



Brain Injury
SA.

Improving the NDIS Experience

October 2019

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Introduction

Brain Injury SA appreciates the opportunity to provide a submission on the current operations of the National Disability Insurance Scheme as well as the National Disability Insurance Agency.

Brain Injury SA offers several different advocacy services, receiving funding from the Department of Social Services for the National Disability Advocacy Program as well as the NDIS Appeals Program. Our NDAP service assists people living with an Acquired Brain Injury (ABI), while the NDIS Appeals Program is available to all people that are affected by a decision made by the NDIA.

Brain Injury SA is also participating in a decision support pilot program conducted through the National Disability Advocacy Program. This program supports people to navigate the NDIS and gain access to the scheme. Those eligible for this program are people with limited decision-making capacity who do not have any other informal supports (e.g. family, friends, or carers) to support them through the decision-making process.

Brain Injury SA also provides a number of therapy and other supports to those living with an ABI in South Australia, including psychology, physiotherapy, speech therapy, occupational therapy and support workers. The contents of this submission were written independently by the advocacy team.

As is discussed in the paper, the NDIA continues to present participants with a significant number of issues across developing, utilising, and reviewing their plans.

A continuing area of concern is for those who are refused access to the scheme. Refusals are often made because of a lack of evidence rather than because a person does not meet the access requirements under the act. However, there is insufficient information and guidance to help applicants find the evidence they require as well as the funds to obtain them. As supports for persons with disability are consolidated under the scheme, there is an ongoing risk of people being left behind.

Accessing the supports provided in an NDIS plan is often difficult for participants. There is limited communication from the NDIA about appropriate ways to use funds in particular categories, limited efforts to connect participants with services and ongoing issues about availability of services, particularly in rural and under-serviced areas.

Efforts to hold the NDIA accountable for unfavourable decisions is currently being limited by an extremely slow review process. Delays through this process are having a number of knock-on effects for people seeking to utilise their plans.

This submission is structured in response to the questions in the Discussion Paper issued by the Department of Social Services as part of this review. We are hopeful that this feedback provides useful guidance on how people interact and engage with the



scheme and is used to improve its effectiveness for prospective and current participants.



Participant Service Guarantee

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

We believe that all of the listed principles discussed in Appendix A of the Discussion Paper are important for the NDIA to adhere to as well as additional ones which will be discussed later in the document.

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

The following is a short summary of the issues currently faced by participants under the scheme:

Timely:

We have experienced extremely long wait times for Internal Reviews to be completed. It is not uncommon for our clients to be waiting upwards of 9 months with some clients waiting over a year for their reviews to be addressed.

Expert:

We often get feedback from our clients when they come to us seeking a review of their plan that they feel as though the planner knows very little about their or their child's disability and that the supports they have been given reflect this.

Engaged:

We have found it extremely hard to get any updates regarding our client's access requests or internal reviews. Often when we attempt to get an update, we will frequently either get no response or will be told we don't have authority to enquire about the person, despite authority forms already being provided.

Decisions are made on merit:

Internal review outcome letters do not always provide enough details as to why a support they are seeking has been accepted or rejected. They also do not provide any information regarding what additional information the participant could obtain to help



them

get

this

support.

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

Consistency:

There needs to be more consistency in the types of supports the NDIA gives people funding for. We have noticed a lot of variance in the funding people are given with similar evidence bases. It seems to depend a lot on who the planner is as to how much funding the person gets.

Discussions and information gathered from different workers at the LACs, the general NDIA Call Centre and other delegates are also often inconsistent.

Transparency:

There needs to be more transparency about what stage of the process the internal review is at. For example, the clients should be given a timeframe as to when their review will be completed. The same information would be useful for Access requests, where it is often unclear how far the application has progressed.

It would also be beneficial for each matter to be assigned to a case worker who can be contacted to discuss things further.

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?

Other service standards and their measures we believe should be included are as follows:

Timely:

- Participants who request an internal review are given an outcome within 3 months of the request.



Expert:

- Subject matter experts are provided in each disability so as to provide understanding as to the level of support required.

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

Instituting timeframes to be followed for events such as access requests, planning meetings, approvals and reviews would also be beneficial. However, these standards must be met and have mechanisms to address delays if they are not provided on time. Current legislative requirements (e.g. access requests to be completed within 21 days or 'reasonably practicable' for internal reviews) are not met consistently.

Greater disclosure of relevant statistics would be a good starting point. The most common area of delays relates to the time it takes an internal review to be processed. We think that publishing the statistics regarding how long internal reviews are taking to be assigned to a review officer and how long they are taking to get an outcome would provide a good measure as to the timeliness of internal review decisions.



NDIS Eligibility and Applications

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

A great number of the clients we have assisted have been denied access to the scheme because of a lack of evidence - but they are not told what further evidence could be provided in order to meet the access requirements. We have also assisted clients who are unable to afford the assessments and reports necessary to meet the access criteria.

For clients with Acquired Brain Injuries it is particularly challenging as a Neuropsychological assessment and report are required to supply adequate medical evidence to meet access. When attempting to access Neuropsychological assessments via the public health system, there are extremely long waiting lists and participants are being asked to wait very long periods of time without necessary supports. If participants attempt to privately source this evidence it can be very costly, providing another barrier to being fairly assessed for access to the NDIS.

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 an appropriate time frame. However, as of the time of writing, this standard is not being met consistently for all applicants and waiting times are often longer.

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

There needs to be some provision of funds to pay for reports necessary for people to gain the appropriate evidence necessary to access the scheme. Under the current system, many people are priced out of getting the appropriate information or face extremely long wait times to access health care providers through the public health system.

Now that disability support is almost entirely consolidated through the NDIS, people who do not have access to the scheme due to a lack of evidence, face significant risks of not getting the care and support that they require.



There are also frequent delays between a person being granted access and the arrangement of a planning meeting. It is common for a person to be accepted into the scheme but not able to begin getting supports in place for upwards of 3 months.

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?

It would be helpful if the NDIA could provide some examples of the types of evidence required in order for people to meet the access criteria.

In cases where somebody has been rejected from the scheme, any guidance from a decision-maker at the NDIS as to what information would be useful would be of great benefit. Quite often applicants do not have a clear understand of what evidence they lack to gain access and will often try and source irrelevant information at significant cost in an attempt to get on to the scheme.

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?

Access request outcome letters do not always provide enough details as to why a person has been rejected from the scheme. It would be good if there were more detail in the access request outcome letter. It would also be helpful if the NDIA could provide some examples of the types of evidence required for people to meet the access criteria.

Furthermore, the NDIA will not supply a copy of the letters to those who have consent to exchange information. It would be helpful for NDIA workers to be able to send information to nominees or those with consent when participants request it in the future. This would allow advocates and other workers to easily assist participants in gaining access to the scheme in a timely manner.



Creating A Plan

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

It is common for new participants of the NDIS to be unaware of what they can request in terms of support and what evidence is required to support these requests. A participant who is new to the scheme and who has not been previously linked with service providers may not have an adequate understanding to be able to suggest how much therapeutic services they may require, nor would they have the supporting evidence due to the lack of support prior to accessing the scheme. It is also common for the participant to wait several months to get a date for their planning meeting, and then wait another several months to receive the formalised plan, this process needs to be much more streamlined to ensure participants are accessing the scheme much earlier than potentially 4+ months after being accepted onto the scheme.

For participants with cognitive disabilities, attending a planning meeting without support sometimes results in a plan that does not meet their needs. Some individuals may downplay the impact their disability has on their day to day life or they may not completely understand the question being put to them. Questions that require someone with cognitive disabilities to rate how much or how often something impacts on them may be harder to judge. The presence of a family member, friend or advocate can provide a broader understanding of the participant's day to day experiences by providing examples.

Planning meetings should always occur face to face where the participant wants this to occur, but this is not always possible or can make the process lengthier than agreeing to a telephone planning meeting.

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

An improvement that could be made to the planning process would be the NDIA communicating effectively with the participant/support network to ensure that they have all the required documents prior to the planning meeting. Clients with acquired brain injuries (ABI) often suffer from cognitive fatigue, memory issues and decision-making issues. In some cases, it would be more beneficial to assess their needs via their supporting documentation rather than 'questionnaire' style as this may not be the most representative of where the participant is currently. Some individuals have told us that they felt the documentation they provided to planners was disregarded.



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?

An appropriate amount of time for the planning process, including the planning meeting and outcome of plan should in most cases take 28 days (excluding complex cases/disabilities). Most people who engage with Brain Injury SA's advocacy services wait upwards of 2 months to receive a plan.

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?

It could be beneficial for a follow up on the pre-planning packs that NDIA send to participants who have just met access. For clients who experience challenges with memory and decision-making this can be a difficult package to effectively utilise without support. Some support to use these packs could be beneficial for a number of clients with limited cognitive and decision-making ability.

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

From our discussions with clients, the NDIA does not communicate with participants in regard to decisions made within their plan. After the planning meeting, the next communication from NDIA is generally once the plan has been approved. This is not conducive to a collaborative and appropriate plan being created for the participant and does not allow the appropriate changes to be made to ensure the plan adequately supports the participant.

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?

The process when starting a participants second plan is significantly easier due to the fact that the participant generally has their relevant supports already in place. In some cases, however, their plans have not been fully utilised due to lack of proper implementation which needs to be significantly considered during planning meetings. As a result, under-utilised funds are often cut from the subsequent plan. It is not that



these supports would not be needed by the applicant, but they were not able to organise someone to deliver them.

One example of this is, a participant received their first plan and it included In-Kind support coordination which was significantly under-utilised due to staff movement. This meant that implementation of other supports in the plan were also under-utilised. The participant had minimal daily contact with support workers and was connected to a Psychologist, however, the support workers were constantly unavailable to assist him in attending these appointments. When he failed to arrive for these scheduled appointments he was also charged for a cancellation.



Using and Reviewing Plans

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

Local Area Co-ordinators are often unable to fulfil their role as a service facilitator for the areas they represent. They do not appear to have the resources to be able to refer people onto appropriate service providers, or otherwise do not understand what is available through a person's plan. We see very few participants with Support Coordination in their plans and LAC's have limited capacity to link participants with their supports particularly past the initial implementation. Under-utilisation of plans should flag a response from LAC's to engage with participants to see why this is happening.

Limited transport budgets restrict how funds in a plan can be utilised especially for participants who live outside of the local metropolitan areas. Support workers are able to spend the time in some cases, supporting participants at social activities and appointments however the mileage component often restricts what is possible.

Waitlists are also common for many services, especially in rural or under-serviced areas.

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?

After a plan has been formalised and given to the participant it is not uncommon to hear that there was no implementation meeting or post-planning support for the participant to understand their plan and adequately implement it.

This is a confusing and convoluted scheme for people with disability to understand and often their care givers who are also new to the scheme and cannot support them as much as they would like. Much more involvement is required post-planning to ensure participants are not left for 6+ months post receiving their plan without resources to implement it. This is understood to be the role of the planner/LAC and there seems to be a lack of ability to fulfil this role currently.



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

Local Area Coordinators who have capacity to assist with the plan roll out and periodic check ins. Otherwise, provision of Support Coordination in plans needs to be more consistent, particularly in cases where a person doesn't have an informal support network or otherwise struggles to make arrangements themselves.

Increased understanding about the capacity of service providers and any waitlists that may be in place to access services would also be beneficial.

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

The significant challenge that participants face when reviewing their plan is being able to acquire the relevant evidence to support their needs, reports and assessments can be costly and currently there is no support in place to assist people with this expense.

Another challenge faced is the extensive time it takes for a decision to be made regarding a review, there is often a lack of communication regarding its status and how long it will take to get an outcome.

A more transparent and open communication line is required between the participant/carer/support person and the NDIA to ensure the participant feels fully supported and listened to during this process.

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

Allocating a specific case worker and notifying the participant of this would allow the lines of communication to stay open between the participant and the NDIA, this may streamline the process and allow for less miscommunications to occur due to being able to speak directly to one worker instead of a whole team of people where there is a higher likelihood of human error being made.

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

There should be a maximum of 28 days between a planning meeting and the provision of a new plan.



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?

One of the significant challenges that participants face after requesting an internal review are the long wait times for an outcome. Some people are waiting upwards of 9 months to over a year, if not longer, for their internal review to be completed.

These waiting periods greatly reduce the benefit of an appeals process within the act. Decisions made as the result of a planning meeting can sit uncontested for over three-quarters of the original plan's lifetime. Occasionally, they extend into the time the plan is scheduled to be reviewed, meaning that there has effectively been no review action taken on the plan as envisioned by the act. These circumstances generate a significant denial of procedural justice, and limit accountability for the Agency's decisions.

During this time updates are rare if they are provided at all. There have been a number of times where we have proceeded to the AAT due to the internal review taking too long to be completed and have been told that the internal review hadn't even been assigned to a review officer yet. These were for internal reviews that had been submitted more than 3 months previously and some more than 6 months previously.

Many applicants, particularly those who experience difficulties with writing and processing information, often have trouble through the review process. While requests for internal review can be taken by a variety of methods (phone, email and through a local office), there is limited opportunity for engagement with a person about why they think a decision was incorrect. Time needs to be taken in order to provide a decision-maker with all relevant information.

When seeking a review of an internal review outcome decision through the AAT, some people may not obtain legal funding assistance and frequently are not able to afford legal services outside of legal aid commissions. While the tribunal is certainly more accessible for self-represented applicants than a court, there remains a significant power disparity between the NDIA and participants. This is only compounded in circumstances where a person's disability means they are not able to present as forcefully as they otherwise might. While advocates are typically more available to assist applicants than legal services, they are limited in the amount of assistance they can provide when matters progress to hearing and involve technical legal arguments.



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

The long wait times experienced by applicants also present some procedural issues for participants unhappy with a plan.

During this time their plan will come up for a scheduled plan review. We have had many participants inform us that they have received phone calls from planners, around the time the plan is scheduled to end. Participants are then told that because their scheduled plan review is due, their internal review can no longer be completed and are asked to withdraw the internal review application. This means that if they receive a new plan from their scheduled plan review that is similarly lacking in funds, another internal review will need to be submitted with the risk of them waiting another year for an outcome.

Alternatively, clients will be advised that their internal review application could be replaced by bringing forward their scheduled plan review. This presents the same concerns as above, further delaying the review of their plan and effectively denying them appeal rights to the AAT.

There have been some instances where delegates have identified gaps in the available evidence presented with an internal review, and then taken the time to respond with requests for further information. While this has the potential to act as a further delaying tactic, good faith engagement on this point can allow both parties to ensure that the most complete picture is presented and assessed.

This matter is further complicated if additional requests for supports need to be made after the review request is submitted. By the time 9 months has passed, a participant's support needs may have changed. They then have to include these requests at the time of internal review, lest they wait another 12 months for a scheduled plan review to arise. While there remains the option to go to the AAT to attempt to have all requests included after an internal review is completed, it is unclear whether the tribunal has jurisdiction to address requests that were not made as part of the original internal review application.

In response to these concerns at internal review, the NDIA often funnels those with additional requests to the change of circumstances option, saying that they cannot have additional matters considered in the internal review. This further limits a person's right to have things reviewed, and does not guarantee that a change of circumstances request will be accepted and considered.

Internal reviewers themselves have often taken an inconsistent approach on this point. Some are happy to undertake requests made once a matter is assigned (presumably mindful of the time that has passed) while others are unwilling to consider matters that were not included in the initial application (which, again, can be upwards of 9 months).



Another issue that has been raised is the unconscionable conduct of reviewers that make contact with the applicant. Several participants that have sought assistance from Brain Injury SA have detailed situations where a decision-maker undertaking an internal review has threatened to remove funding unless an internal review is withdrawn.

In one such instance, an applicant received a phone call in the morning stating that their child's disability 'was not severe enough' and that her NDIS plan had too many supports allocated to a child at that level of capacity. The reviewer also stated that she would be making notes on this case file, and that a reduction in funding would result at the next scheduled plan review. Therefore, if the applicant was to withdraw their internal review, they would be without further review rights before the AAT in the likely event that their supports were going to be reduced.

Applicants also often experience difficulty as to whether Assistive Technology (AT) requests can be appealed through the current process in the act. AT reviews are often done outside the scheduled review cycle of plans, or are otherwise included in plans pending a further quote. In occasions where a request or quote is rejected, there is no clear notice as to what rights a participant has under the scheme to review the decision made under the scheme.

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

The most urgent reform should be to improve the waiting times when an Internal Review is submitted. Applicants who seek the assistance of Brain Injury SA often wait up to and beyond 9 months for a decision to be made.

Applicants cannot go to the Administrative Appeal Tribunal until an internal review is completed. As of the time of writing, it is unclear whether a review can be taken to the Tribunal if the 'reasonably practicable' requirement in section 100 (6) of the *NDIS Act* is not met. A matter has been heard on this point, but we are still awaiting an outcome. Some AAT registries, such as the Adelaide registry, are still willing to accept cases until this point is clarified - but this approach is tenuous and inconsistent between registries. We are hopeful a decision on this matter will be handed down in the short-term but ensuring that the NDIA is responsive via a specified legislative timeframe would be of great benefit to applicants and improve the realisation of their rights to review.

Requests made for unscheduled plan reviews or 'change of circumstances' requests have no obligation to be completed by the NDIA. In addition, they have a review route that only relates to the refusal to consider the request - not the merits of any changes in supports. In light of the significant delays that are faced in other areas of the appeals process, this further restricts an applicant's practical rights to contest a decision made by the NDIA.



When matters are before the AAT, prompt responses to questions and the provision of instructions to solicitors well before case conferences would greatly assist applications, particularly those without legal representation.

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

We request that request for internal review are undertaken and completed within 2 months, ideally sooner.

Reviews that are prioritised under section 5.7.1 of the *Operational Guidelines – Review of Decisions* should be completed within 21 days. This will reflect the urgency and need for intervention where applicants have a risk of harm, instability in accommodations/care arrangements or rapid deterioration. In our experience, there have been little to no improvements in waiting times when a review is prioritised. There is also little communication to indicate whether an application is prioritised after making the request.

More information relating to the status of a review after it has been submitted would also be beneficial. Information such as whether the review has been triaged, assigned to a delegate, is under assessment, or is otherwise pending would be beneficial to determine whether obligations under the act are being complied with.



Legislative Reform

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?

As above, the issues with the time it takes for an internal review decision continue to be of significant concern to participants and greatly reduces the utility of the review provisions in the current act.

Denying a person's request for an unscheduled plan review is often made on an unclear basis because it is entirely at the discretion of the CEO.

The rules about which supports are the responsibility of the NDIS and which supports are the responsibility of other services systems (e.g. health or education) have a level of ambiguity surrounding them. This makes interacting with the NDIS difficult as many people are unsure whether the supports they are seeking are able to be funded by the NDIS or whether they need to seek the supports elsewhere.

28. What changes should be made to the legislation?

There should be a statutory guarantee about how long internal review requests can take. In line with our recommendation above, this should be a limit of at most 2 months.

There are also a number of changes to the definitions utilised by the NDIA that would assist applicants receive supports necessary under the act. Brain Injury SA and its advocacy team would support any change that will assist a greater number of people receive the support they require under the act.



Plan Amendments

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

Under the current system, changes in support funding for a participant require the development and an approval of an entirely new plan. The above discussion around the difficulties experienced with scheduled, unscheduled and internal/external reviews are also relevant to this point.

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?

A plan amendment provision may have some value in inserting funding for assistive technology or other supports that are more ad-hoc or require large initial expenditures. Such insertions with a large up-front cost are well suited to a mechanism that can insert funding for specific items.

Such a provision may also be useful where a change is relatively minor or uncontentious. Support co-ordination is a funding category sometimes inserted into an applicant's plan without the participant intending to use those services. If a decision maker and applicant can agree that funding would be better utilised elsewhere in a plan, a change through a plan amendment provision would simplify the process.

Supports that are more consistent or recurring (i.e. funding for a support worker or therapies) are more complex. If adequately funded to meet the participant's requirements, ensuring that there is a long period of time to develop service agreements and routines is of significant benefit. The insertion of more support hours in a plan that has only two months remaining will be of limited benefit unless that support can be guaranteed for future plans.

Depending on implementation, these provisions could also create uncertainty for participants about the security of their supports. If it is possible for funding to be withdrawn from a particular area, an applicant may be left in the lurch should supports be removed from an area they were actively utilising and relying on.

Again, depending on how the agency intends to use such a provision, plan amendments also require robust review provisions where they cause changes to a plan that an applicant disagrees with. The same issues with the current review system discussed above should be at the forefront of those considerations.



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

Considering that each circumstance is different, a flexible approach to placing demands on applicants would be beneficial. The agency should be mindful that the demands placed on persons with disability often require engagement with allied health professionals and may require significant time.

This is particularly true in the case where the act of gathering information is likely to be expensive or complex. Where an application for home modifications is made, for example, several reports from occupational therapists, installers and builders are often required.

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

As mentioned above, the ongoing issues relating to accessing Assistive Technology supports may be assisted by a plan amendment provision.

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

Addressing the issues above around scheduled, unscheduled and internal/external merits reviews as discussed through these submissions would offer significant benefits for participants. If a plan amendment mechanism allows changes to be done quickly and effectively, we would hope that it would be in conjunction with addressing these other issues.

