



ADACAS

A D V O C A C Y

2019 Review of the
National Disability Insurance
Scheme (NDIS) Act
and
NDIS Participant Service
Guarantee

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1. About ADACAS

The ACT Disability Aged and Carer Advocacy Service (ADACAS) has been delivering advocacy for and with people with disability, people experiencing mental ill health (or psychosocial disability), older people, and carers in Canberra and the ACT for 28 years. ADACAS also provides free (advocacy and information to people with disability in parts of NSW: specifically, in set areas of Shoalhaven, the Eurobodalla Hinterland, Batemans Bay, Broulee – Tomakin, Moruya – Tuross Head.

As an advocacy service, ADACAS is frequently working with people who are “falling through the cracks” in current service systems. We advocate on many issues including access to and quality of service in housing, justice, health, education, employment, NDIS and child protection matters.

ADACAS additionally offer NDIS support coordination to a small number of NDIS participants, and have a Projects/research team currently exploring practical responses to issues arising through advocacy and Supported Decision Making. We have also recently commenced delivering support to individuals accessing the Redress scheme for people who are survivors of institutional child sexual abuse, individuals making submissions to the Royal Commission into Aged Care Quality and Safety, and the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

ADACAS acknowledges the traditional owners of the lands on which we work, and pay our respects to their Elders, and to all Aboriginal and Torres Strait Islanders in our communities.

2. Introduction:

ADACAS recognises that the introduction of the NDIS is an important step in social reform in Australia, and that it has the potential to be the most significant change for the better in the lives of our clients in their lifetimes.

We believe, however, that at the present time the National Disability Insurance Scheme (NDIS) is falling short of the vision. Our views on the performance to date of the National Disability Insurance Agency (NDIA) are formed from the everyday experiences of many of our clients, in the matters we deal with when supporting clients to demonstrate their eligibility for the scheme and assisting participants to get the funds and/or the supports they require to address their identified needs. We continue to participate in systemic advocacy work and to collaborate in the hope that the dreams of the NDIS are realised as empowerment, choice and control for people with disabilities into the future.

3. NDIS Participant Service Guarantee

1. Which of the above principles do you think are important for the National Disability Insurance Agency (NDIA) to adhere to, and why?

ADACAS believes that adherence to all of the listed principles (timely, engaged, expert, connected, valued, decisions are made on merit, accessible) are important, but that some amendments need to be made and a change of emphasis introduced to ensure that the lived experience of people with disability is afforded much greater respect than appears currently to be the case. We also suggest some extra principles (see question 3).

Comments re some of the current definitions:

- **Timely**: the definition provided of the term 'timely' in the discussion paper is largely a definition of what it means to be accessible, not what it means to be timely. There should be elements of "responsiveness" included within the definition of the term timely, and reference made to the impacts of delays that may occur in any of the many transactional stages of implementing a NDIS plan. There is scope for defined timeframe in some elements of both the planning process and its implementation.
- **Engaged**: The definition for the term 'engaged' should imply an active process incorporating connection with the groups listed about operating procedures and processes, and explicitly indicate engagement with individuals with disability, their families, carers and other support persons as well as advocacy agencies, peak bodies and the broader sector .
- **Expert**: - An emphasis on expertise is laudable but should be clearly restricted to expertise about application of the NDIA Act, processes and procedures acknowledging that expertise in a participant's disability is held by that participant. "[NDIS staff] understand what supports are most effective for a person's disability" as a statement implies a position of power in identifying support needs for a person which is antithetical to the rhetoric of the NDIS in its establishment.

We in fact need there to be a level of expertise within the NDIA such that they can be efficient and empathetic, be at the top of their game as administrators, and striving for KPIs which positively impact on participants' ability to get the supports and equipment they need and achieve their desired outcomes. The NDIS staff also need to be sufficiently knowledgeable about disability support that it is possible for people with disability (or families or service providers) to receive *individualised but consistent responses* as opposed to the same person receiving multiple different answers to the same questions depending on who they ask (whether an NDIA call centre staff member, a planner, a senior planner etc).

- **Accessible**: as mentioned above – this definition should be the one that includes concepts of the NDIS being transparent and in process and easy to understand and use.

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

At present, the NDIA is falling short on many of these principles. Responses, especially to review processes, are frequently not timely. Whilst we acknowledge there have been efforts and some improvements since the Commonwealth Ombudsman's report¹ into the Administration of NDIS reviews, clients continue to wait many months for an adequate response to a review request. This includes occasions when a client has experienced an unexpected crisis triggering a need for different and, in many cases, additional supports that have not been anticipated in the plan. One such instance required our service to continue to provide intensive support despite not having funds to do so, and the NDIA still took over three months to complete a review, despite the participant's situation at the time being life-threatening.

There is a very strong need for more staff training to address practical skills in working with people with disability and/or mental ill health reflecting respect for human rights and the functional impact of disability.

Participants report not feeling valued, heard, or listened to in their interactions with the NDIS as demonstrated in the following client quote about their most recent experience with the NDIS:

"It is emotional torture – I'm better off outside of the NDIS. NDIS has a duty of care, to fulfil their role, to be considerate of the impact of their actions/decisions (or lack of decisions) and the impact that they are having on someone's life. The NDIS staff member who spoke to me two weeks ago was so rude / so condescending that my psychological welfare was put at stake in a matter of minutes"

There is also frequently a lack of understanding from planners or NDIA representatives about the impact of their responses/behaviours on function in the context of disability:

"They clearly didn't understand. And if not even the NDIA understands the impact of my disability, despite all the information that I've given them and conversations I've had, what hope have I got that anyone can understand??"

In terms of engagement – there is much scope for improvement. There are multiple examples of situations where the NDIA has failed to engage when attempting to solve systemic issues of implementation, choosing instead to allocate problem solving to internal teams who were consulting only after they have drafted solutions that are satisfactory to the NDIA. A case in point relates to the delays and ongoing issues with home modifications, a problem highlighted by the sector in 2014, and which the NDIA has declared will be responded to in July 2020.

¹ Commonwealth Ombudsman (2018), *Administration of reviews under the National Disability Insurance Scheme Act 2013* May 2018, accessed via: http://www.ombudsman.gov.au/_data/assets/pdf_file/0029/83981/NDIS-NDIA-Final-report-on-administration-of-reviews-under-the-Act.pdf in October 2019.

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

Other potential principles:

- **Reliable:** a person with disability should be able to rely on the NDIA to ensure that they are not left without adequate funding or supports. This comes into play in four ways:
 - *Adequate NDIA plans:* NDIA plans should always cover vital disability related needs of participants. It is unacceptable to have participants put in situations where they can't get to the doctor because they need more expensive transport due to the impact of disability, and need to travel there more frequently than the combination of their income and their travel funds allow. People who are in receipt of Newstart, a Disability Support Pension or other pensions are disproportionately affected on this topic.
 - *Gaps between NDIA plans:* at the present time, despite occasional assurances that, in general, participants will continue to have services funded during gaps between valid NDIS plans (situations where a new NDIA plan is not issued before an old plan ceases), this is not always the participant experience. Participants have at times been forced into situations where they are dependent on the goodwill of providers to deliver support with no guarantee that they will be funded (sometimes they are, sometimes they are not). There are also circumstances where a provider has (often very reluctantly) felt they had to stop vital services as it is not financially viable for them to continue without an assurance that they can be paid for their work, with NDIA participants then finding themselves without support.
 - *Change of circumstance reviews:* it is imperative that there is a quick and responsive reaction when a change of circumstance means urgent plan changes are needed.
 - *Provider of last resort:* we note the responsibility of the NDIA to step in and assist when a provider of last resort is needed.
- **Accountable:** The NDIA must be accountable to people with disability, their families, carers and supporters, to service providers, to disability organisations and the broader community and constituency in relation to their actions (or lack of actions). There are consequences (sometimes life-altering or dangerous consequences) for people with disability when NDIA staff do not respond, do not respond in a timely way, or behave in thoughtless or ill-considered ways. It is imperative that the NDIA also be held accountable, in particular that there be consequences for the NDIA if they do not meet service standards and that this not be only internal.

In relation to reviews (internal and external) – the NDIA has an inherent responsibility to act as a **model litigant**. The NDIA should be being regularly audited and monitored by external and independent agencies on this (and other) topics.

The current NDIA framework often fails to adequately consider the social and environmental aspects of circumstances that can affect the functioning and/or life choices of individuals with disability. As a vital part of Australia's response to its obligations under the United Nations Convention on the Rights of Persons with a Disability (UNCRPD)², it is imperative that Australia is being held accountable also by the international community on the implementation of the UNCRPD and the incorporation of internationally accepted frameworks such as the World Health Organisations' International Classification of Functioning³.

- The principles must acknowledge/incorporate the social model of disability (the social, economic and environmental contributors to disability. The NDIS is narrowly framed to respond to people's functional impairments, often acts on "diagnoses" not function, and this despite there being international recognition that the causes of disability are largely external to the individual. These "barriers" are acknowledged in the World Health Organisation's International Classification of Functioning, Disability and Health (ICF)⁴, which combines social and medical understandings of disability, and takes account of impairments, activity limitations, participation restrictions, environmental factors and personal factors when considering impact. At present, the NDIA needs to take greater account of the social and environmental contexts of an individual's circumstances when assessing them for eligibility or for the scale or implementation of their package. Functional assessment is vital to customising the supports for an individual, but the consideration of funding must take much more account of the social and economic barriers that the individual has faced and may continue to face into the future.

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 Attachment A. Do you think these Service Standards are fitting? Are there other standards you believe should be included?

Additional standards (or amendments) required:

Within Timely:

Timeframes in relation to plan issuance should be in 2 stages – a timeframe to issue the draft, and a timeframe for finalising after the participant gives feedback on the draft plan. Standards must include timeframes also for AAT appeals.

We suggest:

- Drafts of first plans are sighted by participants within XX days (we suggest maximum 1 week) of the planning meeting occurring.

² UN General Assembly (2007), *United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)*, available from: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>, accessed in October 2019.

³ World Health Organisation (2001), *International Classification of Functioning, Disability and Health (ICF)*, available from: <https://www.who.int/classifications/icf/en/>, accessed in October 2019.

⁴ World Health Organisation (2001), *International Classification of Functioning, Disability and Health (ICF)*, available from: <https://www.who.int/classifications/icf/en/>, accessed in October 2019.

- First plan approvals take less than XX days (we suggest maximum 1.5 weeks) after a participant provides feedback on draft plan.
- Second or later plans are approved within XX days (we suggest maximum 1 week) of a participant providing feedback on a draft plan.
- Internal review requests are finalised within (we suggest: 1 month) of the internal review being lodged.
- External appeals (to the AAT) are resolved within (we suggest 3 months) of an AAT appeal being lodged.

Within Engaged:

- The NDIA works with people with disability, *families and carers, advocacy organisations, service providers, industry leaders and peak bodies* to ensure their processes and operating procedures are *clear and* designed to be understood by people with different abilities and needs.

Within Expert:

Please refer to our response to question one, and adjust service standard also accordingly.

Within Connected:

- The phrase “to ensure there are no gaps for NDIS users *where possible*”: [my italicisation]: needs to be re-written: we suggest instead: “to seek to ensure that there are no gaps for NDIS users”.

Within Valued:

- The draft service standard needs to have specific and direct additional measures for the quality of people’s interactions with the NDIA.
- There should be an external agency in contact with people immediately after planning meeting processes conclude, who is asking people directly about whether they felt:
 - Listened to
 - Heard and
 - Valued (i.e. respected and responded to)
 in their interactions with the NDIA: if so, what it was that made them feel that way – if not – what could have been done better, and this feedback needs to be provided as part of processes that the participant/families/supporters have choices around, and feel comfortable with. (I.e. if a participant agrees, it could be given directly back to the participant, or to the participant’s manager, or both, or included instead in the collated information for that week/month etc. (de-identified to maximum extent possible))

Within Accessible:

The current service standard looks only at the needs of specialised groups. Whilst this is vitally important, there needs to be an additional service standard that is measuring whether all people with disability (including those not in the listed specialised groups) can understand and use the NDIS.

Other service standards:

Please refer also to the comments in question 5 as to how additional service standards on reliable and accountable should be measured.

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

As mentioned above - have independent people from a range of external agencies which are trusted in the community and clearly independent of government in their operations (not NDIA or Local Area Coordinator (LAC) staff) interviewing participants immediately after their planning meeting, again after they receive their NDIS plan and in a sampled way during plan implementation.

Participants should be able to control what happens to the feedback they provide – what goes directly to planners or their managers, what counts instead into general statistics etc, so that people can feel safe to disclose that were unhappy with their experience without feeling that there will be negative individualised consequences for doing so.

4. NDIS Eligibility and Access Processes:

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

NDIS participants face the following challenges with the NDIS entry process:

A. Difficulties obtaining the required paperwork/supporting documentation to substantiate reasons that entry is needed especially where heavily weighted on specialist medical advice.

The reasons for these difficulties could include:

- Financial barriers (i.e. the cost of seeing GPs, specialists, allied health experts etc. to obtain paperwork).
- Medical system barriers: individuals might need to wait many months to get appointments with the right medical or specialist staff.
- Lack of familiarity of medical and allied staff of the NDIS entry criteria and of the importance of providing detailed support letters addressing the entry criteria in a comprehensive way.
- Reluctance by some medical / allied health staff to provide (or to provide adequate) supporting documentation: ADACAS is aware of individual medical, allied health or specialist staff who say or try to say to people with disability: “oh I don’t do NDIS paperwork, you will need to go elsewhere”.
- Confusing diagnostic pathways: as the system in application does not prioritise the functional impact of disability but the presence of a diagnosed disability, if a person does not have a diagnosis in relation to their disability, it can be complicated to seek to obtain a recognised diagnosis/diagnoses. This is particularly true if the diagnosis could be one or a combination of multiple diagnoses that crosses over different types of specialist fields (and thus requires navigating a complex medical system (and often different pathways simultaneously) to find the right combination of specialists/expert knowledge).

Additionally, the following hurdles have a sometimes very profound impact:

B. An over-reliance by the NDIA National Access Team assessors on diagnosis/diagnoses as a way of ascertaining whether someone meets the entry criteria to the NDIS (as opposed to looking at functional impacts of disability/ies). There can be many and varied reasons as to why a person might not have or have access to or might not want a diagnosis/es (in some circumstances this can also be inherently related to the nature of the disability itself) – as per the thinking behind the initial design of the NDIS, the scheme should be focusing on functional impact, such that a lack of diagnosis is not precluding people who need disability related assistance from receiving it.

C. NDIA entry criteria that are overly-complicated, and require paperwork or information which might not be available: One example: the definition of permanent (part of which is outlined in the NDIS operational guidelines at:

8.2 When is an impairment permanent or likely to be permanent?⁵): includes “*an impairment is, or is likely to be, permanent only if there are no known, available and appropriate evidence based treatments that would be likely to remedy (i.e. cure or substantially relieve) the impairment (rule 5.4 of the Becoming a Participant Rules);*”.

Many people who have had psychosocial disability for 20+ years might not have been seeing the same GP or same clinic, or may not have had enough money to allow them to see psychologists or psychiatrists in a sufficiently consistent way for there to be anyone external able to attest that a person has tried all the available treatments. Even if someone has seen the same medical / psychological / psychiatric staff: medical records might not have been kept for 20+ years, or changing expectations about what should be included in the medical records might mean that some of the key information that the NDIA is seeking is unavailable. Many conditions have treatments recognised broadly but unavailable/ inaccessible as options to some individuals.

D. Frequent lack of consideration of the inter-related and compounding impacts of co-occurring disabilities and conditions by NDIA National Access Team assessors. In responding to applications for entry to the scheme, NDIA assessors frequently provide an analysis that seeks to separate out the individual disabilities and/or health conditions and each of their impacts on the functional capacity of the potential participant, in relation to each of the entry criteria. Whilst the attempt at transparency in explaining reasoning is appreciated, as a general approach to assessment of applications, this approach has a number of fundamental flaws:

- it can be arbitrary (an attempt to divide what is sometimes indivisible);
- it contributes to the tendency of assessors to overlook the compounding impacts on functional capacity that frequently occur when a person has multiple disabilities/conditions; and
- it means that assessors will frequently unduly privilege medical evidence over the lived experience of participants and/or families/carers.
- It means that an understanding of a person’s needs tend to be viewed through a lens which focuses solely on diagnosis and the impact of functional limitations.

Additionally, given that assessors are rarely medical/disability/allied health experts, it can easily become an arbitrary linguistic exercise (what wording did X expert use?) When someone has multiple disabilities or conditions, the impact is rarely a case of totalling impact of disability A and impact of

⁵ National Disability Insurance Agency (2019) NDIS Operational Guidelines: Disability Requirements, as accessed at <https://www.ndis.gov.au/about-us/operational-guidelines/access-ndis-operational-guideline/access-ndis-disability-requirements> in October 2019.

disability B and the impact of disability C (it is not usually A+B+C). Instead, there is typically an inter-relationship and frequently compounding (not just cumulative) impact. This is a common source of requests to review or appeal and of enormous distress to clients. It is imperative that the access assessment process be reconsidered in light of this.

- E. Inequitable system of entry: the current access process is very reliant on experts (medical and allied health) using exactly the right words in support letters to show that someone meets the entry criteria. Given that different individuals have different level of support available to them with the entry process, and that there is varying knowledge across the experts in the sector (and varying levels of time and commitment available by specialists/allied health staff/experts) to getting the wording right, this creates an inherent inequity between the people who know how the systems work (and/or has expert help to navigate it and to obtain the suitable paperwork) and those who don't have this support.
- F. Designing the NDIA as overly reliant on market frameworks and expectations of informed consumers, both of which are insufficient (alone) to allow the NDIS to achieve its vital human rights and social justice ends.

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?

It is important that the right decisions are made (avoiding unnecessary internal and external reviews), and that they are made in a timely way. Despite the current timeframes, our experience suggests it is rare for a full access experience to take only 21 days.

8. What do you think the NDIA could do to make it quicker or easier to access the NDIS?

- A. Simplify/streamline the NDIS access criteria to make it easier for people with disability to enter the NDIS. The criteria re permanency, and substantial reduction of functional capacity in particular need to be simplified.
- B. Fund independent support people to help people apply to the NDIS and to assist in gathering all the needed paperwork. This independent (note – it should not be LAC nor NDIA) support should be available to all NDIS applicants wanting to enter the scheme.
- C. Change the current model for the access process to a model where individuals start by registering their interest in applying and then receive individualised and tailored expert advice from the NDIA access team staff, provided to the person with disability and also, if nominated by the person, other supports, as to what evidence exactly would be most helpful in their specific circumstance before the person goes to seek out new evidence.

This individualised advice should be made available to them in a format that the person with disability can understand (accessible).

- D. Allocated contact persons: We would additionally suggest that people should be able to communicate with consistent staff (i.e. if they call the call centre about a specific topic, they should be able to go back to the same staff member; if they are dealing with the access team, they should have an allocated contact, if they are dealing with a planner, they should be able to communicate directly with that planner. Acknowledging the reality of staff absences and turnover and timeliness objectives, there should be automatically generated reference numbers available on the portal that identifies which staff member the person spoke with, so that it is easier for everyone to track inquiries and maintain consistent contacts.
- E. Change the application assessment process such that people with multiple disabilities are treated more equitably, in particular so that assessment approach takes adequate account of lived experience and the compounding and inter-related impacts when people have multiple disabilities/conditions.
- F. Re-focus the NDIS entry process back on to considering functional impacts, rather than always requiring diagnoses. Application of the internationally accepted assessment (such as the ICF) that is broader than individual functional impairment tests would likely result in more holistic picture of the person in situ, resulting in better targeted resourcing.
- G. Provide more guidance and training for GPs / allied health staff / specialists on how best to provide supporting documentation/letters which address NDIS entry requirements. Pay GPs, allied health and specialists for their time whilst they undergo the training. Find also a way to build extra incentives into the systems so that GPs/allied health staff/ specialists are incentivised to do a thorough job.
- H. Lobby/negotiate for the creation of Medicare codes for preparing support documentation for an NDIS application or review so that GPs, allied health experts, and specialists and their staff are paid to go through their records and for the time that they need to be able to write strong supporting documentation for people with disability seeking entry to the NDIS or seeking review of their NDIS plan. Note – this time must be fully bulk-billed to Medicare (no gap fees to potential participants allowed), but also must be at a sufficient rate of pay that the experts are incentivised (there is not disincentives) to do a thorough job.
- I. Make available funding for diagnostic tests for people who want and need diagnostic testing to improve their chances to enter the NDIS, and work together with Health departments to make appropriate diagnostic processes easier to access in a timely way for people who want and need diagnostic testing.

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?

At present, we would suggest that the NDIS does not provide sufficient support or information to people when they apply for access to the NDIS.

Please refer to the ADACAS response to Question 8 (points B and C) for additional advice as to what would be helpful to provide.

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?

Whilst we appreciate that the NDIA is seeking to be transparent with their decision-making processes in their current response letters, in our view there is much more that could be done to improve the transparency, clarity and accessibility of their communications.

Letters in response to NDIS applications should be in plain English, whereas at present too often they are in "legal-ese". It would be useful to convey some of the content additionally in visual ways that would make it easier to understand. In situations where a person with disability needs and wants this, the NDIS should make responses in easy English available.

As mentioned above, please refer to the comments in section 4, question 6D (above) with regards to inherent flaws in decision-making processes and changes needed to the current decision-making framework.

5. NDIS Planning Processes:

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

- Complexity of scheme / terminology and jargon / information gaps:
The NDIS uses a lot of terminology and jargon that can be confusing, and is often not clarified or well-explained internally or externally.
- Lack of knowledge of how best to prepare for a planning meeting / amount and level of documentation required
Participants do not always understand how best to prepare for a planning meeting, and the importance of seeking to ensure that any needed reports, quotes or supporting documentation are available in time.
- The support, knowledge and information needed to get suitable planning outcomes:
To achieve a plan that meets their needs in the current system, we would typically recommend that participants have:
 - Completed Pre-planning preparations
 - An excellent knowledge of the NDIS and how the systems work (or someone present with them who knows them, and what they want, and has this knowledge, and can help them to prepare in advance)
 - A written summary of the exact levels of support that they are seeking (and how they want finances to be managed for the different funding areas)
 - Any supporting documentation (reports, quotes and supporting letters as relevant to their various requests)
 - Emotional support with the process (most participants are terrified that their planning meeting won't go well and that they will lose or won't receive vitally needed supports)
 - To have an ability to speak up in relation to what they need (or to have someone present who has the ability to speak up on the person's behalf, in a way that is in line with the person's wishes)
 - and to have a skilled planner.

If any one of these ingredients is not available, it can have a significant and negative impact on the outcome of the planning meeting.

If there is sufficient support coordination funding in the previous plan, a good support coordinator can assist greatly in helping someone to prepare for a planning meeting (and with the planning meeting itself if the participant wants that support on the day).

Unless the participant is very knowledgeable about how the NDIS works, and able to otherwise cover off each of the points above, people without support coordination, or with limited support coordination, can find themselves at a considerable disadvantage and with inadequate plans. This is clearly unacceptable. Everyone should be able to get a plan that meets their needs, regardless of the level of support available to them.

Other challenges can involve:

- Mismatch between skill/expertise/experience of a planner and complexity of the person with disability's circumstances or planning needs
- Lack of preparation from a planner
- Differences between promises and reality – comparing what is said by planners in the planning meeting, and then the reality when the plan arrives.
- Too much complexity around Assistive Technology, home modifications and also in relation to Specialist Disability Accommodation (SDA).
- Disconnect between plan authorises and participant: when there is a process whereby a LAC (or Early Childhood Early Intervention (ECEI) worker) creates the plan, and then NDIA staff approve the plan (usually without the NDIA staff meeting the participant).
- Red tape issue: change in approach re NDIA ceasing their earlier practice of secure emailing of NDIS plans to participant-approved support coordinators: NDIS planners now declining requests to send participant-approved support coordinators a copy of the NDIS plan, instead requiring them to obtain it from the participant (which depending on the nature of the participant's disability and circumstances, can sometimes result in significant delays before the support coordinator can access a copy of the plan), and thus commence the work with the participant to implement it.

ADACAS also notes the need for ongoing, NDIS-specific advocacy (funded outside of the NDIA) and available for people as and when they require it: not just to assist participants in their dealings with the NDIA, but also providing rights-based advice and assistance to participants on any NDIS related issues, including the planning, plan review and implementation processes.

Please refer to the attached ADACAS submission in response to the NDIS Planning Inquiry by the Joint Standing Committee on the National Disability Insurance Scheme, Parliament of Australia) in September 2019 for additional commentary on NDIS planning related topics.

11. Are there stages of the planning process that don't work well? If so, how could they be better?

- Assistive technology processes / home modification processes and SDA processes and the planning meeting frequently don't work well. Need to develop streamlined/easier processes. Home modifications by definition involve the building sector, and nothing devised to date by the NDIA has adequately catered for the various standards, rules and regulations by which that sector is bound (independent of the NDIA).
- Plan finalisation process / need for draft plans: All participants need be able to see and give feedback on draft plans before they are finalised. This allows for reduction in errors, unnecessary reviews, and provides participant opportunity to hear in detail about the planning process offering skill and capacity building to staff in explanation and participants in preparation.

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?

- Duration: Planning processes need to strike the balance between giving participants enough time to ensure they can provide information / ask any questions/ seek clarifications as needed, without the process being so long/time consuming that the participant or the planner is unable to complete it. This should be determined interaction by interaction with the participant.
- Ensure planners are well-trained, and have sufficient time to prepare thoroughly before a planning meeting. A skilled and well-prepared planner, makes a very big difference.
- Continue to improve information about the NDIS, and information to help people pre-plan: there should be good written, audio and video information available to help people with this process. Ensure that there is both plain language and Easy English versions. Develop processes to remind people / provide guidance on how to pre-plan at the time when people are needing to start the pre-planning process.
- Arrange for people without support coordinators to have personalised support to pre-plan: perhaps a LAC (or ECEI) check in (and then if needed) support them with the pre-planning process in advance of the planning meeting?
- As mentioned above, there should be NDIS-specific advocacy available to anyone who needs it, to assist people with rights-based information as required.

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?

- Continue to improve information about the NDIS, and information to help people pre-plan: reference Q12
- Develop processes to remind people / provide guidance on how to pre-plan at the time when people are needing to start the pre-planning process.
- Other information needed:
There is continued need to improve introductory information about important NDIS concepts which are frequently not well-understood, i.e.
 - A. Financial management options:
 - a. The types of financial management options with an NDIS plan (plan managed / agency managed / self-managed)
 - b. The differences between these options,
 - c. the fact that you can choose different financial management options for different parts of your plan, and
 - d. the implications of those choices
 - B. Role of a support coordinator
 - C. Role of a LAC
 - D. How to find/connect to services
 - E. Assistive Technology (what it is, how to get it) etc.

Continue to ensure that information is accessible and that supported decision making is an available access tool.

- Translated information
It would also help to have additional information made available in languages other than English for participants and families from culturally and linguistically diverse (CALD) backgrounds.

14. Is the NDIA being responsive and transparent when making decisions in participants' plans? If not, how could this be improved?

The NDIA is sometimes responsive and transparent when making decisions in participants' plans, however it varies greatly on the planner, and we are also aware of many instances where it has not worked well. Given this:

- Draft plans: We reiterate the need for draft plans, and that a process of participants to have a meeting with a planner to discuss their draft plan and provide feedback before it is finalised helps greatly with transparency and responsiveness and satisfaction with the plan to be implemented.
- Explain and provide written reasons for 'supports declined' decisions: If supports or items important to a participant are not approved, it would also then help to have this explained to the participant in an accessible way. At present, letters are sometimes all that is made available.

Topics where greater transparency is needed:

- the criteria used to make the plan streaming decisions: i.e. the decisions with regards to which participants are allowed to have their plan review meeting with the NDIA, versus which groups of participants are diverted instead to see a LAC. This criteria should be published.
- Role of LAC within planning: When people have their planning meeting with a LAC, it needs to be explained in advance that the LAC is collecting the information, and creating the plan, but that an NDIA staff member is making the decisions about what is included/ not included. This reinforces the importance of ensuring all the key information is in writing so that it is accessible to both the LAC and the NDIA staff member or delegate.

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?

What has improved:

- The quality of the information available from the NDIA
- Some processes have improved (that planning by telephone no longer occurs etc).
- Availability of planners with the expertise to plan appropriately with younger people living in aged care settings.

Continued improvement in these and other areas are needed.

What still needs to improve:

- NDIA staffing levels: we welcome the added staff that the new NDIA CEO is employing. We reiterate the need to remove the NDIA staff cap.

- Multiple participant family plans/planning processes: when there are multiple people within a family who are NDIS participants, the participants should automatically be offered options related to coordinated planning experiences (options to have the planning meetings occur at the same time of year as each other (same day or week or scheduled as the participants prefer), options to have the same planner for both participants if they want this (especially if multiple children are participants in the one family etc)
- Planner experience and expertise (level of training).
- Availability of speciality planners (and delegates) with expertise in working with people with psychosocial disability (taking a recovery approach): despite much talk of the psychosocial disability participant pathway, it continues to frequently be difficult for participants with a psychosocial disability to access a planner with expertise in that area. Even when a planner is available, there is a shortage of delegates with sufficient understanding of psychosocial disability which can mean that plans prepared by planners with psychosocial disability expertise, are then reduced in ways that can have profoundly negative impacts, before the plan is approved.
- Greater understanding of the compounding impact when a person has multiple disabilities / health conditions interacting. It is important planners are better able to take account of this in the way that plans are prepared and issued.

As mentioned above - please refer to the attached ADACAS submission in response to the NDIS Planning Inquiry by the Joint Standing Committee on the National Disability Insurance Scheme, Parliament of Australia) in September 2019 for additional commentary on NDIS planning related topics and other improvements required.

6. Using and Reviewing NDIS Plans:

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

- Knowing where to start once they see a plan
- Understanding the NDIS plan, and the roles/limitations of each of the categories of funding: plans can be filled with terminology / jargon.
- Understanding how and where to access supports and who can help,
- Understanding how to find service providers, and accessing support in decision making around provider selection
- Knowing what to do if support not available.
- Lack of providers of last resort: able to assist when other service providers either unwilling or unable to help.
- Admin/ work involved in being an informed consumer: There is already often extra work involved in living with a disability, without all the extra admin that can come with the amount of work / research involved to become “an informed consumer in the NDIS marketplace”.

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?

- Right information, right way, at right time: The information provided needs to be more tightly managed – to ensure people receive the right information in the right way at the right time (without information overload).
- Draft plan meetings: As previously mentioned meetings to discuss a draft plan / prepare for a handover, would greatly assist.
- Plain language / easy English: it is important that letters and brochures be produced in plain English, and also that Easy Read documents are also made available.
- Titles for funding categories too similar and need to be simplified/ made easier to understand. Why “Assistive technology” instead of terms that are more widely understood “equipment”?

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

- Portal and web service-provider-search functions need to be improved
 - Lists of registered providers should show whether providers are actively offering service in that category of funding at present.
 - Lists also need to be more easily searchable by exact types of support,
 - for therapy support (OT vs Physio vs Dietitian vs Psychologist etc),
 - for core supports: (gardening vs personal care vs shopping vs transport etc)
- Other information that would be helpful:
 - Promotion and access to publically available service provider quality rating system

- Consideration of having live information about service capacity to assist participants seeking a new (or to change) service provider.

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

- Complexity of processes/ terminology (understanding the difference in processes between change of circumstance / internal review / external review / light touch review or plan amendments).
- Amount of preparation needed (and knowing how to prepare).
- Availability of supporting documentation / costs in obtaining same
- Long waits and delays in responses from the NDIA

Please refer to responses to questions in section 4 (re planning) above for further content for this question.

Please also refer to the attached ADACAS submission in response to the NDIS Planning Inquiry by the Joint Standing Committee on the National Disability Insurance Scheme, Parliament of Australia) in September 2019 for additional commentary on NDIS planning related topics.

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

- Remove staffing cap, employ quality and more experienced NDIA staff
- Deal with staff retention issues such that the NDIA can retain experienced NDIA staff
- Return the role of planning and reviewing to the NDIA, so that LACs can take on the community development and connector role that was originally envisaged for them by the Productivity Commission in the review (completed in 2011) that led to the NDIS being established⁶.
- Change the LAC role back to that originally envisaged: by the Productivity Commission in their 2011 report⁷.
- Better training for NDIA staff.
- Improve response times for reviews.
- Fund supporting documentation for participants when this is needed (e.g. as part of access process, or when new diagnostic information wanted by participant and needed to issue an accurate plan).

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

- Plan amendments – if urgent same or next day, otherwise within one week
- Change of circumstances – if urgent – same or next day, otherwise within two weeks.
- Internal reviews – no more than 1 month in total from when review submitted (unless participant asks for more time e.g. to review draft).
- AAT reviews – no more than 3 months in total from date AAT application submitted. (unless participant asks for more time e.g. to review draft).

⁶ Productivity Commission (2011), *Disability Care and Support Inquiry Report*: accessed via <https://www.pc.gov.au/inquiries/completed/disability-support/report> in October 2019.

⁷ Productivity Commission (2011), *Disability Care and Support Inquiry Report*: accessed via <https://www.pc.gov.au/inquiries/completed/disability-support/report> in October 2019.

7. Appealing a decision by the NDIA:

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

Over the past few years, the NDIS appeals via the AAT have been beset with a series of issues:

- Review and appeals processes often inaccessible for people with psychosocial disability or mental ill health: ADACAS has had participants who have been unable to proceed with an internal review or AAT appeal or who have had to withdraw from the AAT appeals process, because the process itself has been too much/impact on wellbeing too great. This means that some NDIS participants have been unable to test NDIA decisions via appeal. This risks a system in which decisions that are affecting people with psychosocial disability or mental ill health are not being as frequently and/or rigorously tested.
- Long delays with internal review and AAT processes: ADACAS has clients for whom just the AAT process has taken more than 18 months, for some over 2 years (after an already lengthy internal review). This is clearly an unacceptable duration for this process. We commend efforts to reduce delays.
- At times - Too many changes of NDIA lawyers /lack of continuity: especially during the longer AAT appeals cases there have, in some instances, been a succession of different lawyers representing the NDIA each for short periods, before handing over to someone new. This caused a very significant lack of continuity, ensured that proceedings became further protracted and usually resulted in a lack of procedural fairness.
- Processes too legal: Participants appealing NDIA decisions to the AAT quickly find themselves in a legal environment, when they were merely wanting support (or changed support) from the NDIA. The extent to which it is a legal environment sometimes has participants thinking they have done something wrong to end up there (when they clearly have not, it is just the way the system is currently working).
- Intrusive processes: in our experience, blanket subpoenas of all health and allied health professionals working with an NDIS appellant occur all too frequently as part of AAT appeals processes.
Why should a person with disability be being forced either to reveal private information unrelated to their disability (one example: whether or not a person with disability had had a pregnancy terminated), or to justify to the AAT why this information should not be revealed, as part of the process of seeking access to or support from the NDIA?
- Lawyers representing the NDIA at AAT at times not acting as model litigant (despite the clear imperative to do so). Throughout the time that ADACAS staff have acted as supports (alongside Legal Aid ACT) through appeals, we have witnessed some terrible behaviour from some of the lawyers then being engaged to represent the NDIA. Whilst some were respectful, others displayed an appalling lack of knowledge of disability or an unwillingness to make reasonable adjustments. We have also witnessed stigmatising attitudes and beliefs (for example, a lawyer

representing the NDIA making harmful comments to a participant who happened to have at one point in their past had a substance use issue). We are pleased to see the more recent changes from the NDIA that are seeming to result in the NDIA engaging lawyers that are more experienced and knowledgeable around disability, accustomed to and complying with the obligation to make reasonable adjustments, and more frequently acting in line with the expectation that they should always in every circumstance be acting as model litigant.

- The names and stories of adult NDIS participants who complete the AAT hearing process as part of their appeal, are currently being made public: this is unacceptable - adult NDIS participants should be afforded the right to privacy and have pseudonyms instead automatically used.

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

Please refer to the attached ADACAS submission in response to the NDIS Planning Inquiry by the Joint Standing Committee on the National Disability Insurance Scheme, Parliament of Australia) in September 2019 for additional commentary on this and other NDIS planning related topics.

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

- Increase understanding amongst reviewers of the compounding and increased impacts that often occur when someone has multiple co-occurring disabilities or health issues, and explicitly acknowledge and ensure this aspect of each individual's situation and lived experience is taken into account when responding to reviews.
- Set fair and reasonable timeframes in which the NDIA will respond
- Show participants draft of plans (and allow for them to provide feedback) before plans are finalised
- Plain language /easy English letters of response by the NDIA
- Continue and improve the AAT Early Resolution team approach:
We are pleased at the introduction of the AAT Early Resolution team, and commend them on efforts to assist in having matters resolved in a more reasonable timeframe. We note the need for the Early Resolution team to be more transparent about who will fund any extra reports requested (especially when these are being requested of people who are seeking entry to (not current participants of) the NDIS.
- Introduce an NDIA “we will manage appeals in good faith” principle:
Participants are sometimes very worried and sometimes have had it explicitly stated to them that their NDIA plan will be jeopardised by appealing – that they will end up with a worse (not better) NDIS plan by virtue of seeking a change to one aspect of their NDIA plan. This is clearly an attempt to discourage a participant from appealing, is duress, and is completely unreasonable. We suggest that an “we will manage appeals in good faith” principle be introduced to the review processes – i.e. a principle which states that the NDIA will act in good faith when looking at a review or appeal (i.e. the reviewers will concentrate on the areas where the participant is seeking change, and not seek to reduce

other areas of the plan unless new additions mean other funding is no longer needed).

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

As stated above, we believe the following timeframes should apply:

- Internal reviews – no more than 1 month in total from when review submitted (unless participant asks for more time e.g. to review draft).
- AAT reviews – no more than 3 months in total from date AAT application submitted (unless participant asks for more time e.g. to review draft).

8. NDIS Act and Rules:

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?

Yes. Many. In particular some of the access criteria (disability requirements) need to be updated/amended, as does the definition of reasonable and necessary.

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

- Improve the way participants and providers interact with the Scheme?**
- Improve the access request process?**
- Improve the participant planning and assessment process?**
- Better define 'reasonable and necessary' supports?**
- Improve the plan review process?**
- Improve the internal merit review process?**
- Improve the way other government services interact with the Scheme?**

In addition to the comments below, please refer to my comments throughout this paper in relation areas of potential areas where change to legislation might assist.

Access:

- In terms of access to the scheme – the definitions of permanent, and substantial reduction of functional capacity need to be simplified, such that it is easier (especially for people with multiple disabilities or co-occurring conditions) to enter the scheme.
- With regards to the criteria of substantial reduction of functional capacity, there should be an acknowledgement that if people have multiple areas of reduced capacity that this is sufficient for the reduction to be considered substantial (even if there is not one clear area of the 6 where by itself the reduction is considered substantial). The very concept of substantial reduction in functional capacity could also be re-considered: does it have international validity in line with the ICF?

Other areas where improvements needed:

- Timeframes for all forms of reviews / appeals: Introduce timeframes for the NDIA must comply with (and consequence if they don't)
- Clean up confusing language around reviews and appeals to introduce simpler / more logical language. Perhaps plan review for the annual review, and then internal appeal / external appeal (instead of review of reviewable decisions) and plan amendment for small changes?
- Co-occurring disabilities: Improved recognition, acknowledgement and response through access, planning and review processes that there is frequently an inter-relationship and compounding impact when people have co-occurring disabilities and/or health conditions.
- Reasonable and necessary: given that each individuals' circumstances will differ– “reasonable and necessary” needs to be a subjective (not objective) test. It is additionally a test that should be applied not just to funds provided to participants, but also one that should be set up as a limit on NDIA actions. Is it the request that the NDIA is making of this participant in regards to that topic reasonable and necessary?
- Travel: changes to NDIS transport policy to require providers to charge transport costs directly to participants when core supports and transport funds are not managed via the same mechanism (i.e. if they are not both plan managed). Impacts can be: participants accruing debts to service providers, red tape, and stress for participants. The gain of NDIA monitoring transport spend does not seem to outweigh the distress/ pain being caused.
- Use it or lose it mentality re NDIS funding: Expectation by too many NDIS planners that if funds are not used, that means that they were not needed in last plan, and won't be needed in coming plan.
- Assistive technology: continues too often to be too hard for people to access the AT equipment that they need in a timely fashion. Impact can be that people get neglected or in some circumstances that there is a risk of abuse.
- Specialist Disability Accommodation: there are discrepancies between the legislation and policy (i.e. the definition of “extreme functional impairment” in relation to how it links with concepts of whether 24 hour daily support is required). Requirements very technical – to the extent it is hard for people with disability and families to establish whether a person is likely to be eligible for SDA type supports or not.
- Connection between SIL and SDA: Some SIL providers are buying properties and becoming both landlord and service provider to people with disability, thus putting people with disability in risky situations (whilst some providers act responsibly, we have seen other providers in this situation misuse their powers/ illegally seek to evict a person with disability from a SIL property with no account of their rights).

9. Plan Amendments:

28. What are the significant challenges faced by NDIS participants in changing their plan?

- Lack of responsiveness / delay in timely responses
- Lack of clarity in knowing that amendments are possible and what types of amendments can be possible and when

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?

- Make it easier for planners to fix errors (i.e. mis-spellings/ inaccurate information re family or supports included, things agreed to in the planning meeting but omitted by accident when finalising the plan, typos or accidental errors with quotes/budgets etc).
- Also assists in situations where circumstances mean that a small change is required (i.e. a change to the way that a particular category of funding is managed).

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

- If the plan amendment relates to something agreed to in the planning process but accidentally omitted from the plan or an error, the planner should be advised as soon as possible / as soon as people become aware of the error.
- There should not however be a timeframe for plan amendments, they should be possible at any time of the year.
- This is to allow for small changes which might be needed at any time throughout the cycle of a plan. (E.g. a particular funding line might be agency managed, but halfway through the plan, needs to become plan managed like some of the other lines already in the plan).

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

- Change in provider availability might mean that a funding type needs to change unexpectedly.
- Gaps between plans.
- Emergency situations – where extra support coordination funds are needed (although perhaps this would be a change of circumstance).
- Where do “light touch reviews” fit with this conceptualisation? (E.g. to add extra support coordination funds, or extra funds in a particular category of funding without all of the usual planning processes nor the need to re-start all of the service agreements etc)

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

- Publish clear plain English (and easy English) information about what is possible and the response times.

10. Conclusion

There continues to be much work to do for the NDIA to achieve the important goals outlined at establishment of the scheme. We support the goal of an inclusive community valuing the participation and contribution of every Australian. With this review, we note the importance of retaining those aspects which are working well, whilst continually improving the aspects that are not. We hope that this feedback assists to that end.