Brotherhood of St Laurence
Working for an Australia free of poverty

Independent Assessments, Access and Eligibility Policy, and Planning Policy

Response to NDIS consultation papers

Brotherhood of St Laurence

February 2021

The Brotherhood of St Laurence and National Disability Insurance Scheme

The Brotherhood of St Laurence (BSL) is an independent non-government organisation with strong community links that has been working to reduce poverty in Australia since the 1930s. Based in Melbourne, but with a national profile, the BSL continues to fight for an Australia free of poverty. The BSL has a strategic focus on building evidence-informed policies and practices that promote community inclusion and participation of all people, especially those experiencing exclusion or disadvantage. This commitment is reflected in our role as a LAC and ECEI provider for the NDIS in the North Eastern Metropolitan, Hume Moreland, Western Melbourne and Bayside Peninsula areas in Victoria. We have been delivering LAC since July 2016 as part of the first phase of NDIS implementation. We commenced as an ECEI provider in November 2016, and now work with around 40,000 people with a disability in LAC and ECEI. Our engagement in this planning and community capacity building is driven by the recognition that people with disability are among the most socially and economically excluded Australians.

Through our Research and Policy Centre and in partnership with the Melbourne Disability Institute of the University of Melbourne we undertake research and evaluation activities with the aim of driving transformational disability policy and informing the successful implementation of the Scheme to support people with disability to live a good life.

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Summary

NDIA consultation for proposed changes to access and planning

BSL welcomes the opportunity to participate in this consultation regarding planned changes to access and planning in the NDIS, including the introduction of independent assessments (IAs).

The rollout of the NDIS has been of tremendous benefit for people with disability – and the broader community – over the past 5 years. As noted by the Productivity Commission in 2011, the previous disability support system was "underfunded, unfair, fragmented and inefficient", and gave "people with disability little choice and no certainty of access to appropriate supports".

It is clear that – by every measure – the NDIS is a vast improvement on the system that preceded it.

Nevertheless, the case for ongoing improvement is clear. We support:

- the Agency's objectives to improve consistency of decision-making and equity;
- the revision of Access processes to focus on the impact of disability on a person's life rather than a specific diagnosis;
- the provision of fully funded assessments which remove many barriers to access.
- Increasing flexibility for plan budget usage.

We have concerns that the agency may be rushing implementation of the changes, and that the results of trials have not yet been evaluated and incorporated into the processes. Given the scope and scale of the proposed reforms, we believe that the Agency will be well served by taking the time to gain more insight from people with disability, their families and carers so that everyone can have confidence that the changes will bring the desired improvements.

With that in mind, BSL has identified a number of improvements to the Policies under consultation, which are itemised in our recommendations.

We thank the Agency for its openness to feedback through this consultation.

Our approach to developing this submission

Four key sources of information and expertise inform the development of this submission:

1. Semi-structured consultations with over 230 BSL NDIS staff members
2. Semi-structured consultations with 18 BSL NDIS staff members who are scheme participants, or family members/carers of participants
3. Open consultations with key organisational stakeholders in the Disability Sector
4. Previous research and policy work undertaken by the BSL Research and Policy Centre together with the BSL LAC team, and on the findings of the numerous reviews and inquiries into the NDIS over the past three years.

In the context of the objectives of the Scheme (as written in the Act), we examined the reforms from three perspectives:

a) Which elements of the proposed reforms will improve the Schemes capacity to deliver on the objectives of the Act?

b) Which elements of the proposed reforms cause concern or increase the risk of failing to delivery on the objectives?

c) What can the Agency do to mitigate the risks?

Semi-structured consultations were undertaken with BSL NDIS representatives including frontline LACs, middle and senior managers. Consultations were undertaken by telephone and zoom and included one on one discussion as well as focus groups. Interviewees were invited to provide feedback on the key elements of the discussion papers. Detailed notes were taken and used to inform the analysis that underpins our response. We sought feedback that informs how the aims and objectives of the proposed reforms can be achieved, and to provide deeper understanding of the strengths and risks of the proposed actions or reforms.

The feedback from participants, families and staff underpins all of our responses and recommendations to the suite of reforms NDIA propose.

As the proposed access and planning reforms are linked, we have responded to the *Access and Eligibility Policy with Independent Assessments* consultation paper and the *Planning Policy for Personalised Budgets and Plan Flexibility* consultation paper within this one submission.

1 Access and planning changes should be assessed against the objects and principles of the NDIS

The NDIS Act recognises and give effect to Australia's obligations as a signatory, (Objects 3:1a) to the United Nations Convention on the Rights of Persons with Disabilities. Australia was an early signatory to the Convention, signing on 17 July 2008. The Convention recognises the human rights of people with disability to participate as citizens in all aspects of social and political life including access to employment and education (United Nations, 2006). As a signatory Australia is committed to protecting those rights and ensuring that people with disabilities are enabled to exercise their rights.

Like the NDIA, we are committed to protecting the integrity of the NDIS Act - especially in the design and implementation of all NDIS policies.

As essential context for this response, Section 3(1)(a)-(h) of the Act are listed below:

(1) The objects of this Act are to:

(a) in conjunction with other laws, give effect to Australia's obligations under the Convention on the Rights of Persons with Disabilities done at New York on 13 December 2006 ([2008] ATS 12); and

(b) provide for the National Disability Insurance Scheme in Australia; and

(c) support the independence and social and economic participation of people with disability; and

(d) provide reasonable and necessary supports, including early intervention supports, for participants in the National Disability Insurance Scheme launch; and

(e) enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports; and

(f) facilitate the development of a nationally consistent approach to the access to, and the planning and funding of, supports for people with disability; and

(g) promote the provision of high quality and innovative supports that enable people with disability to maximise independent lifestyles and full inclusion in the community; and

(ga) protect and prevent people with disability from experiencing harm arising from poor quality or unsafe supports or services provided under the National Disability Insurance Scheme; and

(h) raise community awareness of the issues that affect the social and economic participation of people with disability, and facilitate greater community inclusion of people with disability; and

We note that the objects of the Act clearly set an expectation that the Scheme operates for the benefit of people with disability more broadly (items (c) and (h)), whilst also specifically providing reasonable and necessary supports for participants in the Scheme (i.e. those who meet the access requirements specified in sections 21-25 of the Act).

The principles of the Act specify the importance of supporting people with disability to maximise independence, and in their dealings and communications with the Agency so that their capacity to exercise choice and control in pursuit of their and the planning of their supports is maximised. – Ay reform that erodes these objectives compromises the integrity of the NDIS.

Our submission is guided by analyses of the proposed changes proposed alongside the objects and principles of the Act, highlighting areas of (mis-)alignment.

2 Objectives of the planned reforms

Equity, Consistency and Sustainability

The proposed NDIS access and planning policies seek to make the Scheme more equitable, consistent and sustainable. These areas of focus have emerged because:

- The Tune Review (Tune 2019) and Agency analysis of data have found evidence that individuals and families with a greater access to supportive resources are able to pay for assessments and thus document needs more rapidly and thoroughly. As a result, on average, people in higher socio-economic areas are receiving a greater level of funded supports through the Scheme than those in lower socio-economic areas.;
- There are emerging pressures on Scheme sustainability, particularly through the increase in average annualised committed supports in calendar years 2019 and 2020 (NDIS 2020(7) p60).

The lack of equity and consistency is of particular concern because there is no reason to believe that people with disability in higher socio-economic areas have a higher level of need than people in lower socio-economic areas.

On the other hand, there is also no evidence that level of supports provided to people in these areas is incorrect or invalid. It is therefore possible that people in lower socio-economic areas are receiving a lower level of supports than they would if they had access to the same level of supportive resources.

Therefore, the reforms are seeking to ensure that the information collected for all prospective participants and participants is collected on a consistent basis so that the current economic capacity of an individual has no bearing on the access decision, or the level of support offered through the Scheme.

All of the people that BSL consulted supported the principles of equity and consistency – and recognised that the Scheme must remain financially sustainable over the long-term to ensure that the objects of the Scheme are fulfilled.

Many respondents expressed concern that an exclusive focus on equity, consistency and sustainability is insufficient and that it is vital for the Scheme to also provide:

- *dignity and respect* for people with disability and
- supports that are demonstrably *valid or accurate* for each person, considering their goals, environment and personal circumstances.

Foundations of a sustainable NDIS

Sustainability is an absolute requirement for the long-term success of the Scheme. Equitable supports for people with disability can only be provided if the scheme has sufficient funding capacity to pay for them.

However, defining exactly what is meant by "sustainable" is challenging. Whilst it is generally expressed in terms of the level of budget expenditure which is considered to be acceptable to taxpayers, it is unclear as to constitutes *acceptable*. Is it:

- A specific dollar expenditure amount for the Scheme (e.g. $22bn p.a.)?
- A specific proportion of GDP?
- Considered in the context of other taxpayer funded expenditure which may reduced through the operation of the Scheme? (e.g. Health or Justice expenditure)?
- Considered in the context of economic benefit which arises from the increased economic participation of people with disability and their families or carers?
- Considered by comparing each year, or through individual lifetime cost?

Cost management

Scheme sustainability rests on containment of direct and indirect costs. Direct costs are impacted by the number of people who are deemed eligible for funded supports as well as the value of plan budgets. Containment of direct costs can thus be achieved by maximising the accuracy of the assessments of eligibility for funded supports, and ensuring that such supports build independence and individual capacity wherever possible. Ensuring the right people get the access to the right level of NDIS funded supports is a challenge for the scheme. If the bar is set too high, people who need supports and are excluded are likely to have additional costs long term through adverse outcomes but lowering the bar may result in increased numbers of scheme participants and an increase in scheme costs.

The first trial of Independent Assessments found that eight per cent of assessed participants had results indicating their function fell within an assumed typical population's normal range and therefore were most probably more suited for early intervention (NDIA, 2020 (5)). It is implied this is evidence supporting the use of independent assessments to give a better indication of appropriateness for funded supports. However, our understanding is that no comparison was conducted with people who had previously been declined access, to determine whether people declined under current process might be eligible for funded supports on the basis of their functional capacity assessment results.

Information from such a comparison group would be valuable to inform decisions about the effectiveness of the proposed approach for reducing costs; in the absence of this, there is a risk that the IA approach could result in greater numbers of participants than anticipated.

Social and economic benefits from the Scheme

Now that the Scheme rollout has been completed, we are beginning to see evidence of the benefits of the Scheme for participants, and for our community more generally. The most recent quarterly report includes information about positive outcomes in social participation, with associated positive trends in health outcomes and promising signs of improved economic participation for some cohorts of participants.Ensuring access to community and mainstream support

Providing appropriate support in the community, and ensuring people can access this support effectively helps ensure people only move into the scheme when necessary. If the NDIA do not consider and cater to people with a disability who do not meet access to the NDIS, they risk unmet need, declining capacity, and eventual access to the Scheme.

The BSL notes with concern that the proposed reforms are participant-centric, with little recognition of the role of the Scheme in supporting people with disabilities who do not meet or have not yet met the access requirements for funded supports (Tier 2), or of the critical role of community and mainstream supports in reducing need for funded supports for participants. We believe that these aspects of the NDIS need to be scaled up, not de-emphasised, if the Scheme is going to be sustainable into the future.

This risk is may be exacerbated by the reduction in focus on building capacity of people with disability, which is referenced only once in each consultation paper other than to note removal of line items for capacity building supports.

3 Analysis of Independent Assessment Framework and process

'*Access to the NDIS should not be determined by a person's ability to gather and pay for enough evidence to demonstrate reduced functional capacity*' (Access paper, p5).

The requirement to provide evidence to support an application has been one of the barriers to access affecting people unevenly, with the most vulnerable or at risk people more likely to experience difficulty seeking access, or give up altogether.

Some participants supported by BSL have had access requests declined due to lack of supporting information, some several times. After receiving support to gather the required information, they have subsequently gained access to funded disability-related supports that have increased their independence. Others, including those with substantially reduced function have been deterred by the hurdles at access. For some people, the cost has been a barrier.

Simpler and fairer assessment

Participants and families, and BSL staff consistently supported the goals of a simpler, fairer assessment process to minimise burdens of costs and time, and to increase equity of scheme access. Consistent with NDIA evidence, a common view was that educated and wealthier people did better under current NDIS access and planning processes, and those who experienced barriers such as limited English literacy, or mental health issues needed additional support that was sometimes provided by an LAC or another community support.

The assessment process

Some participants and families welcomed the change to a simpler assessment/access process, and certainty around plan budget which they considered would support earlier access to supports, and make life easier overall:

> *The changes are better, but they need to be clear. We can ask 'what can this get us and how can we use the funds to achieve our goals?'. Assessors will need to be able to build rapport quickly, can't be business types. Need compassionate, experienced, knowledgeable, time so LACs can walk through the dollar value, how it can be used and cost of services. Keep it simple. There are always problems and we need to refine changes. (Parent of Scheme participants)*

Others took issue with key aspects of the proposed process, noting independent assessment process, how results of IAs were to be used, the requirement for a third party to participate in the assessment, lack of transparency or clarity around how plan budgets were to be determined, the move away from goals and individualised supports to achieve them and a reduction of choice and control, despite the stated intention to increase this:

> *My daughter is a participant of the Scheme. She lives independently, works full time, and has just bought her own home. My fear is that the process of independent assessments, where she will be interrogated about her disability and its impacts, will not only leave her without supports, but also increase her anxiety to a point where she will not be able to work. This is not because her disability and its impact wouldn't meet their thresholds, but that she wouldn't complete the assessment.*
>
> *I am also devastated to think I would have to discuss her deficits in detail, without her there. It takes me back to her preschool years and conversations about her only revolving around what she couldn't do, what milestones she wasn't reaching, rather than celebrating her generous nature, warm personality and wicked sense of humour.*
>
> *My daughter has always said I can speak about her, but not for her, and I fear that with the IA process that decision, that agency, will be taken from her. The end result will be that she will exit the Scheme. The irony is that she would need even more support, as a result of the invasive, deficit based, medicalised, 'expert' model of assessment. (Parent of Scheme participant)*

The need for the assessor to be 'independent' of the participant raised several concerns:

- Some people challenged the use of the term, noting that the NDIA controlled the process, so it was not independent; others identified that independence was about not having an established relationship with the person with disability they were assessing.
- The completion of an independent assessment by an unknown or unfamiliar person was raised consistently as a concern by participants, advocates, family members and staff.
    - For example family members expressed concern that negative impacts of the assessment process including anxiety, and distress associated with having to talk about deficits and disability, or retell difficult and complex stories were likely to be greater with an unknown assessor than in the context of an established, supportive relationship.
    - There was also a concern that some participants will not provide information to an unfamiliar person. Others may give an inaccurate representation of their own circumstances that an unknown person would not recognise as needing to challenge.
- Reports from participants and families of participants completing the trial of IAs have already confirmed both have occurred.
- For some, the requirement for independence will increase the complexity of the process for access, rather than simplifying it – as the process increases the number of people who a person with disability needs to tell their story to, including their GP for the eligibility documentation, an assessor, delegate, and an LAC. This was commonly raised as a concern.

There was also very little support for assigning access or budget based on an assessment score.

"Quantifying functional capacity is inaccurate and reductive"

Limited consideration of individual circumstances was identified as having potential to embed inequity, rather than reduce it - people with greater resources were considered more likely to work out how to 'game the system' for better outcomes for themselves or their family members.

Currently, LAC's regularly work with families with multiple participants concurrently to provide a better experience. Some identified this could be lost with the proposed IA approach that focusses on an individual, without full recognition of family/household circumstances.

There was consistent concern raised about a perceived lack of transparency around IA results and decisions, and support for all IA results being made available and greater appeal rights; the inability to review the results of the IA was particularly concerning.

There was interest in how the speed, timing and staging of the rollout, including managing two different sets of requirements would impact on participants and staff, along with a suggestion that transition points be considered to inform timing of requirement for IAs.

Concerns reinforced by trial experience

To date, we have received several reports of problems including:

- no choice of assessor;

- accessibility needs unable to be met;
- limited/no experience of assessors;
- lack of rapport, no preamble or effort to put at ease;
- not a safe or supportive environment to support disclosure;
- assessor having no information about person, context, disability at beginning, not seeking or documenting supporting information;
- repetitive with multiple similar questions;
- challenges understanding complex questions.

A case study illustrating many of these issues occurring in a single assessment is included as Appendix 1.

We believe that all of these issues can be addressed, if the insights from participants, families and carers (and frontline Agency/Partner staff) are taken into account.

A robust quality framework is needed for IAs which steps out best practice, the key skills and competencies required of assessors (in addition to qualifications), and the mechanisms the NDIA will use to monitor, regulate and foster best practice.

It is essential that people with a disability and their families and carers play a leading role in determining what 'quality' looks like to them in Independent Assessments.

The challenges of implementing Independent Assessments are documented in the Independent Assessment Framework (NDIA, 2020(4)). We contend that accurate assessment of function is reliant on:

- The quality of the assessment framework
- Nuanced robust assessment tools sensitive to the impact of disability type and personal characteristics and circumstances
- Clear processes for development, implementation, review and evaluation of the efficacy of the tools, governed by an expert panel that includes experts by experience
- Recognition that living with disability in COVID times requires adaptation to usual processes, and the impact of this on results of standardised assessments has not yet been measured.

There has been a review of the proposed assessment tools using the COSMIN approach, and reliability and validity has been considered, with most, but not all tools meeting the criteria used for the review.

Our consultation identified concerns, including amongst eminently qualified academics and health professionals, that the methodology used and that the selected tools may not be fit for purpose. Three key concerns were identified:

1. Tools used measure functional capacity which does not equate to support need; this is not such an issue for access decisions, but if results are used to inform development of a budget, there is a risk that the budget will not be appropriate for the person's needs
2. Tools were selected to provide a consistency of experience (with a single set of tools for all people in given age bracket) rather than on basis of being suitable or most appropriate for specific disability types
3. Tools selected are appropriate for population research, so will support the provision of data for NDIA use but are not suitable to be used for determining individual support needs.

Accuracy of assessments relies in part on the quality of the tools and related processes. Like NDIA, we recognise the importance of "policy and the processes and tools developed to implement the Independent Assessments … being designed to be inclusive of diverse communities" (NDIS, 2020(1), p 19). No evidence of cross cultural validity was identified during NDIA's appraisal of assessment tool psychometric properties for PEM-CY, PEDI-CAT (ASD), PEDI-CAT (Speedy) or LEFS. (NDIS, 2020 (6), p27-34). Further research should be conducted to determine whether all tools are culturally valid. Some of the tools are available in languages other than English, but they are not all available in Australian indigenous languages, or the most community languages in Australia. The importance of cross-cultural validity and accessibility, including using simple language, translations of written material, and/or interpreter services to support the aim of equity cannot be over-stated, given the diversity within Australian communities.

The standard forms used for functional capacity assessments use complex language. The first question of the CHIEF (Craig Hospital, 2001, p32), used to assess environmental factors asks: "In the past 12 months, how often has the availability of transport been a problem for you? Daily/weekly/monthly/less than monthly/never". The question is long, uses big words and includes multiple issues in the same question. The independent assessment process is already long, but for accurate responses to be gathered, many people will require scaffolding and interpretation to answer effectively. "Can you think about where you wanted to go in the last year? Were you able to get there? Was it hard to get there? What made it hard? Were there places you couldn't get to? Did you have to take a taxi/Uber/Mum's taxi anywhere? Was that because you couldn't get on a train/bus/tram? How often etc" . There is a need for simpler versions and scripts that support consistent responses and participation, that are tested to ensure reliability and validity.

Workforce challenges

Quality assessments are reliant on access to skilled assessors. The consultations identified a range of inter-related issues that impact on (prospective) participants' access to skilled assessors including:

- Skill and expertise of the workforce
- Mismatch between workforce supply and demand
- Mechanisms to monitor and regulate the workforce
- The impact of COVID

Under the proposed reforms, IAs will drive the core of the Scheme – access to funded supports and the level of that funding. As such, the availability of an appropriately skilled, qualified and experienced workforce is key.

Completing the required assessments of a person with disability requires a specific skillset, including the ability to establish rapport quickly, experience in assessment of people with a disability including adapting to ensure accessibility, and understanding of disability and all its complexities. The accuracy of the assessment depends on the assessor asking the right questions and facilitating an accurate description of a person's situation. This will be impacted by their experience, training, depth of knowledge of disabilities and the NDIS itself. The discussion paper does not specify minimum or required standards for the assessors.

Current advertisements for independent assessors offer allied health professionals the opportunity to top up their income, with employment largely casual or short term,. Participants, families and staff all considered it unlikely a casual workforce could deliver a consistently good experience Participant reports of poor experiences during the trial have exacerbated these concerns. The use of sub-contractors is noted to have been permitted under terms of the tender, and confirmed to have been used for IAs by participants who have shared their experiences in the current trial. This amplifies the risks to consistency and quality, and adds greater risks to people's privacy, with their sensitive health information potentially shared with two organisations outside of the NDIA.

Documented shortages in the allied health professions and/or other trained assessors will pose an immediate implementation issue for the timely completion of independent assessments, proposed for all scheme participants over the age of seven. Workforce shortages in relevant allied health fields (Parliament of Australia, 2020(2)) including the three professions most likely to complete functional capacity assessment -psychology, occupational therapy and physiotherapy –, are well documented including by the Joint Standing Committee in their recent NDIS Workforce Inquiry Interim Report (Parliament of Australia, 2020(1)), and the Productivity Commission in the NDIS Costs report (Productivity Commission, 2017). However, despite some attention in Government workforce strategies, shortages persist.

Introduction of independent assessments without the workforce to undertake them will have an immediate impact on timely access to the scheme, compromising the commitment to equity and consistency of participant experience. It will also pose a challenge for participant choice and control.

Geography and related thin markets will also likely pose a problem for the implementation of this proposed policy change. There will be greater challenges, and therefore impacts on participant experience for those living in remote areas. There is strong competition amongst allied health employers, and high vacancy rates already in rural and remote areas with less than 3 per cent of occupational therapists, physiotherapists and psychologists living in remote or very remote areas (Modified Monash MM6-7) (AIHW, 2017).

There is a risk that the intended consequence of improving equity and being inclusive of diverse groups may not be realised due to limitations of the tools and the workforce identified to conduct the assessments. BSL has a long history of involvement with culturally diverse communities, and we recommend training in diversity and inclusion, and cultural awareness as a minimum requirement for assessors.

The consultations highlighted the need for robust monitoring and regulation mechanisms to ensure the adequacy of the assessor workforce and the quality of their work; this is a critical success factor – and the biggest risk – for the implementation of these reforms.

COVID-19 has precipitated greater acceptance of virtual service provision including allied health. This may pose an opportunity to address some of the risks posed by the size and quality of the workforce however it also has associated risks. First, it is unlikely that there will be opportunity for participants living in remote areas to have the same choice of face to face or virtual assessments that city-living participants will be offered. Second, accurate and comprehensive virtual assessments will be very difficult to achieve.

Subjective biases, and the value of a relationship

Many people consulted expressed concern that information gathered by a person not familiar with the person, their circumstances or their way of communicating, would not truly reflect the capacity or support needs of the person, or that an independent assessor may not explore the responses provided by a person in enough depth to be able to appreciate their unique situation and needs. This would potentially reduce funding for supports. Interestingly, the NDIA acknowledges a difference between assessment results for funding purposes provided by a therapist familiar with a person, and an unknown assessor in the Independent Assessment Framework, attributing the difference to "sympathy bias" (NDIS, 2020 (4), p7) rather than a deeper understanding of the participants needs.

BSL's experience suggests that experienced LACs with a longer relationship with a participant are more likely to support them to overcome barriers to participation, and identify more modest expectations of funded supports. LACs regularly to contact people many times and support them for quite some time before they work through their personal barriers, and attend a meeting. There was concern that this level of support would not be provided by an independent assessor to complete the assessment, and that the person may be considered to have withdrawn their access request if they declined an appointment.

Assessment by a person without an established relationship may result in under-reporting for reasons including lack of trust, pride, stigma and compliance effects. There may also be adverse effects including increased anxiety. While it is acknowledged the intention is to recruit experienced allied health workers, these concerns have been confirmed by reports from families who have reported poor experiences during the current trial with participants distressed, or impacted negatively by their experience of an independent assessment.

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> *"How do people with no informal supports get this? I worked with a person who was estranged from family, it took 3 or 4 phone calls to establish rapport. If a stranger called to arrange IA, and they declined it would be seen as withdrawal of access request"*

Some were concerned about participants the number of people involved and times they would have to repeat their story to different people with too many handovers between delegates, assessors and LACs needed on the pathway from access to plan approval.

The Early Childhood Reset recommendations have identified an approach that might reduce these concerns, with 'independent assessments' completed by EC Partner staff (NDIS, 2020(3), a person known to the family, but not responsible for their ongoing support – an approach that might be seen as finding middle ground. This model could be explored for participants aged 7 or 9+ (after EC reset).

Requirement for third party

Under the NDIS Act "*people with disability are assumed, so far as is reasonable in the circumstances, to have capacity to determine their own best interests and make decisions that affect their own lives*" (section 17A(1)). At all points of engagement including access to the scheme and the related assessment we are keen to ensure that these principles are maintained.

While those consulted conceded that use of the third parties may be essential in certain circumstances, they underlined the need for rules and regulations for use of third parties. The discussion paper references "support for decision making policy" that is in development. Our consultations revealed that at minimum this should:

- Specify that a person who has the capacity to represent themselves does not require a third party for an independent assessment
- Include criteria for determining who may require a third party to support their assessment results
- Include criteria for determining how much of the assessment can be completed by a person who knows them well
- Provide guidelines about what will occur when a person has no informal supports, noting the whether this will impact on the outcome of the assessment.

Feedback from participants who have completed the trial to date indicates that the requirement for third party completion of the Vineland assessment was a clear expectation. The discussion paper provides no information to explain how the results of the Vineland will be used or how inconsistencies between the information provided by the person with a disability, and the third party will be managed when determining access and plan budgets.

Alternatives to independent assessment

Under proposed policy, a person with disability cannot choose not to complete an assessment, or it will be treated as a withdrawal of an access request. There is no information available about the support that might be given to enable a person to complete an assessment, nor what will happen should a person discontinue an assessment due to adverse effects.

BSL experience is that some participants need multiple contacts, outreach and support to build their capacity before managing the demands of a pre-planning meeting that typically takes 1 to 1.5 hours. The independent assessment takes double that amount of time, yet there is no reference to support for those who may struggle to attend or to complete the significantly longer, and more rigorous demands of an independent assessment.

We support the possibility of a delegate granting exemption from independent assessment where "individual circumstances may mean it is not possible or reasonable" to complete

(NDIS,2020(1)p21), but believe this should be a reviewable decision. The consequences of the decision to proceed where there are identified risks that a delegate doesn't consider meet the standard for exemption could be significant for a participant or an assessor.

We believe people should have right of review of the results of an independent assessment to address issues relating to the quality of the assessment.

4 Analysis of Access & Eligibility Policy

There was support for the aim of a simpler, more consistent simplifying process for determining eligibility for funded supports, but concern that the proposed two-step process was more complicated.

Our view is that "access" and "eligibility for funded supports" could be considered as two different things: recognising that all people with disability need access to a place to go where they know people will support them. The very act of applying for access is an act of asking for help with disability, regardless of eligibility for funded supports, and regardless of any decision to provide them.

The principle of all people being supported would be strengthened by changing the language so that support for access to general/community supports offered to all people with disability who apply, and funded supports are offered to eligible applicants who meet criteria of significant functional impairment. This change could also apply for eligibility re-assessments to specify that support to access general/community supports will continue when funded supports are no longer required. This may also help to reinforce the sense of celebrating achievement when funded supports are not longer required.

Equitable participation in the access and planning processes is dependent on access to information in language and format suitable for the needs of, and able to be understood by the person, and adequate adjustments to enable participation. The online access request was recognised as an improvement, as an additional way of gaining access, but not as the only option. The proposed reforms are complex, and assessments require comprehension and effective verbal communication in English.

Throughout our consultations it was evident that participants and staff needed additional information to understand what was proposed. There is a need for simple, consistent messaging and language to increase understanding. Challenges included understanding terms, using the same term to describe two different processes, changing the meaning of a term previously used to describe a different process, use of acronyms, and descriptions that didn't actually increase understanding.

Results from the first IA pilot, compared with a "typical population range' suggest 8% of participants assessed were functioning within the typical range, and this interpretation is used to support the case for wider use of early intervention criteria (with greater likelihood of scheme exit), rather than permanent disability supports (NDIS, 2020(5)).

There is no data available regarding prevalence of false rejections (people with access denied, despite limited functional capacity and need), but staff and participants report supporting people with significant functional capacity limitations, and permanent disabilities for whom access was declined. There needs to be clarity of requirements and a clear pathway for people who met initial eligibility criteria but were declined access under current approach to re-apply for access

We therefore support the removal of the lists. The practice of using lists of diagnoses or conditions to inform some access decisions has given a degree of certainty for people with some conditions that that may typically be associated with significant levels of impairment or disability. However decision-making based on diagnosis rather than disability, risks excluding people whose capacity indicates a need for funded support, and including others who may have a diagnosis, but not a significant impairment affecting their functional capacity or social and economic participation.

We agree that a comprehensive assessment of impairment, capacity, performance and participation to be more effective in determining disability than diagnosis..

However, the new requirement to provide all health and disability information, rather than information on primary disability, to be considered for the initial eligibility criteria appears to be inconsistent with this recognition of the central importance of disability-related information. A medical practitioner is required to provide information to confirm a person has a disability, and permanence, to progress to independent assessment, which would not seem to justify the requirement for comprehensive health information. We also note the intention of the NDIA to provide detail on the most appropriate treatment system for health conditions.

We are concerned there is a lack of clarity about the circumstances under which health conditions could exclude people with disability from access to NDIS funded supports. There is a risk that existing conflicts between support systems will be exacerbated.

Participants also expressed concerns that collecting all health and disability information was invasive, and that their sensitive health information would be available to anyone with access to participant records, and that their medical information could be used for research without their informed consent for its use in any given research proposal. Collection of health information should be limited to health issues affecting a person's disability, and access to any health information collected should be restricted, on a need to know basis.

Whilst BSL supports changes to the access process that reduce the cost and other challenges associated with providing evidence to inform access decisions, the requirement for evidence of a person's functional capacity, or the impact of disability is not the only barrier to access. Some people experience considerable difficulty gathering medical information, including their diagnoses due to inconsistent medical care (e.g. children in out of home care, people moving due to family violence); others, particularly some participants with psychosocial disabilities, experience significant challenges attending appointments (in person, by phone or virtual).

LACs currently support people to navigate the access process, and despite the introduction of independent assessments we believe there will continue to be a need for ongoing support for participants to meet the initial eligibility criteria.

Information about how results of independent assessments will be used to inform access decisions is limited at this time. Given the NDIA's commitment to transparency and accessibility, we hope that these will be publicly available in accessible formats by time of implementation.

We recommend that full assessment results are available to participants via the participant portal without requirement to request, and consistent with participant's communication preference e.g. email, letter, braille, and that there is support available for participants to access and interpret the assessment results.

Participants have expressed significant concerns about the limitations to review of access decisions. Results of the independent assessment are used to inform the decision, but are not 'directly reviewable', and a second assessment will only be available "where the assessment was not consistent with the independent assessment framework" (NDIS, 2020(1), p23). However there is no clarity about *how* such an inconsistency will be determined.

We note that the original assessment process recommended by the Productivity Commission included a right of appeal to the "Inspector General" (a role now filled by the AAT).

The framework is a complex document providing requirements of, and rationale for selection of the various elements of the proposed approach, and mechanisms to ensure quality. It will be challenging to compare an individual's experience with the framework, and determine inconsistency. Providing guidance about areas in the framework where inconsistencies may occur, such as an assessor not giving adequate attention to informal observations or personal circumstances, or not demonstrating awareness of sensitivities would improve accessibility of the information and give greater clarity of appeal rights.

5 Analysis of Planning Policy

The proposed planning process flips the current approach to planning, with a budget being prepared and sent to a participant prior to consideration of their goals and aspirations. A familiar event, the planning meeting, has been given a new meaning, and 'reasonable and necessary' is now used to describe funding assigned after considering IA results, rather than supports. Terms used in the recommendations of the Tune review such as draft plans and joint planning meetings have been included in the process, but the terms are used to describe a different activity. The use of known terms can give a sense of consistency to minimise impact of change, but redefining frequently used terms added to uncertainty and confusion during our consultations, and may pose a risk to acceptance and understanding of the proposed changes.

There was considerable discussion about whether plan budgets would be at an appropriate level. Some staff expressed concern that funding might be inadequate for needs, others reported experiences where a plan had been built and submitted, based on goals and needs of a participant, but the cost of supports fell below a typical support package, and funded supports were added, despite not being required.

There is little information available that specifies *how* results of independent assessments will be used to develop a plan or inform plan budgets, and no evidence has been made available of the effectiveness of this approach for assigning funding for supports.

We assume this will be informed by results of the current trial, and use a similar approach to generating a typical support package, based on elements of the assessment results. We are concerned that the proposed approach reduces the flexibility currently available for review of the recommended typical support package, where a person is identified as having a need for funded supports that cost significantly more than the typical support package.

Confidence may be improved if an evaluation of the tools is published to confirm that they can be used to reliably predict the amount of funding required to meet support needs.

As noted in Section 3, functional capacity and support needs are not the same. The difference between functional capacity and support needs may not be adequately considered using the proposed tools, and the resultant plan budgets may therefore not be as closely aligned with needs as if based on support needs.

Further consideration of inclusion of a tool to measure support needs for the trail, and the development of specific assessments that are designed for purpose, should be considered as part of the rollout plan.

It is unclear how information about individual circumstances and environmental factor included in the assessment will be applied to develop a 'personalised budget'. We support the inclusion and consideration of individual factors when developing budgets, recognising that functional capacity alone does not determine need, and acknowledging that equity is not achieved through providing the same to all, but through ensuring support is available for all, based on needs. We sincerely hope that the algorithm that sits behind this approach is sufficiently nuanced to deliver on the commitment to equity. LACs questioned whether the NDIA had considered the difficulties

that would be presented in conducting a planning meeting with a participant who did not agree with draft provided prior to meeting, when the purpose of the meeting is to work through how to use budget/funding.

There was substantial support for the increased ability to use funds more flexibly ("plan flexibility"). The removal of line items and move to (mostly) flexible funding is a significant improvement that reduces the structural complexity of plans.

The main concern respondents expressed around plan flexibility is that the removal of line items specifying specific funding for some supports may create a risk of undue influence over spending decisions, and predatory practices.

Given this, a flexible approach to providing support will be also be beneficial, to enable those who might otherwise struggle, to cope with the demands of decision making and implementing. Regular check ins and improved guidance about decision making will mitigate some of this risk. We appreciate the NDIA's commitment to providing budgeting tools which we expect will be simple and accessible.

Many participants expressed support for longer plan durations, appreciating the certainty of knowing available funding, rather than uncertainty associated with regular scheduled reviews.

Change of circumstances

The planning policy specifies that changes of circumstances will lead to a new independent assessment to inform any updates to the plan. However, in our experience, many changes of circumstances are caused by changing arrangements for carers or housing and do not relate to individual functional capacity changes.

It may be more efficient for the process to provide scope for increasing funds in response to changes in circumstances without an IA.

Choice and control – all the way through?

Some of the planned changes are inconsistent with the stated intent of increasing participant choice and control. Participants can have input into, but not decide on plan features such as frequency of check ins, release and management of funds, and proportion of fixed and flexible funding, with delegates having decision making responsibility. Some participants thought these decisions should be theirs to make, unless there were risk factors identified.

Regular check ins are important as a valued mechanism for ensuring people have the right support in place at the right time, identifying risks for participants who may be vulnerable to isolation, exploitation or harm, and seeling to ensure issues with plan spend are identified and addressed. However, the revised process makes no reference to supports, focussing instead on changes in circumstances and plan spending. We recommend check ins continue to include a review of adequacy and efficacy of supports, as earlier identification mitigates the risks associated with inadequate supports, including to health, safety or functional capacity.

Participants appear to have less choice and control over the check in process, with delegates responsible for the decision of check in frequency and noting that a participant can re-book but

not cancel. This is suggestive of a shift to a compliance, rather than supportive model, and was raised as a concern in several of our consultation sessions. It is not clear what will occur if a participant cannot be contacted for a check in, and we recommend this be clarified.

We recommend participant choice be respected wherever possible, and for the focus of check ins be on supporting participants. We believe a quarterly check in should be scheduled for all participants as a minimum, and the decision re need for more frequent check ins be made by a participant recognising them as the experts in their own needs wherever possible, and this principle be included in the planned support for decision making policy.

6 Recommendations

RECOMMENDATION A: Nothing about me without me

1. Promote the principle of people with disability as experts in their own needs, and support their rights as decision maker wherever possible, and include this in the supported decision-making policy;
2. Ensure use of third parties is based on need/capacity, recognising that a person who has the capacity to represent themselves does not require a third party for an independent assessment;
3. Clarify how Vineland will be completed where a person has no informal supports; how the results of the Vineland will be used & how inconsistencies between the information provided by the applicant/participant and the third party will be managed.
4. Ensure full assessment results and reasons for decisions are available via the participant portal and a copy provided in a format consistent with participant's communication preference and that there is with support available to access and interpret the assessment results
5. Ensure access to information in languages and formats to suit individual needs.
6. Provide accessible and simple budgeting tools including ability to model packages of support, and costs.
7. Enable participants to be decision makers for their plan administration – duration, payment frequency, check in frequency, fund management - wherever possible, with delegate responsibility in response to identified risk or as per supported decision making
8. Limit collection of health information health issues affecting a person's disability, and ensure access to health information collected is restricted, on a need to know basis

RECOMMENDATION B: Measure twice, cut once

1. Defer implementation to enable completion and evaluation of trials and reforms are effective in meeting the objectives of the NDIS, and to build buy-in from people with a disability and their families and carers.
2. Ensure there are measurable objectives assessed against the Objects of the NDIS Act
3. Ensure assessment tools are fit for purpose in a broader range of circumstances:
    a. Conduct further research to determine whether tools are culturally valid, and as reliable virtually as face to face
    b. Identify or develop a simpler assessment tool(s) and scripts that support consistent responses and participation, that are tested to ensure reliability and validity.
    c. Include a support needs assessment tool in trial

4. Consider trialling 'independent assessments' completed by LACs (trained in assessment), alongside the current independent assessment trial, monitor their performance including ensuring inter-rater reliability, and complete a comparative evaluation prior to full roll out of the proposed approach

RECOMMENDATION C: Commit to quality

1. Add "Dignity" and "Accuracy" to the goals of the reforms.
2. Establish a robust quality framework for independent assessments including:
    a. Practice standards, key skills and competencies required of assessors
    b. Mechanisms to monitor, regulate and foster best practice
    c. Strategy/ies to support diverse groups
    d. Review of feedback and complaints to inform and monitor implementation
3. Appoint an external body to oversee the evaluation of the trial and implementation

RECOMMENDATION D: The right support at the right time

1. Ensure there is support offered for each person with disability who asks for help ('applies for access') - consistent with principles of the Act
2. Ensure support is available for people with disability throughout the process of access and planning, implementation and review
3. Develop participant statement and goals at the same point in the process as independent assessments
4. Implement as per Productivity Commission "Suggested assessment process for tier 3" (Figure 7.3, Productivity Commission 2011 p336) to have LAC present at Independent Assessment from while assessment is conducted

RECOMMENDATION E: A plan for all

1. Consider the concept of 'a plan for all': Each persons access request triggers a referral to LAC for a plan which includes goals, building capacity and introductions to community and mainstream services; the plan may or may not include NDIS funded supports.
2. Provide support for people who are ineligible for funded supports to access community and mainstream supports
3. Change language of Eligibility Reassessments to specify that support to access general/community supports will continue when funded supports are no longer required

RECOMMENDATION F: Provide more information

1. Explain how results of independent assessment will be used, and how other information is to be considered to inform access and planning decisions
2. Ensure results of independent assessments are able to be corrected where inaccurate, and content and decisions are reviewable, in line with the recommendations of the Productivity Commission
3. Clarify what happens if a person cannot complete an assessment once commenced
4. Clarify what will occur if a participant cannot be contacted for a check in, and ensure the approach is supportive rather than compliance-focussed
5. Provide guidance for requesting exemptions from IA, alternative information requirements and ability to review decision not to grant an exemption
6. Provide guidance about areas in the IA framework where inconsistencies may occur to improve accessibility of the information and give greater clarity of appeal rights
7. Fund costs of gathering information required for access decisions for people who are granted an exemption from an independent assessment.

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Appendix 1: Participant experience of Independent Assessment

Experience of Victorian scheme participant as reported to BSL:

They rang at 3pm on the day before the assessment, and asked can I do it at 9 am tomorrow. I said that wasn't much notice and asked if I could do it later in the day, but they said No, they only had this option available. I felt like I needed t be there, there was no other option. I had to cancel [work commitment]. There was no suggestion of we could do it another day.

The assessor rang to confirm two hours later, and my wife answered. She passed the phone to me, and the assessor just said "hello?", She sounded like a friend in distress, and I thought, oh my god, what's wrong? There was no introduction of who she is or where she is from.

I didn't know what to expect but went in to it with an open mind. As an LAC, I was thinking how would a brand new person experience this.

She was a young OT, and began telling me this was her first ever assessment. She said her supervisor would sit in, but he came half way through. My training says never say this. We know it's a trial so there isn't a lot of experience.

I was at home, and my internet connection is fast, but there were delays and her connection was not good.

She read out some information about stored on servers in Canada for privacy reasons but no information about how this was used

She gave me a rundown on the tests. She said the Vineland needed a family member or carer. In the paperwork, it mentioned needing to talk with someone but no clear impression, and I thought they would call later. When they planed it yesterday, they didn't refer to the need. My wife had gone to work, so they didn't do it.

At the start, she said she needed to see me doing things around the house. I had a desktop computer, so I asked how it would work. The information didn't say to be on a mobile so they could follow. She left it until the supervisor joined. He said to go and make coffee and bring it

back, but I said they wouldn't see how I did it. They asked me to get a book from the shelf, and said that's ok, but the paperwork said 20 minutes observation.

She had no information about my disability, just that it was a physical disability. She didn't ask if there were other things. I have [additional issues] as well as my [physical disability] . Having so little information seemed like a lack of courtesy. I think they need at least person's name, circumstances, disability type and some basic information, and especially if they were dealing with an intellectual disability, some notes would be vital.

I felt that the answers were not giving a good reflection of my disability. Questions asked about last few days but we have been in lockdown. Last 30 days, last 12 months are during COVID. They don't give an indication of what I can do.

She was reading off the screen, and kept going out of the frame which was very disconcerting. There was no extra information, and no time to build rapport. I volunteered extra information but I got a sense she just wanted me to give the no/mild/moderate response. She had handwritten flash cards which she held up to the screen and that was disconcerting

Tests seemed repetitive, asking same questions over and over. I know some participant will crack it and say I've already told you.

The scheme for life, and this process don't match up

Questions were loaded, and I felt if I answered them the wrong way, my funding would be reduced. It didn't give me confidence.

Im interested in seeking the results, everyone in the office wants to have a chat.

I kept thinking how will it work as an LAC? We will be copping plans with no information, no goals, no statement , no questions about daily life.

There were questions: how is your sexual function? with no warning, no introduction. Are you continent? No preamble or context and I wasn't expecting those questions. I'm getting older and things don't work as they did. There was no teasing out of whether disability related or another cause.

The scale gave no examples and was hard to rate, with no options in between.
None/Mild/Moderate

Big problem or a little problem – how does that matter?

There was no teasing out to get the rights answers, and that's a big part of it; Literally got the question and nothing else.

The jargon needs interpreting by the assessor, if it was a first interaction, it would be very disconcerting. I have a really strong understanding of health and disability, and I felt like laughing, but from anxiety. People will either want to cease or have increased anxiety.

Did not give me any incentive to value the experience. I've always felt there was a need for consistent individual assessment for people to get access, but this is not it.

My wife was called the next day to ask her to do the vineland tool, she advised her only time available is Tuesdays. I work from home on Tuesdays and she wanted me close as she is not confident with video conferencing.

I received an email confirming that the appointment for her would be on Monday. She has a dentist appointment at this time so had not agreed to that.

I attempted to call the supplied number to point out the error and the number kept asking to press 1 for appointment issues, but then just goes blank for a few mins and repeats. I tried 3 times and gave up.