



Brotherhood of St Laurence
Working for an Australia free of poverty

Baptcare

Submission to the
Department of Social Services

Review of the NDIS Act and the new NDIS Participant Service Guarantee

Brotherhood of St Laurence and Baptcare

October 2019

Brotherhood of St Laurence
67 Brunswick Street
Fitzroy Vic. 3065

ABN 24 603 467 024

Ph. (03) 9483 1183

www.bsl.org.au

Thanks to Catherine Viney, Disability Services Manager for Baptcare, and her team for their contribution to this submission. Thanks also to Amanda Pagan, Principal Research Fellow, Inclusive Communities; Susan Hall, ECEI Program Manager, and the rest of the BSL NDIS Leadership team; and all other staff who contributed their insights. Finally, and most importantly, thanks to all the people with disability, their families and carers who generously shared their stories and expertise with us.

For further information or to discuss this submission, please contact:

Professor Shelley Mallett

Director, Research and Policy Centre
Brotherhood of St Laurence and
Professorial Fellow, Social Policy
University of Melbourne
Email: smallett@bsl.org.au
Ph. (03) 9483 1364

Rodney Weston

Director of NDIS
Brotherhood of St Laurence
Email: rweston@bsl.org.au
Ph. 0419 299 874

Diane Brown

Senior Policy Advisor, Inclusive Communities
Brotherhood of St Laurence
Email: dbrown@bsl.org.au
Ph. 0428 572 336

Summary

The visionary purpose of the NDIS is enshrined in the NDIS Act

The National Disability Insurance Scheme (NDIS) was established to replace an unsustainable disability system which was ‘underfunded, unfair, fragmented, and inefficient’ with one which takes a lifetime approach to investing in people with a disability and their families, so they can live an ordinary life (PC 2011, p. 2). This approach recognises that by building the independence and social and economic participation of people with a disability, the NDIS will reduce long-term costs and produce a return on investment to taxpayers.

This is a transformative vision, not only for people with disability and their families and carers, but also for the Australian community. The Scheme’s promise of choice and control and person-centred support is premised on the recognition that all people with a disability, regardless of their background, are entitled to self-determination, full inclusion in their community and having their (reasonable and necessary) needs met. These rights are enshrined in the *National Disability Insurance Scheme (NDIS) Act 2013*, which affirms that people with a disability (alongside their families and carers) can ‘determine their own best interests and make decisions that affect their own lives’ (NDIS Act 2013, s. 17A (1)).

Our submission builds on participant experience and expertise

Consistent with the person-centred principles of the NDIS and with the Review’s focus on participant experience, we sought the views of participants and their families to inform our response. This reflects our broader commitment to amplify the voice of participants, their families and carers, as well as service staff, to improve the NDIS as it evolves.

We spoke to 52 participants and families about their experience with the NDIS in Victoria and Tasmania. Many of these participants were receiving Local Area Coordination (LAC) or Early Childhood Early Intervention (ECEI) services through BSL and Baptcare; others were engaged with a different Partner or Agency planned. We also consulted 34 staff members working on the ground in our LAC and ECEI services. Lastly, we drew on previous research interviews and focus groups conducted with NDIS participants, and on the findings of the numerous reviews and inquiries into the NDIS over the past three years.

Participant experience of the NDIS currently falls short of the Principles articulated in the NDIS Act

Although the NDIS is changing many lives, it is yet to live up to its promise for all people with a disability and their families. For too many people the experience of access, planning and plan implementation can be frustrating and disempowering. Participants and their families told us there was insufficient information, communication and support for them to navigate the participant pathway. They also told us that there was little transparency about what was happening for them, and why or how decisions were made.

While most were able to eventually reach a good outcome under the NDIS, it often came at the cost of their or their loved one’s wellbeing. Many were burnt out and exhausted by the hours, weeks or months of effort required.

Critically, we also saw clear evidence of inequitable access to, and outcomes from, the Scheme. People who are well educated, are able to self-advocate and have financial and social resources to draw on can access the Scheme more easily and advocate for supports more effectively.

What this means for the current Review: an improved Guarantee and an enforceable Act

This Review provides a timely opportunity to enhance the participant experience by strengthening the NDIS Act and developing a Participant Service Guarantee. We endorse this intent and based on our consultations with people with a disability and their families, we propose some amendments and additions to the Guarantee proposed in the Discussion Paper.

That said, we believe these measures alone will not deliver substantive improvement to participant experiences of the NDIS. An investment in the level and quality of support provided across the entire participant pathway is required. Further, participants and their families need to be much more involved in decision-making about their lives.

In addition to removing legislative ‘red tape’, we believe that strengthening the NDIS Act should reinforce the existing Principles and provisions within it. The Act clearly articulates a rights-based vision for the NDIS, which emphasises respect for the autonomy and dignity of people with disability, and their right to participation, including making choices pertaining to their own lives.

To a large extent, it is the translation of these principles into practice that is falling short.

We also recommend some minor amendments to the Act to require the NDIA and its Partners and contractors to be more accountable and transparent about decision-making, and to remove provisions that are inadvertently punitive to people seeking access to the Scheme.

We (and our service staff and participants) understand that the NDIS is still developing, and to get to a mature state will take some years. We hope that the findings of these consultations will help inform a new Participant Service Guarantee, and the ongoing work of government, people with a disability and their families and the disability sector, to advance the NDIS to a mature system that is world-class in its achievements.

Recommendations

Improving the Participant Service Guarantee

1. Ensure that the scope of the Guarantee encompasses decision-making by the NDIA, the Quality and Safeguards Commission and all outsourced contractors. This includes Partners in the Community delivering LAC and ECEI services and the National Call Centre.
2. Modify the definition and measurement of some of the principles in the Guarantee, including changing ‘Expert’ to ‘Collaborative’ and ‘Decisions made on merit’ to ‘Transparent’.
3. Add three principles to the Guarantee to address other key areas the Scheme needs to improve: ‘Fair’, ‘Accountable’ and ‘Efficient’.
4. Co-design the Guarantee’s specific Service Standards with people with a disability and their families and carers. Ensure that those who are hard to reach and not usually consulted are targeted through this process.

5. Specify strong accountability measures associated with the Guarantee, with clear recourse for participants and families if the Guarantee is not delivered. This should include legislating the Guarantee in the NDIS Act to ensure it is legally enforceable.
6. Invest in concurrent reforms required to deliver on the Guarantee, including:
 - a. A consistent, face-to-face, single point of contact for people with a disability and their families from their first interaction with the Scheme. This person must be able to answer their questions, be available when needed, and be connected to decision makers and/or empowered to act to make things happen for the participant and their family.
 - b. Guaranteeing participants and their families the right to speak to the person making decisions about their lives.
 - c. Making publicly available clear and transparent information about eligibility, funding and exclusions.
 - d. Adequate resources to ensure NDIA and contracted staff have enough time to support participants when they need it, for as long as they need it.

Strengthening and enforcing the NDIS Act for improved participant experience

7. Make the existing Principles and Rules in the NDIS Act more enforceable, particularly Section 4 (the underpinning Principles for the Scheme) and Sections 31 and 33 (relating to the way plans are to be developed). Document clear action to be taken if these Principles are not met.
8. Add to the Act or the Rules, a requirement for the NDIA to ensure participants understand its decisions according to the relevant sections of the Act and the Rules. This explanation must be in clear language that the participant and their family understand, and be made in person or over the phone to ensure they do understand and can ask questions.
9. Change Section 26(3) of the Act to extend the timeframe for participants supplying additional information to support their request for access to the Scheme, and to suspend rather than withdraw applications if a participant does not meet this timeframe.
10. Amend Sections 26 and 36 of the Act to make it clear the Agency should provide support and assistance for prospective participants and approved participants (prior to them having an approved plan) to provide required evidence or information (in line with the existing provisions of Section 6). Such assistance could include the provision of experts to conduct assessments or write reports, or funding for the same where a person is unable to afford them.

About us

The Brotherhood of St Laurence and Bapcare are committed to learning together to deliver the best participant experience. Since the NDIS began we've cumulatively worked with approximately 18 per cent of the participants in the Scheme (just over 50,000) across three states, and have nearly nine years' experience in delivering the Scheme.

The Brotherhood of St Laurence

The BSL is an independent non-government organisation with strong community links that has been working to reduce poverty in Australia since the 1930s. The BSL has a strategic focus on building evidence-informed policies and practices that promote community inclusion and participation of all people, especially those experiencing exclusion or disadvantage. This commitment is reflected in our role as a LAC and ECEI provider for the NDIS in the North Eastern Metropolitan, Hume Moreland, Western Melbourne, Brimbank Melton and Bayside Peninsula areas in Victoria. We have been delivering LAC since July 2016 as part of the first phase of NDIS implementation. We commenced as an ECEI provider in November 2016. Our engagement in this planning and community capacity building is driven by the recognition that people with disability are among the most socially and economically excluded Australians.

Through our Research and Policy Centre and in partnership with the Melbourne Disability Institute of the University of Melbourne we undertake research and evaluation activities with the aim of informing the successful implementation of the Scheme in supporting people with disability to live a good life.

Bapcare

Bapcare is a leading, faith-based, not-for-profit social enterprise. At the heart of Bapcare is a pioneering spirit of community service. Bapcare's mission is to partner for fullness of life with people of all ages, cultures, beliefs and circumstances, with the vision to work towards supporting the creation of communities where every person is cherished.

Our experience is built over more than 70-years of providing care and support to vulnerable and sometimes marginalised people in our community. Today, our broad range of services extends across Victoria, South Australia and Tasmania through more than 1,800 skilled and professional staff at more than 40 locations.

Bapcare has been providing LAC services for people with disability since 2008, beginning with the Tasmanian Government, and continuing with the Trial and then Transition of the NDIS in Tasmania. Since 2018 we have also been delivering ECEI on behalf of the NDIA in Tasmania, and LAC services in South Australia.

1 Concerns identified from our consultations about the participant experience

In our consultations, we asked people with disability, their families and carers for specific feedback and suggestions for how their experience of the NDIS could be improved. We also spoke with LACs and ECEI Coordinators to ensure that we heard the feedback of people who don't generally respond to invitations for consultations.

Overall, this feedback confirmed that many people have a positive experience of the Scheme, and numerous people told us how the support they receive through the NDIS has fundamentally changed their and their loved one's lives. Nearly all expressed appreciation for the way in which the Scheme harnesses the goodwill and resources of the community in pursuit of equality of opportunity for people with disability.

Nevertheless, five key concerns about the overall participant experience emerged from the consultations. The issues identified are recurring and require deliberate action to systemically improve the service provided.

Case studies from the people we spoke to, and a summary of the experiences of each stage of the participant pathway are provided in the Appendix.

There is not enough information for participants and their families

Many participants and their families highlighted that their capacity to navigate the NDIS is impaired by both the quantity and quality of the information they can access in relation to the Scheme. They report a shortage of information about how to complete key processes or steps in the pathway, particularly at access and when they try to use their plans. The information available is not transparent, clear or consistent. Critical information – such as the eligibility criteria and what constitutes 'Reasonable and Necessary' supports – is full of jargon and hard to understand. While public information presentations and discussions with LACs or ECEI Coordinators are viewed as useful, the shortage of high-quality documentation available online or to take home makes it difficult for people to apply the information provided to their own circumstances.

The NDIA and its contractors do not always communicate effectively

One of the strongest refrains from the people we spoke to who had tried to contact the NDIS – usually through the 1800 number – was 'No-one called me back'. Participants and families spent a great deal of time 'chasing' the NDIS for information and answers about where their application, plan or review was at, or about how to spend their plan funds. As a result, too many experience the NDIS as a 'nameless, faceless' bureaucracy. This is compounded by complex administrative processes, and limited support throughout the process. This is especially true for those without existing networks, knowledge and resources to draw on.

A proactive, personalised and sustained relationship with a LAC or ECEI Coordinator mitigated this concern, with participants and families who had such a relationship reporting higher satisfaction with the Scheme. LACs and ECEI Coordinators reported that they are eager to be more proactive, but workload pressures and system inefficiencies limit the time available for personalised service.

There is insufficient support for participants and families across the pathway

Participants and their families reported that there are many complex and time-consuming processes, requirements and hurdles, and lots of ways to get it wrong. If you do 'get it wrong', you have to go back to the start of the process. Many people told us they felt 'burnt out' and 'exhausted' by the process of getting, and implementing, a plan that met their or their loved one's needs. Several even told us that managing the administrative burden and associated stress of their or their loved one's plan had caused them to leave a job.

Many people had an excellent planning experience and established a strong relationship with their LAC or ECEI Coordinator. However, others felt 'rushed' and as if they were 'on the back burner' once planning was done. There was generally limited support outside the planning part of the pathway, and many people wished they had someone who they could go to for help when they needed it, regardless of the stage in the pathway.

There is a lack of transparency about decisions and delays

In all the consultations, participants spoke about the fact that they never really knew about what was happening. People often felt they were just 'in the queue'. They rarely knew how long something would take or the process the NDIA was following. Delays were frustrating and sometimes harmful, but what was often most challenging was the lack of communication about what was happening.

Most participants and their families reported that they were unable to speak directly to the person making a decision about their access to the Scheme, their plan or their review. When decisions were made, there was very little explanation of why or how it was made, or who made it. Both timeframes and decisions were inconsistent. Participants and their families and carers knew about inconsistency from discussions in the community with other participants, causing a great deal of frustration and anxiety.

When specific requests from participants, families or carers (usually expressed to an LAC or ECEI Coordinator in a meeting) were rejected by the Agency, there was often no clear rationale provided.

Too often, the NDIS is producing inequitable outcomes

It was also clear from our consultations that the NDIS is producing inequitable outcomes for people across the pathway. This conclusion is backed up by the findings of several inquiries and an emerging body of research (Gruhn 2019; Malbon et al. 2019; Hui et al. 2018; PC 2017).

We spoke to a number of people who had a relatively smooth journey through the NDIS. These individuals or families were almost all well educated, had a high level of functional literacy, confidence and knowledge of systems, and could leverage their networks for support when they needed it. They were better able to understand and navigate the complexity of the system, and to effectively advocate for themselves or their loved one when things went wrong.

By contrast, for a significant minority of people with disability who are particularly vulnerable – usually because of their disability type (psychosocial and/or intellectual), their background (CALD), or their lack of financial and social resources – the NDIS remains inaccessible and impossible to navigate. The access process is particularly problematic for people with psychosocial disability, with many finding the effort required overwhelming and the evidence required too hard to get. A

report by the University of Sydney and Community Mental Health Australia found that (Hancock et al. 2019, p. 3):

many people not applying are in fact those most in need of a high level of support and it is the severity and complexity of their mental illness that is precluding them from engaging in the complex and stressful process required to apply or re-apply.

People from CALD backgrounds also continue to struggle to access the Scheme, as do those who are homeless.

Of particular concern are the stories staff told us about the different outcomes for people with financial resources and those without. Accessing the Scheme was much easier and faster if prospective participants could afford to gather a body of reports and diagnoses, particularly from doctors and specialists who had knowledge of the NDIS. The Joint Standing Committee similarly concluded with regard to ECEI that ‘access arrangements are potentially advantaging families who can afford to source expensive assessments and reports to expedite their child's access to the Scheme’ (Joint Standing Committee 2017, p. ix).

Those who cannot afford this are forced to rely on GPs – often waiting for an appointment at the limited bulk-billing practices in their area – or on waiting lists in the public health system. This can delay their access to the Scheme by months.

While we recognise that the NDIA has developed a number of strategies and action plans for vulnerable groups, we are yet to see enough impact, and there is currently no recourse for people who lack financial resources.

These are the people that rarely participate in consultations with government or other organisations, and whose voices generally do not shape the design and implementation of the NDIS. We also struggled to recruit them to our own consultations and often relied on our staff who work with them every day to tell their stories. We believe this is a matter of great urgency and strongly urge the Review team to consider these issues in depth.

2 What participants want from the NDIS and a Participant Service Guarantee

Throughout the consultations, participants and their families were consistent about what made for a positive NDIS experience, and the things that mattered to them in improving it.

Building on the findings from our consultations for this Review we propose three areas of change to the proposed Guarantee:

- The scope of the Guarantee.
- The definition and measurement of some of the principles.
- Additional principles which we believe are missing.

The scope of the Guarantee

The proposed Guarantee outlined in the Discussion Paper relates almost exclusively to the way the NDIA conducts itself. Changes to the Agency's ways of working are critical to improving the participant experience. However, participants and their families engage with several other parties

throughout their journey with the NDIS, specifically organisations to which functions are outsourced.

The practices, processes and culture of Partners in the Community delivering LAC and ECEI services and the National Call Centre all contribute greatly to the experience and outcomes of participants and their families. The same is true for other statutory agencies, including the NDIS Quality and Safeguards Commission. As such, all government agencies and contracted organisations that work with participants as part of the NDIS ecosystem should be subject to the same Guarantee as the NDIA. The Guarantee should be legislated in the NDIS Act, as suggested in the Discussion Paper, to ensure all parties can be held accountable to it.

The definition and measurement of the principles in the Guarantee

We have some concerns about the unintended consequences of the definition and measurement of three of the proposed Principles: 'Timely', 'Expert' and 'Decisions made on merit'. Every Principle, and the associated standards, goals or KPIs, must be tested against the behaviours that they will drive in practice, and the potential unintended consequences of these behaviours.

We have also made some amendments to the definition of other proposed principles in the table below.

Timely

We endorse the Review's focus on not only the time it takes for participants to get decisions and to access the supports they need but also on *how* those decisions are made. However, there is a sense among participants and families that they do not have the flexibility to drive the timing of their journey – for example they do not feel that they have control over how long they need to develop their plan. It is our experience that an approach that focuses on completing tasks in tight timeframes, without any flexibility for the participant to vary these timeframes, can produce unintended consequences.

Expert

We understand that the principle of an 'expert' NDIA has been included in the Guarantee to address participants' complaints that staff delivering the NDIS did not understand their disability.

It is true that a level of understanding of different disabilities by Agency and partner staff is important, and these experts certainly have their role in the Scheme to provide advice and guidance. During the rollout of the Scheme, such expertise was thin on the ground.

Fortunately, the Scheme is now established, and in our experience, staff knowledge and capability is steadily improving. However, a central point of the Scheme is that people with a disability and their families and carers are *the experts in their own lives*.

The idea of 'experts' telling people with a disability what they need is potentially in opposition to the principles underpinning the Scheme (e.g. S4.8 of the Act). The supports (both funded and unfunded) that participants access are intended to achieve their goals and aspirations, in the context of how their disability impacts on their functional capacity to achieve those goals. Different people with the same condition may have very different goals, very different circumstances and varying community resources available to them.

We believe this principle must recognise participants' expertise in their own lives and the need for the NDIS to bring *complementary* knowledge to this expertise to support the participant's goals.

This would require the NDIS to actively demonstrate its ability to listen to people with a disability, and staff to be adequately trained to interpret the Principles of the Act in the spirit of self-determination for people with a disability and their families.

Decisions made on merit

It is clear from our consultations and numerous other reviews that the NDIS is an opaque system. The criteria for decision-making are well set out in the Act and the Rules; decisions should be made according to these and communicated specifically and transparently to participants and their families. As such, we recommend that this principle be changed to 'Transparent'.

Additional principles

Based on what participants and their families, and our staff told us in our consultations we believe there are three additional principles required in the Guarantee.

Fair

We believe the NDIS should provide a guarantee that they will continuously strive to address issues of inequity that inherently arise in the delivery of human services. As reported through our consultations, the better support you have and/or the resources you can access, the better your experience in the NDIS is likely to be. Building a system that does not support the most disadvantaged to get the right support is in effect failing a group of people who most need the support. For this reason, we believe including 'Fair' as part of the Guarantee is vital.

Accountable

The Guarantee needs to ensure that all NDIS staff¹ are accountable to the principles and standards outlined within it. We suggest that this should mean there are ramifications if the NDIS does not meet all aspects of the Guarantee.

Efficient

We believe that the NDIS should continuously review the balance between the need for administrative processes and approvals against the experience of the participant. As highlighted by the consultations, the NDIS is highly bureaucratic. Participants presently have to complete numerous processes – or wait for staff to complete them – and are often required to provide extensive evidence in a multitude of ways.

For example, participants and families need to justify their request for assistive technology to be included in their plan. Once they get their plan, they then often need to justify the specific make and model of the equipment with further assessments and quotes. Many people go back and forth with the NDIA about what constitutes 'Reasonable and Necessary' and 'Value for Money', the criteria by which the Agency decides on equipment. The negotiation can take months, not only depriving participants of much needed equipment but also tying up the NDIA staff's time in needless administration. This inefficient use of resources burdens an already overwhelmed workforce of NDIS staff, allied health professionals and specialists.

¹In this submission, 'NDIS staff' refers to staff of NDIA and all government agencies and contracted organisations who work with participants as part of the NDIS ecosystem that we recommend should be subject to the same Guarantee.

Revised Participant Service Guarantee

Although we have drafted (below) some revised wording based on our consultations, we encourage the Review team to develop each principle and the standards associated with them through a co-design process with people with disability and their families and carers. Special attention must be paid to engaging with the groups who are consistently absent from these consultation processes as a result of their vulnerability or limited resources.

| Principle | Description | What participants and families told us they want |
|-----------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Timely | <p>ORIGINAL TEXT: The NDIS process will be easier to understand and use, enabling decisions about access, planning and review to happen promptly.</p> <p>PROPOSED CHANGES: The NDIS process is easy to understand and use, enabling decisions about access, planning and review to happen promptly. NDIS staff are proactive and responsive in all communication with participants and their families and carers, and transparent about how long things will take.</p> | <p>Timely decisions <i>and</i> responsive communication: Participants and families want decisions to be made in a timely manner, but more importantly, they want to be regularly updated on the progress of decisions at every stage. They want to know how long something will take and be told when it has been delayed. They don't want to have to chase this information themselves.</p> |
| Engaged | <p>ORIGINAL TEXT: The NDIA engages with people with disability, their family, carers and other support persons when developing operating procedures and processes.</p> <p>PROPOSED CHANGES: The NDIA and its Partners co-design their operating procedures and process with people with a disability and their families and carers. They are always seeking to improve and provide people with a disability and their families and carers with regular and genuine opportunities to provide feedback on what is working and what is not.</p> <p>NDIS staff work with people with disability and their families and carers as equal partners in the development of their plan, and in all decisions about their lives.</p> | <p>Plans that are developed <i>with</i> them and their family: Participants want to be equal partners in the development of their plans. They want planning to consider not just them but their whole family. They want to know that their loved ones are able to live a good life alongside them and not have to fill the gaps that service providers can't meet.</p> |

| Principle | Description | What participants and families told us they want |
|---------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Collaborative | <p>ORIGINAL TEXT: NDIA staff have a high level of disability training and understands the impact particular disabilities have on people’s lives. They understand what supports are most effective for a person’s disability.</p> <p>PROPOSED CHANGES: NDIS staff and delegates recognise participants and their families and carers as the experts in their own lives and disability. They listen to their needs and goals and work alongside them to identify appropriate supports.</p> | <p>Support that values and elicits their expertise and aspirations:</p> <p>Participants want to be listened to and trusted to know what they need. They want to work with someone who asks them what they like to do as a way of forming their goals. They don’t want to just be defined by the things they can’t do and the supports they need.</p> |
| Connected | <p>ORIGINAL TEXT: The NDIA works well with governments, mainstream services (such as health, education, justice services), disability representative groups and providers to ensure people with disability have coordinated and integrated services.</p> <p>No changes proposed.</p> | <p>Support to address the barriers to accessing supports: Participants and their families want to be able to easily use their plans. They want help to navigate their way to services, and to build their capacity to do this themselves.</p> <p>They want the NDIS to work well with mainstream services, and they want to know that they will be able to access the services they need, when they need them.</p> |
| Valued | <p>ORIGINAL TEXT: Participants, their families, carers and other support persons feel valued in their interaction with the NDIS, and know where to go if they need further assistance.</p> <p>No changes proposed.</p> | <p>Continuity and quality of support to navigate the Scheme: Participants and their families want someone they can easily access to ask questions of and to explain things to them. They want this person to be the same through their whole journey, so they don’t have to tell their story over and over again. They want to be listened to and respected. Importantly, they want the person working with them in the NDIS to be able to make things happen – to have the information they need about what is happening for them at that point in time and to be able to progress what needs to happen. If this person can’t make the decisions, they want to be able to talk to the person making decisions about their lives.</p> |

| Principle | Description | What participants and families told us they want |
|-------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Transparent | <p>ORIGINAL TEXT: The NDIA acts in a transparent, informative and collaborative spirit so that participants understand why decisions are made.</p> <p>PROPOSED CHANGES: The NDIS acts in a transparent, informative and collaborative spirit so that participants understand why decisions are made and have a role in that decision making.</p> | <p>Clear and transparent decisions: Participants want to have a say in decisions <i>before</i> they are made. They want to know what they can expect to have funded by the NDIS before they start the planning process. When decisions are made that they don't agree with, they want to understand why and have this explained to them in a way they can understand. They want clear recourse for appealing or making a complaint, and to know what is happening with their appeal or complaint at every step of the process.</p> |
| Accessible | <p>ORIGINAL TEXT: All people with disability can understand and use the NDIS, and the NDIS ensures its services are appropriate and sensitive for. Aboriginal and Torres Strait Islander people, people from Culturally and Linguistically Diverse (CALD) backgrounds, LGBTQIA+ and other individuals.</p> <p>No changes proposed.</p> | <p>Better information: Participants want more information and direction at every point in the NDIS. They want this information to be easy to understand, in plain English or in their own language if they do not speak English.</p> |
| Fair | <p>The NDIS actively works to reduce the potential inequities that may arise by ensuring that the right support and resources are made available at all times to participants in line with their needs.</p> | <p>Equitable outcomes: Participants and families want to know that their background, disability or financial resources will not impact their or their loved one's access to the NDIS, or the level of funding they receive. They want to know that their capacity to self-advocate will be built through their engagement with the NDIS, so they can be independent.</p> |
| Accountable | <p>The NDIS commits to continual review and publication of the adherence to the Guarantee and principles of the Act and can demonstrate that Scheme is continuously being adapted to improve the experience of participants.</p> | <p>To be able to trust the Scheme: participants and families want to know that the NDIS will work on improving things for them.</p> |

| Principle | Description | What participants and families told us they want |
|-----------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Efficient | The NDIS strives to be efficient to ensure administrative requirements do not overburden participants and their families, and to ensure the Scheme is sustainable in the long term. | Reasonable evidence provision: Participants and their families don't mind providing some evidence about their condition or their requests, but they want this to be balanced with trust for their own expertise, and they don't want to have to provide the same evidence over and over again. |

Broader reforms to make the Guarantee effective

While we endorse the Guarantee, we believe there are two fundamental issues that it will not address:

- Decisions consistently happen far from participants.
- There is not enough consistent, face-to-face support.

Bringing decisions closer to participants

The NDIS is a very centralised bureaucracy. By this we mean that all key decisions are made far from the ground where service delivery is happening and, critically, far from participants and their families. Participants and their families do not speak to the person making decisions about their access to the Scheme, their funded supports or the outcome of their review (if they request one). This is one of the most problematic aspects of the Scheme as it currently operates. It is disempowering for people with a disability and their families and contravenes the Principles in the NDIS Act about people with a disability having the right to be 'equal partners' in decisions affecting their lives (NDIS Act 2013, s.4(8)).

We note that the Discussion Paper states that the Agency is introducing the capacity for participants to view draft plans. We believe this needs to be taken a step further and include the right for participants to discuss their plan with the delegate approving it before it is finalised, including during an unscheduled review.

Providing participants with a consistent, single point of contact

It was clear in our consultations that participants and their families need much more support throughout their entire NDIS journey. They need this support to be easy to access, available to them whenever they need it, for as long as they need it, and they need it to be consistently from the same person.

This support is perhaps most critical at plan implementation, when participants and their families are trying to access the supports they need. Almost everyone we spoke to struggled to do this, resulting in delays in fully actioning their plans. Those with support coordination were often unsure who played what role in supporting them and felt as if there were 'too many chiefs telling you too many different things'. Many people are reaching their scheduled review with an underspend – indeed the NDIA's latest figures show on average people are only spending 68 per cent of their plans (NDIA 2019, p.38).

Some people are spending critical time without the support they need. This is particularly harmful in childhood, when delays in interventions can have severe consequences for children with developmental delay. Ultimately, people being unable to access the supports they need also represents a risk for the Scheme, as functional capacity can decline resulting in greater need.

Having a single point of contact who can provide face-to-face support from the first interaction with the NDIS would mitigate many of the frustrations participants experience across the pathway. However, these benefits depend on two things: staff having the time to provide the level of support required by participants, and staff being well informed, skilled and empowered to act to make things happen for the participant and their family.

The quality of the relationship for this kind of support also matters, as demonstrated by an extensive body of literature (Oatley 2016; Benjamin & Campbell 2014; Beresford et al. 2008). Many participants told us that their relationship with an LAC or ECEI Coordinator who was knowledgeable, took the time to get to know them and was always available to touch base or answer questions was the key factor in their feeling secure and satisfied in their NDIS journey. Equally, others told us that having someone who they could call and ask questions of – ‘like a buddy’ – would have made all the difference to their wellbeing and outcomes in the NDIS. Participant experiences with LACs or ECEI Coordinators were inconsistent – both within the same organisation and between different Partners.

Partners in the Community are the face of the NDIS. They provide the primary face-to-face contact that participants have with the Scheme and were originally envisaged as the critical system navigator by the Productivity Commission (2011). However, this on-the-ground delivery is not yet being maximised. A significant amount of LACs’ and ECEI Coordinators’ time is spent on administrative activities, keeping up with numerous changes in procedures, and managing complex or duplicative processes and structures.

If Partners are to be the single point of contact, there needs to be an investment in (a) ensuring they have the time and the incentives to provide the required support; and (b) investing in the practice and training of the workforce.

It must be acknowledged that other, systemic barriers – albeit outside the scope of the current review – also prevent people from accessing the supports they need. It is clear from our consultations that many participants and their families face long waits for services. There are severe workforce shortages, particularly in allied health, limited services in many areas, and dysfunction in the interface between mainstream services such as education and health and the NDIS. In Tasmania, issues in the market are pronounced. Without concurrent investment in urgently addressing these issues, improvements in the participant pathway will have only marginal impact on the ability of people to actually access support.

3 Amendments to the NDIS Act

In addition to legislating the Guarantee (which we endorse), the Review is also tasked with ‘removing legislative red tape’ to improve the participant experience with the NDIS. However, we believe the primary problem with the Act is not red tape, but rather the fact that the provisions of the Act are not adequately adhered to. We also recommend some amendments to the Act to require the NDIA and its Partners to be more accountable and transparent about decision making, and to remove provisions that are inadvertently punitive to people seeking access to the scheme.

Implement and be accountable to the existing Principles in the NDIS Act to promote positive participant experience

The NDIS Act sets out the kind of service people with a disability and their families and carers can expect from the NDIS: one which respects their right to self-determination, recognises them as 'equal partners in decisions that will affect their lives', and invests in support that enables them to exercise choice and control and participate fully in society (NDIS Act 2013, 4(8)). Many of the Principles in the Act align with the kind of experience participants and their families we spoke to said they wanted from the NDIS. In particular, we draw the Review team's attention to Section 4, the underpinning Principles for the Scheme; and Sections 31 and 33, relating to the way plans are to be developed.

The Act is primarily principle-based rather than prescriptive, and we recognise that translating principles into policy and practice is a difficult task, especially in a system as young and complex as the NDIS. However, it is clear to us, from our consultations as well as our years of experience delivering the Scheme as Partners in the Community, that this process of translation is still not complete.

For example, Section 4(9) states that a guiding principle is: 'people with disability should be supported in all their dealings and communications with the Agency so that their capacity to exercise choice and control is maximised in a way that is appropriate to their circumstances and cultural needs'. As we have outlined, people are receiving insufficient support across the pathway, and communications from the Agency are often impossible for them to understand. Similarly, Section 31 of the Act outlines the principles that should underpin the way participants' plans are developed. Many of them relate to concerns consistently raised by participants and families in our consultations, such as that plans were not individualised (31(a)) or determined by the participant (31(b)) and did not take into account their family context (31(c-da)).

We believe any review of the Act should first and foremost look to making the existing principles and provisions about the way the NDIS will engage with people with a disability and their families more enforceable. This could include removing moderating language such as 'should' (as opposed to 'must'), and 'as much as reasonably possible' – an action also recommended by the 2015 review of the NDIS Act (Ernst and Young 2016, p.5). In particular, we strongly recommend that the qualifying language – 'should so far as reasonably practicable' – be removed from the start of Section 31, which describes the way plans should be prepared. The features described in this Section, such as plans are 'individualised', 'determined by participants', and consider family context and other informal supports are fundamental to a quality planning experience and *must* be adhered to.

Make the NDIS more accountable and transparent by requiring the Agency to ensure participants understand its decisions

Many of the issues raised by participants and families, and by LAC and ECEI staff, relate to a lack of transparency regarding decisions about access to the Scheme, inclusion of funded supports, or outcomes of unscheduled reviews.

Participants and their families are required to justify their requests with evidence, which we endorse in the name of accountability to the scope and sustainability of the Scheme.

However, at present there is no reciprocal requirement for the Agency to give its reasons for rejecting requested supports (until an appeal reaches an external authority for review).

Explanation, where given, is usually a limited reference to the eligibility criteria or to 'Reasonable and Necessary'. We recommend that the Act be changed to require the Agency to explain its decisions, according to the relevant sections of the Act and the Rules. This explanation needs to be in language that the participant and their family understand, and in person or over the phone to ensure they do understand and can ask questions.

Remove punitive barriers to access for participants

Section 26(3) states that if a participant does not supply the additional information requested by the CEO within 28 days, then 'the prospective participant is taken to have withdrawn the access request'. As highlighted earlier in this submission, many participants struggle to meet the 28-day timeframe for providing more information, following a request from the Agency (see Appendix, p. 21 for more details). Rejection from the Scheme can have severe psychological impact, and the process of reapplying – if people can work themselves up to it – is exhausting.

This is most problematic for people who are vulnerable, such as those experiencing homelessness, those who have a psychosocial disability or people with limited financial resources or functional literacy. These people are often those who would benefit the most from the NDIS, yet the current arrangements discriminate against the most disadvantaged.

We recommend a change to the Act to extend this timeframe, and to suspend rather than withdraw an application if a participant does not meet this timeframe, to allow participants to resume their request. Combined with greater face-to-face support from the outset, this would help to mitigate many of the challenges people are facing in accessing the Scheme.

At access, evidence requirements mean that people who are poor get a discriminatory level of access and support. This needs to be addressed at the level of either the Act or the Rules.

Appendix: The participant pathway

Participants and their families experience a range of issues across the pathway. Negative issues had a compounding effect; many people feel increasingly overwhelmed, exhausted and disillusioned as they face hurdles and setbacks at each point, and this can result in declines in mental health. For parents of children who know that the longer their child goes without critical early interventions, the more their development will be setback, these challenges have a particularly severe impact.

Accessing the NDIS

The NDIA website indicates a relatively straightforward process: prospective participants call or visit an LAC or ECEI partner (depending on age), visit an NDIA office or call the National Call Centre (NCC) on the 1800 number to request access to the Scheme. They need to supply age and residency evidence, and evidence of their disability, demonstrated by their health professional.

The reality is different for many people. Participants and their families tell us:

- **There's not enough information or support to complete the process, and it's very easy to get it wrong.** Participants and their families report that if you miss a letter from the NDIA, your health professional doesn't word the evidence for your application 'right', or the information in your Centrelink profile doesn't track over to the Agency, it's likely your application will be rejected and you will need to start all over again.
- **Poor communication and punitive timeframes mean people often have to apply more than once.** Completing the Access Request Form (ARF) successfully the first time requires not only functional literacy, but a familiarity with government and systems and, crucially, a high degree of health literacy, given the burden of evidence required from medical professionals.

Not enough information or support to complete the access process

People struggle to 'work out how to get in the front door'. For most people, there is no-one to speak to face to face about the application process. There is confusion about whether or not LACs provide support to access the scheme. Some people are able to access a service provider or advocate who can help them complete the paperwork, but many people don't.

For many participants, their main contact during access is with the NCC on the 1800 number. The ARF is sent out by post, with very little guidance on the process, or where they can go for support to complete it. Prospective participants can call the NCC for more information, but there is little consistency in advice and no capacity for people to contact the same person throughout the process.

This is particularly problematic for people in the deaf community, who have to call the National Relay Service. They may wait a long time just to be connected to that service, after which they have to stay on hold for the NCC. Often after that initial call, the NCC still contact them by phone, despite the fact they are deaf. While there are other options, they are often problematic. Participants can communicate with the NCC via video service or interpreter, but both are in high demand, and dependent on a good internet connection. Participants can also request the form by email, but that is not common knowledge, and isn't mentioned on the NDIS website.

Many people told us they wished they had a clear point of contact and support when accessing the NDIS:

The father of a child with autism spoke about his experience getting access to the NDIS. 'It's hard enough to deal with your son being diagnosed on the spectrum, and then there was no pathway, there was no clear ... 'Here's the information, this is what you need to do, this is the flow diagram to follow'. [...] He explained how having a single point of contact throughout the process would have helped. It should be that 'after your child's diagnosed, then a person is allocated, like maybe a case coordinator, to guide you. They call you up, 'Hi this is x from whatever organisation, I'm calling about your son. What I'd like to do is organise a time to sit down with you'. And then they map it out for you. Rather than you doing the work, right, cos I gave up my job to help my child'. [...] 'The NDIS has done my head in, and at times I've felt like giving up. I've had to give up my career, a very good career, a drop in wages to nothing'. 'The NDIS has fragmented people. [...] Having a go-to person would really help".

There is not enough support to get the 'right' evidence to meet access

For most people, the hardest part is getting the right evidence to demonstrate eligibility. The NDIS is not meant to be based on a diagnosis, so evidence is needed of lifelong functional impairment, in a way that aligns with the eligibility criteria for the Scheme. Without adequate advice from anyone in the NDIS, people rely on the expertise of their health professional to complete the application form.

However, the health sector is still not well versed in what is required by the NDIA. GPs and other professionals often contact LACs for advice on what, and how, to write evidence for access. This means that a participant's chances of being deemed eligible on their first application often depends on whether they can find – and access – a doctor or therapist who knows how to meet this requirement. The cost of gathering this evidence can also be prohibitive.

When access works better through the ECEI gateway

The process is better in ECEI, where the ECEI Partner is able to function as a gateway to facilitate the access process and better prepare families to navigate the NDIS. However, communication breakdowns between different parts of the system can compromise the efficacy of this pathway.

This can have significant detrimental impacts on families who need support to access the Scheme – particularly those who are vulnerable, from CALD backgrounds who do not speak fluent English, who are unfamiliar with the health system and who often have limited formal education.

Families with children who were too old for the ECEI gateway (eligibility ends at 7 years) also spoke about how difficult this was given their need for a specialised response. One participant with an 8-year-old child with autism spoke about the struggle to access the Scheme after he turned 8 and was no longer in the Early Childhood stream:

We need someone to come in and guide the family through the whole process'.
[...] 'I had it easy at the start, [on the old ECIS scheme] it's now switching over because he's older, and I can't get the providers anymore. [...] I don't know what I'm doing anymore.

Poor communication and punitive timeframes mean people often have to apply more than once

Communication from the NDIA during the access process is highly problematic for many people. Requests for further information and communication about whether you have met access or not are by letter and almost always in English – even when people have told the NCC that they do not speak English or are vision impaired. It is generally full of jargon, referencing parts of the Act or

using acronyms. For those without functional literacy, the very first step of accessing the NDIS is daunting. There is no information in the letter about the next steps the participant needs to take. It's not followed up with a phone call or referral to an LAC or ECEI Partner.

The timeframes for completing the application process are strict, and many prospective participants are not able to meet them. LACs told us about people who walk into or call an LAC office after having their application rejected, seeking some understanding of what went wrong. The LACs 'translate' the letter for them, explaining the acronyms and references to sections of the Act.

They told us that aside from the evidence from health professionals not being worded correctly, the most common reason for people being rejected was missing the 28-day window for providing further information. Sometimes this is because they missed the letter in the mail or didn't understand what it was asking for; other times a life event – such as hospitalisation or poor health – has got in the way. For people who needed more evidence from a health professional, waiting lists can make it impossible to meet the deadline.

All of this means that participants who are eligible for the Scheme may be rejected the first, and even the second or third time they apply. When access is denied, the notification letter – again, always sent in the mail, in English and full of jargon – has little information about what their next steps are (e.g. reapply but get different evidence, supply other information), and no sensitivity to what the decision means for the person.

The psychological impact of being denied access to the NDIS is severe. In our consultations, those who had been rejected (but had since met access on the second or third attempt) told us how distressing the experience was. Many felt their disability had been denied, or that they now faced a lifetime without support. It often took people weeks or months to 'work themselves up' to applying again, further delaying their access to support.

Creating the plan

Many participants have a positive planning experience – almost universally underpinned by a relationship with an LAC or ECEI Coordinator who they felt really listened to them. However, other participants we spoke to had experienced the planning process as disempowering and opaque, with very little communication or transparency between the NDIA, LAC/ECEI staff and participants and families.

There is also little clarity in the community about the differing roles and responsibilities of an LAC or ECEI Coordinator, and the NDIA.

Participants consistently identified three issues with planning experiences:

- **Limited ownership of the plan.** They didn't feel they 'owned' their plan. They did not see a draft plan and did not meet or speak to the person making decisions about their needs and goals (unless they were Agency planned).
- **Plans that didn't always match their needs and goals.** They didn't feel they were listened to because when they got their plan, it often didn't match what they had told the LAC or ECEI Coordinator during their planning meeting.
- **Participants don't know why decisions were made about their plans.** When they got inadequate plans, no-one could properly explain how or why those decisions were made.

Limited ownership of the plan

Many participants told us they felt little ownership over their plans. One participant with intellectual disability said she would have had no idea what the planning questions meant without the support of her family to explain the questions to her. Many did not realise at first that the LAC or ECEI Coordinator they were meeting did not actually develop or approve their plans. Many people told us they had expected to see what would be submitted to the NDIA and have a chance to approve it before it was finalised.

The actual process of plan development was very different, disappointing and frustrating many participants and their families. Instead participants and/or their families sat with the LAC or ECEI Coordinator, communicating their goals and needs and the kind of support they wanted. They were unable to see the draft plan submitted and subsequently had no access to the NDIA planner charged with making decisions about their needs and goals. Most then received in the mail their finalised plan, which in many cases bore little resemblance to the discussion held with the LAC or ECEI Coordinator. Many participants are left with scant knowledge of what is in their plan and why. LAC and ECEI staff told us that they often have little chance to talk to the delegate either, and struggle to contact the right person in the agency.

A participant in one of our research projects succinctly described the experience:

You talk about a rapport ... you [the participant] have a two-hour meeting with a person [LAC staff]. You never see them again, so really the rapport building is quite minimal ... They [LAC staff] then put together the plan based on that. It then goes into the behemoth of the NDIS to a planner who has never seen you or anybody else. You don't know who this person is. There's this huge brick wall there. Even the LACs don't have access to whoever the planner is, and they then make all the decisions, so the LAC, from my understanding, can really write whatever they want, but they're not the ones making the decision.

Plans didn't always match needs and goals

While there were many examples of participants receiving plans in the mail that reflected what they discussed with their LAC or ECEI Coordinator, there were also many who were left confused by items that were excluded from the plan without explanation.

Some participants had items added to their plans that they neither wanted nor needed. Others didn't get enough support to meet their needs. Access to support coordination, enough therapy hours and transport funding were consistently raised as supports that people needed but couldn't get. One participant spoke about needing to choose whether to go to the GP or visit her family because of the lack of transport funding and no available public transport.

Participants and their families told us that they felt like they weren't trusted to know what they needed, and that they had to justify supports with significant amounts of evidence from health professionals. This matches the findings of the Joint Standing Committee on the NDIS, who heard repeated evidence of 'what can only be described as the development of a culture of mistrust of participants and their needs' (Joint Standing Committee 2018, p.ix).

Participants don't know why decisions were made about their plans

Participants reported having little knowledge of how long it would take to have a plan approved; of the plan approval and amendment process; and of who to contact to address problems with the plan.

When plans arrived that were different from what they had discussed with their LAC or ECEI Coordinator, there was little explanation beyond supports were not deemed 'Reasonable and Necessary'.

Participants reported inconsistent decisions about funded supports, and several participants told us of anxiety in the community about getting a 'good' or 'bad' planner, with one describing it as 'Russian roulette'.

Using the plan

Nearly everyone we spoke to through our consultations, and our prior research, struggled to use their plans. This was because:

- **There is not enough information or support about how to use funds or access services.** This is particularly challenging for self-managed participants. It takes a long time to figure out how to connect to services, including support coordination or plan managers, and people are unsure of how they can use their funds.
- **There are still significant delays in securing assistive technology (AT) and home modifications.** This is due to overly rigorous assessment and approval processes about what is 'Reasonable and Necessary' and 'Value for Money'.
- **Waiting lists are prohibitive.** There are long waiting lists for most services, particularly specialist and allied health services. Even if everything has gone smoothly through the pathway so far – and for many people it hasn't – and they can figure out how to use their plan, participants and families are often left waiting for months without support anyway.

Not enough support to use plans

Participants and their families told us there is simply not enough support to understand how to spend their plans. The plan itself has very little information on what each area of funding means, and how it can be spent. Participants and families consistently reported feeling overwhelmed by the barriers of figuring out how to use their plans, complying with the 'rules' if they were self-managed, negotiating with providers and navigating the complex interfaces between the NDIS and mainstream services. Several people told us that they had quit their jobs or delayed returning to work because managing their or their loved one's plan and all the other administration involved with the NDIS was 'a full-time job'. One mother of a young child told us she wasn't 'spending quality time with her son' because of it.

For people who are self-managed there is often little to no support to implement the plan, and this caused significant delays and stress for many of the people we consulted. For others, there are 'too many chiefs telling you too many different things', with little clarity about the difference between an LAC or ECEI Coordinator, NDIA planner, Plan Manager and Support Coordinator. Both staff and participants view support coordination as critical for implementing plans, but very difficult to get. For those able to get support coordination the ability to implement the plan rests entirely on connecting with a provider (which can take months) and on them being skilled (quality varies greatly).

Although LACs and ECEI Coordinators are meant to offer some support for implementation, this varied in degree and was rarely enough. Staff reported that they did not have enough time to provide the level of support required.

There is little clarity for people about who they can turn to for support, as one participant describes:

I reckon that would be so beneficial for people [to have someone act as a system navigator], because I get so sick and tired. I sent an invoice to my plan manager, my financial people, and they said oh no you've got to speak to your LAC. So I rang the LAC, and they said oh no you've got to speak to your plan manager.

Unlimited support during implementation is particularly crucial for highly disadvantaged participants.

Delays in assistive technology and home modification approvals

The Agency has made a number of changes to the AT process, including making it easier for people to get replacement AT and limiting the number of quotes required for low-cost AT. However, approval times and funding release for assistive technology and home modifications remains among the most significant issues experience by participants. Delays for AT can have profound effects on the safety and quality of life of people with a disability – especially on the development of young children, those who require prosthetics or orthotics, and those with degenerative conditions. Delays for home modifications² can leave people in unsafe circumstances, and in a case we heard about, trapped in their home unless they have the assistance of a support worker. Participants report a lack of clarity about responses to their AT requests, or why it is taking so long. As one participant said: 'I struggle to understand why thousands of people have to be on a list waiting for answers on if they can have these things to make their lives easier'.

Participants and families need to justify their request for AT to be included in their plan. Once they get their plan, they then often need to justify the specific make and model of the equipment with further assessments and quotes. Many people go back and forth with the NDIA about what constitutes 'Reasonable and Necessary' and 'Value for Money', the criteria by which the Agency decides on equipment.

This negotiation process can take months, not only depriving participants of much needed equipment but also tying up the NDIA staff's time in needless administration.

Waiting lists for services are prohibitive

Almost everyone we spoke to recounted long waiting lists for essential services. There are severe workforce shortages for allied health professionals in particular, and for builders approved to do home modifications. Mental health services are severely limited in both Victoria and Tasmania. Waiting lists for good support coordinators and culturally appropriate services were also long. These issues were understandably most pronounced in outer metropolitan and regional areas, although people in metro areas also struggled.

Reviewing the plan

Scheduled reviews

In many cases, the scheduled review of a plan was far less stressful than the initial plan. However, many of the participants we spoke to had struggled to spend their funding, due to the reasons

² Note home modifications are classed as assistive technology

listed above, or because 'life got in the way'. Health problems, hospitalisations and deaths of loved ones often took precedence over accessing therapies and other supports.

There was significant anxiety among the people we spoke to about having funds taken away through their review as a result of an underspend that was outside of their control. Staff and participants told us about many examples of people losing funding for things in their second plan – particularly transport – without any explanation as to why. There was also a sense among participants that the implications for not spending all of the funds was their fault, and they received little support from the NDIS to help them address the lack of spending.

Unscheduled reviews

While there have been some improvements in the time it takes to complete an unscheduled review, they still take too long, and participants receive little to no communication about progress. There is a significant amount of anxiety in the community about this as everyone knows how long it takes.

Often participants are requesting a review of only one part of their plan. While they are waiting to hear about that, they are able to start accessing the other supports in their plans. However, once their review is concluded, it generates a 'new plan', necessitating new Service Agreements with all providers, even when there has been no change to that part of the plan.

Full pathway case studies

Here we provide two case studies tracking the journey of the participants throughout their entire pathway, to illustrate the challenges faced, and the cumulative effect on people's wellbeing and outcomes.

David and Andrew³

David, who is totally blind (no light perception), and his principal carer, Andrew, first accessed the NDIS in July 2018, and got a plan by November. David had a 'fairly smooth' entry to the NDIS, as they had previously arranged for David to be put on the Victorian Disability Support Register to speed up the access process.

Unfortunately, their planning experience did not mirror the ease of their access to the Scheme. Based on a brochure they received about the NDIS after David met access (which was actually from a planning pilot that never rolled out), they believed that developing his plan would go something like this: they would meet the NDIA planner to discuss David's goals and needs, the planner would come up with a draft plan, and they would then meet to go over it together and make sure it covered what David needed to live his life and meet his goals, after which the planner would approve the plan. The brochure had also stated that an NDIA planner would be available 'upon request' to discuss the outcomes of their plan and to adjust it for any areas of support not appropriately covered.

At their planning meeting with their LAC, David and Andrew learnt that they would never meet the NDIA planner approving David's supports. Instead, the LAC would collect information and present their needs to the NDIA planner. The meeting went well though, and they provided the LAC with a detailed document (based on a pro forma from Guide Dogs Australia) outlining David's

³ All names have been changed

condition, his goals and objectives and what was needed to achieve them. They requested to speak to the NDIA planner before the plan was finalised but were told that was not possible.

When David and Andrew received their plan, they realised that there at least nine significant supports they had discussed with the LAC that would help him work towards his goals had been denied. For example, David was not allocated transport funding because he had been approved for a guide dog, and 'the dog would provide the transport'. They were also denied assistance for growing fruits and vegetables, David's main passion and hobby, due to the property title being in Andrew's name; the NDIA deemed this Andrew's 'responsibility as property holder', despite the fact that he has little involvement with it.

The process left them feeling frustrated and let down. As Andrew says, 'we never got to see what the LAC submitted to the planner... Did she understand our needs and represent them fairly? We will never know!'. They believe the rejection of key supports was in part because they weren't able to 'present their case' directly with the planner. Their plan reflected a 'clear lack of understanding of David and his needs' and they almost 'lost all faith in the system'.

David and Andrew commenced the review process the same day they received the plan but were left completely in the dark about what this would mean. As they describe it:

"We were never informed by the NDIA of its receipt and the timeframe or process. It took nearly six months and the LAC advised that she was no longer involved in this process. She was limited to providing the outcome and paperwork... Eventually, an NDIA planner called to advise the new plan figures. Never did we get a timeframe guide to this process. We did not receive anything to suggest the review had been lodged... we were never provided with a formal outcome to the review. All we were given were revised budgets".

In April 2019, approximately nine months after he entered the Scheme, David had a plan that met his needs. Andrew contacted the NDIA and requested feedback on the review process, but the subsequent phone conversation provided him with no further clarity about how the decisions that led them to this point were made. By this point they were too exhausted by their journey in the NDIS to continue trying to get the information:

"There should have been a formal document stating which items were approved and which were not and why! But as we had a good outcome in totality, exhausted by the process, I left it at that. The whole review process would never have been necessary had we had the opportunity to meet with the NDIA planner at the draft stage of the initial plan as per the NDIS brochure and the Minister's announcement only a week or so prior to planning meeting".

However, their frustrations weren't over. Once they had a plan that met David's needs, David and Andrew now had to figure out how to spend it and negotiate good services with providers.

David's plan had a major capital item: a new guide dog. While they understand that large amounts of capital expenditure need to be paid directly by the Agency (as opposed to handing the money to the participant to pay the provider), they expected to be consulted by the Agency prior to funds being paid. This was deeply disappointing for them, as 'all capital items should have end recipient involvement in the approval to pay process including household modifications, wheel chairs and service dogs etc.'. As they put it, 'that is putting control in the hands of the client which is what the NDIS is supposed to be all about'. Instead, the NDIA released the capital payment to Guide Dogs Victoria without consulting David to confirm he was satisfied with the dog. The result was an unsuitable guide dog, which has since been returned for retraining, which was also

unsuccessful. David is still waiting for a replacement dog that suits his needs, and is unsure of if he actually wants one now.

David had also been allocated support coordination but found the quality of the service lacking. They eventually decided to stop using the support coordinator and work it out themselves. As they are self-managed, they now have to determine what they can and can't spend their funds on, according to the principles of 'Reasonable and Necessary'. They have found this very hard, and their LAC – who is not authorised to make those kind of decisions – could not give them any support apart from sending them the guidelines. They aren't able to speak to anyone in the NDIA who can provide this advice. The 'scary bit' for them is now working out whether they have complied with the rules. Andrew, who manages the administrative and financial burden of self-managing, is concerned about what this could mean if they are audited: 'I want to do the right thing, but there's no one there to help me determine what that is'.

David and Andrew's main recommendations for improving the participant experience are clear: participants need to be better supported throughout the entire process, with face-to-face support to understand 'what the NDIS can mean and do for them', how they can implement their plan, and if things go wrong, what their options are to correct it.

There needs to be more and better communication, and this needs to be proactive on the part of the Agency: they 'had no communication with the NDIA throughout the planning process and any information was only gained by phoning'.

Most importantly, as Andrew puts it: 'the decision maker needs to be involved directly with the client to fully understand the issues and areas of need'.

Despite these challenges, they remain fully committed to the Scheme. As Andrew sums it up:

'This Scheme has the ability to change lives and it is both for David and me, his carer. Whilst the above may sound very critical of the system, the end result is a great plan for David which is helping him to do things he could never have done before. Having said that, it's only because of my professional background, sheer determination and stubborn pig-headed Dutch blood that we got there in the end. Sadly, many don't have access to that...'

Natalie

Natalie is a 40-year-old stroke survivor. She had her first stroke at age 13 and has a range of chronic and complex health problems as a result. She is on the Disability Support Pension but has a long history of working and volunteering in the health and advocacy sectors, and currently works one day a week as a patient support officer at a hospital. She has the same aspirations as any 40-year-old - to maintain a job, to have a relationship, to be independent.

She applied for the NDIS at the end of 2017 but was rejected the first time – she isn't sure why as the letter had very little information, but she thinks it was because her evidence wasn't 'worded right'. It took her several months to work herself up to reapplying, because as she puts it: 'every time you hear no or get declined it feels like a punch in the guts'. She reapplied at the urging of a Professor she knows through stroke research, and who is also a registered physio and assisted her with the application. She was accepted to the Scheme in June 2018.

After calling her local LAC office, Natalie had a planning meeting. She completed in detail a planning booklet about her condition, her needs and her goals, including that she wanted to up

her working days to twice a week. However, when she got her plan, it didn't really match what she had discussed with the LAC. Instead it was quite 'generic' and seemed like a plan for an older stroke survivor. For example, there were no employment related supports in her plan. She had written in the planning booklet that she used a range of walking aids, including a stick, a frame – which give her the most independence – and sometimes a wheelchair. Only the wheelchair was funded in her plan. When she subsequently needed to get a new walking frame, she paid the \$190 out of her own pocket.

During her planning meeting she had spoken about difficulty preparing meals, as she had to hold the knife one handed, and was often very tired by the end of the day. She was also allocated 2 hours for a support worker, 7 days a week, which she neither wanted nor asked for. Natalie has a wide range of informal supports and is quite independent, and her kitchen is very small so for her the best option would be to buy in meals from a provider (which would also be cheaper than the support worker). Natalie considered putting in an unscheduled review to change her plan, but she didn't see much point in going 'into a pile with thousands of other people'.

The biggest issue for Natalie has been trying to implement her plan. She has had very little support since getting the phone call from her LAC to say, in her words, 'congratulations you've got funding for \$100k, see you later'. She has felt entirely overwhelmed by the prospect of figuring out how to spend her funds, and as a result, has not accessed very many supports.

Natalie's plan included funding to get OT assessments for an accessible bed and home modifications, including an automatic door. Due to her disability, she has considerable muscle weakness, and the door to her apartment is self-closing which means it 'takes all of her energy to hold it open'. Natalie submitted the OT assessments for her accessible bed and the home modifications she needed in March of 2019. In June, her LAC called to tell her the NDIA required more evidence for the bed, so Natalie got another report from her OT which detailed the respiratory issues, bed sores and postural issues that she was experiencing.

In October, just before her first yearly review, Natalie was informed her application for the bed had been 'rejected'. There was no explanation about why. Throughout the period from March to October, she received no communications about the bed other than the request for more evidence. When Natalie asked about the other home modifications she was told that they were 'with another department' who were waiting to hear if the bed had been approved before they looked at her reports. She has little clarity about if or when they will be approved. She's now considering using her superannuation to buy an accessible bed. She is also thinking of quitting her one-day-a-week job (despite one of her goals for the year being to increase her hours to two days) due to the impact her NDIS experience has had on her mental health and the constant fatigue she battles because of the pain her inaccessible bed causes her at night.

She recently had her first yearly review and feels extremely anxious about losing funding due to her underspend: 'my big fear is that I'm not going to get a plan for next year because they are going to look at what I haven't spent and think I don't need it'. During her review, her LAC asked her what goals she wanted to work on for the next year; but Natalie had no answer for her – 'you want me to give you goals for next year but that's really hard because I haven't achieved anything for this year. My goals are the same!'.

Natalie is very capable, is a strong advocate for herself and for others, and has a strong network of informal supports. Still, the toll on her mental health from her experience with the NDIS has been considerable: 'you can understand why people give up – which is the point I'm at. It feels like it's been a fight right from day dot of ringing [the NDIS], at every twist, at every corner. If I

had a decent night's sleep I might be able to cope better, I might be able to get through a full day of work. I'm not asking for luxuries, I just want the bare necessities to get me through'.

References

- Benjamin, L & Campbell, D 2014, 'Programs aren't everything', *Stanford Social Innovation Review Spring 2014*, Stanford.
- Beresford, P, Croft, S & Adshead, L 2008, 'We don't see her as a social worker': a service user case study of the importance of the social worker's relationship and humanity', *British Journal of Social Work*, no. 38, pp. 1388-1407.
- Ernst & Young Australia 2016, *Independent review of the NDIS Act*, Ernst & Young, Canberra.
- Gruhn, R 2019, '*It's everybody's business*': multicultural community perspectives on disability and the NDIS, Ethnic Communities' Council of Victoria, Melbourne.
- Hancock, N, Gye, B, Digolis, C, Smith-Merry, J, Borilovic, J & De Vries, J 2019, *Commonwealth Mental Health Programs Monitoring Project: tracking transitions of people from PIR, PHaMs and D2DL into the NDIS – final report*, The University of Sydney & Community Mental Health Australia, Sydney.
- Hui, F, Cortese, C, Nikidehaghani, M, Chapple, S & McCombie, K 2018, *Hard to reach: examining the National Disability Insurance Scheme experience – a case study in Wollongong*, University of Wollongong, NSW.
- Joint Standing Committee on the National Disability Insurance Scheme 2017, *Provision of services under the NDIS Early Childhood Early Intervention Approach*, JSCNDIS, Canberra.
- Joint Standing Committee on the National Disability Insurance Scheme 2018, *Provision of assistive technology under the NDIS*, JSCNDIS, Canberra.
- Malbon, E, Carey, G & Meltzer, A 2019, 'Personalisation schemes in social care: are they growing social and health inequalities?', *BMC Public Health*, vol.19, no. 805, pp. 1–12.
- National Disability Insurance Agency (NDIA) 2019, *COAG Disability Reform Council quarterly report 30 June 2019*, NDIA, Canberra.
- Oatley, C 2016, *Formative evaluation: understanding the praxis and impact of the Local Area Coordination approach on the Isle of Wight*, Southampton Solent University, Southampton.
- Productivity Commission 2011, *Disability care and support, report no. 54*, Productivity Commission, Canberra.
- Productivity Commission 2017, *National Disability Insurance Scheme (NDIS) costs: Productivity Commission study report*, Productivity Commission, Canberra.