



Brain Injury  
**SA.**

## **Proposed Changes to the National Disability Insurance Scheme (NDIS) Act**

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## Introduction

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Brain Injury SA appreciates the opportunity to provide a submission on the proposed changes to the *National Disability Insurance Scheme Act 2013* (“the NDIS Act”). These proposed changes will affect access, eligibility, and planning through the introduction of Independent Assessments, personalised budgets and greater plan flexibility.

Brain Injury SA (BISA) is the peak body for the Acquired Brain Injury (ABI) community in South Australia. BISA provides a range of advocacy services through the National Disability Advocacy Program (NDAP) and NDIS Appeals Program; both programs are funded by the Department of Social Services. Our NDAP service assists people living with an ABI, while the NDIS Appeals Program is available to all South Australians and residents of the Barkly community, NT, that are affected by a reviewable decision made by the National Disability Insurance Agency (NDIA).

BISA is also participating in a decision support pilot program conducted through the NDAP. This program supports people to navigate the NDIS and gain access to the scheme. Those eligible for this program have limited decision-making capacity and no informal supports (e.g. family, friends, or carers) to support them through the decision-making process.

In addition to these programs, BISA also provides a number of capacity building and core support services to the ABI community in South Australia, utilising an interdisciplinary approach of Allied Health specialties including psychology, physiotherapy, speech pathology, occupational therapy, dietetics and support workers. The contents of this submission have been written with reference to the collective experience of the team at Brain Injury SA and knowledge of brain injury.

As is discussed in the consultation papers, the NDIA have acknowledged that the NDIS intake system has risked inconsistent decision-making and inequitable access and planning decisions. A continuing area of concern is that the current process requires people with disability to seek evidence regarding their disability from a variety of professionals, including doctors and specialists, which can result in long waiting times and expense at the cost to the prospective participant.

This submission is BISA’s response to the following consultation papers released by the NDIA:

- (i) Access and Eligibility Policy for Independent Assessments; and
- (ii) Planning Policy for Personalised Budgets and Plan Flexibility.

The contents of this submission are largely based on our primary concerns with the proposed changes. This includes, but is not limited to, the foreseeable outcome of the proposed changes will not achieve the intention of them. Instead it has the potential of



creating a more complex, inconsistent, and inequitable scheme, driven by a speedy roll-out and lacking sufficient time for trial and feedback.

BISA acknowledges that our feedback is restricted due to the limited detail provided in the consultation papers, which are short on pertinent detail, highly repetitive and refer to several external documents. This makes it inaccessible for many. BISA is mindful of endorsing any proposal which provides limited detail but welcomes changes that enable a participant to roll-over their funding, access free assessments, have greater flexibility in their plan and a longer plan duration.

BISA is hopeful that this feedback provides a useful demonstration on how the proposed changes may not overcome the current challenges but will have the potential to negatively affect many people living with an Acquired Brain Injury and within the broader disability community.



## Risks to the Acquired Brain Injury Community

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In Australia, around 3.9% of people have an ABI. This equates to over 900,000 Australians (AIHW, 2007).

As the peak body for the ABI community in South Australia, it is imperative that BISA highlight the unique needs and challenges of this group, in addition to the broader disability community. The proposed changes to the NDIS Act will affect the ABI community in terms of access, eligibility and planning due to a few key factors discussed below.

### Invisible disability

ABI is often referred to as a hidden or invisible disability. This is because a person with an ABI may look and appear high functioning when, in reality, they have a number of deficits significantly affecting their daily lives. For some, these deficits are masked by a desire to present a “pre-injured identity” or may be impacting cognitive, emotional and behavioural function without being obvious to others, particularly within the first 3 hours of meeting them.

As such, the proposed changes to access, eligibility and planning through the introduction of Independent Assessments poses a significant risk of overestimating an individual’s functional capacity and underfunding their NDIS plan.

### Everyone is different

An ABI refers to any type of damage to the brain that occurs after birth. It can include damage sustained by trauma, stroke, infection, substance abuse, disease, or lack of oxygen. As such, the impact of the injury varies significantly from one individual to the next, it affects everybody differently. ABI affects physical and sensory abilities, behaviour and personality, and communication and cognition (e.g. remembering, planning, concentrating and solving problems). Further to this, 42% of people living with ABI are more likely to experience psychiatric disability, depression being most common following ABI (AIHW, 2007). Understanding of the impact of Brain Injury on functional capacity is normally undertaken through collaborative assessment in a variety of context, where insight into behaviour, emotional control, fatigue, cognitive deficit and mental health along with more obvious physical and communication disability. Unpacking its complexity, interrelated aspects and impact on capacity to manage both independence, community engagement and coping mechanisms requires time and sophistication of assessment.



For people living with Acquired Brain Injury, the notion of the NDIS transforming standardised test results or a diagnosis into an individualised plan will be grossly inadequate and is quite alarming. The consultation paper states that ‘a participant’s plan will no longer be based on individual decisions about each and every support based on the current reasonable and necessary criteria...’ As such, if the total budget in a participant’s plan is guided by a diagnosis and their perceived functional capacity, based on a time-limited (three hour) individual assessment by an allied health professional unknown to the participant, then it is our concern that participants living with ABI will be greatly disadvantaged by the proposed changes. This will be discussed later in further detail.

## Difficulty in obtaining evidence

For many of our clients, their brain injury was acquired many years ago. Often they were discharged from hospital without any medical evidence of a brain injury and little, if any support. It is not until many years later, sometimes even decades later, when they seek support and need to gather evidence to meet the NDIS access requirements that they re-engage with the health system. This typically involves a GP appointment and referral for an MRI. Furthermore, unless the individual complains of a chronic headache or is experiencing seizures, this scan will not be covered by Medicare (fmig.com.au) and is a cost to the individual.

Despite lasting deficits, if the injury occurred many years ago, the damaged tissue may have ‘healed’ and will not be reported by the radiographer. It is therefore imperative that the MRI is assessed by a specialist, such as a Neurologist. Although the tissue has ‘healed’ the injury still has an impact on the individual’s daily functioning. However, the necessity of a Neurology report adds lengthy wait times and expense to the individual.

The NDIS has acknowledged that there is a great financial burden on individuals when applying for access to the NDIS and that is part of the reason for the introduction of Independent Assessments. For our client group, however, there is still quite a lengthy and costly process involved in meeting the initial eligibility requirements – establishing a diagnosis and disability permanence.



## Key Concerns to Proposed Changes

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### Key challenge not addressed

To access the NDIS, applicants will still be required to provide evidence of their disability, including if their impairment is, or is likely to be, permanent. As previously mentioned, for some, particularly those who acquired their brain injury many years ago, they will still experience long wait times and potential expenses in order to obtain this initial information, before they qualify for the second stage in the access pathway for the NDIS, that being the Independent Assessment.

**The proposed new access pathway does not streamline, reduce costs or waiting times to the applicant and prospective participant, but rather add an additional layer to the process.**

### Independent Assessments

The NDIS have proposed the introduction of Independent Assessments to assess the functional capacity of prospective and existing participants. The assessment will include environmental and individual circumstances and will be undertaken by qualified health care professionals, including but not limited to occupational therapists, physiotherapists, and psychologists. The NDIS will also fund the Independent Assessments.

However, BISA have several concerns around the proposed introduction of Independent Assessments, particularly for the ABI community.

### Lack of insight

Without generalising, it is quite common for people with an ABI to lack insight into the difficulties and challenges they face post injury, particularly in relation to their cognitive deficits. Our therapists frequently encounter people who under report the difficulties they face during initial assessments and it is only over time and the building of trust that the true impact on their functional capacity is uncovered.

As an example, one of our participants who experienced a traumatic brain injury due to a motor vehicle accident has been receiving weekly occupational therapy sessions for a period of 12 months. Initially he presented as quite high functioning and was involved in a number of community initiatives within the brain injury community. This included offering peer mentorship within the inpatient setting that he was treated at and within a community transition support group. It was about 6 months from his initial



presentation with us that the true extent of the difficulties he faces with executive functioning were revealed. He is an articulate young man who has many hopes and dreams for the future and had he undertaken an assessment which is limited in time and supported by self-report assessment tools, it is highly likely that he would not have received the level of support that he requires to manage his everyday function. The issues he faces are putting a strain on his relationships, but they were only revealed through consistent input from a therapist that both he and his partner learnt to trust with their most difficult issues.

## **Time limited assessments**

BISA identifies significant limitations in the timeframe proposed for the assessment process, particularly in the absence of supporting information by those who have worked with a participant in their period of recovery post injury. This includes:

### *Lack of Insight in and limitation of self-reporting tools*

Under reporting can occur due to limited insight into the impact of an injury, a desire to please therapists (which is a well-researched concept) or a desire to perform well in an assessment. The proposal to limit Independent Assessments to three hours, will not allow people to build trust in the therapist and may unconsciously encourage the desire to perform well or hide the impact of their injury

### *Limitation of assessment out of context*

As an organisation, BISA have undertaken a number of time limited assessments to support people within the criminal justice system to access the NDIS on release from prison. These assessments are often based on limited medical information and rely on observations of the participant and their understanding of the impact of their disability and function. This is complemented by the use of an accredited observational tool of functional independence. However, BISA have identified significant limitation in this assessment process due to the fact that these are completed within an environment where people do not have access to some of the everyday activities that they will be expected to undertake on release. The lack of context means that the results are limited and significantly inadequate in representing the ongoing needs of an individual.

### *Simplification of assessment and individualised needs*

There is an inherent risk that Independent Assessments completed by an unknown therapist in an unknown environment with some time restriction will lead to an inaccuracy of results and may lead to a “grouping” of needs, for example assuming that everyone who has had a stroke has the same needs. Although the proposed changes allow flexibility in the assessment location there are high numbers of people within the ABI community who need to build trust with people before opening up their





homes, particularly if the environment has become difficult to manage because of organisational challenges or physical difficulties. Simplistically, assessment needs to consider multiple factors including the individual's sense of loss and therefore reluctance to disclose the real impact of their injury, the potential complexity of that impact which may or may not be revealed in a three hour window, and the importance of understanding of the individualisation of the brain injury developed over time in a variety of settings.

Our primary concern is that the limited timeframe to conduct assessments (three hours) does not allow sufficient time to get a full picture of a person's functional capacity. However, this concern can be somewhat counteracted by the adoption and use of supplementary reports from the applicant or participant's treating therapist/s.

#### *Formal Recognition of the Limitations of Standardised Assessment*

There have been several matters which have come before the tribunal, including *Arnel and National Disability Insurance Agency [2019] AATA 4778*, where the Tribunal has preferred the evidence of an Applicant's treating professionals over the evidence of an NDIS funded health professional who assessed the applicant for only a few hours. This shows that it is difficult to get to know a person and what they are and are not capable of in only a few hours; and that a treating professional who is familiar with that person is more suitably positioned to assess their functional capacity. Standardised assessment tools have been developed to be applied selectively by therapists to assist assessing progress and better direct therapy, not to provide simplistic and comprehensive profiles of function, particularly when the disability is multi-faceted and its impact complex. It is essential such assessment is supplement for people with brain injury with detailed reporting by those who know the individual well, including professionals working with them and family members where available.

In addition to this, the NDIA's claim that 3 hours is enough time to get a full picture of a person's functional capacity is directly contradicted by their arguments in the matter of *Castledine and National Disability Insurance Agency [2019] AATA 4240*. In this matter, the NDIA argued that the Occupational Therapist had only seen the applicant ten to twenty times before making her recommendations and that this relationship was "relatively new". The NDIA further argued that the Speech Therapist had only met with the applicant seven times. This completely contradicts the NDIA's proposed three-hour Independent Assessment model by a therapist with a non-existent relationship to the participant.



## **Assessor and treating therapists**

For the reasons outlined above, BISA has major concerns as to the adequacy of experience of assessors involved in applying the proposed standardised tools in NDIS application for people living with brain injury.

The consultation papers lack information on the experience of the independent assessor and how much input treating therapists will be able to provide for applicants requesting access to the NDIS and participants undergoing plan reviews. In many cases, those within the ABI community will have been working closely with therapists who specialise in the treatment of ABI and will be able to offer a comprehensive insight into their ongoing needs, progress and predicted outcomes which cannot be accurately gained through a three hour assessment. Those therapists are often working collaboratively with other treating therapists either within the same organisation or across organisations throughout the course of a plan and this enables them to have insight into all aspects of an individual's function and which areas may be significantly reduced.

## **Proposed Selection of assessment tools**

BISA has significant concerns about the proposed suite of assessment tools for the ABI community. The majority of the tools are asking individuals to self-rate the impact of their disability over a period of time (CHIEF 12 months and WHODAS 30 days). Many individuals within the ABI community would be unable to accurately recall the impact of their disability over extended timeframes. Short term memory issues are one of the most common challenges faced by people with an ABI. As therapists working within this space, BISA often work with people who are unable to recall things that happened the day before or even by the end of a session. Whilst the tools may have a good evidence base and provide reliable information on function regardless of diagnosis, they do rely on accurate reporting by the participant. Many of our cohort of participants also do not have family members or consistent carers who can support them with this process or provide a counter narrative to balance the information provided. It would be extremely challenging to assess the complex nature of an ABI in the time frame suggested and almost solely relying on participant reported function.



## Exemptions

BISA identifies an inadequacy of definition of when it may not be appropriate for an individual to undergo an Independent Assessment and a potential negative impact on the ABI community if requested exemption is not granted.

The NDIS have acknowledged that there may be exceptional circumstances where it may not be appropriate to request an individual to undertake an Independent Assessment. For example, where there is a risk of safety or an assessment is deemed inaccessible or invalid. BISA supports the need to grant exemptions and two of the proposed circumstances where exemptions may be warranted. However, the process and details surrounding exemptions have not been sufficiently defined.

It is unclear from the consultation papers:

- What type of evidence will need to be provided in lieu of an Independent Assessment?
- Whether applicants will need to provide evidence relating to their functional capacity?
- Who will fund this supplementary evidence?
- What are the guidelines for granting an exemption based on risk of harm or safety?
- How will the NDIA guarantee consistency in decision making regarding who will and will not be qualify for an exemption?

BISA is particularly concerned that if an applicant requests an exemption for an Independent Assessment but is unsuccessful, then their access request is withdrawn, not denied. This limits the applicant's right to review, as a withdrawn application is not a reviewable decision. This differs from the current process, where, if an applicant does not show sufficient evidence of their disability, as outlined in section 24(1) of the NDIS Act , they receive an 'access not met' decision which is a reviewable decision through a section 100 internal review.

## Plan duration

BISA identifies some potential risks of harm in the proposed plan duration.

Participants will need to complete an Independent Assessment at least every five years, or when there is a significant change in their life, functional capacity and/or their support needs. The Independent Assessments will be used to develop a personalised budget ('NDIS Plan') and will be up to five years long. Whilst longer plans may be welcome by many, a section 100 internal review can only be submitted within the first



three months of receiving a new NDIS Plan. If the new plan no longer meets the needs of the participant, then they can only submit a section 48 plan review and/or request a new Independent Assessment. As oppose to a section 100 internal review request, the NDIA has greater discretion over whether to complete section 48 plan review or Independent Assessment. Therefore, the participant is limited in their review rights for a greater length of time.

Section 48 of the NDIS Act sets out the review of a participant's plan as follows:

### ***Review of participant's plan***

- (1) A participant may request that the CEO conduct a review of the participant's plan at any time.
- (2) The CEO must decide whether or not to conduct the review within 14 days after receiving the request. If the CEO does not make a decision within that period, he or she is taken to have decided not to conduct the review.  

Note 1: The period may be extended under National Disability Insurance Scheme rules made under section 204.

Note 2: Notice of a decision that the CEO makes, or is taken to have made, must be given because of subsection 100(1), and a decision the CEO is taken to have made will be automatically reviewed because of subsection 100(5).
- (3) If the CEO decides to conduct a review under subsection (1), the CEO must commence to facilitate the review within 14 days after so deciding and must complete the review as soon as reasonably practicable.
- (4) The CEO may, on the CEO's initiative, conduct a review of a participant's plan at any time.
- (5) The CEO must conduct a review of a participant's plan before the plan's review date and in the circumstances, if any, specified in the plan.
- (6) The CEO must conduct a review of a participant's plan in the circumstances (if any) prescribed by the National Disability Insurance Scheme rules.

However, if the CEO, or a delegate to the CEO, decide not to conduct the section 48 review, the decision not to conduct a plan review is reviewable under section 100 of the NDIS Act.

It is unclear from the consultation papers whether:

- A request for an Independent Assessment will be treated like a request for a section 48 plan review?
- Whether a decision not to conduct an Independent Assessment will be reviewable under section 100 of the NDIS Act?



BISA notes the absence of detail available on the proposed changes to the legislation as part of this reform at the time of writing.

## Removal of access lists

BISA identifies a potential reduction in consistency and equity of planning decisions through the proposed removal of access lists

Access lists are currently used to determine if someone meets the access requirements, and provide a level of consistency in defining the impact of disability on an individual's function

Details of the access lists are as follows:

- List A includes conditions which are likely to meet the disability requirements;
- List B includes permanent conditions for which functional capacity are variable and further assessment of functional capacity is generally required;
- List C defines programs for which clients of other schemes are generally considered to satisfy the disability requirements without further evidence;
- List D includes permanent impairments which children under 7 years old do not require further assessment;
- List E defines qualifying programs in NSW.

The purpose of these lists is to streamline access to the NDIS. By removing them, people with disability will be required to seek information and evidence, causing unnecessary expense, time delays, stress and frustration. In turn their proposed removal appears counterproductive to the expressed purpose of the proposed changes, namely to improve consistency and equity in access and planning decisions.

BISA is particularly concerned with the removal of lists "A" and "D". Considering, Independent Assessments are not being proposed for children under the age of 7 years, the removal of List D seems like an unnecessary change.

List A includes impairments including but not limited to:

- Brain injury resulting in paraplegia, quadriplegia or tetraplegia, or hemiplegia where there is a severe or total loss of strength and movement in the affected limbs of the body;
- Permanent blindness in both eyes;
- Amputation or congenital absence of two limbs; and
- Severe cerebral palsy

By removing this list, applicants with severe disability, such as Tetraplegia (quadriplegia) due to brain injury, would need to prove that they have a disability, and



that it is, or is likely to be, permanent. This is unnecessary, insulting and frustrating for the individual.

## Personalised budgets and plan flexibility

Independent Assessments will be used to develop a participant's personalised budget ('NDIS Plan'). The most radical change to planning is that budgets will be flexible, and not fixed to individual supports, except in regard to Specialist Disability Accommodation and high cost capital supports. While this provides greater choice and control, it poses a number of concerns, detailed below.

### Abuse or misuse of funding

One of BISA's primary concerns relating to plan flexibility is the potential for this to have a negative impact on the well-being of the participant. For example:

- It could be misused or abused by overzealous partners, families, potentially participants and/or service providers with a lack of control on pace or application of expenditure. BISA are aware of participants who contact their support coordinators like case managers, and often draw down on this support very quickly, leaving them vulnerable to shortfall of service provision.
- BISA has experience of partners of participants who, with their best intentions, want to push a participant to engage in extensive therapy to improve their functional capacity beyond their abilities. This results in rapid expending of resources leaving the participant without sufficiency to meet their ongoing maintenance needs.
- Where multiple service providers are engaged, multiple service agreements are made and can result in a premature exhaustion of funds when controls on expenditure are insufficient.
- There is the risk that service providers and families may misappropriate funding e.g. to purchase more generally useful equipment or assistance without consideration for other required supports.

These issues cannot be fixed by training alone. BISA supports increasing the flexibility in utilisation of support resources by participants but identifies a need for some strict safeguarding controls to be in place.



## **Determining reasonable and necessary funding**

BISA identifies significant risks to participants receiving adequacy of funding in the introduction of these changes to NDIS access and associated legislative changes required for implementation.

In the consultation papers, the NDIA has indicated that they would be seeking to implement 'funding levels' based on the information gathered from Independent Assessments. At this time, BISA have no knowledge of how such assessments will translate to funding but anticipate it is proposed to streamline funding into some tiered arrangement against the results of the Independent Assessment tools applied.

This is different from the current model, where NDIS plans are built by assessing each 'reasonable and necessary' support that a person needs and providing them with a personalised plan. Provided the requested supports meet the scheme's requirements, outlined in section 34 of the NDIS Act, participants can identify and request items or supports which are important to their independence and social participation and ensure that they can all be fully funded.

Removal of the 'reasonable and necessary' test currently in place is likely to remove a participant's ability to argue which particular supports are important to them and replace it with a flat actuarial assessment of 'what is typical for your level of disability' that will disempower participants and is likely to leave further funding shortages.

Changes to the test would also dilute extensive case law produced by the Federal Court and Administrative Appeals Tribunal, resetting the progress made in this area. This, in turn, is likely to create more inconsistency in decision-making as the NDIA and individuals fight to interpret any new legislation. A great strength of the current system, imperfect as it is, is the way it is required to consider a person's particular situation and provides a structure to articulate those requests. It should not be changed nor individualisation of funding reduced. Significantly, in this consultation process, the proposed changes to the legislation, particularly section 34 of the NDIS Act, must be outlined and available for feedback by the community prior to implementation or policy change.

## **Release of funds**

BISA recognises the protection offered to counterbalance increased flexibility by the release of funding on a monthly or quarterly basis. This system does however require sufficient flexibility to account for participants who wish to engage in therapeutically



recommended, intensive therapy, which will require additional funding in the first month or months of a plan to best achieve goals set.

## Appeal rights and complaints

### Resolving disagreements

It is widely acknowledged that the review process and complaints process are particularly difficult for unsupported participants or participants with limited informal supports.

Appropriate avenues and areas of assistance are not sufficiently communicated. As such, any further changes to this already confusing system must be clearly explained. The NDIS must inform participants of their review rights and options, how to make a complaint and who can assist them.

BISA is concerned that the outsourcing of complaints regarding Independent Assessment is shifting responsibility and accountability away from the NDIA and may result in much frustration for the complainant and inadequacy of resolution of the complaint.

### Right to review

As previously mentioned, BISA holds significant concern that the following decisions relating to Independent Assessments are not reviewable:

- A decision not to grant an exemption to an Independent Assessment
- A decision not to conduct an Independent Assessment when requested by a participant

BISA identifies that the proposed changes will limit the review rights of people with disability. For example, if an individual does not wish to complete an Independent Assessment and requests an exemption but is unsuccessful, then their access request will be withdrawn. This is not a reviewable decision and differs to the current access pathway where an applicant who did not satisfy eligibility criteria would receive an 'access not met' decision, which is reviewable.

These concerns can be alleviated by adding both decisions to the table of reviewable decisions listed under section 99 of the NDIS Act.





## Limitations in Providing Feedback

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Our feedback to the proposed changes to the NDIS Act is limited by the lack of clarity and depth provided by the consultation papers and follow up consultation phone calls with the community engagement team at the NDIA.

The NDIA need to confirm the following:

- What, if any, changes to the wording of the legislation will be made to accommodate the proposed changes? Particularly sections 21(1), 24(1) and 34
- What weight will be given to progress reports prepared by an applicant or participant's treating allied health professional/s?
- When, if at all, such progress reports it will be reviewed? And by who?
- What will constitute a diagnosis in order to qualify the first eligibility criteria? (e.g. will a letter from a GP stating that an applicant has ASD be sufficient, or will an applicant require a formal report?)
- Will the results of the second trial be published or available for discussion, prior to the proposed rollout expected in mid 2021?
- How do the NDIA plan to transform standardised test results into individualised plans?
- What type of evidence will need to be provided in lieu of an Independent Assessment?
- Who will fund this supplementary evidence when an exemption from an Independent Assessment is granted?
- What are the guidelines for granting an exemption based on risk of harm or safety?
- How will the NDIA guarantee consistency in decision making regarding who will and will not be qualify for an exemption?
- Will a request for an Independent Assessment will be treated like a request for a section 48 plan review?
- Will a decision not to conduct an Independent Assessment be reviewable under section 100 of the NDIS Act?

