Australian Government
Department of Social Services

# Improving the NDIS Experience: Establishing a Participant Service Guarantee and removing legislative red tape

**Discussion Paper** 



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# Introduction

## The Government's commitment to the NDIS

The National Disability Insurance Scheme (NDIS; the Scheme) is the most substantive social policy reform in Australia since the introduction of Medicare in the 1970s. The NDIS is transforming the lives of people with disability, their families and carers. The Government is committed to providing choice and control to NDIS participants, to create opportunity in the pursuit of their goals and the planning and delivery of their supports.

The NDIS is administered by the National Disability Insurance Agency (NDIA) in line with the *National Disability Insurance Scheme Act 2013* (NDIS Act) and associated NDIS Rules. Since the NDIS began to be rolled out in 2013, the Government has worked in collaboration with state and territory governments through the Council of Australian Government's Disability Reform Council to resolve policy issues, jointly fund, and provide appropriate governance for the Scheme.

The NDIS has provided support to over 300,000 participants. Overall satisfaction rates of those who have NDIS plans currently stands at 90%. However, not surprisingly given the scale of this national reform, challenges have existed for some participants. For instance, some people with disabilities, their families and carers have expressed concerns about the time taken by the NDIA to consider applications for access to the Scheme, to approve plans, and support participants through review processes if they are unhappy with the NDIA's decisions. Some participants have also expressed concerns about the consistency of high quality decisions being made by the NDIA.

# How is the Government already improving the NDIS?

The Government, in conjunction with the NDIA, continues to roll out improvements to better support NDIS participants, their families, and carers. This includes initiatives to improve the quality of planning, communication with participants, their families and carers, and the administration of reviews. Significant efforts are also underway to address concerns about the timeliness, quality and consistency of decision-making and to provide stakeholders with further information about how access and planning decisions are made.

Much of this work is being delivered through the NDIS Pathways Reform, which commenced in December 2017, and is progressively being rolled out. As an example, the new Participant Pathway is progressively providing a single point of contact for participants, easier-to-read plans, and is ensuring that NDIA staff have appropriate training in, and understanding of, the diverse needs of people with disability.

When NDIS processes are not effective, timely, and well-understood it particularly impacts key cohorts such as children, people with psychosocial disability, those requiring Specialist Disability Accommodation (SDA) or home modification, and those in need of assistive technology (AT). This is why the Government, in

conjunction with the NDIA, has already removed some of the red tape for these participants.

The Government has recently announced the creation of an interim plan of \$10,000 for children whose support needs are not categorised as complex and who have experienced delays (over 50 days from having an access decision to getting a plan) with the Early Childhood Early Intervention approach. For children with complex support needs, they will immediately be streamed to an NDIA Early Childhood specialist to develop their plan and appropriate funding package.

Since mid-2018, improvements in relation to assistive technology have progressively been put in place, with quotes no longer being required for assistive technology products costing less than \$1,500, and reducing the number of quotes required to two for products over \$1,500. Further improvements to the NDIS's processes for non-standardised assistive technology are currently being piloted, including a specialised assistive technology and home modification assessment process focussed on plans for those with complex needs.

Changes announced in February 2019 to the SDA Pricing and Payments Framework have provided greater surety to providers and investors, and a resulting increase in supply will enable more choice for eligible participants in terms of their living arrangements. The NDIA also established an SDA Reference Group, demonstrating the willingness of the NDIA to listen, and to learn, from the lived experience of those engaging with NDIA processes.

## The Participant Service Guarantee

The NDIS Act and accompanying Rules govern the way in which the NDIA makes decisions, seeks information, and delivers on the aims of the NDIS. To help the NDIA further refine its processes to be more helpful and transparent to those working with the NDIS, the Government has committed to review the NDIS Act and NDIS Rules.

The Review of the NDIS Act will not change the design and intent of the NDIS. Rather, the Review is focussed on removing red tape and making the participant experience with the NDIS better.

As part of the Review, the Government has committed to introduce a new NDIS Participant Service Guarantee (the Guarantee). The Guarantee is to be developed and legislated in close consultation with people with disability, their families, carers and supporters, as well as state and territory governments. It is intended that the Guarantee will take effect from 1 July 2020.

The Guarantee will set new standards for shorter, but realistic timeframes for people with disability to get their NDIS plan and have their plan reviewed. Cutting red tape through the Review, combined with specific service standards under the Guarantee, will assist people with disability to have positive and consistent experiences with the NDIS.

The Government has also committed \$2 million in additional funding for the Commonwealth Ombudsman to allow it to monitor the NDIA's performance against

the Guarantee timeframes, and to support NDIS participants pursuing complaints about the timeframes they have experienced. In the interests of transparency and good governance, the legislative requirements under the Guarantee will include appropriate metrics for the NDIA to report on as part of its existing quarterly reporting to the Disability Reform Council.

## Undertaking the review

Mr David Tune AO PSM, former Secretary of the Commonwealth Department of Finance, has agreed to undertake the review as the Expert Reviewer. Mr Tune retired from the Australian Public Service in 2014 before leading reviews into Parliamentary entitlements and the impact and effectiveness of changes to the aged care system. His proven experience in public administration will be of great value to the review process.

Mr Tune is expected to hand down recommendations to government for consideration by the end of 2019, in order to support the roll out of the Guarantee from 1 July 2020.

## **Consultation process**

This review is designed to be shaped by the experiences of people with disability, their families and carers.

To support this, the Government is seeking feedback about people's experiences with the NDIS and what should be included in the Guarantee. The Government also needs to know what else is important to consider in reviewing the NDIS Act. This will ensure the Guarantee, and any amendments to the NDIS Act recommended as part of Mr Tune's review, captures what matters most to people with disability, their families and carers.

Feedback can be provided in response to this discussion paper through a formal submission, or through an online survey hosted on DSS Engage. Easy Read and multiple language versions of both are available. Formal submissions can be provided in any form you choose and you will have a choice to make them publicly available or ask that they remain confidential.

Community forums will also be held across a number of locations in Australia to hear from people with direct experience of the NDIS. Advisory bodies, advocates, representative groups, carers groups and provider groups are also welcome to attend these events.

It is up to you how you would like to engage with this process.

More information about the consultation process can be found at DSS Engage: engage.dss.gov.au

## Purpose of this discussion paper

Through this discussion paper, we are seeking some general comments about the operation of the NDIS, what the Guarantee should look like and any other relevant issues. It includes key discussion questions to guide your response.

The insights gathered through your response to this discussion paper will help inform what the Guarantee will look like and how it could operate efficiently, effectively and safely within the NDIS.

This discussion paper outlines a number of areas for your feedback. It is not expected that everyone should comment on everything in this paper or answer all the questions. You are encouraged to comment on the issues you feel are most relevant, including issues not covered by this discussion paper.

Individuals are welcome to respond formally to this Discussion Paper. The online survey and face-to-face meetings will also allow individuals to share specific issues they have experienced in engaging with the NDIA. These specific experiences are valuable in developing the Participant Service Guarantee.

The discussion paper can guide representative, advocacy, provider and other groups in making a formal written submission and responding to the themes of the consultation process.

This discussion paper, among other resources, will be available at the public meetings to help support the conversation.

In addition to the online submission processes through DSS Engage, submissions can also be posted to:

NDIS Consultations Department of Social Services GPO Box 9820 Canberra ACT 2601

Or emailed to:

NDISConsultations@dss.gov.au Subject: Participant Service Guarantee – Written Submission

# What could a Participant Service Guarantee look like?

The NDIA already undertakes public reporting on a quarterly basis as part of its accountability to governments and the Australian community, and sets out key performance indicators as part of this reporting. Internally, it also undertakes training, process improvements, and other work so that participants have a successful experience.

There are many approaches across business and government to ensure people get responsive and quality service. These approaches include quality frameworks designed to encourage good internal processes, statutory timeframes for responsiveness, service standards to set good practices, or statements of rights or charters intended to make it clear what users can expect.

The Government has already committed that the Guarantee will include legislated timeframes. A key issue is what these should be and any other aspects of the NDIA's service that should be part of the Guarantee. Both the NDIA and the community may appreciate clear guidance in the Guarantee regarding *how* NDIA decisions should be made, as well as *when* those decisions should be made. This could include reference to particular types of consultation, engagement, or the provision of appropriate information.

We're proposing that the following principles could be part of the NDIS Participant Service Guarantee. These principles may or may not be legislated alongside specific timeframes.

Principle	Description
Timely	The NDIS process will be easier to understand and use, enabling decisions about access, planning and review to happen promptly.
Engaged	The NDIA engages with people with disability, their family, carers and other support persons when developing operating procedures and processes.
Expert	NDIA staff have a high level of disability training and understand the impact particular disabilities have on people's lives. They understand what supports are most effective for a person's disability.
Connected	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.
Valued	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.
Decisions are made on merit	The NDIA acts in a transparent, informative and collaborative spirit so that participants understand why decisions are made.

# Possible principles for NDIA service standards

# PrincipleDescriptionAccessibleAll people with disability can understand and use the NDIS, and the<br/>NDIS ensures its services are appropriate and sensitive for Aboriginal<br/>and Torres Strait Islander people, people from Culturally and<br/>Linguistically Diverse (CALD) backgrounds, LGBTQIA+ and other<br/>individuals.

### Key discussion questions

1. Which of the above principles do you think are important for the NDIA to adhere to, and why?

All of the proposed principles are important aspects of quality service delivery. The NSW Carers Advisory Council would want to see key performance indicators (KPIs) for each of the principles that provide realistic service delivery expectations for both the NDIS provider and recipient.

### Timely

Many NDIS participants are reliant on services that directly impact their wellbeing and the longer they wait for decisions, the more they may experience stress and anxiety. It is better to inform participants of proposed timeframes for decisions so that they can make future plans, than to not respond or to respond in an untimely manner.

It is vital that people with a disability receive help **when** they most need it. Lengthy delays can lead to exacerbation of the negative impacts of their disability and place significant additional stress on their carers. For example:

- someone who urgently needs a new wheelchair may be totally isolated pending approval for a new one under their NDIS plan
- someone suffering from a severe chronic illness, such as cystic fibrosis, may experience severe acute exacerbations of their illness, requiring urgent assistance in order to keep them out of hospital or to minimise their stay in hospital. Such exacerbations can come on very suddenly, rendering the person seriously ill and in urgent need of assistance such as professional in-home physiotherapy.

It is important that people with a disability, their families and carers have access to support and understanding from all levels of Government. The NDIS is a good scheme but it lacks flexibility, choice, control and adequate funding to meet the needs of the person that it is meant to support.

The current model is not working well for all individuals with a disability and is not always providing peace of mind for the person that it was meant to support.

## Engagement

It is essential that all key stakeholders are engaged in developing an NDIS plan, and these stakeholders must include carers. Without this wider

engagement it can be very difficult to develop an appropriate support plan. Some people with a disability are not always able to effectively or fully advocate for themselves. For example, someone with a severe intellectual disability or someone suffering from an acute psychotic episode of mental illness. In addition, carers and other family members can contribute valuable understanding to the needs of the person with a disability and often have a vital role to play in the implementation of their loved one's NDIS plan.

## Expert

Where possible it is beneficial to employ NDIS people who are knowledgeable about the sector or who have a vested interest in the sector. This could be combined with the **engaged** principle, where you employ people who have experience as carers or with a disability, to design your processes and operations as this lived experience will mean the person has a long term interest in the process being done well.

While it would be an advantage if NDIA staff had expertise in particular disabilities, it's not realistic to expect them to be across the details of all disabilities. What is more important and realistic is to give them quality training, so that they can ask the right questions in each case, so as to understand the needs of each individual they are trying to assist. In addition, they need an expert understanding of the support services available or where to go to find that information.

## Connected

This is very important so that people with a disability and their carers receive the best possible services available to address their need, in their locality.

## Valued

Every member of the community has the right to feel respected and valued.

## Decisions are made on merit

There are limited resources available and demand greatly outweighs supply. It is of critical importance that those resources are allocated based on relative need.

This could be altered to 'decisions made consistently and on merit'. There is strong anecdotal evidence from carers of high variance and subjectivity to interpretations of the guidelines, assessments completed, and decisions to approve/reject requests. Potentially, clearer principles to guide decisions will help the NDIA to make more consistent decisions and enable staff to ensure the participant has a fair and positive experience. When decisions are not transparent, inconsistent and unclear, it leaves the participant and their carer feeling that they cannot rely on the system to protect their interests.

Currently it appears there are major inequities in the way that NDIS resources are distributed.

#### Accessible

There must be a **'provider of last resort'**. If services aren't available or are refused, for example for people with severe disability or challenging behaviours, what is the responsibility of the NDIS? There needs to be a transparent mechanism to support these people through the NDIS when no other option has been successful.

For people from a CALD background market improvement is needed to find quality CALD service providers.

For Aboriginal and Torres Strait Islander recipients and carers, service providers must be able to demonstrate cultural competency and ongoing support and training to continue to develop and enhance this competency.

2. In your experience with the NDIA, do you think they fulfilled the above principles? If not, how are they falling short?

The NDIA has made participants, families and carers feel valued in the sense that this initiative itself is transformative. The program is empowering participants to control their services and has given funding which families otherwise did not have or could not afford.

However many carers are feeling devalued and unengaged – the NSW Carers Advisory Council hears from some carers who feel totally devalued in the process. Many planners remain reluctant to engage with carers and other family members.

Participants and their carers/families need to be able to access provider information in much more accessible formats. The current portal is difficult to navigate. There should be an interactive website where registered services can be searched by category, type of service delivery, not just geographic location. This is of particular importance in rural and remote communities. For example, if I am a carer of a 4 year old boy with challenging behaviour with an NDIS plan, living in an isolated rural town and need specialist behaviour support, can I easily access a list of providers who provide this service in my area, and also via Telehealth, or who are prepared to travel?

Planners and LACs need better knowledge of services available in rural and regional areas. We are aware of examples of participants being allocated funding for services that are not available in their area, and where they have no capacity to travel to access them.

People who have a severe disability as a result of chronic illness frequently report that NDIS planners are unable to understand the impact of their disability on the core disability domains such as mobility and communication. As a result, they are denied an NDIS plan and may be advised that they have a health condition and not a disability. For example, someone suffering from severe cystic fibrosis whose lung volume is 30 percent or lower can barely communicate and will have extremely limited mobility. Yet they are frequently being denied access to the NDIS.

## **Review of plans**

Many families are waiting months for their reviews to be assessed. Whilst waiting for review, participants are missing out on much needed support.

Lengthy delays are reported for people waiting for their first NDIS plan and/or their review. In addition, the NDIS fails to cater promptly for people who experience sudden acute exacerbations of their disability (again for example, someone with cystic fibrosis who develops pneumonia and needs regular and frequent access to in-home physio).

The NSW Carers Advisory Council is aware of a family who requested a plan review in April 2018 and as of September 2019 they still have not received a response.

When carers meet with service providers to look at getting equipment, they are often advised that the NDIA will take 6 months or longer to respond, and it is a very difficult process.

When a call is made to the NDIA portal the advice varies greatly between each person that you speak with and it is very frustrating that the people you call for assistance do not know the systems well.

## Inequitable decision making

The NSW Carers Advisory Council is aware of countless examples of people with similar levels of disability getting NDIS plans that differ vastly in value. There are a range of causes - including differing levels of expertise between NDIS planners; communication barriers due to disability, language barriers, literacy and skill levels of participants and carers, lack of internet access/digital literacy; and lack of information about how and what to apply for and what evidence to provide.

There are decisions made to continually change the system (e.g. TTP rates, new prices, shifts in funding processes for equipment depending on the complexity). These changes are not always well explained, and perhaps more time should be put into phasing in these changes in a way that is manageable for the participant and providers.

The capacity of families to implement an NDIS plan for a child needs to be considered when plans are developed, and support coordination needs to be more readily included. In Western NSW several families with extremely complex psycho-social situations are not provided with support coordination in a child's plan. This most likely relates to the ability of planners/LACs to understand/access the complexities of these situations. There have been examples where parents have been unable to continue to care for their child, have experienced extreme family stress, and needs have not been met. Some of these issues could have been alleviated with a more appropriate plan and the assistance of support coordination to engage and access.

Service guarantees need to be given for ECEI access, and also funded supports if there is not local early intervention centre, as is the case for example in Mudgee.

#### Service providers

At present, there are too many service providers claiming to be able to create a 'management plan' to support individuals. Many of these services providers are charging unreasonable fees to deliver service. For example, physiotherapy was previously charged at \$65.00 per session, now Plan Managers are charging \$174.40 per session. How can this be sustainable?

Providing allocation for travel to services, or for service providers to travel to clients, should be considered in every plan in a rural area. It is critical that both are considered; if service providers can't/won't travel to clients, then carers and/or participants often have to pay this expense out of pocket.

Support Coordinators, where they do exist, should not be placed in organisations that are providers of significant amounts of NDIS services as there is a potential conflict of interest, If the 'economies of scale' aren't great enough for support coordinators to exist outside of large, NDIS dependent organisation, then perhaps their cost of service needs to be increased.

3. What other key principles are important for the NDIA to follow, that could be included in a Participant Service Guarantee?

**Equity** should be added as a principle so that people with the same level of need, get the same quantum and quality of service.

**Quality** is another principle which should be focussed on. NDIA staff should provide quality support to people with a disability and their carers

This sector demands high quality, empathetic, accountable service providers who provide quality services to the participants. This needs to be enforced in better monitoring and assessments of who can become a service provider and how they deliver their services. Letting the market respond to demand creates opportunities, however this is not an industry that can go without strict government guidelines and controls because the risk of harm to people who may be in very vulnerable circumstances is too high.

For example, it can be difficult to find Vietnamese-speaking (or other language) service providers. Families have met service providers who have minimal experience in the sector, with little business experience, and put families at risk by being able to operate without strong guidelines governing their operations. This can deter families from spending their funds, because they would rather not expose their family to a potential high risk incident. Ultimately this reflects poorly on the success metrics for the NDIA if funding allocated to the NDIA is not used.

Families and individuals with a disability are under significant and unnecessary stress due to excessive red tape and complex processes they need to deal with to get the service that is required for the individual.

It is important that people with a disability, their families and carers have access to support and understanding from all levels of government.

4. One way to measure these principles is through a set of 'Service Standards'. Some ideas for what these Service Standards could be are listed in <u>Attachment A</u>. Do you think these Service Standards are fitting? Are there other standards you believe should be included?

Yes, in particularly the SLAs in the timely principle. More metricated service standards should exist to better measure the effectiveness of these principles being applied.

Quality could be a principle added where benchmark scores in participant satisfaction surveys are included as service standards.

There needs to be a standard around providing timely responses in an emergency situation.

5. Do you have any ideas on how we can measure how well NDIA has delivered on each of the principles?

Participant surveys sent out to all participants to assess all of these elements on a numeric scale.

Ongoing randomised face-to-face quality-control interviews and/or focus groups with NDIS participants and their carers to measure aspects of quality.

Operational aspects of timeliness could be measured through the various IT platforms that are used by NDIS providers. For example, turnaround time from initial contact with an NDIS participant to provision of a plan; benchmarking plans, both quantum and content, with NDIS participants with similar disabilities.

# The NDIS participant experience

## Building an NDIS Participant Service Guarantee

There are many parts to the NDIS experience. Participants require a clear understanding of what the NDIA needs at various steps in their journey, and then appropriate time to seek evidence or other information. The Guarantee is only intended to apply to NDIA decision-making processes.

## Existing requirements under the NDIS Act

Existing legislative timeframes for the NDIA's decision making are set out in <u>Attachment B</u>. They apply to access decisions, nominee processes, the provision of information to participants, including copies of approved plans, and a broad duty to ensure decisions are made as soon as practicable.

The NDIS Act also includes a variety of processes designed to enable NDIS participants to be heard, seek reviews or changes, and make complaints. The NDIA is responsible for handling internal reviews of decisions and complaints in the first instance, with external reviews referred to the Administrative Appeals Tribunal (AAT) and complaints referred to the Commonwealth Ombudsman or the NDIS Quality and Safeguards Commission if the individual is not satisfied with the NDIA's response.

Part of the development of the Guarantee will involve hearing about the experience of participants in engaging with those mechanisms. More broadly, how the NDIA provides information and explains its decisions could be an appropriate service standard under the Guarantee.

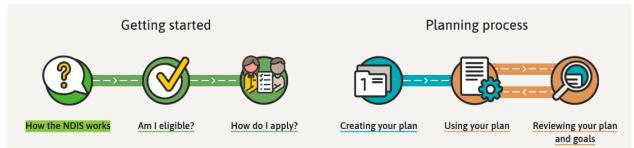
## Participant pathway

Following feedback from participants and stakeholders that their experience with the NDIS had not met their expectations, the NDIA has developed a new NDIS Participant Pathway.

The new NDIS Participant Pathway is the result of workshops and discussions with over 1,200 people with disability, their families and carers, providers and others, to understand key challenges and opportunities that have emerged as the NDIS has been rolled out.

For the purposes of this discussion paper, the new NDIS Participant Pathway is used. The new NDIS Participant Pathway is being progressively rolled out, and is expected to be available nationally by 2020.

The new Participant Pathway consists of two phases, each of which can be stepped out into specific interactions a participant will have with the NDIA. As part of the new Pathway, the NDIA will ensure each participant has a single point of contact.



People with disability may use many different resources in their engagement with the NDIA – for example, family members or carers can assist in filling forms or gathering information, and informal and formal advocacy supports may also be used.

The role of the Local Area Coordinator (LAC) is also important for a participant's NDIS experience. The LAC helps participants with NDIS processes such as accessing the NDIS, creating an NDIS plan, implementing a plan, and reviewing a plan. The LAC also helps participants to better understand what supports are available in their local community, how the NDIS works with other government services, and how participants, their families, carers, and friends can continue to support each other and help each other in a sustainable way.

The information below outlines the major steps an NDIS participant will take as they work with the NDIS, and identifies key discussion questions.

## Getting started: Eligibility and application

What the participant needs to achieve:

- learn about the NDIS and how it fits in the broader scheme of supports
- decide to proceed to access
- receive an access decision.

This phase is focussed on the early engagement of an individual with the NDIS, including working closely with the relevant LAC to better understand what other supports may exist in their community for people with disability, information on mainstream state or territory government services, and how the NDIS works within this broader context.

Based on eligibility criteria, a participant makes the decision to apply to access the NDIS. The LAC or Early Childhood Early Intervention (ECEI) partner can assist in completing forms and gathering evidence. The participant will also need evidence from medical and other professionals.

The NDIA will consider the access request and accompanying evidence and will make a decision. The NDIA may request more information if the evidence provided is not sufficient to make a decision.

## Key discussion questions

6. What are some of the significant challenges faced by NDIS participants in the access process?

Inconsistency with experience for participants.

Families wait for months to get approval for equipment that is reasonable and necessary for the wellbeing of the participant, for example a wheelchair for a child who has outgrown their existing wheelchair. A family in country NSW has been waiting for over eight months for approval for their son who has Muscular Dystrophy. It can be a demeaning, frustrating and stressful process.

Assessment processes are very time consuming – carers are often time poor and people with a disability are often unable to participate fully in the assessment process. Applicants are required to complete detailed paperwork, even if they are acutely ill.

The assessment process also assumes a level of literacy that many NDIS participants and some carers do not have. LACs are not always available to assist these potential recipients through the approval process.

NDIS lacks responsiveness for people with a disability whose needs fluctuate from day to day, or week to week.

The NSW Carers Advisory Council is also aware of families who have had a very positive experience.

7. The NDIS Act currently requires the NDIA to make a decision on an access request within 21 days from when the required evidence has been provided. How long do you think it should take for the NDIA to make an access decision?

21 days is reasonable in a non-emergency situation. However, there should be a cap on how many times the NDIA can go back to request additional information and give another 21 day SLA. This could be escalated to more in-depth communication with the participant and their carer to retrieve the right information to make a decision within 42 days maximum.

NDIS should have the capacity to respond with 24 - 48 hours in emergencies, for example, if a carer is ill and unable to provide support, or if a person with a chronic illness develops acute illness and needs in-home support. 8. What do you think the NDIA could do to make it quicker or easier to access the NDIS?

In addition to the suggestion above to have more in-depth communication to gain necessary information, the following would assist:

- Streamlining the paperwork
- Greatly enhancing the training to planners so that they:
  - have the capacity to ask the right questions to determine level of disability and how it impacts on a person's life
  - recognise and understand the vital role that carers play in supporting someone with a disability, and are able to appropriately and effectively engage them
  - recognise that if carers are not appropriately supported through the NDIS, eg with respite, the person with a disability will increase their overall reliance on the NDIS.
- 9. Does the NDIA provide enough information to people when they apply for access to the NDIS? If not, what else could they provide that would be helpful?

Participants and their carers/families need to be able to access provider information in a range of much more accessible formats. The current portal is very difficult to navigate. There should be an interactive website where registered services can be searched by category, type of service delivery, as well as the current geographical location.

The use of the portal also assumes NDIS participants and their carers have a level of digital literacy and access to devices and telco plans that enable and allow for regular ongoing internet access. This is not always the case particularly for participants and carers in rural and remote communities who may have to access the portal through their mobile phone using significant amounts of data and increasing the cost of their tel co plan.

10.Is the NDIA being transparent and clear when they make decisions about people's access to the NDIS? What could the NDIA do to be more open and clear in their decisions?

Not always. There needs to be better channels for people to have a timely conversation about why the decision was made, for example, a phone call, meeting or online chat, and the opportunity to review the material in advance of this.

## Planning processes 1: Creating, your plan

What the participant needs to achieve:

- understand current supports and prepare for planning
- create a plan to achieve goals and outcomes
- receive an approved plan.

This phase is structured around the individual goals and outcomes of the specific participant. A participant's plan must include a statement of goals and aspirations, prepared by the participant. This sets out the goals, objectives and aspirations of the participant and the current context for their planning- including living arrangements, informal and other community supports, and their involvement in social and economic opportunities, including employment. The NDIA must have regard to the statement of goals and aspirations when deciding on the supports to include in a plan.

The planning processes are intended to ensure the plan is appropriate to support the participant to meet their social and economic participation goals, including the purchase of reasonable and necessary supports. For example—an outcome could be to live independently, and the associated goal is to develop their life skills. Funded supports might therefore include learning how to cook or manage their money, which would enable the person to live independently.

The NDIA's existing survey data tells us how people with disability feel about their planning experience—whether they feel their planner listened to them, whether they had enough time to tell their story, and whether their planning meeting had gone well.

The NDIA is already putting in place improvements to the planning process so that participants can view draft plans before they are approved and have a level of oversight and comfort about what their approved plan will include.

## Key discussion questions

10.What are some of the significant challenges faced by NDIS participants in the planning process?

The arbitrary categories created in the LAC's planning forms don't allow for much flexibility in a reasonable situation. Could this form be reviewed with participants engaging in the process?

Reluctance of planners to accept input from carers and other family members

Lack of understanding from some planners as to how requested supports can contribute to goals, for example:

 someone living with severe cystic fibrosis who needs access to daily inhome physiotherapy in order to stay well and have the capacity to participate in employment and other aspects of community life

- carers who are caring for someone in need of 24x7 support, and need respite in order to maintain their own health and well-being. If this is not approved as a legitimate part of an NDIS plan, person with a disability may cease to get the support they need from their carers due to carer health breakdowns.
- 11.Are there stages of the planning process that don't work well? If so, how could they be better?

Have more staff who are trained to do quality assessments effectively and efficiently, to ensure quality outcomes and to ensure that staff feel like they have enough time to get all the information.

12. How long do you think the planning process should take? What can the NDIA do to make this quicker, remembering that they must have all the information they need to make a good decision?

#### 21 days - 30 days

Consider widening the definition of who can provide evidence. For example, supporting evidence may be required from a medical specialist. In rural and remote communities potential NDIS participants and their carers can wait anywhere from 12 to 18 months to have a specialist appointments. Who else could be considered to provide appropriate medical evidence in these circumstances?

13.Is the NDIA giving people enough, and the right type of information, to help them prepare for their planning meetings? If not, what else could they provide?

A copy of the assessment questions in writing before the meeting will be helpful for NDIS participants and their carers to gather appropriate evidence and consider their responses prior to the planning meeting. Often there is not adequate time to sit, read through carefully and provide thoughtful responses without preparation. It would make the meetings run more effectively and efficiently if participants/families and cares could prepare the answers beforehand. 14.Is the NDIA being responsive and transparent when making decisions in participants' plans? If not, how could this be improved?

Many participants and their carers remain mystified, and often upset, with the plans they receive. The language they need to use is different and not commonly understood. For example respite care is not a term used in NDIS planning yet it is the commonly understood term in the community.

The planning process could be enhanced if planners allowed NDIS participants and their carers to tell the story in their language, and the planners help them translate their language into the NDIS framework. It would be beneficial if the NDIS participants and carers were able to review this during or immediately after the planning meeting to ensure that their needs and concerns were adequately and appropriately addressed.

15.If you have been in the NDIS for more than one year, is it easier to make a plan now than when you first started? What has the NDIA improved? What still needs to improve?

The planning process seems to vary depending on the LAC allocated; how much time they have; how much they understand about the system; how patient they are; and how deep their understanding is of disability. If this could be more consistent and standardised in terms of training, then it will improve the system.

## Planning processes 2: Using and reviewing plans

What the participant needs to achieve:

- activate and implement plan
- use your plan to achieve outcomes
- get support using plan
- review outcomes and progress.

The NDIS is designed to increase a person's skills and independence so they can live a better life. As the participant works towards and achieves their goals, the amount of support they need will likely change. Each scheduled plan review is an opportunity to reflect on the participant's progress in achieving their outcomes and goals and to consider 'next steps' along that journey, including whether those funded supports are appropriate.

A participant can also seek an unscheduled plan review if their circumstances change suddenly or if they feel the plan does not meet their current needs.

During this phase, the participant gains access and understanding of their plan, including managing their budget and allocating funding appropriately. The participant

then needs to make effective choices about the supports they need. This requires the NDIA to be clear about the information provided about the plan and to produce documentation that is easily understood. It also requires markets and support providers to be equally clear about their services, quality and pricing.

#### Key discussion questions

16.What are some of the significant challenges faced by NDIS participants in using the supports in their plan?

Finding quality service providers. They sometimes have minimal disability experience, little business experience (cannot invoice correctly), or do not offer culturally appropriate services.

In some rural communities some NDIS approved providers such as small stand-alone allied health practitioners are opting out of being approved providers due to excessive compliance costs. This is impacting in these rural communities as less NDIS approved providers are available.

17.Is the NDIA giving people enough, and the right type of information, to help them use their plan? If not, what other information could the NDIA provide?

More information on how to find quality service providers and put more mechanisms in place to prevent fraud and excessive price gouging; not after the fraud has occurred but more steps beforehand to stop it from happening. It is traumatic to have fraudulent people enter your house and spend time with your loved ones.

18.What other advice, resources or support could the NDIA provide to help participants to use their plan and find supports?

Links to advocacy organisations or community centres that have experience in the sector and can connect families with services.

Given lack of support coordination funding, it would be good to have online services or grants given to large organisations to assist with this general service.

Also this experience needs to be beyond a google search for service providers because this tells you nothing about the quality of the services.

19.What are some of the significant challenges faced by NDIS participants in having their plan reviewed (by planned or unplanned review)?

Different LACs may feel differently about the situation, so there is a risk of inconsistency.

20.What can the NDIA do to make this process easier or more effective?

More consistent and robust training of LACs and planners. The training could include the lived stories of carers and NDIS participants to provide real-life examples about how the NDIS impacts on participants and carers.

21. How long do you think plan reviews should take?

21 days. Funding should not be cut off immediately when decisions are made because it jeopardises services being provided during this time. This process needs to be improved by informing families of when the plan will be changed before it happens so that participants can make plans for this transition with their service providers.

## Appealing a decision by the NDIA

The Government and the NDIA recognises that participants may feel the NDIA made an incorrect decision. If a participant is unhappy with a decision under the NDIS Act, they can seek an internal review of an NDIA decision. If they are still unsatisfied with the outcome of the internal review, they can seek an external review of the decision through the AAT.

## Key discussion questions

22.What are some of the significant challenges faced by NDIS participants when they seek a review of an NDIA decision?

Timeliness of responses particularly around review situations. One NSW Carers Advisory Council member has not received a response to an appeal sent via email to the Parramatta office for over a year now.

23.Are there other issues or challenges you have identified with the internal and external review process?

24. How could the NDIA improve the decision review process?

Response:

25. How long do you think reviews of decisions should take?

21 days maximum

# Removing red tape from the NDIS

## What does the NDIS Act do?

The NDIS Act came into force in 2013 and set the framework for the NDIS, including the creation of the NDIA. The NDIS Act sets out the objectives and principles under which the NDIS operates, giving effect in part to the United Nations Convention on the Rights of Persons with Disabilities.

The NDIS Act is supplemented by the NDIS Rules. The NDIS Rules are legislative instruments made under the Act. They set out further laws on matters of detail in relation to the operation of the NDIS and must be read in conjunction with the NDIS Act. There are currently 33 Rules in force covering areas such as becoming a participant, plan nominees (situations where others, such as legal guardians or carers can make decisions on a participant's behalf), children (how the NDIA deals with participants under 18 years of age), plan management (how participants can use their plan and spend their allocated funding), and protection and disclosure of information.

Operational processes undertaken by the NDIA are not the same as the NDIS Act or the Rules.

## The legislative framework

In accordance with legislative provisions, the operation of the NDIS Act was reviewed in 2015. This review was undertaken during the Scheme's trial period and, as a result, there was limited experience to measure tensions between legislative provisions and the eventual scale of NDIA operations. The 2015 review made largely technical recommendations that were mostly endorsed by the Council of Australian Governments (COAG), including changing the formal name of the NDIA (currently National Disability Insurance Scheme Launch Transition Agency), and clarifying the distinction between a plan review (when circumstances change) and a merits review of a plan (when a participant is unhappy with the approved plan). However, these amendments have yet to be legislated. The NDIS Act Review presents an opportunity to reconsider these issues—and they have been included for consideration at <u>Attachment C</u>.

### Key discussion questions

26.Do you think there are parts of the NDIS Act and the Rules that are not working or make things harder for people interacting with the NDIS?

Operational processes made by interpretations of the NDIS act and rules are the larger problem.

Guidelines given to planning staff mean that they are often reluctant to approve essential respite for carers who are looking after people with extremely high needs.

27. What changes could be made to the legislation (if any) to:

a. Improve the way participants and providers interact with the Scheme?

Could there be an addition to the legislation for breaches to the scheme by a service provider which creates legal consequences for their actions or for the NDIA itself if it breaches the legislation through its operations.

b. Improve the access request process?

c. Improve the participant planning and assessment process?

d. Better define 'reasonable and necessary' supports?

Yes – it could be further defined to explicitly describe what this means, including practical examples, for different types of disabilities.

Respite for carers of participants should be more clearly available, and defined in the legislation.

e. Improve the plan review process?

f. Improve the internal merit review process?

g. Improve the way other government services interact with the Scheme?

## Plan amendments

Feedback from participants, carers, family members and the NDIA indicates that making changes to a plan is restrictive and that planning decisions should be made in a timely manner to best support the interests of the participant. For example, under the NDIS Act changing who manages a plan triggers the development of a whole new plan. Similarly, adding or amending new funded support categories such as AT also requires a new plan to be developed and approved—or for the planning process to be delayed until all information is available.

Legislative changes to the planning process could be included in the NDIS Act through introducing the concept of a 'plan amendment'. A 'plan amendment' would occur when the participant's goals and outcomes do not need to be changed, but minor changes need to be made to ensure it remains fit for service. This would speed up the NDIA's processes and make the plan more of a living, useful document. This approach could also theoretically be used to put in place plans that are not 'complete', with additions such as AT, home modifications or SDA to be added later once appropriate supporting material is available.

#### Key discussion questions

- 28.What are the significant challenges faced by NDIS participants in changing their plan?
- 29. How do you think a 'plan amendment' could improve the experience for participants? Are there ways in which this would make things harder or more complicated for people?

Yes, however this process should be trialled first to iron out any issues with service providers and give participants and service providers enough notice to prepare for the change in processes and training of staff.

30. How long should people have to provide evidence that they need the changes they are requesting in a plan amendment?

4 to 6 weeks in general circumstances. There may be circumstances when gathering evidence could take longer for example in rural and remote communities where it can be very challenging to access medical practitioners in a timely manner; so there needs the flexibility with response times.

31. Are there other situations during the planning cycle where a quicker and easier way to make changes may be necessary?

Yes, in all emergency situations – person with a disability becoming acutely ill and needing urgent support; carer experiencing a crisis and unable to care.

## 32. How else could the NDIA improve the process for making changes to a plan?

# Attachment A: Potential ideas for Participant Service Guarantee Service Standards (for discussion)

Principle	Description	Service Standard
and use, enabling decisions about	The NDIS process will be easier to understand	The NDIA makes decisions in a timely and responsive manner:
	and use, enabling decisions about access, planning and review to happen promptly.	<ul> <li>Once the NDIA has appropriate information, Access requests are made in XX days.</li> </ul>
		<ul> <li>Participants are offered a planning meeting within XX days of receiving their access met decision.</li> </ul>
		<ul> <li>First plan approvals take less than XX days after their access decision.</li> </ul>
		<ul> <li>Plans are approved within XX days of their final planning meeting, following the provision of all necessary evidence.</li> </ul>
		<ul> <li>Plan amendments are considered within XX days of the request.</li> </ul>
		<ul> <li>Plans involving SDA or AT requests are made within XX days of the information being provided.</li> </ul>
		<ul> <li>Participants who request an internal reviews of decision are contacted within XX days of the request.</li> </ul>
Engaged	The NDIA engages with people with disability, their family, carers and other support persons when developing operating procedures and processes.	The NDIA works with people with disability to ensure their processes and operating are designed to be understood by people with different abilities and needs.
Expert	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.	NDIA staff has a high level of disability training and understands the impact particular conditions have on people's lives. They understand what supports are most effective for a person's disability.

Principle	Description	Service Standard
Connected	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.	The NDIA works constructively and collaboratively with the broader service system to ensure that there are no gaps for NDIS users where possible.
Valued	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.	The NDIA ensures that the broad community understands the purpose of the NDIS and where they can go if they need further assistance.
Decisions are made on merit	The NDIA acts in a transparent, informative and collaborative spirit so that participants understand why decisions are made.	The NDIA acts in a transparent, informative and collaborative spirit.
Accessible	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.	The NDIA provides information to meet the needs of specialised groups, including CALD, LGBTQIA+ and Aboriginal and Torres Strait Islander people, to enable them to access the NDIS like any other citizen.

Engagement	Section	Current arrangement
Access	Access decision s21	Currently 21 days to make an access request decision or request further information from a participant. Existing timeframes rule extends this to 42 days if the access request is made within 12 months of the NDIS commencing in a region.
Access	Access decision s26(2)	Currently 14 days for the CEO to make an access request decision following the receipt of additional information requested by the CEO to support a decision. Existing timeframes rule extends this to 28 days if the access request is made within 12 months of the NDIS commencing in a region.
Access	Access decisions 26(3)	Currently if a participant does not provide, within 28 days requested information to support an access decision, the participant is taken to have withdrawn the access reques unless the CEO is satisfied that it was reasonable for the participant to have provided information beyond that period.
Planning	Commencement s32(3)	Currently the CEO must commence facilitating the preparation of a plan as soon as reasonably practicable
Planning	Approval s33(4)	The CEO must endeavor to decide whether or not to approve the statement of participant supports as soon as reasonably practicable.
Planning	Plan Copy s38	The CEO must provide a copy of a participant's plan within 7 days after the plan comes into effect.
Plan Review	Plan copy s47(3)	The Agency must provide a copy of a new plan within a days of receiving a request by a participant to change their goals and aspirations
Plan Review	Review decision s48(2)	The CEO must decide whether or not to conduct a requested review within 14 days of receiving a request from a participant
Plan Review	Commencement s48(3)	The CEO must commence facilitating a plan review within 14 days of a review decision and complete the review as soon as reasonably practicable.
Nominees	Cancel s89	For participant nominees who are appointed at the request of participants, the CEO must cancel the appointment of the nominee as soon as practicable is requested by the participant or the nominee.
Nominees	Cancel s90	For participant nominees who are appointed at the initiative of the CEO must decide whether to cancel the appointment of the nominee within 14 days if requested by the participant.

# Attachment B: Current timeframes for CEO and NDIA decisions

Engagement	Section	Current arrangement
Nominees	Cancel s91	If a nominee is suspended on reasonable grounds that they have or are likely to cause physical, mental, or financial harm to a participant, the CEO must provide the nominee with 28 days to provide a statement as to why their appointment should not be cancelled. The CEO must decide whether to cancel the appointment as soon as practicable after receiving the statement or cancel the appointment as soon as practicable if no statement is provided.
Dispute Resolution	Review decision s100(6)	If a review of a reviewable decision is sought, the reviewer must make a decision as soon as reasonably practicable that confirms, varies or sets aside the reviewable decision.

# Attachment C: COAG agreed amendments from the 2015 NDIS Act Review

Section to be amended	Description
Subsection 4(2) and subsection 4(8)	Amend the general principles in section 4 to remove moderating language (e.g., 'to the extent of their ability' and 'to the full extent of their capacity'). Section 4 intends to guide actions; however some of that guidance is qualified and it is unclear why.
Subsection 4(9)(a)	Add new principle to reflect the centrality of people with disability and their inclusion in a co-design capacity. The concept of centrality and the importance of people with disability being involved in the design of the NDIS is already recognised in the NDIA's corporate plan, but there is benefit in enshrining this as a principle in the NDIS Act.
Subsection 4(12) and subsection 31(c)	Amend principles that directly reference carers so that they align with the 'recognise and respect' terminology of the <i>Carer</i> <i>Recognition Act 2010</i> .
Subsection 4(15)	Amend subsection 4(15) to reflect the importance of a diverse and sustainable market that provides choice and control and high- quality supports to people with disability.
Subsection 5(d)	Amend principle to include a reference to lesbian, gay, bisexual, transgender and intersex status of people with disability, so that their experience is recognised alongside the cultural and linguistic circumstances and the gender of people with disability.
Section 8, section 9, Chapter 6 heading and subsection 117(1)	Replace the NDIA's legal name, the "National Disability Insurance Scheme Launch Transition Agency" with the name it is known as in the Australian community "National Disability Insurance Agency" to reduce confusion amongst stakeholders.
Sections 9, 31, 33, 36, 37, 41, 47, 48, 49, 50, 55, 78, 79, 96, 99 and 104	"Review" is used in two different ways in the NDIS Act, which is a source of confusion for stakeholders and the NDIA. "Plan review", is a review of the supports in a participant's plan to ensure they continue to meet the participant's needs, whereas "review of decisions" refers to a merits review of a decision.
	To clarify their different purposes, "plan review" will be renamed "plan reassessment" (or some other term to be agreed).
Subsection 14(a)	Provide greater definition of Information, Linkages and Capacity Building in the legislative framework. As the nature and scope of ILC was not agreed when the NDIS Act was drafted, the current definition of ILC is both brief and broad.
	A new definition should expand the NDIA's funding power to fund persons or entities to provide information relating to disability and disability supports; and to provide assistance to build capacity amongst providers and people with disability and their families.

Section to be amended	Description
Subsection 17A	Require the NDIA CEO to take into account the guiding principles in section 4 including that people with disability have the same right as other members of Australian society; people with disability should be supported to contribute to social and economic life; and people with disability should be supported to receive reasonably and necessary supports. This amendment will ensure that all people acting under the NDIS Act, including the CEO, are guided by the same principles.
Subsection 31(d)	Remove "where possible" from the paragraph, as the words are redundant due to the presence of the words "as far as reasonably practicable" in the introduction to the section.
Subsection 48(2A)	Insert a subsection to allow the Minister to make a Rule that would provide greater guidance to the NDIA CEO on the rights of participants to request a review of their plan.
Section 55	Broaden the powers of the NDIA CEO to obtain information about people who have not yet made an NDIS access request to ensure the integrity of the NDIS. The use of personal information and the need to obtain a person's consent are still covered by federal and jurisdictional privacy laws.
Subsection 60(1) and section 61	Remove subsection 60(1) and section 61, which relate to protected information as they have no application, as the <i>Privacy Act 1988</i> (Cth) already permits the NDIA to collect the information this subsection provided.
Section 90	Insert a discretionary power for the NDIA CEO to suspend or cancel one or more of a nominee's appointments, if that nominee ceases to be the guardian of the participant.
Subsection 104(3)(f)	Include "carers" in this paragraph, which outlines the list of considerations the NDIA CEO must take into account when deciding whether a person should take compensation action. Currently, the NDIA CEO only considers a participant's family, which does not address the role of primary caregivers who are not family members.
Subsection 127(2)(a)	Clarify that Board members can be appointed on the basis of having "lived experience of disability", regardless of if they have experience in operating insurance schemes, financial management or corporate governance.
Section 174	Amend the timeframe for the NDIA to produce its Quarterly Reports from "1 month" after the end of the quarter to "6 weeks", to allow the NDIA more time for in-depth data analysis.
Subsection 174(5)	Remove this subsection as it relates to the publishing of the first NDIA Quarterly Report and has no further application.
Subsection 182(2)(c)	Amend 182(c) to clarify that a provider is entitled to claim payment, if a participant dies before the provider was paid for providing a support to them.

Section to be amended	Description
Subsection 209(3)	Clarify that the Minister must consider all the objects and principles of the NDIS Act when making NDIS Rules, not only financial sustainability.