

# Chapter 4

## The Hunter trial site

4.1 This chapter presents the committee's evidence on the achievements and the challenges facing the National Disability Insurance Scheme (NDIS) in the Hunter trial site in New South Wales.

### The public hearings

4.2 The committee held public hearings in Newcastle on 5 and 6 May 2014. On 5 May, the committee took evidence from 17 participants and carers and 25 individuals representing service providers. On 6 May, New South Wales Government officials from Ageing, Disabilities and Home Care (ADHC) officials and New South Wales National Disability Insurance Agency (NDIA) officials in the Hunter trial gave evidence to the committee.

4.3 The committee's public hearings in Newcastle raised a number of issues specific to the progress of the Hunter trial site, as well as various broader themes raised at other trial sites. These themes are developed in chapter 6 of this report.

### Progress of the Hunter trial site

4.4 Table 4.1 presents the statistics of the Hunter trial site until 31 March 2014. It shows that the bilateral agreement between the Commonwealth and New South Wales Governments planned for a total of 3,000 participants over 2013–14 in the trial site. As of 31 March 2014, there had been 2,720 access requests, 2,042 participants had been accepted into the Scheme, and 1,724 participants had plans. On these measures, the Hunter trial site recorded the second-highest intake of the trial sites behind Barwon.

4.5 Data from the NDIA's Third Quarterly Report shows there are some notable features of progress of the trial in the Newcastle local government area relative to the other trial sites. The Hunter trial site recorded the highest number of ineligible requests. In the first nine months of the trial, the NDIA in the Hunter assessed 461 persons or 17 per cent of its applicants as 'ineligible'. The average percentage of ineligible requests across the four trial sites was 10 per cent. The table also shows that only 68 per cent of participants in the Hunter trial site are accessing mainstream services. This was the lowest proportion of any trial site.

**Table 4.1: Key statistics of the Hunter trial site (after 9 months)**

	Hunter	Barwon	South Australia	Tasmania
Number of participants in bilateral agreement	3000	4,076	1565	792
Number of participants with plans, 31 March	1,724	2,113	979	585
Access requests	2,720	3,108	1,449	744
Accepted as eligible	2,042	2,495	1,152	685
Ineligible (i)	461	205	116	19
Other (ii)	217	613	297	59
Average days from access request to plan approval	54	49	51	56
Average time from application to commencement of services	79	101	76	90
Review of decisions	14	26	12	-
Participants accessing mainstream services (% of total)	68	92	88	76

Source: National Disability Insurance Agency, *Quarterly Report to COAG Disability Reform Council*, 31 March 2014.

(i) This figure relates to the intake for the 12 months from 1 July 2013.

(ii) This is a combination of 'in progress', 'closed', 'revoked' and 'withdrawn'.

### ***Transition to the NDIS in the Hunter trial site***

4.6 From 1 July 2013, the first stage of the NDIS commenced for people living in the local government area of Newcastle. People living in the Lake Macquarie local government area will enter the Scheme from 2014, and people living in the Maitland local government area will access from mid-2015 (see Table 4.2). From July 2016, the NDIS will progressively roll out in New South Wales and by July 2018, all eligible residents will be covered.<sup>1</sup>

**Table 4.2: Transition arrangements in the Hunter trial site**

Category of participant	Date of transition
A person who resides in Newcastle City and receives Australian Government disability services or New South Wales disability services, or Australian Government mental health services	From 1 July 2013
A person who resides in Lake Macquarie City and receives Australian Government disability services or New South Wales disability services	No later than 30 June 2014
A person who resides in Maitland City and receives Australian Government disability services or New South Wales disability services	On, or after, 1 July 2015

Source: Fact Sheet: Entry for existing clients of Australian and State Government funded disability programs – New South Wales, <http://www.ndis.gov.au/document/237>

1 National Disability Insurance Agency, *Fact Sheet: Entry for existing clients of Australian and State Government funded disability programs – New South Wales*, <http://www.ndis.gov.au/document/237> (accessed 21 July 2014).

## Achievements of the Hunter trial site

4.7 As in the Barwon and Tasmanian trial sites, in Newcastle the committee heard many positive stories from participants, carers and family members about their experience with the NDIS. These include:

- participants are able to access supports;
- positive feedback on planning processes and the attitude of planners; and
- the positive effect of the Scheme on participants' lives.

**Table 4.3—Participant feedback**

YTD	Total responses	Very good	Good	Neutral	Poor	Very poor
Overall, how would you rate your experience with the planning process today?	784	571 (73%)	169 (22%)	33 (4%)	10 (1%)	1 (0.1%)
NSW	179	148	27	4	0	0
South Australia	272	157	83	21	10	1
Tasmania	58	52	6	0	0	0
Victoria	275	214	53	8	0	0

Source: National Disability Insurance Agency, document received 8 July 2014.

4.8 Ms Laurel Lambert has a daughter who is an NDIS participant and also acts as a guardian and an advocate for other participants. She told the committee:

I applaud the NDIS. It is everything that many of us have asked for for many years, so thank you.

...there are some really good stories coming out too. There are some really good stories. People who are now receiving support who hitherto had never been able to get that support, and that is great to see.<sup>2</sup>

4.9 Ms Lambert told the committee that in her experience:

...the planner was very respectful. She managed me quite well, which I thought deserved a bit of acclamation. In terms of her presence on the day, she was very respectful and she listened appropriately.<sup>3</sup>

4.10 Another parent of a participant, Mr Michael Fitzpatrick, was glowing in his praise for his son's planner, his package and the process generally.

I am very fortunate. My son's package was very good. We had a very good planner. As to the process for us, we were very excited; we got on the web-checker and got our names in there early. Our package was finished in early

2 Ms Laurel Lambert, *Committee Hansard*, 5 May 2014, p. 9.

3 Ms Laurel Lambert, *Committee Hansard*, 5 May 2014, p. 9.

November last year. We had four meetings with the planner in our home, because at the time service providers were not invited to come along to the sessions. I think service providers should be allowed to come along. I think that has changed now. So we had about three or four meetings with our planner. Our planner had understood Connor's needs a bit before they came out. It went backwards and forwards quite a bit. It took about four visits, four sessions.

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We spent many months planning and getting our information ready. We looked at informal supports as well as formal supports. When the planner came out, we gave them a three-page document about exactly where all of our support and informal support was coming from at the time. Our support was basically six hours a week worth of nursing support. That is now nine hours a week of nursing support, plus we are also getting some community participation support. Our process was good, but it is because we were informed, our planner was informed and we had a good working relationship that we were able to make that happen. I do not think a lot of people have the ability to do that and they need that support from other people.<sup>4</sup>

4.11 Mr Kevin Parsons, who with his wife cares for their 35 year old daughter, Caroline, was another who offered praise for the Scheme, its processes and what it has actually delivered:

The NDIS has made a positive difference for our daughter in that she is getting services now that are relevant to her needs. That has occurred because, for the first time in her life post-school, she had someone from an agency responsible for the provision of funding for her services sit down with her and go through her aspirations and what it was that she really needed to lead a fulfilling life.<sup>5</sup>

4.12 Mr Parsons told the committee that her daughter's package of supports has assisted her to keep mobile, where there had been deterioration in her mobility over time. Prior to the NDIS, Caroline 'was not actually achieving things, because in many cases the support worker had to do the things that Caroline should have been doing'. As a result of receiving and accessing her package of NDIS supports:

That has changed. Her program is now significantly based around keeping her mobile, because she wants to be mobile. Doing aqua therapy programs and those sorts of things is more relevant to her now than what she was getting under the previous arrangements.<sup>6</sup>

4.13 Mr Parsons recognised the important role of the planner in contributing to their positive experience:

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4 Mr Mike Fitzpatrick, *Committee Hansard*, 5 May 2014, p. 16.

5 Mr Kevin Parsons, *Committee Hansard*, 5 May 2014, p. 16.

6 Mr Kevin Parsons, *Committee Hansard*, 5 May 2014, p. 17.

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...it really worked for us because we had a good planner. We were well prepared. A concern for us is that there are many parents and carers who may not be in the same position as us and therefore will get a different sort of plan to the one we achieved. Our experience has been interesting in that we decided not to self-manage, because of other issues that we have as a family, and thought we would take the easy path, but the reality is that, even those who do not self-manage have to actually manage the process, because, in part, a plan is in black and white, and the one that we have is a little difficult to understand. It is not so difficult, I guess, if you were there as part of the process. With the planner involved in the process, we understand it and we understand it very well.<sup>7</sup>

4.14 Mr James Bailey, a young man who suffered severe brain injury in an accident, told the committee:

...I am lucky to be a participant in the NDIS. I was lucky that I had previous service providers, nurses, caseworkers and also my family to inform me and help me in the NDIS process. Their experience in managing my previous packages was needed as the NDIS planning was quite detailed, and a lot of questions were directed to the NDIS planner. After specialists' reports were gathered, and after a few hiccups, the plan was finalised very close to my previous packages, thanks to the team around me and our hardworking local NDIS planner...

Every morning I wake up and smile because I know my life is better now, I get to choose what I want to do and that makes me feel responsible. If I could not do these things I would feel old, sad and bored. I am happy NDIS funding supports me to live a happy and full life.<sup>8</sup>

4.15 James' mother, Carole, corroborated her son's positive experience as an NDIS participant to date. She told the committee:

Our service provider sent us paperwork regarding NDIS and thus the process of becoming a participant began. To access information we went online and also spoke to our service providers. We also used the MyAccess checker tool. After the first meeting James had some assessments carried out. With all our meetings we had insisted that all the people who were contributing to James's wellbeing be allowed to attend these meetings to impart their knowledge of James's needs also. Thank you very much. Our planner was very diligent in producing a package that was very similar to previous funding packages. The main differences were reduced funding for speech pathology and massage therapy, which was a bit disappointing. James has always had a good rapport with his carers and service providers, and the decision was made to remain with them. These people know and understand James, and they help make his life enjoyable, fun and worthwhile.

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7 Mr Kevin Parsons, *Committee Hansard*, 5 May 2014, p. 16.

8 Mr James Bailey, *Committee Hansard*, 5 May 2014, p. 20.

In summary, I feel that James was very lucky to have a wonderful group of carers and people around him who all contributed to this outcome...<sup>9</sup>

4.16 Disability advocate, Mr Cain Beckett, told the committee that the NDIS will lead to positive change in the way that people with disability are treated in Australia. Specifically, he noted that:

It is the inclusion aspect of the NDIS that I think is going to cause change. The processes that we are hearing a bit about today are about asking people with disabilities what they want and what they need. Whilst that is obviously challenging if you have not done that before, it is part of a journey that we are on to change the way society thinks about asking people with disabilities what they want. Most people would be very surprised, for example—perhaps the members of the panel are not—to hear that 42 per cent of the people shot by police have a disability, on the figures that the Human Rights Commission recently looked at; or that right now we have people that have been locked up for 10 years without charge because they have a disability in Australia. This is a continuum that we are on about changing the way society works for people with disability.<sup>10</sup>

4.17 Mr Beckett explained that he was fortunate to have had choice and control in his supports from a young age under the previous system. Many people did not have this and, in consequence, had much worse life outcomes. As he explained:

My mum was a scientist and she looked at what I needed as a person with a disability and figured out that the standard supports and services that were being offered as a default when I was born were not appropriate and, scientifically, did not work. So we went self-managed 40 years ago. I have absolutely no doubt that, as a result of that, that is the only reason that I am not in a wheelchair and that I have a career. If I had done what was being told was the right thing to do, and for the fact that we received death threats for not doing that, I would be in a wheelchair and I would be on the disability pension permanently. That would be where I would be at right now. You can see it as clear as day. I know that in the population of people with disabilities that are out there at the moment there are people now who are missing those chances to change their trajectory because of the way the service system works.<sup>11</sup>

4.18 Mr Beckett told the committee that the NDIS was a chance to change these missed opportunities for people with disability. He added:

That is why the scheme will ultimately be hugely beneficial for Australia from an economic perspective. We cannot afford to keep shutting out

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9 Ms Carole Bailey, *Committee Hansard*, 5 May 2014, p. 20.

10 Mr Cain Beckett, *Committee Hansard*, 5 May 2014, p. 23.

11 Mr Cain Beckett, *Committee Hansard*, 5 May 2014, p. 23.

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15 per cent of the population. So, in that sense, please focus on: what are we changing? What are we doing differently than we used to do before?<sup>12</sup>

4.19 There was also praise for the Scheme at the Newcastle hearing from service providers in the area. Ms Beth Gwalter, the Managing Director of Recovery Station, providing occupational therapy services, told the committee:

It is extremely pleasing to be able to say that all of the participants we have worked with have received assistance in the form of equipment, home modifications, assessments or interventions which have made amazing improvements to their lives. Because of the NDIA, we have seen families change, individual lives improve and quality of life increase, which is wonderful.<sup>13</sup>

### **Challenges of the Hunter trial site**

4.20 This section identifies some of the challenges that have faced the implementation of the NDIS in the Hunter trial. The committee heard evidence that identified the following challenges in the Hunter trial site:

- participants' forums and the role of advocacy;
- the NDIA's communication with stakeholders;
- the role of the planner and the readability of plans;
- the flexibility of the planning process;
- self-managing plans;
- issues facing service providers;
- the Stockton Centre and supported accommodation;
- young people living in aged care facilities;
- public liability insurance;
- early childhood supports; and
- reproductive and sexual health.

#### ***Participants' forums and the role of advocacy***

4.21 One of the main issues that arose from the public hearing in Newcastle was the need for participants and carers to have a forum in which their views and experiences could be heard. Ms Lambert put her concerns as follows:

...the question I would ask you is: why is there not a structure in place to allow us to give feedback in a constructive manner to NDIA and work

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12 Mr Cain Beckett, *Committee Hansard*, 5 May 2014, p. 23.

13 Ms Beth Gwalter, Managing Director, Recovery Station, *Committee Hansard*, 5 May 2014, p. 35.

collaboratively together to give you real life experience and help you to perhaps modify and adjust as the need requires?...

I would like to see some formal structure set up where people with disability and their carers are able to operate and connect with NDIA in probably a structured way to provide that feedback.

I am getting a constant flow of information as more and more people proceed into the NDIA experience, and that sort of feedback is very useful for all of us to get together and say, 'Okay, can we look at doing something about making this a little better and improving stuff for the people who will come after us.'

I guess what I am looking at is trying to get together a group that could meet on a regular basis, where the NDIA could give us feedback about where they are at and we can give them feedback about what is happening for our sons and daughters or family members with a disability.<sup>14</sup>

4.22 The committee asked the NDIA's Chief Executive Officer, Mr David Bowen, if the Agency had plans to establish forums in trial sites to gain feedback from participants. He responded:

We will now start to extend out from that with mechanisms for this informal consultation. We would propose to do it with local groups. So, in South Australia, it would be appropriate to have one around autism, for example, because there are a lot of issues that are central around that. That is part of the communications strategy. Louise and I have wanted to kick some of this off by ourselves, first doing a visit, not just to staff but to providers and participants, to reinforce to everyone—including, the agency, the sector, the participants, right through to the very top of the agency—that we are interested in hearing from people, hearing their experiences, and responding to that. That was our thought. We think it is appropriate to set that as a starting point and then build structures underneath that, inviting people in on a more regular basis.<sup>15</sup>

4.23 Several witnesses at the Newcastle hearing on 5 May 2014 emphasised the importance of an advocacy role for prospective and actual participants to navigate their way through the process and gain an informed and positive outcome. Ms Bailey expressed her concern that the process of becoming a participant:

...seems to be aimed at people who can make decisions for themselves, who can access the internet and negotiate their way through this process, or have family et cetera who will do this for them. I do wonder what happens to others who cannot do these things, who do not have family or a good network of caring people around them. Who looks out for them?<sup>16</sup>

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14 Ms Laurel Lambert, *Committee Hansard*, 5 May 2014, p. 8.

15 Mr David Bowen, *Transcript of meeting with NDIA*, 8 July 2014, p. 3.

16 Ms Carole Bailey, *Committee Hansard*, 5 May 2014, p. 20.



4.24 The same sentiment was put by Mrs Salzano of the group Family Advocacy. Her concern was for those people with disability negotiating the planning process who did not have a family member or friend to advocate on their behalf. She asked:

...how are the interests of the most vulnerable people with disabilities going to be safeguarded in these processes and how are opportunities for them going to be maximised, recognising the potential limitations that currently exist?<sup>17</sup>

4.25 Similarly, Ms Melanie Schlager, a member of Community Disability Alliance Hunter (CDAH), asked:

...if the person does not know that they need help, then how do they ensure that they get a good plan? I have heard so many people this morning say: 'We went along to the NDIA with our three-page document,' or whatever. But what do you do if you do not have that? How can we create a level playing field for those people so that they get a fair and equitable chance to have a plan that meets their needs?<sup>18</sup>

4.26 Another advocate, Mr Ken Clift, expressed concern that people with cognitive or intellectual disabilities are not getting adequate advocacy support unless they are accompanied by a carer or family members. As he told the committee:

I am speaking as someone who has made several referrals of people with intellectual disability to the NDIS. It would not have happened had I not been able to spend up to two working days which each of those people to walk them through the system. Basically most of my clients cannot read or write. If they can read or write it is usually not adequate to the standard that they would need to get through the NDIS portal. Having said that, I can say that the NDIA agency is fantastic, they have been really helpful, but there is this barrier. A few people have already raised that unless there is an independent support person who is trusted by the person who is trying to become a participant in the NDIS, that person may not even get past the access checker. That is the main point I wanted to make: especially for people with intellectual or cognitive disabilities, the access setup at the moment is not good, unless they know someone, unless they have a family member, and my clients tend not to have family members, my clients tend to be people on the fringes of society and people going through the legal system who may not have anyone to speak for them. There needs to be a means to outreach to those people to bring them into the system and hopefully they can benefit the system and society can benefit from them being in the system rather than being an expense on the system.<sup>19</sup>

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17 Mrs Maree Salzano, *Committee Hansard*, 5 May 2014, p. 21.

18 Ms Melanie Schlager, *Committee Hansard*, 5 May 2014, p. 30.

19 Mr Ken Clift, *Committee Hansard*, 5 May 2014, p. 24.

4.27 This view was also put by Dr Geoff Rigby of the L'Arche community, an international federation representing people with disabilities. Dr Rigby told the committee:

It would appear to us from our experience that the planning process within NDIA does not make adequate provision for the fact that many people with intellectual disabilities do not have the opportunity to adequately develop plans that truly reflect their needs. In some cases, these people have come from institutional backgrounds and other disturbed and damaged backgrounds and carry a great deal of fear that, if they do anything other than accept the status quo they find themselves in, they may well be removed from what may be seen by them to be an okay place to live at present. Some people with intellectual disabilities have poor communication skills or, in some cases, no speech at all.

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From our experience, it would seem that many of the current NDIA practices have been developed for people who have disabilities other than intellectual, and these people are far more able to express and advocate for their needs. We want to highlight these limitations and suggest that a more equitable system be put in place to take the needs of people with intellectual disabilities into account when developing plans and assessing their needs. We suggest that provision be made to set up a group who have the necessary skills to offer assistance for people with intellectual disabilities, especially those who have communication difficulties. We believe that such a service and the associated funding are not readily available at present.<sup>20</sup>

4.28 Ms Caroline Daley expressed her desire to see greater informal supports put in place to assist her in caring for her daughter. She noted that this was also the feedback that she had received from other families:

In particular they have had difficulties with family members looking after their loved one—I am talking mainly about children, Siobhan's age and younger. Going out and asking friends or anyone like that to do that is quite a challenging thing for them. Within that peer support realm, to be able to see something for parents of young children to help them develop those skills and confidences—<sup>21</sup>

4.29 Ms Daley told the committee that she has been involved in the development of CDAH. CDAH offers informal supports, including planning cafes.<sup>22</sup> She provided the committee with further information on the format of these events:

To date we have run 3 Planning Cafés - these are facilitator run sessions discussing issues of importance to people with disability and their families

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20 Dr Geoff Rigby, Chairman, Hunter Friends of L'Arche, *Committee Hansard*, 5 May 2014, p. 36.

21 Ms Caroline Daley, *Committee Hansard*, 5 May 2014, pp 13–14.

22 Ms Caroline Daley, *Committee Hansard*, 5 May 2014, p. 14. The Community Disability Alliance Hunter was established in 2013 as a user led disability support organisation. It was established through some funding from the Practical Design Fund.

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within the Hunter region - with another couple planned in the coming months. Planning cafés are only open to people with disability and family members and we regularly turn away 'service providers' who attempt to join the meetings.<sup>23</sup>

4.30 Ms Linda Hughes, a representative of CDAH, explained the benefit of these planning cafes:

It has been said so often that people who are well prepared who go to the NDIA seem to come out with better outcomes, so we are running at the moment what we are calling planning cafes. They are monthly peer support meetings...to help people think about their plan before they go to the NDIA and also the other side of it: how, when they come out of the NDIA with their plan, they can then implement that and how they can translate a piece of paper with 35, 16 or 10 line items into what might be a great life for the person with a disability or for themselves, if it is a person with a disability themselves.<sup>24</sup>

4.31 Ms Hughes' colleague at CDAH, Ms Catherine Mahony, told the committee that:

...there is an incredible need for independent peer support, for independent advocacy for people with disability and their families going through the process. In all the input that you have heard this morning—the confusion, the lack of information—there is a need for a really clearly articulated step-by-step process from the first meeting to the final handing over of the plan and then its enactment...There is an incredible need for information and advocacy in all aspects of that process.<sup>25</sup>

### ***The NDIA's communication with stakeholders***

4.32 A related theme raised at the Newcastle hearing was the need for stakeholders to receive better information. This issue has a number of dimensions. Service providers, for example, wanted better information to be given to participants from planners about the services that providers offer. Ms Gwalter, who runs a private occupational therapy practice, told the committee:

...establishing stronger relationships with planners and regional support officers, and educating them on the different functions of all service providers would be beneficial. Some NDIA staff have a lot of expectations around communications and are very hands on and instructive, while others take a step back and do not seem to know much about occupational therapy or the services we provide and are unable to make sensible

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23 Ms Caroline Daley, correspondence received 8 July 2014, available at [http://www.aph.gov.au/Parliamentary\\_Business/Committees/Joint/National\\_Disability\\_Insurance\\_Scheme/Correspondence\\_received](http://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/Correspondence_received)

24 Ms Linda Hughes, *Committee Hansard*, 5 May 2014, p. 19.

25 Ms Catherine Mahony, *Committee Hansard*, 5 May 2014, p. 9.

recommendations. Education on what each service provider can do for an individual is key in getting the individual the outcome they desire.<sup>26</sup>

4.33 Service providers also requested better information from the NDIA about its policies and procedures. Ms Gwalter noted that these policies and procedures:

...are changing all the time within the NDIS, and the scheme is progressing and growing every day. These developments are not being communicated to service providers effectively. Often we learn things, whether in regard to new administrator forms or processes, just by a chance conversation with NDIA staff or other service providers. Another example of these inconsistencies and the lack of communication is that we have spent large amounts of time developing our own report templates as there was no provision of these for consistency with what the planners expected. We have not had any feedback on this, but we keep getting referrals. To us, that means we must be on the right road, but a lot of the time we feel we have been left lying in the dark.

Additionally, unlike other government agencies such as the Department of Veterans' Affairs, the NDIA does not appear to have any formal feedback mechanism or consultation processes with providers. These may exist, but we have not been approached about them. Having these processes in place would give us and planners clarity around our roles and processes and engagement with participants. There have also been instances where this lack of communication has led to planners operating at odds with what participants have identified to us, the service providers, as in their best interests—that is, planners making decisions against the identified needs of participants.<sup>27</sup>

4.34 Chapter 6 of this report makes key recommendations aimed at improving the NDIA's feedback processes and the accuracy and timeliness of its online materials.

### ***The role of the planner and the readability of plans***

4.35 Several witnesses in Newcastle emphasised the importance of the planner's role in ensuring a positive outcome for the participant. Ms Lambert, for example, told the committee:

It is my view at this stage that the quality of outcome for the individual is invariably connected to the quality of the preparation and the calibre of the planner. The planners do obviously have different skills and abilities, and there are many, many people out there who do not have resources to be able to prepare in a way that is meaningful. Also I think the process of building a good life for your son or daughter takes a long, long time; it is not something that can happen overnight.<sup>28</sup>

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26 Ms Beth Gwalter, *Committee Hansard*, 5 May 2014, p. 35.

27 Ms Beth Gwalter, *Committee Hansard*, 5 May 2014, p. 35.

28 Ms Laurel Lambert, *Committee Hansard*, 5 May 2014, p. 9.

4.36 There was significant support among participants and carers at the Newcastle hearing for the role of planners (see above). However, several participants and carers expressed their concern with the complexity and rigidity of plans. Ms Lambert told the committee:

...families cannot understand the format of the plan. I have sat for up to 3 hours with families, trying to decipher what that plan actually means for them. Just the way it is formatted is too difficult.

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Many of the carers I work with are aged. I have carers who themselves have intellectual disability, and younger carers. It really is too difficult for them. They do not understand, at the end of the day, what the heck this means. What does four hours, or 3.2 hours, of something or other mean? It is a very prescriptive document. That is something that frightens me as a carer because the current issue for me, with my daughter in the state system, is that we have extraordinary flexibility in that bulk-funding arrangement to be able to respond to her needs immediately and do what is required, within her goals, for her to continue to progress through her life and achieve her objectives. She is doing it, but the way in which the NDIA plan is written very clearly delineates that this amount is to be spent on X and this amount on Y, and I have not yet experienced whether that is going to thwart her ability to be able to call on supports outside of it if she needs to.<sup>29</sup>

4.37 Ms Caroline Daley, the mother of a 14 year old girl with severe cerebral palsy, also noted that plans were 'quite difficult to understand'. Ms Daley opted that her daughter would fully self-manage her plan. She told the committee that:

I would like to see something that is more aligned to the goals and the objectives as opposed to line items around pricings in particular. Also, you need to determine the hourly rate. It should be quite apparent. You need to calculate that back out again. That is pretty much the one thing that service-provider-land talks in. Being able to get that information quite easily would be ideal. Being able to relate to goals is a lot easier. I think it would also initiate more change when people do approach service providers. At the moment we have directly employed staff, we have employed a subcontractor and we are now also using an agency and have approached a couple of agencies. So I have a personal range of quite a few different approaches we have gone through.<sup>30</sup>

### *The flexibility of the planning process*

4.38 The committee heard in Newcastle concerns about the lack of flexibility in plans. Mr Parsons told the committee:

When you get your plan back, you have a number of line items. It says you have the flexibility to shift between those line items as long as you do not

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29 Ms Laurel Lambert, *Committee Hansard*, 5 May 2014, p. 9.

30 Ms Caroline Daley, *Committee Hansard*, 5 May 2014, p. 12.

overspend. The reality is that it is difficult to shift between those line items, because, one, other people involved in the process, like service providers, do not understand that there is a level of flexibility; and, two, the systems within NDIA do not allow the level of flexibility that we, who were involved in the development of the plan, thought was there. As a result, there is a real risk that the individual who needs the service will not get the service unless they have someone who can advocate on their behalf to work through the issues. We have made phone calls to NDIA. Unlike others, we have got pretty immediate responses, and we have got the changes necessary to meet the individual situation that has come up that was intended to be covered by the plan but, in the black and white, for others it seems was not.<sup>31</sup>

4.39 Ms Linda Hughes, a representative of CDAH, also identified challenges with the inflexibility of NDIS plans.<sup>32</sup> She told the committee:

I just want to say things about the line items on the plans. It is really rigid. For example, someone with fairly complex disability might end up with a plan with about 35 line items. That might be something like self-care, weekday; self-care, Saturday; self-care, Sunday; self-care, evenings; community participation, weekdays, evenings—so each of those is a separate line item, and it is really up to interpretation by the service provider about how flexible they will be. I know of somebody who was not able to have a support worker go to a concert in Sydney because they did not have evening support, even though they had a month of Sundays.<sup>33</sup>

4.40 Ms Hughes explained that the NDIA's processes for a service provider to claim have influenced how service providers interact with participants:

I think the issue around that is that the rigidity is because the providers have to claim back—I think that is the term—to the agency, to the NDIA, so some providers are being very rigid in how they use it because they have to claim back within those line items. Other providers are doing it in a way that suits families better. I think that is where the rigidity comes from.<sup>34</sup>

4.41 Ms Hughes also told the committee that whether a particular line item was transferrable from one timeslot to another 'seems to be up to interpretation by the service provider'. She also noted that she had been in planning sessions with two different planners who gave her two different answers.<sup>35</sup> This issue of consistency in the NDIA's approach is addressed in more detail in chapter 6 of this report.

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31 Mr Kevin Parsons, *Committee Hansard*, 5 May 2014, p. 16.

32 Ms Linda Hughes, *Committee Hansard*, 5 May 2014, p. 18.

33 Ms Linda Hughes, *Committee Hansard*, 5 May 2014, p. 18.

34 Ms Linda Hughes, *Committee Hansard*, 5 May 2014, p. 19.

35 Ms Linda Hughes, *Committee Hansard*, 5 May 2014, p. 18.

4.42 Ms Hughes suggested that one option to add flexibility to the current system is to enable the line items for social participation and self-care support to become a global budget—'so long as you are using it on support or you are using it in the right way'. She noted, for example, that with the New South Wales Government's current funded programs such as the Supported Living Fund, there is a lot more flexibility.<sup>36</sup>

4.43 Chapter 6 of this report comments on the issue of the lack of flexibility in plans more generally. The NDIA has advised that it is moving away from a line-by-line approach to planning items and adopting a model based on clusters or bundles.<sup>37</sup> The committee welcomes this new approach.

### *Self-managing plans*

4.44 A self-managed plan is one where the NDIA makes a direct payment to the participant, who is then free to choose and pay their own service providers. As of 31 March 2014, only two per cent of participants in the Hunter trial were self-managing their plans (see Table 4.4). As Mr Cain Beckett told the committee:

We have heard a little bit this morning about people attempting to forge a new pathway and be self-directed and some of the challenges of managing their own funding and insurance and so on. I think it is really important that we develop as many supports and processes as we can to help people do that. At the moment there is a very high percentage of people who are choosing to leave their funds with the NDIA, I understand. I expect that will change over time as the rollout continues, but if we end up with a system where all we have done is change the funding model we have not achieved very much. So we need to make sure that we encourage and facilitate people that want to make that choice if they so choose.<sup>38</sup>

**Table 4.4: NDIS plan management arrangement**

State	Agency Managed	Combination	Plan Management Provider	Self-Managed
NSW	68%	30%	0%	2%
SA	83%	12%	0%	5%
TAS	66%	31%	0%	3%
VIC	71%	29%	0%	1%
<b>Total</b>	<b>72%</b>	<b>26%</b>	<b>0%</b>	<b>2%</b>

Source: National Disability Insurance Agency, *Quarterly Report to COAG Disability Reform Council*, 31 March 2014, p. 18.

36 Ms Linda Hughes, *Committee Hansard*, 5 May 2014, p. 18.

37 Mr David Bowen, *Transcript of meeting with the NDIA*, 8 July 2014, p. 4.

38 Mr Cain Beckett, *Committee Hansard*, 5 May 2014, pp 23–24.

4.45 The committee did take some evidence in Newcastle from participants (and their carers) who were opting to self-manage their plan. Mr Fitzpatrick, who manages his son's plan, told the committee of a few of the hiccups in having chosen this option:

...in February I had a lengthy discussion with a service provider that lasted several hours because they were not charging the listed price. As a self manager, I needed to know the price. Apparently, there was a price change in December when the New South Wales award increase was introduced, but the price list was not updated on the agency website until 28 April. As a self manager, I need to know that pricing so that I can ensure that it is all being done adequately. It is that communication again.<sup>39</sup>

4.46 Ms Hughes, who self manages her son's state funding with ADHC, explained their current arrangements as follows:

We recruit his support workers, and then they get signed on by the employer, by the disability service, which then fulfils the obligation of statutory employer, or statutory employment obligations. We advertise and recruit and such. We get support workers who work only with my son, so they do not have to dash off anywhere else, although sometimes they have to dash off to uni. He is a young man, and most of his support workers are students. We create a bit of a roster. We also have a lot of informal support with my son with family members in particular, so any gaps in the day will be filled by me or other family members.<sup>40</sup>

### ***Issues facing service providers***

4.47 The committee is aware that one of the major challenges in successfully moving to full scheme will be to create and sustain a competitive service provider market. Some service providers may amalgamate. Many new providers may come into the market, and some may leave the market altogether. However, it is important, in the short, medium and long-term, that there are service providers to cater for participants' needs as enabled in their plans. The NDIA has acknowledged the challenge of keeping demand and supply for disability services in broad sync.<sup>41</sup>

4.48 The committee took some evidence in Newcastle that there are gaps in service delivery. Mr Parsons told the committee:

The issues that have come up for us are going out of the area on an extended holiday and being able to access services in other areas. That was a real issue. I had to really chase that through myself. There was some support from NDIA. They identified a service provider that was registered in the area that we were going to. But I think we need to do more as a community to encourage service providers in other areas to register so that,

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39 Mr Michael Fitzpatrick, *Committee Hansard*, 5 May 2014, p. 15.

40 Ms Linda Hughes, *Committee Hansard*, 5 May 2014, p. 19.

41 Dr Bruce Bonyhady, Board Chairman, National Disability Insurance Scheme, *Address to the National Press Club*, 9 July 2014.



if we have people from this area going out into their area, they can continue to get some service whilst they are there.<sup>42</sup>

...

...in terms of the viability of service providers, we are seeing all the hourly rates. We look at it and we say: 'Yes, that funds the workers. What about the organisation?' An organisation does not exist without bricks and mortar or the ability to pay rent, to buy buses to get our people around or to buy respite houses. That is not clear to me. Maybe it is there somewhere, but I guess as a parent I would want some surety about the viability of service providers long term.<sup>43</sup>

4.49 The ability of service providers to remain viable will depend in part on their own efforts to market their services, identify demand, receive information and communicate with participants and their carers. Broadly, all businesses face these challenges. In the newly-established market for disability services, however, the committee heard of some particular problems.

4.50 Ms Tonina Harvey, the General Manager of Community Services for ParaQuad New South Wales, told the committee of a number of her concerns relating to the operation of her service under the NDIS:<sup>44</sup>

- firstly, she noted 'major concern about the rates allocated for care services and the implication this has on participants and on the sector in the long term';
- secondly, she had not been 'fully advised' on when block funding would end and the process for transitioning people who are not yet in the NDIS;
- thirdly, she claimed that the NDIA has not assisted her organisation to gain access to consumers—'in fact, this is discouraged'. She noted that her organisation was 'excluded from approaching NDIA staff with any resource or orientation information about our services'. Rather, the information that it had received was from forums, seminars and conferences where there were discussions with people that had had experience with planners;
- fourthly, she told the committee that some organisations 'have successfully planted their shopfronts next door to the NDIA office here in Newcastle'. In her view, this strategy 'disenfranchises' other providers; and
- finally, she noted that her organisation had been marketing widely, which included a roadshow along the central coast.<sup>45</sup>

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42 Mr Kevin Parsons, *Committee Hansard*, 5 May 2014, p. 17.

43 Mr Kevin Parsons, *Committee Hansard*, 5 May 2014, p. 18.

44 Community Services for ParaQuad New South Wales is a peak disability organisation providing clinical support and personal care for people with spinal-cord injuries and other high-level physical disabilities. Community Services for ParaQuad New South Wales also operates a subsidiary company in Newcastle called BrightSky Australia, which offer equipment, incontinence and women's care products for people who live independently at home.

4.51 To date, the committee has not had an opportunity to examine in detail the strategies that service providers are employing to market their services and understand the newly created market. This is an area of committee future interest (see also chapter 3).

4.52 The committee notes that service providers can identify and inform participants of their services through the Local Area Coordinators. Further, the names and details of registered service providers in the various trial sites are on the NDIA's website.<sup>46</sup>

### ***The Stockton Centre and supported accommodation***

4.53 The inadequacy of the stock of supported accommodation in the Hunter area was of particular concern to many witnesses at the Newcastle hearing. They highlighted the New South Wales Government's decision to close the large residential centre at Stockton and—among other matters—the pressure that this will place on the small existing stock of supported accommodation options.

4.54 The committee acknowledges that many people in the Stockton Centre and who have family members in Stockton, have ongoing concerns about the impact on residents from the proposed closure. Mr Parsons was one witness to express his concern with the availability of places for supported accommodation. He told the committee that in terms of these places:

I know we are going to be competing. There are a whole lot of people in Stockton to be placed in whatever arrangements, and we see that our daughter will obviously be competing for places with many, many people, but I do not see a structured plan there going forward....

We talked to the Cerebral Palsy Alliance and others about what the future holds, and they said: 'Support and those sorts of things we can do. Bricks and mortar are a problem.' We could look at it in a range of ways, I guess. There are some of us in the community that can contribute maybe financially to some of these things, but there is no structure. There is just nothing there that takes us forward and allows us to get some comfort in what the future holds for our children.<sup>47</sup>

4.55 The committee has also received correspondence from concerned family members of Stockton residents. Ms Jean Koshemakin wrote in a letter to the committee:

My sister, Joy Robinson, has been living at Stockton Centre, Stockton NSW for fifty years...I am already very unhappy with State Government plans to break up the Centre and transfer people to group homes, which will be

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45 Ms Tonina Harvey, *Committee Hansard*, 5 May 2014, p. 40.

46 See 'Registered Service Providers', <http://www.ndis.gov.au/providers/registered-service-providers> (accessed 10 July 2014).

47 Mr Kevin Parsons, *Committee Hansard*, 5 May 2014, p. 17.

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placed under the administration of non-Government organisations from 2018. I have always supported the NDIS because I saw it as a way to increase services and choice to people in the community who now have very few supports. I had no idea it would be misused to put at risk essential services that Joy needs and take away her and my right to choose her staying where she is well cared for, safe and happy.<sup>48</sup>

4.56 The committee does note that some relatives and disability advocates expressed positive views about the decision to close down the Stockton Centre and argued that it was the right outcome. Mr Ron Sharkey provided the following evidence to the committee:

I would like to make the point that there are a lot of relatives who are very supportive of all this, who are supportive of the closure of Stockton and the move into group homes. My sister has been in Stockton for 60 years...I think, in the future, when people have a choice, it will be a lot better world.<sup>49</sup>

4.57 The committee emphasises that the closure of the Stockton Centre was not a consequence of the NDIS. It was a decision of the NSW State Government as part of its long-held policy of deinstitutionalisation of state-run residential centres. As such, the closure of the Stockton Centre is not a matter of direct relevance to the NDIS. It appears that the NSW Government will either fully or at least substantially fund the cost for the alternative accommodation for all residents leaving the Stockton Centre. The Chief Executive of ADHC, Mr Jim Longley, told the committee the budgetary processes to build this alternative accommodation are underway.<sup>50</sup> The committee understands on advice from the NDIA that it has no obligation to contribute to this cost from its budget.<sup>51</sup>

4.58 In his budget speech to the NSW Parliament, the State Treasurer, the Hon. Andrew Constance noted:

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48 Ms Jean Koshemakin, Correspondence received, 12 February 2014.

49 Mr Ron Sharkey, *Committee Hansard*, 6 May 2014, p. 8. See also comments of Mr Kurt Fearnley, Disability Advocate & member of the Independent Advisory Council, *Committee Hansard*, 6 May 2014, p. 10.

50 Mr Jim Longley, Chief Executive, Ageing, Disability and Home Care, Department of Family and Community Services, *Committee Hansard*, 6 May 2014, p. 23.

51 Ms Louise Glanville, National Disability Insurance Agency, *Correspondence received on 25 July 2014*.

Today we are investing \$587 million to deliver Ready Together, to assist people move to the NDIS and \$30 million towards new accommodation for people with disability in the Hunter Residential Centres.<sup>52</sup>

4.59 At the public hearing in Newcastle on 6 May 2014, the committee took evidence from ADHC officials on the progress of the New South Wales Government's plans to deinstitutionalise its large residential centres. Mr Longley told the committee:

The New South Wales government remains committed to devolution from all large residential centres. Those people with disability who are currently our clients will be our clients until such time as they are with the NDIA, and they will be in accommodation, and that accommodation will be the best and most appropriate that we are able to organise.<sup>53</sup>

4.60 Mr John Ryan from ADHC provided the committee with the following detail on the progress of consultation with people currently living in large residential centres in NSW. He told the committee that:

...the redevelopment of large residential centres in Western Sydney is underway and will be complete by 2015. Stockton, Kanangra and Tomaree are going through the budget processes at the moment. It is a large project, but it is possible—as it happens, we are actually starting to develop a land bank for people at Stockton, because we are presuming that the people at Stockton will behave fairly similarly to the people in Western Sydney, where an awful lot of people will choose to change their location when we give the opportunity to families...

It is our intention to have some sort of an answer for everybody who is living in Hunter residences, which are those three centres, by 2018. We are only, at this stage, at the consultation phase, where we are going to families—at the moment, only in Stockton—and saying to them, 'Look, this is what we have in mind.' ...

Once we have explained to families, shown them working models of what is involved, frequently they say, 'Oh, is that what you've got in mind? We would love it if our family members could move closer.' And only about 80 people who live in Stockton actually have a person responsible or family members living in the Newcastle area, so we are expecting a considerable number of them will actually choose to relocate their family members to other parts of the state, and we will build them brand-new houses, with their friends, that will better meet their needs than Stockton does.<sup>54</sup>

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52 The Hon. Andrew Constance, Treasurer, New South Wales Government, *Budget Speech*, [http://www.budget.nsw.gov.au/data/assets/pdf\\_file/0020/124328/2014-15\\_Budget\\_Speech\\_-\\_Budget\\_Paper\\_No.1.pdf](http://www.budget.nsw.gov.au/data/assets/pdf_file/0020/124328/2014-15_Budget_Speech_-_Budget_Paper_No.1.pdf) (accessed 15 July 2014).

53 Mr Jim Longley, Chief Executive, Ageing, Disability and Home Care, Department of Family and Community Services, *Committee Hansard*, 6 May 2014, p. 22.

54 Mr John Ryan, Ageing, Disability and Home Care, Department of Family and Community Services, New South Wales, *Committee Hansard*, 6 May 2014, pp 21–22.

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### *Young people living in aged care facilities*

4.61 At the Newcastle hearing on 5 May 2014, the committee heard of other cases of a young person living in an aged care home (see also chapter 2). Mr Colin Brodie told the committee that his 29 year old son currently resides in a residential aged care home. He noted that the federal government's Young People in Residential Care Program (YPIRAC) funding initiative was 'very greatly appreciated' as it 'provided for at least a modest array of services and assets to make up some of the shortfall that exist in the system for young people in aged care facilities'. Mr Brodie added:

One of the great reliefs that we appreciated by way of that YPIRAC funding was that there was a modest array of services provided, one of which was therapeutic massage. Massage has been of tremendous benefit, if you can imagine not being able to move and the relief. It is a therapy in itself.<sup>55</sup>

4.62 However, Mr Brodie expressed his concern that under the NDIS, massage is not provided and once signed to be an NDIS participant, YPIRAC funding ceases. He elaborated:

We have been advised that, once you sign up to the NDIA, the YPIRAC funding ceases. We have been advised that, once you sign up to the NDIA, massage ceases. We have been advised that, if you do not sign up to the NDIA by a certain date, YPIRAC funding ceases. So we are left in a complete conundrum as to how it could transpire that in regard to the NDIS, which was introduced on the basis that everything would be better now, we find that quite the opposite applies. There is a meanness of spirit, no doubt driven by budget constraints, in regard to the packages that have been provided to other people that we know of. It is not uncommon at all for services that are currently being provided to have been either withdrawn or reduced. I find it extraordinary. I have written to the NDIA in regard to this matter, pointing out what I have just related to you, and I have reiterated my inquiry several times since the original inquiry that I made nearly two months ago, only to have been told that it has simply been referred to head office. It seems to be too hard.<sup>56</sup>

4.63 The committee emphasises that its focus is on systemic issues rather than individual matters. That said, the committee is of the view that the matter raised by Mr Brodie does have wider implications. It asks that the NDIA review the matter, and cases similar, to see what is an appropriate intervention or service that meets the needs of participants in the Scheme.

4.64 The broader issue of young people transitioning from funding assistance under the New South Wales YPIRAC program to the NDIS was raised by Ms Penny Paul from the Summer Foundation. She told the committee that the work of her

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55 Mr Colin Brodie, *Committee Hansard*, 5 May 2014, p. 27.

56 Mr Colin Brodie, *Committee Hansard*, 5 May 2014, p. 27.

organisation is focussed on ensuring that young people are not forced to live in aged care. She provided the following evidence:

In January 2013, we began a number of projects related to young people in nursing homes in the NDIS, to locate young people in nursing homes in the trial sites, to build their capacity to access the NDIS and to conduct research about the information needs of them and their families to participate. Building on this work, we have now launched an NDIS connections project in the Barwon and Hunter trial sites and anticipate appointing a project officer in the ACT shortly. We have already identified a number of young people in the launch sites, supported them to register with the NDIS and assisted them through the planning processes. We have had some excellent outcomes to date.

...While achieving some excellent outcomes, eligibility to the YPIRAC program was limited to people under 50 years of age. YPIRAC concluded on 30 June 2011, so there are many young people in nursing homes who are not able to access YPIRAC or who have entered a nursing home since the program concluded. The number of young people in nursing homes nationally remains stubbornly high. The Australian Institute of Health and Welfare data indicates that there are 6,209 young people residing permanently in RAC nationally. There were 2,692 permanent admissions between 1 July 2012 and 30 June 2013. Two hundred and ninety two of these people were under 50 years of age. There are 149 people under the age of 65 in the three local government areas that comprise this launch site, 72 of whom entered in the 2012-13 year and so will not have had access to YPRAC funding. These figures do not capture the young people in respite or transitional care within the aged-care system. While the data is both compelling and vital, for planning purposes, it does not help us locate those individuals or their families to provide them with the information about how to access the NDIS or that, indeed, they are eligible.

Provision has been made to transition existing YPIRAC clients to the NDIS...They have received YPRAC funding and have been brought across. But many of the young people in nursing homes are neither YPIRAC clients nor clients of state funded disability services, because that is regarded as double-dipping. As a consequence, they will not be known to the National Disability Insurance Agency and so will not be transitioned across in the trial sites.

There are three preconditions to the scheme delivering for young people in nursing homes. Firstly, they must be made aware of their eligibility. Secondly, they must be provided with the support they require to participate and thirdly, they must be empowered to exercise the choice and control that is at the heart of the scheme's design. Our research of the trial sites shows that most young people in nursing homes are not aware of the NDIS. They have not engaged with that so far. We know that family members are a vital source of information about the NDIS for this target group. Without the close involvement of family members or links to advocacy organisations

the NDIS misses out—these people are potentially going to miss out on this program.<sup>57</sup>

4.65 Ms Paul urged the committee to consider a 'protocol' to ensure that all young people in nursing homes, and their families and carers, are informed about how to make an access request to the NDIS. She suggested that those without support should be referred to an advocacy agency to support them through the NDIS planning process.<sup>58</sup>

4.66 Ms Paul also argued that the 52-day social leave rule<sup>59</sup> should be waived. She reasoned:

...if you have lived in aged care for a while you will be very hesitant to move out, and so you are going to need that thing where you might spend two days a week out of aged care and build that up over time. People very quickly run out of time, with 52 days, and then are very concerned that they may have lost that bed, so they are not prepared to try new things.<sup>60</sup>

4.67 On notice, the committee asked ADHC to respond to the committee's concern about future accommodation options for the young people living in a state-funded aged-care home in Wallsend. The New South Wales Government responded that eight of the nine young people in the Wallsend home have transitioned to the NDIS with the remaining client expected to complete their plan 'in the very near future'. It added that as Wallsend is within the Hunter trial, those young people with NDIS packages will become clients of the NDIA and ADHC will no longer provide their supports. The NSW Government also noted that the YPIRAC program is writing to those previously supported through the program to advise them that all future supports will come through the NDIA.<sup>61</sup> Chapter 6 recommends that the NDIA also take action.

### ***Public liability insurance***

4.68 In Newcastle, the committee heard that public liability insurance for carers is not offered in insurance policies. Ms Daley told the committee that in her case, she is employing one person directly to care for her daughter within the home. She told the committee that she has not been able to find an insurance company to cover this employee and added:

Traditionally, if you had a home and contents insurance policy that included a public liability component, it would cover those particular staff. However,

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57 Ms Penny Paul, *Committee Hansard*, 5 May 2014, p. 28.

58 Ms Penny Paul, *Committee Hansard*, 5 May 2014, p. 28.

59 This rule states that after being absent from a residential aged care facility for a total of 52 days in any one financial year, if there any further absences required the resident pays the full-bed fees. The rule applies to all permanent residents of aged care.

60 Ms Penny Paul, *Committee Hansard*, 5 May 2014, p. 28.

61 New South Wales Government, Family and Community Services, *response to question on notice number 7*, received 23 June 2014.

as soon as you say they are doing attendant care or personal support, they are not covered under that particular policy. There does not appear to be any other product that does that. I have still got insurance brokers out there looking.<sup>62</sup>

It is a matter that I would really like investigated, because it is one of the big things that is preventing a lot of people from being able to go down that path...

It appears as though the UK have some quite good insurance policies and products to cover that direct employment, but there is nothing even remotely comparable within Australia at this point in time.<sup>63</sup>

4.69 Mr Michael Fitzpatrick told the committee that he faced the same difficulties.

In regard to the insurance issue, this is something I am going down the track of self-managing for my 15-year-old son as well. He has high medical needs. There is a specific clause in all insurance policies in Australia which specifically excludes a person from employing a person as a carer for someone who lives in the same household. It is in all insurance policies.<sup>64</sup>

4.70 Mr Fitzpatrick added:

I spoke to the agency [NDIA], and the agency referred me to the Insurance Council, who provided me with the names of several different insurers. I went through about half-a-dozen different insurance brokers, who within three or four days came back to me and said, 'We're going to refer you to our underwriters, because we can't work it out.' The underwriters then came back to me and discussed the specific scenario with me. I had two or three of them talk to each other, and they came back to me and said, 'We don't know how we can get around this in Australia,' and they said, 'We would love for the agency to come and talk to us, because the government has enacted this scheme but the insurance is nowhere near ready to do exactly what I want it to do.'

...

One provider actually told me to go and talk to the GIO about insurance because that is what their clients did and that was the coverage that their clients had. When I spoke to the GIO they said, 'We have never had that insurance in the 12 years that the person worked here,' so I am quite concerned that the information provided by service providers is not relevant and is not accurate.<sup>65</sup>

4.71 The committee contacted the Insurance Council of Australia to ask its view on two issues:

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62 Ms Caroline Daley, *Committee Hansard*, 5 May 2014, p. 14.

63 Ms Caroline Daley, *Committee Hansard*, 5 May 2014, p. 13.

64 Mr Michael Fitzpatrick, *Committee Hansard*, 5 May 2014, p. 15.

65 Mr Michael Fitzpatrick, *Committee Hansard*, 5 May 2014, p. 15.



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- (a) whether carers of a person with disability are covered by the public liability component of the person with a disability's home contents insurance policy; and
  - (b) whether there is any insurance available for a carer who is employed to care for someone in the same house.

4.72 The ICA responded:

A household public liability policy held by the person with a disability may not respond to injuries suffered by family members whether or not they are providing care services. Family members and people employed or contracted by the householder are often excluded from the policy as other insurance may apply.

Carers who provide care commercially as sole traders can take out public liability insurance to deal with any injury to the person with a disability caused by their negligence. They can also take out personal accident insurance to compensate them in the case that they suffer an injury. In these circumstances, it may be prudent for the carer to seek the advice of a specialist broker as to the types of insurance they may need.

4.73 In terms of insurance cover for a carer employed to care for a person in the same house, the ICA noted that workers compensation can be taken out by the employer to cover employees. For a family member carer, there is personal accident insurance and various life insurance policies including income protection, total permanent disability and health insurance. The ICA concluded:

Though the provision of individual products is a commercial matter for each insurer, public liability and other commercial products are available in the marketplace. We suggest that in home family carers seek advice as to the potential insurance for their own risk of injury and risk of injury to others.<sup>66</sup>

4.74 The committee asked the NDIA whether these issues of gaps in insurance cover had been raised previously with the Agency and if so, whether the Agency had discussed these concerns with the ICA. The NDIA responded:

The National Disability Insurance Agency is in the process of publishing materials developed in conjunction with participants who wish to self-manage.

Workers compensation insurance is readily available for people employed by a participant.

Public liability insurance is available but is more expensive as there is limited call for this type of insurance at this stage.

It is intended to discuss this matter with the ICA but whilst the market remains as small as it is, there may not be a viable business prospect for an insurer. A more attractive market prospect will emerge with increased

numbers of participants in the National Disability Insurance Scheme and an increased take-up of self-management of funds by participants.<sup>67</sup>

### *Early childhood supports*

4.75 The committee received data from the NDIA showing that in the first nine months of the Hunter trial, the average package costs for children aged 0–4 years was \$14,624.<sup>68</sup> At the public hearing in Newcastle on 5 May 2014, the committee received evidence from Mr Jim Hungerford of the Shepherd Centre that the NDIS funding model for early intervention supports 'does not work'. Specifically, he told the committee that the NDIS early intervention model:

...is written around \$6,000, \$12,000 and \$16,000 per year. Unfortunately, to provide the level of support to enable these children to speak, the average cost is somewhere between \$18,000 and \$20,000 per child—that is across the children who need less support as well as the children who need the high level of support. So there is a significant shortfall. In conjunction with that, there is the expectation that, for children who have multiple disabilities—and approximately a third of our children have got needs in addition to their hearing loss—there is no increase in the early intervention funding because it is a transdisciplinary package. However, there is clearly a significant increase in the effort required from all of the services that are supporting those children, so there is a further shortfall there.<sup>69</sup>

4.76 Mr Hungerford told the committee that while the average costs per child fell well below the NDIS' funding model, for high-needs children, 'we would be spending well in excess of \$20,000'.<sup>70</sup>

4.77 Mr Hungerford also drew the committee's attention to the broader implications of the introduction of the NDIS for his organisation's funding model. He described the current situation faced by the Shepherd Centre as follows:

...donors are already saying to us, 'We do not need to give as much money to you because the problem is solved by the NDIS.' So we are at risk of being caught by a pincer movement in terms of lack of funding.

...

Our charitable funding. At the moment, we receive a lot of philanthropic support. However, donors, because they hear all of the positive success stories of the NDIS, have the expectation that they can put their money into other causes rather than our cause. So we are at risk of the NDIS not

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67 National Disability Insurance Agency, *response to question on notice number 18*, received 16 June 2014.

68 National Disability Insurance Agency, *Information provided to the Parliamentary Joint Standing Committee on the National Disability Insurance Scheme*, received 8 July 2014

69 Mr Jim Hungerford, *Committee Hansard*, 5 May 2014, p. 34.

70 Mr Jim Hungerford, *Committee Hansard*, 5 May 2014, p. 34.

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equalling our funding need, and then, at the same time, our charitable dollar decreasing.<sup>71</sup>

4.78 Mr Hungerford told the committee that if the NDIS falls short of children's funding needs, and organisations like the Shepherd Centre are unable to cover the shortfall in costs through fund-raising efforts, there would be consequences in terms of poorer early intervention outcomes. He explained:

The children will not be able to get to primary school with age-appropriate spoken language. They will then need to have higher levels of support whilst they are in school. They will not be able to achieve as good employment and social outcomes, dramatically increasing the cost to the community in the future, as well as, clearly, curtailing the opportunities that those individuals have in front of them. As a result, I request that the committee review the early intervention funding model for children in this sort of situation and, in particular, the arbitrary cut-off in funding limits.<sup>72</sup>

4.79 Mr Hungerford told the committee that his organisation had made 'a number of representations' to the NDIA and the Chief Executive Officer who has understood where they are coming from and is sympathetic to that. However he goes on to clarify:

Our problem has been much more with what has been written, because the \$16K limit has been written into the TD packages, and also with what actually gets funded on the ground.<sup>73</sup>

4.80 As mentioned in paragraph 5.74, the committee has noted that it has been advised by the NDIA that there are no funding caps.

4.81 The committee flags that the issue of the NDIA's assessment of early intervention support packages is discussed in detail in the following chapter of this report. In particular, the focus of chapter 5 is on the NDIA's operational guidelines for transdisciplinary packages for children and the effect that this document has had in constraining package costs.

### ***Reproductive and sexual health***

4.82 At the Newcastle hearing, Family Planning New South Wales gave evidence highlighting the importance of sexuality and relationship issues for people with disability. The organisation is seeking to become a registered service provider in the Hunter trial site. It currently runs an education program for service providers to support people with disability in the area of sexuality and relationships, as well as offering a range of resources for people with disability. Mr Rob Hardy, Senior Health Promotion Officer with Family Planning NSW, told the committee:

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71 Mr Jim Hungerford, *Committee Hansard*, 5 May 2014, p. 34.

72 Mr Jim Hungerford, *Committee Hansard*, 5 May 2014, p. 34.

73 Mr Jim Hungerford, *Committee Hansard*, 5 May 2014, p. 34.

We would like to put on the radar the gap that exists in the provision of specialised services for people with disability in supporting them around their sexuality and relationships. This may include managing life changes around puberty; managing sexual behaviours of concern, which are often the concern of service providers and family members; supporting and participating in intimate relationships, things like developing dating skills; and negotiating safe and lawful sexual relationships and other life stages, such as menopause. The gap exists because clinical services are able to offer a very limited role in supporting people around health matters and clinical matters. The disability service sector has historically not ventured into the area of supporting people in this area, so a large gap exists between those two areas.<sup>74</sup>

4.83 Mr Hardy told the committee that his organisation is well positioned to provide a new service providing individualised support for people with disability around sexuality issues. For the service to work properly, he emphasised it would be important for NDIA planners to include sexuality and relationship issues in their assessments. Mr Hardy argued that planners' assessment tools 'should specifically include the area of sexuality and relationships'.<sup>75</sup>

### **Committee view**

4.84 This chapter has noted the various achievements of the Hunter trial site over the first year of its operation. Since the publication of the Third Quarterly Report in March 2014, the Newcastle Local Government Area has accepted its two-thousandth NDIS participant. Participants in the Hunter are accessing a range of services and spending their package funding. And, as this chapter has detailed, there are many positive stories from participants and their carers highlighting the important role of their planner, their satisfaction with the planning process and the change that the Scheme has made to their life. The committee congratulates the NDIA, participants, carers, family members and service providers for their achievements to date.

4.85 As with the other NDIS sites, the trial phase in the Hunter has raised a number of challenges that require the attention of the NDIA, advocacy groups, service providers and others. None of these challenges are insurmountable but they will require the various stakeholders to communicate and the Agency to show initiative in coordinating a response.

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74 Mr Rob Hardy, *Committee Hansard*, 5 May 2014, p. 37.

75 Mr Rob Hardy, *Committee Hansard*, 5 May 2014, p. 37.