



Government of **Western Australia**  
**North Metropolitan Health Service**  
**Mental Health, Public Health and Dental Services**

Submission by the Neurosciences Unit, North Metropolitan Health  
Service Mental Health, Public Health and Dental Services  
to the Department of Social Services –2019

# Review of the NDIS Act and NDIS Participant Service Guarantee

This submission was prepared by the Neurosciences Unit staff.

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## INTRODUCTION

The Neurosciences Unit is a Perth based, statewide service providing assessment and case management services for adults with neurodegenerative conditions (e.g. Huntington's Disease, young onset dementia). Additionally the Neurosciences Unit provides Allied Health assessment services for children and adults with a wide range of presentations including neurological conditions and mental health issues. The Neurosciences Unit is part of the North Metropolitan Health Service (NMHS) - Mental Health, Public Health and Dental Services (MHPHDS; Health Department of Western Australia).

We welcome the opportunity to provide input regarding the '2019 Review of the NDIS Act and NDIS Participant Service Guarantee'. This contribution was put together by the staff of the Neurosciences Unit based on the experiences working with clients accessing or attempting to access the National Disability Insurance Scheme (NDIS). This submission was also reviewed by the NMHS MHPHDS Executive.

As a representative group of allied health, nursing staff and medical practitioners (neuropsychologists, social workers, speech pathologists, mental health nurse, neurologists and psychiatrists) working with individuals requiring support from the NDIS, we have responded to a range of the discussion questions outlined in the 'Improving the NDIS Experience: Establishing a Participant Service Guarantee and removing legislative red tape - Discussion Paper'. We acknowledge the excellent work that the NDIS has done to date and recognise that there are numerous challenges ahead. Clients of the Neurosciences Unit greatly benefit from the services they access via NDIS funding and we seek to further support ease of access.

Our responses will be limited to areas that primarily impact our clients and the staff that support them. Our responses are largely based on the experiences of our clients and staff, but also do include more general perceived issues with the delivery of NDIS services.

## PART 1: SELECTED KEY DISCUSSION QUESTIONS AND RESPONSES

### Accessible

2. In your experience with the NDIA, do you think they fulfilled the above principles? If not, how are they falling short?
  - Individuals with disabilities can have impaired communication, cognition, decision making as well as reduced insight into their difficulties and needs. These challenges can be at odds with the fundamental principle of “participant centred” planning and support. Where this principle is applied strictly, it can actually be to the detriment to individuals with cognitive impairment. There needs to be more explicit recognition of the fact that there are a subset of participants who require support and input from a support person and/or advocate.
  - The NDIS does not consistently facilitate or take into account the perspectives of support people/advocates when creating plans or selecting services. There is a lack of clarity with regards to how participants can nominate a support person or advocate. Furthermore, the process for doing so is complex, particularly when attempting to alter the support person/advocate.
  - In order for the NDIS to fulfil the needs of participants who have cognitive impairment and reduced insight, easier and stronger processes for the involvement of support persons and advocates need to be included in the legislation and Participant Service Guarantee.

### Eligibility and Application

6. What are some of the significant challenges faced by NDIS participants in the access process?
  - The nature of the NDIS being a participant led process can be a barrier to those with reduced insight or cognitive impairments, particularly if individuals do not have support people or advocates. Although this does not prevent access, it is more challenging and at times results in individuals not receiving services they might otherwise be eligible for.
  - Currently the NDIS is not accepting third party verbal access requests even when the participant is present. Again this has created particular difficulties for participants with reduced insight and cognitive impairments. As a case example, NDIS staff insisted on speaking only with a participant, even though the client consented for their next-of-kin and professional to liaise with the agency in the presence of the participant. As a result, the participant provided a wrong address to NDIS and other inaccurate information.
  - The NDIS do not appear to be accepting third party referrals with consent from the client; however this is inconsistent. The operational guidelines state an access request can be made by ‘a person, or someone who is able to act on their behalf’. The

interpretation of this is inconsistent as sometimes third party referrals with consent are accepted and sometimes NDIS staff insist that only the person themselves can make that request. It's also unclear whether 'someone who is able to act on their behalf' refers only to someone with Guardian status or can it be a support person or advocate.

- Currently within Western Australia, there's a lack of agencies that can provide specialised support for individuals to access NDIS. As an example, our agency was the nominated contact for a participant living in Jurien Bay whose plan included Specialised Support Coordination. The planner provided a lengthy list of Specialised Support Coordination agencies, but none of those contacted could provide said service in that area. This required the amount to then be converted to Support Coordination before an agency could proceed, resulting in further delays for the participant while this was resolved.
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?
- The 21 day time frame is reasonable; however this is largely not being met and is often taking up to 3 months.
8. What do you think the NDIA could do to make it quicker or easier to access the NDIS?
- There are a number of immediate actions the NDIS could take to make access easier and quicker. The following are the more pertinent ones which could drastically change the user experience:
- Upskilling of NDIS staff to have a greater understanding of disabilities and the needs of people with disabilities.
  - Encouraging discussion and/or consultation with professionals who are known to the participant and have specialised knowledge about the disability.
  - Acceptance of third party referrals with consent from the participant.
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?
- A large amount of the information is online. This assumes that all participants and those supporting them are able to access the internet or have computer literacy, which is often not the case for our client group. Other government services tend to have local offices where people can obtain information, whereas this is not the case for NDIS.

- Information and materials provided by the NDIS is not always translated into other languages or is translated inappropriately. Further translated materials (either digital based or paper based) would greatly improve access for individuals for whom English is an additional language or dialect.
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?
- Currently the NDIS does not provide specific details regarding decisions to decline service access. Details are also not communicated with agencies that are attempting to support individuals with an application for access.
  - When declining access requests due to insufficient evidence, an option is not provided to add additional information. Currently, clients must re-apply or launch an appeal. It may be more efficient and fairer to simply request the provision of further information.

## Planning processes 1: Creating, your plan

11. What are some of the significant challenges faced by NDIS participants in the planning process?
- There are a range of challenges faced by NDIS participants in the planning process including:
    - NDIS planners lacking an understanding of the participant's needs and disabilities as a whole.
    - Participants are required to predict functional level in advance. This is often unrealistic in neurodegenerative conditions.
    - Participants are required to make static plans that do not capture decline.
    - Cognitively impaired clients do not always have insight into the services they require.
    - Good outcomes appear heavily dependent on having strong advocate input into plans. Advocates are not always invited or aware of planning meetings and participants at times assume this will happen automatically. Participants are not fully advised as to who they might like to include in the planning process and how this can be achieved.
    - Plans are dependent on a planners' knowledge of services available and what a client may be eligible for. This approach relies heavily on individual knowledge and leads to inequity.
    - Planners are not consistently recording information presented at planning meetings for the Plan Builder. As a result plans can be end up being quite inappropriate and require further review. This can further delay the commencement of services or mean services being provided are inadequate or inappropriate.

- Participants are being asked to choose a financial plan management model (i.e. Self; Plan; or NDIA-managed) with insufficient information about what this would mean for them and the responsibilities involved.
12. Are there stages of the planning process that don't work well? If so, how could they be better?
- There are a number of issues with various planning stages. Some of the issues and suggested improvements are as follows:
    - Planning process and Plan Building are conducted separately which is a hindrance and adds time to the overall process.
    - Planners do not always have access to documentation provided to the access team. Very often information needs to be resubmitted. This is onerous and places unnecessary burden on the participant, their support person/s and clinicians.
    - Planning needs to be a transparent process and currently there is limited access to drafts of plans.
    - Many planners are advising clients there is no capacity to review the plan before it is finalised. This ultimately leads to inappropriate or inadequate plans.
    - Portal access is only available to the participant which is an issue for those participants with cognitive impairments who have difficulty navigating the internet generally. Portal access should be given to nominated support persons or advocates.
    - Planners have often not reviewed information prior to planning meeting so they are unaware of the circumstances and nature of clients condition/s. Largely, planners have been inadequately prepared for meetings.
13. 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?
- 4 weeks is a reasonable time frame if there are no major adjustments or changes required.
  - Review of draft plan should be part of the process. Accepting the plan without review is wholly inadequate and inappropriate.
  - As the sector to support individuals with disabilities is growing rapidly, planners may not have up-to-date knowledge of the services available to a client. This further necessitates draft plan reviews.
  - Ensuring planners have all information available when they commence the planning process (e.g. information/reports that have been previously supplied to NDIS).

14. 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?
- The NDIS Preparation guide is good if they have support to navigate and complete the planning books.
  - Participants and their families often believe that the NDIS undertake assessments. There can often be is confusion from participants regarding the planner's role. For example, participants often believe that a planner is the assessor. Planners should clarify their role in the process and the roles of others at the NDIS in simple language. Visuals would also help support client understanding of NDIS staff roles.
  - There is a lack of understanding regarding what services can be funded as part of an NDIS plan i.e. what is considered 'reasonable and necessary'. Ideally NDIS would provide more education through examples of the types of services and equipment that can be provided.
  - Example plans for different conditions would be useful.
  - Participants should be given information about the different plan management models and responsibilities involved prior to a decision being made. For example, what will participants have to arrange and what will service providers organise for them under different management models; how will services be sourced and organised under different models? Who will be responsible for ensuring funds are spent as allocated/intended under the different models?
15. Is the NDIA being responsive and transparent when making decisions in participants' plans? If not, how could this be improved?
- Broadly speaking we feel that in this area the NDIA is not being transparent with participants with regards to their plans.
  - Decisions seem to be planner dependent and based around factors such as a planner's knowledge of the disability and what is reasonable/necessary for the person's disability. Additionally, a planner's ability to communicate decisions to a participant is vitally important to transparency.
  - Responsiveness and transparency would greatly be improved by simply adding drafting to the planning process.
16. 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?
- Accessing and planning has become more difficult since the trial phases/sites.
  - There are now less localised contacts and reversing this would greatly improve ease of access.
  - It's become difficult to advocate for participants. Given issues with lack of insight and cognitive impairment for some participants, providing channels for advocacy would improve plan construction, implementation and decision-making.



## Planning processes 2: Using and reviewing plans

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

A number of significant challenges are faced by individuals attempting to participate in utilising the supports prescribed in their plan. These include:

- Accessing appropriate supports and finding providers, particularly if a participant is outside of metro area.
- A lack of capacity with providers.
- Finding service coordinators.
- Self managed participants not understanding how to use the portal system.
- Participants choosing an unsuitable plan management model due to a lack of understanding.
- Participants having to choose a plan management model in the planning meeting when they do not have all of the information and no working understanding of the models and the responsibilities involved.
- Lack of understanding of the responsibilities of self-managed plans.
- Improper selection of a plan management model can impact subsequent plan review if funding hasn't been fully utilised.
- Fragmentation of service delivery when participants need to engage multiple service providers to have their needs met. Participants can feel overwhelmed having to access many different providers for varying services, with some participants preferring to access all or most of their services from one provider.
- Lack of whole service provision (e.g. one agency provides service provision, one provides intervention etc.).
- No service coordinators within metro area with availability.
- The list of Registered Service Providers in Western Australia is 49 pages long and printed in a very small font, thus making it both inaccessible and overwhelming for participants.

18. 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?

- The NDIA is providing good information, however some strong additions would be:
  - Provide a specific list of localised services to participants that are relevant to them and have the capacity to provide services.
  - Access to Mabel App (available in eastern states), for those that have capacity to use it.
  - Further 1:1 support in providing information where possible and appropriate. Currently, information sessions are large and informal which does not suit a number of clients.

19. What other advice, resources or support could the NDIA provide to help participants to use their plan and find supports?
- Providers and their partners should provide up-to-date information regarding the services they deliver, timeframes and costs. The NDIS/NDIA should have oversight of the partnering agencies to ensure that these are kept up-to-date. This information would facilitate implementation of a plan in a timely manner.
  - In situations where difficulties arise with a participant and/or family being able to access services that support their goals, the NDIS/NDIA should facilitate eligibility for support coordination rather than requiring a plan review to add this in.
20. What are some of the significant challenges faced by NDIS participants in having their plan reviewed (by planned or unplanned review)?
- Small changes to plan should not require the whole plan be reworked (soft touch review) e.g. if a participant wishes to change their management model.
  - The time it takes to review a plan is too long and bureaucratic (e.g. requiring meetings and renewed paperwork and approvals) when the need is critical and urgent.
  - Lack of planning around major life transitions such as moving to supported accommodation, which will require a significant increase in funding but where the timing can't always be anticipated. Providers are often left with an empty bed while a plan is reviewed and developed to fund the placement. This may delay a participant's move, even though the participant and their family are ready and a suitable accommodation option is identified and available. An estimate of accommodation funding that is required should be noted in a plan where residential care is identified as the most appropriate option and is likely at some point in the future.
  - Inability to top up plan with one off funding in critical and urgent circumstances in which a review could still then be undertaken. People are held with the same funded supports until the review and new plan is approved.
21. What can the NDIA do to make this process easier or more effective?
- NDIA needs to be proactive and prepare participants and their families for review, particularly plans involving people with neurodegenerative conditions. This is especially important if further supporting medical/ allied health evidence may be required.
  - An ongoing relationship with an NDIA employee. For example, if a participant meets with a planner face to face for the review, they should be able to direct all further enquiries to this person once plan approved.
22. How long do you think plan reviews should take?
- 28 days (4 weeks) is an appropriate length of time for standard reviews. Where there is an urgent and critical need there should be an alternate mechanism for an

expedited review to happen within an appropriate timeframe. For some participants in extreme circumstances this may be within 24 hours, whereas for others this might be a week or two.

## Appealing a decision by the NDIA

23. What are some of the significant challenges faced by NDIS participants when they seek a review of an NDIA decision?
- There is no clear set timeframe for appeals to be resolved. As a result it is often quicker/easier for participants to submit a new access request. This is a clear failure of the appeal process.

## The legislative framework

27. 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?
- There are significant gaps within the legislation with regards to nominating an advocate or support person for individuals who lack the capacity to support themselves through the application process.
28. What changes could be made to the legislation (if any) to:
- a) Improve the way participants and providers interact with the Scheme?
- Increase collaboration with and input from the nominated person.
  - Facilitate avenues to advocate for participant.
- b) Improve the access request process?
- Increase collaboration with and input from the nominated person.
  - Facilitate avenues to advocate for participant.
- c) Improve the participant planning and assessment process?
- Increase collaboration with and input from the nominated person.
  - Facilitate avenues to advocate for participant.
- d) Better define 'reasonable and necessary' supports?
- Provide examples and case studies for both applicants and professionals.
- e) Improve the plan review process?
- Increase collaboration with and input from the nominated person.
  - Facilitate avenues to advocate for participant

## Plan amendments

29. What are the significant challenges faced by NDIS participants in changing their plan?
- In addition to the previously discussed points with regards to plan creation, currently the time taken to make amendments is prohibitive and inappropriate to changes that require a prompt response (e.g. crisis situations).
30. 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?
- Plan amendments with a consistent planner (similar to a key worker) could reduce the time involved in planning and implementing adjustments. Additionally, a consistent point of contact may reduce the burden placed upon participants in having to retell their story and changing conditions to another staff member.
31. How long should people have to provide evidence that they need the changes they are requesting in a plan amendment?
- The length of time can depend on factors such as prospect of changes being permanent or temporary. For example, if carer is requiring treatment in hospital then a permanent change is not required and the evidence requirements should be quick and responsive. If there are more permanent changes in a participant's circumstances or functional capacity, then supporting documents from medical/ allied health should also be accepted. Professionals who have completed an assessment that they are qualified to undertake should be able to generate immediate change to a support needs assessment.

## PART 2: CLOSING STATEMENT

The Neurosciences Unit, North Metropolitan Health Service – Mental Health, Public Health and Dental Services, thanks the Department of Social Services for the opportunity to comment on the review of NDIS Act and NDIS Participant Service Guarantee. We look forward to responding to any proposed draft amendments or guidelines and would appreciate the opportunity to be involved in future forums and consultations. We note that had time permitted, we would have liked to address additional issues with regards to how ‘reasonable and necessary’ is defined in the legislation and the lack of clarity surrounding psychometric measures to demonstrate functioning. We would be happy to provide comment on these issues at the Department of Social Services request.