

Chapter 5

The South Australian trial site

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

The public hearings

5.2 The committee held public hearings in Adelaide on 7 and 8 May 2014. On 7 May, the committee took evidence from 15 participants and carers and 8 individuals representing service providers. On 8 May, South Australian Department for Communities and Social Inclusion and South Australian National Disability Insurance Agency (NDIA) officials gave evidence to the committee. While the South Australian trial presented similar broad themes as the other three trial sites, it raised specific issues regarding the transitioning of children aged 0–5 years into the Scheme.

Progress of the South Australian trial site

5.3 Table 5.1 provides some key statistics relating to the progress of the South Australian trial site. The table shows the progress of transitioning participants against the bilateral agreement between the Commonwealth and South Australian governments. As of 31 March 2014, 1152 participants had been found eligible to access the Scheme and 979 participants had approved plans.¹ This represents a 62 per cent transition approval rating against the agreed bilateral figure for the first year's intake in 2013–14 of 1565 participants.

Table 5.1: Key statistics of the South Australian site (after 9 months)

	Sth Australia	Tasmania	Barwon	Hunter
Number of participants in bilateral agreement	1,565	792	4,076	3,000
Number of participants with plans, 31 March	979	585	2,113	1,724
Access requests	1,449	744	3,108	2,720
Accepted as eligible	1,152	685	2,495	2,042
Ineligible (i)	116	19	205	461
Other (ii)	297	59	613	217
Average days from access request to plan approval	51	56	49	54
Average time: application–commencement of services	76	90	101	79
Review of decisions	12	-	26	14
Participants accessing mainstream services (% of total)	88	76	92	68

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

1 National Disability Insurance Agency, *Quarterly Report to COAG Disability Reform Council*, 31 March 2014, p. 12.

Transition to the NDIS in South Australia

5.4 This section discusses the transitional arrangements in South Australia for the 2014-15 cohort. Table 5.2 below shows the phasing schedule for the South Australian trial site. It displays the process through which the South Australian Department for Communities and Social Inclusion (DCSI) intends to transition clients into the NDIS.

Table 5.2: Transition arrangements in the South Australian trial site

	2013-14	2014-15	2015-16	2016-17	2017-18	2018-19	2019-20
Transition timing	0–5 year olds	6–13 year olds	13–14 year old	Transition to Full Scheme		Full Scheme	
Client numbers	1565	4688	5085	32–34,000		Over 100,000	

Source: South Australia NDIS bilateral agreement. Note: All yearly intake number are cumulative.

5.5 The South Australian trial, like the Tasmanian trial, opted for an aged-based introduction to the NDIS. South Australia's first priority has been to transition children under the age of six—birth to five years old—bringing them in quarter by quarter, age cohort by age cohort. From 1 July 2014 the trial started transitioning children aged 6–13 years. Children aged 14 will be included from 2015.

5.6 As shown in Table 5.2, the next intake of participants will bring in an additional 3123 in 2014–15 from 1 July 2014 expanding the South Australian trial site to 4688, nearly triple the 2013–14 number of 1565. In 2015, a further 397 participants aged 14 will enter the trial site.²

5.7 As all participants in this trial site are very young children, all responses have been provided by parents or carers and for the purpose of this chapter they will be referred to as carers.

Achievements of the South Australian trial site to date

5.8 As in the other trial sites, the committee heard from the National Disability Insurance Agency (NDIA) South Australian trial site manager, Ms Meryl Zweck, that there have already been some important achievements in the site. These are:

- participants' positive views of their planning process;
- significant progress in approving plans;
- new trial of pre planning discussions;
- regional and remote support;
- Indigenous disability and employment opportunities; and

2 *Schedule C: Bilateral Agreement for NDIS Launch between the Commonwealth and South Australia*, 7 December 2012, p. 7.

- participants self-managing plans.

Participants' positive views of their planning process

5.9 The committee notes that Table 5.3 shows according to the NDIA survey results, 89 per cent of South Australian respondents stated that their experience with the planning process was either 'very good' or 'good'. The committee emphasises that all survey work data should be transparent and accurately reported. In chapter 6 of this report, the committee recommends the need for greater clarity on how NDIA surveys are conducted and compiled.

5.10 The committee heard positive feedback from Mrs Dollard who recounted her experiences with her child's first NDIS plan at the South Australian trial site:

Our first planning meeting was fantastic. It all happened in our home; my husband was there and my son was there. We had about two sessions with our planner. We had time to go through our goals with her really carefully. She listened to us. She was fantastic. At no point did I feel confused or anything. So that was a really great process for us. The plan came through and we were very happy with it.³

Table 5.3—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 (58%)	83 (31%)	21 (8%)	10 (3%)	1 (0%)
Tasmania	58	52	6	0	0	0
Victoria	275	214	53	8	0	0

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

Significant progress in approving plans

5.11 Ms Zweck highlighted the South Australian trial site achievements to date, including processing the initial backlog of transitioning participants, stating that:

The first nine months of the scheme have been both rewarding and challenging...Third quarter data has been released and demonstrates sound performance, with significant progress and plan approvals, including addressing the backlog that had developed in the first six months. For South Australia that means 89 per cent achieved against the bilateral agreement*.

3 Mrs Michaela Dollard, *Committee Hansard*, 7 May 2014, p. 10.

But probably more importantly, 979 children have now had plans approved in South Australia...⁴

Likewise, our interactions with service providers facilitate collaborative relationships and continual learning and improvements. This work is underpinned by a strong, pragmatic working relationship with the SA government. Progress with the scheme in South Australia has been sound.⁵

5.12 NDIA noted that the number of days between when an access request for a plan is made by a participant and when supports are approved in South Australia is 51 days just below the average of 52 days across all trial sites.⁶

5.13 Further, Ms Zweck noted that in South Australia:

The majority of participants and their families are accessing the scheme under early intervention provisions. Transdisciplinary packages are increasingly being funded to support families to enable flexibility and recognise the frequently changing needs of young children, and access and information is being provided statewide through a network of metropolitan and regionally based local area coordinators. The scheme is ensuring that parents are linked into local mainstream supports and is strengthening the sustainability of supports provided by families and carers. There are early indications of providers expanding their services and developing innovative responses to enable choice for participants.⁷

New trial pre-planning discussions

5.14 As part of the NDIA's facilitation of information, the NDIA informed the committee that it had begun trialling pre-planning workshop discussions designed to assist and inform carers and participants about the planning process:

[O]ur local area coordinators and regional areas meet with parents to assist them with preplanning activities and connection to the mainstream and community supports.⁸

Regional and remote support

5.15 The committee also heard evidence about how the Agency was engaging with people in regional and remote communities who will be accessing the Scheme:

4 Ms Meryl Zweck, *Committee Hansard*, 8 May 2014, p. 20.

5 Ms Meryl Zweck, *Committee Hansard*, 8 May 2014, p. 20. *[This percentage is based on a pro-rata figure of the bilateral agreement for the 2013–14 year].

6 National Disability Insurance Agency, *Quarterly Report to COAG Disability Reform Council*, 31 March 2014, p. 15.

7 Ms Meryl Zweck, *Committee Hansard*, 8 May 2014, p. 21.

8 Ms Meryl Zweck, *Committee Hansard*, 8 May 2014, p. 21.

In regional areas, we recognise the uniqueness of each region and the challenges of providing funded supports across a range of activities to a relatively small number of children in a vast geographical area.

While seeking individual responses for participants, we are also working on ways to facilitate increased options for families and service provision. In remote areas, we are working closely with NPY Women's Council and the Tullawon Health Service through the KW Health Alliance to develop local solutions and culturally appropriate responses informed by community members. We are ensuring that we incorporate their expertise and views into how we can design our processes and communication materials to address these challenges.⁹

Indigenous disability support and employment opportunities

5.16 As part of the Agency's engagement in regional and remote communities, Ms Zweck elaborated on NDIA's work with Indigenous communities and with the national peak disability organisation representing Aboriginal people with disabilities, First Peoples Disability Network:

We continue to work with other government agencies and their capabilities to ensure that processes are sustainable and scalable. First Peoples Disability Network support us in this engagement and in facilitating NDIA access to community members. Insight from these projects has been very valuable, and we are exploring how we may formalise our input from these agencies on an ongoing basis.

Two additional areas of focus include how we effectively communicate and share information about the scheme with Indigenous and culturally and linguistically diverse groups, including designing communication and engagement strategies. Secondly, in recruitment activities, we are looking to see how we can create innovative employment opportunities to maximise engagement with Indigenous groups.¹⁰

Participants self-managing plans

5.17 The committee notes that South Australia has the highest rate of self-management of plans out of the four trial sites at 5 per cent of total plans approved with 12 per cent undertaking a combination of agency managed and self-managed.¹¹ The committee commends the early progress that the South Australian trial site has made in promoting the option of self-managing plans. In keeping with the Scheme's intent to provide greater choice and flexibility, the committee considers that there needs to be greater support and encouragement by the NDIA for participants to gain

9 Ms Meryl Zweck, *Committee Hansard*, 8 May 2014, p. 21.

10 Ms Meryl Zweck, *Committee Hansard*, 8 May 2014, p. 21.

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

the necessary skills to become self-managers of their plans and that this should be a key objective for every site.

Table 5.4: 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%
Total	72%	26%	0%	2%

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

5.18 The committee heard that self-management of plans has had a greater uptake in South Australia primarily to ensure that carers are able to manage the allotted funds under their child's transdisciplinary plan. Mrs Michaela Dollard who self manages her three year old son, Harry's package stated that:

I self-manage and have always self-managed, so again I was happy with that process, because it allowed me to spend my funding where I could. It also allowed me to try out new therapists and to access private therapy on recommendations from other parents and whomever. That was good. It was flexible and I was really happy with that.¹²

Challenges for the South Australian trial site to date

5.19 As with the other trial sites, the committee heard responses from stakeholders about areas and processes that represent challenges in the implementation of the NDIS. This section identifies some of the challenges that have faced the implementation of NDIS in progressing with the South Australian trial. The committee heard evidence that identified the following challenges in the South Australian trial site:

- transition challenges in South Australia;
- the culture within the NDIA;
- NDIA complaints and reviews;
- communications from the NDIA;
- the planning and assessment process;
- support needs assessment tool;
- transdisciplinary packages;

12 Mrs Michaela Dollard, *Committee Hansard*, 7 May 2014, p. 12.

-
- additions to transdisciplinary packages;
 - providers views of transdisciplinary packages;
 - participants using fund managers;
 - the backdating of plans; and
 - the role of advocacy.

5.20 South Australian trial site manager, Ms Zweck, gave the committee a detailed account of the challenges facing the South Australian trial site to date. Ms Zweck acknowledged and articulated the array of individual challenges stating that the organisation is constantly working to improve its operations:

We are a learning organisation and in this spirit acknowledge that there are refinements and improvements that can be made to the processes we use to implement the scheme. For example, clearer operational guidelines in regard to 'reasonable and necessary' have improved the capacity of staff to communicate their decisions with families and service providers.¹³

5.21 Ms Zweck also noted a number of site specific issues that have been particularly challenging for the NDIA staff:

...[T]hings specific to South Australia: there is a need for an increased definition for developmental delay and eligibility in access requirements; implementation of the transdisciplinary approach and the role of the primary service provider still needs to be explored and trialled; travel and transport costs to deliver a service in regional and remote areas need to be clarified; there is a need to implement strategies to ensure the continued contribution of donors in terms of fundraising; the funding for access to tier 2 supports can be an issue; and there are concerns about the impact of the increased numbers of participants and year 2 phasing.¹⁴

Transition challenges in South Australia

5.22 As highlighted above and in paragraph 5.5, a significant challenge in the South Australian trial site is the ability of the NDIA and the South Australian Government to process the increased intake of participants into the Scheme. Under the South Australian bilateral agreement, 4688 participants are scheduled to join the South Australian trial site by the end of 2014/15 (estimated cumulative total including 2013/2014 intake). This requires the NDIA to process twice as many participants in 2014–15 as it did in 2013–14. This will effectively triple the number of participants in the South Australian trial site with an additional 397 participants entering in 2015.

5.23 Both the Executive Director for Disability SA, DCSI, Mr David Caudrey, and the NDIA South Australian trial site manager, Ms Meryl Zweck, shared their concerns

13 Ms Meryl Zweck, *Committee Hansard*, 8 May 2014, p. 20.

14 Ms Meryl Zweck, *Committee Hansard*, 8 May 2014, p. 22.

with the committee regarding the capacity and readiness of the trial site to process this next cohort starting from 1 July 2014. Mr Caudrey states that in regard to 2014:

We are already beginning to be concerned, both in terms of our processes and NDIA processes, that in year two [2014] we are...working at double the rate because we are bringing in children from six through to 13.¹⁵

5.24 Ms Zweck also told the committee that in regard to the 2014 intake:

[Y]ear 2 [2014] additional participant numbers remain unresolved and expansion issues for those aged six to 13 will be considerable; and our workforce needs to be developed and implemented, particularly in the remote and regional areas...We expect to see the vast majority of participants in year 2 [2014] of the scheme, and the challenge for our staff will be to continue to provide a high level of responsive service to our current participants and providers while substantially increasing the number of participants who are seeking access to the scheme.¹⁶

5.25 Ms Zweck also said that NDIA was working to address similar transitioning issues for remote Indigenous communities in Year 2:

[R]emote Aboriginal communities; year 2 [2014] additional participant numbers remain unresolved and expansion issues for those aged six to 13 will be considerable; and our workforce needs to be developed and implemented, particularly in the remote and regional areas.¹⁷

5.26 The committee is cognisant that all sites will face increases in the number of participants requiring transition to the Scheme as it approaches full scheme. This will impact considerably on both the capacity of the jurisdiction and the NDIA to process the expected numbers. The South Australian government has highlighted this concern with the size of the current transitioning cohort and with the future cohorts commencing in 2016.

5.27 The committee understands that this issue is still being dealt with through Council of Australian Governments (COAG) and phasing arrangements for 2014/15 are yet to be finalised.

The culture within the NDIA

5.28 In understanding the culture of the Agency and how this was operating, the committee heard evidence from a number of carers about their experiences with the NDIA planners and about the culture in the Agency. Although some carers were happy, the committee heard examples where carers encountered both welcoming and unwelcoming, sometimes rude and terse behaviour during interactions with NDIA

15 Mr David Caudrey, *Committee Hansard*, 8 May 2014, p. 3.

16 Ms Meryl Zweck, *Committee Hansard*, 8 May 2014, p. 22.

17 Ms Meryl Zweck, *Committee Hansard*, 8 May 2014, p. 22.

staff. For example, Ms Diana Ots, mother of an NDIS participant, stated that she found that the staff appeared to have become very judgemental:

I am concerned about comments from planners that lead me to believe that an unhealthy culture has formed in certain NDIA offices. Comments I have heard are along the lines of: 'Other participants are asking for too much, which is why we are cutting back'. Because participants are talking to each other, they are finding out what they did not get and requesting reviews. This attitude alienates participants from each other and creates an 'us versus them' environment. I feel that the total cost of the plan should be irrelevant to the planner; it leads to judgement and pressure.¹⁸

5.29 Ms Mia Lester, mother of a two year old with multiple disabilities including blindness, recounted a similar tone from her first planning interview:

The process, I felt, was subjective and not factual. It was not based on all of the medical reports that I had provided prior to the meeting...The planner was rude. She was like talking to a machine. Her responses were just really well rehearsed.¹⁹

5.30 In examining some of these accounts, the committee spoke with the South Australian NDIA management team about the planners and the culture within the South Australian trial site. The committee enquired as to what the NDIA was doing to create a positive culture with their planners.

5.31 Ms Zweck explained that there are extensive induction training processes for new staff:

[A]s part of staff's commencement with us they took quite extensive induction training, which included those aspects of the value of the agency and the culture of the agency and reinforced what that would look like to them. The sorts of things that our planners would say to us that, I suppose, reinforce what the culture and the values are do not appear to be reflected in the perceptions or the experiences of what the families are indicating to us. So one is that sort of training approach. The other thing that we do is that we have meetings where I stand up, I talk about the vision and the culture of the agency, and I talk about that with all staff. That is then reinforced through my directors of service delivery, who work very closely with the administration staff, the planning staff and also the local area coordinators. We are continuing to message that...

...When we actually have feedback from participants, as I said before, we will actually have a discussion about that at our management team. We will talk about, 'Does that mean we need change processes in some way?'²⁰

18 Ms Diana Ots, *Committee Hansard*, 7 May 2014, p. 4.

19 Ms Mia Lester, *Committee Hansard*, 7 May 2014, p. 8.

20 Ms Meryl Zweck, *Committee Hansard*, 8 May 2014, p. 24.

5.32 In the committee's meeting with the NDIA on 8 July 2104, the NDIA Chief Executive Officer, Mr Bowen informed the committee that the Agency would be undertaking a 'culture audit' of its services that would seek to address and capture feedback on all Agency interactions with its stakeholders. In addition, NDIA stated that it was implementing a further feedback mechanism in each trial site of conducting regular local participation forums.²¹

5.33 The committee also heard from the Operations General Manager, Ms Liz Cairns who told the committee that the NDIA's quality framework is expanding to cover more qualitative data and KPIs on the Agency's interactions with stakeholders:

We have had a quality framework in place since July last year. I have just recruited a new quality and innovation team that is taking the existing framework, which I think has provided us with some useful information to date, but clearly needs to be expanded, both in response to this process and also in response to where we are in our organisation.

So it will catch all the possible sources of information, including the qualitative customer satisfaction engagement that we need to do in addition to the survey. It will look at complaints. It will drill into records in terms of timeliness of responses. Then run we will run that through a continuous improvement process. The outcome of that will effectively be a recourse analysis: what is the change; what is the reason for a particular issue or deficit; is it about an individual staff member; is it broader than that; is it a training issue; does it need to be dealt with by way of a process change?

The other thing we are introducing is a set of KPIs for the operation staff, which will talk to the key deliverables of the scheme—for example, client outcomes being achieved and scheme sustainability. But in response to this particular issue we have two. One is around timeliness; particular time frames around responsiveness to phone calls, emails and written communication. And an aspect of the KPI for each individual will be their score against our behaviours and values.²²

NDIA complaints and reviews

5.34 In providing the committee with information about the achievements of the South Australian trial site, NDIA trial site manager, Ms Zweck noted that the trial site had received:

...37 complaints and 18 requests for a review of decision. An application for review has been lodged with the Administrative Appeals Tribunal.²³

5.35 In reference to the complaints, the Ms Zweck stated that:

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

22 Ms Liz Cairns, *Transcript of meeting with the NDIA*, 8 July 2014, p. 4.

23 Ms Meryl Zweck, *Committee Hansard*, 8 May 2014, p. 20.

These complaints [the above quote] largely relate to funded supports, particularly the level of reasonable and necessary supports included in plans, the implementation of the transdisciplinary approaches and planning outcomes. Many of the latter arise from confusion with the definition of the no-disadvantage provisions agreed between governments. While many have interpreted this as ensuring maintenance of the dollar value of specific items, the agency has attempted to retain a focus on maintaining and/or increasing the overall outcomes for the person in the context of the goals of the scheme and as required under the intergovernmental agreement.²⁴

Communications from the NDIA

5.36 A concern that was consistently raised with the committee by participants and providers who participated in the hearing in Adelaide is the complexity of the Scheme and lack of clarity of information provided by the Agency. The committee notes that others not present at the hearing may not have had the same experiences.

5.37 Mr Philip Martin, Chief Executive Officer, Muscular Dystrophy Association noted that:

From our point of view, regrettably, the vagaries of the political system and the inconsistency of the parameters for the trial sites have created circumstances where a lot of clients are very confused about when they can get something and what they can get. It was initially in fact overpromised and at this point under-delivered. Many of our direct service workers and our clients are overwhelmed by the volume of changing information and the nature of the information. We would ask the agency to consider a series of well thought through, clearly articulated information to families and people with disability... We are getting a lot of information directly from the agency about what is happening in the rollout, but it is without context of what may be available within the new system.²⁵

5.38 Evidence has also been brought to the committee's attention of the constant changing of documents on the NDIA website with little version control to identify whether a particular document is current or not. A recent example brought to the committee's attention, was the *NDIS planning guide and workbook* that one day appeared with a new section, *Step 4 Approve your plan*—that stated:

...that your planner would send you a copy of your plan to approve, and if you are happy the supports will meet your needs and how they will be managed, you can approve your plan.²⁶

5.39 A new version appeared on the NDIA website a day or so later where Step 4 becomes *Implement your plan* with no mention of approving it or the supports.²⁷

24 Ms Meryl Zweck, *Committee Hansard*, 8 May 2014, p. 20.

25 Mr Philip Martin, *Committee Hansard*, 7 May 2014, p. 30.

26 National Disability Insurance Agency, *Planning guide*, 16 June 2014, p. 13.

5.40 The committee also heard evidence from Ms Anna Van Den Brook, mother of three year old Amir, who spoke about the challenges of getting accurate information about a lifting device and vehicle modifications she required for her child:

I was told to refer to the NDIA website at my last meeting in November regarding vehicle modifications. They said the guidelines were on there. I spent ages searching the website, and they were not up. I contacted the NDIA a number of times before they got back to me and was told, they're being altered and we'll email them to you.' So they were not on the website. Quite frankly, I do not have a spare minute in my day to sit down searching for things that people should know are there. I got them and the early guidelines stated that vehicle modifications would not be provided for children under five.²⁸

5.41 On a related communications issue, Mrs Louise Trinkle, mother of an NDIS participant referred to the NDIA not returning phone calls and e-mails.²⁹

5.42 In replying to questions from the committee on the issue of poor communications, the NDIA acknowledged that clear and concise communications is an issue they are addressing:

Our communication and agency communication products could be improved at all levels, including in our interactions with families and carers and in describing the participant pathways, our decisions and the review options. Plan implementation is challenging for all parties. For example, where there are multiple providers within a transdisciplinary package, it can be difficult.³⁰

5.43 The committee heard from Dr Bruce Bonyhady that the Agency is working with a greater focus to improve communications consistency:

...[W]e are working to strengthen our training and internal and external communications. So, for example, guidelines are guidelines and there is greater consistency.³¹

5.44 After Ms Lester recounted the reception she received in her first planning meeting, she explained the change in the planner's behaviour at the next meeting. She also explained that before attending the second meeting she engaged the services of a professional advocate to assist her with the planning assessment:

Between the first planning meeting and the repeat planning meeting the tone was very different. It seemed as though the planner had actually read all of the reports that I had provided. I sort of felt like there was such a shift

27 National Disability Insurance Agency, *Planning guide and workbook*, 20 June 2014, p. 13.

28 Ms Anna Van Den Brook, *Committee Hansard*, 7 May 2014, p. 6.

29 Mrs Louise Trinkle, *Committee Hansard*, 7 May 2014, p. 20.

30 Ms Meryl Zweck, *Committee Hansard*, 8 May 2014, p. 21.

31 Dr Bruce Bonyhady, *Transcript of meeting with the NDIA*, p. 1.

in her attitude, her tone with me, that it was more to get rid of me, because I had sent her a formal agenda that I had set for the second meeting. I had refused to come on site and said that I would be calling the meeting in home with my advocate and with my husband present. The second planning meeting, I felt as though from that first meeting, where she had said to me, 'Expect to get nothing more than one home visit a week,' all of a sudden I had the funds to pay for two, plus one on site somewhere. I was also provided with a draft plan, which I was told did not exist, was not a possibility.³²

5.45 The committee in its future work plan will monitor the implementation of these remedial actions.

The planning and assessment process

5.46 The committee heard evidence about a range of matters relating to the planning and assessment process. These include information about the assessment process, attitudes and conduct of planners and the importance of tailoring plans to suit individual needs.

5.47 The majority of participants' carers at the South Australian hearing told the committee that they felt confused about the planning process. The committee reiterates that there was only a small number of witnesses at the hearing. Participants' carers explained that they would have a conversation with the planner and come to a verbal agreement, that would agree to some supports but not others—which they felt were required. The carer would want to pursue the missing support but would be told they can only dispute the plan if they agree to the plan. And if they agreed to the plan they would not want to draw on it because they wanted the missing support.

5.48 Ms Lester described her daughter's first planning session:

I felt my treatment during the planning meeting was disgusting. I was not listened to. I was not allowed to discuss everything I had brought with me. The way that the planning process started was with the planner putting her hand up to me and telling me to stop and that she would be asking the questions. I had put a lot of time and effort into preparing for that meeting. I would probably estimate it at about 50 hours. The planner only had the decency to take one little piece of paper that I had brought in with me with her to look through at a later stage. I felt the planner assessed my daughter's competencies on the spot with trivial questions based on my opinion from which she made her own assumptions. I was only allowed to choose three or four of the most important goals for my list for my daughter, as if the rest were not really important enough to be considered.³³

32 Ms Mia Lester, *Committee Hansard*, 7 May 2014, p. 8.

33 Ms Mia Lester, *Committee Hansard*, 7 May 2014, p. 8.

5.49 The committee heard from Mrs Dollard who told the committee about how the funding in the plans didn't take account of the interplay between the age of the child and what their next stage of development is in going to kindergarten or going to school:

My son is about to start kindie...I was not aware...that each of our therapists will need to visit the kindie... A quarter of his therapy will actually be assigned to training kindie staff and developing programs for them. Once you take a quarter out of a 50 per cent drop then that is another huge thing.³⁴

5.50 The committee asked the NDIA if it could clarify how the planning process functioned—how much is written down and how much is done separately by each planner. Ms Zweck responded by explaining that:

Once we have had that planning conversation and we develop the plan that includes the funded supports we would have a discussion again with parents about that. That may not necessarily be face to face; it could be over the telephone. We would talk to them about what their package would look like and we would try to have a negotiation to resolve things at that point.³⁵

5.51 Ms Zweck added that:

We do have a senior planner for quality assurance, who actually works very closely with those people who seek a review of our decisions and also undertakes the independent internal review. We also have a national quality assurance framework, where we start to look at particular areas that might be themes. That is, to look at things like access decisions, what is included in funded support plans and those sorts of things. It gives us actual feedback around quality assurance.³⁶

5.52 In response to a question from the committee about whether anything was written and provided to participants or if plans are provided upon participant's request, Ms Zweck responded:

We would usually talk about it verbally with, potentially, a draft plan, but we do not necessarily want to bring the plan into being yet

...

we cannot provide it as an approved plan—but as a draft, yes.³⁷

5.53 The committee also asked whether anything was provided to participants in writing, during the planning process about the no disadvantage test. NDIA Operations General Manager, Ms Liz Cairns, responded:

34 Mrs Dollard, *Committee Hansard*, 7 May 2014, p. 14.

35 Ms Meryl Zweck, *Committee Hansard*, 8 May 2014, p. 23.

36 Ms Meryl Zweck, *Committee Hansard*, 8 May 2014, p. 24.

37 Ms Meryl Zweck, *Committee Hansard*, 8 May 2014, p. 29.

I do not think it is, but I think it is a really good idea and we will take it back, I think, as part of the need to have really appropriate communication products. We are trying to convey some really complex agreements.³⁸

5.54 The committee is aware that the confidence of the public in the Agency and the success of the NDIS will rest in part with how well the Agency is able to communicate effectively with its stakeholders. The committee welcomes the Agency's implementation of strategies to receive feedback and assess and improve behaviour and communications across the Agency and will continue to monitor their success during the life of the committee.

Recommendation 4

5.55 The committee recommends that as part of the planning process, NDIA implement a process similar to normal insurance industry practices, where participants are provided with: clear disclosure documentation (about the planning process that includes reference to the 'no disadvantage test'); a written draft plan; incorporates a 'cooling-off' before a package is agreed; and requires participants to sign their final agreed plans. The committee believes that this is a fundamental element of the original intent of the policy to empower and provide choice to people with a disability in the National Disability Insurance Scheme.

The Support Needs Assessment Tool

5.56 The committee heard how the Support Needs Assessment Tool plays a significant role in assisting an NDIA planner to assess the appropriate support package for a participant.

5.57 The committee asked the Chief Executive Officer for Autism SA, Mr Jon Martin what role his organisation had in assisting in the development of the assessment tools to assess children with autism. Mr Martin responded saying that Autism SA had:

No formal role at all. We are involved in the trial site working party and have been allowed to comment on particular elements of both the eligibility criteria and the layered approach to the funding levels for the transdisciplinary package. But we feel that this has happened almost after the horse has bolted. It would have been good to have that information and advice early in the piece, considering the extensive work done around the Helping Children with Autism package and also the Better Start program. There was a lot of information gathered on best practice, how diagnosticians link with service delivery planning—all those kinds of things. That has not really been considered or incorporated, from our perspective, into the planning and assessment model.³⁹

38 Ms Liz Cairns, *Committee Hansard*, 8 May 2014, p. 29.

39 Mr Jon Martin, *Committee Hansard*, 7 May 2014, p. 32.

5.58 Mr Martin in response to further questions about whether the assessment tool needs further work for testing autistic children replied that he thought it was:

[A] very generic tool that is more geared towards people who are physically or cognitively disabled. It does not necessarily pick up on the sensitivities related to autism spectrum disorder.⁴⁰

5.59 Mr Martin added that:

In South Australia we have a very comprehensive process with the diagnosticians network that we operate. The diagnosis is made on the basis of a multidisciplinary assessment. They have all been accepted by the NDIA. But nationally there is not a consistent approach to diagnostic assessment. I know in other states and territories where there are launch sites they have experienced difficulties.⁴¹

5.60 The committee asked the NDIA if they were undertaking any work into the early childhood intervention issues. Ms Cairns responded stating that:

Ongoing work is continuing between that part of the agency and the sector more broadly about establishing what the evidence base is, including some of the high-end, complex autism programs.⁴²

The trans-disciplinary packages

5.61 The majority of participants (90 per cent⁴³) that entered the NDIS in the first year of the South Australian trial site require Early Childhood Intervention Services (ECIS) which provides specialised support and services for infants and young children with developmental delays or disabilities. Often, because of the level of multiple disabilities these children have, they require coordinated multidisciplinary services that interface across disability, health, education and Indigenous services. Additionally, South Australia also has the second highest incidence (26 per cent) of autism across the trial sites.⁴⁴

5.62 The funding of an early intervention for children with disabilities was one of the central ideas regarding the economic sustainability in disability funding identified by the Productivity Commission in its 2011 report, *Disability Care and Support* (PC Report) which states:

...[T]he overarching objective of early intervention is to incur expenditure on a particular intervention today that, not only improves individual

40 Mr Jon Martin, *Committee Hansard*, 7 May 2014, p. 32.

41 Mr Jon Martin, *Committee Hansard*, 7 May 2014, p. 32.

42 Ms Liz Cairns, *Committee Hansard*, 8 May 2014, p. 26.

43 National Disability Insurance Agency, *Quarterly Report to COAG Disability Reform Council*, 31 March 2014, p. 13.

44 National Disability Insurance Agency, *Quarterly Report to COAG Disability Reform Council*, 31 March 2014, p. 33.

outcomes beyond that which would occur in the absence of the intervention, but lowers the costs and impacts associated with the disability for individuals and the wider community over the longer-term.⁴⁵

5.63 The committee notes that in recognising the ECIS requirement for a coordinated approach, the NDIA introduced multidisciplinary packages referred to as trans-disciplinary (TD) packages in October 2013. The NDIA told the committee that the development of the packages were:

[I]nformed by experts in early childhood services that evidence based practice requires a transdisciplinary, family centred, key worker approach to services to children with disability under six and their families.

Transdisciplinary teamwork involves a team of professionals who work collaboratively, and share the responsibilities of evaluating, planning and implementing services to children and their families. Families are valued members of the team, and are involved in all aspects of intervention. One professional is chosen as the primary service provider for the family, and acts as the conduit for the expertise of the team. The full team remains involved, and the primary provider reports back to the team constantly.⁴⁶

5.64 As a result of their young age, South Australian participants' packages were made shorter in length than other trial site packages. As such, the trial site has the highest number of plans that require early review of any site at 23 per cent, as noted in the *Third Quarterly Report*:

[T]he proportion of plans requiring review less than 12 months after the plan commenced is higher in South Australia compared to the other trial sites, as expected, as South Australia only has 0-5 year olds in the Scheme. However this proportion has fallen substantially since the previous report. As participants move to their second and subsequent plans, the distribution of plan lengths in South Australia has shifted away from 3-6 monthly plans towards annual plans.⁴⁷

5.65 At the Adelaide hearing, the NDIA told the committee that it has recognised that many of these ECIS children have multiple needs that impact on the level and cost of care that they require. The NDIA stated that:

The majority of [these] participants and their families are accessing the scheme under early intervention provisions. Transdisciplinary packages are increasingly being funded to support families to enable flexibility and recognise the frequently changing needs of young children, and access and information is being provided state-wide through a network of metropolitan

45 Productivity Commission, *Disability Care and Support*, 10 August 2011, pp 608 – 609.

46 National Disability Insurance Agency, *Early childhood intervention – transdisciplinary approach to service provision, Information for NDIA staff, service providers participant families*, 2 October 2013, p. 1.

47 National Disability Insurance Agency, *Quarterly Report to COAG Disability Reform Council*, 31 March 2014, p. 13.

and regionally based local area coordinators. The scheme is ensuring that parents are linked into local mainstream supports and is strengthening the sustainability of supports provided by families and carers. There are early indications of providers expanding their services and developing innovative responses to enable choice for participants.⁴⁸

5.66 In the *Second Quarterly Report* (December 2013) the Scheme Actuary foreshadowed that new operational guidelines were being developed for a number of supports :

[O]perational reforms are underway, such as development of guidelines for typical volumes of travel, domestic assistance, community participation, therapy, and respite, along with work on a national assistive technology strategy. Implementation of these reforms will impact trend analysis.⁴⁹

5.67 The committee heard that due to their short length many of the South Australian packages came up for review in early 2014, and some carers were shocked and dismayed when they found that their new package funds were cut by approximately half with no explanation.⁵⁰

5.68 Mrs Michaela Dollard who reported a very positive initial planning experience found the second planning meeting quite different:

When it came to our second plan meeting, our funds were about to run out. It was booked in for about a week before. I had been trying to get a meeting before that, but they were very busy. It did not happen with our planner either, so it was someone completely new, someone I had not met before. Because of how well the first plan meeting went, in hindsight I went in a little naively, thinking it was going to be the same. Looking back, I probably was not as prepared as I should have been, but I was not given any documentation on what to bring with me and I was not told that I would need to fight our case again. I assumed that we would have a bit of a rollover. Everything was working; Harry was making great gains. Why wouldn't we just keep the plan the same?

His second plan is slightly less than half of his first plan. At the meeting I felt quite bamboozled. I realised I was quite ill-prepared for it and I was not prepared to go into battle either. I did not realise that is what was going to have to happen.⁵¹

5.69 The committee heard from Mrs Wendy Hosking who had been supporting her six year old by increasing her mortgage until she gained entry into the Scheme. Mrs Hosking explained that at her first planning interview she was told:

48 Ms Meryl Zweck, *Committee Hansard*, 8 May 2014, p. 21.

49 National Disability Insurance Agency, *Quarterly Report to COAG Disability Reform Council*, 31 December, 2014, pp 14-15.

50 Mrs Michaela Dollard, *Committee Hansard*, 7 May 2014, p. 14.

51 Mrs Michaela Dollard, *Committee Hansard*, 7 May 2014, p. 14.

'We are now approving transdisciplinary packages for a maximum amount of \$12,000. I have the discretion to approve up to \$16,000 in more complex cases.' She said: 'More can be approved if it goes to a higher authority...

That was a shock because initially we had been told it would be needs based. What I was asking for and what we are currently providing is well beyond that, so obviously it was not going to go nearly as far as we had hoped...

The process of the NDIS planning had already put a lot of stress on us to get it all ready; I thought, 'Emotionally I can't cope with having to appeal this, so I won't go to an appeal. I will just accept what I've got; I've had nothing so it's a bonus.' And I do really appreciate it, because I do not feel, necessarily, that the government should be paying for my daughter.⁵²

5.70 The reduction in package costs may not affect all South Australian recipients as mentioned by Ms Ots who commented:

[P]articipants that are reasonably happy are the ones with the more minor or moderate disabilities. They pretty much seem to be happy with the system, from my experience. The ones who have anything a little bit more complex are the ones who are not happy. There are big gaps in the crossover between medical treatment, therapy and the schooling system—nobody knows where medical goes or where therapy starts. There are a lot of gaps. The more complex the issue, the more gaps. There is no differentiation between a minor thing and a more severe complex one.⁵³

5.71 A number of carers also spoke to the committee regarding the consistency of the packages for similar disabilities, Mrs Liz Cohen noted the inconsistency of planner's decisions to include travel costs in the TD plan:

Families have been upset that travel has not been separated out of the transdisciplinary package and put within the package where other families have actually had it separated from that service provision. We would just like to identify that there are some inconsistencies with what families are receiving and we know—everybody in this room would know—that families talk, and so they are very well aware of what they are receiving and what other families are receiving.⁵⁴

5.72 The committee questioned the NDIA on the 8 May 2014—noting it had heard similar examples at both the Barwon and Hunter trial sites related to children's TD packages—as to whether the NDIA had provided sufficient rational reasons why their packages were cut by half. Ms Zweck stated that:

52 Mrs Wendy Hosking, *Committee Hansard*, 7 May 2014, p. 16.

53 Ms Diana Ots, *Committee Hansard*, 7 May 2014, p. 21.

54 Mrs Cohen, *Committee Hansard*, 7 May 2014 p. 33. NDIA state in their Pricing, Payments and Supports document that travel costs are to be included in the cost quoted for a program of supports, such as trans-disciplinary early childhood intervention, and are not payable as additional items.

I think what I am also hearing from you is the way that we communicate that decision is not clear to families, that they do not actually understand what the reasons are behind it.⁵⁵

5.73 The committee enquired about the timeframe for the introduction of the TD approach and the decision to set them at particular levels. The NDIA explained that there had been a change in policy and that new TD packages and operational guidelines were introduced in January 2014.

5.74 The advice contained in the NDIA fact sheet accompanying the operational guidelines for TD packages for children states that:

Costing of services is to be within the pricing levels outlined on the Agency's price list. Provision of a mix of therapies and a key worker for the family are expected to fall into one of the three categories;

- a) Level 1 – low needs – up to \$6000 to \$8000 per annum,
- b) Level 2 – medium needs - \$8001 to \$12000 per annum, or
- c) Level 3 – high needs - \$12 0001 to \$16000 per annum.

Level 1 (low needs) is generally appropriate for a child with a developmental delay, or mild disability, who is developing slower than their peers.

Level 2 (medium needs) is generally appropriate for a child with a disability or developmental delay who either has moderate single and/or multiple areas of needs/concern that require specific intervention, or behavioural concerns or some family complexities that require referral to other agencies.

Level 3 (high needs) is generally appropriate for a child with a disability and/or severe developmental delay, multiple disabilities, severe behavioural difficulties, rapid deterioration and/or complex health/medical needs who has severe and/or needs that require specific intervention.

It is expected that the NDIS will fund necessary and reasonable early childhood interventions that are intensive where the intervention is able to deliver significant improvements within a period of approximately 6months. Up to four periods of early intervention may be funded.⁵⁶

5.75 Ms Liz Cairns, NDIA's Operations General Manager said that:

55 Ms Meryl Zweck, *Committee Hansard*, 8 May 2014, p. 27.

56 National Disability Insurance Agency, *Individualised transdisciplinary services for children with disability*, Fact sheet: NDIA staff, service providers participant families, 6 May 2014, p. 2. See also National Disability Insurance Agency, *Operational Guideline – Planning and Assessment – Supports in the Plan – Supports for Early Childhood (v 1.0)*, 11 March 2014, http://www.ndis.gov.au/sites/default/files/documents/og_plan_assess_supports_early_childhood.pdf (accessed 22 July 2014).

The operational guidelines are designed to support staff in what we understand is likely to be an appropriate response to a typical circumstance. They are not caps, and they are not limits.⁵⁷

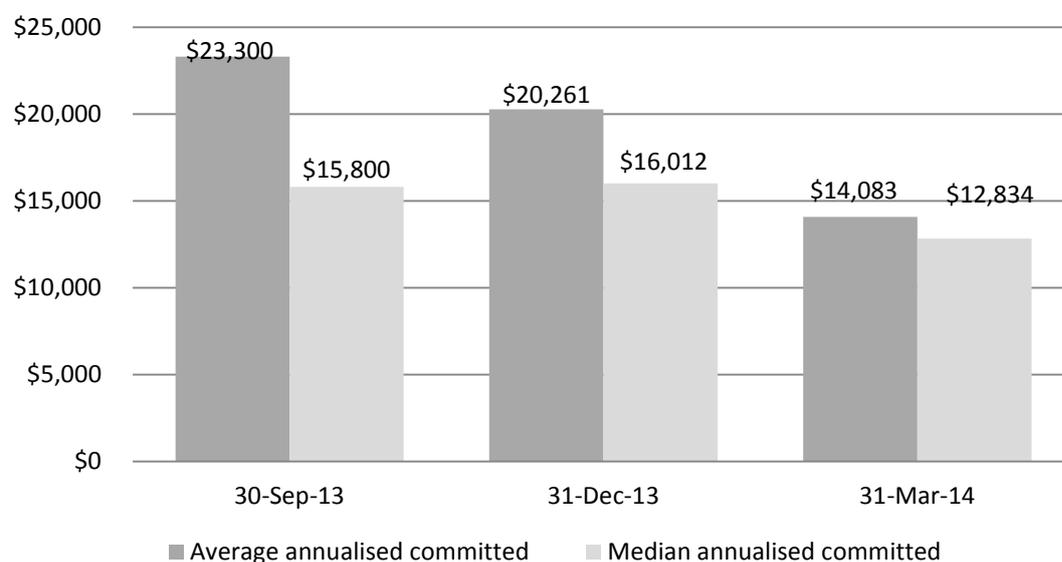
5.76 This point was reiterated by Dr Bonyhady at the public hearing in Canberra:

The operational guidelines make it very clear that these are guidelines. They are not mandatory limits.⁵⁸

5.77 In the NDIA's first quarter report, the average annualised plan cost in South Australia was \$23,300 and the median price point was \$15,800. At the end of the third quarter in March 2014, after the implementation of the new operational guidelines, the South Australian average annualised package had reduced to \$14,083 and the medium annualised committed package cost was down to \$12,834.

5.78 Since the introduction of the new operational guidelines for TD packages in January 2014, the average annualised package cost for South Australia decreased by \$6178 from the December 2013 quarter. As of the 31 March 2014, the South Australian package costs are the lowest average annualised package cost out of the four trial sites. The change in average South Australian package cost can be seen in Figure 5.1 below.

Figure 5.1: South Australian annualised package costs



Source: National Disability Insurance Agency, Table 2.1.9. *Real, average and median costs of individualised support packages*, Quarterly Reports to COAG Disability Reform Council: 30 September 2013, p. 38; 31 December 2013, p. 54; and 31 March 2014, p. 30.

57 Ms Liz Cairns, *Committee Hansard*, 8 May 2014, p. 24.

58 Mr Bruce Bonyhady, *Committee Hansard*, 14 May 2014, p. 4.

5.79 While the NDIA emphatically states that there is no cap or limit on the TD packages, the committee is of the view that the effect that the operational guideline advice had on planners would appear to have significantly influenced a reduction in approval of the cost of packages.

Additions to trans-disciplinary packages

5.80 This section highlights the issue of where the new funding levels are insufficient to cover a range of supports required by a participant. The committee heard evidence that when the requested package supports exceed the standard level 1–3 packages (see paragraph 5.74), the local planner is unable to grant approval. The committee noted that this requires approval to be sought from NDIA executive—generally in Canberra—which takes some time and then potentially jeopardises meeting the early intervention needs of the child.

5.81 Providers also gave evidence regarding TD packages, stating that much of what an individual actually receives as a package often depends on their ability to articulate their needs which raises the issue of the role of effective advocacy that will be discussed further on in this chapter. Mrs Amanda Haskard stated that:

If you have a standard TD plan they are going through quite nicely. When you have requests that are over and above, then, lately, it does feel like each one of those then needs to go through some kind of escalation method. It was not like that in the early days. So I do feel that there has been a shift.⁵⁹

5.82 With the changes made to transdisciplinary packages, many carers have told the committee of the long waiting periods 'for a decision from Canberra' for approval of supports that exceed the standard funding levels 1-3. Ms Amanda Van Den Brook relayed her frustration:

I got the plan. I really do not have time to sit down and go through and try to understand how this all works—is something funded or is something not funded?—and I feel that no-one really explained terms to me. We were talking about reviews and appeals and getting things added on. I have requested things to be added on and I have been told to fill in a review and go through it that way. I do not have time for that. I emailed and asked for simple, small things to be added on, and I have not received any response. It has been over a month and I have not received a response, and the email has been resent. I do not have time to go for reviews and I do not have time to go through appeals.⁶⁰

5.83 The committee at its 8 July meeting received evidence from the NDIA which indicated that 10.5 per cent of children in South Australia with a primary diagnosis of autism have plans where the agreed costs of early intervention exceed the guidelines of \$16 000.

59 Mrs Amanda Haskard, *Committee Hansard*, 7 May 2014, p. 26.

60 Ms Van Den Brook, *Committee Hansard*, 7 May 2014, p. 7.

5.84 The NDIA also provided evidence to the committee that stated as at 31 March 2014, across the Scheme, there were 1558 children aged 0–6 years with an approved plan. Of these children, 267 exceed \$20 000 when calculated at an annualised cost (NDIA notes that some of these plans were for periods less than 12 months).⁶¹

Provider views on trans-disciplinary packages

5.85 The committee also heard from providers regarding the impact of the TD packages and how the levels of funding amounts are impacting children's services particularly for children who are deaf or hearing impaired. Mr Michael Forwood, Chief Executive Officer for Cora Barclay Centre told the committee that:

Some of the recent changes to the so-called transdisciplinary funding packages put a few things in jeopardy. In the first place, if a child only has one disability, \$16,000 does not cover the cost of the early intervention program, which would cost more like \$20,000 to \$22,000 per child per annum. Secondly, the newly introduced high, medium and low cost differential brought in within the TD package as indicative caps of funding based on the perceived extent of the disability does not work with children who are deaf and hearing impaired. Logically, this may be appropriate and applicable for people who have got care needs related to intellectual and physical disabilities, but to learn to listen and speak and to participate effectively in the mainstream school system someone with bilateral hearing loss that is mild or moderate will need the same program as a person who has severe and profound hearing loss. In fact, some of the children with lower levels of hearing loss may be disadvantaged when compared to kids who are profoundly bilaterally deaf who have got dual implants because the access to speech and language available to a bilaterally implanted child could be superior to that available to a child who has bilateral moderate loss or moderate-severe loss. This is the technology that helps the kids here who have implants.⁶²

5.86 Mr Forwood continued, noting the commercial impact of what he described as the TD funding caps on his business and sharing the advice that he had provided the NDIA. The committee, as mentioned at paragraph 5.74, has been advised by the NDIA that there are no funding caps:

We have said to the NDIA and I have said to David Bowen [NDIA CEO] that if you fund a \$22,000 per child per annum program for 70 kids at a rate of \$16,000, \$12,000 or \$10,000, we will either be out of business within two or three years, because it will not be financially sustainable, or we will have to compromise the program. We have measured and published the outcomes of centres catering for a cohort of over 700 children with hearing loss but no additional disabilities, and over 90 per cent of the children develop age-appropriate speech, language and comprehension by age 5... The tightening up of funding through capping and squeezing—a

61 Mr David Bowen, *Correspondence with Committee*, 8 July 2014, p 3.

62 Mr Michael Forwood, *Committee Hansard*, 7 May 2014, p. 28.

phenomena of the last couple months—puts in jeopardy the objects of the scheme.⁶³

5.87 In written evidence provided on 8 July 2014, the NDIA noted that it is commissioning work on developing the guideline approach for autism. The Agency has engaged an internationally recognised epidemiologist and academic, Dr Katrina Williams, to convene a group of experts to update the research evidence for the management of autism. It told the committee that this work will lead to the development of more specific guidelines for needs assessment and reasonable and necessary interventions for children with autism. The NDIA will also commission a similar project for children with sensory disabilities (hearing and/or visual impairment).

Recommendation 5

5.88 Based on the evidence received on trans-disciplinary packages, the committee recommends that the Agency undertake a review of the current arrangements regarding trans-disciplinary packages, in particular, the operational guidelines and advice and training it provides to its planners. This review should encompass and be informed not just by clinical experts and researchers, but it should also consult participants, carers and providers.

The backdating of plans

5.89 The committee heard of a number of incidents where participant's plans had had their start date backdated. This issue of backdating plans had been raised with the committee at other trial sites (see chapters 2 and 4). The implications of backdating, which were also raised in the Barwon chapter, were that some providers were impacted in that they incurred expenses for services from packages which were not valid.

5.90 The committee discussed this issue with the NDIS at two separate private meetings in Canberra. The NDIA Chief Executive Officer, Mr David Bowen, told the committee that there had been two ICT system errors that had affected how dates were registered in the NDIA system:

I have done some investigation on this and I would like to start by saying that there is not one instance we have discovered where a planner has deliberately backdated a plan. But we have two system problems that were in fact resolved by December. The first was that during July-August, when we were just starting, planners were putting on the plan the date when they commenced the discussion and that was being reported as the commencement date. When the word 'dataset' was going to the states they were using that to turn off supports for people, and that was leading to a service gap because the date the plan is effective is the date of the plan approval.

63 Mr Michael Forwood, *Committee Hansard*, 7 May 2014, pp 28–29.

...

That is the first one. The second one is also a system problem, in that we would have a plan that was concluded and approved. A person would come in and have a discussion about some variation to supports. When we made those variations to the supports, the system we were operating in did a write-over of the approval date. So you had a circumstance where a plan had a date of commencement that was earlier than the date of approval, because the date of approval had been written over with the latest date.

When I first heard this I thought, 'It is extraordinary that we are operating in a system that does a write-over in what is supposed to be a longitudinal database.' So we have fixed that up. While the date will change, we have a record of the first day on which the plan was approved, and that is the date on which the services commence.⁶⁴

5.91 The NDIS has since acknowledged that a number of providers had been impacted and that it has made a commitment to reimburse providers for any out-of-pocket expenses upon receipt of an itemised invoice.⁶⁵

The role of advocacy

5.92 The committee also heard from a number of carers and providers who spoke of the benefits of using an advocate to assist them with the planning process, particularly in understanding the complexity of the Scheme and providing support through the planning process. Ms Lester advised:

I had read every booklet, leaflet and pamphlet I could get my hands on that were provided at all the morning teas and seminars prior to my daughter becoming a participant of the scheme. I had read the word 'advocate' many times. I have gone back through all of these booklets and I cannot actually find anywhere that says there are organisations of advocates. I do not know whether that is because I am young or I have not asked the right questions, but during the whole process I was never told that there is actually a group of people who can be advocates rather than just me presuming that I am the advocate of my daughter.⁶⁶

5.93 The committee enquired as to how Ms Lester found this person.

I had started a Facebook page for my daughter... It was purely a fluke that one of those people, who has a child with a disability who she has been dealing with for 15 years, asked me, 'Have you called an advocate?' I said, 'What do you mean?' She gave me the number of an agency. I called the agency and they commenced assisting us immediately...Without her I would not have known that I could question many things that I had many more rights than I was led to believe. She is on her way. She had a meeting

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

65 Mr David Bowen, *Correspondence received*, 8 July 2014, p. 3.

66 Ms Mia Lester, *Committee Hansard*, 7 May 2014, p. 11.

today that she could not cancel. I tell everyone I talk to, 'Get yourself an advocate,' because she has been worth her weight in gold. She gave feedback to me that the NDIS was insinuating that advocates would not be required anymore because of this fantastic new scheme where everybody has choice and control. Mine was the first complaint that she received and, since me, she says they have not stopped coming. I am wondering how many other people do not realise that there are actually organisations of advocates rather than just this wishy-washy 'advocate' word that is in all of the literature.⁶⁷

5.94 The committee also heard from Mrs Amanda Haskard about advocates sitting in on planning meetings:

As a support provider, we are offering to be at the planning meetings with them. We have had a little bit of resistance of that from the agency. We understand their point as to why they do not necessarily want providers at meetings, but we believe it is parents' choice to have us there. We are circumventing it by generally attending all of the planning meetings with our families.⁶⁸

5.95 The committee also heard from Mr Phillip Martin, Chief Executive Officer of the Muscular Dystrophy Association, on the importance of advocacy services:

I believe this system is exceptionally vulnerable to decisions that were taken between six and eight years ago to remove funding for advocacy, which has then left a hole in the planning and a major gap in the development of cost-beneficial or cost-neutral outcomes as well as the opportunity to get maximum outcomes for people.⁶⁹

5.96 Mr Martin expanded on the advocacy role especially concerning autism advocacy services:

At the moment we have block grant funding from the Commonwealth, individualised funding from the Commonwealth, block grant funding from the state, individualised funding from the state and individualised funding under an NDIS model. The autism adviser roles, for example, are funded by a block grant from the Commonwealth. We have been put on notice that it is highly unlikely that they will continue, though they have been an immense and very effective support for the autism community in assisting families—especially in the pre-planning process before families even get to the NDIA—through the process of getting to understand the diagnosis; working through the grief process with accepting a diagnosis; how families can tell their extended family members; how to support siblings of the person with the diagnosis through that process; and what kinds of supports and systems might be necessary to best move that family to a position where they are effectively integrating and supporting their son or daughter.

67 Ms Mia Lester, *Committee Hansard*, 7 May 2014, p. 11.

68 Mrs Amanda Haskard, *Committee Hansard*, 7 May 2014, p. 27.

69 Mr Phillip Martin, *Committee Hansard*, 7 May 2014, p. 31.

So we would like that to continue, in terms of the autism adviser role, but, as I said, we have been put on notice that that is unlikely to continue.⁷⁰

Recommendation 6

5.97 The committee notes the importance of the role of advocacy services in ensuring quality plans and supporting participants in the planning process. The committee recommends that certainty regarding the role and support for advocacy services in the NDIS be urgently resolved through the Ministerial Disability Reform Council.

Committee view

5.98 The committee recognises that there have been many achievements made in the South Australian NDIS trial. Many participants are receiving supports and moving on with their lives. Perhaps as expected, because of the age cohort South Australia has had a difficult and emotional experience transitioning to the NDIS. As Mr Jon Martin said:

We are implementing an NDIS, and if that were all we were doing we would probably be going full throttle, gung-ho, and achieving unbelievable outcomes. But we are also trying to unscramble the state funding system and moving to individualised funding. We are also trying to unscramble the old Commonwealth system with HCWA and Better Start.⁷¹

5.99 There are many significant challenges identified in the South Australian trial site. Some of these challenges are common to all trial sites, such as the accessibility and readability of information for participants and carers and the need for a more consistent approach to communications. Others are just emerging such as working with regional and remote communities and Indigenous people with a disability. However, some of the challenges in South Australia are not unique but more prevalent due to the age cohort currently transitioning into the Scheme.

5.100 In moving forward, the committee notes that the NDIS has indicated that it will be working closely with all stakeholders to continually improve processes and particularly the planning process in respect to children and autism. The planning conversation and draft plan need further consideration specifically as highlighted the inclusion of a cooling-off period and a right to appeal before a plan is implemented.

5.101 Furthermore, the committee consistently heard that participants want to sign their final plan. The committee is of the view that this is not just about completing a process; it is central to the overall intent of the Scheme to increase choice and control. It is also about empowering the participants in taking their first steps to achieving their goals.

70 Mr Jon Martin, *Committee Hansard*, 7 May 2014, p. 32.

71 Mr Jon Martin, Chief Executive Officer, Autism SA, *Committee Hansard*, 7 May 2014, p. 32.

5.102 It is evident to the committee that some plans, particularly some trans-disciplinary plans, have been assessed strictly in accordance with the operational guidelines by planners and as such have excluded some participants from the supports they require. Where this is particularly a concern is in respect to children who quite clearly have permanent disability such as hearing loss, and where early intervention will provide cost-effective outcomes exactly as envisaged by the Productivity Commission, it is unacceptable. The committee was however encouraged by NDIA's acknowledgement at the hearing that:

The guidelines...are not cast in concrete. Ongoing work is continuing between... the agency and the sector...about establishing what the evidence base is, including some of the high-end, complex autism programs...we have the evidence, I would certainly expect to see that we will get some further information and instructions out to staff, or in fact change the guidelines. We are clearly satisfied that the evidence means that the current guidelines are insufficient.⁷²

5.103 The committee will carefully monitor the future amendments and modifications to this operational guideline as the next round of trial sites begin.

72 Ms Liz Cairns, *Committee Hansard*, 8 May 2014, p. 26.