# Strengthening Scheme Reforms to Access and Planning

Independent Advisory Council to the NDIS
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## Executive summary

The Independent Advisory Council (Council) to the National Disability Insurance Scheme (NDIS) was requested to provide advice by the National Disability Insurance Agency (NDIA) Board and Senator the Hon Linda Reynolds CSC, Minister for the NDIS, on Scheme reforms, including independent assessments. Council convened a consultation process to assist in the development of this advice.

The objectives of the consultation were:

* to hear from the Council and wider disability community regarding concerns raised, including what issues require further engagement and how further engagement should occur
* to provide guidance to the NDIA Board and Minister on what specific changes need to be incorporated to the Government’s access and planning proposals, including independent assessments, in advance of the Minister’s planned consultation on exposure drafts of the legislation.

This advice consolidates feedback from consultations with the disability community[[1]](#footnote-2)*.* The recommendations aim firstly to make the proposed changes to access and planning simpler, fairer, more respectful and safer for participants. Secondly, the recommendations seek to rebuild trust with the disability community through a more transparent, collaborative and forward-looking approach to ensuring the NDIS meets its objectives relating to participants and sustainability.

The feedback on which Council’s advice is developed was constrained by the timelines for consultation, dictated by the timing of the next meeting of the Ministerial Council[[2]](#footnote-3). Given these time constraints, the consultation proved challenging, and consultations would have been enhanced by a greater attendance and diversity of participants including but not limited to people: with disabilities, from Aboriginal and Torres Strait Islands, from culturally diverse backgrounds and families of young children. Council advice however reflects views expressed at these meetings and Council strongly recommends that future consultations engage in meaningful ways with key state and territory groups and participants in determining nature and priority of future Scheme reforms.

Many individuals participating in the consultations recognised that the Scheme needed to be fairer and more equitable and returned toward the vision outlined in the [2011 Productivity Commission Report](https://www.pc.gov.au/inquiries/completed/disability-support/report) in which assessments[[3]](#footnote-4) were a foundational element to ensure equity. The NDIA stated that the lack of a valid, reliable approach to measuring participant needs has led to inconsistency and inequity in plan decision making so that people with similar disabilities in similar circumstances receive different amounts of support. The NDIA also outlined factors that had led to an unaffordable growth in expenditure challenging Scheme sustainability.

Consultation participants outlined additional challenges to Scheme sustainability that had resulted from the many other foundations of the Scheme and its ecosystem that were also never developed, were poorly implemented, or underfunded. Participants stressed that a focus on independent assessments in the absence of commitments and supporting funding to address shortcomings of other weak foundations such as the National Disability Strategy (NDS) and Tier 2 [Information, Linkages and Capacity Building (ILC)](https://www.ndis.gov.au/community/information-linkages-and-capacity-building-ilc) program would not meet the Scheme’s objectives for participants or address underlying sustainability challenges.[[4]](#footnote-5)

Some of the foundations identified lie outside the responsibility of the NDIA and include a poorly funded and inconsistently implemented first NDS, lack of independence of the NDIA from the Department of Social Services (DSS) and insufficient and inadequately directed investment in Tier 2 to enable a well-funded ILC and a strong network of Disabled Persons Organisations[[5]](#footnote-6) and Family Organisations. Responsibility for other foundations fall to the NDIA with limitations identified in the inadequacy to date of a Local Area Coordination (LAC) strategy to support people with disability to be included in the community, the inadequacy of participant support for decision making and capacity building, and the inadequacy of pathways from group homes to individualised living options. Council recognises however the work currently being undertaken by the NDIA on “A new approach to home and living”, Support for Decision Making, and the ability for scheme reforms to change the priorities of LACs away from planning to plan implementation and community building.

The Board and the Minister requested the Council to provide formal advice related to specific changes to the access and planning proposals, including independent assessment, not whether these changes should go ahead. Consultation participants provided feedback on options aimed at addressing participant and community concerns about independent assessments and Council developed a set of recommendations that aim to make independent assessments and the use of the yet to be finalised Personalised Budget Model (PBM) simpler, fairer, more respectful, and safer for participants.

Council recommended that independent assessments not proceed in the current form as conducted in the pilot and that the independent assessment and PBM are co-designed with Council and representatives of Disabled Persons’ Organisations. Furthermore, Council recommended that the draft legislation outlining changes to access and planning is made public in highly accessible formats for a minimum of 8 weeks to provide greater transparency and enable the disability community to provide meaningful feedback. Recommendations aimed at making the use of independent assessments and the Personalised Budget Tool simpler, fairer, more respectful, and safer for participants are described below.

Recommendations related to the conduct, review and quality assurance of assessments seek to address participant concerns about the validity, reliability, sensitivity and responsiveness of the assessment and assessors.

Recommendations related to the PBM seek to establish a quality assurance framework, supported by a robust review process, to address participant concerns that an algorithm cannot do justice to the breadth and depth of the challenges and support needs arising from their disability in their unique personal and environmental circumstances. These recommendations strongly highlight the need for more effective engagement and co-design in this area, ultimately leading to the greatest possible transparency about the fairness and operation of the Personalised Budget Tool.

Recommendations related to implementation, governance and review seek to give assurance to participants that a new system (that is viewed with great concern and suspicion by the disability community) is reviewed by the external eyes of Council and representatives of Disabled Persons’ Organisations through co-design and increased oversight. The advice has made recommendations to the Minister that the NDIS Act retains goals and aspirations as part of reasonable and necessary supports, that plan budget decisions remain reviewable and appealable, and the Act includes strengthened safeguards related to support for decision making and participants experiencing multiple disadvantage.

Recommendations related to provider practice (directed at the NDIA and the NDIS Commission), the relationship with the disability community (directed at the NDIA) and with the whole of government (directed at the Minister) position the access and planning proposals in the broader context of the erosion of trust in services, in the NDIS and in governments more generally. Participants want Governments to be respectful and to live up to their rhetoric about citizenship and inclusion in a welcoming community. In this context, the advice recommends strengthening Tier 2 with an additional and independent budget allocated to the NDIA and a plan for its investment co-designed with Council and representatives of Disabled Persons’ Organisations.

The rebuilding of trust was a major theme of the consultation, acknowledging that independent assessments galvanised existing frustrations into action. The contested view of the purpose of the reforms heightened distrust and when independent assessments were described as a process to achieve equity and support Scheme sustainability, many participants feared a loss of support or that they would be ‘exited’ from the Scheme. The challenges associated with the failure of the first NDS contributed significantly to their perception that Scheme exit is unsafe in the absence of any alternatives in the community or mainstream service systems.

Despite many proposed NDIA reforms being focussed on participant experience, erosion of trust has occurred as a result of persistent challenges experienced by many participants. These challenges arise from:

* unfulfilled commitments by individual Local Area Coordinators (LACs)
* staff turnover
* frequent, inconsistent and poorly communicated policy and guideline changes
* reasons for the reduction in plan budget not understood
* participants funded into group homes[[6]](#footnote-7) despite policy intent of less restricted alternatives
* wait times for assistive technology; and
* adversarial responses to reviews and appeals.

NDIA has recognised many of these challenges that were documented in the Tune Review and has made a significant commitment to improve service delivery through the Participant Service Charter and Participant Service Improvement Plan.

The NDIA’s lack of transparency around challenges facing the Scheme contrasted with the language often used by the NDIA on ‘co-design’ and ‘partnership’. Representatives of the disability community felt side-lined. They wanted to contribute to the Scheme as partners, to analyse challenges and co-design solutions that work for participants and meet Scheme objectives. They acknowledged that trust is a two-way process and expectations need to be clarified. They called for the establishment of a compact that:

* outlined clear expectations about the relationship between the NDIA and the disability community and for practical steps to rebuild trust; and
* outlined some key features of effective collaboration and co-design that support existing governance and statutory responsibilities
* identified priority areas for collaborative work that will provide the opportunity for mutually beneficial meaningful engagement and more participant focussed outcomes.

Council cannot claim that the changes recommended will secure support for the introduction of independent assessments. Council believes that significant concerns about the assessments need to be meaningfully addressed and mitigated through:

* key changes to the conduct of the independent assessments as outlined in the recommendations of the advice
* the NDIA’s future engagement with Council and the broader disability community.

Council heard varied views on the question of timing of the implementation of access and planning proposals in relation to the release of the draft legislation. On one hand, Council felt it would not be meeting its responsibility to participants to affirm changes that could have such a profound impact when legislative changes had not been reviewed. On the other hand, Council has become increasingly aware of the sustainability challenges and their significant risk to the Scheme’s future. In response to the Tune Review’s Rec 4 (calling for improved guidance and clarity on the application of the ‘Reasonable and Necessary’ test) and in the absence of consistent and reliable measures of participant need, the NDIA is increasingly tightening administrative rules on reasonable and necessary supports to control costs. These changes reduce transparency, result in reductions in plan budgets for some participants and impact on participant choice and control. Council is of the view that secrecy erodes trust and thereby, calls upon the Minister to release the draft legislation with a minimum of 8 weeks consultation. Council further offers to assist DSS with the co-design of a consultation process that would facilitate the views of people with disability, their families and carers.

Council is looking to any legislative changes around access and planning to provide enhanced requirements in relation to support for decision making that takes a lifespan approach and strengthened safeguards around participants experiencing multiple disadvantage including on the basis of gender, Aboriginal and Torres Strait Islander and culturally and linguistically divers background, people who are LGBTIQA+ and people requiring complex support.

The disability community wants to work in partnership with the NDIA on the development and implementation of key Scheme reforms and Scheme sustainability. Respectful listening and collaborative work to address gaps identified in this advice will contribute to the rebuilding of trust. Council submits the following recommendations to provide a way forward.

## Recommendations

All recommendations are directed to the NDIA unless otherwise identified.

### Access and Planning Proposals

Council recommends that:

1. Independent assessments do not proceed in the current form as conducted in the pilot and that both the independent assessments and the Personalised Budget Tool are co-designed with Council and representatives of Disability Support Organisation to be simpler, fairer, more respectful and safer for participants.

Council recommends that the Minister

1. Makes public the draft legislation outlining changes to access and planning for a minimum of 8 weeks to enable the disability community to meaningfully provide feedback and enhance transparency by making reform priorities explicit.

#### Independent Assessments

That the NDIA make changes to independent assessments to ensure that they meet the objects of the NDIS Act 2013 (Cth) and provide safeguards for participants. Recommended changes include:

3. Conduct of assessments

* 1. All elements of the independent assessment design, including the toolkit and practice guidance, should be designed in partnership with the disability community to deliver flexible approaches to the greatest extent practicable for the most complex participants that do not have supports, have experienced trauma or have complex behavioural support needs. Sequencing of design and implementation should be built in genuine co-design with the disability community, with an agreed path forward which allows the necessary time to design for participants with most complex needs in the most complex situations.
	2. Design of independent assessment tool kit and processes should include ‘simplicity’ as a guiding principle. Many participants currently find navigating the NDIS to be a complex task and are concerned that another layer of complexity may be added to their experience.
	3. Provision for matching assessor to participant in relation to allied health speciality as a priority with a commitment to match gender and cultural safety and literacy where requested and possible.
	4. The employment of people with disability and direct family members as disability experts in an expert advisor role, with advice and training available to all assessors about appropriately supporting people with disability through the assessment process and/or assessment methodology, for example auditing requirements of an assessor organisation or participating in an assessment team.
	5. Participants, family members and carers are recognised as a primary source of information.
	6. Specific co-designed practice guidance is required for independent assessments for participants:
		1. In transition from institutional environments, including but not limited to people transitioning from hospital, the criminal justice system, Residential Aged Care, out-of-home care or who experience sudden changes in health or living.
		2. In group homes, with particular reference to people who lack informal support
		3. Who experience multiple disadvantage including on the basis of gender, Aboriginal and Torres Strait Islander and culturally and linguistically diverse background and LGBTIQA+ identity.
	7. The sharing of appropriate pre-existing information with an assessor before assessment. With the pre-existing information being available and being required to be considered by the assessor and any delegate of the NDIA throughout the access and planning process including for reviews.
1. Review of assessments
2. Prior to NDIA decision making, participants are able to review their assessment to ensure it is a true and accurate reflection of their functional capacity and the information they provided to the assessor.
3. A clear and transparent quality assurance and complaints process is developed so that participants can make corrections, a complaint or seek a review of the results of the independent assessment before it is used for Agency decision making.
4. NDIA contracts with Assessment Organisations
	1. There are clear rules regarding the contractual terms that organisations engaging assessors are engaged upon, including but not limited to:
		1. Skills and experience required.
		2. Collection of data on number of assessments completed, outcomes of assessments, complaints made, participant satisfaction, performance reviews by representative bodies, employment of people with disability and enaction of Disability Action Plans with high level data to be reported back publicly.
		3. Transparency in the reporting of key performance metrics for assessor organisations including:
			1. Adequate flexibility in time per assessment to ensure all documentation is considered and the person with disability has sufficient input to the assessment.
			2. A ban on any key performance indicator for assessor organisations based in any way on potential or actual participants in the NDIS being denied access or no longer being participants on the NDIS.
		4. A ban on contracts that do not enable face-to-face assessments. The exploration of the use of Aboriginal Community Controlled Health Organisations to undertake assessments on their own or in partnership with others may assist in providing face to face assessments in remote areas.
		5. Once an accreditation process is established contractual obligations on assessment organisations should require the use of accredited assessors only.
5. Training of assessors and assessor organisations
	1. The development and delivery of training to assessment organisations and assessors is co-designed and delivered with and by representatives of Disabled Persons’ Organisations[[7]](#footnote-8)
	2. Minimum annual levels of training per assessor are required, with specialist training required to undertake assessments for individuals with complex support needs.

#### Personalised Budget Model (PBM)

Council is unable to provide advice in relation to the PBM because it is still in development and not available for review. Council however proposes the following considerations:

1. Development
	1. Is consistent with the objects of the NDIS Act
	2. Is co-designed with Council and its Reference Groups and Disabled Persons’ Organisations
	3. Ensures transparency (being a clear record and explanation of how a personal budget has been calculated), timeliness and sufficiency
	4. Is sensitive to participants who receive whole of life supports from one provider, recognising the need for additional decision support to transition to a support from multiple providers
	5. Supports the sustainability of the NDIS.

#### Implementation, governance, and quality assurance of IAs and PBT

1. Information
	1. The development of information for participants about independent assessments and the use of the PBM is co-designed designed and delivered in a range of accessible formats including Easy English, Plain English, Auslan and video with representatives of Disabled Persons’ Organisations.
2. Implementation
	1. The implementation of independent assessments and the PBM should not begin until
		1. Further Council advice has been informed by viewing the draft legislation
		2. A cohesive Scheme reform co-design process has been agreed by Government and the disability community. Implementation should proceed slowly to allow for ongoing development of systems and assessor and planner skills, and continuous improvement; and informed by the Joint Standing Committee
		3. Support for decision making policy has been finalised and is being implemented
	2. Any reduction in plan budgets arising from the use of the PBM or decision to exit a participant from the Scheme resulting from an IA involves a stepped down approach in a transition period with the provision of support to participants to reorganise support and to mitigate risks related to safety, including access to community/ILC supports, and a streamlined access pathway for re-entry if required.
3. NDIS Act

Council recommends that the Minister that in any changes to the NDIS Act:

* 1. The definition of reasonable and necessary supports as set out in s34(1)(a) and informed by s33(1) in the NDIS Act continues to include a reference to the “goals, objectives and aspirations included in the participant’s statement of goals and aspirations”.
	2. A plan budget decision remains reviewable and appealable under the NDIS Act. Adequate support is provided to people with disability within the assessment, review and appeal process through advocacy, user led organisations and appropriate agency processes. This should be measured through self-reports from participants with data made publicly available.
	3. Key safeguards are incorporated in the Act including strengthened
		1. Lifespan approach to support for decision making
		2. Safeguards around participants experiencing multiple disadvantage including disadvantage including on the basis of gender, Aboriginal and Torres Strait Islander and culturally and linguistically diverse background and people who are LGBTIQA+ and people requiring complex support.
1. Governance, quality assurance, and improvement of independent assessments and PBT
	1. Council and its Reference Groups have a lead role in the ongoing oversight and continuous improvement of the Quality Assurance Framework, Assessor Competency Framework, and Independent Assessment Toolkit and Personalised Budget Tool.
	2. Work is undertaken to commence the development of a proprietary independent assessment tool kit that is fit for purpose and includes tools related to cultural diversity. The toolkit to be co-designed with representatives of Council and Disabled Persons’ Organisations, and to draw on NDIA data and expert review.

Council recommends that the NDIS Commission

* 1. Works with the NDIA, Council, key professional groups and the disability community to establish an accreditation process of assessors including for assessor agencies. The accreditation process will use panel review processes that include representatives of Disabled Persons’ Organisations.
1. Statutory review

Council recommends that the Minister makes provision for statutory review of independent assessments, the PBM, and their impact on plan budgets and outcomes for people with disability. Initial review after two years and a progress review after five years.

### Relationship with the disability community

1. The NDIA works with Council and key representatives of the Disabled Persons’ Organisations to develop:
	1. A compact or partnership agreement to outline expectations for working together that recognises the statutory decision-making responsibilities of the Board and the NDIA, utilises co-design to ensure that these accountabilities are achieved and moves toward best practice co-design in a statutory environment.
	2. A roadmap of, and framework for engagement on issues including
		1. Scheme reforms of:
			* independent assessments
			* the development of the plan budget
			* planning
			* strengthening choice and control
			* a lifespan approach to funded and unfunded supports for decision making
			* budget flexibility with support
			* home and living ensuring coherence of interim decisions with policy intent
			* employment.
		2. A strategy to build transformational investment for contemporary supports
		3. Revised Local Area Coordination strategy.
		4. Ensuring that the NDIA take a lifespan approach and includes the voice of children
		5. A transparent forward view on the sustainability challenges the Scheme faces and how the NDIA intends to tackle them.
2. Council recommends that the Minister acknowledges the financial implications of the NDIA’s commitment to effective collaboration and co-design, (including funding for Disabled Persons’ Organisations that participate in co-design work) and views this as a fundamental component to addressing sustainability challenges.

### Provider Practice

1. Council recommends that the NDIA in its market stewardship role:
	1. Stimulates the use of evidence-based provision of supports with safe and self-directed pathways from group homes to mainstream, community living options.
	2. Uses the flexibility enabled by the personalised budget process to promote diversity of opportunity for participants in selecting a wider range of service providers.
	3. Addresses gaps in service provision and workforce availability. For example, provider of last resort in remote areas.
2. Council recommends that the NDIS Commission strengthens:
	1. Its model of good practice for providers by the establishment of a participant voice at the governance level of the Commission.
	2. Its registration requirements on providers to require
		1. Avoidance of client capture except in exceptional circumstances for which criteria are clear.
		2. Avoidance of conflict of interest for participants in Supported Independent Living (SIL) with the one agency providing support coordination and SIL other than in exceptional circumstances such as in rural and remote areas
		3. The use of evidence-based models of service provision
		4. Providers to be accountable to participants for the achievement of outcomes
		5. Providers to demonstrate that they are employing people with disability and have people with disability in governance roles.

### Whole of Government

1. Council recommends that the Minister make representations to the Disability Reform Ministers to seek:
	1. More equitable and sustainable funding base be negotiated between Governments to fund the Scheme. This includes ensuring that the NDIA is funded to operate effectively in the service of people with disability and their families.
	2. A reaffirmation of the commitment to the insurance principles of the Scheme including transparent monitoring and reporting, with oversight of an independent skills-based governance board that includes commercial and other appropriate expertise to manage an insurance scheme of this size and complexity and a legislatively based powerful advisory council
	3. Feedback on the appointment of additional members with lived experience.
	4. A funded commitment by all partner governments to a strong National Disability Strategy that
		1. Is implemented and monitored by strengthened National and State-based Disability Councils working together with appropriate National and State oversight bodies
		2. Includes increased funding and a co-design plan for a revitalised Tier 2
		3. Reports annually to Parliament and the Australian people on the achievement of measurable outcomes
	5. The strengthening of Tier 2 with the implementation of an additional and independent budget allocated to the NDIA and a plan for its investment be co-designed with Council and representatives of Disabled Persons’ Organisations.
2. It is proposed that 1% of total NDIA expenditure on support be allocated for this purpose and be distributed locally across Australia in accordance with the population of people with disabilities. This quantum of investment would be comparable to the $200m originally recommended for this purpose for the Productivity Commission in 2011, approximately $270m in the current year to about $350m over the forward estimates. If this approach is adopted the ILC could be redesigned to focus on delivering improved accessibility of government services and raising awareness of the services throughout the community of people with disabilities to support DSS’s responsibilities for the NDS while maintaining alignment with broader NDIA objectives and linkages with Council.
3. If Government does not agree with this proposal, ILC should return to NDIA with resources outlined above.
	1. A commitment to expeditiously review and determine the responsibilities of the NDIS and other mainstream service systems and a commitment to ensure more seamless support for participants across the interface.
	2. A clear strategy that facilitates open employment.

## Introduction

### Purpose of Advice

The Independent Advisory Council (Council) to the National Disability Insurance Scheme (NDIS) was requested to provide advice by the National Disability Insurance Agency (NDIA) Board and Senator the Hon Linda Reynolds CSC, Minister for the NDIS, on Scheme reforms, including independent assessments. Council convened a consultation process to assist in the development of this advice.

The objectives of the consultation were:

* to hear from the Council and wider disability community regarding concerns raised, including what issues require further engagement and how further engagement should occur
* to provide guidance to the Board and Minister on what specific changes need to be incorporated to the Government’s access and planning proposals, including independent assessments, in advance of the Minister’s planned consultation on exposure drafts of the legislation.

This advice consolidates feedback from the disability community into recommendations that will make proposed changes to access and planning fairer and safer for participants. It acknowledges the criticality of key foundational elements of the Scheme and recommends additional and independent funding for Tier 2 be allocated to the NDIA and a plan for its investment co-designed by Council and representatives of Disabled Persons’ Organisations. The advice also recommends the development of a compact between the NDIA and the disability community to rebuild trust with an outline of priority areas for a more transparent collaborative approach to ensuring the NDIS returns to sustainability.

The consultation process supporting the request for advice was designed by Council with the support of NDIA staff. It was independently facilitated and commenced in Sydney on 10 and 11 June with a forum of Council Members and nine others drawn from its Reference Groups and Disability Representative Organisations (RDOs) who attended in their own capacity, to strengthen expertise and to ensure wider input from the disability community. Consultation also included the NDIA’s CEO Forum and meetings convened by State and Territory Disability Advisory Councils or their equivalent.[[8]](#footnote-9) The draft advice was discussed at a meeting of Council and representatives from the two-day forum, held on 1 July, and subsequently approved by Council.

This advice has been drafted to advise the Board and the Minister on what specific changes needed to be incorporated to the Government’s access and planning proposals, including independent assessment, not whether these changes should go ahead. The short timelines for consultation, dictated by the timing of the next meeting of the Ministerial Council made the consultations challenging and may have unintentionally excluded people with certain types of disability and people from particular cultural backgrounds due to lack of diversity of attendees at the State and Territory arranged consultations. The Council has also not seen any draft legislation or the final design of any suggested Scheme reforms. The Council is strongly of the view that for any meaningful Scheme reforms to take place it is necessary for any legislative or Scheme reforms to involve an accessible consultation process, which is mindful of the need for participation of people with disability and their families. This consultation needs to occur over an extended time period and include specific accommodations for individuals with complex support and communication needs, from different cultural backgrounds and/or living in rural and remote Australia.

## Community feedback about access and planning proposals

### Shared vision of the NDIS returning to its original intent

Many individuals participating in the consultations recognised that the Scheme needed to be fairer and more equitable and returned toward the vision outlined in the [2011 Productivity Commission Report](https://www.pc.gov.au/inquiries/completed/disability-support/report) in which assessments were a foundational element of Scheme design.

The Productivity Commission recommended that “assessments would be conducted by allied health professionals approved or appointed by the NDIA and trained in the use of the tools.” Key points of the proposed process were that “assessors would be continually assessed for their appropriate use of the assessment tools; the assessment would not be ‘rubber stamped’. Prior to making budgetary decisions, the NDIA would confirm that the particular assessment followed the appropriate protocol and was consistent with a ‘benchmark’ range of assessed needs of other people in similar circumstances. Deviation outside the norm would require further investigation”.[[9]](#footnote-10)

The NDIA stated that the absence of a valid reliable approach to measuring participant need has led to inconsistency and inequity in plan decision making, so that people with similar disabilities in similar circumstances receive different amounts of support. The NDIA also outlined factors that had led to an unaffordable growth in expenditure, challenging Scheme sustainability.

Consultation participants gave clear messages that there is a myriad of other foundations of the NDIS and its ecosystem that were also never developed, poorly implemented, or underfunded that have contributed to challenges in Scheme sustainability. The strongest message across consultations was that a focus on independent assessments in the absence of commitments to missing, underdeveloped and underfunded foundations will not meet the Scheme’s objectives for participants or address underlying sustainability challenges.

Participants described missing and poorly implemented foundations as:

1. The poorly funded first NDS.
2. The lack of investment in Tier 2 including a well-funded and well-directed ILC, a strong Disabled Persons’ Organisation network, a LAC strategy that supported people with disability to be included in the community and the National Injury Insurance Scheme.
3. The independence of the NDIA from the DSS, and the impact of this influence on, for example, time frames that undermine efforts at collaboration and co-design, and investment in an appropriate IT system.
4. Governance and funding arrangements between the States, Territories and the Commonwealth whereby challenges to Scheme sustainability have little impact on States, and challenges at the interface leave participants without often critical support.
5. Participants left without effective support for decision making and a vision of a contributing life and ineffective planning leaving them without the right supports to achieve their outcomes.
6. The ineffective market stewardship role with inadequate stimulation for innovation to provide, for example, clear pathways from group homes to individualised living options and gaps in service provision, for example, provider of last resort in remote areas.
7. Providers that have captured participants in traditional service models with little accountability for the lack of achievement of outcomes.
8. The adversarial rather than collaborative nature of reviews and appeals, and the absence of a process to assist participants and their families understand the reason for the plan budget decision and assist them to make effective use of their plan prior to seeking a review.

Participants at the final consultation meeting on 1 July received a written update about the ILC program under DSS outlining the aim of DSS as “to maximise alignment with the priorities of the new National Disability Strategy (NDS), which is being developed following extensive consultation with the disability sector.”

Consultation participants, especially those who had been involved in the design of the Scheme were concerned that the briefing indicated a move away the desired intention of people with disability being heavily involved at all stages of Tier 2 capacity building. Rather, the update envisaged a heavy reliance on bureaucratic structures and decision-making by governmental committees and Commonwealth-State negotiations, acknowledged to be a necessary part of achieving an enhanced National Disability Strategy for the period 2020 to 2030 to help all people with disability traverse improved accessibility of government mainstream services across all States and Territories. The budget allocated to DSS for the purpose of the updated ILC strategy will be a necessary investment in achieving this improved accessibility of government services and raising awareness of the services throughout the community of people with disabilities.

It is the view of Council however that this objective should not be confused with the core purpose of Tier 2 of the NDIS, which is the development of a living, breathing organism of Disabled Persons’ Organisations, Peer Support networks and true Local Area Coordination through engagement with local community organisations and local businesses. The function of this network is to act at the gateway to Tier 3 of the NDIS in helping:

* people with disability prepare for an individual support package and to exercise true choice and control through assistance with capacity building and support for decision-making, and also
* people with disability not eligible for an individual package to access other local supports and opportunities, including linkages to the ILC developed for the National Disability Strategy.

It is Council’s strong view that ILC needs to be administered by the NDIA to ensure effective coordination and integration of the program alongside the Agency’s implementation of Local Area Coordination and utilising NDIA data to most effectively target investment.

Council thereby strongly recommends that an additional and independent budget be allocated to the NDIA and that a plan for the use of this investment in broader Tier 2 functions be co-designed with Council and representatives of Disabled Persons’ Organisations. It is proposed that 1% of total NDIA expenditure on support be allocated for this purpose and be distributed locally across Australia in accordance with the population of people with disabilities. This quantum of investment would be comparable to the $200m originally recommended for this purpose for the Productivity Commission in 2011, approximately $270m in the current year to about $350m over the forward estimates.

This investment would serve multiple purposes including:

* developing the local ecosystem which has been sadly lacking over the past decade,
* assisting people with disability prepare for a different legislative process of eligibility assessment and resource allocation,
* provide a viable pathway for people outside of individualised funding,
* expand the local reach of the NDIA and enhance opportunities for innovation and development
* provide a tangible demonstration of trust in the sector to be a constructive partner in the development of a successful NDIS.

The proposal outlined above is the preferred proposal of Council. If that is unacceptable, Council proposes that either:

* the ILC return to the NDIS with enhanced resources as identified in the recommended proposal or
* ILC remains in DSS with a commitment to
	+ co-design with Council and representatives of Disabled Persons’ Organisations and
	+ invest in capacity building through DPOs and Disabled Family Organisations

### Feedback on independent assessments

An important part of all consultations was to hear and record feedback from participants on options aimed at addressing concerns and making independent assessments safer and more respectful for people with disability. Appendix 1 provides a record of key messages of consultation participants.

Recognising that the advice requested by the Board and the Minister related to specific changes needed to be incorporated to the access and planning proposals, including independent assessment, not whether these changes should go ahead, Council developed a set of recommendations that address key areas of concern of the disability community to make independent assessments and the use of the yet to be finalised PBM simpler, fairer, more respectful, and safer for participants.

Council recommended that independent assessments not proceed in the current form as conducted in the pilot and that the independent assessment and PBM are co-designed with Council and representatives of Disabled Persons’ Representative Organisations. Furthermore, Council recommended that the draft legislation outlining changes to access and planning is made public in highly accessible formats for a minimum of 8 weeks to provide greater transparency and enable the disability community to provide meaningful feedback.

Recommendations related to the conduct, review and quality assurance of assessments seek to address participant concerns as to whether:

* there will be a process for individuals who are not be able to complete an independent assessment because of the risk of harm, the inability to complete the tool or because of their very complex circumstances
* assessors will have the knowledge, skills, and personal background relevant for the broad participant cohorts
* the assessment will be high quality, valid and reliable
* the assessment will give a complete record of their need, because it is a one-off event conducted by a stranger
* there will be inaccuracies in the assessment
* NDIA contracts with assessor organisations require an identified percentage of current participants to be found ineligible. Recommendations seek to increase transparency about the contract key performance measures.

Given that the PBM is still in development, recommendations seek to establish a quality assurance framework to address participant concerns that an algorithm cannot do justice to the breadth and depth of the challenges and support needs arising from their disability in their unique personal and environmental circumstances. These recommendations strongly highlight the need for more effective engagement and co-design in this area, ultimately leading to the greatest possible transparency about the fairness, implementation, and operation of the PBM.

Recommendations related to governance, implementation and review seek to give comfort to participants that the independent eyes of Council and representatives of Disabled Persons’ Organisations will co-design and provide oversight over a system that is new (and viewed with great concern and suspicion by the disability community) and has the potential to impact on their lives so heavily. In addition, requirements in the NDIS Act seek to ensure goals and aspirations remain part of reasonable and necessary support, plan budget decisions remain reviewable and appealable, and the Act is strengthened with safeguard related to support for decision making and for participants experiencing multiple disadvantage.

Recommendations related to provider practice, the relationship with the disability community and with the whole of government position the access and planning proposals in the broader context of the erosion of trust in services, in the NDIS and governments more generally. Participants want Governments to be respectful and to live up to their rhetoric about citizenship and inclusion in a welcoming community. In this context, the advice recommends strengthening Tier 2 with an additional and independent budget allocated to the NDIA and a plan for its investment co-designed with Council and representatives of Disabled Persons Organisations.

Council cannot claim that the changes recommended will secure support for the introduction of independent assessments. Council believes however, that significant concerns about the assessments need to be meaningfully addressed and mitigated through key changes to their conduct and through the NDIA’s future engagement with Council and the broader disability community. The disability community wants to work in partnership with the NDIA on the development and implementation of key Scheme reforms. Respectful listening and collaborative work to address gaps that have resulted from the missing, poorly implemented, and under-funded foundational elements identified in this advice will contribute to the rebuilding of trust.

## Trust

Whilst for many Australians, the NDIS has been life changing, the missing foundations of the NDIS and its ecosystem have made life more difficult, contributing to thwarted expectations and an erosion of trust between the disability community, Government and the NDIA. The independent assessments galvanised existing frustrations into action and led to the Minister’s decision to pause the legislative timeline for changes to the NDIS Act.

Major concerns expressed by representatives of the disability community include the contested views of the purpose of the reforms, the experience of participants, and the community’s expectations of co-design and partnership.

The contested view of the purpose of the reforms heightens distrust. The NDIA describes the independent assessments as a“fundamental part of the reform process to ensure the NDIS is equitable, sustainable and, most importantly, provides an improved experience for participants”. The disability community describe independent assessments[[10]](#footnote-11) as “fundamentally alter(ing) the individualised and personalised nature of the NDIS”*,* with concern that an“increasingly automated process will not adequately consider individual need and circumstance”*.* Significantly, when independent assessments are described as a process to achieve equity and support Scheme sustainability, many participants fear a loss of support they have come to rely on, or that they will be exited from the Scheme that has come to be their only source of support. The failure of the first NDS contributes significantly to their perception that Scheme exit is unsafe*.*

Despite many NDIA reforms focussed on participant experience, erosion of trust has occurred as a result of persistent challenges experienced by many participants. Trust is eroded when:

* commitments made by individual staff are not fulfilled,
* staff turnover means the response to each contact is made by a different LAC,
* the reason for cuts to plan budgets are not understood,
* there is inconsistency between the policy intent of moving away from group homes while plan budget decisions leave participants with no options other than SIL, and
* participants’ right to review or appeal of a decision is met with a highly adversarial and emotionally costly responses.

NDIA has recognised many of these challenges that were documented in the Tune Review and has made a significant commitment to improve service delivery through the Participant Service Charter and Participant Service Improvement Plan.

The NDIA’s lack of transparency around challenges facing the Scheme contradicts the co-design partnership language often used by the NDIA, without apparent awareness of the expectations created in the community. In the context of turnover of Ministers, Board Members and bureaucrats, the disability community rightly feels ownership of the NDIS. They want to contribute to the Scheme as partners, to understand challenges and to come up with solutions that work for participants and address Scheme sustainability.

The NDIA has made genuine efforts to engage with the disability community, establishing regular forums, reference groups and advisory panels, releasing regular and detailed information about its operation and its outcomes, and releasing draft policies for feedback. The disability community has viewed these strategies as information dissemination and consultation after decisions have been made, and they see the results as the Agency designing for people rather than with people. The community recognised that moves toward co-design need to take into account the responsibilities and accountability of the NDIA and Board as the statutorily appointed decision maker and want to move to best practice in co-design in a statutory environment.

### Rebuilding trust

Rebuilding trust will need to be a two-way process. The NDIA work in related to “A new approach to home and living” and “Support for Decision Making” are examples of new level of collaboration and demonstrate a recognition of the valuable contribution of the disability community to good policy making.

The NDIA commitment to the forums guided by Council is an important step in an engagement process from which trust can be earned. The disability community has emphasised the importance of co-design as a partnership approach to implement the core principle of “Nothing about us without us”. Their honest engagement shows deep interest to work collaboratively with the NDIA and be part of the problem analysis and solution.

Consultation participants called for practical steps to rebuild trust. Steps included acting on the advice of Council, employing more people with disability, appointing more people with disability to the NDIA Board and being transparent about the problems the NDIA is trying to solve and the constraints it is under, rather than just consulting on the solutions. Participants called for the establishment of a compact or charter that outlined clear expectations about the relationship between the NDIA and the disability community. This would be a place to co-design shared expectations of a future working relationship and a roadmap of shared work on sector reform.

All expressed strong interest to work in partnership to develop a more transparent approach to ensuring NDIS returns to sustainability, including work with States and Territories.

### Priority areas for collaborative work

Issues of shared interest on which the disability community want to work in partnership with the NDIA include:

* Scheme reforms of
	+ independent assessments
	+ the development of the personalised budget
	+ planning
	+ strengthening choice and control
	+ support for decision making
	+ budget flexibility with support
	+ home and living ensuring coherence of interim decisions with policy intent
* A strategy to build transformational investment for contemporary supports
* Local Area Coordination strategy focusing on supporting people with disability to be included in the community
* A transparent forward view on the sustainability challenges the Scheme faces and how the NDIA intends to tackle them.

## The way forward

The priority areas for collaborative work provide the opportunity for mutually beneficial and meaningful engagement. It provides the mechanism to rebuild trust, which can be confirmed by clearly outlined expectations in a compact.

The disability community also wants to work in partnership with the NDIA and Government to build the foundations of a sustainable NDIS and its ecosystem, including:

* A more equitable and sustainable funding base be negotiated between Governments to fund the Scheme. This includes ensuring that the NDIA is funded to operate effectively in the service of people with disability and their families.
* A funded commitment by all partner Governments to a strong NDS that is co-designed and monitored by strengthened National and State-based Disability Councils working together with appropriate National and State oversight bodies, and with annual reports to Parliament.
* A reaffirmation of the commitment to the insurance principles of the Scheme including transparent monitoring and reporting, with oversight of an independent skills-based governance board that includes people with and without disability with commercial and other appropriate expertise to manage an insurance scheme of this size and complexity, and a legislatively based powerful advisory council.
* An additional and independent budget for tier 2 to be allocated to the NDIA and a plan for investment in the broader Tier 2 to be co-designed with Council and representatives of Disabled Persons’ Organisations.
* A commitment to efficiently review and determine the responsibilities of the NDIS and other mainstream service systems and a commitment to ensure more seamless support for participants across the interface.
* A clear strategy that facilitates open employment.

## Appendix 1 Key messages from consultation

The feedback provided in this attachment is a representative sample of comments by consultation participants often drawing on their exact words. The commentary responds to eight themes identified by the NDIA in response to participant concerns.

### Theme 1 – Exemptions and alternative processes where required

* A lot of people will seek an exemption leading to question the eligibility for an exemption.
* You could have an opt-in process with requirement for an independent assessment if there is a significant change in plan at key life stage transitions.
* Where people have unchanging needs, it would be abusive to require them to continually undergo an independent assessment.
* Instead of designing a system for exemptions, design a system with alternative or adjusted processes that works for all people with whatever support is needed to participate in an independent assessment. Alternative or adjusted processes would include a multi-disciplinary team approach and the use of previous assessments and reports.
* Target groups that may require alterative processes include participants currently in the complex support needs pathway, people living in or leaving in institutional environments (e.g. hospital, criminal justice system), in out of home care, experiencing an emergency, people with intellectual disability who do not have a key informant and people with high and complex needs including behaviours of concern.
* Alternative independent assessment pathways need to consider consultation with behaviour support specialists, support co-ordinators, individual advocates, and families.
* Interim independent assessments may be required for people during an emergency, and people leaving hospital or the criminal justice system.
* Consider whether trauma and abuse require the process to be undertaken by a trusted person.
* If someone disagrees with the process, provide mediation without recourse to legal action.

### Theme 2 – Choice of assessor and how appointments are booked

“NDIA has contracted assessors already, released two days after the previous consultation process, meaning reasonable to question if decisions about assessors was made before the end of the last consultation process – looks like consultation was not being taken seriously”.

Concerns about specific cohorts

* For people in rural and remote areas make sure they are able to have face-to-face assessments as an option.
* Where there are multiple participants in one family need to coordinate assessments.
* Independent assessments will be very difficult for people with psychosocial disability who have weak links to the NDIS and lack trust.
* Aboriginal and/or Torres Strait Islander people require culturally appropriate communication.

#### Strategies to enhance trust

* Enable participants to choose the key traits of their preferred assessor when booking, including allied health speciality and any cultural characteristics.
* Provide participants with information:
	+ to understand purpose and process of assessments and their rights related to assessments. Recommended use of DPOs and DROs to develop and disseminate information
	+ about their assessor in advance, to enable participants to get to know assessor to ensure they are understood, and to build trust.
* Enable participants to meet with their assessor prior to the assessment.

#### Assessment process

* Ensure there is informed consent for the assessment.
* Ensure participants know they can be supported by someone they trust.
* Where families and carers are used as informants in the assessment, respectfully ask the opinion of both.
* Enable the participant to use allied health staff with whom they have been working to conduct the assessment.
* Ensure the participant understands next steps.
* Ensure the booking process is supportive, including face-to- face booking options.

#### Procurement

* Gateway team of assessors who can work with different people.
* Ensure procurement contracts require the recruitment of assessors of diverse backgrounds, for example Aboriginal and/or Torres Strait Islander and Culturally and Linguistically Diverse (CALD) people, and from the LGBTIQA+ community.
* Ensure appropriate coverage in regional, rural, and remote areas.
* Expand the independent assessment panel to include Aboriginal Community Controlled Health Organisations.
* Ensure appropriate qualities, knowledge, and skills of assessors including ability to identify abuse and control.

#### Enable allied health professionals who know the participant to undertake assessment

* Choice and control should allow participants to choose their allied health professional to be their assessor.
* Manage any real or perceived conflicts of interest using an “interests’ management framework”.
* Participants questioned whether independent assessors would be “truly independent” when they are selected, contracted, and funded by the NDIA – they are servants of the NDIA, meeting the NDIA's expectations.

### Theme 3 – Conduct and experience of the assessor

#### Concerns about the efficacy of the assessment

* Independent Assessments won’t work for Aboriginal and/or Torres Strait Islanders, or people with foetal alcohol spectrum disorder (FASD), especially in remote areas.
* Team approach to assessments so that each assessment is undertaken by the appropriate allied health professional(s) together with a person with disability who understands the issues faced by the person being assessed. This approach was used in auditing employment services and in some services for people with psychosocial disability.
	+ Organisations that have secured assessment contracts could be required to partner with DRO and other user-led organisations to recruit suitable people with disability who would receive training in their role as co-assessors.

#### Competence of the assessor

* Concerns that assessor will not have the knowledge required to cover the wide range of disabilities as well as having cultural knowledge. Need specialised assessors for people with complex needs.
* Extensive training required. Partner with DROs to develop and implement disability-specific training for assessors (and fund them to do so).
* Revisit existing procurement process and assessment tools with strong input from people with disability and their representative organisations.

#### Using allied health staff who know the participant

* Independent assessment should be undertaken by a professional who knows the person.
* Participants and families will have challenges in providing the “right information”:
	+ Independent assessment is a deficit-based assessment. Parents familiar with a strength-based approach are very poor at voicing deficits and children, adolescents and some adults may experience emotional challenges hearing a list of their deficits.
	+ Many participants do not understand the scales used in assessments and are thereby poor informants.
	+ Many participants have “good” days and “bad” days, which assessments need to consider and demonstrate understanding on.

### Theme 4 – Use of pre-existing participant information

* Different approach required in early intervention.
* Criticism of an assessment process that is diagnostically blind.
* Each assessor to reach out to participants in advance, to get a feel for the participant prior to the assessment so that the assessment can be tailored to the individual participant.
* “The pre-existing information needs to be provided by the participant, or with the permission of the participant”.
* Enable participant to “submit recent assessments and diagnostic information, but there must be transparency as to how that is used and fits into the algorithm for the plan budget. Need consideration that there are no unintentional incentives to seek additional assessments and that the provision of additional information does not advantage some people over others.”
* Use of a multi-disciplinary team for complex assessments.
* “Differentiate between new and current participants. For new participants more information is required but the NDIA could create a different independent assessment approach for participants already in the Scheme so they can have a shorter assessment”.
* Importance of additional information for many people with mild intellectual disability (especially those without key informants) who may talk up their skills or confabulate.

### Theme 5 – Checks, inputs, review before the assessment is used in decision making

* “Can participants see all questions prior to the assessment?”
* “If the assessor does not have enough information to determine all support needs, would the assessment process make provision for the assessor to identify this?” Provide participants with the opportunity to review what has been written about them prior to its use for decision-making.
* Enable participants to answer some questions before the independent assessment.
* Pre-fill questions duplicated across the tools.
* Establish an Independent Disputes Office – somewhere for people to go if things go wrong, so people feel safer in the process with the right safeguards.

### Theme 6 – Ongoing oversight, evaluation and improvement of assessment tools and systems

Assessments should be flexible, transparent, generate validity and reliable information, and be transparent about their use in decision making.

#### Tools

* Concern about the efficacy of tools. For example, the deaf and hard of hearing community saw tools not appropriate for children.
* Concern as to whether tools are culturally sensitive.
* None of the tools have been trialled with Aboriginal and/or Torres Strait Islander people.
* Assessor should not be limited to a set number of tools.

#### Quality assurance and review

* Co-design a quality assurance framework and assessor competency framework process with Council and DROs including measures of participant trust of assessor, whether participant’s human rights being upheld and feedback from participants and the community.
* Empower the Council to provide oversight over the independent assessment process and toolkit (for example, review data, make recommendations, publish reports) to support continuous quality improvement and rigorous monitoring and evaluation. Review of the independent assessment outcomes to be included in legislation.
* Develop accreditation for assessors including panel review processes for assessor agencies.
* Co-design an evaluation of the impact of independent assessments, and the resultant plan budget on participants.
* Embed the results of decisions enabled by independent assessments in the Actuarial quarterly report.

#### Implementation

* Delay implementation of independent assessments at scale until completion of more trials and evaluation, and missing elements of NDIA ecosystem are considered.
* “Where PBT generates a variation of +/- 15% from current budget, it needs automatic review”.
* People should have a right to appeal assessment information used to determine individual plans.

Ensure safeguards, such as

* A time-framed administrative review with an independent reviewer, especially in the first few years.
* Support and advocacy available to participants.
* Review complaints data.
* Legislative reviews.

#### Improvement

* Need a human rights frame to measure extent to which a person’s human rights are protected and their independence is enhanced.
* Consider value of a bespoke tool(s) for some populations, e.g., people with intellectual disability and Autism, where neither is the primary disability.
* Ensure tools make a connection between the outcomes of participants as a result of the independent assessment.
* Start work on developing a proprietary independent assessment tool (including co-design with the sector, academic review, and NDIA data).

### Theme 7 – How funds are managed in a plan

* Concern that cost of independent assessments will come out of a participant plan.
* Participants need access to advocates.
* “Concern at the lack of transparency with personalised budgets, where participants want to understand how support budget calculated”.
* Pleased that funding intervals will be longer than monthly, and funding will be rolling until the end of the plan.
* “Will need to be a very easy mechanism for participants to get an advance from the agency if they need more funding for something in that quarter. Needs to be a simple process so they can access funding quickly, have flexibility and can remain in control of their lives”.
* “Moving people into allocated budget. This is a whole different way for participants to manage their funding, budgeting is a difficult concept for most people.”
* “Providers notorious for sending in billing late – becomes more difficult to manage so we need easy tools to navigate this”.
* Plans being altered need to have a mechanism that helps transition from one plan to the next.
* Maintain the aspect of self-management.
* “Transparency needed of the research and evidence base behind the funding amounts. Rationale for budgets needs to demonstrate what has been considered.”

### Theme 8 – Plan adjustment in unique circumstances

* Question of what constitutes a “unique circumstance”.
* There needs to be a timely response around emergencies.
* “Where participants need a plan review as a result of deterioration, will they require an independent assessment prior to the review? Guidelines would help NDIA or planners to understand the trajectory of different degenerative conditions”.
* The fixed budget should include Specialist Disability Accommodation (SDA), major home and vehicle modifications, behaviour supports and support for complex out-of-home care. Everything else should be flexible.
* “Budget setting guidelines should be co-designed with disability sector and people with co-morbidities.”
* Need to be responsive to the needs of children is unique, different from adults and needs a separate consideration process.

### Feedback not captured elsewhere in the advice

#### Scheme sustainability

* “The ‘problem’ is not with people with disability, but rather disability service providers who charge exorbitant prices – especially in regional and remote areas”.
* “Sceptical about sustainability conversation”.
* “If insufficient funds allocated to the Scheme, then it needs to be properly funded – don’t throw it back on individuals.”
* “Please release all the underlying data and assumptions. These are forecasts based on many variable externalities. Most people I know have cut back on services for the last 12 months, the agency has continually struggled to meet plan targets and has had underspends. The Productivity Commission's major 2017 report forecast the Scheme's cost would reach $30.6 billion in 2024-25, about $1.2 billion less than what is now predicted. In Commonwealth terms that’s a pretty small over-shoot.”
* “We can fix Scheme sustainability without implementing mandatory independent assessments”.
* “Do not accept some of the forward projections – not outcomes.”
* “Accept there is a sustainability problem – Ministers in all tiers of Government need to work out a formulation for the distribution of funding of the NDIS that recognises changes in the last 10 years and move on from the 2009/10 bilateral agreements.”

#### Pace and rationale of reform

* “I think it’s really important Council reflect the clear opposition from the vast majority of people in the Australian Capital Territory Disability Reference Group to this set of changes to the NDIS. They are not acceptable to us”.
* ​“Without time, how can we rebuild trust, when fundamental changes are being made to legislation without sufficient time to consider and engage with all the matters that need to be discussed”.
* “Not sure what the problem is and the NDIA is jumping to solutions.”
* It’s very hard to answer the “broader reform” question when several of the areas for the reform appear to be non-negotiable.
* “All sounds like a repeat of the Robodebt Scheme”.
* “Unfair that participants being blamed for issues of Scheme sustainability where there are many other factors”
* “I don’t recognise these as ‘reforms’ they are changes (arguably cuts) with no positive connotations”.
* “Why are we focussed on independent assessments rather than fixing the myriad of issues that are inherent in the Scheme now? The issues NDIS participants have had since the Scheme was introduced have never been addressed”.
* “Equitable access to the Scheme is essential but the way independent assessments are proposed will not solve equity issues”.
* “How much does the NDIS save compared to leaving people without support? More participants and more payments is likely reflective of need. If you cut the Scheme, you are condemning someone to go without support and that will cost other systems far more.”
* “I disagree that introducing independent assessments are to build a better planning model. You just talked about the cost forecast then the introduction of independent assessments”.
* “Mainstream services that were going to be there for people not eligible to NDIS are not there, and should be. If not in the NDIS, nothing is available.”
* It is impossible to support changes (including to legislation) that we haven’t seen.

#### Nature of consultation problematic

* “NDIA does not clearly differentiate between issues already decided and those up for discussion, people are asked to comment on a predesigned plan”.
* “Minister says these changes will be the largest to Scheme since its inception. If this is the case, then this consultation process does not cut it”.
* “Current consultation process is inadequate to the challenge that lies ahead.”
* “So called consultations are insulting and disrespectful approaches to engagement.”
* All time taken by NDIA providing information, little time to hear from the community.
* Consultation fatigue, NDIA asking for feedback on lots of proposals simultaneously.
* “How can they call this process co-design?”
* Manner of consultation will not rebuild trust.

#### Independent assessments

* “Blunt instrument, not contextual to social model of disability, or people’s personal experience of disability and contributing social factors, so much more than individual impairments”.
* The independent assessment pilot demonstrates that the independent assessments do not work. Mass rollout will be worse than the pilot.
* “I will not be having a barely trained stranger come into my home and watch me make a cup of tea, tick-off a set of check boxes and then try and make a cursory judgement on my support needs. We also need to think about people not in the room especially people with autism and episodic disability where this kind of assessment is really problematic”.
* “Don’t have trust in the independent assessment process – was optimistic, participated in the pilot but haven’t seen any results after a very extensive assessment at home. Asked to give NDIA feedback on process but without having seen a report, recommendations, impact that independent assessments might have had on our plan and future”.
* The feedback survey design is narrowly focussed on the assessment, rather than the impact the independent assessment process will have on a participant.
* “I would also like to mention that the independent assessment model leaves many participants feeling distressed and disempowered. Three hours of talking about what you can’t do is awful. Surely, we aim to empower people with disability.”
* “The tools have never been linked to funding in any other context. Many professional bodies have raised flaws with this approach.”
* An independent assessment (when done right) could be a good elective option for those that don't have a team of professionals that are able to provide comprehensive reports each year.
* A simplified form of independent assessments was proposed. Features included:
	+ *There are risks associated with the current approach (including contracting IAs to large organisations) that will result in building layers of added complexity and systematisation (e.g. additional training for assessors; governance oversight; review processes; and quality assurance). This will make the system even harder for people with disability to navigate, especially people who have cognitive impairments, psychosocial disability or don’t have English as a first language. In this sense, it won’t work to move the system to greater fairness and equity.*
	+ *A simplified approach would look at developing (one or more) simpler tools that are effectively a minimum viable product/tool to land a ballpark funding amount. This would be tailored to the NDIS, rather than trying to use ‘off-the-shelf’ standardised tools that have little or no connection to the Scheme’s outcomes and imperatives.  The tool/s would be co-designed with people with disability drawing on quality-of-life measures/tools that are already validated tools. Tools that are specific to certain populations (e.g. ATSI) could be developed this way also. Some of the pros include: the tool (and system) can remain relatively simple; by co-designing, people with disability are brought along on the journey; and multiple tools/approaches can be developed and trialled at small scale simultaneously. Cons include that the tool/s are not necessarily standardised or validated (initially at least)*
	+ *Rolling trials could build the tools, with data from every 1000 participants being used to refine the model.*
	+ *Assessment could include measuring people’s level of independence; and the*extent of valued membership of mainstream community life*through things like education, employment and friendship networks. It would be human rights based and resistant to being manipulated to say something is ‘capacity building’ when it really isn’t*
	+ *A simple approach would also have a different approach for new entrants to the Scheme vs existing participants. New participants might have a more comprehensive set of technical assessments that reduce the need for them to provide other evidence, especially for people for whom this will be difficult.*

#### Differentiating between different cohorts

* Concerns that the ‘difference’ in Northern Territory (NT) compared to other states, is not being considered in how the Scheme is developing and delivered. Especially related to high proportion of Indigenous people and those living in remote and very remote areas where concerns that disability statistics are grossly underrepresented in NT communities, and has the highest underutilisation of plans.
* Requirement related to primary disability: for many, there is not a primary disability. For example, people who are deaf blind, people with intellectual disability and autism.
* People falling between the cracks and the need for advocacy.

#### Planning

* Redesign planning to strengthen inclusion in the community, capability building and vocational opportunity.
* “NDIS planning meetings are very stressful.”
* “Planning should start from aspirations and not deficits. When looking at the NDIA personalised budget paper, clearly, we’re moving away from building plan budgets on goals, which is what Tune said in the review. NDIA seems to be cherry picking what to implement.”
* “There are important issues about plans being implemented without full discussion and consent of the participant. Two issues come to mind on this on. Firstly, it appears that perhaps NDIA staff are not actually documenting on the database, the particular conversations with the participants. Such as ‘Please call XYZ participant back to arrange a time to discuss the new plan’. Secondly there needs to be some form of verification that the participant has actually agreed to the plan. This is common practice in the business world.”
* “I wonder if at the end of every financial review of a person's plan the participant is also able to give feedback about what did and didn't work”.

#### Supports

* Need more equitable access to Support Coordination.
* “NDIS support for people in emergencies is inadequate – participants can wait weeks for the NDIA response. Pre NDIS, people in Western Australia (WA) could ring the Disability Services Commission and get a response within hours.”
* More support to self-manage.
* “Still today, people’s plans in Tennant Creek and other places in the Barkly area simply lapse. They have a Coordinator of Supports on board, yet still plans lapse. This is such a disincentive to people. Many now say ‘why bother’? I give all my information away, they come to my home, then I need to start all over again”
* “The assessment I had with an independent occupational therapist (OT) to assess whether I needed $500 mounted binoculars costed $1300 and took 10 minutes in my home. The OT had never heard of my disease, so I needed to explain it to her. She had never heard of mounted binoculars, so I provided all information to her including my diagnosis and prognosis which she cut and pasted into her report. She cut and pasted the information I provided on the equipment. This whole exercise took $1300, took so many months to get a decision on, that different equipment was no longer the best available, so I then had to get another assessment. No wonder there is a cost blowout. This needs to be resolved in a transparent fashion.”

#### LACs

* Concern about frontline capability and Partner Strategy (empathetic planning, early connections).

#### Interface

* Need joined-up planning with multiple service systems. For example, for people in Residential Aged Care.
* “States and Commonwealth need to stop passing the buck.”

#### Tier 2

* “Roll out of Tier 2 has been an unmitigated disaster.”
* Expectations about how to bring about transformative change in communities are at best naive and at worst, a costly waste of government money.
* “The fascination with funding resources, websites, and apps at the expense of investing in people with disabilities as local community leaders of change and community development are a cause for real concern”.
* “Combine adequate funding for DPFOs, DROs and NDPA into ILC with specific consideration for minority groups and people special needs and comorbidities”.
* “NDIS has been turned into a ‘rent-a-friend’ service replacing informal supports that could have been strengthened”.
* “Failure of the NDIS ILC programs with decision to direct 80 per cent of ILC program to LAC and then remaining 20 per cent used without a clear plan”.

#### Other

* Government needs to redevelop its procurement policies to give priority to disability led businesses or to Australian Disability Enterprises which can demonstrate transition pathways to open employment
* “Enormous disparity of power between participants and services and participants and NDIS – NDIS can call on big legal guns in appeals.”
* “Financial vulnerability of participants, people in group home charged $350 for a 30-minute massage.”
* Minister’s discussion about participant fraud needs to be in context of fraud perpetrated by providers.
* NDIS has a leadership role in advancing human rights and it should act as model citizen.
1. sourced from Council and its Reference Groups, members of Representative Disability Organisations (RDOs), the NDIA’s CEO forum and meetings convened by State and Territory disability advisory groups. [↑](#footnote-ref-2)
2. As defined in Section 9 of the *National Disability Insurance Scheme Act 2013* with functions described in section 12. [↑](#footnote-ref-3)
3. conducted by allied health professionals or appointed by the NDIA and trained in the use of the tools. Productivity Commission (2011) Disability Care and Support, No54 P305 [↑](#footnote-ref-4)
4. The term “Tier 2” is taken from the Productivity Commission (2011) Disability Care and Support, No54 pp 12-13 and refers to services for anyone with, or affected by, a disability. [↑](#footnote-ref-5)
5. Disabled Persons’ Organisations refers to Disability Representative Organisations, Disabled Persons’ Organisations and Family Organisations [↑](#footnote-ref-6)
6. And other congregate settings [↑](#footnote-ref-7)
7. Disabled Persons’ Organisations refers to Disabled Persons’ Representative Organisations, Disabled Persons’ Organisations and Family Organisations [↑](#footnote-ref-8)
8. Consultation in SA was convened by the Department of Health (SA) and consultation in ACT was convened by the ACT Disability Reference Group. [↑](#footnote-ref-9)
9. Productivity Commission (2011) p305 [↑](#footnote-ref-10)
10. Drawn from Disability sector statement on the Australian Government’s planned reforms to the National Disability Insurance Scheme Accessed <https://everyaustraliancounts.com.au/ndis-sector-statement/> 10 June 2021 [↑](#footnote-ref-11)