

Chapter 3

Participants and planning

Background

3.1 People with disability are at the centre of the NDIS. This chapter concentrates on the stories, accounts and experiences the committee heard in each of the separate sessions of its public hearings in 2015. The majority of the evidence related to how people entered the system and navigated the planning process.

3.2 Of the projected 460 000 National Disability Insurance Scheme (NDIS) participants, there are currently 19 817 active and inactive¹ participants in the existing NDIA managed trial sites.² 17 303 of these have now received an approved plan.³

3.3 The central tenet of the Scheme is to support a person with a disability to lead an 'ordinary life'. The NDIS Independent Advisory Council (IAC) provided the committee advice on what factors they consider make up an 'ordinary life', and what barriers people with disability face in trying to reach that goal. The IAC recommend that the NDIS should provide people with disabilities reasonable and necessary supports to facilitate the enablers of an ordinary life:

- positive relationships;
- a sense of belonging;
- individual autonomy;
- active involvement in decision-making;
- active engagement in community;
- using one's unique strengths in ways that provide a challenge; and
- making a contribution.⁴

3.4 Barriers such as negative attitudes that view disability as a tragedy; service models that congregate people and segregate them from their communities; individualised support that acts as a paid friend rather than as a life facilitator; and risk

1 Active participants are those who are currently eligible, are not deceased and have a client status of "Active". Inactive participants are all other participants, including participants who are now deceased or have chosen to exit the scheme, as well as participants who have had their eligibility revoked.

2 There are a further 688 participants in the WA NDIS MyWay site. (WA NDIS MyWay quarterly report – June 2015).

3 National Disability Insurance Agency, *Quarterly Report to COAG Disability Reform Council*, 30 June 2015, p. 18.

4 NDIS Independent Advisory Council, *Reasonable and Necessary Support across the Lifespan: An Ordinary Life for People with Disability*, NDIS Independent Advisory Council Advice 2014, Attachment A1, p. 4.

management approaches that deprive people of ordinary opportunities, were all identified by IAC as things could prevent people reaching their potential.⁵

3.5 The practical challenge for the NDIA is how to structure the support to enable an ordinary life to be achieved. The committee notes that the Agency does this through the provision of 'reasonable and necessary' supports that help a participant live an ordinary life. These supports are provided under ten 'life domains' which are intended to encapsulate all of the supports that may be required for a person to reach their goals and aspirations and enable social and economic participation. The ten domains are:

- Learning and applying knowledge (e.g. understanding and remembering information, learning new things, practicing and using new skills and ideas),
- General tasks and demands (e.g. doing daily tasks, managing daily routine, handling problems, making decisions),
- Communication (e.g. being understood and understanding other people),
- Mobility (e.g. getting in or out of bed or a chair and moving around in your home and community),
- Self-care and special health care needs (e.g. showering/bathing, dressing, eating, toileting),
- Domestic life activities (e.g. preparing meals, cleaning, housekeeping and home maintenance),
- Interpersonal interactions and relationships (e.g. making and keeping friends and relationships, coping with feelings and emotions),
- Community, social and civic life (e.g. community activities, recreation and leisure),
- Education and training, and
- Employment.⁶

3.6 The philosophical approach that addresses barriers and aims to facilitate a person's inclusion in society, rather than focussing on their disability is one of the key principles underpinning the Scheme. The committee agrees with this approach and notes the evolution of this principle through to the provision of supports that are having a dramatic and empowering effect on the lives of people with disability. The committee met with and listened to substantial numbers of participants in trial sites across the country, and heard overwhelmingly positive accounts of these impacts.

5 NDIS Independent Advisory Council, *Reasonable and Necessary Support across the Lifespan: An Ordinary Life for People with Disability*, NDIS Independent Advisory Council Advice 2014, Attachment A1, p. 4.

6 National Disability Insurance Scheme, *Operational Guideline – Planning and Assessment – Assessment of Participants' Needs (v2.0)*, 16 January 2014, p. 2.

Nevertheless, there were some recurring issues common across the country that will require ongoing efforts to resolve. Many of these, the committee notes, were in the planning process.

The planning process

3.7 After eligibility for a person with disability is determined they enter the planning process and begin to design their package of supports. The person begins the process through a planning and assessment conversation where they are required to complete a Participant Statement setting out their current situation in terms of their living arrangements, daily routine, relationships and supports from others. The Statement should also include the person's goals and how they wish to achieve them.⁷ The Statement is discussed at the planning and assessment conversation.

Pre-planning process

3.8 Before people with disability are in a position to apply to become participants in the Scheme, many require support at the pre-planning stage to assist them to engage fully with the Agency. The support provided by advocates is crucial to participants at this stage, and the committee anticipates that the role and funding of advocates will be explored in the forthcoming Information, Linkages and Capacity Building framework.

3.9 The ability of the participant to fully understand and engage in the planning process was discussed frequently at the committee's public hearings. The pre-planning process to prepare a person for the formal planning process was raised by participants and providers as an area that could often confuse and overwhelm participants. The ACT Disability and Aged and Carer Advocacy Service recounted conversations they had with concerned families who had been to information sessions in preparation for the Scheme:

We are certainly meeting families who say, 'We went to the pre-planning information sessions and it's all too much. It's all so confusing. I can see I'm going to need help to go through this process.'⁸

3.10 People with Disabilities Australia (PWDA) also cited an example of a client they were working with who had no pre-planning or preparation prior to the planning process so were left at a distinct disadvantage:

There has been an example of where it does not work well: we heard via a boarding house owner that, when the launch site started in the Hunter, she on her own took her residents and started their entry into the scheme. There was no pre-planning. There was no process or involvement of others, so an individual ended up in a planning process without any knowledge of the

7 National Disability Insurance Scheme, *Planning and assessment fact sheet*, 22 July 2014, p. 1. Available at: http://www.ndis.gov.au/sites/default/files/documents/assessment_and_planning_factsheet.pdf.

8 Mrs Fiona May, ACT Disability and Aged and Carer Advocacy Service, *Committee Hansard*, 27 March 2015, p. 26.

current level of services that they were already receiving that are funded by the state and what else they could think about in their lives.⁹

3.11 PWDA continued that a lack of preparation, or an individual not having all the resources and assistance they require before entering the planning process can have a significant impact on the outcomes of the planning process, and their subsequent care needs:

One gentleman put forward that he would actually quite like to play tennis, so he got \$1,600 a year to play tennis. Because he moved into the NDIS on that plan, he lost all of his other services—or potentially did—because they had not been mentioned. They had not been factored into the planning process. He lost his transport mobility allowance, so he was going to end up with some funds to go and play tennis but nobody supported him to do that.¹⁰

3.12 While this situation was rectified, it does illustrate the potential dangers of allowing plans to be made for people without full cognisance of all the factors involved.

3.13 The importance of pre-planning support is also amplified in certain groups. Amparo Advocacy highlighted the resources required to equip a person from the CALD community with enough information to make informed decisions about their own situation:

In the Barwon region they decided that, even in trial sites, many people from CALD backgrounds are unaware of the NDIS, and it is taking significant resources to assist those individuals and their families negotiate the system. They cite one settlement worker providing 50 hours of support just to support one person to negotiate finding out, getting a diagnosis, being able to participate and understanding the planning process.¹¹

3.14 ACT Disability and Aged and Carer Advocacy Service submitted that the NDIA pre-planning sessions are welcome, but many people need more one-to-one assistance to apply the information to their own situation. This is creating a burden on organisations within the sector:

They are finding that they are really needing that one on one information support, rather than the information they might get at preplanning sessions, ...which provide generic information which is too high level for them to actually apply to their own situation...People are telling us that those preplanning sessions are not meeting their needs and that the volume of information, if they just try to search for information—for instance, on the website—is overwhelming and confusing. So we are finding that we are getting more and more calls and requests to provide small information

9 Ms Sue Barnes, People with Disability Australia, *Committee Hansard*, 27 March 2015, p. 68.

10 Ms Sue Barnes, People with Disability Australia, *Committee Hansard*, 27 March 2015, p. 68.

11 Ms Maureen Fordyce, Amparo Advocacy, *Committee Hansard*, 9 April 2015, p. 6.

sessions to groups of parents, for instance, or those kinds of things, to provide that information.¹²

3.15 According to witnesses, provision of support around pre-planning is also not routinely covered in funding packages for an individual, whether through the NDIS or block funding arrangements. Therapy Focus in WA commented that pre-planning falls between the cracks because the person is not yet a participant of the Scheme:

There is a lot of work gone into pre-planning, and it is not funded necessarily...But the block funding does not cover the pre-planning work that we do and, because it is not yet covered by a plan, it is also not covered by the NDIA.¹³

3.16 Focus ACT said that some of their clients were confused with the terminology when initially entering the planning process:

[M]any others say they are dismayed and confused when confronted with a new approach and new language such as 'clusters', 'line items', 'core capacity' and 'bundling' in relation to themselves or a family member.¹⁴

3.17 ACT Disability and Aged and Carer Advocacy Service also discussed how they had to 'translate' the terminology of line items into what the supports will be and what aspects of a person's life they will cover:

The plans themselves are actually very difficult for someone to understand. To translate a series of line items and amounts into something that is meaningful in terms of what a week, month or year will look like is quite complex when there are a lot of services in a plan. We are doing that work with our clients. It is taking our advocates many, many hours to do that translation.¹⁵

3.18 The committee also heard a number of positive accounts of the planning process more generally. Those participants who were already in a state or territory disability system spoke of a smooth transition into the NDIS:

The actual access was very straightforward. My children had gone through special needs schooling. They were in the system for many years. They were expected. We had a very short planning period. We had three meetings for each child. That went smoothly. It was very professional. I have been back to my planner a number of times since, with things that have not quite been right—item numbers that have not quite fitted, things to help me get the service agreements up and running—and I have found them to be flexible, which is great.¹⁶

12 Mrs Fiona May, ACT Disability and Aged and Carer Advocacy Service, *Committee Hansard*, 27 March 2015, p. 26.

13 Mr Matthew Burrows, Therapy Focus, *Committee Hansard*, 9 April 2015, p. 26.

14 Mrs Tina Siver, Focus ACT, *Committee Hansard*, 27 March 2015, p. 1.

15 Mrs Fiona May, ACT Disability and Aged and Carer Advocacy Service, *Committee Hansard*, 27 March 2015, p. 28.

16 Ms Leslea Geary, *Committee Hansard*, 27 March 2015, p. 29.

3.19 Community Connections in Canberra also described the planning process in general as a very positive experience for their clients. While flagging some issues around the implementation of the plan and the choice of providers, they were supportive of the efforts the NDIA have been making to ensure the process is as supportive as possible:

Just generally around the planning process, Community Connections has found this to be a really positive thing. It has been our experience that all plans have been conducted in a pretty open and collaborative manner with the NDIA. It is our experience that the people who have been through the intake process have informed us that they have generally been happy with the packages they have been allocated, and there is a general feeling that the supports they have received are reasonable and fair. And people generally have a sense of trust in the organisation.¹⁷

3.20 Ms Richards, a parent of a 29 year old man with disabilities was also very positive in her experience of the process. Despite her apprehension at the start of the process, she described the process and those involved in it in as being extremely helpful, professional and compassionate:

I am the parent of a 29-year-old man who has profound total disability and needs 24-hour support and assistance with every single area of his life at all times. He went through the NDIS process at the end of last year. My story is very positive. I think what often happens in forums like this is you tend to get the negative stories and the problems, which is as it should be because they need to be addressed, but my story is 100 per cent positive. I talk to a lot of families. The families that I know who have been through the NDIS all have really positive stories, and I think you need to know that. There are many, many ecstatic families out there.¹⁸

Plan flexibility

3.21 Taking a holistic approach to the formation of a plan that matches the supports with the goals and aspirations of the person was deemed crucial by all stakeholders. Flexibility and the evolution from rigid line items to describe items and supports were also cited as important factors in building a plan. However, the committee heard contrasting evidence about how widespread this flexible and holistic approach actually is.

3.22 Mr Gregory Mahony, the parent of a 15 year old boy with autism, described his frustration with over use of bureaucratic terminology such as 'line items' and 'number of hours' to describe elements of his son's plan. Mr Mahony stated that 'goals are referred to as that number of hours, not the goal', he suggested that the cultural change required to allow more flexibility in plans still needed to be realised:

The culture and structure of Disability ACT and Therapy ACT, I am afraid, are still alive and well. That is my concern. I know there is a lot of goodwill at the same time, but it is a battle against that...our strategy as a

17 Mr Ian Ross, Community Connections, *Committee Hansard*, 27 March 2015, p. 18.

18 Ms Sally Richards, *Committee Hansard*, 27 March 2015, p. 38.

family has been to have him out everywhere in every possible environment and to explore how things work out. But you say that to a NDIA spreadsheet and they want a line item for that support, that service, that activity. That is the cultural change I am talking about.¹⁹

3.23 The NDIA responded that they are trying to move away from rigid line items by introducing clusters and bundles of supports that can be ascribed to a broader goal. However, they pointed out that not all supports are able to be bundled, such as those provided 'in-kind', but insisted the work they are doing to reduce line items into four categories of support types will increase flexibility in the implementation of the plans:

The bundles are used wherever possible in order to create the best flexibility amongst plans. Some things are line items where it might be a capital purchase—such as when people were talking about continence before. Also there are some particular restrictions around where a service might be provided in kind...

There is work being undertaken at the moment around reducing those line items for participants. There is an aim to move to just the four separate support types and being able to make sure that people have more flexibility within that, so that work is being undertaken at the moment.²⁰

3.24 The committee also heard from WA Disability Services Commission (DSC) Executive Director, Dr Ron Chalmers on flexibility in NDIS My Way plans. While accepting that flexibility within a plan is a legitimate aspiration, Dr Chalmers emphasised the need for the integrity of the plan to be maintained, and for funding designed for specific purposes to be used as intended. If a person wanted to amend their plan substantially they would have to return to the My Way coordinator to revisit it. Dr Chalmers described a scenario where people would query how they could use their funding:

During the planning process, if someone says, 'I need support with daily assistance, showering, and what have you, I need support with recreations' and if it is clearly identified in the plan, can the individual just shake that all up and say, 'I'm going to spend it all on just one area and I can ignore what is in the plan'? No, because there has to be integrity in the plan, otherwise it becomes, 'I'll spend all that money on the overseas trip that I want to make.'²¹

Consistency of supports

3.25 Consistency in the plans, and the types of supports included in a plan were raised across the trial sites. The NDIA in the ACT trial site reported a 'high level of consistency' from a study undertaken by an independent consultant.²² The Scheme Actuary also informed the committee of her role in ensuring consistency across the

19 Mr Gregory Mahony, *Committee Hansard*, 27 March 2015, p. 37.

20 National Disability Insurance Agency, *Committee Hansard*, 27 March 2015, p. 48.

21 WA Government, Disability Services Commission, *Committee Hansard*, 9 April 2015, p. 8.

22 National Disability Insurance Agency, *Committee Hansard*, 27 March 2015, p. 55.

trial sites, and Mr Bonyhady, the Chair of the NDIA Board expressed his optimism that with an increasing quantum of data they 'are very confident that over time, through the actuarial team working with the operational team, we will get the national consistency that people expected and wished for when this scheme was introduced.'²³ However, the committee heard of variations in the types of supports provided in a plan for people in ostensibly similar circumstances.

3.26 The Autism Association in Perth suggested that there needs to be further work done with planners to improve their level of knowledge and thereby produce more consistent assessments of need:

I think there maybe needs to be more training of the planners around how to make an assessment of the level of need when allocating those transdisciplinary packages. It is very inconsistent. We will see children who have got level 1 transdisciplinary packages but, when we do our assessment, we find they definitely have a higher level of need; and then we will have other children that come through that require less support in relation to therapy services but are getting a higher level of funding. So I think there needs to be more work done on the consistency in the allocation of transdisciplinary packages.²⁴

3.27 Valued Lives, a peer-to-peer support organisation found that some of their clients were receiving varying levels of funding for support coordination which makes it difficult to deliver a consistent service:

As a model, to deliver that is very difficult because the number of support-coordination hours that need to be picked up to deliver one consistent face-to-face person is going to be very difficult. So we have a lot of inconsistencies coming in with the support coordination. We have some with reasonable amounts, we have others with none—that we would consider in our My Way role to have definitely required ongoing support—and then we have a mix and match in between.²⁵

3.28 Just Better Care who operate in the ACT and south-east New South Wales shared their experience of clients that have had very different outcomes from the planning process. Mr Nelson, the Chief Executive discussed plan outcomes in the context of how well supported the participant was in understanding the process prior to beginning discussions:

Some of it is the degree of advocacy that those people can present when they are presenting their plan. But in other cases we have had people who have been in the system who are very good advocates and who have come out with relatively poor results and other people who have gone in virtually

23 Mr Bruce Bonyhady, National Disability Insurance Agency, *Committee Hansard*, 5 June 2015, p. 27.

24 Ms Tasha Alach, Autism Association, *Committee Hansard*, 9 April 2015, p. 17.

25 Ms Bronia Holyoak, Valued Lives, *Committee Hansard*, 9 April 2015, p. 34.

stone cold and have come out with much better results as far as those things go.²⁶

Plan reviews

3.29 There is opportunity for participants to review their plans and make amendments either due to changes in their circumstance, or because they have developed their thinking around the plan. The committee heard in some cases people have revisited their plans on numerous occasions, and the NDIA or My Way have been happy to facilitate that. However, the committee also heard instances where participants' opportunities have been limited.

3.30 The committee heard of an instance in the My Way trial site where the planning process for one participant had not been satisfactory, and while they did have the opportunity for it to be reviewed, the process, and the relationship between the participant and the agency had suffered:

We have had issues with one coordinator. In relation to that coordinator, in terms of this person's plan leading up to 1 July, they wanted it reviewed three months after that date, and we asked them what the issues were and said, 'We can get the coordinator back in and engage with them,' and they said, 'No; we don't want to talk to that coordinator anymore because we were not happy.' So that conversation sort of developed, and they said that they felt it was a rushed process. And the words that this person used were, 'I felt bullied into developing my plan.'...That was an issue with one My Way coordinator.²⁷

3.31 The committee also heard of a three-month period whereby a participant could request an internal review of their plan. MIDLAS, a disability advocacy in Perth suggested that people had limited options as a result of exceeding that period:

There have been quite a high number of clients who have sought assistance from MIDLAS after their plan has been implemented. These clients are often passed their three-month internal review date, which does reduce their scope for appealing decisions made by the agency.²⁸

3.32 MIDLAS also argued that if people were more informed and had a greater understanding of the plan, and the items therein, the need for formal internal reviews would be reduced. Despite her comments, Ms Butt from MIDLAS stated that she had been 'really impressed...with the internal review process.'²⁹

3.33 Just Better Care reported circumstances where their clients had their plans reviewed on a number of occasions, without a satisfactory resolution being achieved:

We have had a number of people who have gone through the process in that planning stage up to three times—I think with a couple of them it has been

26 Mr Fergus Nelson, Just Better Care, *Committee Hansard*, 27 March 2015, p. 12.

27 Mr Peter Seaward, Strive Warren Blackwood, *Committee Hansard*, 8 April 2015, p. 12.

28 Ms Megan Butt, MIDLAS, *Committee Hansard*, 9 April 2015, p. 30.

29 Ms Megan Butt, MIDLAS, *Committee Hansard*, 9 April 2015, p. 31.

four times—and in the end it has been: 'This is the plan, and that's it.' A couple of those are going to take that further to their appeal process.³⁰

3.34 The committee heard that there was considerable ambiguity around what was understood by the three month review period for a plan. The committee heard evidence in Perth that suggested that the three month limit on changing a plan was not set in stone, with some witnesses reporting a high degree of flexibility if the participant was not satisfied with their plan. Therapy Focus informed the committee that their experience was very positive when requesting a plan be revisited:

We have 180 or more participants in the NDIS hills trial site area, and that has not been our experience with interactions with the NDIA; it has actually been very positive. We have had interaction back and forth regarding plans. If there are issues with plans, if we feel that what is in the plan does not meet the person's needs, then they are more than happy to talk to us and are very responsive along those lines, much as what you have described.³¹

3.35 There is formal guidance published by the Agency that sets out the steps a participant can take to review their plan. This includes some indicative timeframes in which reviews can take place depending on who is requesting the review and for what purpose. One of the stipulations is that a plan will not be reviewed in the first six months (or three months) unless circumstances have changed:

[R]equests for a review of your plan will generally not be approved within six months of the plan being approved (or within three months where the plan is for a shorter period) unless you can demonstrate that your circumstances have changed, or there is new information which is likely to affect our assessment of your need for funded supports.³²

3.36 However this does not seem to explain the impression that some witnesses have that a plan can only be reviewed in the first three months.

Self-management of plans

3.37 The flexibility of supports within plans is substantially increased if a person with disabilities, or their family and carers, manage the plan themselves. The committee heard a number of accounts of people self-managing some aspects of their plan. The number of people totally self-managing in the NDIA Scheme is still low at around six per cent,³³ however many witnesses expressed a desire to eventually go down that route. In the My Way Scheme the figure for people in the 'self-managed domain' is higher at approximately 30 per cent.³⁴ Although the overall figure for total self-management in WA is 9 per cent as displayed in Table 3.1 on the following page.

30 Mr Fergus Nelson, Just Better Care, *Committee Hansard*, 27 March 2015, p. 13.

31 Mr Evan Williams, Therapy Focus, *Committee Hansard*, 9 April 2015, p. 6.

32 National Disability Insurance Scheme, *Reviewing your plan*, 6 January 2014, p. 1.

33 Dr Ken Baker, NDIA Independent Advisory Council, *Committee Hansard*, 5 June 2015, p. 7.

34 WA government, Disability Services Commission, *Committee Hansard*, 9 April 2015, p. 1.

3.38 Table 3.1 displays the current distribution of trends in plan management for NDIA managed trial sites. It is worth pointing out that NDIA notes that a participant who is receiving any 'in-kind' support [essentially state-based support/contribution] cannot solely manage their plan. The NDIA also note that 'the management of the plan in this instance refers to the financial management of the plan. Participants can self-direct their supports whilst the agency manages the financial side of the plan.'³⁵

Table 3.1: Trends in plan management

State	Agency Managed	Combination	Self-Managed
NSW	52%	46%	1%
SA	68%	20%	12%
TAS	50%	46%	4%
VIC	72%	28%	0%
ACT	48%	41%	11%
NT	93%	7%	0%
WA	60%	31%	9%
Total	62%	33%	6%

Source: NDIA, *Quarterly Report to COAG Disability Reform Council*, 30 June 2015, p. 39.

3.39 Table 3.2 displays the situation in the WA NDIS My Way site:

Table 3.2: WA NDIS My Way trends in plan management

Region	Totals			Plan Management Options					
	Total current plans	Number of unfunded plans	Number of funded plans	Service-provider managed ¹	%	Self-managed ²	%	Combination managed ³	%
Lower South West	688	45	643 ⁵	188 ⁴	29	223	35	232	36

Source: WA NDIS My Way, Quarterly Report, June 2015, p. 12.

3.40 The committee notes that the NDIA and WA NDIS My Way use different definitions of self-managing, especially around the issue of in-kind support.

3.41 Dr Ken Baker, appearing in his capacity as a member of the NDIA Independent Advisory Council (IAC), postulated that one of the reasons that people are not self-managing their plan is down to the administrative burden involved, and that this was something being explored through innovative approaches across the country:

I think one of the reasons that has been low is that people do not want to take on the administrative burden of managing their own funding. There are schemes around Australia where there is an intermediary organisation that

35 National Disability Insurance Agency, *Quarterly Report to COAG Disability Reform Council*, 30 June 2015, p. 39.

manages that administrative burden for individuals. I think that is what most individuals would want. That is something we can learn from.³⁶

3.42 Division 3 of the *NDIS Act 2013* and the *National Disability Insurance Scheme (Registered Providers of Supports) Rules 2013* provide for the management of funding for supports under participants' plans. According to Dr Baker these provisions are framed too narrowly, and are preventing organisations registering as plan management providers.³⁷

3.43 The support and confidence required to self-manage was highlighted by Queenslanders with Disability Network. Mr Webb from the Network echoed many of the sentiments of witnesses in saying that he wanted to get to a position where he would be able to manage his own plan:

I am very interested in self-direction. I want to be able to self-manage and self-direct my package. As soon as I can get my head around some of that stuff, I want to be able to do it... It should be encouraged by the agency.³⁸

3.44 The administrative burden as a reason for people not self-managing their plans resonates with the committee as it concurs with accounts of witnesses across the country. Ms Nicole Avery, a parent to two boys with Autism, recounted her story of self-managing her sons' plan. Ms Avery described the flexibility that came with self-managing, but also the challenges the process presented:

[F]or our first year of the plan we chose to self-manage. We spent a year trying to find support workers. We were knocked back by 10 different support workers because they saw on paper two teenage boys with autism—Oh, my God!—and they decided that we were a little bit too difficult to work with.

I was then diagnosed with whooping cough in May of last year. We had everything go to pot. We spoke with our My Way coordinator, who re-purposed some of our funding, and we were able to employ our next-door neighbour to supervise the boys while I was ill.

It came time to write the two new plans in October, and we had learnt a lot. We changed things around a lot more. We chose to employ a support worker to supervise the boys while they were home-schooling via distance education so that I could work as well. We were able to find two support workers we employ. I manage through Xero. I have the same financial manager. My husband is an accountant.³⁹

3.45 Mrs Kerry Carroll, a parent of a woman with disabilities in the NDIS My Way Scheme also provided valuable insight into the complexities of self-management, and the expertise required. Mrs Carroll espoused the benefits of self-managing and the

36 Dr Ken Baker, NDIA Independent Advisory Council, 5 June 2015, p. 7.

37 Dr Ken Baker, NDIA Independent Advisory Council, 5 June 2015, p. 7.

38 Mr Nigel Webb, Queenslanders with Disability Network, *Committee Hansard*, 13 March 2015, p. 30.

39 Ms Nicole Avery, *Committee Hansard*, 8 April 2015, p. 37.

difference it had made to her daughter's life. As a family, they also utilise the 'Xero' bookkeeping application to manage the financial aspects of the plan and recommended that the Agency provide guidelines, training and support for those willing to explore self-management:

There were no set guidelines to help us set up as a self-manager, and I really think there should be. There are no templates for forms, timesheets, programs advice, accounting packages for money control and reporting advice to the My Way group. All these had to be created by me. The pressure of this was very intense for the first six months. Luckily I have a financial background being a licensed conveyancer. This prepared me for the need for accountability in relation to the funds provided by the My Way from NDIS. Not everyone would have this background. I think that some form of education in relation to this should be provided to first-time self-managing families to avoid self-management imploding and ultimately failure for all, which would be a crime for disabled folk. The threat of losing the funds, if they are not used each year, is quite daunting considering that Leah's health is fragile and sometimes requires hospitalisation, which then creates a problem with funds being used. There needs to be more flexibility in this area.⁴⁰

3.46 Dr Chalmers from the WA DSC promoted the activities of an organisation established in WA that specialises in self-management. Individualised Services provides materials to support participants on various aspects of self-management such as taxation, insurance, superannuation, risk management, and recruitment of staff.⁴¹

Transition issues in the psychosocial/mental illness sector

3.47 One of the more contentious issues currently arising is how those with psycho-social or mental illness will transition into the Scheme. The committee heard from witnesses in Brisbane who work in the Commonwealth Government's Partners in Recovery Initiative (PIR)⁴² that supports people with severe and persistent mental illness with complex needs, and their carers and families. Ms Michelle McAllister, representing the PIR National Organisation Reference Group, proposed a number of recommendations around how people with psycho-social and mental illness who are currently under the auspices of PIR should be transitioned into the NDIS:

The first is that the Queensland state managers group and the national PIR Organisation Reference Group be considered as a point of reference for psychosocial disability. The second is that the PIR's infrastructure, skills and experience is considered around the bulk purchasing for either an ILC pilot, in particular for information referrals and linkages. The third is that the flexible funding expenditure in PIR be used to better understand how the needs of psychosocial disability can be supported, and that there be further exploration of how the PIR assessment, coordination and planning

40 Mrs Kerry Carroll, *Committee Hansard*, 8 April 2015, p. 26.

41 WA Government, Disability Services Commission, *Committee Hansard*, 9 April 2015, p. 10.

42 For further information see about the PIR Initiative see <http://www.pirinitiative.com.au/about/overview.php>.

functions in NDIS trial sites interface with NDIA to inform readiness and transition.⁴³

3.48 Ms Coffey from the same group also highlighted the difficulties the PIR initiative has had in engaging those with mental illness. Ms Coffey stated that if the NDIA is to ensure equity in access to the Scheme, then it will have to adopt similar measures to engage with these potential participants. Such measures include outreach services to capture those not currently in the system, or at least not in on a continual basis:

We have learnt through the process since 1 October, from over 860 participants who our support facilitators have been working with, that in order to think about any sort of transition from community-based mental health to an NDIS environment there needs to be some outreach facility and some outreach capacity. Outreach is really crucial for people who are isolated, who are perhaps not in contact with mental health services but are in contact with other areas of the community, whether they be a neighbourhood centre or a housing provider for the homeless.⁴⁴

3.49 The committee did hear some very positive evidence about the impact that support through the NDIS can have on people with psychosocial disabilities. Ms Jennifer Adams, who spoke at the ACT trial site hearing, recounted her experience as a person with a psychosocial disability and as a carer of someone who is also a participant:

It has been life changing for both my son and me...The really huge thing for me as a carer, who is also a client, is that I do not have to do everything anymore. The NDIA, when I said I did not feel up to going into their office, said, 'We'll come to you', and that means so much. They have come to me three times now, and a cab brought me here today. They listened.⁴⁵

3.50 However, this is a message that does not seem to be getting through in the Northern Territory. CatholicCare in told the committee in Darwin that they could not see how the NDIS was going to improve the circumstances of people in their care with mental illness:

Our interest is from a mental health perspective, not the traditional disability. I think, for us, we have found the whole thing quite difficult. It feels to us that mental health and our inclusion was very much an afterthought. We are really struggling to see how, from a mental health perspective, things are going to be better for people with a mental health issue in Barkly. From what we see there are going to be fewer services available to them once the trial comes to a full realisation.⁴⁶

43 Ms Michelle McAllister, PIR National Organisation Reference Group, *Committee Hansard*, 13 March 2015, p. 44.

44 Ms Pauline Coffey, PIR National Organisation Reference Group, *Committee Hansard*, 13 March 2015, p. 46.

45 Ms Jennifer Adams, *Committee Hansard*, 27 March 2015, p. 39.

46 Ms Jane Lloyd, CatholicCare NT, *Committee Hansard*, 21 July 2015, p. 14.

3.51 The Mental Illness Fellowship of Australia in NT was also concerned about the impact on current services when the NDIS rolls out. The Fellowship cited a number of Commonwealth programs and state services they believed would be sacrificed to fund the NDIS:

Our concern is that the NDIS is not going to be independently funded and that the scheme is being implemented at the expense of the current services that are operating well. We know that the DSS funded PHaMs and carer respite programs, as well as DoHA's day to day living program and the ATAPS programs and Partners in Recovery are all in scope to fund the NDIS. We are also concerned that the NT government, which currently spends \$88 million on disability services, will be forced into the NDIS agreement at a cost of \$96 million, leaving our state funded services, such as our own My Place, unfunded.⁴⁷

3.52 The committee heard of the importance of continuing the Personal Helpers and Mentors scheme (PHaMs) in particular to assist the transition to the NDIS for people with psychosocial illness. ACT Health supported the Commonwealth's decision to continue block funding for PHaMs, which they said would assist in the continuity of service:

With the Personal Helpers and Mentors scheme, which is one of the Commonwealth components of the transition, the Commonwealth was a very well aware of the potential risks if they simply stopped their contractual arrangements with organisations such as Rainbow prior to the phasing in of clients. So they were very responsive to those concerns. The Commonwealth has announced that they will continue that block funding so that we do not have that problem of services stopping before individuals transition in.⁴⁸

Local Area Coordination (LAC)

3.53 One of the general principles under the *NDIS Act 2013* ("the Act") is that 'People with disability should be supported to receive supports outside the National Disability Insurance Scheme, and be assisted to coordinate these supports with the supports provided under the National Disability Insurance Scheme.'⁴⁹

3.54 Since 2013, the NDIA have been experimenting across various trial sites with the LAC models with a view to take a preferred model forward nationally. According to the Agency's last annual report (2013-14) they had looked at various options, including whether LACs would be a core NDIS function or be outsourced:

During the first 12 months of operation, several LAC models have been trialled, including LAC services being outsourced to community organisations, and the Agency directly employing all LACs. In the Hunter

47 Mrs Lorraine Davies, Mental Illness Fellowship of Australia in NT, *Committee Hansard*, 21 July 2015, p. 21.

48 ACT Government, *Committee Hansard*, 27 March 2015, p. 45.

49 *National Disability Insurance Scheme 2013*, s. 4(14).

trial site, some LAC functions are provided through a NSW Government contract with a non-government organisation (Ability Links). The Ability Links LACs perform community linkage functions and largely work with those who are not eligible for the NDIS. In Tasmania, LAC services are contracted through the Gateway service, operated by Mission Australia and Baptcare and in Barwon and South Australia, the NDIA is responsible for directly employing all LACs.⁵⁰

3.55 The committee heard in Queensland in March 2015 that the NDIA seem to have settled with a model informed by the WA LAC program. The Agency also told the committee that LACs would develop within the Information, Linkages and Capacity Building (ILC) framework. The committee was given the impression that LAC would be a core function whereby the LAC coordinators would be employed by the Agency, or in some cases, by states and territories.

[W]e will be applying an NDIA approach, which is largely informed by the Western Australian model to local area coordination...

We are currently trying to work through some of the issues we have been hearing about...around whether we have got it right in terms of our business processes, and what are the points at which we should be communicating with people, and how much of our staffing profile would be better placed to be the local area coordination profile, both the local area coordination funded under the information linkages and capacity building, and also from agency operating...⁵¹

3.56 The WA LAC program has been operating since 1988 and is based on flexible, person-centred approaches aimed at placing choice and control in the hands of people with disability, their families and carers. It also focuses on building partnerships between the government and the community sector and maintaining connections with mainstream supports and services.⁵²

3.57 However, at the committee's hearing in Canberra in June 2015, the Agency informed the committee that they were hoping to outsource local area coordination to community organisations, and had conducted market testing to gauge the viability. The Chief Executive also referred to Tasmanian and New South Wales versions of LACs as possible models:

[T]he sourcing of the local area coordination. We have done quite a lot of work on that. We have developed a lot of details about how that will work and we are market testing, noting that it is all very aspirational to say, 'We will source it out,' and there will be all these community organisations there who may be able to deliver it; we are market testing that at the moment.

...

50 National Disability Insurance Agency, *Annual Report 2013-14*, 15 October 2014, p. 55.

51 National Disability Insurance Agency, *Committee Hansard*, 13 March 2015, p. 64.

52 Disability Services Commission, *WA NDIS My Way, Frequently asked questions*, <http://www.disability.wa.gov.au/wa-ndis-my-way/wa-ndis-my-way/frequently-asked-questions/> (accessed 9 September 2014).

We have literally just finished the first round of that market testing, and the level of interest is very high. Of course, we have been operating multiple different versions of local coordination. Already in Tasmania we have Mission and Baptcare as outsourced Tasmanian government service providers. In New South Wales we have Ability Links run by St Vincent de Paul from New South Wales. It is not an unknown proposition here.

3.58 The Agency provided further information on the market testing exercise in a response to a question on notice. According to the Agency the exercise comprised a 'series of conversations' with representative organisations from the 'insurance, human services and disability support sectors to discuss views on the values and skills that would be required from the market place.'⁵³

3.59 One of the drivers for outsourcing LACs is the levels of savings it would provide to the Agency. In March 2015 the committee was told that they would need around 9000 staff nationally.⁵⁴ In contrast, the Agency's evidence in June 2015 was that they had revised that figure down to 2700 staff.⁵⁵

3.60 One of the potential pitfalls of outsourcing LAC services is that they would presumably be outsourced to service providers. Having providers do both was raised as a potential conflict interest. In WA, Activ Foundation accepted that there was a potential for a conflict to arise, but they argued that this is premised on the idea that providers will consider the organisation before the person. Activ suggested that this is easily negotiated by ensuring the organisation's ethos reflects the principles of the Scheme:

I think it is part of it in the sense of understanding that the potential for conflict of interest can exist. How do we deal with it? We have lots of internal discussions around where our priority lies. A part of our internal discussions is: Activ provides a lot of services around the state, and so we have breadth of service and we have breadth of spread, if you like, in terms of scope. However, we do not see ourselves as having a right or an entitlement to be the organisation that people come to, and our discussion internally—particularly in terms of choice and freedom, or choice and control, which is the underpinning principle of the NDIS...⁵⁶

3.61 The MS Society, also in WA, promoted the advantages of a provider being involved in the planning as utilising the expertise and experience a provider may bring:

It is not about us as the MS Society wanting to provide everything for everybody; it is about us recognising that our staff often have a long-term relationship through health and other services that we are providing with that individual. We know about issues such as cognitive impairment, their

53 National Disability Insurance Agency, answer to question on notice, 5 June 2015, (received 23 July 2015).

54 National Disability Insurance Agency, *Committee Hansard*, 13 March 2015, p. 64.

55 National Disability Insurance Agency, *Committee Hansard*, 5 June 2015, p. 21.

56 Mr Tony Vis, Activ Foundation, *Committee Hansard*, 8 April 2015, p. 3.

denial of their condition and the impact of that condition on their health and social relationships et cetera. We actually want to bring that expertise to the table to help inform that planning process to get the best outcome for the individual.⁵⁷

Committee view

3.62 The predominant sentiment and experience of the NDIS by participants to date has been positive. The committee heard a number of highly personal accounts from people about how the NDIS has transformed their lives, and the lives of those they care for. In sites where the transition is further developed, like the ACT, or where some infrastructure was already in place such as the WA NDIS My Way site, the difference in the lives of most participants has been what the committee hoped it would be.

3.63 The focus of achieving an 'ordinary life' for a person with disability is supported by stakeholders. The term represents recognition of the broad spectrum of supports that a person with disabilities needs to allow them to reach their full potential as active participants in society. As the architects of the Scheme envisaged, the approach taken is one that concentrates on how the Scheme can facilitate a person's goals, rather than an approach which concentrates on the disability. The committee continues to wholeheartedly support this principle.

3.64 The provision of reasonable and necessary supports under *ten life domains* appears well thought through, and should facilitate a holistic support infrastructure that concentrates on the barriers to an ordinary life. Likewise the recognition of the enablers of an ordinary life.

3.65 Notwithstanding the positive direction the Scheme is taking, there are implementation aspects of the Scheme that need to be improved. The overall planning process is certainly improving, but the committee found inconsistencies in the assessment and application of supports and funding across the trial sites.

3.66 The information and support required by participants in the pre-planning stage is an issue to be resolved. While the committee accepts that the role and funding of advocacy will be further defined in the context of the ILC framework, there is currently a structural gap in the support available to people before they enter the Scheme, or in the early stages of the planning process. As the Scheme enters transition there is a sharp rise in people accessing the Scheme, people being unprepared and requiring longer to complete a plan because of their unpreparedness will only exacerbate pressure on the Agency.

Recommendation 1

3.67 The committee recommends that National Disability Insurance Agency work with stakeholders to ensure that pre-planning information for potential

57 Ms Susan Shapland, Multiple Sclerosis Society of Western Australia, *Committee Hansard*, 9 April 2015, p. 3.

participants adequately provides all information required for people to make well-informed decisions about their disability care and supports.

3.68 The committee also heard of cases where participants were unable to easily translate the description of supports and services in their plan into what they will actually look like in their lives. The terminology and bureaucratic processes such as the use of 'line items' can sometimes appear rigid and devoid of the holistic ethos of helping a person achieve the goal of leading an ordinary life.

3.69 The committee understands that progress is being made whereby supports are bundled together, and are aggregated in a way to allow for flexibility within the plans. However, this is still limited to a relatively rigid structure of support types. The committee supports greater flexibility within the plans and while it accepts that maintaining the integrity of plans is important, it would like to see a culture develop within the Agency where decisions are based on the actions of the overwhelming majority, rather than the risk that a small number would act inappropriately.

Recommendation 2

3.70 The committee recommends that risk management practices around the flexibility of supports within plans are underpinned by the principle of choice and control for participants.

3.71 Getting the plan correct the first time reduces the burden on the Agency and allows the participant and their family and carers to activate all aspects of the plan as quickly as possible. The committee understands this will not always be possible and was pleased to hear that people are generally experiencing flexibility when it comes to amending or altering different aspects of their plan. However, there were some witnesses who said they had been told that there was a three month time limit to a review period, and after this the plan could not be altered. While there are some time limits set out in various guidance documents, and a time limit is legislated by the Act with regard to a formal request for a plan review, there is obviously some misunderstanding around this issue that needs to be clarified and communicated to the sector.

Recommendation 3

3.72 The committee recommends that the status of guidance for plan reviews is clarified and communicated consistently across National Disability Insurance Agency publications.

3.73 The aspiration of all stakeholders in the Scheme is that participants will eventually manage their own plans to some degree. Currently the proportion of those self-managing is low at around 6 per cent in NDIA managed trial sites. The committee is hopeful that as the Scheme evolves, the confidence of participants to self-manage also increases.

3.74 The higher proportion of people self-managing in WA with My Way is indicative of a more mature system whereby people have already been in receipt of individualised care packages and this experience and knowledge has assisted them in navigating the system. That said, there were those in the NDIS My Way site who

argued for much more training and support to be able to self-manage, which may include specific assistance in IT, staff management and procurement practices.

Recommendation 4

3.75 The committee recommends that the National Disability Insurance Agency and NDIS My Way provide access to training and technical support to those participants who want to self-manage some or all of their plans.

3.76 The rollout of a consistent Local Area Coordination model across the country is critical in making the Scheme operate in the interests of the participant, providing an essential link between them and the service providers. There is a mature model operating in WA which has been adapted from a long term program, and the benefits of this continuity are apparent. The committee acknowledges that the WA situation is unique and therefore cannot be replicated wholesale in other states and territories, but there are specific elements of the WA LAC system that the NDIA suggested could underpin LAC models in other areas.

3.77 The committee welcomes the NDIA's flexible approach to the design of LAC models across the country. The models utilised in NSW and Tasmania where community organisations have been contracted to provide the services appears to have been successful in those areas. This approach is being further explored by the NDIA, who are looking at outsourcing LAC services to community organisations once the Scheme rolls out nationally. The NDIA informed the committee that they had conducted a market testing exercise to assess the potential and capacity of the community sector to provide LAC services. While the committee supports exploring various options for delivering these services, it recommends caution in making decisions regarding a model of service delivery on a national scale until further market testing is undertaken and the evidence base broadened.

Recommendation 5

3.78 The committee recommends that the National Disability Insurance Agency and the Department of Social Services carry out more in-depth research to assess the viability of various Local Area Coordination delivery models before any commitment is made.

3.79 The committee notes that certain data is not available on a regular basis in the NDIA quarterly reports. Data such as the number of providers and what service they provide by state – whether they are new providers in the sector or existing sector providers. This information helps inform the market and participants of whom, what and where services are being delivered enabling informed choices to be made by all.