that. What is happening is that carers, who are often vulnerable, older carers with their own health problems, are actually being faced with having to take on a full-time support coordination role, which previously a funded case manager would have provided. We are seeing that a lot. I think the pointy end of it is that with those particularly vulnerable carers but across-the-board we are seeing an overall increase in coordination of support that may decrease over time as people get used to the NDIS but is still a really real experience for carers; it is causing a lot of stress.

Mr Harms mentioned that we are looking at no State and Federal funding for respite really at the moment and while there is, as Ms Katrakis referred to in her opening statement, the integrated carer support, which will be rolling out starting from this month and will have some component of respite included in terms of referrals to emergency respite, we have been really concerned in watching the development of that at the Federal level that there is still an understanding or expectation that the need for respite will be met under the NDIS and therefore no carer-dedicated planned respite will be needed and really they will just need some emergency respite. That, even still, relies on existing supports that can be referred to, which, in our experience, are disappearing, so you cannot link to something that does not exist.

The Hon. SHAYNE MALLARD: On the same theme, you said that once people got used to the NDIS you might see a reduction in the transition role because we are focused on problems with the transition. Carers that are providing a coordination role are not being supported and that is a transition issue. I would like to focus on that. How big a problem is that? You did say it may well reduce once people get their systems set up, which might be the experience you are seeing already. Do you have some numbers around that?

Ms JUDD-LAM: I am not sure if I have numbers on me but I can certainly take that on notice to look at that more specifically. Where we get our information from around the coordination of supports, like I said before, is from our experience in delivering previous programs to people who have transitioned or are transitioning and also from our coordination of support services ourselves. We previously had a program that was Ageing, Disability and Home Care [ADHC] funded called the Older Parent Carer Support Coordination Program, which was specifically for ageing parent carers of adults with mainly intellectual disability. That was providing support coordination to the carer to help them care, help them plan for the future and set in place supports for the person that they were caring for.

Sadly that program was defunded when ADHC ended and the support that was provided under that program does not exist within the NDIS other than by accident—if the carer gets that support through the person's plan. So we dealt with a lot of carers who really needed that intensive one-to-one support to use the internet who may not be able to do that themselves, who had health problems, who were ageing, who were looking at complex planning around housing and things like that for the person they cared for. We were able to transition a lot of those people to the NDIS and be there as they were planning. Many of those people did not receive funded support coordination, which is interesting given they were receiving a support coordination program as carers in their own right and people we are dealing with now who have coordination of supports often do not have an adequate number of hours or they may have those hours reduced in the second plan or in a review.

In transition, what we are really seeing is a huge crisis with particularly vulnerable carers taking on a huge amount of support coordination that they are not equipped for and therefore the person is not spending the money in their plan; they are just overwhelmed and the local area coordinators have been also overwhelmed and not able to provide that plan implementation support to them. What I said before about that probably reducing over time, that is a guess just based on once the system settles in, people will have plans and it will be more about plan reviews, people will be more used to the system.

However, I think there will be an ongoing challenge because support coordination funding under the NDIS is very limited and does not really take into account the carer's situation in terms of determining need and it is meant to reduce over time. So while there is a recognition that some people will need support coordination funding ongoing, the overall picture is you get it until you build your capacity and then it is taken away. I think in the long term there is going to be a lot of families who are going to be expected to basically become case managers because case managers do not exist as a funded support anymore so I think it is a really bad problem at the moment but it will probably been an ongoing problem as well.

The Hon. SHAYNE MALLARD: There is your eight hours.

Mr HARMS: Yes, that is right. I would just like to add that I think this is an issue that particularly impacts people with psychosocial disability and other forms of cognitive impairment because they obviously do need additional support to make decisions and to navigate complex systems. We are lucky when their families and carers happen to have those skills but we cannot rely on that as a linchpin of the architecture of this scheme. We need to be able to provide a funded service for that. Although it will reduce as people get their supports in place because people tend not to like too much change if they have got psychosocial disability—

The Hon. SHAYNE MALLARD: Or in general?

Mr HARMS: That is right, or in general, indeed. It is not going to disappear for those people, particularly if they are not satisfied with the kinds of support they are getting. They are going to want to change them around and they are going to need assistance with that. I think this is something that is going to feature ongoing.

Ms SMIT-COLBRAN: We are of the opinion that because mental illness is a fluctuating disability often, people do require a constant level of support coordination in many cases and it is not really clear that the NDIS will provide or continue to provide support coordination at review. We have noted that a number of carers in the consultations that we conducted earlier in the year and in online surveys have mentioned that they do not have access to support coordination and these carers have reported difficulty accessing supports in some cases.

Ms KATRAKIS: I make one other point in terms of the Older Parent Carer Support Coordination Program that provided that coordination of supports. We delivered that across different regions of New South Wales but particularly in Dubbo and the Far West, working with a range of Aboriginal families. Now that that program has gone, a lot of those families have not transitioned to other providers nor have they got support coordination in their plans or got the NDIS. There seems to be a big gap in regional, rural and remote areas, particularly with Aboriginal communities and families.

The Hon. COURTNEY HOUSSOS: I want to thank you for your submissions and for supporting the incredibly important work of carers. The point you have made about the expansion of the role of caring is very important and will be a crucial part of our work. We heard earlier this morning from Uniting, which said that families with young children are actually relinquishing them because of the lack of support. Are you aware of this situation? I am getting some nods from Ms Judd-Lam.

Ms KATRAKIS: I would say we are aware of the situation. I probably would not be able to add anything specific about that other than we do hear about that. A lot of families do get to that breaking point because there are not the supports in place and they feel they have nowhere to go. For a family to get to that point to relinquish a child, that it must be terrible. We do hear about that; we hear about many families almost getting to that point, trying to do everything to put things in place because the caring role that they are doing is relentless.

We have had a family recently that we were providing support coordination to with a child with very, very profound disability, physical and intellectual, that was 24/7. For a family that was reasonably well off, able to bring in other supports, but within the NDIS it was still a 24/7 role. That family was reaching breaking point and unfortunately the child passed away because of her condition but it was getting to the point, not that they were going to relinquish, but they had no out, not even with those other supports. They could not sleep; they needed to be turning the child. She would be screaming during the night, all these kinds of things. It was a relentless situation.

Ms JUDD-LAM: If I could add as well. I think the key policy issue there is that for children there is a real strong arm around any kind of funded respite, while for teenagers and adults there are short-term accommodation options within the NDIS pricelist that can facilitate an overnight stay or something like that. Something that we have been noticing people coming to us more and more about is that there is an expectation within the NDIS around what is reasonable for parents to provide. If you look in the legislation and the rules around that, it mentions that it is important for us to consider what is reasonable for families and communities to provide before supports are funded. We have not been able to find in any kind of official capacity, although we have heard enough references to practice that there seems to be a rule of thumb within the NDIA, if a child needs around-the-clock care there are quite high standards as to how much of that care should in the NDIA's opinion be provided by the parents.

A number of these cases have gone to the Administrative Appeals Tribunal [AAT] and been tested but basically the kind of message we have heard sort of third-hand from some of those families is that the NDIS is saying, "It is normal to look after a child around-the-clock so we will only fund support for you that is additional as a result of the disability." Some of these parents are staying up all night and then having to go to work the next day. There is a single rule of thumb that I have heard referred to about "eight hours"—it is reasonable to provide eight hours of support during the night for a parent. Again, I have not seen that documented anywhere but there are definitely families in which there is a real kind of challenge with the NDIA that, no, the parents should be providing that care.

We have also heard of a number of cases of families no longer being able to access vacation care and after school care because it has been said by the NDIS, "We will not fund that because that is funded by the education department." The families have said, "My child has special needs and cannot go into a mainstream after school care or holiday program." Then they are not able to access any of that. We have heard of carers giving up work, reducing their work hours simply because they are not allowed to get funded after school and vacation care that would be suitable for their child or for someone to accompany them to that service. I think in that child group there is that real problem that not only is respite being phased out as a concept but also if you are going to get it at all, you are not going to get it if you have a child. You are really going to be expected to be doing that 24/7 role and have supplementary supports put in.

The Hon. COURTNEY HOUSSOS: In effect what you are saying is that people are receiving a lower level of support because their respite has been taken away, the children are receiving less and parents or carers are having to fight for the actual services that they are being provided with?

Ms JUDD-LAM: In many cases. In a lot of cases people are receiving more support and they have got a better situation than they had before. We do not want to downplay that but I guess our job is to advocate on the issues. There are definitely not one or two, there are a lot of families who have really had to fight, have lost a lot of things and it has really impacted their families. I think people are getting that resolved slowly but often it is through formal appeals, going to the AAT, and ministerial intervention. It should not have to take that to get something that you have demonstrated need for.

The Hon. COURTNEY HOUSSOS: I note that both of your submissions talked about the importance of disability advocates and the ongoing funding of those. What are your thoughts about the role of a public advocate, public defender or public representative? This was raised in the Ombudsman's submission and it was also talked about earlier this morning. I know it is a recommendation from the Law Reform Commission but I am interested to hear your thoughts on this?

Mr HARMS: I do not mind hopping in here. We have long thought that there really needs to be a commissioner for vulnerable people to look after the needs of all vulnerable people in this State and around Australia. Although I have heard of parents getting to the end of their tether and saying that they would like to step away from looking after young children, I have also heard this from carers of adult people with significant disability support who get nothing much from our service systems.

To qualify to get into the NDIS I think there are 61,000 people from all around Australia and about 20,000 people in New South Wales are eligible, yet we know there are probably more like 250,000 people with significant psychosocial disability support needs around Australia.[2] That missing middle is not catered for in what we are putting forward at this stage. There is a big gap and that needs to be filled through the cooperation of clinical mental health services and all the other forms of disability support from housing to everything else that is needed to keep a person well and safe in the community when they have those kinds of disabilities or illnesses. There are so many ways in which a person who has got psychosocial or intellectual disability or vulnerability can fall through the cracks and there is no-one in particular whose job it is to identify these gaps and then to systematically advocate for them to be closed over and met.

So while the NDIS is a giant strides forward for the people who qualify for it, what it is making very clear are the people who are not eligible and who are not going to be supported adequately by anything in particular that we have got on the drawing board or that we have actually got implemented at the moment. So we think a commissioner for vulnerable people would be an excellent idea, just to start looking at all those people who are not good customers, who cannot clearly identify what they need and then demand it from whoever needs to provide it—the people who actually need support to explore or understand their own needs and then to get them met from a service system. So we strongly support that idea and the NDIS has clearly demonstrated the area in which this could be a huge boon to the community.

Ms KATRAKIS: We would certainly support the ongoing need for advocacy and individual advocacy. We are not funded for individual advocacy, we do systemic advocacy but through support coordination we can work with families to advocate for better supports within plans. That is not always available for everybody and we think that needs to be available for everybody.

The Hon. SCOTT FARLOW: Where is respite falling down? One would think in the planning stage that something like respite would be considered and catered for. Where is the impediment? What is happening? Are plans focusing on the person with a disability and not potentially on their carers?

Ms KATRAKIS: The plan is focusing on a person with a disability. Now within the development of that there is that flow-on effect of a person with a disability getting engaged in something that they want to do, choice and control and everything else, there is a flow-on effect that that might provide a respite effect for the carer then that will happen. But it is not assessing that family holistically—

The Hon. SCOTT FARLOW: So there are secondary considerations?

Ms KATRAKIS: It is a secondary consideration, not primary. But there is not the assessment of the carers separately or that whole family situation as to whether even that care can informally continue, what supports are needed to enable that network of support within that family to happen.

The Hon. SCOTT FARLOW: It is just taken as a given?

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[2] See correspondence received from Mr Jonathan Harms on 22 October 2018 regarding clarification on evidence

Ms KATRAKIS: That is right. I mean, when we raised this with a Minister an example was given. They assessed that a child with a disability needed to go to a bowling class and that he was going to do an activity there. The parents could take him there and go and have a cup of a coffee while he was doing his bowling. That is not respite. First, did they want to go to that facility? Did they want to go along? They probably said that they would need to intervene if the child's behaviour was challenging, they were on site so then they are involved in it. They are not having a break.

The Hon. SCOTT FARLOW: They also have the travel time in that?

Ms KATRAKIS: That is right. It is not really a break for the carer; it is not focusing on their needs. Respite is not just carers sitting back, putting their feet up and having a cup of tea. It might be, but often times it is an opportunity for them to get stuff done that they do not get any other opportunity to do.

Ms JUDD-LAM: We have no problem with a plan being focused on the needs of a person with a disability. Had carer support and respite funding not rolled into the NDIS, then we may not even be having this conversation. But because that has now disappeared and the funding of that is in the NDIS and is not being replicated, as Ms Katrakis said, it is really about the assessment of carers' needs. Some carers are accessing what they need in that planning conversation, but it really relies upon the knowledge and the goodwill of the planner and of the participant to actually identify that as a need and to work together to build that into the plan. In some cases, like with children, as we were saying before, there is a flat out no about certain types of respite. Certainly the word is not popular and it is not really part of the NDIS vocabulary, which we understand as well, but, again, if it was being covered elsewhere we would not having this argument. There is definitely an assumption, and a very explicit assumption, of the NDIS that if someone's needs are adequately captured in a plan, a person with a disability, then there should not be a need for respite.

And again, in a perfect world, yes. But a lot of people are not getting adequate supports from their plans. As we said earlier, there is an assumption that there is an ongoing carer role for NDIS participants; there is a lot of support coordination happening. So while you are expecting carers to continue to care you cannot assume that their needs will be captured without actually assessing them. There is an opportunity for carers to make a carer statement under the NDIS plan, but this is not something that has been formalised or promoted or is mandatory, so it is very variable as to if someone even asks a carer "What about you?" or "Does this arrangement work for you? Is your caring role sustainable?" So it really is about having that conversation with the carer. The main reason we are worried about it is because it is not happening anywhere else.

Mr HARMS: I will just add that when we asked about this we were told this is a scheme to support the person with the disability; it is not a carer support scheme. That is very reasonable in its way, but there is a whole group of people who have got their own support needs that are not being addressed at all. In the UK, that earlier report that I cited, within 12 months, I think, of them introducing individualised funding packages for people with disability they supplemented it with dedicated carer support schemes because they realised that those needs were not being addressed by the machinery that was not specifically set up to address them at all, which is pretty much what you would expect.

Ms SMIT-COLBRAN: We would point to the significant difference between participant needs and carer needs; they are two different worlds often, especially in the case of psychosocial disability where a person may not identify that their carer has needs or, in fact, they have a carer where somebody is providing them with significant support. We have noted and heard from many carers that they have been excluded from NDIS processes or they have not been asked to actively participate in NDIS processes and, as a result, their needs really have not been heard. Specifically, where the person with a psychosocial disability does not want the carer to be involved, then that is an element of their own choice, but it needs to be balanced by having access to carer supports available outside of the scheme. In addition, there is a huge number of people who are not eligible for the scheme and who do require these type of supports, particularly in the area of mental illness, as we know, because in many cases there is not a lifelong disability.

The CHAIR: That has been wonderful evidence from the perspective of the carers. We have received a number of submissions, including your own, and we have heard from a range of witnesses, but you have really given us a particular focus. It has been very detailed evidence and you have given us insights which, at least up to this point, we have not been looking at probably thoroughly enough, but I am sure it is going to inform our final deliberations and our report and recommendations. Thank you very much for your effective organisations and thank you for the wonderful work you are doing on behalf of people who are in great need.

(The witnesses withdrew)

ELYSE CAIN, Advocacy Manager, NSW Council of Social Services, affirmed and examined

YA'EL FRISCH, Project Officer Advocacy, NSW Council of Social Services, affirmed and examined

SERENA OVENS, Executive Officer, Physical Disability Council of NSW and Convener of the NSW Disability Advocacy Alliance, affirmed and examined

MATTHEW BOWDEN, Co-Chief Executive Officer, People with Disability Australia, NSW Disability Advocacy Alliance, affirmed and examined

The CHAIR: I take this opportunity to welcome into the public gallery a number of people who have joined us in the last half an hour or so. It is great to have you here at the New South Wales Parliament. I know a number of you are people with disability, and are advocates and carers as well. This is a very important inquiry that Portfolio Committee No. 2 is undertaking. We can only proceed and do a thorough and detailed inquiry to produce a report and recommendations where we have participation and involvement from people who are either themselves disabled or they are advocates for the disabled or may be involved in caring. It is great to have you come along. You are most welcome and it is great to hear directly from you in this inquiry.

On behalf of the two organisations you have put in submissions. They have been received and processed. The NSW Council of Social Services, your submission is No. 152 and for the NSW Disability Advocacy Alliance, your submission is No. 294. We have received them and they have been incorporated as submissions to this inquiry. You can take both of them as read. I will invite you shortly to make an opening statement, so there is no need to read from the submissions per se but rather set the scene, and once that has been done we would like to share the questioning around between the members of the Committee. Who would like to make an opening statement from the NSW Council of Social Services [NCOSS]?

Ms FRISCH: I would. On behalf of NCOSS I would like to thank you for inviting us to appear today. As my initial point I would like to reiterate that we firmly support the Stand By Me campaign and the work of our colleagues here. Because of that support, like our colleagues, we welcome the announcement for additional funding in April but we truly believe that the New South Wales Government needs to commit to long-term funding for disability advocacy which is crucial to assist people with disability to access mainstream services whether or not they are eligible for the NDIS. Secondly, disability advocacy and information organisations have a crucial partnership with government in delivering the Disability Inclusion Act and, as I am sure you have already heard, the NDIS freezes the need for advocacy for people who need assistance.

In our submission to this inquiry, we included a report that NCOSS produced in April which highlighted the gaps in mainstream service provision which resulted from the closure of the Department of Aging, Disability and Homecare. It drew on our consultations across the State and with our key members in the disability sector. These gaps were documented following consultation with our members and stakeholders and illustrated the challenges of these gaps, the effect of them on people with disability. We made a recommendation as to a way forward. We are happy to say that since the release of the report there has been some action in some areas—for example, funding announced in the budget for the funding of specialist intellectual disability health service. We welcome this and other developments but there is more work to be done as seen in the challenges faced by people who need access to swallowing supports which can still be funded.

In relation to the remaining gaps to support the recommendations of our members, particularly People with Disability Australia, Physical Disability Council of New South Wales, Council for Intellectual Disability—all of these groups have given evidence to you or will do so—and we support their recommendations as to the gaps. NCOSS has recently completed our consultations around the State. This year there have been a number of comments that have come out in relation to the implementation of the NDIS and people missing out. In particular, I would like to talk about two gaps that have been highlighted. The first is about people falling through the cracks because they are ineligible for NDIS.

In relation to people missing out on mental health services, we have heard that the lack of access to these services because of the closure of ADHC has put increasing pressure on mainstream services such as community mental health services. Antisocial behaviour caused by the loss of these supports have made people vulnerable to eviction and homelessness. It illustrates the lack of disability supports and the increasing pressure on mainstream services. We have also heard from people who have lost community participation supports because of the community care supports scheme and have experienced less independence and greater isolation because of the lack of, for example, domestic assistance and community transport.

In relation to community transport we would like to emphasise that the small increase that has been announced by the New South Wales Government is really insufficient to cover the increased need and the service is erratic, particularly in rural areas. There is increased demand. What we need is actually a far greater increase of this, a doubling of community participation funding over five years. In conclusion, we would like to emphasise that the New South Wales Government has a responsibility to support all people with disability and ensure no-one falls through the cracks, whether eligible for the NDIS or not.

The CHAIR: Opening statements do not get much better than that. It was articulate, rich with information, comprehensive and set the scene very nicely. Thank you for that great opening statement.

Ms OVENS: On behalf of the 22 organisations that form the NSW Disability Advocacy Alliance I too thank you for the opportunity to provide evidence this morning. We are a coalition of independent advocacy, information and peak representative organisations currently funded by the New South Wales Government. Some of us are statewide disabled people's organisations, providing the voice of people with disability directly. Others are advocacy and information organisations providing vital support, particularly in regional and rural communities around New South Wales. The New South Wales Government has guaranteed that within two years our organisations will lose every cent of our New South Wales funding. This is despite the crucial role we provide in representing and supporting the human rights of people with disability in New South Wales.

One of our member organisations, Blind Citizens NSW, has been providing peer support and working to make New South Wales a more accessible inclusive place for blind people since 1910—yes, 108 years—and the Government is poised to pull the pin on that. The NDIS currently provides individually funded packages for 97,000 people with disability in New South Wales. Yet there are a further 1.2 million people with disability in New South Wales who do not get an NDIS package and who rely on our services to help them get a fair deal, be it for transport issues, accessing schools and TAFEs, navigating the justice system, getting decent health services, accessing the physical environment or dealing with horrific cases of violence, abuse, exploitation, neglect and discrimination.

The terms of the inquiry ask us to look broader than the NDIS. We are gravely concerned for people with disability in NSW who are ineligible for the NDIS and for the loss of disability supports in New South Wales that are a result of its implementation. To this end we would highlight the following points. In recent reports, both the Senate Standing Committee on Community Affairs and the Australian Human Rights Commission state the critical role independent individual and systems advocacy contribute in preventing and addressing violence against people with disability and in building inclusive communities. They also acknowledge that our organisations should sit outside the safeguarding framework to ensure our independence is maintained, as our role may involve challenging the NDIS at times. State and Federal systems must take steps to ensure our powers and future in this sphere is assured.

Our organisations also work hand in hand with the current Government. We provide expert advice to over 100 government and other advisory boards and committees and, like today's hearing, submit on many inquiries and consultations saving government millions of dollars on expensive consultants. Consultants cannot tell government what living with disability in New South Wales is like, only people with disability can do that. In fact, a recent commissioned report indicated that for every dollar spent on advocacy the government received a return of $3.50, an unusually high return on investment and extremely effective use of resources.

The Government has legislation that we play a critical role in delivering at State and local levels. The objects and principles of the NSW Disability Inclusion Act 2014 can only be delivered if there is a direct investment in New South Wales peak advocacy organisations. Further, the Boarding Houses Act 2012 relies on the safeguarding role that disability advocates play. The NDIS will not deliver on these obligations for the New South Wales Government and it is unconscionable for the Government to walk away from the commitments made to people with disability in these important pieces of legislation. Finally, I believe that the small step of funding independent disability advocacy, information and peak bodies would be a drop in the New South Wales budgetary bucket and would be of immense benefit to the government and mainstream systems.

The CHAIR: A comprehensive opening that covered a number of points that will lead to questions.

The Hon. COURTNEY HOUSSOS: I congratulate you on an excellent campaign, the Stand By Me campaign. I thank Ms Frisch and Ms Cain for NCOSS's well-researched and detailed response. It is informative for us as a Committee. Thank you very much. My question is around the public advocate. This was something that was put forward by the New South Wales Law Reform Commission, the Ombudsman raised it and we have talked about it today. This is separate to the role of the community advocate but provides a greater level of oversight, particularly when it comes to programs such as the NDIS. I would be interested to hear the views of both your organisations about such a role?

Mr BOWDEN: It is certainly something we support. The introduction of a public advocate role, other jurisdictions have a similar office and we see it as useful. It complements the independent advocacy sector. It provides another supporting voice that peak organisations play in each jurisdiction. One of the things that we really hope the New South Wales Government does if it introduces the position of public advocate and an office of the public advocate is that this is also independent of other government agencies, that it is independent of organisations or offices such as the Office of the Public Guardian, New South Wales Trustee and Guardian, and it sits separately from the Ombudsman as well. It is important that the public advocate is able to critique the functions for people with disability of those offices as well, and those appointed statutory positions. That, I hope, explains our position in supporting the public advocate.

The Hon. COURTNEY HOUSSOS: Absolutely, and makes some important recommendations around that. Thank you very much.

Ms FRISCH: We would like to endorse these points and highlight that this role will be complementary, instead of the continuation of the funding for the community advocacy beyond 2020.

Ms OVENS: If I could also add to that, as mentioned, generally what has been recommended is that the community level advocacy is what feeds up many times to that high level public advocate. We see things early on, hopefully before they get to the point of needing the public advocate, but we can support systems change and ensure that where there are issues and where the public advocate is seeing them, we can also go in and assist in reinforcing and/or helping with change across that. It is a three-tiered structure that would work best.

The Hon. COURTNEY HOUSSOS: I say at the outset that all Committee members are great supporters of the NDIS and the promise that it offers. However, I am deeply concerned about the gaps and the people who are not being supported through the NDIS and who should be. What two or three specific things could the New South Wales Government be doing now that it has effectively privatised its whole department that were previously being supported that are no longer being supported? I am happy if you want to mention more than two or three.

Ms OVENS: One of the things, as we have addressed, is the advocacy supports and systems. Information advocacy and peak representational organisations support everybody, whether they have a plan or not, whether they are funded or not in the NDIS. If someone does have a plan, they get general day-to-day supports through support coordination, someone with limited time and limited funds, to help them navigate what they need for their plan on a day-to-day basis. What that support coordinator cannot do, and what is missing for people who do not have a plan, are the advocates who would support someone if they have an issue, perhaps when they are looking through the justice system and may be incarcerated, when they cannot access a building, literally, because the physical access is unavailable, when transport is an issue for them, or when they are discriminated against.

Again, ability linkers, something that the Government has put in place, are great. They too link people with services within the community, but they do that as a one-to-one, and they often come to us where the service or the issue is great and they need us as advocates to then work with the person they are linking. We become part of that system, and they often even come to us just to find out what services might be available in a community, because many of us have been there for 25, 60, 100 years and have amazing relationships with the other services and other supports within the area.

Mr BOWDEN: My organisation, People with Disability Australia, is funded by the New South Wales Government to provide advocacy support to people with disability who live in assisted boarding houses. These are private establishments where groups of people with disability are paying to live in those places to receive both housing but also disability support. They are mostly people with psychosocial disability, but not exclusively. There are many people with intellectual disability, acquired brain injury, et cetera, living in boarding houses. One of the things that has occurred since Ageing, Disability and Home Care [ADHC] have ceased providing assistance to people in boarding houses, the Government is still playing a monitoring and licensing role, but it has stopped all case management services to people in boarding houses. And so this is work that has come to our organisation.

We have not received any increase in funding or resourcing to do that. This is people's assistance to apply to transition to the NDIS, people having assistance with any pre-planning or support within a planning session, then all the day-to-day life of somebody in a boarding house, and these are people who very often need quite considerable assistance with organising things such as medical appointments, dental appointments, accessing the community, having contact with family members, et cetera. The job that case managers would do has now completely disappeared until people get into the scheme—and not everyone is, of course, in a boarding house. Boarding houses have a considerable number of people who are over the age of 65, and so therefore are ineligible for the scheme. It is the role of us as an organisation providing advocacy support that is filling that gap of case management.

Ms OVENS: Additionally, where community care and support services are no longer available, someone may not have been deemed eligible for the NDIS, we are seeing people who are falling through the gaps, where their care and supports have gone to keep them in the home, their day-to-day help with meals preparation and some light support. For one example, we have a gentleman who has had to be moved out of home into hospitalisation because he was no longer able to care for himself in the home. This is a great gap. If it is picked up, that is great and he gets some care, but it is a much greater strain on the health system as he sits in a hospital bed where he probably did not need to be if he had that more minor care at home. Often, it can be for quite a long period of time while we try to sort out where that care can come from now that the gap is there without that service.

The Hon. COURTNEY HOUSSOS: I would like to touch on that point. Ms Frisch raised this in her opening statement, which is a key point. If people are not provided with the supports through the NDIS ultimately they are either proactively coming into contact with the health system or at times coming into contact with the justice system, or other government departments or agencies.

Ms OVENS: Correct. Other service systems will take the brunt of the gaps that are being caused where services are disappearing if someone does not have the support of the NDIS in a plan situation.

The Hon. COURTNEY HOUSSOS: During the last hearing the Committee heard evidence that in effect that means people are in hospital or in jail who should not be there, who should be being supported through the NDIS. Is that correct?

Ms OVENS: Very much so, or even if they are not supported through the NDIS, they need the support of the State Government to ensure that they are not in systems taking up much-needed beds or people are in jails where they should not be, just because they are unable to speak for themselves correctly and tell the story of what may have happened, particularly in the case of someone with an intellectual disability where telling that story can be a lot more difficult.

The Hon. COURTNEY HOUSSOS: That is an excellent point. It might not be through the NDIS; it might be through the State Government that they need the support. Sorry, Ms Frisch and Ms Cain, I cut you off.

Ms FRISCH: That last point was a good opening for my point, which is to endorse all the points that have been made but look at the original question, which was to say, even though the department is closed, what are the actions? We would say the fact that the department is closed is just negative for us. The New South Wales Government still has the responsibility to do all the things that were done before and all the other departments will just have to increase their responsiveness and ensure that all the functions that ADHC was providing in the mainstream system are fulfilled. It is good to see that, for example, one year of funding has been given to the criminal justice program. These just need to be funded long-term, because long-term under the Disability Inclusion Act the New South Wales Government maintains the responsibility, notwithstanding that a particular department is closed.

Mr BOWDEN: I make another point around what the impact of the absence of the New South Wales Government being the service provider of last resort has had on disability advocacy organisations, the NDIS market, the service providers, are not providing a guarantee of support or service in the same way that was a guarantee given to people with disability by the State Government. That worked really well for a small but important cohort of people who, for a range of reasons, have difficulties engaging with services. They might be viewed by services as being challenging, complex, or antisocial in respect of their engagement. The non-government sector, the private sector, might walk away from those people and they are walking away from those people now. The New South Wales Government was not doing that. It would always say, "We are here to assist you, regardless of what is going on. We will try and try and try to get the supports right in a way that is centred around you, that gets to know you and engages with you in a really positive way."

The market is failing people with disability in that respect, so this is coming to disability advocates to sort out and try and broker a positive working relationship between the service provider and the person with the NDIS plan. We can be successful with that some of the time but not all of the time. We are seeing people facing evictions who would never have been evicted from a group home or respite service run by the New South Wales Government because there was that commitment to always be there to provide that assistance. There is not the same level of commitment, unfortunately, given by the non-government sector. This is another critical piece that attention really needs to be put to.

Ms DAWN WALKER: Thank you all for coming. I too would like to acknowledge the Stand By Me campaign and the work you have done, but also the work ahead to ensure the funding beyond 2020. We know that advocacy organisations play a critical role in informing people with disability of their rights. Can you tell us approximately how many people in New South Wales disability advocacy organisations support each year and where these people would need to turn to get similar support?

Ms OVENS: Obviously as advocacy organisations we support anyone with disability who may need support and in turn their carers and families as well, should they call for that. Different organisations do different things. For instance, my organisation would, in various ways and forms, cover more than 20,000 people in a year through either the supported expos and providing information through systems advocacy, through education, through our website, through our resources, through our inquiries line. We have many, many inquiries. We have seen more than a 20 per cent increase in inquiries over the past year and the past three years, with at least 15 per cent of those being additional inquiries related to the NDIS. If we are not around, then those questions, I do not know where they will go to.

Most of the organisations in the campaign will either close or will lose between 33 per cent and 50 per cent of their current services through a loss of New South Wales funding. That will mean huge gaps for people with disability and nowhere to get that voice. From a systems perspective, it means people will have to do things individually. That takes so much time out of what should be everyday life. A wheelchair user who wants to catch a train to anywhere needs to sit down and plan that journey. They cannot do it spontaneously on the day because they may not be able to access either of the stations they are trying to get to or from. Even if they can access them, they may need to ensure someone will be there with a ramp to enable them to get on or off the train. Sometimes that does not happen and they can be stuck on a train calling at the station that they need to get off at. They then have to turn around and resume the journey. There are many things we do to try to take that daily discriminatory routine off someone and allow them to have an average normal life the same as the rest of us.

Ms DAWN WALKER: You have mentioned in your evidence that along with issues like discrimination, accessing transport, you assist government departments and agencies. Can you expand on that work?

Ms OVENS: Sure. All of the organisations do so in many different ways, but particularly for systemic advocates, we often sit on many government advisory boards and panels. PDCN, the organisation that I work with, is involved in more than 25 advisory boards, from the New South Wales accessible transport committee to the Minister for Innovation and Regulation, the Social Innovation Council, the New South Wales Family and Community Services implementation advisory committee for the Disability Inclusion Action Plan. I could go on. The names are so long we could be here forever. In providing that information and being on those committees, we give expert advice of people with disability on how to change, how to be inclusive, how to build a better New South Wales and, as I said, at a much cheaper cost than we would if we had involved a consultant, many of whom would not have the disability knowledge or the background that we get from our own members feeding in on what is important to them, what changes they need to see happen, what is still not working well for them within community.

Ms DAWN WALKER: It appears we are in a time of great change in the sector with the NDIS. It appears intuitively that that is a time that you would need an advocacy service. I find it disturbing that this is now a time when advocacy services are looking down the barrel of losing funding and have had to spend so much time and effort trying to survive during the NDIS transition period. Can you expand on the ways that your organisations assist with NDIS for clients and the whole NDIS process?

Ms OVENS: I will give an example and then I will throw to Mr Bowden. The NDIS, we agree, is an amazing reform. We of all organisations were very supportive and still are supportive and are working very hard to ensure it becomes a reform that is a positive one for everyone with disability. However, what we are doing and having to do at this point in time is assist people through that process, be it providing education to help people understand how to navigate the NDIS, how to access it in the first place, how to action a plan and ensure that they are getting what they need for their plans. It is taking more and more of our time and effort and, as you said, it takes away from our day-to-day role, which is looking at the bigger system, ensuring we can make change across all New South Wales through all systems, be it health, education, employment, justice et cetera to ensure that people with disability are fully included members of the community.

Mr BOWDEN: The role the advocacy plays is really a critical one. It is going to always be required in respect of a safeguarding provision for the scheme and for people with disability who are engaging with the scheme. One of the large areas of our work is about assisting with the intersection between the scheme and mainstream services, be that child protection systems, justice systems, education et cetera, so that the plan and supports in other environments are working in a way that is conducive to a person having a good life. The market is also not ready, particularly in areas in rural and regional and remote locations in New South Wales. People have money in their plans and they are not able to spend it because there is not the service system there, or there might be only a fly in, fly out service.

For example, therapists are not on the ground, so you might not have an occupational therapist or a speech pathologist for your child in a remote area. They might only visit once every six months or annually, and so you might be on a long waiting list for that service, and then you get the service but you can only spend a small amount of your plan on that and you are not getting the therapy that you actually need. Until that point when the market is fully responsive to need—because there is a large gap between those two things—it is very important that disability peak organisations are able to describe that and what that is like to government and to the NDIS and also to the market that the NGO providers say this is what is needed and what works.

We are providing examples of how the solutions might be met and creative ways that supports can be provided to people with disability in remote locations and to persuade initiatives that look at a different structure for providing disability supports than just a pure private market response to need. One of the things that we have been busy in is assisting people with their internal reviews. There has been a large variance in the quality of people's plans. Many people with disability have been unhappy with the plan that they have received. It has not met their needs. We have been supporting people to go through the process of seeking an internal review, talking to people about their rights to do that, and then also walking with them through an appeals process when that is required. That is always going to need to happen. There is no human service system that can be perfect and there will always be a need for decisions to be reviewed and appealed.

The Hon. SHAYNE MALLARD: Continuing the same discussion about funding for advocacy, I think this Government has extended the transition period to 2020, is that right?

Ms OVENS: Correct.

The Hon. SHAYNE MALLARD: What is the role for the Federal Government in the NDIS to be funding advocacy, as opposed to the States?

Ms OVENS: Advocacy itself is not funded within the NDIS at all individually or systemically. The Federal Government plays a role in funding advocacy and does so through the National Disability Advocacy Program to the tune of $20 million a year federally. They still do that.

The CHAIR: Is that spread $20 million across the Commonwealth?

Ms OVENS: That is spread across the Commonwealth.

The CHAIR: Six States and Territories?

Ms OVENS: Exactly.

The CHAIR: I did not mention the islands.

Ms OVENS: That is right, across all States and Territories. That is to stay and has not increased. The loss of $13 million from the New South Wales State funding means that more than half of all advocacy, be it individual, the information, be it systemic advocacy and peak organisations, will be lost in 2020 when the New South Wales Government does not fund advocacy from that point.

The Hon. SHAYNE MALLARD: What about the other States?

Ms OVENS: Victoria has maintained its advocacy and is looking to increase and build a stronger advocacy sector. It has recognised for quite a number of years the huge inherent value of advocacy to the whole system. The Queensland Government has stepped up and also committed to funding its advocacy services as well. And other States and Territories at this point are looking to follow suit, but not all. We would like the New South Wales Government to realise the benefit of a very small amount of money for what is a huge saving—

The Hon. SHAYNE MALLARD: Historically it has been a strong funding source for advocacy compared to other States.

Ms OVENS: Absolutely.

The Hon. SHAYNE MALLARD: Compared to the Federal Government.

Ms OVENS: We fund advocacy. I would say that we are still very much underfunded. Today I still turn people away unfortunately because we are not able to support the work that is needed on a constant basis. I have no hesitation in saying that the New South Wales Government has funded advocacy. But what we are saying is that it is incredibly important that it continues to do so and it does not rely on what will be less than half the funding by relying on the Federal Government alone.

The Hon. SHAYNE MALLARD: Is the funding for NCOSS under a question mark from the State or is that separate? Essentially this is disability funding, but does NCOSS have that same issue?

Ms CAIN: NCOSS does not have funding that is specifically put aside for disability advocacy but obviously when ADHC wrapped up that was a huge part of our core funding that was taken away as well. We have been impacted but not to the same extent.

The Hon. SHAYNE MALLARD: Ms Ovens, did you say that 1.2 million people in New South Wales do not qualify for NDIS?

Ms OVENS: Correct.

The Hon. SHAYNE MALLARD: How did you arrive at that figure?

Ms OVENS: There are 1.37 million people in New South Wales with a disability and at the moment we have approximately just under 97,000, as quoted at the first hearing in July that are currently given an individual plan under the NDIS. In general it is assumed that we will have approximately 140,000 by the time the scheme is fully rolled out in New South Wales.

The Hon. SHAYNE MALLARD: I do not have the figures with me but on the first day of the inquiry I think the Committee was told that 97 per cent had transitioned across from State funding to—

The Hon. SCOTT FARLOW: Those who were previously receiving State funding.

Ms OVENS: Correct. As I understand it, 52,300 people as of June had rolled across from State government funding into the NDIS and, yes, that might be a high percentage of people who receive funding through ADHC but there are many more people—as we were saying 1.37 million—in New South Wales who have a disability who rely on advocacy services. They may not need a plan to assist them in such a way but unfortunately there are many people, be they really competent or people with significant disabilities, that rely on our services when something happens to assist them through a process.

The Hon. SHAYNE MALLARD: To be clear, the 1.2 million were not being funded by the State previously? The cohort that is there under your definition of "disability", which is probably not the definition used by—

Ms OVENS: No, the definition of "disability" under the ABS.

The Hon. SHAYNE MALLARD: They did not qualify for support from the State.

Ms OVENS: I never said they were. There are some people who probably needed to and I think we are going to pick it up.

The Hon. SHAYNE MALLARD: I think it is implied that they fell through the gaps.

Mr BOWDEN: But they are being represented by our organisations. We provide a voice for all people with disability and so that is a service, if you want to couch it in terms of service provision, where when we are engaging with government, talking about how cultural and sporting events are held in this State and how those are accessible, that we are talking about the accessibility for blind or deaf people or people who might not be ever received ADHC funded support, and people who might not get supports from the NDIS. But they are still people with disability who live in New South Wales; they are still people who need specific supports and adjustments made so that people can fully participate in our society and our communities in the events that we hold. That is what we do. This is what disability peak organisations do.

The Hon. SHAYNE MALLARD: That is an argument for the future for NDIS to broaden its reach to more people?

Mr BOWDEN: I am not saying that.

The Hon. SHAYNE MALLARD: We are looking at a cohort that the State supported and have gone across and about transitioning—

Ms OVENS: The State has an obligation to everybody with disability under both the Disability Inclusion Act and the NDIS. There are so many different obligations that it still needs to meet, whether a person has a plan under the NDIS. Until people with disability can be fully included members of society, we would suggest that it is still incredibly important the State commits to helping those people.

The Hon. SHAYNE MALLARD: I wanted to be clear though. You said "ineligible for NDIS and do not qualify for NDIS". They were also not qualified for State support earlier? That is what I wanted to be clear on.

The CHAIR: That was a very useful session. The Committee may have further questions and our secretariat will liaise with you, the answers to which must be supplied within 14 days.

(The witnesses withdrew)

(Luncheon Adjournment)

JIM SIMPSON, Senior Advocate, NSW Council for Intellectual Disability, affirmed and examined

ANTHONY MULHOLLAND, Member, NSW Council for Intellectual Disability Advocacy Group, sworn and examined

DAVID BRIGGS, Advocacy and Policy Officer, Council for Intellectual Disability, affirmed and examined

The CHAIR: Thank you for making time to come along this afternoon to give some evidence to the inquiry. We have received submission No. 120 from the NSW Council for Intellectual Disability Advocacy Group and submission No. 148 from the Council for Intellectual Disability. They have been formally incorporated as evidence to the inquiry and have gone onto the inquiry's website. You can take those as read but I invite witnesses from the organisations to make an opening statement if they wish to do so. Once that is done we will share the time around and ask some questions to elucidate the submissions.

Mr MULHOLLAND: My name is Anthony Mulholland. I am 36 years old. I am an Aboriginal man. I live in Penrith. I was born with an intellectual disability. I have a hidden intellectual disability. I play touch football in an inclusion league for people with a disability in the Penrith area. I am very grateful because I am one of the leading scorers. I used to live with my mum, but now I live independently. I have lived by myself for five years. I have only limited support because I can achieve a lot by myself. It took me a long time to get the right support to move out of home but I still need support in certain areas of my life.

It is important for me that people with disability have a voice and speak up. I like to do advocacy work. I find the reward is to see the achievements I can achieve to help other people achieve things that they had been never been able to achieve and seeing the outcomes of what it can be like and also seeing the success of what I can achieve to help people achieve things, because I know it is hard. Having an intellectual disability, there is a lot that goes on you. It is also my way to make sure that my friends do not have the problems I have had and what I have gone through to achieve what they can achieve.

The Government tried to close advocacy. I was part of the Don't Silence Us campaign to stop the cuts. I do a lot of advocacy to make sure transport is accessible for people with disability. I am on an Access Committee for Penrith City Council. I am also on the accessible transport committee with Transport. I used to get support from Ageing, Disability and Home Care [ADHC]. I have been on the National Disability Insurance Scheme [NDIS] for a while now. The NDIS has caused me and my friends a lot of stress and headaches. It is like always we have to prove ourselves. We always have to fight to make things right. We should not have to fight. I am here today because I want you to listen to people with disability about how to make the NDIS work and listen to us about how the New South Wales Government can make things better. Thank you.

The CHAIR: That was very clear and precise. I am sure we will have some questions of you after the next opening statement.

Mr SIMPSON: In our submission we have highlighted a range of flaws that we saw in the way in which the New South Wales Government has gone about the transition into the NDIS and its own exit from service provision, including the pace of transition and the lack of choice and control that was inherent in what happened. I am happy to give thoughts about how that could have been done better if the Committee would like me to in answer to questions, but just right now I would like to focus on issues that the New South Wales Government has control over and has responsibility for from here on in. The first is the interface with justice. There are some quite good things happening there in terms of what the Government is up to now. There is a lot to be done but there are some good initiatives. I am happy to talk about those later as well. Similarly in relation to health, there were some major gaps that were there with the closure of ADHC. There has been in a lot of ways a very positive response from NSW Health.

Some of the really problematic issues that still continue are in relation to the whole issue of provider of last resort, which was traditionally an ADHC role and one that non-government service providers did not feel equipped for. That is a major problem right now with ADHC having closed services and the National Disability Insurance Agency [NDIA] not having any adequate system in place. The lack of that problem having been addressed means that it is likely that there are a lot of people with intellectual disability currently in jail or in hospitals or psychiatric hospitals not because they need to be there but because that provider of last resort structure is not in place. The Ombudsman has had some really important roles in relation to people with disability up until now. Most of that has gone over to the new Quality and Safeguards Commission, but there are some important gaps that we are very keen to see filled by maintenance of the Ombudsman's role. Their role of reviewing deaths in care in relation to the health system, which the Quality and Safeguards Commission does not have responsibility for, is a particularly important one.

Flowing from the fact that ADHC tended to be the provider of last resort and the niche provider for people with more complex needs, there is a major issue about security of tenure in people's accommodation as we move into the new environment. Under ADHC, political and public service obligations meant that it was very rare, if ever, that people were evicted from their ADHC-supported accommodation. Non-government organisations quite naturally do not have those same obligations. The Government has consulted about legislation in relation to that issue. We saw some fundamental problems with the consultation proposals. I am more than happy to talk about the issue of how to ensure that people's security of tenure in their accommodation can be safeguarded if the Government proceeds with legislation.

Another very important forward-looking issue is what is the role of disability strategy leadership in the New South Wales Government from here on in? We have got the NDIS but there are a range of really important issues that New South Wales is still responsible for, including the whole issue of inclusion of people with disability within mainstream services and the community, plus ongoing looking at the gaps and the demarcation issues with the NDIS. We have really valued the role that the Department of Premier and Cabinet has played increasingly over the last few years in providing some leadership at a central agency level on those sorts of issues and we would strongly advocate that if governments of whichever persuasion are fair dinkum about people with disability being entitled to a fully included life in their community, we would look to the political parties to commit to maintaining central agency leadership responsible to the Premier or another senior Minister for that kind of disability strategy leadership. It is very hard for that kind of role to have oomph if it is in a comparatively junior portfolio.

Finally, the issue of advocacy—and I know you have heard from the Stand By Me coalition, which we strongly support across the ranges of advocacy. To use ourselves as an example, what has been central to our being over the years is developing and supporting the role of people with intellectual disability as leaders in our organisation and as leaders in public debate and Mr Mulholland being here today is an example of that and other people who are present in the room are great examples of that. If the New South Wales Government stops funding disability advocacy in two years time, our capacity to provide that support and development for people with intellectual disability as leaders and in public debate will stop. People with intellectual disability will be silenced. That is something that is of grave concern to us. Thank you.

The CHAIR: Thank you, Mr Simpson. I direct this question to you, Mr Simpson. The notion of the provider of last resort is a term that has been used by witnesses on the first hearing day and again today. Is that based really on custom and practice or is it rooted in statutory obligation somewhere? It would be appreciated if you can shed some light on that?

Mr SIMPSON: Custom and practice; I am showing my age. I have been around the disability advocacy field for over 30 years. Historically we had the State Government Disability Services, which were basically institutionally running big institutions and then we had non-government organisations, which were basically developed by parents who wanted something better for their sons and daughters. The non-government sector at that time certainly, and over time continuing, did not see itself overall as at all well equipped to deal with people with more complex behavioural needs. That has always been the role of government, never spelt out in legislation but absolutely spelt out in practice.

The CHAIR: Understood. Thank you for that.

The Hon. COURTNEY HOUSSOS: Thank you very much, Mr Simpson and Mr Mulholland, for your excellent opening statements that were very informed and will be very useful for us. I have a couple of questions for you, Mr Simpson, and then one for you, Mr Mulholland. Feel free to jump in, Mr Briggs, if you would like to contribute at any point. Mr Simpson, are you aware of specialised disability accommodation [SDA] funding being reviewed if a person with a disability leaves or is evicted from their group home?

Mr SIMPSON: I am not specifically aware of that. I know there are a lot of problems around specialist disability accommodation but I am not specifically aware of that so I cannot really help.

The Hon. COURTNEY HOUSSOS: You said there are some issues around that. Would you like to outline some of those issues for me?

Mr SIMPSON: Yes. There is certainly a really big major issue about the adequacy of the availability of supported disability accommodation funding and what that is going to mean in terms of availability of supported accommodation for a lot of people who need it into the future.

The Hon. COURTNEY HOUSSOS: We have been told anecdotally of people who are leaving former ADHC housing one way or the other and are having their SDA reviewed or there is no guarantee that it will continue to be there?

Mr SIMPSON: That does not surprise me but I am not specifically up on that issue.

The Hon. COURTNEY HOUSSOS: No, that is fine. I have asked a number of people today about the role of the New South Wales Law Reform Commission's recommendation about a public advocate, public representative or public defender—we have lots of different titles. I am interested in your thoughts about the value of such a role?

Mr SIMPSON: Sure. There are a number of roles that the Law Reform Commission has recommended there. In essence, we at least in principle agree with the recommendations of the commission in relation to the kinds of roles that a statutory body should take on. We emphasise what the commission themselves emphasised, that what they are talking about is quite separate from community advocacy; they are complementary roles rather than a public advocate reducing the need for community advocacy. We would really strongly emphasise the need for complete independence of a public advocate. It is stated in the body of the commission's report the kinds of roles that are being talked about. Unless a public advocate is totally independent, we would have grave concerns about the community acceptance and efficacy. When I say total independence, I mean annual reports to Parliament, security of tenure for the holder of the public advocate position and complete administrative separation, in particular from the NSW Trustee.

Currently the Public Guardian is within the administration of the NSW Trustee. We would see that as highly problematic for a public advocate whose advocacy might quite often be directed towards the NSW Trustee, which is an organisation with a very mixed history and reputation. We would also emphasise some of the coercive functions that are proposed. We support the right to be able to enter premises and demand people answer questions in the context of suspected abuse or neglect. But in terms of the broader advocacy functions that are proposed for a public advocate, the other thing I want to emphasise is that we would see continued community advocacy funding as a higher priority. We are certainly not opposed to the public advocate having those sorts of roles; it would be a useful part of a full rights protection schema, but it should not be seen as a higher priority than continuing community advocacy, which, apart from many other things, is more cost efficient. Public service roles are much more expensive than community advocacy.

The Hon. COURTNEY HOUSSOS: That is an excellent point. I have one final question for you. You talked about the role of the position in government, that it needs to be quite senior, either within the Premier's department or a senior Minister?

Mr SIMPSON: Yes.

The Hon. COURTNEY HOUSSOS: I understand there is an inclusion unit within Family and Community Services [FACS]?

Mr SIMPSON: Yes.

The Hon. COURTNEY HOUSSOS: Have you had any interaction with that?

Mr SIMPSON: Yes.

The Hon. COURTNEY HOUSSOS: That has also informed your submission?

Mr SIMPSON: No insults to what is happening there, I mean their responsibility is for the disability inclusion planning system, which has existed in one form or another since the Disability Services Act 1993. Our overall strong view is that that kind of unit just does not have the oomph where it is a small part of a comparatively junior portfolio like FACS as opposed to being within a central agency.

The Hon. COURTNEY HOUSSOS: Mr Simpson, I note your use of the word "oomph" and I love it. I thought it existed solely in my family. Mr Mulholland, thank you very much for your submission and for coming along today.

Mr MULHOLLAND: You are welcome.

The Hon. COURTNEY HOUSSOS: You said that the NDIS has brought lots of stress and worry to you and your friends. Can you explain why?

Mr MULHOLLAND: I think when you get the NDIS—I was previously on State Government funding and there was too much red tape when you had the stress of the NDIS, there is too much red tape. The forms were very complicated, beyond my comprehension. A lot of us are numeracy and literacy underweight, we do not know how to read and write really well and it was hard for us. The forms were so complex they were beyond the comprehension of our understanding. It felt to us that the questions were not being reasonable. It was also hard because it was confusing. They made unnecessary things like they rang us with unnecessary phone calls. I had a phone call where the bloke asked me, "Can you stand up for five minutes?" I am like, "What type of question is this? Am I a little kid?" We feel like we are being led like little kids with the complicated forms.

We also feel like the system has put us down because what we got with previous funding is not being put in this funding. Also the local area coordinators [LACs], the local coordinators change their roles every so often and when we come to our reviews they do not make the same review, they make it more complex for us. But there is also one other issue I had with the NDIS that was very confusing—they did not tell me what I needed to know. I found out—it made me cry, very upset—and I said to David that I was at a meeting with my coordinator and I saw how much money I had in and they did not tell me what I needed to know. I felt like I could have used that and I lost it because what NDIS tell us is not what we need to know, they only tell us what they think we need to know.

By not telling us the whole story it made me and my friends feel confused and irritated. It felt like we were being led on a chain by the Government when they are supposed to be looking after people with disability. You know it is very nice that you are doing it but it is very stressful on me and my friends; it gave us headaches, pain and confusion. A lot of us do not know—the forms were so complex, they were not easy to read and then when they came back it was beyond my comprehension so I was like, "I am out of it. I cannot understand these forms they are too complex."

The Hon. COURTNEY HOUSSOS: Who helped you?

Mr MULHOLLAND: I had a support service, they helped me. They could only do part of it; I had to give examples. The questions were even beyond their comprehension, these were questions beyond the comprehension of people, normal people. These were questions that were not necessary to be asked so they were very confusing questions about what did we want to do with our lives when many of us have never been given the opportunity. It was about our opportunity and it did not feel like you were asking us the questions. It felt like you were demanding the questions be answered on the piece of paper as if we did not know what they were saying.

The Hon. COURTNEY HOUSSOS: Can you tell me about touch football?

Mr MULHOLLAND: Oh boy! That is actually one of my best things because the service I am with has a touch football and it is really good for the community engagement for people with disability, but it is also sad because I recently found out I could get State Government funding to do it but NDIS did not cover it so I had to spend all my money for my social club on that. That hurt me because I did not get to see my friends for three months because all the money I had saved in my funding to go out with my friends had been put on touch football. So that was community integration and that is sad because when you think about people with disability you do not think about what is community integration; it is about short-term gains for long-term pain. I call it "long-term pain" because every time we achieve something some obstacle is put in our way to achieve it and we get stressed.

Ms DAWN WALKER: Mr Mulholland, in your submission you spoke about the NDIS staff and some frustrations about their lack of training in dealing with people with a disability. Could you elaborate a little bit more on that?

Mr MULHOLLAND: I think the thing was that they did not have the proper understanding of people with disability and all disabilities. So they might be specialised in one disability but they are not specialised in another one. So where I was there was only one service and that was only specialised for one particular group with a disability, not other groups of people with intellectual disability. It is about having the training and understanding of disability, the understanding of the different types of things people have to go through. It is about knowing people with disability. I found the complex thing was that the staff also changed all the time so the person who was reviewing you once—this person reviews you this year, next year there will be someone else.

They know things about you but that person does not know anything about you so you are square with one and we do not what is going to happen. That is what stressed us out because that person can put a submission in but it may not be as important as the other submission. The LAC seem like they are changing staff like we change shoes. Every so often they are changing staff constantly and that is stressful because it stresses us out. The staff are not adequately trained for people with disability, they do not have the understanding of what we have gone through, they do not explain to us in easy terms. They do not put it in easy read, they put in complex words. It is all about staff training and awareness of disability.

Ms DAWN WALKER: Mr Simpson, you mentioned about the security of tenure in accommodation and I know the work your organisation does is important for those systemic issues. Can you elaborate on those systemic issues, including the tenure of accommodation?

Mr SIMPSON: Sure. As I think I mentioned, historically people did not have any written contract at all—no, I do not think I did mention this but people did not have any written contract at all about their accommodation rights, they were not tenants, but in practical terms there was an understanding that you had accommodation for as long as you needed it in, for example, an Ageing, Disability and Home Care [ADHC] group home.

The Hon. BRONNIE TAYLOR: An understanding but nothing formal, whereas now there is or there is not?

Mr SIMPSON: Sure. We have moved—

The Hon. BRONNIE TAYLOR: That is actually protection, is it not?

Mr SIMPSON: Well it could be an illusionary protection.

The Hon. BRONNIE TAYLOR: Butt it is legally binding as opposed to there not being something before, is that not correct?

Mr SIMPSON: That is correct.

The Hon. BRONNIE TAYLOR: I will let my colleague continue with her questions. I will get a turn later.

Ms DAWN WALKER: But there is an addition to that answer, is there not?

Mr SIMPSON: Yes, let me elaborate. You are right, there are obviously advantages to everybody in having things in black and white as long as it is fair. The difficulty is that we have gone from a virtually, invariably respected understanding that you have got security of tenure to a written contract that says you do not have security of tenure. The Government's first go at it said that you could be evicted for any reason on 90 days' notice or if your behaviour was problematic on 30 days' notice, irrespective of the fact that if your behaviour is problematic it may well be because you are not getting the right disability support.

The Government in response to our advocacy has insisted on some further protections for the first two years of the transfer of accommodation from ADHC to non- government agencies but is now consulting about legislation, which would go back to what I was saying before—eviction for any reason on 90 days' notice and eviction if your behaviour is problematic on 30 days' notice. Sure, moving to contracts is good as long as the contracts are fair. The suggestions we have made for how best to address this is to build into the statutory regime at least a starting assumption that this is your home for as long as you want and need it, as things have always been. Secondly, to have a robust role for the NSW Civil and Administrative Tribunal [NSW Civil and Administrative Tribunal] so that if there is a proposal to evict someone from their supported accommodation it would be in a robust, rights-protection-focused way adjudicated on by the NCAT.

The Hon. BRONNIE TAYLOR: That would go without saying though, would it not? Are you insinuating that people could come in now when they have a legal contract to reside in a premises and be kicked out without looking at the reasons and no help? Is that what you are saying?

Mr SIMPSON: Yes. I am not saying that—

The Hon. BRONNIE TAYLOR: Are you aware of that happening?

Mr SIMPSON: Certainly, historically, absolutely.

The Hon. BRONNIE TAYLOR: Would you be able to give us evidence of that as a follow-up?

Mr SIMPSON: I can certainly say that historically, and this goes back to the whole thing about the provider of last resort business, we have had regular reports over time from families in relation to their family member being told by a non-government organisation, "We can't meet your needs", so he or she has to leave. The Government has then filled the gap in relation to the provider of last resort and that has been the quite consistent historical situation. The danger now, of course, is that if we do not have a government system, where is that provider of last resort? We and others have been raising this issue with the NDIA since at least the start of the Hunter trial site. The NDIA's response has been very slow; they are now working on this issue of provider of last resort and we have had some input to that. I must say that the kind of ideas they have got are quite positive, but the current progress is quite glacial in pace. In the meantime the big problem is that the New South Wales Government has exited from service provision before there is some alternative system in place.

The Hon. SCOTT FARLOW: Mr Simpson, just to that point, you noted, I think, historically examples. Were any of those examples ever linked to the Hunter trial or since the NDIS has come online?

Mr SIMPSON: The Hunter trial is not a good example in this respect. In the Hunter trial people transitioned into the NDIS before ADHC started exiting from service provision. So it is only since the Hunter trial that people in the Hunter have been transferred out of that into non-government services. Anecdotally we have heard of people who have been exited more recently as well—for example, in the context of the Community Justice Program of ADHC.

The Hon. COURTNEY HOUSSOS: Can I just ask one follow-up question on that? You make an important point about the Hunter trial site and the ADHC services being there. Can you provide us with some feedback about whether that was a better setup in terms of the transition and that allowed a better utilisation of the NDIS with a safety net in place?

Mr SIMPSON: I think that is a complicated question. In respect of ensuring security of accommodation and support for people with complex behavioural needs, which is the real pointy end that we are focused on here, that was better. In other respects it may have just given a false picture of what was required in the trial if ADHC was sitting there when it was planning to ultimately exit. I think the big question here is whether—and we will not know, frankly, for some time with certainty, but the very reasonable fear is that the State Government exiting from service provision will mean that this issue of provider of last resort is not adequately filled into the future, with the result that people with disability, especially people with complex needs, will suffer and the State Government may well find itself meeting the cost of meeting their needs in the highly undesirable context of jails and psychiatric hospitals.

Mr MULHOLLAND: Can I just add one comment to what was just said? I have listened to what you have said. You have got to think about one thing with people with disability: A lot of them are not like you, not like us; they do not know about contracts. So why do you put a contract when they have no idea what a contract is? A contract to them is beyond their comprehension. I have friends that have severe disabilities; they do not know about contracts, so why are you putting contracts in place when they do not know what they are about? They do not know the rules, regulations. The staff are the ones who are responsible for them. It is about the staff making aware that if they have got behavioural problems to deal with it, help them. It feels like you are just chucking them out onto the street and not caring about them, and that is how it feels. You have got to remember a lot of us do not know about contracts. I only learnt about a contract when I had to sign a house contract. A lot of them, we have got to go down to their level and think about do they understand what a contract is? No, because they have never signed a contract because it is way beyond their comprehension.

Ms DAWN WALKER: I want to ask about a systemic issue with people with an intellectual disability, which is the jails. You just mentioned that. I wanted to give you an opportunity to maybe elaborate on that. We have heard other evidence that people with intellectual disabilities are finding themselves in jail due to the lack of the right disability support. Could you perhaps give us some information on that?

Mr SIMPSON: Sure. Late last year we conducted a roundtable on meeting complex behaviour support needs in the NDIS, and this is a report that is referred to in our submission. That was attended by the chair of the NDIA, senior people from State Government agencies, people from Disability Advocacy, professionals in the field et cetera. One of the issues that was looked at at an expert table was the issue of access to the NDIS and support for people who are in trouble with the justice system, and what emerged really clearly from that group of experts—and they were not just people from the community, they were people within government et cetera—was that people are currently being stuck in jail or are being at risk of being sent to jail for want of the disability support that they used to get under the old ADHC system.

On a more positive note, there are at least three things the Government is doing at present, which I applaud: first, they are conducting what is called the cognitive disability diversion program trial in two local courts. Secondly, the Attorney General recently announced $5 million recurrent funding to set up a justice support program to provide support for people with disability as victims or perpetrators of crime through the justice system and I would trust that that would include linking people into disability support if they needed it. Thirdly, the Community Justice Program, which is something that the Government has every right to be very proud of—governments of both sides of politics have had the right to be very proud of—is having provided support in the community for people with intellectual disability who otherwise would have been in jail. The NDIA is taking a narrower view of its role; the Government in the recent budget has announced funds to continue that program at least for the next two years. We wait to see the detail of that. But they are three positives that I would certainly applaud the Government for, but we are yet to see how those things play out. There are major problems to be addressed.

The Hon. SHAYNE MALLARD: Thank you for your submissions. Mr Mulholland, I wish everyone would give us a submission like your organisation. In your submission there is a lot of reference to red tape, and also in your verbal submission you talked about headaches with the red tape and paperwork. I think we all concur with that generally. But is that a transition problem, do you think, or do you think that is going to be a problem going forward?

Mr MULHOLLAND: It is both. What the problem is, the red tape is because a lot of them got State Government funding, but when NDIS came in they missed out on half their funding they got through State Government because it has been blocked because it has not been looked at as something to achieve. So the red tape is about blocking the system. The system that they got when they were in State Government—for example, being able to access the community—has been blocked by the NDIS because it has not been put under the NDIS. So there are too many loopholes. Obviously it is a transition program and unfortunately the transition to State from the Federal Government has been stressful because a lot of my friends are not able to access the community anymore; they are missing out on getting out in the community, being able to live their life.

Mr BRIGGS: There have been more restrictions on some of the pools of funding.

Mr MULHOLLAND: The restrictions are very sad. It feels like to us we have been kept on a chain. We do not like that because we want to be able to go into the community like everybody else. The community is part of our lives, but you are putting us behind because you are not giving us support. The reviews are becoming a nightmare. We do not understand why we need a review. The way we look at a review, sorry to say this, but this is how we look at it. The review is a way of getting rid of an amount from us saying, "Okay, you got this amount of money this year, next year we will give you this amount". It is a way of getting rid of things. We say the review should be done over time. So if things change after six months they should have a review but every year you should not have to have a review of the NDIS plan. It should just go, "Okay, is this working for you?" "Yes." "Anything new you want to add?" "Yes." Be more flexible. I know some of the issues were some people had areas where they wanted money put in one area but they could not use it for other areas. It was stuck there. It is the resource material.

The Hon. SHAYNE MALLARD: The NDIS staff, your group refers to them. Obviously they are getting training across the scope of their work as well. Are you finding it improving?

Mr MULHOLLAND: Assessments are hard because they are complex. The problem is the staff are changing at the NDIS, Every year they move staff from here to there. So it is like he was last year, I am this year, and he is next year. It is complex for them. It seems like the staff adequate training is not being done. I do not know what type of training they are getting but I think it is not there. I think the problem is they are not listening to everything the person is saying. They are only taking down what they need to take down. It is also listening to the person to see what they have achieved, but also see what they have done with themselves, what they want to get out of the NDIS. It is not about what do you want to give us, it is what do we want to get out of the NDIS. Freedom. A lot of my friends want the freedom to be able to move out of home, be able to live a life, be able to live in the community, and not have red tape.

The thing is it is also difficult because one of the biggest areas they done to red tape is transport. The cuts to transport training have been disgusting. Now some of my friends cannot even get out of home because they have no idea how to travel on trains, buses or ferries. They have not got mum or dad there. How are they supposed to get out? They cannot get out of their homes. A lot of the red tape is about the little things in life. To achieve a big goal there are certain steps you have got to go to to achieve a big goal and those steps are not being put there. You might have one step; I have NDIS funding. The next step might be they have not given me training. I have got a job and I want to go by myself but I cannot because the Government is not giving travel training funding. It is a loophole. Too many loopholes are being put in that are not being looked at.

The Hon. SHAYNE MALLARD: I think that has been very helpful for us. Mr Simpson, thank you for your submission. You bring a breadth and depth of experience to the Committee. It is a balanced presentation. You talk on page 8 of gaps in services and you give the Government credit for NSW Health having allocated $4.7 million a year for intellectual disability health services.

Mr SIMPSON: Yes.

The Hon. SHAYNE MALLARD: You are saying that NSW Health has identified a gap and has moved to fill it. Am I interpreting that correctly?

Mr SIMPSON: That is right. Two things have happened in parallel, we have been advocating towards and more recently working with NSW Health on the whole issue of health inequalities for people with intellectual disability for 15 to 20 years. The need to have specialist intellectual disability health teams to backup mainstream health professionals has been recognised by NSW Health and the recent budget initiative is very positive and one that flowed from a working party that we were fortunate enough to be on. That has filled some of the gaps in things that ADHC was previously doing for want of health doing it. There are still gaps remaining.

The Hon. SHAYNE MALLARD: It is good to see nearly $5 million in recurrent funding allocated to that area.

Mr SIMPSON: Absolutely.

The Hon. SHAYNE MALLARD: A quick response, it seems to me. Can you highlight some of the other gaps?

Mr SIMPSON: Probably the biggest one is in relation to mental health. ADHC used to fund regional psychiatry clinics. NSW Health recognises that issue and there is current consideration in relation to action there. I am fairly hopeful that something will happen there soon. My biggest concern is in relation to the network of nurses that ADHC had in each ADHC region. Disability support workers in places like group homes are not nurses in general, they are not medically trained. What that network of nurses did was resource group homes to make sure they were doing good health promotion linking people to the right health service.

While the $4.7 million will help there, there is a major gap at that disability service level which I fear will lead to further avoidable deaths. Strong New South Wales research last year, as the Committee is probably aware, showed 38 per cent of deaths of people with intellectual disability in New South Wales are potentially avoidable, twice the rate for the general community. And that flows clearly from both problems in the disability service system and the health system. That is probably a little longer than you wanted.

The Hon. SHAYNE MALLARD: The network of nurses you feel are needed to support the group homes?

Mr SIMPSON: Yes.

The Hon. SHAYNE MALLARD: They have gone out?

Mr SIMPSON: Yes. The $4.7 million will help to some degree there but there will still be a gap.

The Hon. BRONNIE TAYLOR: One quick question. I looked at your submission, which I cannot pull back up because of my IT skills. One of the things we have consistently heard is the time lag between being able to say there is an issue and having it resolved. Your submission is different to most things we have heard regarding contacting the NDIA to tell it about the issues they are having—that its response and ability to understand is really good but there is a time lag.

Mr MULHOLLAND: Yes.

The Hon. BRONNIE TAYLOR: You said in your submission that it was not easy to contact. Can you clarify?

Mr SIMPSON: Certainly, the fact that they operate on a call centre system, the size of growth of their staffing and therefore the quality of their staffing is very patchy, the ability to get on to the right person in the agency who can provide educated responses to a participant's questions is ongoing difficult.

The Hon. BRONNIE TAYLOR: It is quite different to what we have heard.

Mr SIMPSON: Okay.

The Hon. SCOTT FARLOW: Mr Mulholland, I can tell that when you are playing touch footy you do not like to play on the bench, because I can see you itching to answer each question.

Mr MULHOLLAND: Do not worry; I am sneaky.

The Hon. SCOTT FARLOW: One thing that has been a theme and that picks up on the Hon. Bronnie Taylor's point is that when it comes to the assessments, planning and local coordinators understanding intellectual disabilities, understanding psychosocial disabilities and understanding people on the autism spectrum seems to be a little more complicated than it may be with physical impairments. Do you think that is a fair assessment?

Mr MULHOLLAND: Yes, that is. The problem is that every disability is unique. We want to make it easy read material because we cannot easily read material. Pictures would work better because sometimes words, I still have difficulty reading words. It is hard. I sometimes say to people—I try to make it in my own way. Pictures and symbols work. It is not one size fits all for the application. If you made it one size fits all then you are not thinking about that person; you are only thinking about "Here is the application. This is a simple application" when it can be complex for them. They will not want to get support; they feel like they are being forced. It is about making it more accessible, more easy to read.

Mr BRIGGS: How long did it take you to get your assessment?

Mr MULHOLLAND: Sometimes it takes up to eight months to get the assessment back. Because the thing is we do not look disabled. This is a big issue. I will say this from a personal perspective: I have been knocked back on many applications. I was told by someone I do not have a disability because they do not look at us as disabled and that is where there is often a misinterpretation. We have to prove ourselves over and over again. I said to him, "Do you want me to get a brain scan of my head?" That is how we feel. We feel like our hair is going to fall out because we have to constantly prove ourselves. Every day we have to prove ourselves. The fact is that when we say we have a disability no door opens for us; the door locks on us, and every other person with a disability gets the door open—welcome. If you have not got a disability you wait in the queue. It is hard because we have a disability.

We do not all look disabled. Fifty per cent of people with an intellectual disability do not look disabled. You would be surprised. You go to watch my football team, you would be surprised who does not look disabled and who does look disabled. It is about making the form easier to read and more understandable. Also, the reviews have to be done by the same person who did it the year before, not change staff. The staffing changes are what stresses us out with the applications. When it comes back, it does not always come back in our easy to read terms. Also, one of the things that was raised by a friend of mine is, why do they call it an insurance scheme? We do not know what insurance is. Also, how do you explain to a person with a disability—it is a very interesting question I have been thinking about—how do you explain the money to them when they cannot see it but you can use it for this? How do you explain to them that it is not money that is seen, it is money that is hidden, it is not in their wallet?

The CHAIR: That is a very good point. I conclude with this question directed to Mr Simpson. This is a quote from a submission the Committee has received, and these numbers are probably familiar, they have been accounted for and commented on in other submissions. The quote is from the Mission Australia submission on page 8. The third last paragraph states:

> In NSW, the NDIS is expected to benefit up to 140,000 people with disability.

We have heard that figure on more than one occasion during these hearings.

> According to the ABS survey of Disability, Ageing and Carers 2015, there are over 1.3 million people with a reported disability in NSW—

This is another figure I am sure you are familiar with, it has been well commented on by others, and whilst I have not looked at that, it is presumed it is a broad definition of what having a disability means—

> … and close to, 450,000 people have a profound or severe core activity limitation.

I am still struggling to comprehend the gap. There are140,000 people who are coming into the scheme, and it is around 100,000 at present and we hear that will increase to 140,000, maybe 150,000. But we have this other group of 450,000 with a profound or severe core activity limitation, which is a subset of the 1.3 million. Taking the 450,000 for a moment, if they are not to be caught by the NDIS scheme because they are not entitled to be, what is the provision for their care, service and attention over time?

Mr SIMPSON: It is a very big and hard question.

The CHAIR: Am I missing something?

Mr SIMPSON: No, you are not.

The CHAIR: This is not reflecting on the Government or anyone else for that matter, but the people who set up the scheme obviously had the very best of the best in terms of being able to look at the numbers and yet there is this variance, which is gaping. I hope "gaping" is not an exaggeration.

Mr SIMPSON: The expression "oasis in the dessert" you have probably heard on the Committee during this inquiry?

The Hon. SCOTT FARLOW: I do not think so.

The CHAIR: We have heard it now.

The Hon. SCOTT FARLOW: You are the first.

Mr SIMPSON: The fear is that the 450,000, or 140,000, whatever it is in New South Wales who are participants in the NDIS, will be in an oasis surrounded by the rest of the 1.3 million out there in the desert.

The CHAIR: But nobody ever wanted that, surely.

Mr SIMPSON: No. So what the success of the NDIS is predicated on is for the rest of those 1.3 million, there being a wide range of community support, not the specialised kind of disability support that we are talking about for participants, but nonetheless a wide range of disability support, and that is partly through the information linkages and capacity building arms of the NDIS. But for the New South Wales Government's responsibility, it emphasises enormously that responsibility under the Disability Inclusion Act, under the National Disability Strategy, to make all State government services fully accessible to and responsive to the needs of people with disability.

To use our health advocacy just as one example, things like the very rushed nature of emergency wards, things like the very limited training and communication skills that doctors and other health professionals have in working with people with intellectual disability are just not good enough. New South Wales retains an enormous responsibility to ensure that its mainstream services, whether they are justice, health, education or transport, are responsive to people with disability so that we do not end up with that oasis in the desert.

The CHAIR: Thank you for your evidence this afternoon. It has been very strong and clear and has provided valuable supplementation to the information that came to us via your submissions. Thank you for the wonderful advocacy work that you do. The representation in advocacy work is important, not just to get us up to this point but for the ongoing work to be done to ensure that this achieves our intentions.

(The witnesses withdrew)

ELLEN SMALL, Policy Officer, Physical Disability Council of NSW, affirmed and examined

TONY JONES, Policy and Advocacy Manager, Spinal Cord Injuries Australia, affirmed and examined

GREG KILLEEN, Senior Policy and Advocacy Officer, Spinal Cord Injuries Australia, affirmed and examined

SERENA OVENS, Executive Officer, Physical Disability Council of NSW, on former affirmation

The CHAIR: I welcome witnesses from the Physical Disability Council of NSW and Spinal Cord Injuries Australia. I invite both organisations to make an opening statement. I confirm for the Physical Disability Council of NSW that your submission No. 191 has been received and processed and forms evidence to the inquiry. With respect to Spinal Cord Injuries Australia, your submission No. 296 has been received and is on the inquiry's website and forms evidence to this inquiry. You do not need to go into your opening statements in detail; we can take both submissions as read. Set up the scene and once you have completed your opening statements we will share the questions between the Committee members.

Ms SMALL: Thank you for inviting the Physical Disability Council of NSW [PDCN] to provide evidence to this inquiry. PDCN is the New South Wales peak organisation for people with physical disabilities and our core work is systemic advocacy, education and the provision of information, ensuring people with physical disabilities can become full members of the New South Wales community. Our evidence today is directly informed by the emerging and urgent issues experienced by our members and service users, all of whom are people with a disability. Overall, PDCN is highly supportive of the National Disability Insurance Scheme [NDIS] and its aims. However, in reference to its success in providing choice and control in the initial rollout period in New South Wales, PDCN would suggest that the inconsistency in the quantity of NDIS plans and issues faced by NDIS participants when implementing their initial plans would indicate that this has been an incredibly varied experience.

For instance, a PDCN board member received funding through his first NDIS plan for both home modifications and assistive technology. Previously, he had been required to self-fund items and also rely on informal supports to achieve some tasks around his home. In stark contrast to this experience, we have another stakeholder who received a plan that significantly reduced his continence aid funding, leaving him unable to pay for more than one-third of his yearly catheter requirements. In addition, all of his transport allowance was removed. As a person with spina bifida who had significant balance issues, this meant severely restricting his ability to get around in the community as he was then unable to pay for much-needed taxi transport.

As illustrated in our report, PDCN is also gravely concerned about the gaps occurring for people with disability and their families in the transition from State to NDIS services, particularly for those previously receiving Community Care Supports Program [CCSP] funding who are now ineligible for funding under the NDIS. Again in the case of another stakeholder, the loss of home care services meant that his health deteriorated greatly. He was unable to remain at home and was hospitalised at a significant cost to the New South Wales government. In addition, the closure of the Department of Ageing, Disability and Home Care [ADHC] has resulted in a lack of options for people with complex support needs or challenging behaviours. ADHC previously provided wraparound services, including case management, housing and crisis support.

PDCN is concerned that private service providers will be apprehensive or choose to not take on challenging clients due to the costs involved and that this may leave individuals with complex care and support needs without appropriate services and without a provider of last resort. Currently NDIS pricing arrangements, which are based on direct hours of support, impact on the ability of disability support workers to deliver services which are personalised and responsive to individual needs. In many cases, service providers cannot provide staff training and development, ongoing supervision, and care coordination due to having inadequate hours funded for this purpose. The NDIS has also seen a greater casualisation of the disability workforce in order to meet the demand for flexible services. We feel this has created safety and service issues for service providers and people with disability.

Finally, PDCN is a member of the New South Wales Disability Advocacy Alliance, which spoke to this inquiry earlier today. We would like to raise the issue of continued funding for disability advocacy services. As a systemic advocacy organisation, a majority of PDCN's work falls outside the remit of the NDIS and is about creating system changes to support all people with disability, so making the New South Wales community more inclusive and accessible. PDCN sits on over 25 advisory committees and in conjunction with written submissions and consultations ensures issues are identified and addressed on a larger scale than would be possible with individual advocacy or at times by an individual alone. The New South Wales Government has an obligation to its people. Without continued State funding of independent advocacy and peak bodies, those with disability would be far worse off. Finally, we support the issues that will be highlighted by our colleagues Greg Killeen and Tony Jones from Spinal Cord Injuries Australia [SCIA].

The CHAIR: Thank you. That is a detailed and comprehensive opening statement.

Mr JONES: Thank you for the opportunity to give evidence. I should say at the outset that while Greg and I both work in disability advocacy, we are also both participants in the NDIS scheme. In SCIA's submission to this inquiry we raised two issues: continuing confusion, contradiction and service gaps emerging across the health and disability interface; and the removal by the New South Wales Government of vital funding of disability services for advocacy and information. This accounts for 50 per cent of all of SCIA's grants. Like other organisations addressing this Committee, the permanent removal of such funding will have a profound effect on our ability to operate as we currently do. It also concerns SCIA greatly of continuing NDIA administration problems.

There have been some improvements with the recent reforms in the participant pathway. Positively, I have personal experience of this, having had a fairly smooth entry into the NDIS with my first and second plans. There continues to be much frustration in seeking feedback or consultation, or advice for that matter, when clear errors emerge in a participant's plan. Firstly, it is very difficult to be able to communicate to the right NDIS staff member, whether it is planners, branch managers or otherwise. By comparison to the funding models that existed under the Department of Ageing, Disability and Home Care with phone numbers and addresses listed by regions, the NDIA has no such information. There must be a reason behind why the NDIS does not list phone numbers for local officers or even some office addresses.

With regard to plan implementation, there is still significant under-utilisation with a total of 48 per cent of participants having utilised less than 50 per cent of their funding allocation. Errors persist in not acknowledging the wishes of participants and how they want their funding to be managed—agency, plan managed or self-managed. Even when reviews are successful with changes in funding allocations, the resulting new plan errs in not reinstating how the plan and funding is to be managed, much to the frustration of the participant. With assisted technology, we still see plans of participants with significant assisted technology requirements for vital equipment such as wheelchairs, hoists, commodes and expensive pressure mattresses containing no funding for repairs and maintenance.

As I am sure Committee members are aware, getting any significant changes to participant plans can be a long, drawn-out process following the formal review pathways such as an internal review and then if that is not successful, external reviews through the Administrative Appeals Tribunal. This can take months before getting any outcome. The NDIA, it would appear, is at capacity with undertaking unscheduled reviews, as the recent Commonwealth Ombudsman report showed, and the Administrative Appeals Tribunal is struggling with its NDIS workload leading to delays in outcomes. SCIA would like to see the time factors of the review process significantly improved.

During the first public hearing into this inquiry, Committee member Shayne Mallard put a question to New South Wales government secretaries about the fate of some people with disability who were previously receiving disability support from the New South Wales Government who were not eligible for the NDIS. Secretary Coutts-Trotter made the point that some of those were supported to test their eligibility with the NDIS. This would have been specifically for those recipients of the Community Care Support Program. Other than a letter they would have received stating that their funding would be ceasing and that they must now apply to the NDIS, I do not know what other support was provided by the department. And many of those did literally fall through the gaps.

For whatever reason, FACS did not pass on their details to the NDIS national access team to test their eligibility, as has been the process and experience of others in receipt of New South Wales Government disability programs. Nor were they told that there is a provision in section 21 of the National Disability Insurance Scheme Act which states that a person meets the access criteria if the chief executive officer is satisfied that the person was receiving supports at the time of considering the request, as prescribed in the NDIS rules. In those NDIS New South Wales participant rules, it lists 44 prescribed State government programs and six Commonwealth programs. CCSP is one of those programs. The SCIA has been assisting some of those clients through the AAT, all of which have had their original decision that they did not meet the access criteria overturned through appeal. In no case had they been previously told about this possible pathway. It is only through contacting us or another advocacy organisation that they have this knowledge that they were able to get changes made through the AAT.

No doubt there would be some CCSP recipients, having applied to the NDIS and been knocked back because they do not meet the disability criteria, who would most certainly now have no access to any services because they had no knowledge or support through the review mechanisms to test the full provisions of the National Disability Insurance Scheme Act. With the examples above, generally speaking, you might have someone with a disability previously receiving supports and had them removed because they are either isolated or lacking any support structures or perhaps simply did not make contact with an advocacy organisation then they are most certainly not getting supports they might be entitled to.

The CHAIR: Thank you, Mr Jones, it was a very considered and thoughtful contribution which will stimulate questions from Committee members.

The Hon. COURTNEY HOUSSOS: You both have an incredible amount of valuable knowledge that you have shared with the Committee, and I cannot say thank you enough. I want to touch on something referred to in the submission of the SCI and touching on your final point, Mr Jones, which was that individual participants are forced to battle with the NDIS—those were your words—so we are seeing very different outcomes for individuals and there is no guarantee that someone will receive a fair hearing from the NDIA or a fair service, which I find mind boggling. We have the situation where the health department and the NDIA are also battling it out and it becomes a buck-passing exercise between two levels of government instead of working out the best outcome for the individual. Do you agree with that characterisation?

Mr JONES: Yes. I just think there has not been any consistency. For example, we have assisted someone in the Hunter region who received their first plan. They were in hospital at the time, came back home, ended up getting a pressure injury and went to community health to get some support. They were then told that because they are now a NDIS participant that they were not really entitled to community health and that they should be seeking those supports through their NDIS plan. It was eventually agreed by community health that they would provide some wound management but at the same time they utilised their NDIS for regular catheter changes.

Some time down the track they had to go back to community health again for wound management and they had the same resistance and push-back by community health. In place now are called transitional leads in all the local health districts whose role, as far as I understand it, is to work through some of these issues and that can make a bit of difference. Participants' experience in dealing with the agency around getting support for the areas that you might have used community health for in the past is not always consistent with the funding. Some people will get it for catheters and some do not.

The Hon. BRONNIE TAYLOR: In the past if a person had a pressure sore, they would ring the community nurse and they would come and sort it out. Because the community health service is not a NDIS provider now they cannot access that service?

Mr JONES: Community health is saying that because you actually have a plan that you are meant to be utilising a private service provider for that funding. I think the expectation was when the NDIS rolled out, whether it is through community health, because it did lose some funding when the NDIS rolled out, or whether that aspect had gone into the agency or gone into the funding of the NDIS because I know community health were a service provider of CCSP—

The Hon. BRONNIE TAYLOR: That is right.

Mr JONES: I think there has been some confusion around that. We have actually met with NSW Health on this particular issue and it has acknowledged this is an issue, as has the agency. It seems to come down to the applied principles and the interpretations of the applied principles. As anyone will know, when it comes to complex disability it is not always a black and white issue.

Mr KILLEEN: Can I clarify something?

The CHAIR: Yes.

Mr KILLEEN: The technical issue we have here is that NDIS is to fund disability supports, supports that are specific to deal with your disability. People with quadriplegia manage their bladders often with catheters. The NDIS will fund continence consumables, including the catheters. Health is saying that the changing of that is disability maintenance, which is what we would argue the case. NDIS is saying that its interpretation, in some areas, is it is a chronic health condition, it is a health issue. That is the crux of the argument: Health is saying it is a disability, NDIS is saying it is chronic health—depending on where you are, who you are, where you live, the area health and your circumstances. If you are fully aware that you need to get funding for a catheter change through your NDIS package or plan, you would be asking for that in your original application and subsequent review. If you do not know to ask for it because you actually do not know you are about to be knocked back from your longstanding community health services when you go for your original interview if it is not in your plan, if it is not as your goals, if it is not in your services, you do not get NDIS funding.

The Hon. BRONNIE TAYLOR: Surely that needs to be fed back to the NDIA and sorted out. To supply you with the physicality of your equipment and your catheters and not the person who is probably doing your catheter change for 10 years is not right. Surely the advocate can advocate that the NDIA sorts that out.

Mr JONES: We have met with the agency on this particular issue and they have recognised it as a problem. There is apparently a senior working group that is dealing with this issue but we have not get any further feedback.

The Hon. COURTNEY HOUSSOS: Just to get an idea, how long has this been an issue?

Mr KILLEEN: Since the word go.

Mr JONES: More than 12 months.

Mr KILLEEN: The NDIS has been going five years.

The Hon. COURTNEY HOUSSOS: They have a senior working group. This is a clear, very basic problem that needs to be resolved, as the Hon. Bronnie Taylor outlined.

Mr KILLEEN: Choice and control. That is all we hear: choice and control.

Mr JONES: Clearly someone is paying for it. Whether or not it is cost shifting, or who knows what the issue is.

The Hon. BRONNIE TAYLOR: I certainly hope people are having their catheter changes.

Mr KILLEEN: The participant should have choice, whether they choose to have Health do it or they get funding in their plan to have some private nurse do it.

The Hon. BRONNIE TAYLOR: But the people who do the plan should make sure that is in there because you are not going to have a catheter without a regular catheter change, are you?

Mr KILLEEN: The people who do the plans have got absolutely no idea about disability.

Ms OVENS: I think that is part of the issue.

The Hon. BRONNIE TAYLOR: That is something we can fix.

Ms OVENS: It is something we can fix and I hope we do so quickly. Certainly from the instigation of the NDIS and the rollout in New South Wales, of which we are obviously one of the first, this is where we have seen very varied experiences from people who have good knowledge of disability to people who have no knowledge of disability who have stepped into a role.

The Hon. BRONNIE TAYLOR: It is a new process and things are going to happen, but that is fixable.

Ms OVENS: It is fixable and it should not take months of calls and months of toing and froing when someone needs a catheter change that day, then and there.

The Hon. COURTNEY HOUSSOS: Catheters is a specific issue. Insulin injections is another one.

Mr JONES: Insulin is a huge can of worms.

The CHAIR: Please explain.

Mr JONES: I have firsthand experience of this because I have type 1 diabetes, but I can administer my own insulin. Ideally, when someone gets a funding package, you really want to be able to utilise your own carers to provide that insulin administration because it offers a sense of continuity of care. But in many respects service providers do not feel confident around this whole issue. It is a grey area in that the policy around whether or not a support worker is able to actually administer insulin is an issue of itself. The agency itself is reluctant to want to fund nursing support for that because of the cost. But not only that, from the point of view of the participant getting access to a registered nurse at the times that you need insulin administration is very difficult. It is a very difficult issue.

The Hon. COURTNEY HOUSSOS: And the same goes obviously for oxygen tanks. That is a life-and-death issue. You need an oxygen tank, but whether it is a chronic health issue—

Mr JONES: That is still provided through Health.

The Hon. COURTNEY HOUSSOS: I am using these as examples of teething problems that are being faced on a daily basis. Instead of having a clear and consistent policy across the board for individuals or transitional leads, it is being dealt with piece by piece instead of with a clear and consistent set of guidelines.

Mr JONES: Just to give you one last example on this whole issue, our organisation has an emergency and after-hours service for the Randwick and Botany municipalities and we have a registered nurse available for those areas. Up until the rollout of the NDIS, it was funded by ADHC. When the NDIS rolled out, that funding was removed and so we started charging participants in those areas. Unfortunately, not everyone has been able to get funding for those areas because the NDIS is saying it is a health issue. But ironically the funding came from ADHC prior to the NDIS rolling out. Clearly, these issues need to be worked through.

The CHAIR: The word "demarcation" comes to mind.

Ms OVENS: "Intersection" would be better.

The CHAIR: Ms Small, in your opening statement you made a comment about the likelihood of significant costs or ongoing costs for the New South Wales Government in disability services. Could elucidate on what you mean by that?

Ms SMALL: That was in relation to what Mr Jones also said about individuals who previously were receiving low level disability supports through the Community Care and Supports Program [CCSP] provided by ADHC. Many of them are no longer eligible for the NDIS or they have not actually gone through and tested their eligibility for the NDIS. Now that they are not receiving services we have had numerous individuals who we know of who have ended up in hospital.

The CHAIR: Without using names of individuals, could you give a couple of examples of conditions that would be illustrative of your point? Sorry to put you on the spot, but just help us to understand what we are talking about.

Ms OVENS: We have one gentleman who has psychosocial disabilities and some physical issues and cannot necessarily care for himself at home who has had help with meal preparation and with self-care. It is low level but it is keeping him at home. Unfortunately, when his CCSP package was removed and he was not considered eligible for the NDIS he lost those supports and was trying to do those things by himself. He was unable to maintain his health and was then hospitalised because of the gap, so to speak, that has since happened because of the transfer of ADHC services.

The Hon. BRONNIE TAYLOR: Sorry, what was he unable to maintain?

Ms OVENS: His ability to stay in his home and his health and he has ended up in hospital.

The Hon. BRONNIE TAYLOR: But what happened? Did a service just stop coming?

Mr JONES: Yes, essentially that is what happened.

Ms SMALL: Yes, he lost his services.

The CHAIR: Is that gentleman still in hospital as far as we know or is he out of hospital?

Ms OVENS: He was in hospital for a fair amount of time. I am unaware at this exact point in time where he is.

The CHAIR: Would he pass through emergency into a ward in a hospital?

Ms OVENS: And hold a bed. We have had people in hospitals for months whether or not because of CCSP or other services where they are held until such time. Some of them might be eligible for plans and yet have not had a plan administered or prepared and they are held until such time as they can get their plan instigated, get the funding and then find services to get them back into the home and be supported. We have another situation which is a person who has recently had a major stroke and needs significant services. He has become and is deemed eligible for the NDIS but he is actually sitting in aged care services at the moment. It is the only place capable of taking him until such time as that plan can be fully prepared. He can then find services and supports that will allow him to go back into his own home and transition back out. We are talking about two months that I know of now that he has sat in an aged care facility completely inappropriately amongst people with dementia whilst he waits to get the services and supports he needs to transition to his own home.

The CHAIR: Waiting for the consideration of his plan and the assessment and all of that.

Ms OVENS: Correct. There are a number of things. There is the plan itself to be approved, there is the services to be approved along with that and then there is the support coordinator to be put in place to then assist him finding services that will then allow him to move on. He has never had services before, he has never had a disability before. He has now got a significant disability. Those things can take months. Yet in that time, whilst he is sitting in an aged care facility, he is not getting the true rehabilitation that he needs as well to ensure that we can very speedily operate and bring back as much as we can of his physical ability after the stroke whilst he sits in that scenario. It is that sort of mid-ground where you are in suspension waiting for things to happen.

The Hon. COURTNEY HOUSSOS: How old is he?

Ms OVENS: He is in his early fifties with two young children that he cares for.

The Hon. BRONNIE TAYLOR: I imagine he would have been in hospital for quite some time too, which is why he had to be transferred to where he was before he could go home.

Ms OVENS: Correct, because in order to get him out of the hospital bed he needed to go to somewhere. He was not able to go directly to home.

The Hon. SHAYNE MALLARD: Mr Jones, in your very detailed opening submission it seemed to me that there was an issue around a lack of communication about the ability to appeal if you are refused NDIS funding. Is that what you were saying to us with regard to the process?

Mr JONES: Yes. My understanding is that for anyone in receipt of New South Wales government funding, we were under the impression that once there was a removal of those services, that Family and Community Services would be passing on details to the NDIS, the national access team, and then the national access team would make contact with those individuals for them to either make an application or be able to speak with the NDIS around their eligibility but there seems to have been quite a lot of people who were not contacted so they had to just make an application off their own bat. I know from the agency's perspective, it thought of this as just an administration error, so, yes, I do not know.

The Hon. SHAYNE MALLARD: What recommendation would you like to see around that?

Mr JONES: I think anyone who was in receipt of services should have been contacted around the change and particularly given some information around what to do with making an access request and a discussion around eligibility, what those eligibility requirements are and where to get assistance if you needed some help with an advocacy organisation.

The Hon. SHAYNE MALLARD: And appeal rights, from what you were saying?

Mr JONES: Yes, absolutely.

The Hon. SHAYNE MALLARD: Now that is historical; the transition is now well underway. Is that a problem we still need to address or have we got past that hump?

Mr JONES: We have still got people making access requests who are not meeting the access request and who are not really aware of the appeals process.

Ms OVENS: Can I add to that?

The CHAIR: Please do.

Ms OVENS: In June there were more than 600 people from the Community Care Support Program who had not come forward or been able to be contacted where the Government was trying to do so. That is the big issue; the fact that many of these people are very isolated, particularly in the CCSP area where we see a high percentage of those people with psychosocial disability. They are not often interested in dealing with people they do not know. They often isolate themselves, so just getting a letter that might tell them that transferring is going to happen is not enough; we need to ensure that we continue to try to work with whomever might be used to supporting them to ensure that they get that contact and that they are aware, as Mr Jones said, that they have the right to access the NDIS, and if they are not considered eligible, that there are steps and processes in place. These are the things in retrospect and still that we are struggling to see happen as people in that particular program do not engage.

The Hon. SHAYNE MALLARD: I understand it would be a very difficult cohort but their current funding from the State or the services they were getting would have stopped so they would certainly be confronted, even if they were isolated, with the fact that there would be no more support, would they not?

Ms OVENS: Unfortunately it does not mean that they come forward and request anything. It may mean they just drop off the list and it happens quite a lot.

The CHAIR: Thank you very much. The evidence has been very informative and added very nicely to submissions, so thank you very much. This material provides excellent firsthand insights into the matters for consideration in our terms of reference. Once again I thank you for coming along.

Mr KILLEEN: Could I make a comment?

The CHAIR: Yes, please.

Mr KILLEEN: It is in regard to the reviews about the NDIS and the impact on State-funded disability support services. We have been talking a lot about the potential impact on the non-continuation of funding for New South Wales advocacy services. The advocacy service funding also has information service funding and there are information services out there that are essential for people with disability to be able to access timely and appropriate information for their needs to utilise the NDIS services. So when they want to get their plan, they want to then use their funding for social inclusion to enhance their economic participation, they need to get information from somewhere.

Organisations like Spinal Cord Injuries Australia, which is in its fifty-first year, has been running an information service and has years of built-up resources. It has a library and knowledge; it provides information for people specifically with spinal cord injury and similar physical injuries. If that funding stops, all that knowledge and information, if it is not funded elsewhere—and you cannot get funding in your plan to access information—will simply be lost. It is crucial that the State Government continues to fund, and increases the funding, for not only the advocacy but information services and resources because it will just be lost otherwise and that will be a shame, and shame on the Government for actually defunding such services.

The CHAIR: Thank you for that excellent point. It is very appropriate to make a point about the provision of information.

Mr JONES: Have we got time for one last comment?

The CHAIR: You, Mr Jones, can make one final comment, yes.

Mr JONES: In the earlier group of witnesses you make mention of the significant number of people who would fall outside eligibility of the NDIS. One group we are concerned about is those aged over 65 who are newly injured and have a catastrophic injury, whether it is a spinal cord injury or an acquired brain injury [ABI]. They are now having to deal with My Aged Care but it is limited in what it provides. The highest level of funding you will get is a level 4 home care package, which roughly equates to around $50,000. Now if you end up with a high-level spinal cord injury, that is just not going to cut it and so that falls heavily on families.

Just one aspect of this is that as far as I am aware now those people over the age of 65 are entitled to what is called seed funding—specialised equipment essential for discharge. The New South Wales Government, through EnableNSW, will give them the funding for all wheelchairs, hoists and all of that equipment but it does not include ongoing maintenance of that equipment. Now if all you have got is a $50,000 My Aged Care package, that is meant to include all of your equipment needs and for maintenance of that. If Enable just changed that policy where it also included ongoing maintenance of that equipment, that would make a significant difference to those people. It is worth considering.

The CHAIR: That is a valid point you make. Thank you for that; it is very clear. Thank you again and thank you for your wonderful advocacy and representation on behalf of your constituents. We will take this information away and use it in our deliberations, report and recommendations.

(The witnesses withdrew)

GRAHAM VIMPANI, Senior Staff Specialist, Hunter New England Health, affirmed and examined

JACQUELINE SMALL, Royal Australasian College of Physicians, affirmed and examined

IMELDA TODD, Industry Adviser, Occupational Therapy Australia, sworn and examined

KIM BULKELEY, Industry Adviser, Occupational Therapy Australia, sworn and examined

The CHAIR: The Committee has received the submission of Occupational Therapy Australia, submission No. 290, and the submission of the Royal Australasian College of Physicians, submission No. 160. Both submissions have been formally received by the Committee and they appear on the website for this inquiry. They will be considered as evidence in this inquiry. It is not necessary to go through those submissions in detail but if you set the scene in your opening statement it will provide the maximum opportunity for the Committee to share questions around about those submissions and the matters raised in your opening statements. We will start with an opening statement on behalf of Occupational Therapy Australia.

Dr BULKELEY: Thank you for the opportunity to appear before the Committee today. Occupational Therapy Australia [OTA] is the professional association and peak representative body for occupational therapists in Australia. As of June 2018 there were 5,700 registered occupational therapists working in New South Wales. OTA is a strong supporter of the NDIS with the focus on providing individualised support for participants, underpinned by informed choice and control of their plans and funding. Occupational therapists contributed to the design and implementation of the scheme during trial phases and continue to support the transition to full rollout.

Occupational therapists work with people with a disability, their families and others to maximum outcomes in their life, including daily living, social and community participation, work learning and relationships. We recognise the opportunities that the NDIS presents, particularly for consumers who have much more say over the supports they receive, as well as for small business owners of private and not-for-profit therapy services. However, our members are acutely aware of ongoing problems with the rollout of the NDIS in New South Wales.

The effectiveness and appropriateness of NDIS plans is highly dependent on a planner's experience and understanding of an individual participants needs. Unfortunately, our members report that many planners lack such experience. The increases in failure of first plans is a huge drain on NDIS resource and results in unacceptable delays. The shift away from the New South Wales assistive technology scheme, EnableNSW, has resulted in considerable disruption to the provision of equipment to NDIS participants. This is an area where occupational therapists are heavily involved. They are receiving inconsistent advice about processes and do not receive direct or timely feedback about their assistive technology applications from the NDIA. People who do not meet the criteria for the NDIS but were previously in receipt of services are also of grave concern—the previous presenters talked about this. We have heard of instances where people relied on support with domestic tasks, shopping and accessing social activities but they no longer receive this support due to an ineligibility. The needs of these people must be recognised and addressed.

Our members have indicated that there is inadequate regulation of some product suppliers and therapists have observed significant increases in the price of products quoted by some suppliers since the rollout of the NDIS. Occupational therapy is a registered health profession with an obligation to observe a code of ethics, standards, guidelines and scope of practice. Despite this proven commitment to clinical excellence, the NDIA is requiring additional layers of regulation. The administrative burden and financial costs associated with this provider verification is placing such pressure on small private practices that some occupational therapists are leaving the disability sector, when in fact the sector requires an expansion of allied health providers.

There are emerging shortages in the occupational therapy workforce, particularly in rural and remote areas of New South Wales. This has impacted on the accessibility of early intervention supports for children particularly and OTA notes that timely access has become increasingly difficult with long wait times as the workforce fails to keep pace with the growing demand. This increased demand has led private practices to recruit more staff, resulting in the employment of new graduates who require training and upskilling in this specialised area of practice.

We are hearing that too often inexperienced providers are working without adequate support and supervision. The privatisation of Ageing, Disability and Home Care [ADHC] has had significant consequences for occupational therapy service delivery in New South Wales. This has particularly impacted new graduates as there is no clear replacement for the role ADHC took in employing new graduates, resourcing and supporting practice development, student placement initiatives and continuous quality improvement. New pricing arrangements for provider travel are also impacting the supply of occupational therapy services, especially in rural areas, with providers reviewing the reach of their service delivery footprint because of these limitations.

We welcome the opportunity to work with the New South Wales Government to facilitate the implementation of the NDIS to achieve the best outcomes for the citizens of New South Wales who are impacted by disability. We recognise the complexity and applaud the aspirations of this important public policy initiative. However, we seek action from government to address the areas of concerns we have raised in our submission. Thank you for your time.

Dr SMALL: Although I know the Committee has received well over 200 or 300 submissions predominantly from individuals, I think due to the centrality of the voice of experience of people with disability and their families I would like to start and end with a quote. It should be reminded that I am a paediatrician, so I often refer to families and children, but we do reflect that the needs are across the life span, as I also highlight. One family spoke to a colleague of mine and said, "We moved back to Australia because we thought the system would be more helpful than in Italy, but we made the wrong decision. I should have stayed with my family and the therapy systems there." This was a father of a young boy with autism and global developmental delay who remained on an early childhood early intervention waitlist.

The Royal Australasian College of Physicians welcomes this opportunity to appear and give evidence before the Committee today. Our college represents over 17,000 fellows and 7,500 trainees across over 30 specialties in Australia and New Zealand. These include rehabilitation medicine physicians, who have a particular interest in physical disability and acquired brain injury, and developmental paediatricians, who have a strong interest in promoting the health and wellbeing of NDIS participants. But I would like to add that I am sure that most of our members would have intersection and support the needs of people with disability in one way or another at one time in their career.

Today I speak to you on behalf of the RACP, but I practise in New South Wales as a developmental paediatrician and have worked in disability for over 20 years and have extensive connections within the disability sector. The RACP has contributed physician and paediatrician perspectives and expertise at various stages of the rollout across Australia, although we would dearly love to have a much greater influence in that early planning, and has produced valuable online guides for medical specialists about the NDIS to support our members. The RACP strongly supports the NDIS and its underlying values and principles, including individual autonomy, non-discrimination of full, effective participation and inclusion in society. We also recognise that the rollout of the NDIS has led to other sectors reflecting on their own roles in the life of people with developmental disabilities, and that certainly is the case in the health sector as well where people with disability have a shortened life span of 25 years compared to the general public.

We consulted extensively in developing our recommendations, which I will not go through, but I will highlight some areas of particular concern, and stress, as you have heard from the previous speakers and from my colleagues here to the right, that this reflects not only the needs of children but adults with physical disabilities and other types of disabilities as well. There are problems, as I think you have already heard from other speakers, in relation to access. We are seeing a substantial increase in demand for comprehensive assessments that are expensive and time-consuming but valuable none the less, but there is an increased demand with the rollout of the NDIS, extensive demands for long documentations, repeatedly filling in questionnaires, writing more reports, and these are resulting in lengthy delays for the person to access the NDIS before they can access any of the services or start the whole process, and this is seen not only within the early childhood years but also with my rehabilitation colleagues.

There are problems with planning, as I know you have heard from other speakers, in that the highly variable plans and funding are provided that do not match the needs of the person. This is particularly the case where there is challenging behaviour where the line item is rarely used, even for children with complex and severe challenging behaviour, where their violence can risk harm to other people. Allied health therapy provision for adults with physical disability is often absent, and you have just heard about catheters that a colleague of mine was clear for you to be aware of. There are challenges for particular groups: adults with disability requiring therapy, as I have mentioned; children with severe challenging behaviour are often poorly supported by the NDIS; families with complex needs, particularly those who are more socially isolated and come from a different language background have added vulnerabilities in their contact with the NDIS; and those children who require intervention, such as children with autism spectrum disorder who are progressively being excluded if they are perceived to have mild needs that do not require specific support.

There are some specific health issues. Swallowing assessments were previously undertaken by specialist speech pathologists within the disability sector, but now I have been informed that this responsibility is being transferred to health without the expertise or transfer of funding. Swallowing problems can create significant health problems for people with developmental disability. If they have discoordinated swallowing it can lead to pneumonia and even death; so it is a very significant issue. There is a lack of coordination and communication across the sectors the like I have never seen before in my 20 years of working in this area. This is resulting in higher stress and professional challenges for many of my colleagues as we endeavour to provide the support and collaboration with other sectors that we believe that these children and families absolutely require, but are frustrated in our attempts to do so.

We believe that the way that the NDIS is being rolled out is contributing to inequity for children with developmental disabilities. We already know that a significant component of their outcomes is due to the additive socio-economic disadvantage that children with disability experience. As I mentioned to you, my adult colleagues are particularly concerned, particularly those in rehabilitation—you have already heard that there are lengthy and increasing delays in people who are in hospital getting the funds and support they need in order to be discharged; there are issues around transport; and people are not being accepted into the NDIS despite very significant impairment if they have physical disabilities due to a variety of health problems. In conclusion, I would like to also quote from another parent who has said to a colleague of mine, "So there's nothing. I can't see community health anymore. I don't have money". She was discussing her worries about the loss of services while waiting for the ECEI. Thank you.

The CHAIR: Thank you, Doctor. I think you have set the scene. If that does not invite questions I do not know what will. They were both very good opening statements and there is much detail in there that we will try and work our way through in the next 20 minutes or so. We will commence with the Hon. Courtney Houssos.

The Hon. COURTNEY HOUSSOS: Thank you very much to both of you. Those anecdotes make it very compelling for us. Obviously we are hearing this stuff all the time, but those kinds of examples really highlight for us that the promise of the NDIS is not being delivered on the ground. With that as the starting point, and, Dr Small, it is very fortuitous that you are a paediatrician; I think I might tap into some of that knowledge as well. I noted in your submission that you said that ECIA NSW/ACT estimates that by 2019-20 there are likely to be 9,037 to 12,065 children with delays in New South Wales that are not likely to receive an individualised funding support package under the NDIS but still require some degree of support from other government systems and the community. My first question is: How are they going to be accessed and what is in place at the moment?

Dr SMALL: The bottom line is I think it is unclear how these children are going to be supported. We have seen, particularly around children with autism, that the NDIS has recently flagged or denied that they are planning to introduce greater restrictions, but I think that they always foreshadowed that they would not support all the children who are diagnosed with a significant developmental delay or disability, and I think it is really challenging to know what to do with those children. It is very important that children are supported in the mainstream sectors, but that is usually not enough for children with additive needs, particularly in the early years where we know time is crucial; you can lose time and lose opportunities for future development. Can I just invite my colleague Graham Vimpani as a paediatrician to make some other comments?

Professor VIMPANI: The only clinical work I do now is two clinics for children who are in out-of-home care, foster care or kinship care in Tamworth and Inverell. The difficulty that I experience is actually pre-NDIS—the ability to get diagnostic assessments that will support my clinical diagnosis. That is because of the shortage particularly of psychologists in rural areas. If I want to get a child accepted by the NDIS they have got to be level 2 autism spectrum, and to get a psychological assessment in Inverell you need to be lucky enough to get into Royal Far West at Manly or to go to Queensland because there are no psychologists with training in the ADOS, the Autism Diagnostic Observation Schedule, in either Armidale or Inverell. You have to go much further afield to get that. If they do not get a level two they are not likely to be accepted by the NDIS. That is a very important issue, is the lack of services in rural areas to support kids with disability.

The Hon. COURTNEY HOUSSOS: What you are requiring there is a diagnosis in order to access support. That is not supposed to be the premise of the NDIS. It is supposed to be as needed, not on the basis of a diagnosis. That is not happening in practice.

Dr BULKELEY: Could I make a comment. There are the two streams around early childhood intervention. There is the individual funding stream and that is around a higher eligibility and assessment criteria level and then there is the early childhood early intervention [ECEI] path that is more open. But in that early childhood early intervention path there is not the full range of supports that perhaps some of the children that have a range of difficulties might need. There is some supports that do not require the assessment level but there are others that do.

The Hon. COURTNEY HOUSSOS: We heard this morning, similar to the first anecdote that Dr Small gave us, that children are on the early intervention wait lists for 12 months, which is the window that they require the support within. So parents are required to pay for it themselves with the hope of recouping it at a future point or are left languishing on a wait list, which is clearly unacceptable.

Dr SMALL: That is not a passive period of time. That is a time when parents are using every effort, going to every effort they can make in order to get the support they need for their child, which is an additive stress, and we know stress can be toxic. Comprehensive diagnostic assessments can be very valuable, I do not understate that. But when I started in this field a letter from a good general paediatrician documenting the general delay was sufficient to initiate access to an early intervention sector. We have transformed what is required to access support for a very young child through a process that was meant to do the opposite. I am seeing families come back to me for another diagnosis to again sign-off in a way that never happened before. The NDIS has introduced additive requirements that never existed before.

The Hon. COURTNEY HOUSSOS: That is valuable feedback. I note in the OT Australia submission it talked about the bureaucracy from the practitioner perspective but we have heard a lot of feedback of bureaucracy from a participant perspective. That is a great example of where previously there was a lower requirement for entry to care. I would be interested to hear from OT Australia as well. Some of the reports or diagnoses required can be onerous and very expensive. We heard this as well particularly for children with autism. I would be interested in both your perspectives on that.

Ms TODD: I think particularly for parents having to go to pay for reports privately, which are sometimes up to $1,000 each, can be very expensive and that is not the way the system was meant to work. You were not meant to have to prove in order to get access to it. That puts people at certain disadvantage, not only in terms of finding someone to do the assessment but the financial one.

Dr BULKELEY: The other aspect of this is workforce. The waiting times for the childhood early intervention services are not about assessment and eligibility because that is a much more soft entry point but that is about workforce and not having the capacity growing at the rate at which it is needed when the other services have been taken away and are no longer receive funding. That is about the implementation lag where these services have not been able to upscale. That is especially so in rural and remote areas. I do quite a lot of research in western New South Wales, in north west areas such as Brewarrina, Bourke, Lightning Ridge. There are services out there and the ECEI providers were only announced in June and July this year and the others were unfunded from 30 June this year. So that transition has been incredibly difficult and it has meant that a lot of people are in a really difficult situation with having no ongoing funding to provide support but they do not want to walk away from clients and responsibilities.

The Hon. COURTNEY HOUSSOS: Workers are left in the position that they are taking the burden of the service provision or acting as advocates on behalf of participants.

Dr BULKELEY: I have had workers describe it as grieving about not being able to provide support to families they have known for some years in an early intervention service and now they have to say, "I cannot see you any more."

The Hon. COURTNEY HOUSSOS: Dr Small and Professor Vimpani, are you hearing any reports of pressure for specific diagnosis because if you have level two autism you are more likely to receive support than ADHD, or the like. Is there any pressure on practitioners to receive that diagnosis?

Dr SMALL: There is an expectation that we want to help children and we want children to get the support they need. One of the major difficulties with the levels for autism is that the Diagnostic and Statistical Manual of Mental Disorders [DSM-5] from which they arise specifically states that the levels should not be used. We are being forced into a position of using professional terminology in a way that was not intended and for which we know there is little evidence around what that really means. Even using autism levels, according to the DSM, is very challenging in itself. That has come into practice only because of the NDIS. DSM-5 provides the criteria for autism. The latest edition, the fifth edition, introduced the concept of levels in order to recognise the different functional abilities, that children with autism do not have a single type or degree of deficits. But, they were not intended to be used in the way the NDIS has directed them to be used.

The Hon. SCOTT FARLOW: This is largely directed at Dr Small and Professor Vimpani. We have heard a little today in terms of health provided care, you outlined some of those challenges yourself when it came to swallowing and things provided under the NDIS. I am trying to work out the real impact of that on the ground. For instance, the issue of swallowing and that being treated under the health bucket rather than the NDIS bucket, what is the impact? Are the services not being provided or is it a funding disputes behind the scenes?

Dr SMALL: I think it is probably a combination. In addition, there will be skills. That skill set previously existed in the disability sector and we are yet to see the full impact. Some of the people that require specialised support have had an assessment and a plan in place to support them. We will continue to see the impact grow over time. There is an issue about funding and there is an issue about skill set and delivering the service. If health was not in the position of delivering the service they might not actually realise that now the disability sector is expecting them to deliver it. There are a range of other concerns in the health sector as well, not just with swallowing.

I am sure you are well aware from the ADHC budget there were funds for a range of services that stretched into health services. It also funded professorial positions at the developmental disability department at the University of New South Wales and these were funded in order to improve the health and wellbeing of people with developmental disabilities and all of that funding has been lost as well. We are still seeing the impact of that loss of funding in the health sector. There is widespread impact. The reality for individuals is that they could be hospitalised more, they could have serious illnesses and they could die because their needs are not being met.

Dr BULKELEY: I have worked in the disability sector in early intervention as an occupational therapist with a lot of children who had swallowing issues. I was thrilled to see the change in the lives of the young children because they got the appropriate support. We used to think that children with a disability all had to be really skinny and small and we realised that they were actually malnourished and not getting the food they needed. We treated that and managed that with an interdisciplinary team: speech pathology, our colleagues in medicine, physiotherapists and occupational therapists around positioning. This happened in an everyday way in the person's home. The child did not go into hospital, get treated for that swallowing condition, and then was fixed and went home. This is an integral part of their disability that needs to be managed in an ongoing way. In my view it is clearly in the remit of the NDIS to support and manage that, and maintain the skills in the workforce that can support people with swallowing issues who have a disability in their home and in their community.

Dr SMALL: I agree with that very much as an interdisciplinary practice. I would also add, a psychologist working with challenging behaviour, particularly around mealtimes. But my advice is that the NDIS has directed that they are not the funder or provider of these services any more.

The Hon. SCOTT FARLOW: With respect to the diagnosis issue and the challenges that exist in being able to have the diagnosis, largely to qualify for an NDIS package, when it comes to the practical impact of that, is the largest problem the wait time to be able to get the diagnosis? Or is there something more significant in the challenge in being able to get that diagnosis, that it may not become evident at an early point or the like?

Dr SMALL: The immediate impact is lengthier delays, but in some areas the services are not available for a comprehensive assessment, and I think it is particularly a challenge in rural areas. Particularly a delay is the main impact, but we do not know how long that delay is, and then the additive consequences. It is worth conceptualising the needs of children with disability—and again, forgive me for talking about children, I am a paediatrician—but there may be a primary biological underlying factor, such as a genetic abnormality or some other factor leading to the disability. But there are secondary and tertiary impacts if the child does not get the support they need. They can have lifelong impacts as well. Early intervention can reduce or eliminate some of those additional disabilities that accrue because they have not built up some of those earlier skills. Some of that is not necessarily reversible.

The Hon. SCOTT FARLOW: I am trying to understand how much of this is an issue now with the introduction of the NDIS, and how much existed prior to its introduction. Are these issues that you would face regularly prior to the introduction of the NDIS?

Dr SMALL: There were not enough services before and it was not perfect. I do not think we have gone from a perfect system to an imperfect system. But there have been problems that have been introduced that we did not experience before. It was possible to work collaboratively across sectors, and I still work very closely with some of my colleagues in education, and we are both really desperate and despairing because we have lost the capacity to collaborate with the disability sector in any sustained way. We have lost the leadership of the disability sector. I know that Ageing, Disability and Home Care [ADHC] had a very important role in the health sector, a very influential role in the health sector, but at a cross-government level we have lost that. We have lost some of the leadership that they brought in policy and practice development that you have heard. There are some things that the NDIS has introduced that were not present before. There is a new and growing demand for assessments and reassessments to meet eligibility criteria that are beyond what is appropriate from a clinical perspective.

The Hon. SCOTT FARLOW: Occupational Therapy Australia's submission outlined that for some clients, particularly proactive clients were mentioned, the NDIS has its benefits as well. I imagine you have two cohorts, those that are on top of their management, are able to maximise the benefits of the NDIS, and those who are not able to do that and perhaps are falling through the cracks in the system. Would that be a fair assessment from your perspective?

Ms TODD: Yes, I think that would definitely be a fair assessment of that. Those people who have the ability, or have a nominee that has the ability to work the system tend to be much better off, that is correct.

The Hon. SCOTT FARLOW: We have heard some of that evidence as well as the inquiry has progressed, with some people who are well able to manage their own cases finding lots of benefits, and those who are more challenged in that respect have unfortunately not been able to get the benefit of the NDIS at this stage.

Ms TODD: That is correct.

Dr SMALL: Can I just reinforce, that is a really major concern because it is entrenching and extending the disadvantage that children with disability experience. The loss of other parts of the sector that we used to fund—I am sure you heard from the NSW Council for Intellectual Disability [CID] this morning that there has been a loss of funding for advocacy services that might go some way to address the inequity. There has been loss of funding for group-based services, such as parenting programs, for which there is a strong evidence base. We have lost some of these, or are losing some of those programs that we have had before that are effective.

Ms TODD: I would second that. Most of my practice is in western and south-western Sydney, and yes, there is some real disadvantage there with those people managing their plans.

Dr BULKELEY: The other point, to follow on from Dr Small's comments around some of the things that we have lost, ADHC was not perfect but they held a role with support and development of not only government disability service providers but also non-government disability service providers, and there is no-one who has stepped into that role. So that, for example, I would often be called as I work in the university now, and new graduates will call me up and say, "I have got a job in the disability sector, Kim. How can I learn about this?" And I would refer them to the ADHC core skills website where there were a number of practice guides and current information that had been developed by the ADHC therapists around starting work in this area. Those have been pulled off the website now that ADHC no longer exists and those sorts of resources are not available for people who are entering the sector. And we want more people to enter this sector, we have a shortage. That responsibility has just fallen away and those resources were tremendous and really well utilised by people.

The Hon. BRONNIE TAYLOR: Surely we could find where those resources were and have them restored. If they were prepared and on the site, surely we could find where they were and give them to the main providers. If there were new graduates in those roles, I imagine that would be pretty scary, going in and dealing with really complex situations and a very complex scheme.

Dr BULKELEY: Yes, absolutely.

The Hon. BRONNIE TAYLOR: Could we access those? Has anyone advocated to do that?

Dr BULKELEY: I have been trying to chase up access to some of those things. Some have been maintained on the Family and Community Services [FACS] website, a small number of them, but the majority have not. The issue is around updating and currency of the materials, because things do change fairly rapidly and I think that is the primary concern of FACS with keeping things on a website—

The Hon. BRONNIE TAYLOR: It is not that they are not there any more, it is that they are not updated?

Dr BULKELEY: They are not there because of that. But they were still being used up unto 30 June. I had a lot of therapists still accessing them and using them, and then they went.

The Hon. BRONNIE TAYLOR: As the head of occupational therapists, would you have that sort of information on your peak body website, about the latest and the greatest and the best ways to do things, or not?

Dr BULKELEY: Disability is one of many areas of practice in occupational therapy and we certainly are looking at developing practice guides, but because ADHC had developed these very specific and comprehensive resources, that was their core business.

The Hon. BRONNIE TAYLOR: I guess they are not there because NDIS is, so I wonder how we can look at making sure that we get those resources up and running again?

Dr BULKELEY: Also, a lot of the organisations now do not have a remit to look at that kind of resource development across organisations, they are just looking in-house. They are not then necessarily made available across the sector.

The Hon. SCOTT FARLOW: They are not open source, effectively.

Dr BULKELEY: No.

The CHAIR: I have a final question—and I am sure my colleagues are tired of hearing the same question and the same numbers. The NDIS in New South Wales has nearly 100,000 participants in the scheme, scaling up to about 140,000 in round numbers, which is generally the figure used. We have juxtaposed against that the Australian Bureau of Statistics definition of disability. Specifically the Survey of Disability, Ageing and Carers 2015 numbers indicate that there are more than 1.3 million people with a reported disability in New South Wales, and specifically close to 450,000 people have a profound or severe core activity limitation—obviously a medical term. I am perplexed that we are shooting for the 140,000, but we have this huge variation, not just up to those that fall within the 450,000 cohort but beyond that. Am I missing something here? There is a swathe of people out there—beyond 140,000—that have a disability in one form or another, some of them quite severe, who do not appear to be eligible to a plan under the NDIS. What is going to happen to those people?

Dr SMALL: I think there are many aspects of concern that are arising from the rollout from the early experience of the scheme. I share your concerns that there are some fundamental aspects about how the scheme was designed that raise concerns and that require a careful rethink. One core issue is about how it was funded and what the expectations were. A person-centred scheme would deliver supports to the people who need it, not a number of people who are determined to be needing supports. That is one of the significant flaws in the design of the program. Another is that it is entrenched, a dislocation from other providers and other professionals who want to work with and support the child.

The CHAIR: Can you say that again?

Dr SMALL: It is entrenched, a dislocation and a disconnect between other sectors that want to work with and support the needs of that person. The issue you highlighted is a core concern that many of us share. We want to see people who need support receive the support they need.

The CHAIR: Thank you very much. It is very sobering testimony. Once again, I appreciate you coming along this afternoon and making yourselves available to speak to your submissions but also for allowing us to push and probe about some specific details.

(The witnesses withdrew)

TROY WRIGHT, Assistant General Secretary, Public Service Association and Community and Public Sector Union, affirmed and examined

NAOMI FRASER, Respite Client Liaison Officer, Department of Ageing Disability and Home Care, affirmed and examined

SHELLEY ODEWAHN, Student Access and Inclusion Project Officer, Southern Cross University, affirmed and sworn

NATALIE LANG, Branch Secretary, Australian Services Union, sworn and examined

NED LAMBLEY, Disability Support Worker, Hunter Region, Australian Services Union, affirmed and examined

DENNIS RAVLICH, Manager, Member, Industrial Services Team, NSW Nurses and Midwives' Association, sworn and examined

MARC HOPKINS, Senior Professional Officer, NSW Nurses and Midwives' Association, affirmed and examined

NOLA SCILINATO, Organiser, NSW Nurses and Midwives' Association, affirmed and examined

The CHAIR: I commence by thanking our extensive panel this afternoon. I apologise for the size of this panel. There is no disrespect. It is the final day of the inquiry's formal public hearings and we wanted to ensure we are able to accommodate everyone. Please do not take it as a reflection on the importance of the evidence you have provided by submission. I formally acknowledge the receipt of your respective submissions. Submission number 209 is the submission from the NSW Nurses and Midwives' Association in conjunction with the Australian Nursing and Midwifery Association. Submission number 343 is from the Public Services Union of Australia and the Community and Public Sector Union New South Wales, and submission number 304 is from the Australian Services Union, New South Wales and Australian Capital Territory services branch.

Those submissions have been received and processed through the Committee secretariat. They stand as evidence to the inquiry. They are to be found on the web page for the inquiry and we will be drawing on the material within those as we work towards developing our report and recommendations. I will get each organisation to make an opening statement, if you wish to do so. You do not need to draw down in detail what is in your submission, because you can take it as read. Set the scene and once we have worked through the three organisations we will start with questions.

Mr WRIGHT: The association would firstly like to sincerely thank the Committee for the opportunity both to make a written submission and appear before it today. We recognise the overwhelming volume of responses it has received and appreciate the chance to be among those chosen to make further representations. With me today are two of our members and delegates who we believe may be able to best assist the Committee in its inquiries. To my left is Naomi Fraser who is an employee of ADHC until 1 November 2018 when, to borrow a term from our comrades at the federation, she will be industrially conscripted to the private sector.

Not only does Ms Fraser have direct experience to share on the process of privatisation as an employee, but also she is highly knowledgeable in the area of respite services and the impact the implementation of the NDIS in New South Wales has had upon the families that rely upon them. To her left is Ms Shelley Odewahn, a Student Access and Inclusion Project Officer at Southern Cross University in Lismore. Ms Odewahn is amply qualified to comment on the implementation of the ND1S from the assessment and case planning perspective, and particularly from the context of regional New South Wales.

The issues confronting the Committee in the course of this inquiry are intimidating in both terms of sheer numbers and complexity. Our submission alone traverses many of the terms of reference of the inquiry, including relevantly for our members, the industrial ramifications of the forced transfer of ADHC employees to the private sector and the consequent issue of workforce sustainability. But perhaps unusually for a union, today we would like to concentrate our attention on an issue of public policy, that being the provision of a public sector safety net of service provision. The issues regarding the design and operation of the NDIS are but one part of the Committee's inquiry, and to some extent, the problems that arise there are beyond the control of the State Government alone. What we know already, however. is that any concerns that have arisen through the introduction of the NDIS have been exacerbated by the New South Wales Government's additional decision to cease any level of direct service provision in its own right.

The O'Farrell New South Wales Government, when negotiating the NDIS with the Federal Government, obtained a condition in the heads of agreement that no other State or Territory was granted; that there be no residual service provision by the State, effectively meaning that all public sector services which were within the responsibility of ADHC were to be privatised. Representatives of both the government and the department have repeatedly claimed this was a decision made because of the introduction of the NDIS. The experience and position of other States and Territories shows this to be untrue and to claim so is misleading. It was a voluntary abrogation of responsibility, leaving the provision of most basic and essential services for the most vulnerable people in society to the whims of market forces.

The provision of social services for those in the community who rely on them must be the core business of this building and those within it. Whilst differing views may be held as to how this responsibility is approached, what is clear is that the abandonment of public sector service delivery by the State, as is being done in the disability sector, is a unique experiment. Our health sector, our education sector and our child protection sector, for example, all rely on a mix of government and non-government service delivery. A total privatisation of any of these fields would be considered outrageous. Yet somehow it has been decided that this is an efficient and appropriate model for disability services.

From the announcement of this proposal up until its implementation, the association repeatedly raised concerns with any interest group that would listen that this was a proposal doomed to fail. Without a public sector safety net providing services to those beyond the capacity of the private sector, the association predicted people would land in other, less appropriate services such as the State's hospitals, its aged care system, its child protection agencies and even corrections. To consider it in the crudest terms, effectively the cost to the State Government of providing services to people with a disability will be transferred from a specialised agency such as ADHC to less appropriate services and sectors.

Our submission includes numerous examples of this occurring already, only 12 months after implementation. Rather than being a proposal doomed to fail, sadly it is already a policy decision that is failing and will continue to fail without dramatic intervention. Our submission is not ideological rather it contains many case studies and examples of the current system's shortcomings as provided by our members both within ADHC and outside it. I would, however, like to highlight to the Committee the example of one young woman who is literally before the Committee today.

In the public gallery is Ms Kym Flowers, a 34-year-old woman who has cerebral palsy, and her parents Lee and Penny. Ms Flowers has been a resident of a non-government supported accommodation service up until this year. Her diabetes recently worsened and she now requires insulin treatment five times a day. On account of her disability Ms Flowers is unable to administer this treatment herself, and as it must be supported then by a registered nurse. As such she is beyond the capacity of her non-government service provider. Ms Flowers is currently passed between NSW Health and the NDIA who respectively claim that her needs are either a disability or a health issue. In the meantime with no government-operated accommodation available in her area, and no comprehensive wrap around case management service of the kind that ADHC previously provided Ms Flowers has now been a resident of Sutherland Hospital for more than six months.

Our calls for the re-establishment of a public sector safety net in our submission are not new. Nor is this position any longer isolated, it has been supported by other stakeholders before you including regulatory bodies, non-government service providers, and parents and carers themselves. But we recognise our calls in our submission for the re-establishment of, and investment in, public sector service provision as a safety net would require brave decision-making beyond politics. We hope that our submission and the material that we bring before you today emboldens the Committee to make that step.

Ms LANG: I thank the Committee for the opportunity to appear before it today. I have with me Ned Lambley who is an Australian Services Union [ASU] New South Wales and Australian Capital Territory Branch Executive Member and a frontline disability support worker in the Hunter region. Ned has worked in a variety of roles in the NDIS. He has worked in the sector prior to the NDIS, during the pilots and since the full roll-out holding a variety of roles, including as a support worker and a team leader.

In New South Wales ASU members have a long and proud history in the provision of disability services through non-government organisations [NG0s]. This decades' long service provision has been in the areas of advocacy, employment, social and recreational support, children's services, independent living and residential care. In the historic equal pay case won by ASU community and disability members in 2012, the Fair Work Commission found that these workers employed by NGOs were doing the same job as public service workers engaged in community and disability jobs. They found that it was not the skills, qualifications, competencies or responsibilities that differed just the pay. The basis of the Equal Remuneration Order, arising from this case, is that community and disability workers employed by NGOs will be paid the same as public service workers because they do the same job.

ASU members were actively involved with people with disability, family, carers and advocates in the campaign for the national disability insurance scheme [NDIS]. As advocates, carers and support workers ASU members strongly support the right of people with disability to have control and choice in the supports and services they access for daily living. Non-government organisations providing disability services is not a recent phenomenon in New South Wales, prior to the NDIS being rolled out NGOs were providing 60 per cent of disability services in this State. ASU members want to make sure the NDIS is the best it can be. However, the NDIS desperately needs a strategy to deal with workforce development, training and job quality.

This strategy must ensure the following: that wages and working conditions are attractive enough to recruit and retain the tens of thousands of new workers required as the NDIS rolls out; that work in the NDIS provides for good secure jobs with regular working hours and predictable income for workers; that career paths in the sector are developed so workers can see a positive, long-term future working in this field; and, finally, that there is a systematic strategy for ongoing training and professional development of the workforce so the diverse needs and aspirations of people with a disability can be supported

I would like to focus on the final part of that: the need for a strategy to support ongoing training and acquiring of new skills and qualifications for the workforce under the NDIS. Disability sector workers are highly skilled and passionate about what they do, but their capacity to have their skills recognised, to develop new skills and to retain relevant, person-centred qualifications is severely limited. Continuing professional development, in-house training and induction, and access to study leave for formal qualifications is now rarely provided for in the sector. As the sector has become more competitive, access to these supports has been diminished as providers drive to reduce costs.

To address this concern, we commissioned the Australia Institute's Centre for the Future of Work to develop a detailed and costed proposal for a national portable training entitlement system for NDIS workers. This would involve each NDIS worker accruing credits as they work in the NDIS to use for ongoing professional development to acquire new skills and qualifications over their career that is relevant to best practice, contemporary disability support work.

It would cover the course costs, release costs and backfill. If funded by State and Federal governments combined, it would cost less than just one cent for every dollar of NDIS funding. We are proposing that it be contained in a separate fund administered by the NDIS Quality and Safeguards Commission so that participants' packages are not affected. I would like to note that the Federal Parliament's Joint Standing Committee on the National Disability Insurance Scheme recently released a bipartisan report backing the ASU's proposal. I would be happy to take your questions on it today and on any other aspect of workforce needs under the NDIS. Again, I would like to thank you for the opportunity to appear before you today.

Mr RAVLICH: On behalf of the association and the federation we welcome this inquiry and the opportunity to provide evidence to the Committee today. We believe the inquiry is timely as it occurs at a moment when we can actually reflect upon some lived experience of the rollout of the NDIS in New South Wales. Just reiterating, in New South Wales our membership includes nurses, enrolled nurses and assistants in nursing working in either the government or non-government sector, State or Federal. So in that sense, we are agnostic. To be clear, the association has and continues to support the NDIS but it must not simply read well on paper. It must be implemented in a way to provide tangible superior benefits to people with disability.

Disappointingly, as reflected in our submission and in many others received by the Committee, problems are being encountered in converting a most worthy concept and legislative framework to a practical and effective day-to-day scheme that truly delivers independence, choice and control to people with disability. Unless its implementation and approach is truly centred on people with disability and sufficiently resourced to provide timely and adequate services and support, the productivity to the community, along with the individual dignity it was meant to liberate, will not be realised.

Unfortunately, in New South Wales this struggle was compounded by the decision of the New South Wales Government to use the rollout of the NDIS to vacate the field entirely as a provider of disability and accommodation services. To be clear, that is a decision that the association and our members have rejected from the day it was announced. That is not because the NGO sector has no role to play. We recognise in this State that approximately 60 per cent of such services have been provided by the NGO sector. But the converse is equally true and cannot be ignored. Some 40 per cent of such services were provided by the New South Wales government. This equated to approximately 1,000 nursing positions alone being employed by FACS to provide the support and complex care required. That was no accident, in our view. Government services were required for those with profound disabilities or complex comorbidities and were provided via a clinical framework of care incorporated within FACS services, which included collaborative networks with the public health system which some of the previous speakers before the Committee were speaking about.

The withdrawal of government-operated services reduced choice, which seems to be the very antithesis of the NDIS philosophy. It removed the option completely to continue to have one's needs met by FACS. It has created a situation whereby current models of care being provided in an integrated way to those in the New South Wales community with complex health care and disability support needs are being eroded and lost. As a result of this decision, the New South Wales Government then proceeded to manage the transfer of services and lives in a very paternalistic fashion. It effectively determined by way of tender on behalf of people with disability living in FACS group homes who their new group home provider would be and who would be their new service provider—commitments made on their behalf to last for two years. In the view of the association and its members, there must be a reliable and accountable government sector option for people with disability: not just an option of last resort. For many it is the option of first resort due to their complex and multiple needs.

Concerns that the clinical care models may not be maintained following transfer resulted in the New South Wales Government—as set out in our submission—applying or feeling compelled to apply a service continuity obligation so that the model of care utilised by FACS for the 12 months immediately prior to transfer would by and large need to be retained for two years post transfer by the NGO provider. That is great in theory but, as with other commitments, it has been almost impossible to police and enforce by people with disability, their families, workers or their representatives.

The transfer of FACS services, assets and staff to NGOs along with commitments about care or employment arrangements will not likely be dealt with by organisations established to oversight the NDIS such as the NDIS Quality and Safeguards Commission. Those aspects of how the NDIS is being implemented in New South Wales require heightened accountability and transparency—and this Committee is beginning that process—but it must be underpinned by some independent New South Wales system established to be able to audit and review the New South Wales-centric aspects associated with the NDIS rollout.

The Hon. COURTNEY HOUSSOS: Thank you to all of the unions not only for your submissions but also for your opening statements. I think they really highlight so many of the public policy issues. I think as the PSA noted, usually you are here advocating for workers but in this situation it is remarkable that across the board the same issues are being identified by so many stakeholders. I appreciate that workers are often the ones who are seeing this being rolled out and have that firsthand experience. With that in mind, I will first ask a question about workers. I would be interested to hear from each of the different unions about it.

We have heard lots about the job opportunities that should flow from the rollout of the NDIS and the growth that should be occurring but what we have actually seen—and, to be fair, it is in a range of submissions—is that there is a more casualised workforce under the guise of being more flexible in its approach. I would like each of you to provide me with a bit of feedback about how that is impacting on your members and if you have any solutions for us.

Mr WRIGHT: Thank you for the question. The majority of our members experiencing the transition or the privatisation to the NGO sector are employees of group homes. So they were 24/7 shift workers. What they are experiencing in their work is an increased focus on cost-related items as opposed to non-cost related items. There is a shift about what can be charged for and what cannot be charged for. Fortunately for us, our State award was quite rigid and we did a fair bit of work in the Industrial Relations Commission before the transition occurred to try to lock in issues such as rostering and rostering principles. I will give you an example. In ADHC homes, in part at least due to the complexity of many of the residents in ADHC homes, we had waking sleepover shifts. We had staff awake 24/7 who were able to check on the residents and provide care. Many of the NGOs and their award does not contain that; they are sleepover shifts and you are allowed to sleep. So there are minor tweaks at the moment. That is partially because in the transition their conditions were locked in for two years.

I have to admit as a union we are having to do a hell of a lot of work in all sorts of agencies. Given that ADHC is broken into 17 parts now with approximately 10 different providers, we are doing a hell of a lot of work enforcing those conditions in the award. That is not just about our members and their working rights and conditions, it is more about their concerns about professionalism and the care and responsibility of their work. There are minor tweaks at the moment. We are not sure what happens after the two-year transition periods occurs, but we are adamant that the models that went across with ADHC need to be maintained for residents' safety and security.

Ms LANG: Certainly our members worked in the NGO sectors prior to the introduction of the NDIS during the pilots and the rollout. Mr Lambley will shortly talk to you about his personal experience. Our members are increasingly reporting a lack of secure work. That is workers who have worked with the same employer prior to the NDIS and since. We are seeing a pattern of shifting the risk and pushing it further down onto the direct worker—so the risk of what if somebody cancels a service and trying to minimise contractual obligations to workers. What that means is we are increasingly seeing workers who are forced to work for multiple employers and even perhaps as a sole trader to supplement their income simply to have some predictability of a pattern of work and an amount of income to be able to live by.

We are really at a loss as to why anyone would be driven to take such a low road when the NDIS, as you rightly said in your question, did have such a promise of job opportunities and I think it really does still have those opportunities to provide good, valuable, secure jobs but, in particular, career paths and that is why I thank you, in your question, for asking for possible solutions. That is why, based on our members' experience, we commissioned the Australian Institute to do that report into putting together a proposal for portable training entitlement.

The NDIS is built on a principle that NDIS participants are not an homogenous group. We are individuals with individual aspirations, desires and needs for support. However, we are treating the workforce like an homogenous group and as long as we do that we simply will not have the breadth or the depth of skills to match the NDIS promise of participants being able to exercise choice and control to meet their own goals and aspirations. Imagine if we invested in building career paths that allowed for specialisation. The will of the workforce is very much there. Disability support workers are crying out for opportunities to pursue areas of their interest that do match the needs and desires of the participants that they support.

A worker spoke to me with the person that they were supporting, a young woman in the NDIS, about the need for menstrual support as an area of specialisation; that in 2018 in Australia we do still have instances of women with intellectual disability being forcibly sterilised essentially and that is a massive human rights breach. Imagine how we could overcome that by having a support worker base where we have specialists in menstrual support who could, at the earliest possibility, be putting in place appropriate supports and plans for that particular NDIS participant. There are so many other areas that would be very fulfilling careers and very valuable supports in an NDIS environment, such as the experience of women with intellectual disability who have some of the most outrageous rates of sexual and family violence perpetrated against them.

We have incredible workers in the family violence sector, also members of our union, and bringing together those areas of specialisation with the specialisation of disability support work would be incredibly meaningful and fulfilling in an NDIS environment. There are so many other areas and I am sure the Committee has heard a lot about the gaps in areas of service delivery but those actually present opportunities for incredible career paths and great supports around community mental health and specialist supports for children with autism, as we heard from previous witnesses.

The workforce is absolutely willing and desirous of having those good, strong careers and the NDIS is very capable of providing them, provided that we have an investment by government, at all government levels. That means we need the Federal and State governments to get onboard and jointly invest in a portable training entitlement. That means with the workers receiving and accruing that entitlement, regardless of where they are working, we can overcome some of the challenges of this insecure work we are seeing while building strong career paths that will allow people like Mr Lambley to want to build a career and stay in the sector.

Mr LAMBLEY: My experience has been a fairly lengthy one from a couple of different perspectives. I have worked in a management role prior to the NDIS rollout, during the rollout and then following on from it. There is a lot more casualisation because, as has already been touched upon, there is that push to minimise the risk. For myself, my first job in the industry was a permanent job, coming in with no experience. The job that I applied for, that was what I was offered. That was over 10 years ago. From there my second job was a full-time position and I then worked full time right up until after the NDIS was rolled out.

I recently came back from overseas and on re-entering the job market I have taken two casual positions because there is no permanent work available. When I was working in a management role, we did recruitment and there is certainly enormous potential for jobs. There are a lot of jobs out there. It has never been hard to get a job in this industry. There have never been more people wanting to do this work than was available. Now there is nowhere near the number of people required who are interested in doing the work. People like myself who have experience and have built up their skills, we are now looking to leave the industry because we need a permanent job. I want to buy a house and I cannot do that doing this sort of work.

When I first started as a manager we used to go through a recruitment process. We would hire people who had the right skills, the right experience and the right temperament and personality to match with our clients. As things progressed, we got to the point where we would hire anybody who applied for the job, anybody who is willing to do the work, and we would put them with any client, just to fill gaps in the roster. We did not have the luxury of picking the right person for the job. We just need people who were willing to do it. Thank you.

Mr RAVLICH: I think that the observation that staff are told that they will be in a powerful negotiating or bargaining position because of the demand for positions is one that Family and Community Services [FACS] sought to use to reassure their staff prior to transfer but the reality is or at least the reality thus far is that for our members they are essentially either transferred employees who are covered by the copied State award for at least the minimum period of two years or those providers are using the Nurses Award from the Federal system, which is the basic safety net.

It is little wonder then that some of these providers are running into significant attraction and retention issues already trying to attract and retain competently qualified and skilled nurses in the disability space. It is little wonder because when you look at the difference between the copied State award and the Nurses Award, for example—and I just use these to demonstrate the differences that are currently at play in the marketplace—the top rate for a nursing assistant, for example; the difference between the FACS award and the Nurses Award is nearly $4,000 per annum to the benefit of the copied State award. But let us jump straight to the registered nurse level.

The maximum rate of pay and the difference in the maximum rate of pay per annum is something like $27,500 per annum, so it is little wonder that these providers are having difficulty in a very competitive marketplace to attract and retain registered nurses and the like and unfortunately our experience already within a matter of months is that models of care that transferred from FACS and were labelled "Nursing Models of Care"—those that required a significant or a total reliance on nursing classifications in certain group homes to provide that care—are already being eroded by way of replacing their skills and clinical competency with others, partly because they say they cannot attract nurses, partly because it seems that it may well be an economic decision to try to manage their costs. Ms Scilinato has had direct experience in dealing with one or two of the non-government organisation providers in that space.

Ms SCILINATO: In relation to casualisation, as my colleague said, a lot of our members transferred across as permanent employees. Any new employees who are being employed are all being employed either as casual or permanent part-time. One provider is only employing people for 60 hours a fortnight. For others there are big vacancies. In one organisation that transferred across there were only nurses, that is, registered nurses, enrolled nurses and assistants in nursing and I think three disability support workers went across. This was what they call a nursing model for people who had comorbidities other than their disability. At this point in time that number of unlicensed workers has increased to 24, so they have actually filled positions that were previously held by nurses. Our members are really quite concerned about this because they have also reduced the number of registered nurses to be able to supervise what happens. The staffing arrangements that existed at transfer were one registered nurse across two houses that were co-located. Now that has changed and in some houses there is not regular supervision by a registered nurse.

The CHAIR: At all?

Ms SCILINATO: At all, and that distresses everybody who hears it but our members are really concerned because they have often looked after the residents for decades. They were transferred across from FACS. They have known these people; they are often considered part of the family. They are really concerned about what is going to happen as it transfers. A lot of our members are also towards the end of their working careers and there are not sufficient people being trained who have knowledge of disability and the health problems associated with it.

The Hon. COURTNEY HOUSSOS: A couple of different unions having been talking about the question of specialisation. There is an opportunity for specialisation here but it requires some assistance from government. There is a clear gap that we could be addressing. I turn now to public policy. In particular, I wish to ask Mr Wright and the Public Service Association about the case of Ms Kim Flowers, which I raised directly with the Minister during the budget estimates hearings. I thank the Flowers family for coming today. This Committee has heard a lot about the clashing between the health department and the NDIA. We have been told in previous testimony things like the transitional heads in the local health districts are there to problem solve these types of cases and I am interested to hear how Ms Flowers' case has played out. Has there been any support from the New South Wales Government or has it been left to the Flowers family and yourselves to advocate on her behalf?

Mr WRIGHT: We might have to take on notice some of the details about Ms Flowers's case and check with Ms Flowers if she is happy to share that information. But I will say from my experience with people who have been assisting her—I have not been directly involved but people I work with have been—that there is an enormous amount of frustration about being ping-ponged back and forth between agencies. Ms Flowers' case is horrific—namely, someone 34 years-of-age required to live in a hospital bed for more than six months because there are no other options. It is horrific but it is not isolated, and it is horrific but it is not unpredicted.

It is exactly what many people—our union proudly at the time as well—said could occur. Ageing, Disability and Home Care [ADHC] has always operated as that safety net. ADHC was always there for that 40 per cent of people whose complex medical needs or behavioural needs were beyond that of the private sector and non-government organisations. It has always been there. It is the same model of service provision that happens in so many areas of government and that is what a ADHC did. If you take away that safety net it is only natural that people will have to rely on services that are not appropriate.

Ms Flowers is relying on a service that is completely inappropriate for her and there appears to be no answer. I have heard that Ms Flowers' family have been advocating at various levels, through health, external agencies, non-government organisations and ADHC, and they just seemed to be knocked around, pushed and passed around. That experience of being knocked around: "Sorry, it is not an health issue; it is a disability. Sorry, it is not a disability; it is a health issue." I suspect the Committee has heard several horror stories of that and it is occurring elsewhere for us as well.

I understand we have got examples in our submission about that happening with education as well: "Sorry, that is not an education issue; it is a disability. No, it is not a disability; it is education." People with a disability do not deserve this. They do not deserve to be pushed around, treated as a line item and not in an agency's budget. There needs to be a holistic approach. That holistic approach was there with ADHC; it is not there now. We are only 12 months down this path and it is falling apart. Unfortunately, Ms Flowers is one example of the people who get affected.

The Hon. COURTNEY HOUSSOS: It is very useful for our inquiry to see real life examples. I should have said earlier that I appreciated across the three submissions there were case studies that really illuminated the points that have been made by yourselves and other stakeholders. Thank you very much. Mr Wright, you made the point that this is clearly not the appropriate place for Ms Flowers to be, it also not the best financial outcome for the State.

Mr WRIGHT: No.

The Hon. COURTNEY HOUSSOS: If these gaps are not addressed they will ultimately be addressed by the State—whether it is through the health system or the justice system or elsewhere—but they are not being appropriately addressed.

Mr WRIGHT: Our proposal for a reinvestment in ADHC is cost neutral to the Government. The Government is going to be paying through the nose for placements in hospitals like for Ms Flowers or beds in correctional centres for other people, it will just come out of a different budget. ADHC is cost neutral; it is saving other areas. Otherwise there is going to be an increased drain on our aged care, our child protection, our health system and our correctional system. Not only is there an economic drain—and, like I said, that is in the crudest of terms—it is horrible outcomes for individuals.

The Hon. COURTNEY HOUSSOS: Ms Fraser, this morning the Committee heard from one of the big providers that we have families and carers in such a desperate situation that they are actually being faced with "relinquishing children" because they have nowhere else to turn. We have heard also from carer representatives that this is a situation that they are familiar with and part of the problem is because of a lack of respite care. I am interested in your thoughts on that particular issue and whether you are familiar with that occurring as well?

Ms FRASER: I would agree with that. The amount of respite that was provided under the ADHC system met the needs of many families very well. Jumping to the NDIS funding model, which was opposed initially to respite, a lot of families are crumbling. The people I directly support have identified the limited number of days that they are getting as being inadequate. They are also talking of relinquishing children. For those people who support adults, they are pushing them into supported accommodation because they acknowledge that they can no longer cope with the level of funding that they are receiving. It is really tragic.

Ms DAWN WALKER: I just want to go back to the information the Nurses and Midwives Association gave in its opening statement about the transfer of staff from FACS to non-government organisations. Could you just explain a little bit more about that situation, the outcomes you are seeing from that and perhaps the uncertainty after the two years?

Mr RAVLICH: It was a very unusual situation. Legislation was passed through the Parliament that essentially gave the Minister for Disability Services the right to unilaterally transfer employment from FACS to a non-government provider. The legislation explicitly says, as we note in our submission, that it did not require the consent of the employee. I think we used the term "industrial conscription". It was quite unusual and quite a significant use of legislative power in that regard. Our members, those thousand or so nurses who worked in that sector, were immediately confronted with a situation where they felt disempowered and had no choice. They felt as if they were being transferred not dissimilar to a home or an asset that was going across to the non-government organisation sector. Having said that, the same legislation did set out a series of protections, some of which are mirrored in other privatisation processes, and one of those was, for example, a two-year employment guarantee—the incapacity of the non-government organisation provider to then seek to supersede or replace the copied State instrument for the first two years and the like.

It would be fair to say in the significant number of years in debating and discussing this with FACS and the Government since 2012, some of those commitments and guarantees are difficult or certainly impossible for the union to enforce because we are not party to any of those contractual arrangements. Often we do not know the finer detail of those contractual arrangements on behalf of employees. The employment relationship that was entered into by the Minister, whilst we know the broad headlines we are not to know how that was actually articulated with the non-government organisation provider in detail. Certainly some of those aspects or protections would not be those that the Fair Work Commission, for example, would be able to enforce or police because they are really outside of the industrial instruments themselves. It really is, as was explained to us, that they can go off to the Federal Court and enforce their rights. That is a significant erosion of the manner in which rights were protected in New South Wales previously under the New South Wales Industrial Relations Commission, which effectively was able to deal with almost any dispute arising in a particular workplace.

So we have a number of members who fear that there is going to be this cliff that they are facing in two years' time where, depending on the profile of the workforce, they will either seek to restructure—and I think we note in our submission that already there is a buzz around some of the places that once two years comes we are not having a nursing model. The thing that is particularly egregious is that none of these discussions talk about what the residents of those group homes need, what their choices are in relation to the profile. The strengths that we are collectively talking about here are the complementary aspects that all of the varying professions and employees bring to this space, how they assist in providing a robust system that can protect 360 degrees of that particular resident's needs, and that is what is being lost and, I think my colleagues might be able to add to it, there certainly is a fear that really they are in a transit lounge heading towards oblivion.

The CHAIR: Mr Lambley, either from your own experience, because you have explained to us that you have worked before in this area, but through your role with the organisation and the union, being in contact with people doing this work, when you talked about the casualisation of the work and work being done as a casual contract of employment now as opposed to a permanent contract of employment, can you give us some examples—and I am not asking you to personalise this—of the types of hours per week we are talking about and the fluctuations that might be visited upon those casuals, just so we get a sense of understanding what casual work does mean in the context of this particular example?

Mr LAMBLEY: It is a bit of a tricky one to really nail down. I worked last week with a gentleman who was working across two jobs; he was working 70-hour weeks as a casual across two jobs. Other people who I have worked with they might go a week with no work because the client that they work with is in hospital. They could go a month with no work or they could suddenly have no work because their client has left the service or has passed away. That is from my own personal experience. As far as broader, I do not know if Ms Lang has more perspective on that.

The CHAIR: Before we go to Ms Lang, with respect to the example of 70 hours a week, was that across two providers?

Mr LAMBLEY: That was across two providers, yes. He was working obviously more than full-time hours with at least one of those providers each week to be getting his 70 hours. The organisation that I was working with him for was his second job and he took shifts with them around his first employer. I know when I worked with him it was the Monday of the pay fortnight and at that point he received a call asking if he could do a night shift that night and he said he was happy to do it but it would require overtime approval because he was already up to his 76 hours for that fortnight on his roster as of that first day of the fortnight.

The CHAIR: Would it be your evidence, Mr Lambley, that at least one of the reasons that he would be prepared to work up to that number of hours is at least in part because of uncertainty about whether or not in the following week or weeks ahead he will have a reasonable minimum number?

Mr LAMBLEY: Absolutely, yes. It is one of those things: you make hay while the sun shines. There is always that fear that if you say no to a shift why would they offer you another one?

The CHAIR: And it is your experience that this is a real challenge for casuals because it is sort of take it if it is there; if not, there is the risk of not knowing when the hours might come around again?

Mr LAMBLEY: Absolutely. It was a consideration for me in coming here today, in fact. I turned down a shift to come here today and that was a consideration: Is that going to negatively impact on my ability to get shifts in the future?

The CHAIR: Which is a key vulnerability for casuals. Ms Lang?

Ms LANG: If I may supplement that with the experience of some other members that we know of. We know of some workers who are on contracts as little as two hours a fortnight as their guaranteed minimum hours, knowing full well that they would be working and needed to be employed to take on additional hours, but it is about minimising the risk. Of course then the impact that has on the worker themselves is how do you organise child care with some predictability of when you may receive a shift? And that is driving workers out of the sector. Similarly, we know the dropout rates around undertaking training, especially when it is at the expense of the worker themselves and it is not in paid time, is if you are in one of these precarious employment situations where you do not know when the next shift is going to come and you have got a class on to be able to attain your certificate and you get the phone call to say you can have a shift if you come in now, that worker is forced to make a heartbreaking decision of the future of their career and undertaking this qualification or attending the shift to simply have some predictability of their own income to put food on the table.

We see instances where this is genuinely the current hungry mile where the text message gets sent out to all of the workers first thing in the morning and the first person to text back is the one who gets to work that shift. It is definitely an unacceptable lack of certainty and predictability for the workers, but that comes with it an unacceptable lack of predictability and certainty for the NDIS participants.

The Hon. SHAYNE MALLARD: I am not sure who would like to answer this. You would be familiar with the Government's submission, which is on its website, No. 313. The Government refers to this statement, and I would like some comment: "NSW's approach to the transfer of specialist disability services has retained the skilled and dedicated NSW Department of Family and Community Services disability workforce. As at 10 August 2018, more than 9,565 direct service delivery staff in NSW had transferred to non-government organisations". It goes on further to say, "By supporting the establishment of the NDIS, including through service transfers, there will be more jobs in the disability sector with around 30,000 new jobs expected to be generated in NSW as a result of the NDIS". That is the opposite to what you put before.

Ms LANG: I do not agree it is the opposite view because I think we quote that in our submission as well, that prediction of the growth in the sector of jobs. The challenge is ensuring that they are good jobs. It is also a challenge about ensuring that the workers who are coming in to take these 30,000 new and emerging positions are workers who are supported to be able to attain skills and qualifications and experience.

The Hon. SHAYNE MALLARD: I think we all agree with that, and I really appreciate the discussion in your opening statement that talks about the skills and training. But that is 9,565 people transferred from the government into the community sector. Is that loss of union membership, first of all? Is that an issue? There would certainly be a loss of your members.

Mr WRIGHT: No. I anticipated that question that somehow our interest in this process would be one of self-interest. I can assure the Committee it is not. We have the capacity to continue to represent and enrol those members and have done so.

The Hon. SHAYNE MALLARD: Outside the government sector?

Mr WRIGHT: Outside the government sector. This is not a matter of coverage, this is not a matter of us spitting the dummy that we have lost members out of this process; we have not. All we have heard are increased concerns about the conditions under which they work and the professionalism in the work they perform. The NDIS is constantly pumped in the media as a great jobs generator and I believe it would and could be, but at the same time we are hearing about a workforce development crisis. I draw the Committee's attention to the fact that before any State Government services were handed over to the private sector there was an interview with the head of Northcott on *Lateline*, I think it was on 14 February or thereabouts last year, and she was openly indicating that the solution to the workforce crisis is for people on 457s to deliver the NDIS. We would argue that there have been, as you have indicated, almost 10,000 qualified, skilled workers that have crossed over from the public sector to the private sector.

If there is a workforce crisis that emerges in the private sector it is because they have failed to renumerate and honour the conditions of employment those people have crossed over on. They are dedicated, professional public servants that have chosen disability services in the State sector as their career. Many of our members have been with ADHC for 10, 20 years—they love their job, they love the people they work with, they enjoy it, they are rewarded for it. If there is a workforce crisis coming up it is because we are going for the cheapest workers not the best workers.

The Hon. SHAYNE MALLARD: Would they be picked up in the public sector union, those workers? Who would cover them now they have left the PSA and gone into the private sector?

Mr WRIGHT: We are continuing to cover the cohort of work that crossed from the State Government to the private sector.

The Hon. SHAYNE MALLARD: The workers that were members of the union?

Mr WRIGHT: The cohort of work.

The Hon. SHAYNE MALLARD: The workers that were in the union?

Ms SCILINATO: The transferring workers.

Mr WRIGHT: Yes, the workers in the union.

The Hon. SHAYNE MALLARD: I am not assuming all 9,000 were in the union.

Mr WRIGHT: No.

The Hon. SHAYNE MALLARD: What percentage would have been?

Mr WRIGHT: I would prefer to keep that confidential unless I have to reveal that.

The Hon. SHAYNE MALLARD: In front of your colleagues. I would ask that to be put on notice.

Mr WRIGHT: Certainly, I will provide that on notice.

The CHAIR: That brings us to the conclusion. On behalf of the Committee thank you for coming along and providing an opportunity to get into a level of detail beyond what was provided in the submissions. Thank you for the excellent work you are doing advocating for and representing the interests of workers in this area in the State.

Ms LANG: Chair, there is one error in submission 343 of the Public Sector Association of New South Wales. I have discussed this with my colleagues at the PSA and we would hand up a letter that rectifies that error from the submission.

The CHAIR: Yes. Provide that to the secretariat and we will take it into consideration.

(The witnesses withdrew)

TIM REARDON, Secretary, Department of Premier and Cabinet, on former oath

MICHAEL COUTTS-TROTTER, Secretary, Department of Family and Community Services, on former oath

ELIZABETH KOFF, Secretary, NSW Health, on former oath

PETER SEVERIN Acting Secretary, Department of Justice, on former oath

The CHAIR: A warm welcome to our next panel of witnesses all from the New South Wales Government. The final panel of witnesses on our final hearing day. Thank you for coming along to round out the range of points raised in the oral evidence and the submissions. Is there an opening statement the Government would like to make to cover some of the issues dealt with thus far or would you like us to begin questioning?

Mr REARDON: We have a short opening statement. I, on behalf of my colleagues, thank you again for the opportunity to come back and appear before the Committee. We have been listening to the issues raised throughout the inquiry to date. The transition to the National Disability Insurance Scheme has been a significant effort in regard to the transition of services and individuals to the scheme. New South Wales has also worked to help prepare the workforce and sector for transition with significant investments made into workforce and sector capacity building initiatives.

While 1 July 2018 was a significant milestone for the scheme in New South Wales many issues raised throughout the inquiry relate to the ongoing implementation of the scheme, including NDIS planning and plan review time frames, support for people to access and navigate the scheme, and support for particular groups of people including those with complex needs, children and young people in residential or aged care. The Commonwealth and NDIA's prioritisation and engagement on some of this work is paramount to continuously implement the scheme and meet the needs of customers. Improved capabilities across NDIA planners, local area coordinators and support coordinators will be continuously required. This will help improve the experience of people trying to access the scheme and implement plans and ensure plans fund the reasonable and necessary supports for people with disability.

New South Wales continues to advocate with the NDIA as the organisation responsible for ensuring participants are able to access specialist disability services, to introduce a longer term response where a participant is unable to access services for a number of reasons. We have also heard through the inquiry that there are concerns about services for people with disability not eligible for the NDIS and specific support New South Wales provides to people with disability. The Government is aware of the risks that potentially arise with the transition to the scheme and potential gaps in services. A range of supports for people with disability have therefore been funded during the early years of full scheme and these programs are listed in the New South Wales Government response. I conclude by stating that some of these are just our observations from the hearings to date and now we look forward to the Committee's final report and recommendations.

The CHAIR: You have probably been quite busy today and may not have had the opportunity to observe the proceedings but we had an excellent range of witnesses today, in addition to the first day of hearing, and they have brought a range of issues to the inquiry. When the Committee members have a chance to read through the *Hansard* it will lead to supplementary questions that can be answered in due course. The evidence today builds on what has been provided and provides an extension of some of the concerns already raised and elucidated.

The Hon. COURTNEY HOUSSOS: Thank you all for making time to come back, the Committee appreciates it. Something that has been canvassed extensively by myself and other Committee members through the process is the question of early intervention support, particularly for children, but early intervention more generally. There is no doubt that there are a number of people who are outside of the NDIS and who are still requiring support. How are they being provided with support by the New South Wales government? Because there is no doubt that without access to support it is going to entrench disadvantage.

Mr COUTTS-TROTTER: Depending on the nature of people's needs those responses differ, of course, in each of our service systems. I read with interest the submission, for example, of Early Childhood Intervention Australia and their concerns about children who might be referred by early childhood partners to mainstream community settings, so for example a community run preschool funded by colleagues in the Department of Education. They have done some considerable work and are now beginning to implement a strategy to build the inclusiveness of those community preschool settings, so training for staff, minor capital works to make facilities more physically accessible and scholarships for early childhood educators who want to develop a disability specialty. Depending on the service system, there will be a range of responses. It is quite a hard question to answer across the board. But if you made it more service specific, then we could give you more useful detail I think.

The Hon. COURTNEY HOUSSOS: I will come back to you on notice. But immediately the thought comes to mind of children, particularly on the lower end of the autism spectrum, who have been subject to some public debate about whether they are going to receive NDIS support or not. The Royal Australasian College of Physicians' submission estimated that there are roughly between 9,000 and 12,000 children with delays in New South Wales who are not going to receive individualised funding from the NDIS. You have given one example within the education system, how in the health system are they going to be supported?

Mr COUTTS-TROTTER: I turn to my colleague.

Ms KOFF: We have a number of diagnosis and assessment services across the State which are absolutely critical, because it is the early intervention, which you described, that is so important in starting therapy as early as possible to get the best possible outcomes. We also had additional funding in this budget for regional assessment services, which will include autism in that. I think one of the challenges is rural access, because the diagnosis and assessment services are primarily metropolitan-based, and we are keen to be able to support rural access to those services also. So Health will continue to provide those. At the moment we are in the process to have a tender to provide for rural and regional services also.

The Hon. COURTNEY HOUSSOS: Have you outlined where they will be?

Ms KOFF: No.

The Hon. COURTNEY HOUSSOS: And how many there will be?

Ms KOFF: No.

The Hon. COURTNEY HOUSSOS: Do you have a time frame for when they will be in place?

Ms KOFF: The tender is out at the moment for us to put them in place, but there is always referral to the metropolitan diagnosis and assessment centres that we have, which are staffed by therapists with physicians with specialisation in developmental disability and assessment that develop the ongoing plans that still can be delivered locally once they have had the initial assessment.

The Hon. COURTNEY HOUSSOS: You said that there is a tender out.

Ms KOFF: Yes.

The Hon. COURTNEY HOUSSOS: Do you have a start date for when services will be available?

Ms KOFF: No, I do not know. I can take that on notice.

The Hon. COURTNEY HOUSSOS: I am interested in this battle between the NDIS and the health system. We talked a little bit about the transitional leads last time, and you said they were providing advocacy supports for individuals as they battle with the NDIS, essentially. The Committee has seen a number of individual cases that are still unresolved. Where to from here? Is there any kind of higher level approach that is resigned to be addressing? I am specifically thinking of the issues that have come up such as insulin injections, oxygen tanks and catheters. I am sure there are a host of other issues that are subject to this ongoing discussion.

Mr REARDON: Just to clarify, do you mean how we might monitor across the board in the governance we talked about last time about where the National Disability Insurance Agency [NDIA] delivers its services and where we as New South Wales are picking up residual and transitionary services across the board, or specific to Health?

The Hon. COURTNEY HOUSSOS: There is a problem with individuals who need these services, and instead of there being a clear and policy-driven approach across the board it seems like it depends on the local health district [LHD], or the planner, or any range of unique set of circumstances, that means that different people are getting different answers. Is there a way of escalating this? Is this the way that this is being addressed?

Mr COUTTS-TROTTER: I might offer some reflection on that and then invite Ms Koff to give some health system detail.

Ms KOFF: Then I am happy to support.

Mr COUTTS-TROTTER: Last time we were before the Committee we talked about the groups that had been formed to try to bring clarity to these really important policy questions because they play out in very profound ways in people's lives. If you cannot administer insulin, you need help to do it. It is an absolute necessity. New South Wales has led that work. I remind people that the scheme is co-governed by all nine jurisdictions. New South Wales has got eight of these nine jurisdictions to agree at a really explicit level of detail about the appropriate boundary between the healthcare systems and the NDIS on each of these issues. Minister Williams has been trying to bring that to the Disability Reform Council to get a policy decision on it. We have worked long and hard to try to get these issues addressed as a matter of urgency at a high policy level, and in the interim just try to manage case by case as best we can to meet people's proper needs.

Ms KOFF: I think that is the reality for us from the health system perspective, that there does seem to be individual planner variation as to what is approved and what is not approved. I did describe in the first session that we have had to put in structures within the health system to be able to understand those differences, and for us to be able to then prosecute or challenge them in a coherent way. And we always attempt to solve it locally, because if we can expedite a solution at the local service delivery level, that is the most preferable place to resolve the issues. However, it has been frustrating in some quarters where we get quite a difference in variation to support for various types of services and we have the internal mechanism first of all within Health, that then we have the opportunity to take it to the New South Wales board for the NDIS and raise it at that level.

We also raise it via the AHMAC, the Australian Health Ministers' Advisory Council, where we had the NDIS come and speak to us. I think that is one of the challenges we have experienced, because NSW Health was the first one to lead off and sign off on implementing this, and some of the other States have not had the lived experience of what we have done. We have been strongly vocal in taking it via the NDIS board in New South Wales and via AHMAC, that we need to go back to the applied principles and the tables of support to understand what the, I guess, demarcation line is with what is NDIS and what is Health provided. It would be fair to say that it is blurred sometimes, it is not black and white. There does tend to be a grey area in between, and I think that is potentially what is causing the frustration with some clients now and the delays and time it has taken to solve some of these issues.

The Hon. COURTNEY HOUSSOS: Let me give you a specific case of a young woman who was just here. I do not know if you saw Ms Kym Flowers?

Ms KOFF: Yes.

Mr COUTTS-TROTTER: Yes.

The Hon. COURTNEY HOUSSOS: Who has been in Sutherland Hospital for six months, I think it was, because she is unable to receive her insulin injections in her current supported accommodation.

The Hon. COURTNEY HOUSSOS: It seems to be at a stalemate. She is in an inappropriate location. It is costing the State. It is not helpful for anyone in this situation. What is the next step for her?

Ms KOFF: We have similarly escalated those issues, as I have said, by the working group that we have got, the senior officers working group, and getting some standardisation in those applied principles and how they are applied. One of the challenges that we experience, and I reflected on this earlier, when the NDIS was developed they called it an iterative design process. We thought we might know what to expect when the NDIS was implemented, but the reality sometimes plays out somewhat differently, and I think that is what we are experiencing in cases with insulin injections. Is it a medical or health service, or is it something to support the disability to reside in the community? That is where there seems to be pinch points that we are experiencing, but we are keen that those issues are escalated and we feel we have a lot better traction now with the applied principles. The AHMAC working group work through the disability Ministers so that we will be able to expedite those rather than on a case-by-case issue. That is what is causing the delay. Sometimes these issues are resolved on a case-by-case issue, which I do not think is the most effective and efficient way to manage them.

The Hon. COURTNEY HOUSSOS: There is a role for both. The policy needs to be addressed. Have you resolved the issue that Ms Flowers is facing? Have any of your transitional leads been doing anything for Ms Flowers?

Ms KOFF: Yes. My team at the Ministry is in regular contact with Ms Flowers' mother and are well aware of the situation. We would agree, a hospital setting is not the ideal situation for someone in Ms Flowers' position. Hospitals are for acute care and should be used as thus. It is not a good home environment for anybody to live in in a permanent capacity.

The CHAIR: Ms Koff, do you think a nursing home is a suitable environment?

Ms KOFF: No.

Mr COUTTS-TROTTER: No.

The CHAIR: Would you be surprised that that family has had it raised? I am not in a position to say who raised it, but at least at a broad level some consideration was raised about whether she should go into a nursing home.

Ms KOFF: I do not know whether I am allowed to reflect personal opinion, but I have worked in health for many, many years and to my way of thinking young people who are put in aged care facilities—despite the fact they are called nursing homes they are actually aged care facilities—the support and environment for a young person I do not think is appropriate.

The CHAIR: I have not spoken to the family, but if anyone after today's hearing is able to make contact with the family and tell them that is off the table, that would provide great comfort and assurance to the family, because they feel, at least in some sense, that is a distinct possibility and if that can be set aside as quickly as possible, that would be greatly appreciated.

Mr REARDON: We will seek to do that. I wanted to round out that the comment you are making is about doing both things, dealing with case by case and dealing with the customer directly. My opening comments were about the NDIA's role, us working with them to ensure they resolve cases quickly and us also collecting the body of evidence about lessons learnt. So if they are common issues we get common responses. The other level is bringing that back to the policy level. As I said to you in the first hearing, our governance is such that we want a single New South Wales voice when we take those things back to the national level so we can say if there are common issues for a group of clients and there needs to be change or more refinement, that is what we will continue to do, and that is why we have the governance in place that we do at both levels.

The Hon. COURTNEY HOUSSOS: I want to return to Ms Koff. After today, what can be done for Ms Flowers? I wholeheartedly agree with the Chair and ask that the question of aged care facility be taken off the table, but what next? What is NSW Health doing for Ms Flowers?

Ms KOFF: We are continuing to support her current needs, which is critical. As I understand, she was in a home beforehand and when she had acute exacerbation of her condition she was admitted to hospital. It would appear that the support that she required then was withdrawn while she was in hospital, hence she has been maintained in hospital. I think that should be our first priority, to support her in her current condition. We will continue to advocate and escalate, because I do not think, as I have mentioned, that the hospital is the appropriate environment. We will continue to liaise with the local NDIS providers and escalate it by the formal channels. I am sure there is precedent, to my understanding, about the insulin injection that has come forward in other cases, which should set the policy going forward.

The Hon. COURTNEY HOUSSOS: I appreciate that, but it is still not being applied to her case. If you can take that on notice, I would appreciate it, and I am sure her family would as well. I want to raise the issue of respite. Providers, carers and workers have consistently raised today the effects that the lack of respite and inappropriate respite from the NDIS is having on carers. We heard this morning it has led to families being forced to, in their words, relinquish children. I would be interested in knowing if there are any efforts by the Government to provide respite services to families.

Mr COUTTS-TROTTER: Yes. To address the concern that children who really are not unsafe with their families are being "relinquished" into the care system, I can assure you and the Committee that we are talking about a very, very small group of children with disability who are using more than 90 days of temporary accommodation outside the home each year. There are about 45 children in that category and probably another 100 right on the borderline. We have set up a protocol with the National Disability Insurance Agency. The government has resourced a team inside Family and Community Services and we are working case by case, I hope purposefully, with the NDIA to have decisions about amounts of temporary accommodation provided outside the home reviewed.

The NDIA planners, for a period, took a rules-based dogmatic response to that. There was a 90-day rule and that is it, without considering any of the nuances of a family situation. Our aim in that work is to try to work with families to support the family to be able to keep their child at home for much of the year as possible, and the work we do with the NDIA is to try to act as a facilitator or possibly, on occasion, an advocate, to ask the agency to reconsider some of the planning decisions that may have been made previously. But we are talking about 150 children in a population of 1.7 million children in New South Wales. For each of those families, it is an incredibly consequential issue, but I want to reassure people it only affects, thankfully, a tiny number of children.

The Hon. COURTNEY HOUSSOS: According to the NDIA submission, 27 per cent of people who were not previously receiving disability support are now receiving support from the NDIS. How many people who were previously receiving support from State-based disability services are not receiving support from the NDIS?

Mr COUTTS-TROTTER: I should take that on notice to give you an accurate response.

The Hon. COURTNEY HOUSSOS: When you take it on notice, can you tell me who is receiving less support and who is receiving none at all.

Mr COUTTS-TROTTER: There were 4,000 existing clients largely of the Community Care Support Program that did not get access to the NDIS. I think we touched on that last time.

The Hon. COURTNEY HOUSSOS: And we have heard more about that today, that is why I am interested. We have heard a lot about provider of last resort. I know this is a phrase that does not really have a definition, but it seems to be used colloquially within the sector. Does the New South Wales Government have any plans to be a provider of last resort or provide services in any way to people who are not able to access NDIA or NDIS services, but may have already been approved for a plan?

Mr COUTTS-TROTTER: Since the 7 or 9 July the NDIA, following some work that we did with the agency, has established a maintaining critical supports function which is, I think in more colloquially terms, a provider of last resort. They contract a range of disability service providers so that if a NDIS participant's support become ineffective, or if they are inadequate or circumstances change or their support coordinator or the person themselves cannot make use of their funded package to provide the supports they need, the NDIA has on contract now I think nine disability support services who can provide direct service either in the home or in supported accommodation. So if there is a crisis there is now a range of organisations contracted across New South Wales by the NDIA that are there to provide a last resort response. It has been called twice, I think, in South Australia since July. It has not been called on in New South Wales apparently since July.

The Hon. COURTNEY HOUSSOS: Will you provide the Committee the name of the nine providers?

Mr COUTTS-TROTTER: Marymead, Northcott, the Australian Foundation for Disability, Life Without Barriers, Uniting and Live Better.

The Hon. COURTNEY HOUSSOS: Do they provide services on a geographic basis?

Mr COUTTS-TROTTER: I need to ask the NDIA to provide information that I, in turn, can provide the Committee.

The Hon. COURTNEY HOUSSOS: They have not been called upon. What is the process of calling upon that provider?

Mr COUTTS-TROTTER: There is an escalation pathway within the NDIA that can be activated by health or justice colleagues. It can be activated by families, support coordinators and the like. I will ask the NDIA to describe the mechanism for you because it is their mechanism.

The Hon. COURTNEY HOUSSOS: I respectfully say that there is a consistent issue that has been raised by almost every single participant that has appeared before the Committee today and not one of them has mentioned that there have been any plans underway by the NDIA to address it.

Mr COUTTS-TROTTER: As I say, they have had it in place since, I think, 9 July.

The Hon. COURTNEY HOUSSOS: Perhaps the Committee can ask the NDIA on notice what it is doing to raise awareness of it because there is clearly not much awareness out there. Who is responsible now for the 330 roughly people who are still living in the large centres at Stockton, Tory Lodge and Kanangra.

Mr COUTTS-TROTTER: All those people are participants in the NDIS that services are provided by Family and Community Services through a disability services division. We are responsible for providing services.

The Hon. COURTNEY HOUSSOS: Who is the Minister responsible?

Mr COUTTS-TROTTER: Minister Williams is responsible.

The Hon. COURTNEY HOUSSOS: Given the inability to resolve the Kym Flowers matter—and I am happy for any one of you to answer this question—how can Summer Hill families have any comfort that with the privatisation that their concerns will be addressed in a timely manner?

Mr COUTTS-TROTTER: First, the residents at Summer Hill have all been participants, I think, in the NDIS for 12 months or more. There is a model of medical support there that is currently funded by the NDIS. There is nothing that I am aware of that suggests that will change with a non-government organisation coming in in November to take on the operations of the facility. We have put in place the same arrangements for staff so there is a two-year job guarantee for ongoing employees and a six-months job guarantee for casual employees. There is nothing that I am aware of that would suggest that families or residents or friends or networks have any reason to be concerned.

The Hon. COURTNEY HOUSSOS: Their concerns are specifically around the level of service that needs to be provided will not be paid for by their NDIS packages. For example, oxygen tanks that were previously provided by ADHC will not be provided under their new NDIS packages or they are going to be left in this arm wrestle with the NDIA. How will that be resolved?

Mr COUTTS-TROTTER: I think that is a set of concerns rather than something that has actually happened. The new provider has refreshed plans, as I understand it, in with the NDIA at the moment and the feedback I get is that there is no sense at this point that any of those fears and concerns will come to pass.

The Hon. COURTNEY HOUSSOS: During the budget estimates hearing families in the gallery were in tears because they felt that their concerns were not being addressed and that they had very real fears for the safety of their children.

Mr COUTTS-TROTTER: I completely acknowledge that. That is why I checked again before I came before this Committee to get the latest advice on how things are progressing towards the service transfer. I think people need to know that there is nothing that we are aware of that should cause them concern.

The Hon. COURTNEY HOUSSOS: The question I asked the Minister in budget estimates which he chose not to answer was: Can the Minister agree the safety of those residents? Do you feel comfortable making that guarantee?

Mr COUTTS-TROTTER: Can I guarantee the safety of those residents, yes, absolutely.

The Hon. COURTNEY HOUSSOS: Will they be receiving the same level of service?

Mr COUTTS-TROTTER: They are NDIS participants at the moment. Their services are funded through the NDIS. There is no information I have got that would suggest to me that any of that would be compromised because a new operator comes in.

Mr REARDON: However, if you want to raise any specifics with us that we need to take into account leading into the next few months, we are happy to take that on board.

The Hon. COURTNEY HOUSSOS: I specifically ask around the funding of the oxygen tanks. Who will pay for the oxygen tanks?

Mr COUTTS-TROTTER: I will take that question on notice and respond to you.

The Hon. SHAYNE MALLARD: Ninety-six thousand people have transferred or are getting NDIS services from the cohort NSW Health clients before. The Committee has heard about individual cases in submission about some of the problems. Can you give the Committee an indication of the quantum of any problems out there? Can you provide an assessment of how you think the transition has gone?

Mr REARDON: I will kick off. We discussed it last time so I will do it in summary form. We have been together as a NDIS Board at a secretary level since 2015. We have gotten ourselves as ready as possible for a full go-live on 1 July 2018. We have gone live with well over 90,000 participants. We tracked those participants closely leading up to the go-live and ensured that we brought that down to a very small number where there was still eligibility being assessed. I think we got it to 99 per cent of participants who were eligible commenced with the scheme or soon thereafter.

Customer satisfaction rates were in about the mid-80s for the early parts of the scheme and clearly efforts will be made to continue to improve that. That is why the NDIA is in business. We are playing our role with a significant amount of residual functions and transitionary functions, and the Government, as we said last time, has funded that for $87 million in this current financial year in 2018-19 with funding in the subsequent year and the year after that as well. We will track those. We will stay together as an NDIS Board at the New South Wales level. We will have one voice both to the health and disability services ministerial councils and ultimately through the Council of Australian Governments. Our desire is to see the NDIA successful and to do its job well and to have a customer focus as part of its DNA and how it goes about its business for every single client with which it comes into contact. We will assist it with everything we can to ensure that is the case.

The other things we want to do, and would ask that the Committee take on board, are where there are individual cases, we would like to understand those. Where there is a collection of similar issues and lessons to be learnt that we are able to take that back and advocate it through the national processes to keep monitoring and adjusting what we do as we continue to roll out and learn lessons as we go as well. That is reasonable summary where we think it is at from a whole of New South Wales perspective. I will ask Michael to ask for more specifics on that.

Mr COUTTS-TROTTER: Actually the 96,000 participants includes, I think, around 26,000 people who were not existing clients of New South Wales disability support services. They are people who are now getting supports that were not being provided by services delivered or funded by the New South Wales Government until the creation of the NDIS

The Hon. SHAYNE MALLARD: Who was providing those services to them?

Mr COUTTS-TROTTER: In many cases they are people who are brand new. They were not getting any specific supports at all.

The Hon. SCOTT FARLOW: What does that cohort look like?

Mr COUTTS-TROTTER: I guess it would look a bit like the cohort in total, so younger people, children. The supported accommodation system in New South Wales is a rationed system and the NDIS for the first time offers the prospect of it not being a rationed system. I think the Productivity Commission estimates that 28,000 people across the country need disability supports provided through a supported accommodation environment and about 15,500 people are currently getting it. You are beginning to see the promise of the NDIS being delivered.

The Hon. SHAYNE MALLARD: That is a very important point. We have heard from a number of advocates about the 1.2 million people under various statistics in New South Wales that self-identify as having a disability but that 26,000 growth is the NDIS delivering to more people than we could before, which I think is a point we have not really picked up on.

Mr COUTTS-TROTTER: Yes, and with an investment focus. In a rationed system you tend to have to rise to crisis before the ration system gives you priority, which means that the supports you get come too late and opportunities are often missed. An investment approach is a complete shift in thinking. As the scheme matures it will be transformative for people who have had to wait too long for the reasonable and necessary supports they need to genuinely be included in the life of the community and contribute.

The Hon. SHAYNE MALLARD: My second question is directed to Ms Koff. There have been a few positive things for your area, NSW Health. The NSW Council for Intellectual Disability pointed out to us today that on a very positive note NSW Health has allocated a new $4.7 million a year for intellectual disability health services. You should be congratulated on that. They have suggested in their submission a recommendation that NSW Health should audit the health care left by the cessation of ADHC funding for intellectual disability health services. Do you want to comment on what work you have done there, what you are aware of and if there are any gaps?

Ms KOFF: Certainly. I think people with disability often have extensive interactions with the health system. That is the reality of the nature of the acquiring of many of the disabilities. They have a very strong relationship with the health system in an ongoing way and we will continue to provide all their healthcare needs that we need to. With the implementation of the NDIS and some of the issues that have been touched on, there is a grey area in the middle that we need to get right. We are very keen in the health system to continue to support the health needs of those people with comorbid psychosocial disability and intellectual disability because it is not a one-off episodic healthcare need that these clients have. It is an ongoing support of their health needs in conjunction with their social needs that they have which is supplied by the NDIS. We need to work in partnership very closely with them and we will continue to work in partnership to deliver the care that these clients need.

The Hon. SHAYNE MALLARD: How was that $4.7 million ongoing funding identified? Was that identified in the early phases of the NDIS starting up?

Ms KOFF: I think if you reflect on the history of how ADHC and NSW Health always work together, and I am going back even predating the NDIS, the health services were in Health for a while and then they transferred over to ADHC and then they transferred back to Health. I think they have been back and forth between the services over a number of years. Always it was grappling with where is the boundary line between the healthcare service delivery requirements and the disability service requirements. But one thing I will say about these health professionals that work in this area is they are extraordinarily committed to working with people with disabilities. They are extraordinarily committed to the best interests and best outcomes for these patients and they have been very active in the space in supporting what we are doing to maximise the benefit of the NDIS. So we will continue to do something. I am glad there was some positive feedback.

The Hon. SHAYNE MALLARD: Plus what you told us about the community care support that you are providing when you saw that gap. Do you want to comment on if you think there are other gaps in that area?

Ms KOFF: I think, as I said, we went in to the NDIS with eyes open as to what we thought it would look like and how it would manifest itself in reality. That is why we have been very committed to supporting the process in health care because there are boundaries issues that do tend to complicate some of the decisions that have played out to this Committee. At the end of the day though Health will always be there to support these clients. As we move down the pathway of full implementation—the scheme is still relatively in its infancy—and if we identify these further needs we have a strong sense of obligation to provide those services.

The Integrated Service Response is a service we identified so that where there are complex cases that are struggling that Health has a leadership role in bringing the government agencies together in conjunction with the NDIS to resolve some of these schemes. Also with the Safe and Supported at Home [SASH] program, we are funding that to be able to support clients who were previously disability clients that did not meet the NDIS requirement and we will provide ongoing healthcare support in the community and topped up with some social support through the ComPacks scheme. I think it is our obligation for equity and social justice to ensure we provide care for these clients.

The Hon. SCOTT FARLOW: One of the issues we keep on hearing about is the interface between the New South Wales Government's responsibility through Health and the Federal Government's responsibility now through the NDIS. New South Wales transferred across $3.2 billion to the Federal Government for the NDIS, with additional funds from the Federal Government provided to implement the NDIS. In a sense I would have thought that things that were provided by ADHC before would simply translate across to be provided by the NDIS and anything that Health provided before would be maintained. Why has it not been that simple?

Mr REARDON: I think the key with the NDIS is you are moving to a customer-centric approach to services and you as the customer—as we have said multiple times in our evidence, the person with a disability is there to manage their own life how they wish to manage their own life and there has been for the first time a scheme that is wrapped around them, not them having to reach out to every single area of a government. It is very much a different service delivery model and a service delivery model that, as we said in our evidence last time, has been 10 or more years in the making. To get to here is a very positive thing, but it is a very different service delivery model.

I will leave it to Mr Coutts-Trotter and Ms Koff to make a couple of comments about that transition and of everything that has gone to the $3.2 billion to the Commonwealth should be theirs and Health is ours. All I can say is we have mapped through with a lot of specificity around areas that are NDIS and that are in the tables that meet the criteria. Where it is outside that and it is an interface issue we have mapped and specifically mapped in this budget, next year and the year after multiple areas where we believe there are interface issues that we need to pick up and we have put in quite a bit of transitionary funding for those.

We will keep iterating that, whether it is advocacy or other areas. We will keep monitoring and adjusting as we go but I do not think it is a one size fits all because a service delivery model is so different. It is what people with disability wanted in terms of our scheme design, that they were placed at the centre, quite rightly, but that does mean that you are moving away from somewhat of a pillared or siloed approach of supply side with big agencies to a customer-centred approach, and long may it continue to be that way, but it is a very difficult apples-with-apples comparison. I will leave it there and ask Mr Coutts-Trotter and Ms Koff to add their comments.

Mr COUTTS-TROTTER: I would just reiterate the observations that Ms Houssos made earlier that there were inconsistent decisions made by planners. There is the sum total of a lot of different people making a set of decisions that might look a little bit different in different places, some unresolved policy issues some of which get resolved like the insulin issue by the Administrative Appeals Tribunal; others we are trying to resolve through the Disability Reform Council ministerial decision-making, plus there is a long history between Health and Disability in New South Wales and every other State. There were these points of disagreement in an internalised State-operated system for 30 or 40 years as well, so there is history playing out, there are the challenges of transition, inconsistent decision-making within what we would say are clear rules and then there are rules that need to be clarified. Put all that together and you kind of get an explanation of some of the things that the Committee has been hearing.

Ms KOFF: I would just say increasingly internationally we are finding the blending of health and social service delivery and it is playing out in aged care at the moment and it is playing out in Disability. The challenge for us is how to provide the services in the most appropriate way that delivers the benefits of both social services and health services working in unison.

The Hon. SCOTT FARLOW: As part of the $3.2 billion that was transferred across, part of that originally, and still is, the funding that was received by advocacy organisations. Of course the Government has now funded through the transition advocacy until 2020 in New South Wales. I imagine that was done with an expectation—and that expectation may still come to fruition—that advocacy would be funded through the NDIS in some form. Could you perhaps outline your thoughts on how the NDIS should fund advocacy?

Mr REARDON: I will kick off with what we have done and then hand over to Mr Coutts-Trotter again. We have funded for several years now going forward advocacy at a level that is $13 million per annum for the next couple of years. That level, we think, is appropriate to ensure there is managed transition of that function. We will monitor pretty closely how that goes and again it is just one of the areas where we did not want to see a service delivery gap. It was a positive thing about us having a one New South Wales approach with the NDIS Board. A range of those areas were raised and collectively we took those to government and government did respond in kind with allocating us funding for that advocacy. So we now have a couple of years to ensure that we get the transitions right and the roles of NDIA and others about that advocacy in the longer term is something we will need to consider as we move through the next couple of years, but Mr Coutts-Trotter might want to add to that.

Mr COUTTS-TROTTER: We had assumed that the information linkages and capacity grants and the system that they would enable would be more advanced in New South Wales than it is. I think, from memory, $19 million of $46 million of available information, linkages and capacity building [ILC] grants were distributed by the Commonwealth earlier this year. The problem with that slightly slow development is that, as you would have heard from Ms Rundle in her testimony, the NDIA is hoping to use that grants program to build advocacy and individual advocacy capacity. She explicitly said that. What is unknown here is what things will look like in 12 or 24 months and what effect a mature ILC-funded system in New South Wales will have in supporting the kind of advocacy that clearly people consider is necessary and important to inclusion.

The Hon. SCOTT FARLOW: One area we consistently hear good reports on is New South Wales' approach to mental health in comparison to other States in maintaining CLS funding, maintaining the Housing and Accommodation Support Initiative [HASI] in New South Wales. From your perspective, Ms Koff, how much of a difference has that made in New South Wales for particular people with psychosocial disabilities?

Ms KOFF: I think we made an extraordinarily wise decision in Health maintaining control over the HASI program. HASI is housing and supported accommodation and there are levels of HASI. The whole idea is to provide both clinical support and social support for people with mental health to reside in the community. Part of the conversations that we had in discussing whether we should contribute to the NDIS program, both cash it out or in kind, was that we believe the dominant contributor to the HASI is, in many cases, the clinical or therapeutic intervention that is required. We saw it as a primary health function with some social support to it. When I talked to my counterparts in other States, they are really experiencing some difficult challenges now in having contributed some of their community-based mental health services to the NDIS.

Ms DAWN WALKER: I have one question really. I wanted to tease out again advocacy support and advocacy services because, to be quite frank, we have had a very informative day. Many of these organisations have been providing that sort of support for decades and we have availed ourselves of that experience and knowledge. What they do is provide systemic information to us all in terms of making policy as well as helping individual people with their issues. I am really struggling to understand how solution of the funding of these organisations and the potential non-funding of these organisations is being looked at as providing individual advocacy potential to NDIS clients because what these organisations are able to provide to us all is much broader than that. I am wondering if you can just elaborate on that for me, please?

Mr REARDON: I will repeat what I said, which is, we provided two years worth of transitional funding so we can have some time to work through how that exact work will work through, which is the transition period. We can take on board a whole range of comments that the Committee may wish to raise with us about advocacy but that is why we have done what we have done. We have got 24 months to work through how that transition is, otherwise we would have been in a position where we would have been talking about not having transitional funding for advocacy. We do have it, which is a good position to be in, and some time to sort through further levels of detail. I will have to pass over to Mr Coutts-Trotter for the next level of detail in the question.

Mr COUTTS-TROTTER: I do not mean to be unhelpful but I think the position is we do not know what the landscape will look like in 24 months time. It is very clear the NDIA is putting a lot of time and attention into thinking about how they use the ILC grants program to build the kind of community capabilities that they think are necessary. We cannot form a judgement yet about how effective that will be in 12 months time. It has not been effective enough to date. That is absolutely clear and the Government agreed to fund transitionary arrangements for advocacy organisations because the ILC grants program has just not stood up quickly enough and was not effective in supporting this kind of capability. As you hear from NDIA giving evidence, it is clear that they are focusing their attentions on that very issue with ILC funding. As I say, there is considerable ILC funding. It would be larger in New South Wales than advocacy organisation funding through ADHC.

Ms DAWN WALKER: Are they taking into account the information resources that advocacy services provide?

Mr COUTTS-TROTTER: Yes.

Ms DAWN WALKER: The Committee has heard testimony that that is also a very important aspect of advocacy services?

Mr COUTTS-TROTTER: A fundamental objective of the ILC program is to support those kinds of information resources, absolutely.

The Hon. COURTNEY HOUSSOS: I am happy for you this question to be taken on notice. I am interested in what your target is for people with disability within your departments and what the current levels of employment are across your departments?

Mr COUTTS-TROTTER: The government-wide target is 5.6 per cent of the public sector workforce identifying as people with disability. The levels of disability employment vary greatly by cluster and the year- on- year targets for improvement, and while they sum up to that 5.6 per cent they would be different for different agencies based on the state of reform: Are they getting smaller or getting bigger? What are the opportunities to better open up the workforce for people with disability? There are some agencies that have some kind of clearer earlier opportunities to really be an employer of choice for people with disability.

Mr REARDON: We have a Public Service Commission that is fairly focused on this in terms of us driving across the 10 clusters the target of 5.6 per cent. The same as we put quite explicit effort into women in leadership roles and Aboriginal leadership roles, it is the same with people with disability—we want more and more people within the public service to reach that target. It is similar to the action plans that clusters put in place. So in areas such as transport, if you think about the transport system and what we hold ourselves to account for in disability access standards for buses, ferry wharves, train stations, et cetera, we will put the same level of effort into ensuring that we bring more people with disability within the New South Wales public service because there is a lot of opportunity.

The Hon. COURTNEY HOUSSOS: I will not miss a chance to plug Bardwell Park station when you are coming up with the list—my local station. If you could provide the Committee on notice with those figures across clusters, agencies, however you want to break it down. If 5.6 per cent is the target, who is meeting it and who is not meeting it? What are figures for each one of those?

The CHAIR: Thank you for coming along. It has been very helpful for government representatives at such a senior level to appear at the conclusion of this public hearing. Thank you also for the important work you do on behalf of the people of New South Wales.

(The witnesses withdrew)

(The Committee adjourned at 17:38)