

**Proposed Changes to the NDIS Act : Independent  
assessments and planning and young children**

**Spinal Cord Injuries Australia Policy  
and Advocacy Team Submission**

**February 2021**

## National Disability Insurance Agency

Via upload to <https://www.ndis.gov.au/community/have-your-say>

### Introduction

Spinal Cord Injuries Australia (SCIA) welcomes the opportunity to offer a submission to the National Disability Agency (NDIA) on proposed reforms to access and eligibility policy, planning policy and support for young children in the National Disability Insurance Scheme (NDIS) Act. SCIA strongly supports the goals of the *NDIS Act*<sup>1</sup> and the continual improvement of the NDIS process for all participants and applicants. The NDIS represents a major opportunity for eligible people with disability to maintain choice and control in their lives and truly become equal members of Australian society.

This submission reflects many of the central issues and SCIA's recommendations related to proposed reforms of access and eligibility policy and planning policy. Most of SCIA's concerns relates to the present uncertainties and lack of participation of people with disability in the co-design of the proposed reforms

### About Spinal Cord Injuries Australia

SCIA is a for-purpose organisation working for people living with spinal cord injury (SCI) and other physical disabilities. SCIA was founded by people with SCI over fifty years ago; people with disability make up over 25% of our staff, and the majority of our Board live with SCI. SCIA is a national, member-based organisation that serves 2,500 members made up of people living with disability, their family, carers, researchers, and other professionals in the sector.

SCIA's Policy and Advocacy Team provides individual and systemic advocacy, and supports self-advocacy, with the aim of ensuring that people living with SCI and other disabilities do not face barriers in exercising their independence and realising their human rights. SCIA's individual advocates have extensive experience assisting people with a range of disabilities, including providing support for NDIS appeals and internal reviews in NSW. The team strives to achieve inclusivity and change for people with disability, their family members or carers.

SCIA also provides several NDIS Support Services including support coordination and plan management to people with disability in NSW and in Western Australia.

### Submission consultation

The recommendations collated in this submission are founded on feedback and reflections from SCIA members with personal experience with the NDIS, and SCIA plan managers and support coordinators who directly work with NDIS applicants and participants in NSW. Additionally, SCIA co-hosted a public roundtable with the Physical Disability Council of NSW and Muscular Dystrophy on the introduction of independent assessments with approximately 50 attendees.

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<sup>1</sup> *National Disability Insurance Scheme Act 2013* (Cth).

## Recommendations

1. *The national rollout of IAs in their current format should be postponed beyond July 2021 and only occur after further consultation with the disability sector.*
2. *Information about the role of IAs should be published in all accessible formats and disseminated to people with disability, their support networks and the wider disability sector and public information sessions should be held.*
3. *Access lists should remain in place to continue to provide a preliminary guide to health professionals.*
4. *The IA toolkit should focus on understanding a person holistically and consider their current participation in activities and future goals.*
5. *IA participants should be matched with assessors who have specific expertise in their disability/ies or have sufficient knowledge of their disability/ies.*
6. *The matching process should account for IA participants' circumstances, considering whether a person is from an ATSI and/or CALD background, gender and age, among others.*
7. *IA assessors should undergo rigorous training for accreditation and re-accreditation, including adopting a trauma-informed approach.*
8. *The list of IA exemptions should be open and include circumstances, among others, involving risk of distress to the IA participant and in which a person is yet to be discharged from hospital or a rehabilitation centre. Additionally, IAs should be suspended if the process is causing the IA participant distress.*
9. *Multiple safeguards should be implemented before the national rollout of IAs to ensure they protect IA participants interests and achieve their goals.*
10. *IA assessors should receive information about an IA participant about their circumstances prior to an IA and IA participants should understand clearly the role of an IA and the choices they have in the IA process.*
11. *Implementation of proposed reforms to planning policy should be postponed beyond July 2021 and only occur after further consultation with the disability sector.*
12. *The NDIA should establish multiple monitoring mechanisms to assess appropriateness of NDIA delegates' decisions and provide guidelines on what factors delegates account for in a draft plan, and budget.*
13. *Participants should be offered the opportunity to contact NDIA representatives and receive reliable and accurate information to best understand decision-makers' reasons.*

14. *The NDIA should clarify how participants and their support teams should prepare for planning meetings.*
15. *Participants should have the opportunity to discuss the level of funding during the planning meeting.*
16. *The NDIA should regularly produce and publish new information relating to available supports, services and technologies that may suit participants.*
17. *Include support coordination and Supports for Assistance with Daily Life in the list of fixed supports, if and where there is a need.*
18. *The NDIA should guarantee that transport funding, as a direct fortnightly payment, will be maintained and also retain transport funding in a participant's plan for those not receiving a direct payment, in the proposed reforms and produce updated guidelines that allow regular release of funds for transport supports on a needs basis.*
19. *Check-ins should be conducted according to a participant's preference and be managed by the same NDIA representative.*
20. *The NDIA should clarify its policy on the rollover of funds and adopt a flexible approach including allowing rollover beyond the proposed maximum 12 months.*
21. *The NDIA should provide participants with tailored information packs and offer public information and training sessions to assist in any transition to the proposed model.*
22. *Children aged over 7 should have consistent, long-term, flexible support to meet their changing needs.*
23. *The right to appeal the results of an IA should be integrated into the legislative framework to protect the interests of IA participants.*

## 1. The development and introduction of independent assessments in the NDIS

Before this submission deals with the substantive material raised in the consultation papers related to access and planning, SCIA would like to highlight its concern with the development process for the introduction of independent assessments (IAs).

Following the recommendations of the Productivity Commission,<sup>2</sup> affirmed in the recommendations from the Tune Review,<sup>3</sup> and following announcements from the Minister for the NDIS,<sup>4</sup> it has been anticipated that some form of assessment of a person's functional capacity would be integrated into the NDIS process. However, the journey leading to the introduction of IAs has unfortunately lacked genuine, ongoing consultation and co-design with the disability sector, current and prospective NDIS participants and applicants, and their support networks.

The introduction of IAs forms a major component of the "most substantial package of reforms to the NDIS since its establishment".<sup>5</sup> As such, it was to be expected that the people whose lives will be most impacted by these proposed reforms should be at the centre of consultation and co-design of IAs. While reports claim that the design of IAs was informed by input from a reference group from the NDIS Independent Advisory Council (IAC), other disability organisations and academics,<sup>6</sup> it is very unclear how extensive this consultation was and how much input was sought from the target population for IAs – prospective and current NDIS participants and applicants and their family members. The current consultation process is ad hoc and does not allow for genuine engagement and reflection on the implementation of IAs before their scheduled introduction in mid-2021.

Further, as the following sections illustrate, the recommendations and evidence underpinning the introduction of IAs do not justify a national rollout to all prospective NDIS applicants and the 412,543 current NDIS participants of IAs in their current form.<sup>7</sup>

### 1.1. Tune Review recommendations on independent assessments

Recommendation 7 from the Tune Review supported the introduction of a new model of functional capacity assessments.<sup>8</sup> However, while the Australian Government's response supports this recommendation,<sup>9</sup> the specific comments and sub-recommendations made in the Tune Review have either been ignored or not genuinely incorporated into the proposed reforms. For example, the report emphasised that the program would "**require extensive consultation with participants, the disability sector, service providers and the NDIA workforce**".<sup>10</sup> As noted above, the ad hoc and accelerated nature of the present consultation could not be characterised as extensive.

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<sup>2</sup> Productivity Commission, *Disability Care and Support*, Report No. 54, 2011, p. 327.

<sup>3</sup> David Tune, *Review of the National Disability Insurance Scheme Act 2013: Removing Red Tape and Implementing the NDIS Participant Service Guarantee*, December 2019, p. 67.

<sup>4</sup> Minister for the National Disability Insurance Scheme, Hon Stuart Robert, 'The NDIS Plan', Speech, 14 November 2019; Minister for the NDIS, 'Landmark reforms to deliver on the promise of Australia's NDIS', NDIA, 28 August 2020, <https://www.ndis.gov.au/news/5207-landmark-reforms-deliver-promise-australias-ndis>.

<sup>5</sup> Ibid.

<sup>6</sup> See for example, National Disability Insurance Agency, 'Independent Assessments: Selection of Assessment Tools', September 2020, p. 15.

<sup>7</sup> As of 30 September 2020.

<sup>8</sup> *Review of the National Disability Insurance Scheme Act 2013*, p. 67.

<sup>9</sup> Australian Government, 'Australian Government response to the 2019 Review of the *National Disability Insurance Scheme Act 2013* report', August 2020, p. 7.

<sup>10</sup> *Review of the National Disability Insurance Scheme Act 2013*, p. 66.

As the report notes, the success of IAs in the NDIS will largely depend on **“the willingness of prospective participants and participants to work with NDIA-approved functional assessors”**.<sup>11</sup> However, following consultation with SCIA members who are current NDIS participants, many felt wary of the process and engaging with an independent assessor. Below are some of their responses:

*“I won’t talk to anyone unless I know them and I won’t talk about my life so openly with complete strangers.”*  
[NDIS participant and SCIA member]

*“It’s important not to be dictated to about how you get [an IA]...Once a person is on the NDIS, they should be able to choose their therapists...it stands to reason that those people are the ones that do reports on you...it makes no sense to go to see some independent person who meets you for four hours.”*  
[NDIS participant and SCIA member]

The evidence from both pilot projects will not reflect willingness to engage with assessors as participation in the projects is voluntary, and more recently incentives have been introduced.<sup>12</sup> This will only be accurately tested during the rollout.

The report also identifies several ‘key protections’ that should be adhered to. The first of these protections reflects the importance of participants or applicants’ choice: **“the right to choose which NDIA-approved provider...undertakes the functional capacity assessment”**.<sup>13</sup> However, the consultation paper limit this protection as **“where possible, applicants will be able to give their preferences about which organisation they would like to complete their independent assessment”**.<sup>14</sup> Choice and control is a fundamental legislative object of the NDIS and this clause limits this from the outset of a person’s interaction with the scheme.<sup>15</sup>

The second key protection relates to **“the right to challenge the results of the functional capacity assessment, including the ability to undertake a second assessment”**.<sup>16</sup> The consultation paper outlines that **“applicants can only seek a second assessment where the assessment was not consistent with the IA framework, or if the applicant has had a significant change to their functional capacity or circumstances”**.<sup>17</sup> While standardised tools will be used during IAs, there may be a degree of inconsistency, due to a variety of reasons including:

- Varied professional backgrounds of assessors,<sup>18</sup>
- Choice of activity undertaken during the IA,<sup>19</sup>
- Whether an appropriate support person is present,

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<sup>11</sup> Ibid.

<sup>12</sup> National Disability Insurance Agency, ‘Latest News: Improvements to the second independent assessment pilot’, 8 February 2021, <https://www.ndis.gov.au/news/5967-improvements-second-independent-assessment-pilot>

<sup>13</sup> *Review of the National Disability Insurance Scheme Act 2013*, p. 66.

<sup>14</sup> National Disability Insurance Agency, ‘Consultation paper: Access and Eligibility Policy with independent assessments’, November 2020, p. 18.

<sup>15</sup> *National Disability Insurance Scheme Act 2013* (Cth) s 3(1)(e).

<sup>16</sup> *Review of the National Disability Insurance Scheme Act 2013*, p. 66.

<sup>17</sup> National Disability Insurance Agency, ‘Consultation paper: Access and Eligibility Policy with independent assessments’, November 2020, p. 23.

<sup>18</sup> See Department of Social Services, ‘Improving the National Disability Insurance Scheme: Better Participant Experience and Improved Access and Planning’, Australian Government, Information Paper, 24 November 2020, p. 9.

<sup>19</sup> National Disability Insurance Agency, ‘How independent assessments will work?’, 3 December 2020, <https://www.ndis.gov.au/participants/independent-assessments/independent-assessment-q-and/how-independent-assessments-will-work>.

- The location or medium of the IA (virtual meeting, in person, at the assessor’s office, at home, at a public place),
- Whether the assessor can communicate directly with the applicant/participant or if there is an interpreter present,
- Whether the assessor has knowledge of particular disability types, and
- Whether the assessor comes from a similar cultural background.

When a person’s choice of assessor has already been limited, it is even more appropriate for a person to seek a second IA if there are sound justifications, beyond a change in circumstances or a failure to adhere to the IA Framework (which may be unknown to the applicant/participant).<sup>20</sup>

This also relates to the report’s recommendation that **“the NDIA should not implement a closed or deliberately limited panel of providers to undertake functional capacity assessments”**. If a person’s choice of assessor is going to be guaranteed, the NDIA must cast a wide net to ensure that there are numerous providers and assessors available on the panel *prior to* the program’s rollout. Information related to each assessor and assessor organisation should be transparent and made available to applicants/participants before they indicate their preference for which assessor or organisation suits them. Statistics recording the number of assessors and assessor organisations, their professional backgrounds and other indicators (including whether they come from a culturally and linguistically diverse background or if they identify as Aboriginal and Torres Strait Islander) should be publicly available and included in the NDIA’s Quarterly Reports. Further, the NDIA should provide specific details regarding the initial and ongoing training programs assessors undergo before they conduct IAs.

### **1.2. Productivity Commission recommendations on assessments and developing a ‘toolbox’<sup>21</sup>**

The introduction of IAs is also supposed to align with the recommendations of the original report published by the Productivity Commission (PC) in 2011. However, based on the information contained in DSS’s Information Paper and the consultation paper there seem to be discrepancies with the specific recommendations from the PC. First, it is a little unclear what degree of information will be provided to assessors prior to conducting an IA on a participant or applicant apart from their contact details, but the PC suggested that assessors should receive **“information about a person’s relevant medical conditions and specialist assessments would be made available to [them]”**. The report also focuses on consistent monitoring of the assessment process, ensuring that it falls within the scope of the World Health Organisation’s International Classification of Functioning, Disability and Health (ICF). It also reiterates the importance of regular monitoring and accreditation of assessors. These specific issues will be later discussed in this submission.

### **1.3. Reliance on findings from the pilot projects**

The methodological gaps of the first pilot project and the lack of reliability of its findings provide little empirical support for delivery of IAs in their current form. Further, results from the second pilot project has yet to publish significant results that further support implementation of IAs on a national level. The following section will briefly identify the gaps that the pilot projects have not addressed.

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<sup>20</sup> This will be further discussed in the ‘Other comments’ section of the submission.

<sup>21</sup> Productivity Commission, *Disability Care and Support*, Report No. 54, 2011, p. 21.

### 1.3.1. First pilot project (November 2018 to April 2019) <sup>22</sup>

The data from the first pilot project was highly limited in its empirical reliability. Firstly, there is a major issue with underrepresentation and applicability to the national NDIS population. IAs in the first pilot project were only conducted on participants and applicants with ASD, ID and PSD.<sup>23</sup> While this group represented 63% of all NDIS participants, it is still difficult to extrapolate the results from this pilot to those with spinal and neuro conditions, and other physical disabilities. Further, the data only related to participants and applicants living in metropolitan NSW.<sup>24</sup> IAs will have a great effect on those living in rural and remote areas and it is vital to evaluate their experience of IAs to determine whether the available pool of assessors is appropriate for them. Additionally, 71% of participants and applicants were male, only 1% were from an Aboriginal and Torres Strait Islander background and 7% identified as from a culturally and linguistically diverse background. Additionally, the data was skewed by age as 64% of participants and applicants were aged 14 years and under.

Further, while the participation rate of 28% (145) of the 513 participants and applicants may be 'statistically valid',<sup>25</sup> it seems inadequate. Further, of these 145 survey respondents only 35 were participants (7%). The rest were participant nominees (e.g. parents, carers and others). It should be noted that participants were all aged 7 and above.

The timing of completion of the survey is also important to fairly understand a participant or applicant's opinion of the IA and its role in their NDIS journey.<sup>26</sup> The first pilot revealed that of the 145 survey responses, 126 were completed directly after the IA and only 19 were completed after the planning meeting (13%).<sup>27</sup> This difference indicates that more data needs to be collected at the stage after the planning meeting to determine exactly what impact IAs may have on the discussion and how a participant's plan may be impacted by its results. As such, the satisfaction rates published in the report may not be truly representative and consider all variables affecting participant's views.

As a final comment on the first pilot project, there was a major discrepancy between the report, published in September 2020,<sup>28</sup> and a response given during Senate Estimates in October 2020. The report stated that **"in the first pilot, surveys were administered by telephone or face-to-face"**, however in response to a question on notice, the NDIA replied that **"all participant and participant representative surveys were conducted online"**. These contradictory responses are concerning as it reflects either a lack of accuracy or transparency in communications from the NDIA.

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<sup>22</sup> Data and findings quoted in this sub-section from National Disability Insurance Agency, 'Independent Assessments: Pilot learnings and ongoing evaluation plan', September 2020.

<sup>23</sup> Autism Spectrum Disorder, Intellectual Disability and Psychosocial Disability.

<sup>24</sup> Note that NSW participants only represent 31.5% of all NDIS participants, as of 30 September 2020.

<sup>25</sup> Commonwealth, *Senate Estimates 2020-2021: Community Affairs*, 29 October 2020, Answer to Question on Notice NDIS SQ20-000299 (NDIA).

<sup>26</sup> Noting that obviously in the pilot studies of IAs it is not expected that IAs will impact access or planning decisions.

<sup>27</sup> Commonwealth, *Senate Estimates 2020-2021: Community Affairs*, 29 October 2020, Answer to Question on Notice NDIS SQ20-000303 (NDIA).

<sup>28</sup> National Disability Insurance Agency, 'Independent Assessments: Pilot learnings and ongoing evaluation plan', September 2020.



### 1.3.2. Second pilot project (Late 2019, October 2020 to present) <sup>29</sup>

The early findings from the second pilot project are also limited in light of the postponement resulting from the COVID-pandemic. The published report on both pilots' findings noted that "readers should interpret these findings cautiously when generalising to IAs more broadly".<sup>30</sup> As such, the findings published in the report will be considered in light of further results released following the completion of the second pilot.

It is as yet unknown when the findings from the second pilot project will be released, despite assurances that the pilot would be finished by early 2021.<sup>31</sup> While it was hoped that a significant portion of 4000 invited participants and applicants who had undertaken IAs would complete the pilot survey, as of 11 November 2020, of the 4896 pilot IA invitees, only 215 had accepted, 185 had declined and 4,496 had not yet responded. During questioning in Senate Estimates, it seems that a statistically significant result requires responses from at least a further 715 respondents.<sup>32</sup> Regardless, even if all 4,496 were to respond to the survey, this would represent less than 1% of all NDIS participants, let alone applicants. It is hoped that this figure of 715 is reached in due course and the pilot's results (including demographic breakdowns) are published in the near future. It is difficult to determine exactly what impact the pilot's findings will have on the improvement of IAs ahead of their rollout.

Generally, it is unclear exactly what purpose this pilot serves. During Senate Estimates in October 2020, the NDIA answered that "**the findings from the second IA pilot evaluation will refine the national implementation of IAs and provide learnings to improve the model for national rollout**".<sup>33</sup> During a public consultation, NDIA representatives indicated that the pilot would be completed in July 2021. If the purpose of the pilot is to "inform how [the NDIA] implement independent assessments later this year",<sup>34</sup> when the time set for the conclusion of the pilot is simultaneously the start of national rollout it seems impossible that there is the possibility for meaningfully making improvements to implementation based on the pilot's learnings.

Additionally, while ongoing monitoring has been promised throughout the rollout of IAs, it is still unclear what format and extent this will take.<sup>35</sup> Further, remembering that the Tune Review emphasised the need for extensive consultation with the disability sector, it is hoped that consultation remains ongoing following the findings from this consultation period and this is finalised shortly.

In light of the above issues, particularly the existing accelerated timeline, the national rollout of IAs should be postponed to allow for further open-ended consultation with existing participants and

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<sup>29</sup> This submission has relied on information provided on National Disability Insurance Agency, 'How independent assessments will work? – The second independent assessment pilot', 11 January 2021, <https://www.ndis.gov.au/participants/independent-assessments/second-independent-assessment-pilot/how-does-independent-assessment-pilot-work>.

<sup>30</sup> National Disability Insurance Agency, 'Independent Assessments: Pilot learnings and ongoing evaluation plan', September 2020, p. 16.

<sup>31</sup> Commonwealth, *Senate Estimates 2020-2021: Community Affairs*, 29 October 2020, Answer to Question on Notice NDIS SQ20-000340 (NDIA).

<sup>32</sup> See Commonwealth, *Senate Estimates 2020-2021: Community Affairs*, 29 October 2020, p. 58.

<sup>33</sup> Commonwealth, *Senate Estimates 2020-2021: Community Affairs*, 29 October 2020, Answer to Question on Notice NDIS SQ20-000345 (NDIA).

<sup>34</sup> National Disability Insurance Agency, 'What happens with the information from the pilot?', National Disability Insurance Scheme, 21 January 2021, <https://www.ndis.gov.au/participants/independent-assessments/second-independent-assessment-pilot/what-happens-information-pilot>.

<sup>35</sup> Commonwealth, *Senate Estimates 2020-2021: Community Affairs*, 29 October 2020, Answer to Question on Notice NDIS SQ20-000340 (NDIA).

prospective applicants. Additionally, the results from the second pilot project need to be published and thoroughly analysed before the rollout itself.

**Recommendation 1:** *The national rollout of IAs in their current format should be postponed beyond July 2021 and only occur after further consultation with the disability sector.*

## 2. Independent assessments

This section will address the proposed introduction of independent assessments and their impact on both applicants to the NDIS and existing participants.

For many people with disability and their support networks, in the past accessing the NDIS has presented many challenges. These challenges have included managing confusing administrative paperwork, obtaining expensive medical reports and assessments from multiple specialists and challenging negative access decisions, which in many cases have been successful when reviewed. Often people have struggled to ‘fit’ within the boxes required by the NDIS when they have multiple disabilities or are classified as ‘complex’. This has often caused distress, anxiety and frustration and many have called for the simplification of the process. It was not surprising then that the Tune Review made several recommendations relating to reform of the access process and future impact on during the planning process:

Standardised functional capacity assessments would improve the quality and consistency of NDIA decisions. If undertaken at the point of access it would also improve the participant experience by mitigating the need for the participant to provide further information about their functional capacity later in their NDIS journey. The administrative and financial burden felt by both prospective participants and participants to provide evidence to the NDIA should be minimised.<sup>36</sup>

Keeping these recommendations in mind as well as information from DSS,<sup>37</sup> the following comments and feedback will be based on an understanding that IAs aim to:

- A. Increase consistency and transparency of access and planning decisions;
- B. Provide accurate, valid and reliable information about a person’s disability and its impact on their entire life;
- C. Increase fairness and equity to all NDIS applicants and participants;
- D. Allow people “more and better opportunities to take part in everyday life and pursue their goals”,<sup>38</sup> and
- E. Minimise financial and administrative burdens for applicants and participants.

### 2.1. Learning about the NDIS

It is crucial for new applicants to understand the role of IAs in the NDIS as they will be a central aspect affecting their eligibility and access to NDIS-funded supports. The most significant information an applicant must have before undergoing an IA is the degree of control they have in choosing the location, time(s), day(s), assessor or assessor organisation (within the limits prescribed by the NDIA), activity undertaken for assessment, and support person(s) attending. While it is important that applicants should be aware of the practical aspects of the IA process, there are several features of IAs that applicants also need to know. These include:

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<sup>36</sup> Tune Review, p. 59.

<sup>37</sup> DSS, ‘Improving the National Disability Insurance Scheme: Better Participant Experience and Improved Access and Planning’, p. 8.

<sup>38</sup> Ibid.

- The purpose of IAs: IAs will not be based on a person’s diagnosis. IAs are an assessment of the crossover between a person’s functional capacity and environmental factors;
- Evidence of permanent disability: People still require evidence from their treating professionals to assess their eligibility;
- The role of IAs: Applicants must understand that NDIA delegates’ decisions will be based on the results of IAs;
- Re-assessment: People must be made aware that according to current guidelines a second IA will only be conducted if there is a change in their circumstances or if the assessor incorrectly conducted the IA; and
- Impact on NDIS plan: Successful applicants should be made aware of how an IA will affect a determination of their draft budget and plan.

This information should be written in plain English and shared with applicants/participants through existing networks and platforms including: the NDIS website, disability service providers, health practitioners, disability advocates, liaison officers (in hospital and detention settings) among others. This information should be made universally accessible through translation into multiple languages and different levels of Easy Read English. Multiple case studies could also illustrate the impact of the IA process on different people with different primary disabilities. Additionally, public information sessions should be provided to applicants, their families and carers.

***Recommendation 2:*** Information about the role of IAs should be published in all accessible formats and disseminated to people with disability, their support networks and the wider disability sector and public information sessions should be held.

## 2.2. Accessing the NDIS

In removing the access lists, the NDIA should carefully consider how the ‘Information for GPs and health professionals’ section and its associated ‘Eligibility and medical conditions FAQ’ page<sup>39</sup> of the NDIS website should be updated. This issue raises the following questions:

- At present, the FAQ page refers to the Access Lists, however following the introduction of IAs will this list still be provided?
- If there is no reference to the Access Lists or specific diagnoses, will GPs and health professionals be provided with alternative guidance? If so, in what form?

With the removal of access lists, there is concern about how this may affect GPs and health professionals’ understanding of ‘permanent disability’ as defined under s 24 of the *NDIS Act*. There is a risk that GPs and other health professionals’ interpretation of permanence may be subjective and individual to the specific practitioner. This is an area that generally requires greater clarity and consistency between health professionals, government, the NDIA and other government agencies. It would be helpful to provide such information and guidance to Local Health Districts and Primary Health Networks to disseminate to local health practitioners.

Health professionals understanding of the distinction between disability and chronic, acute or palliative health conditions may be further complicated as the current guidance is currently very unclear. The classification as understood in the NDIS seems to conflict with the principle of universality, which underlies the World Health Organisation’s International Classification of

<sup>39</sup> National Disability Insurance Agency, ‘Eligibility and medical conditions FAQ’, National Disability Insurance Scheme, 14 October 2020, <https://www.ndis.gov.au/applying-access-ndis/how-apply/information-gps-and-health-professionals/eligibility-and-medical-conditions-faq>.

Functioning and Disability (ICF).<sup>40</sup> This is significant as all IA tools are supposed to align with the Activities and Participation provisions of the ICF, as recommended in the *NDIS Act* and 2011 Productivity Commission Report.<sup>41</sup>

Universality recognises that diagnosing health conditions and assessing functional capacity should not be used as tools to label people with disability as a separate group. At present, applicants to the scheme still require a diagnosis of a permanent disability to fulfil initial eligibility criteria. This already seems to imply that they are being labelled as a separate group. With the introduction of IAs, this may be further discriminatory, as the current toolkit focuses on categorically determining a person's functionality, in other words, by concentrating simply on what a person can and cannot do. Without a specific emphasis on understanding a person's goals and participation in social, economic and cultural activities in an IA setting, it may become easier to disenfranchise people with disability.

An IA should attempt to understand a person holistically, accounting for the diagnosis of their chronic health consideration, its impact on a person's day-to-day functionality, social determinants<sup>42</sup> and their aspirations. It is only by gaining this holistic view of a person, their health and their environment that the NDIA may compare people in similar circumstances when making access and planning decisions. This is a particularly significant issue as the results of a person's IA may inform not only an access decision, but also future planning decisions.

**Recommendation 3:** *Access lists should remain in place to continue to provide a preliminary guide to health professionals.*

**Recommendation 4:** *The IA toolkit should focus on understanding a person holistically and consider their current participation in activities and future goals.*

### 2.3. Undertaking an independent assessment

It is clear from our public consultations that the success of IAs rests on respecting the needs and wishes of IA participants and their support persons. The majority of those who have been consulted are highly worried, uncertain and sceptical about the introduction of independent assessments as it poses another 'hurdle' to accessing supports. For many existing participants there is a feeling that they have undergone so many challenges to establish a plan that they are satisfied with, that it is unnecessary to introduce a new tool. If the NDIS seeks to protect a person's choice and control, this must also be reflected in the IA process too.

Protecting applicants and participants by ensuring that IAs are conducted appropriately, reliably and safely is crucial to avoid disengagement and dissatisfaction with the process, which will be critical to its success, as noted in the Tune Review.<sup>43</sup> Often this will involve allowing as much flexibility to the process as possible, with particular focus on the matching process between the IA participant and assessor. The success of this process will be affected by the size of the pool of assessors and the NDIA should make every attempt to allow the preferences of the IA participant to be followed. This section

<sup>40</sup> World Health Organisation, *Towards a Common Language for Functioning, Disability and Health*, WHO/EIP/GPE/CAS/01.3, Geneva, 2002, p. 14.

<sup>41</sup> National Disability Insurance Agency, 'Independent Assessment Framework', August 2020, p. 14.

<sup>42</sup> According to WHO, these include: income and social protection; education; unemployment and job insecurity; working life conditions; food insecurity; housing, basic amenities and the environment; early childhood development; social inclusion and non-discrimination; structural conflict; access to affordable health services of decent quality. WHO, 'Social determinants of health', WHO, 2021, [https://www.who.int/health-topics/social-determinants-of-health#tab=tab\\_2](https://www.who.int/health-topics/social-determinants-of-health#tab=tab_2).

<sup>43</sup> Tune Review, p. 67.

will analyse specific aspects of the IA that will contribute to a person's sense of its benefit to their NDIS journey.

### 2.3.1. Assessors

#### 2.3.1.1. Expertise

It is understood that the list of assessors will include a variety of allied health professionals, however it must be recognised that the number of disabilities experienced by NDIS applicants and participants in different circumstances are numerous. As such, assessors need more than simply their professional qualification, they need accurate knowledge about a person's disability/ies. Many SCIA members and others with disability have repeated that they have been frustrated by interactions with people who do not understand the basics of the possible impacts of their disability. For example, one practitioner asked what date a person with spina bifida acquired their disability. As such, each assessor should have at the very least a basic understanding of the disability/ies or health condition/s that impacts the person. This is particularly relevant when conducting the initial informal conversation with an IA participant as they may fail to ask questions that will be specifically relevant to understanding the participant's life. Alternatively, many people can become disengaged if they are repeatedly answer questions that are irrelevant for their functionality or circumstances. This requires a degree of preparation by the assessor which will be discussed later in Section 2.6.2. Also, when discussing which activity to complete during the IA, an assessor must be sensitive to the appropriateness of the activity to the IA participant and ensure that it respects their dignity. For example, an assessor should allow the IA participant the choice of activity and only make suggestions if they have a sufficient level of knowledge before that will reflect that person's level of functionality.

Further, some people prioritise the need to have an assessor who has been working in their field for at least a couple of years with sufficient experience with patients and clients, which could be included as a factor in the NDIA's accreditation process. Ideally, many noted that they would prefer an assessor with lived experience of disability, either as a person with disability or as a carer or support worker.

As will be discussed, trust in an assessor's expertise and knowledge of their disability is very important, particularly when an IA participant is denied specific choice in assessor. As one person highlighted: **"Clients have preference with virtually every other aspect of services, why should that not be the same when conducting an individual assessment, which is pivotal in not only determining whether they get access to the scheme but also the value of their plan?"**

#### 2.3.1.2. Personal traits

There are several traits that an assessor should possess to effectively engage and understand an IA participant's experiences. Every assessor should have a high degree of empathy with patients and IA participants. SCIA has heard of numerous incidents in which service providers and treating health practitioners have failed to appreciate a person's needs and unique voice. This is closely tied to an ability to actively listen to an IA participant as they describe their situation. Assessors should not enter an IA with preconceived notions of people with disability or the person's specific diagnosis and assert what they assume is that person's experiences. As already mentioned, trust will be a cornerstone to the IA process and IA participants and their support persons need to be assured that assessors have their best interests at heart and will objectively assess their situation without bias or ulterior motives. If an IA participant or support person feels that they cannot trust an assessor, there may be a risk that people 'present' themselves in a deliberate manner that does not reflect their actual circumstances.

### 2.3.1.3. Other considerations

There are several other factors that should be considered when matching an assessor to an IA participant as the degree of comfort between them may materially affect the responses given. These factors include:

- Whether a person comes from an Aboriginal or Torres Strait Islander background (ATSI);
- Gender of IA participant or assessor;<sup>44</sup>
- Whether a person comes from a culturally and linguistically diverse background (CALD);
- Age of assessor;<sup>45</sup> and
- Age of IA participant.<sup>46</sup>

Children are particularly vulnerable in an IA setting and will be at greater risk of distress when being 'assessed' by a stranger. As such, it is preferable that parents and guardians have ultimate choice of assessor as this will increase the child's ability to trust them. There are several other considerations that should be evaluated before conducting an IA and this list should remain open to further suggestions following consultation with people with disability.

**Recommendation 5:** *IA participants should be match with assessors who have specific expertise in their disability/ies or have sufficient knowledge of their disability/ies.*

**Recommendation 6:** *The matching process should account for IA participants' circumstances, considering whether a person is from an ATSI and/or CALD background, gender and age, among others.*

### 2.3.1.4. Training

Assessors should initially and in an ongoing manner undertake mandatory training programs. These should include, but not be limited to: cultural awareness training, disability awareness training, gender awareness training, adopting a trauma-informed approach, mental health training, de-triggering, intersectionality, personal bias training and conflict resolution. These training programs should be an integral aspect of the accreditation and re-accreditation process for assessors.

**Recommendation 7:** *IA assessors should undergo rigorous training for accreditation and re-accreditation, including adopting a trauma-informed approach.*

### 2.3.2. Accessibility

A priority for assessors should be universal accessibility. For people with physical disability, assessors must ensure that the location of the IA is disability accessible. In terms of communication, ideally an assessor should be able to communicate in an IA participant's preferred language. Admittedly, in the early stages of the rollout of IAs this may not be possible, but this should be a goal the NDIA's Assessor Panel strives for. Additionally, assessors must be aware before an IA of an IA participant's communications accessibility needs, such as required assistive technology or needs for documentation in Easy Read English, or if they have communications impairments. In other words, assessors should not rely on IA participants or their support persons to volunteer this information beforehand, they

<sup>44</sup> While gender has already been identified as a guaranteed choice for IA participants, it should be noted that this includes male, female and other gender identities.

<sup>45</sup> Many NDIS participants aged over 50 with spinal cord injury have admitted that they would feel uncomfortable discussing continence issues with an assessor under 30 years of age.

<sup>46</sup> Children aged 8 and above should have the option to have their entire support team present during assessments and have their parent or guardian present at all times.

should proactively establish accessibility needs prior to the IA and implement appropriate adjustments.

## 2.4. Exemptions

SCIA supports the current exemptions listed in the consultation paper relating to risk and safety or if an assessment is inaccessible or invalid. However, other circumstances should be included on this list and the two current exemptions further clarified. This section outlines other circumstances in which an applicant or participant should be considered exempt from undertaking an IA:

### 2.4.1. Risk, safety and trauma

Many people with disability have been affected by trauma for various reasons and undertaking an IA can be confrontational and triggering. Ultimately, an assessor will be a stranger to an IA participant and this can cause reluctance, fear and disengagement for many and when the risk of harm is foreseeable, they should be made exempt. As one SCIA member outlined: “[I] **won’t talk to anyone unless I know them and I won’t talk about my life so openly with complete strangers**”. Also, it is inappropriate to categorise psychosocial conditions or trauma as severe before considering whether a person is exempt, a delegate should carefully consider the circumstance of any IA participant, and particularly those in which any form of trauma or psychosocial condition has been identified.

For example, applicants or participants who have been, or are affected by domestic violence, an IA poses a great risk to their sense of wellbeing, particularly if an assessor is entering their natural setting. Additionally, if a support person is suspected to be a perpetrator it is completely unacceptable for an applicant or participant to undertake an IA. Other such circumstances include where a person or their support persons experience drug and alcohol problems, homelessness or any others who are in vulnerable settings. Even in situations where an assessor has been trained in adopting a trauma-informed approach, it may still be inappropriate for a person to undertake an IA.

For people with ASD, the experience of undertaking an IA may be particularly harmful. Often, for those with a diagnosis they have previously undergone numerous tests and delegates should closely examine how a person has reacted in the past to such tests and whether they are likely to experience assessment fatigue or distress in a longwinded process.

### 2.4.2. Inaccessibility

Inaccessibility should be an immediate exemption. This may arise in numerous circumstances. For example, when an applicant or participant wishes to undergo an IA in a specific form, i.e. face-to-face, but there is no assessor physically available in that area to conduct the IA face-to-face, a person should be forced to undertake an IA via video chat or on the phone. This is particularly relevant for those living in rural and remote areas. Without this guarantee, there would be a differential treatment of those living in these areas and serve as discrimination against a cohort that has already been identified as a priority group. Additionally, if it is impossible to arrange an in-person interpreter for a face-to-face IA session, but this is a preference for the applicant or participant (rather than a translator over the phone) an exemption should be allowed. Further, if technology poses a barrier to a person undertaking an IA, perhaps due to computer illiteracy, and their only option is a face-to-face assessment, but this is impossible due to unavailability of an assessor, they should be exempt.

### 2.4.3. Invalidity

Accuracy and validity of results is a major aspect of achieving the goals of the introduction of IAs. For many people, as the IA relies largely on self-reporting there may be several issues that arise that would produce invalid results. For example, one participant noted that her family member’s ability to report

on their functionality is severely impaired due to their acquired brain injury. Alternatively, another person noted that their support person was in denial about their spinal cord injury and would likely overestimate their functionality during an IA. These circumstances are inevitably going to produce invalid IA results. Additionally, when a support person cannot be identified or is physically unavailable to attend an IA, which is particularly relevant in current circumstances with COVID restrictions, an exemption should be made.

In cases where there is a concern about invalidity, adjustments could be made, if requested by an IA participant. For example, many people are concerned with the volume of questions asked during an IA and their ability to respond accurately to so many questions, even over the course of multiple IA sessions or with an unlimited timeframe. As one person noted, **“It takes time to consider it, put it aside, think about it, reflect on it and get it right”**. This may pose particular challenges for people with acquired brain injury, intellectual disabilities and cognitive impairments. Without accurate responses this will limit the accuracy, validity and reliability of IA results. As such, all participants should be offered extensive information and resources to understand broadly the assessment process, what to prepare for and the types of questions to be asked. If such an adjustment is not possible, but concerns still remain about an IA participant’s ability to accurately self-report on their functionality and environmental circumstances an exemption should be made.

#### *2.4.4. People with recently acquired injuries*

An IA will likely provide invalid or unreliable results for many people with acquired injuries. For many people awaiting discharge from hospital or rehabilitation centres, NDIS supports are required to return home. However, at this stage many people’s functionality is fluctuating as they are undergoing treatment in their rehabilitative journey. Additionally, the trauma involved in adjusting to a life with disability can cause great anguish and an IA can pose additional mental distress.

For those in hospital or rehabilitation settings, they often find it difficult to assess their own functionality as they have not returned to their natural setting or are aware of what supports will be most beneficial to them on their return. During an Engagement Project with SCIA members, many people with recently acquired injuries reported that **“I don’t know what I need”** and **“I don’t know what I don’t know”**. There is a great risk that people will not be able to return home if they do not have NDIS supports in place and this may greatly increase wait times before discharge, particularly when state-funded programs do not fill this gap in providing supports to return home. This cohort should not be forced into short or medium term accommodation against their will. Instead, people with acquired injuries should be allowed to submit their medical documentation from hospital or rehabilitation centres and then undertake an IA after they have developed more of a routine in their natural setting.

#### *2.4.5. People awaiting discharge from an institutional setting*

As above, others in institutional settings should not need to undertake an IA before receiving NDIS supports to allow them to return home, including, among others, those people with disability residing in correctional centres, juvenile justice centres and immigration detention.

#### *2.4.6. Suspension of an IA*

Finally, in circumstances in which an IA is in progress and a support person or assessor becomes aware that an IA participant is in distress, there is a positive duty to immediately suspend the IA. In these circumstances, it will be appropriate to allow an exemption when there is clear evidence that a person is being harmed by the IA process, even if there is no diagnosed psychosocial condition or other factor that was previously identified.



**Recommendation 8:** *The list of IA exemptions should be open and include circumstances, among others, involving risk of distress to the IA participant and in which a person is yet to be discharged from hospital or a rehabilitation centre. Additionally, IAs should be suspended if the process is causing the IA participant distress.*

Further, delegates should be flexible in assessing whether an applicant or participant is exempt from completing an IA, it should not be viewed as a fixed, 'limited' list of exemptions.

## 2.5. Quality assurance and promoting trust and transparency with IAs

There should be numerous quality assurance mechanisms in place, *before the national rollout of IAs*, to meet the expectations of applicants and participants, and their support teams. The following recommendations would act as safeguards to serve this purpose:

- Regular auditing by independent third parties to measure applicants and participants' satisfaction of the IA process;
  - This should involve regular self-reporting from applicants, participants and their support persons in the form of surveys prior to, directly following and after an access or planning decision has been made to assess opinions and impact of IAs;
  - This is critical as IAs will affect different cohorts of people with disability differently, and is particularly relevant for SCIA's membership, as very little data during the pilot has been collated or published on people with physical disability;
- The establishment of a consumer reference group related to assessment of IAs, which could be integrated into the NDIS's Engagement Panel;
- A reference group to be established within the NDIS Independent Advisory Council;
- A robust, accessible, efficient and independent complaints mechanism that has been trialled during the second pilot;
- A public inquiry that is conducted within the first six months, and after the first 12 months of the national rollout of IAs;
- An opportunity for the disability sector, including advocacy and peak bodies, to comment on the rollout of IAs and its impact on the disability community;
- Re-assessment and continuing professional development programs to regularly monitor the accreditation of individual assessors and assessor organisations (this is particularly critical if the toolkit is updated in the early stages of the rollout);
- Statistics related to IAs (including details about the depth of the Assessor Panel, length of IAs, locations of IAs, medium of IA) should be collected and regularly included in the NDIA's Quarterly Reports;
- The impact of IAs should also be assessed regularly against the performance indicators that will be outlined in the upcoming Outcomes Frameworks set out by DSS, accounting for the new National Disability Strategy; and
- Applicants and participants should have the opportunity to record IA sessions and use such recordings if necessary to support complaints.

**Recommendation 9:** *Multiple safeguards should be implemented before the national rollout of IAs to ensure they protect IA participants interests and achieve their goals.*

Apart from these safeguards, first and foremost, as is later discussed in this submission in Section 4.1, all applicants, participants and their support persons should have the opportunity to appeal the results of an IA through internal review or an appeal to the Administrative Appeals Tribunal (AAT).

## 2.6. Communications and accessibility of information

Effective communication and universal accessibility of information is vital for applicants and participants to feel that they have agency when navigating the NDIS. This applies to every aspect of the NDIS journey as well as it relates to the introduction of IAs. Additionally, applicants and participants should be made aware of what information assessors receive regarding their circumstances prior to an IA. At every step, people should be provided with information written in plain English, via email or post and additionally have the option to discuss the process orally with an NDIA representative or assessor organisation. This section will answer these various questions. As already mentioned all communications and information should be universally accessible (formats must include multiple translations, Easy Read English documents available, spoken word documents).

### *2.6.1. What information should IA participants receive prior to an IA?*

Participants should receive clear information regarding each step of the IA process, the name of the assessor organisation and, at the very least, information regarding the profession of their assessor and the training they have undertaken prior to the IA. This information should include information available on the NDIS website: IA Framework, assessment toolkit (specifically highlighting which tools may be used during an IA). Again, these should be made available in all formats, including Easy Read. IA participants and their nominated (or designated) support person should also be given the opportunity to converse with an NDIA delegate beforehand to clarify any questions or concerns they may have. One recurring question asked during the public consultation was whether when answering questions about functionality, people should reflect on their functionality when they have disability supports in place or their level of functionality when there are no supports in place. People's understanding of how to answer questions can radically affect their responses. Additionally, many people have told SCIA anecdotally that they already find it difficult to self-report on their own level of functionality, so understanding the specific goals of questions will be crucial to producing accurate results.

The degree of choice IA participants have with IAs should also be emphasised. For example, they must be aware that they have choice over their support person, location, time and day, specific IA activity and the number of sessions that the IA may be conducted over. Further, they should be aware that they may submit a preference for the gender of the assessor, and as the Assessor Panel grows, other specific preferences (for example, if the assessor identifies as being from a culturally and linguistically diverse background or age). There should not be any misconception among IA participants and support persons that there is a hard limit on the length of IAs. Such a misconception places a significant amount of pressure on IA participants and may lead them to give rushed, invalid responses. Additionally, as recommended above, IA participants and support persons should be clear that they have the choice to suspend an IA if a person becomes distressed or if the IA poses a risk to their physical or mental wellbeing.

### *2.6.2. What information should an IA assessor receive prior to an IA?*

At present, it is very unclear what information assessors will receive prior to conducting an IA. During consultation, many people felt that it was rather better for assessors to have more rather than less information. However, before an assessor receives any information, an IA participant must first consent to its provision to the assessor or assessor organisation. Keeping this in mind, this information could cover the following details, including:

- Basic demographics: age, gender, education, ethnicity, marital status, employment, housing status;
- Whether a person is of Aboriginal or Torres Strait Islander;

- Whether an interpreter is required;
- Name of support person and their relationship with the IA participant;
- Details of a person's disability/ies;
  - Primary disability and, if applicable, other listed disabilities (particularly psychosocial conditions);
  - Past medical reports and assessments relating to a person's disability/ies;
  - A general synopsis of a person's individualised care plans in each area of support;
- Whether an IA participant has a history of trauma, domestic violence or homelessness; and
- Whether a person has completed assessments from the toolkit previously and the results from these assessments if available.

It is vital that IA participants feel that assessors have a basic understanding of their circumstances before meeting them. Assessors must be sensitive to IA participants' situation, use appropriate language and avoid conflict by aggravating participants by repeating questions or seeking irrelevant information. This is particularly important as many IA participants will have undergone numerous assessments, including those from the IA toolkit, in the past and many already feel that IAs are unnecessary.

### *2.6.3. What information should participants receive following the IA and in what format?*

The information that IA participants receive following an IA should be flexible depending on the preferences of the IA participant. All assessment results, including raw data (including answers to specific questions) and the assessor's observational comments, should be made available on request. A summary report should also be produced in all accessible formats. Information from an IA report or raw results may be very triggering for IA participants and cause distress, which is why receipt of results should be consent-based. Additionally, many of the results and raw data may be very difficult to interpret and IA participants and their support persons should have the opportunity to speak to the assessor, member from an assessor organisation or an NDIA representative to discuss the results and how to interpret them. IA participants should also receive a summary report or the opportunity to request all assessment results prior to an access decision being made or before a planning meeting. In planning meeting, IA results can be a valuable tool in determining the supports a person needs, and as such, IA participants and their support team (including support coordinators) should be able to familiarise themselves with the results before planning meetings.

**Recommendation 10:** *IA assessors should receive information about an IA participant about their circumstances prior to an IA and IA participants should understand clearly the role of an IA and the choices they have in the IA process.*

## **2.7. Conclusions on independent assessments**

There is great concern among the disability community about the introduction of independent assessments. Every effort should be made to ensure that people with disability and their support networks feel they can safely participate in the IA process and that it will successfully contribute to their engagement with the NDIS. This will involve a focus on flexibility and an individualised approach to assessments. There needs to be ongoing engagement with people with disability, their family members and others regarding IAs and the IA Framework and toolkit should be revised in light of this feedback. Additionally, it should always be remembered that a person with disability and their support team understands their needs best. In relation to minimising costs to an applicant to the NDIS, there should be further consideration of possible duplication between evidence required to meet the initial criterion of a permanent disability and an IA's results. In evaluating IAs, the five goals outlined in Section 2 should always be kept in mind. At present, in light of the concern among those directly

affected by IAs it is again recommended that the national rollout of IAs be postponed until people with disability have been fully consulted and the process has been empirically proven to be successful.

### 3. Proposed planning policy and flexible budgets

As with IAs, the proposed reforms to planning policy have been met with uncertainty and apprehension in SCIA's external and internal consultations. While some of the specific reforms are welcome, there are still a lot to be clarified and re-worked to meet the needs of prospective applicants, existing NDIS participants and service providers. It should be noted that many people feel that it has already taken a long time for participants to receive the right supports in their plans and these reforms may place them at square one. As such, to implement such radical reforms requires evidential justification and support from participants and applicants.

**Recommendation 11:** *Implementation of proposed reforms to planning policy should be postponed beyond July 2021 and only occur after further consultation with the disability sector.*

This section will examine various aspects of the proposed reforms that will profoundly impact a participant's NDIS journey.

#### 3.1. Role of IA results in determining a person's draft budget and decision-making

It is very unclear how an NDIA decision-maker will treat the results and reports from a person's IA. It must be reiterated that while ensuring consistency of budgets across the Scheme's participants is an aspect of maintaining the financial sustainability of the NDIS, the focus should always be upon supporting the disability needs of the specific person in their unique circumstances. It has already been recommended that IAs need to focus on a holistic assessment of the IA participant and this should certainly include consideration of their future goals. It is particularly worrying that discussion of a participant's goals will only be had during the planning meeting and may not be a factor in a delegate's assessment of a draft budget.

Similarly, there should be sufficient flexibility to acknowledge that a draft budget can be negotiated to better meet the participant's needs. The IAC's recent Meeting Bulletin described a presentation by the Scheme's Actuary and the establishment of a Personalised Budget Tool (PBT).<sup>47</sup> It should be emphasised that such modelling should produce a budget *estimate* only. It is a starting point through which to understand a participant's circumstances, and many other factors should then be considered in increasing or decreasing their level of funding in the draft plan.

The consultation paper included a question concerning 'assuring' participants that they have received the right level of funding. Again, the emphasis should be on 'ensuring' participants receive a level of funding that meets all of their disability needs. As with IAs, there should be numerous quality assurance mechanisms in place, similar to those outlined in Section 2.5. In relation to planning policy reforms specifically, there should be:

<sup>47</sup> Independent Advisory Council, 'Independent Advisory Council Meeting Bulletin', 4 February 2021, <https://static1.squarespace.com/static/5898f042a5790ab2e0e2056c/t/602055973cfe453321ca5709/1612731801320/Bulletin+-+Council+-+Meeting+6+-+4+Feb+2021+-+2021-02-08+-+PM+Approved.pdf>.

- Regular reviews by the IAC (bi-yearly reports) and the establishment of a sub-reference group on consistency in levels of funding in plans;
- If a PBT is introduced, there must be regular internal and external auditing of the PBT's performance, measuring against metrics relating to NDIS participants' demographic data (age, gender, disability/ies, location, housing status, employment status etc.) and reference to goals included in plans;
- Continued regular reporting of average plan budgets of participants in Quarterly Reports;
- Continued regular reporting on the incidence of internal reviews and AAT appeals of planning decisions;
- Mechanisms to establish satisfaction levels with plans, with results published in Quarterly Reports; and
- Guidelines on how NDIA decision-makers take account of IA results and equating levels of support between participants in similar circumstances (beyond the draft estimate produced by the PBT). For example, there should be clarification on whether a delegate may take into consideration a participant's previous plans.

These are simply a few suggestions that could be initiated and built upon if and when the planning reforms are implemented.

**Recommendation 12:** *The NDIA should establish multiple monitoring mechanisms to assess appropriateness of NDIA delegates' decisions and provide guidelines on what factors delegates account for in a draft plan, and budget.*

#### 3.1.1. Communicating reasons for decisions

Currently, many participants find it difficult to understand the reasons for planning decisions. They either receive too little information or too much information that is complex to understand. On trying to follow up with the NDIA they have often found it impossible to get a satisfactory response.

This needs to be avoided in the future. The focus on explanation of reasons is vital, particularly when IA results inform a delegate's decision and the participant may have already formed a view on the accuracy of these results. Participants must be offered guidance to explain reasons. Such guidance must be thorough and genuine and be universally accessible in writing and orally if requested. Publication of a 'Guidance to understanding IA results or planning decisions' is insufficient for this purpose.

**Recommendation 13:** *Participants should be offered the opportunity to contact NDIA representatives and receive reliable and accurate information to best understand decision-makers' reasons.*

### 3.2. Pre-planning preparation

For both new and existing participants to the NDIS, these proposed reforms represent the most radical changes to the planning process and for many people it is a complete reset of their understanding of the NDIS. This will not be more evident than at the pre-plan meeting stage, when participants have received their draft plan and IA results before their planning meeting.

For new participants, establishing whether a draft plan meets their needs will be very daunting as they have likely never had access to NDIS supports before. For existing participants, it will be very clear if

there is an issue with a draft plan as they can resort to their former plans for reference. Either way, if a participant wishes to challenge the draft budget it seems they will have little recourse before the planning meeting (this issue will be further discussed in Section 3.4). As such, it is highly confusing exactly what participants are expected to prepare and bring to a planning meeting. Participants have already posed the following questions:

- *Do I need to bring quotes or invoices to a planning meeting?*
- *Do I need to bring supporting evidence or advice from my treating allied health professionals, including reports from occupational therapists for access to AT?*
- *How do I know whether the draft plan matches my goals before they have been drafted during a planning meeting?*
- *How do I know beforehand that the budget matches my total number of supports I require?*

These questions seem to remain unanswered and they must be addressed and clarified before any further action is taken to implement the proposed reforms. Another aspect of the pre-planning stage is understanding by participants of the results of their IAs. Discussion of IA results has already been mentioned in Section 2.6.2 above, however it should be re-iterated that participants need a very clear understanding of an IA's results. They should be communicated before a planning meeting in plain English and other accessible formats. Further, whoever is guiding the participant's understanding of the results should be very knowledgeable about the technical aspects and terminology that are included in the results and competent at communicating this information to the participant and their support team respectfully and competently. They should also be acutely sensitive to the potentially triggering nature of the results. Mutual understanding and trust between all parties supporting a participant is critical to creating a plan that meets their expectations and actual needs.

Pre-planning meetings may be even more important if the proposed reforms are implemented. Participants need to have their voices heard and understood by their whole support team, support coordinators, plan managers, LACs and NDIA planners, before any planning meeting occurs. For many of these parties having information about the draft plan will be critical to understand how a participant may utilise their funding 'flexibly' when they are unsure exactly which supports will be needed. Participants should also be made aware of the types of supports that they can use their NDIS funds for and be given information about local services that may suit their needs before a planning meeting. This could involve including case studies to illustrate how others have innovatively used their NDIS funds previously.

**Recommendation 14:** *The NDIA should clarify how participants and their support teams should prepare for planning meetings.*

### **3.3. The planning meeting and utilising a plan**

Planning meetings are the single most important opportunity for participants and their support team to assert their choice and control over their level of support. During SCIA's consultation with the NDIA, it has been asserted that the planning meeting does not involve a 'negotiation' over the level of funding a person receives, rather it is time to determine how the funding will be used to meet their needs and goals. This is a highly concerning prospect. It disenfranchises a participant's voice and in

cases where a person's funding is lower than in previous plans (prior to the reforms), it is likely to produce conflict, or at the very least, significant confusion. It is recommended that negotiation of levels of funding should be an element of planning meetings. As such, participants and their support team should be able to bring evidence to support claims for greater levels of funding and receive support before a planning meeting to collate this evidence.

A planning meeting should not be the first opportunity to discuss a participant's goals. It has already been recommended that consideration of a participant's goals needs to be included in IA and these goals should inform every step of the process, including the NDIA delegate's decision-making. The planning meeting should be a reaffirmation and re-visiting of the participant's goals. It should not be the first time that a participant's goals are communicated. Every party attending a planning meeting should be aware of the general goals a participant has prior to the meeting itself.

In terms of plan implementation, throughout the course of a plan, participants should regularly receive universally accessible information in hard copy and digital about available supports, services and technologies that may be relevant to them. Currently participants receive a hefty PDF document that is confusing and often irrelevant. Participants should be provided with a series of booklets that are categorised according to service and service area that is in a readable format. Similar guides could also be produced to the 'Guide to Self-Management' to aid participants when using their plan and deciding which supports or services best suit their needs.

**Recommendation 15:** *Participants should have the opportunity to discuss the level of funding during the planning meeting.*

**Recommendation 16:** *The NDIA should regularly produce and publish new information relating to available supports, services and technologies that may suit participants.*

### 3.3.1. Fixed supports

The proposed fixed supports (SDA, home modifications and high cost AT) are appropriate inclusions in the list of fixed supports. It should be noted that repairs and maintenance for AT and equipment should be included in the list of fixed supports too. Generally, the list of fixed supports should be open, and particularly as the current system involves multiple categories of support it may be appropriate to include current supports in the fixed budget where there is a need. This should be determined on a case-by-case basis. For example, for participants with high disability needs, if it is appropriate and where there is a need to list Supports for Assistance with Daily Life in the fixed budget, it will ensure they are not left underfunded.

Additionally, for new participants, many existing self-managed participants and others, support coordination is a vital factor in how a participant best utilises their funds *effectively and innovatively* to suit their needs and goals. General and specialised support coordinators assist participants in navigating, identifying and sourcing appropriate supports in their local area and should be included as a fixed support in many participants' plans.

**Recommendation 17:** *Include support coordination and Supports for Assistance with Daily Life in the list of fixed supports, if and where there is a need.*

### 3.3.2. Transport supports

For many SCIA members, retaining NDIS funding for transport supports will be critical if the proposed reforms are implemented. Many members are heavy users of taxi subsidy schemes and require direct, fortnightly payments to ensure they have autonomy. The NDIA has already signalled that transport supports are a priority by increasing funds in recent months,<sup>48</sup> however this should be guaranteed in guidelines prior to the implementation of the proposed reforms. For example, transport supports may be categorised as a fixed support, the funds for which are released fortnightly to accord with taxi subsidy usage.

**Recommendation 18:** *The NDIA should guarantee that transport funding, as a direct fortnightly payment, will be maintained and also retain transport funding in a participant's plan for those not receiving a direct payment, in the proposed reforms and produce updated guidelines that allow regular release of funds for transport supports on a needs basis.*

### 3.4. Check-ins and release of funds

As with all aspects of the proposed reforms, check-ins and release of funds should be guided by the needs and preferences of the participant.

#### 3.4.1. Check-ins

Check-ins will become an important, regular opportunity for participants to engage with the NDIA and reflect on their NDIS plan. However, they should not become opportunities to formally 'assess' a participant's use of their plan. It should be an opportunity for reflection and sharing advice and knowledge and making adjustments where needed or requested.

They should be conducted as flexibly as possible. They should be offered over the phone, via videoconference or if possible face-to-face. Participants should be offered the opportunity to conduct check-ins over multiple sessions and outside of business hours if preferred. There should not be a time limit to these conversations and NDIA staff should actively listen to participants and their support persons' reflections without judgment.

In the past, many participants have reported engaging with NDIA staff who tell them what they need without actually listening to the experts in the participant's life – the participant and their carers. NDIA staff should adopt an empathetic, trauma-informed approach, sensitive to the participants goals and needs.

Support persons should be involved in check-ins, if nominated by the participant, in order to assess a participant's situation and the impact of their NDIS plan on their extended network, including their family members and other support persons. The conversation itself should be dynamic and not simply a 'tick the box' exercise.

It has been repeated throughout this submission that trust is a critical element of the NDIS's success and this could be achieved in the check-in process if a single NDIA staff member is allocated to a participant to conduct regular check-ins. Some people have become disillusioned in their interactions with the NDIA as they repeatedly speak to different staff, have to explain their story and get different responses from different people. Consistency is an important element in building a successful

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<sup>48</sup> National Disability Insurance Scheme, 'Changes to transport supports', 7 December 2020, <https://www.ndis.gov.au/news/5732-changes-transport-supports>.



relationship between the NDIA and participants. Following a check-in, participants should receive a written hard copy or digital record of the reflections made during the check-in.

**Recommendation 19:** *Check-ins should be conducted according to a participant's preference and be managed by the same NDIA representative.*

### **3.4.2. Release and rollover of funds**

While the release of a participant's funds will be negotiated during a planning meeting, it should also be recognised that many other factors may necessitate the need for early release of funds, for example, changes in a service provider's policy or rates or an immediate short-term change in a person's circumstances. Another situation may arise when participants wish to access AT or a new AT product becomes available, they may require an early release of funds (if the support is not categorised as a fixed support – high cost AT). Release of funds in these circumstances should not trigger a plan review or variation. Also, it should be noted that plan managers may prefer a particular funding release interval and this should be factored in during the initial negotiation during the planning meeting.

Many people consulted for this submission raised concerns with the proposed rollover of funds. First, the consultation paper mentions that funds up to a threshold will rollover, however how is this threshold determined? Additionally, if a person is entitled to a five year plan, it seems counterintuitive to limit rollover of funds to 12 months. This is particularly the case when people experience unexpected events, including an unplanned hospital stay or in the current COVID pandemic or in circumstances in which they plan to take a holiday requiring extra funding for support. As such, the rollover of funds should not disadvantage people due to unexpected circumstances or planned short-term holidays or excursions.

**Recommendation 20:** *The NDIA should clarify its policy on the rollover of funds and adopt a flexible approach including allowing rollover beyond the proposed maximum 12 months.*

### **3.5. Transitioning to the new planning model**

This new planning model will affect every person involved in the NDIS and there needs to be multiple mechanisms in place to prepare everyone for the changes. This involves information sharing, training and evaluation.

As always, all information should be published on all platforms, including the NDIS website, social media, information forums, in all universally accessible formats. Further information should be disseminated to all existing participants, NDIA staff and LACs, service providers (particularly support coordinators and plan managers) and other NDIA Community Partners. Many NDIS participants have reported that they have been told incorrect information from NDIA when contacting them about their rights. There is a very great risk of misinformation spreading with the current lack of clarity around specific details and the mistrust that has arisen in the past due to a lack of transparency between participants and the NDIA.

It is vital to maintain trust between all partners participating in the NDIS and this could be facilitated by holding virtual and face-to-face information sessions, and training sessions for plan managers and support coordinators.

Participants themselves should receive tailored information packs that outline the specific impacts to them. These packs should be tailored to account for different people's management types, location and current circumstances. Information should include an overview of the new process; a table outlining a participant's rights and role; an FAQ section; and examples of case studies of people in similar circumstances. Additionally, participants should be given the opportunity to speak directly to an NDIA representative to clarify any questions they may have about the new process.

If the proposed reforms are implemented, there must be a thorough evaluation phase that tracks the efficacy of the process and participants' satisfaction in a similar manner to the evaluation measures mentioned in Section 2.5.

**Recommendation 21:** *The NDIA should provide participants with tailored information packs and offer public information and training sessions to assist in any transition to the proposed model.*

### **3.6. Other concerns with planning reforms**

As already discussed, the approach towards flexibility will be beneficial for many participants. However, there is a concern that adopting a 'flexible budget' may lead some to planners to refuse to fund certain supports as they interpret them as not relating to a participant's disability. This could lead to further interfacing issues with other systems (i.e. health, justice, education etc.). It could also lead to unilateral decisions as planners may refuse to fund certain supports if not approved previously in a planning meeting. The benefits of flexibility should be supported by empowerment of the participant to determine their supports throughout the course of their plan.

#### **3.6.1. Children aged 7 and above**

For children aged 7 and above, their increased vulnerability should be regularly acknowledged and acted on. With the Early Childhood Reset it is also a very unclear area, particularly with the proposed age increase in ECEI from 7 to 9 years. This uncertainty should lead to even greater support for this cohort as they wait in limbo before set guidelines are set. Changes in assistive technology (AT) and equipment may be more pressing for children as they grow physically and they should be automatically placed on priority lists for AT. For example, if a child is confined to a wheelchair that they have grown out of, it may compromise their ability to attend school or participate in other activities.

Children of all ages experience regular developmental change and as such their level of support must be very flexible as their needs change in shorter intervals and as they approach new milestones within shorter timeframes. They may require more regular check-ins, however this should not necessarily be assumed, it must be an ongoing dialogue between the child, their parents or guardians, their support team and the NDIA.

It has already been recommended that check-ins are conducted by the same NDIA delegate, but this is even more significant for children. Not only should the same delegate be assigned, but they should have individual caseworkers that understand their history and can liaise with all members of their support team on a regular, open basis.

**Recommendation 22:** *Children aged over 7 should have consistent, long-term, flexible support to meet their changing needs.*

### **3.7. Conclusion on Planning policy**

The proposed reforms to planning policy will be a major shift for all parties involved in the NDIS process and many have already shown reluctance to reforms, when the current system, while complex, has been successfully managed for many participants. These reforms could pose major setbacks for many existing participants who should not be disadvantaged in the process of achieving consistency if the driving motive is minimising costs. Additionally, for many participants utilising a plan with substantial funds in the flexible budget may be an overwhelming experience as they may use funds irresponsibly, without consideration of their actual day-to-day needs or their aspirations. As such, these participants need a significant degree of support in utilising these plans, and as such, support coordinators, plan managers and LACs will act as critical guides in achieving the maximum possible in the best interests of the participant.

## **4. Other comments**

### **4.1. Independent assessment appeal rights and timeframes**

The first section of this submission reiterated that the Tune Review found that a key protection for any form of independent functional assessment must involve incorporating a right to appeal the results of the IA itself (not just decisions listed under s 99 of the *NDIS Act*). Considering the restriction on participants and applicants in their choice of assessor or assessor organisation and the possible variability in the manner in which an IA is conducted, it is logical to conclude that a person's access decision or their planning funding budget may be affected by results produced by one assessor as opposed to another. In light of this possibility, it is only reasonable to appeal the results of an IA and seek a second IA.

If the right to appeal IA results is guaranteed, specific timeframes should also be enforced to ensure that an IA participant has the opportunity to make a timely, direct appeal of the IA results they have received. In other words, they should receive IA results prior to an access decision or the release of a draft plan. This timeframe should be integrated into the Participant Service Guarantee.

At present, it is still very unclear at what point an IA participant will receive their IA results – prior to access decision or release of a draft plan? Before or following a planning meeting? IA participants should be assured that they will receive the IA report soon after their assessment, and before any access decision or draft plan has been released. Then they should be informed of their right to appeal the results and the procedure to follow if required. Without this guaranteed appeal and timeframe, many IA participants will feel they have been treated unfairly and disenfranchised by the process.

**Recommendation 23:** *The right to appeal the results of an IA should be integrated into the legislative framework to protect the interests of IA participants. Additionally, IA participants should receive IA results prior to a delegate making any access decision or draft plan.*

#### 4.2. Possible amendments to making rules under the *NDIS Act*

DSS's Information Paper made clear that "a new rule will make clear that NDIS funding is not to be used to purchase the service of a sex worker or devices solely for sexual stimulation".<sup>49</sup> While the legislative amendments to the *NDIS Act* have not yet been released, one possible avenue to introduce such a rule would be an amendment to s 209, re-categorising rules made under s 35(1)(b) to Category D, which would only require consultation, rather than agreement, with all State and Territory governments. If this amendment were made, the precedent it sets is highly concerning. Effectively, the Federal Government could unilaterally deny funding of supports, defining the boundaries of NDIS, without formal agreement from other State and Territory governments. This could de-legitimise the role of these governments in their contributions to the NDIS and it could be used as a political tool that could disadvantage all NDIS participants across Australia. SCIA recommends that such an amendment should not be proposed.

#### 5. Conclusion

It is evident that the current expedited timeline will not afford people with disability and their support networks sufficient time to provide genuine input into the proposed reforms or prepare for their implementation. This is particularly concerning as any consultations should be *ongoing, genuine and thorough* if the NDIS is to be truly effective: "[Its] strength [should be] the disability community's sense of ownership of it, driven in part by its extensive consultation processes".<sup>50</sup> Without consultation and genuine, responsive engagement, there is a greater risk of misinformation, distrust and risk of harm to prospective applicants and existing participants. Empowering choice and control should be at the heart of all NDIS processes, as legislated in the *NDIS Act*. But it is the choice and control of participants, not administrators, that is paramount.

If the Agency requires further information or has any queries about the content of this submission, please do not hesitate to contact SCIA.

Kind regards,

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<sup>49</sup> See Department of Social Services, 'Improving the National Disability Insurance Scheme: Better Participant Experience and Improved Access and Planning', p. 4.

<sup>50</sup> Australian Civil Society CRPD Shadow Report Working Group, *Disability Rights Now 2019: Australian Civil Society Shadow Report to the United Nations Committee on the Rights of Persons with Disabilities, UN CRPD Review 2019*, July 2019, p. 5.