

Submission to the Joint Standing Committee on the National Disability Insurance Scheme NDIS Independent Assessments

31 March 2021

“People with disabilities need to continue setting their own NDIS goals and being funded appropriately to be able to achieve them. People should have their own therapists and medical professionals who know and assess them, and write reports for the NDIS. Why the NDIS thinks that treating professionals would put their own professionalism at stake to write favourable reports for participants is questionable.”

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INTRODUCTION

VALID congratulates the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) for making available this opportunity to provide feedback on the National Disability Insurance Agency's (NDIA) proposal for Independent Assessments.

After campaigning for decades to fix the underfunded and broken disability support system, VALID, along with thousands of people with disabilities their families and advocates, welcomed the introduction of the NDIS. We celebrated that the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) was set as the foundation for the Scheme. We were pleased to see that the General Principles in the NDIS Act 2013 were strong and clear, that people with disability would:

- Be supported to “realise their potential”
- Have “the right to exercise choice and control, and to engage as equal partners in decisions that will affect their lives”
- Have certainty that they would receive “the support they need over their lifetime”ⁱ.

Since 2013, VALID has supported thousands of people with intellectual disabilities and their families to make the best of what the NDIS has to offer. We have seen many people finally getting their freedom and independence – moving into a home of their own, getting a job, volunteering, and meeting new people. At the same time, we have seen many people stuck in a holding pattern – same group home, same group programs, same everything. In some instances, people's lives have become worse because they are underfunded, or because their support services are not willing or able to work with them, or they do not have the resources they need to navigate the NDIS.

VALID has worked closely with the NDIA from its inception and has been a strong contributor to its work in the areas of housing, employment, planning, supported decision-making, consent, working with people with complex support needs, and much more. VALID is an active member of several NDIA committees and NDIS Independent Advisory Council sub-committees.

VALID is not opposed to the concept of independent assessments which were suggested by the Productivity Commission Report in 2011 and recommended by the Tune Review in 2019. We engaged in early discussions with the NDIA about Independent Assessments in good faith, on the understanding that there would be thorough testing and evaluation, and that assessments would be voluntary. However, when the results of the first pilot were published, and when we were advised of the Federal government's decision to enforce compulsory assessments as a 'Scheme sustainability' measure, we became extremely

concerned. The final straw came for VALID in discussions about the second pilot, where the NDIA ruled out the need to test and evaluate the method that will be used to decide participant budgets – the NDIA-designed ‘Personalised Budget Tool’. In VALID’s view, this decision defied acceptable standards in disability policy making and we concluded that the NDIA’s proposal could only be based on a cost-cutting agenda and not on the rights and needs of Australians with disabilities.

On 9 September 2020, VALID issued a Statement of Concern to its members about Independent Assessments (see Appendix A), followed by an Open Letter from our CEO, Kevin Stone AM, on 19 November 2020 stating our firm opposition to the proposal, and announcing our withdrawal from further consultations (see Appendix B). VALID received a letter on 3 December 2020 from the NDIA’s CEO, Martin Hoffman, which stated he believed VALID “to be mistaken in its understanding” of the proposal (see Appendix C). Since then, VALID has actively campaigned against the NDIA’s proposed Independent Assessments.

We commend recommendations already made by our national peak body, Inclusion Australia (NCID), in its recent submission to the NDISⁱⁱ, and the statement made by disability advocacy peak bodies, *Disability sector statement on the Australian Government’s planned reforms to the National Disability Insurance Schemeⁱⁱⁱ*, released on 11 March, 2021.

This submission outlines VALID’s concerns about the impact of compulsory assessments on adults with intellectual disabilities and their families and our recommendations for change. We make our submission in good faith and affirm our commitment to making the NDIS the best disability support system in the world.

VALID asked its members and subscribers to tell us what they think of the NDIA’s plan for compulsory assessments. We received more than 200 responses from people with intellectual disabilities and their families in two weeks. The quotes in this submission are their words.

“I do not understand why anyone would think an assessment – a time limited and one-off process – could ever formulate complex outcomes. Compulsory assessments will reduce supports. Are we dealing with human rights here or not?”

ABOUT VALID

VALID is an award-winning Disabled People's Organisation that has been at the forefront of advocating for people with intellectual disability and their families in Victoria since 1988. VALID provides empowering advocacy support: we stand behind people to support their self-advocacy; we stand beside people to assist them in asserting their rights and seeking justice; and we stand before people who require representation to ensure their rights are promoted and defended.

VALID provides independent individual advocacy support to more than 250 people with intellectual disabilities annually, as well as self-advocacy workshops, peer-led training for more than 1500 families, self-advocacy networks for more than 300 people, 30 peer action groups in regional and rural communities, the annual Having a Say Conference with more than 1000 delegates and distributes information and advice to a network of more than 18,000 e-newsletter subscribers.

VALID also runs projects in partnership with disability and community organisations and governments nationally. VALID is the Victorian Agency Member for Inclusion Australia (NCID) and a member of Inclusion International. VALID is funded via grants from the Victorian State Government and the NDIS Information, Linkages and Capacity Building program, and is not an NDIS service provider.

Vision

VALID is committed to the vision of an Australian nation in which people with a disability are empowered to exercise their rights – as human beings and as citizens – in accordance with the UN Declaration on Human Rights and the Convention on the Rights of Persons with Disabilities.

Mission

VALID's mission is to promote and protect the human rights of people with an intellectual disability and to champion their rights as citizens to community presence, choice, respect, community participation and self-determination.

Aims

VALID aims to empower individuals with intellectual disability to:

- Exert control and influence over the decisions and choices which affect their lives
- Inform and influence the policies, processes and practices of disability service agencies, governments and other authorities
- Exercise their human rights and citizenship status within their local communities.

EXECUTIVE SUMMARY

The National Disability Insurance Agency (NDIA) is proposing to replace goals and individualised planning with compulsory functional assessments – they call it Independent Assessments. VALID took part in early discussions with the NDIA about Independent Assessments in good faith. We understood that the process would be co-designed, that there would be tested and evaluated properly, and that it would be voluntary.

However, when we saw the results of the NDIA's first pilot of Independent Assessments in 2018-2019, we were concerned. Then we were told that Independent Assessments would be compulsory because the NDIA have a budget problem. We learned that the compulsory assessments would be run by organisations hand-picked, and directly funded by, the NDIA itself. It became clear that one of the reasons why the NDIA wanted to make the changes is because they believe allied health therapists are biased.

VALID has asked the NDIA a lot of questions about Independent Assessments. We have not been satisfied with their answers. In VALID's view, the NDIA have failed to produce clear evidence to justify compulsory assessments. The NDIA have not done the work needed to prove to people with disabilities and their families that compulsory assessments will uphold and protect their human rights. They have not convinced us that people with intellectual disability will not be worse off.

VALID supports the idea of assessments that are independent of government, the NDIA and other vested interests. We are proud that the National Disability Insurance Scheme Act 2013 is built on the foundation of the United Nations Convention on the Rights of Persons with Disabilities and includes principles about choice, control and the right to engage as decision-making equals.

We believe that the NDIA's proposal for Independent Assessments puts the NDIS that people with disabilities and their families fought for in danger. VALID's submission explains our opposition to the introduction of Independent Assessments and makes recommendations for positive change.

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THE NDIA HAS BIG PROBLEMS

The NDIA say that compulsory assessments will solve problems with funding inequality. However, VALID believes the NDIA needs to fix other problems including:

- Mistrust of people with disabilities, families and advocates
- Planning that is focussed on goals, aspirations, needs and rights
- Giving information to allied health therapists about what the NDIA want to know
- Making NDIS access easy and free
- Support for decision-making, and more.

MISSING EVIDENCE

Scheme sustainability

The NDIA says that we need compulsory assessments to solve problems with ‘Scheme sustainability’. They have failed to show the evidence that the budget is at risk, if and how the proposal will save money, and not harm people with disabilities in the process.

The postcode problem

The former Minister for the NDIS, Stuart Robert, has said people from more affluent postcodes get more funding than people living in disadvantaged areas. The NDIA has failed to show us why this is happening, how compulsory assessments will fix the problem, and to prove that there is no agenda for funding cuts overall.

“Sympathy bias”

The NDIA say that allied health therapists that know a participant well, have a bias that makes their reports less trustworthy than an assessor who doesn’t know the person at all. The NDIA have failed to give us evidence that allied health therapists working with NDIS participants now are misrepresenting participants’ support needs or that contracted assessors will not be biased in favour of the NDIA.

Disability, not functional impairment

The tests the NDIA is using in the trials are not fit-for-purpose. The tests focus on functional impairment, but the NDIA is instead using them to predict how much funding people need. The NDIA have failed to describe, test or evaluate how this can work.

Data, data, data

The tests the NDIA are using will collect a lot of personal data about Australian citizens with disabilities and it is unclear if or how this data will be used by other government agencies. The NDIA has failed to show how collecting this data will help people with disabilities and that it won’t harm them.

UNINTENDED CONSEQUENCES

VALID is extremely concerned that the NDIA is focussing only on the benefits of Independent Assessments. It is highly likely that there will be major negative impacts including services turning underfunded people away and massive pressure on state systems which remain the last resort. We predict that some people will pass the assessment test and get a good outcome, and others will fail and go without support.

WHAT IS AN INDEPENDENT ASSESSMENT?

An assessment should be independent of the decision-maker – in this case the NDIA. Assessments should use the right tools for the individual at the time. The NDIA have cherry-picked recommendations made by the 2011 Productivity Commission report and the Tune Review to match their own plan for Independent Assessments. Assessment tools must be valid, reliable *and* person-centred.

OVERWHELMING OPPOSITION

Many people with disabilities, families, advocacy organisations, peak bodies, allied health associations, and independent statutory agencies have publicly said that compulsory assessments are a bad idea. This should matter to the Federal government and the NDIA. It is unacceptable that the views of people with disabilities and their supporters are being ignored by decision-makers.

CONCLUSION

VALID strongly opposes the NDIA's current proposal for compulsory assessments. VALID believes that the proposal is not aligned with the UNCRPD, the NDIS Act and its General Principles, and does not meet the expectations of NDIS participants, their families and supporters. As always, VALID will work with decision-makers to get it right for people with intellectual disabilities and their families. However, VALID will continue to campaign against Independent Assessments unless there is a major overhaul of the principles, design and implementation of the proposal. We thank the Joint Standing Committee on the National Disability Insurance Scheme for the opportunity to make this submission. We hope that the Committee will make the recommendations that are needed to ensure the NDIS is the best it can be – an NDIS that works for everyone.

RECOMMENDATIONS

- 1** Immediately stop the rollout of compulsory assessments
- 2** Make transparent the proposed methodology for formulating personal budgets on the basis of functional needs assessments
- 3** Undertake an independent evaluation of both the proposed methodology and the outcomes for participants
- 4** Commit to improving the planning process through co-design including a focus on individual goals and aspirations, the potential contribution of the participant, and their needs and human rights
- 5** Co-design comprehensive training for all NDIA staff, including senior management, on intellectual disability including history, rights and practice
- 6** Fund independent person-centred planning for all participants who want or need it
- 7** Publish detailed guidance for general practitioners, specialists and allied health therapists about the information the NDIA needs for access and planning
- 8** Provide free allied health assessments for people accessing the NDIS for the first time through Medicare with the therapist of the participant's choice
- 9** Complete a review of all Administrative Appeals (AAT) outcomes relating to access and allied health therapy and consider changes to NDIS operational guidelines that better reflect AAT decisions
- 10** On the basis of evidence provided through an independent evaluation, co-design with the disability sector a fit-for-purpose method for conducting credible, reliable and voluntary independent assessments

1 WHAT WE KNOW & WHAT WE DON'T KNOW

VALID has consistently requested information from the NDIA about critical details of proposed compulsory assessments. We have not received the information we need to be certain that the proposal will not be harmful to people with intellectual disability and their families. While we have read all the information that the NDIA has published on its proposal and attended many meetings with NDIA staff and management, many questions remain unanswered.

1.1 What we know so far

- The assessments will be compulsory for people accessing the NDIS for the first time and for existing participants
- The assessments will be undertaken by an allied health therapist who the participant has never met
- One allied health professional will complete the compulsory assessment – the professions that can complete the assessments include occupational therapists, physiotherapists, speech pathologists, clinical and registered psychologists, rehabilitation counsellors, and social workers
- The assessment requires a minimum of 20 minutes face-to-face time with the participant and the NDIA expects the full process, including observation, assessment and report writing to take between 2½ and 3 hours on average
- If the participant refuses a compulsory assessment, they may be blocked from using NDIS funding or removed from the Scheme (the NDIA uses the word “exited”)
- The NDIA will decide who is exempt from compulsory assessments and participants cannot challenge this decision
- Participants will not automatically receive a copy of their assessment but must request one from the NDIA – they will only receive a summary not the full report
- The compulsory assessment report will be the main source of evidence that the NDIA will use to decide how much funding will be allocated in a participant’s plan
- The NDIS plan built on the basis of the report is reviewable but the compulsory assessment report is not
- Participants will not have a planning meeting with a Local Area Coordinator or NDIA planner as they have previously – they will instead have a plan implementation meeting where they will be told how much funding they have received and how they can use it
- Most requests for a plan review will require a new compulsory assessment to be completed - the NDIA will decide how often a compulsory assessment is required for each person
- All participants will be required to have a ‘support person’ (e.g. family member) at their assessment who must provide information without the participant present in the room

- The NDIA has chosen the organisations that will complete the assessments – these organisations cannot provide other allied health supports to participants
- The NDIA chose a small group of academics to select the tools – they did not independently commission a university to do the work
- The current trial of independent assessments did not include an external research ethics review
- The tools that are being used in the trials are used worldwide for screening and assessing functional impairment but were not designed to determine how much funding an individual needs
- Some tools chosen were designed for people with particular disabilities but are being used on all participants during the trial – for example, the Vineland Adaptive Behaviour Scale is used with people with intellectual disabilities, autism, and developmental delays, and the Care and Needs Scales assessment is designed for people with Traumatic Brain Injury – both are being used on participants without these disabilities in the pilot
- The NDIA have created a Personalised Budget Tool which will take the scores from the functional impairment assessment and use a ‘calculator’ to determine how much funding a participant receives – this tool has not been released publicly or subjected to independent evaluation
- Neither the current nor previous pilots have evaluated the NDIA’s Personalised Budget Tool’s accuracy in allocating funding to participants

1.2 What we don’t know

- How or if the evaluation of the trial will determine whether the tools used accurately projected the cost of each participant’s supports and if this information will be published
- The consequences for the NDIA or the contracted assessors who are administering tests outside their professional expertise – for example, a physiotherapist is not typically trained to undertake a Vineland assessment although this is taking place during the current trials
- What information participants will be given about the contracted assessors so that they can choose one from the panel
- How the assessor will decide which tests to run and which ones to omit
- What training the assessors will receive in working with people with different types of disabilities and support needs
- How other information about the participant will be considered and weighted by the NDIA delegate when they build the plan including the participant’s lived experience, their goals, past plan values, information from their own treating professionals, potential risks of reduced supports, and quotes from service providers
- How the NDIA have developed the formula they will use to weigh up all the available information about a participant to decide what their final funding package will be

- What is included in the NDIA's 'Participant Interview' and 'Participant Information' tool and how it was developed
- What information the NDIA have used to determine the average funding package (currently known as a 'Typical Support Package') that should apply to people with similar functional impairments
- How the NDIA will decide whether the information provided by a support person is accurate, objective and free of conflict of interest
- How the NDIA will determine that the 'support person' attending the assessment gave accurate information about the participant
- Who the NDIA will consult with if the participant is unable to self-report their needs and do not have a family member or person independent of their service providers to assist them
- How the NDIA will decide whether the compulsory assessment produced accurate and reliable results that reflect the participant's circumstances and will not put them at risk
- How participants who lack capacity to challenge a decision will lodge and pursue an appeal
- How the NDIA will decide who is exempt from compulsory assessments
- How the NDIA will build a plan for people who are deemed exempt
- How participants who are unable to request a copy of their assessment report due to disability, or who do not have a Plan Nominee, will get one
- How the NDIA will decide what constitutes 'refusal' to take the test – for example, the person will not answer the questions; the person will not let the assessor in their home because they are afraid of strangers; the person leaves the assessment
- How compulsory assessments will work for people living in forensic disability services, people in custody or prison, people in psychiatric wards, or people living in hospitals
- How much money the NDIA will spend on compulsory assessments and what it will cost if it doesn't work

“There is absolutely no transparency in explaining whether these assessment tools were ever meant to determine funding levels for disability supports. If the NDIA are using some sort of formula to extrapolate the results into a plan budget then show us this formula! How has it been validated? Just having pilot after pilot to demonstrate people with 'like' needs end up with similar funding is dehumanising. It does not take into account goals or aspirations, or the needs of families. The NDIS should be transparent with ALL aspects of this proposed change.”

2 THE NDIA HAS BIG PROBLEMS

The NDIA says that introducing compulsory assessments will solve the problem of participants with similar support needs receiving significantly different levels of funding. While we agree that it is essential that all participants receive enough funding in their plans to meet their needs, we disagree that compulsory assessments are the answer.

2.1 The problem of mistrust

VALID has had concerns since the launch of the NDIS about the use of allied health therapy reports as the main way that participants must prove their support needs. In the beginning, we had high expectations that NDIA planners would respect the participant's own experience of what they wanted for their life, and their views about what works and doesn't work for them – that they would trust them. VALID believes that from trust comes honesty and creativity, and the real possibility that people will build their independence over time.

VALID's experience is that people with intellectual disabilities are more likely to be forced to produce reports and to be assessed over and over because their 'lived experience' is not trusted: they are considered unreliable witnesses by NDIA planners. Similarly, their families, independent advocates and support services are often considered biased and treated with suspicion. Without trust, there is resentment, resistance to change, over-reliance on paid support and perpetual congregation. The cost of mistrust has been and will remain expensive for the NDIS.

“Trust that people who know the person well want the best for that person, and listen. Most people are reasonable and just want enough funding for the supports they need to live a reasonable life. Meeting with strangers can be extremely stressful for people with intellectual disabilities and their families. Why assume that they need to be interrogated and treated as though they are asking for too much?”

2.2 The problem with planning

The NDIA is proposing a monumental shift away from personalised and individualised planning. The meeting that a participant has with a LAC or NDIA planner has been central to the way that the NDIS has worked. Up until now, the process has been that the LAC or NDIA planner meets the participant and their supporters – including family, friends, independent advocates, support coordinator, disability services, allied health therapists – and talks about the participant's goals, living situation, what's working with their plan and what's not working, and what they need for the next plan.

The NDIS Act (2013) lists ‘Principles relating to plans’ including that planning should be “individualised”, “directed by the participant”, and “...with the aim of achieving his or her individual aspirations”^{iv}. It is VALID’s understanding that the NDIA is proposing stopping planning meetings altogether. Instead, an NDIA planner will present an already approved plan, based on the outcome of the compulsory assessment – as well as whatever else the NDIA delegate, who has not met the person, chooses to include – in a plan implementation meeting. We understand that there will be very little scope to change what is included in the plan that is provided in the implementation meeting. This was confirmed in a letter received by VALID from NDIA CEO Martin Hoffman on 3 December, 2020:

Participants with similar functional capacity in similar life situations will receive a similar overall budget amount. We will use the experience and data gained over the past seven years, together with the large volume of pilot assessments currently being undertaken, to formulate those consistent budget amounts. Planning will then be about how to best use those funds by, with and for the individual participant so they can indeed pursue their goals and have great lives. (see Appendix C)

The NDIA has asserted that the introduction of compulsory function assessments will improve the consistency of their decision-making processes which they admit have caused “a high number of requests for review of access decisions, subsequent overturned decisions, and participants applying multiple times to gain access, and high levels of complaints.”^v VALID has observed this first-hand. We support hundreds of people with intellectual disabilities each year due to the inconsistent decision-making of NDIA’s staff and delegates. This a problem the NDIA can solve by training and supervising its own staff properly.

“The planners need better training!!! It is simple really, try listening to those that know the participant the best. If the reports submitted are unclear, follow up with the professional who wrote them. Not that hard really! It is OK to call for more information when things are not clear. Train the planners!!!”

While VALID certainly agrees with the NDIA that NDIS planning needs to be improved, we do not believe the planning process should be replaced by a compulsory assessment and an NDIS-designed calculator. A regular face-to-face meeting with participants can be a critical safeguard where a participant is reliant on paid supports and has few other, if any, people in their life. The NDIA is introducing regular (e.g. quarterly) phone check-ins as a safeguard but this will not work for everyone, especially for people whose access to phones is controlled by their service provider, and/or they are unable or unwilling to speak on the phone due to

their disability. The NDIA should not forget that the late Ann-Marie Smith never had a face-to-face meeting with the NDIS before she died of neglect at the hands of service providers.

If the NDIA is to remove planning from its remit, it must be replaced by funded independent person-centred planning for people with intellectual disabilities, and all other participants who want or need it, and these plans must form the foundation for the allocation of individualised funding. Individualised planning cannot be replaced by an algorithm.

2.3 The problem with allied health reports

The NDIA has spent hundreds of millions of dollars on commissioning allied health reports, many of which were never needed. For example, an Occupational Therapist or Speech Pathologist may be required to write a report justifying the purchase of an iPad for a person who needs access to communication apps but doesn't already have a device. The cost of the therapist's report often exceeds the cost of the iPad.

The NDIA consistently rejects the allied health reports they have themselves required because they say the reports do not include the details that the NDIA want. But the NDIA will not explicitly tell participants or therapists what is missing. Worst of all, the NDIA have refused to publish detailed guidance – including the preferred assessment tools – for allied health therapists that would solve the problem. VALID has asked for this information to be provided to participants and allied health therapists many times.

“It isn't that there is a problem with the current approach. NDIS choose to ignore reports. Planners and delegates should be forced to have greater accountability to listen to ALL reports. They currently ignore parts of reports.”

In 2018, VALID was receiving a high number of calls from participants, families, allied health therapists and service providers who had been told to seek reports from allied health therapists to justify their supports, and then found that the NDIA rejected the therapist's recommendations. In the absence of any other available information to guide report writing, VALID published a free guide to writing therapy reports – *10 steps to excellent NDIS therapy reports: VALID's guide to NDIS therapist reports for allied health professionals*. The guide has been directly downloaded from VALID's website more than 12,000 times, and has been shared throughout Australia by therapy associations, disability service providers, advocates, training providers, and is available on a wide range of NDIS-related websites. VALID understands that it remains the key document used by therapists who are learning to write NDIS therapy reports. We believe the NDIA should have published a similar document – they have not.

VALID believes that the lack of guidance from the NDIA about what they want from allied health therapists has wasted an unreasonable amount of time and money for everyone involved, and is a major contributor to the high number of reviews sought by participants. In 2018, VALID, Villamanta Disability Rights Legal Service and Victorian Legal Aid assisted Jake Castledine, and his mother Janice Castledine, at the AAT to appeal the NDIA's allocation of therapy hours for Mr Castledine. The process took three years, thousands of hours of legal and advocacy staff time, and imposed unconscionable stress on a family already under extraordinary pressure. The Castledine family won their case^{vi}, and the example has been used by many NDIS participants in their own battle with NDIA planners who refuse to incorporate the recommendations of treating allied health professionals in NDIS plans. The published AAT decision supported the premise that therapists who know the person, and have worked with them for a period of time, are a better judge of what the person needs than NDIS delegates and the Technical Advisory Team.

Ms Parsons, a senior employee of the NDIA, who admittedly holds impressive qualifications and has had significant work experience in the disability sector, expressed a view about what was appropriate for Mr Castledine as part of proposing an integrated MDT support. However, the Tribunal does not accept Ms Parsons' evidence as it relates to how many hours of speech therapy or occupational therapy are required by Mr Castledine, primarily, because she is neither a speech pathologist or occupational therapist, and also because she has never had the opportunity of making direct observations of Mr Castledine and his present ability to communicate with others and to undertake activities of daily living.^{vii}

Since then, the AAT has made more decisions that challenge the NDIA's proposal for independent assessments. In September 2020, an independent assessment was determined to be less accurate than the participant's own treating clinician (Ray v. National Disability Insurance Agency). The decision stated that "The Tribunal considers the observations made by Ms Barry [Mrs's Ray's psychologist] are more reliable than those made by (the independent assessor), as Ms Barry has seen Mrs Ray on approximately 50 to 60 occasions, including out of the comfort and familiarity of her home environment, whereas (the Independent Assessor) had only seen Mrs Ray once for a period of three hours in her home environment."^{viii}

The NDIA has not made systemic changes to its approach to both requiring and respecting allied health recommendations following these AAT decisions. VALID believes that it should.

2.4 Problems with access and supporting evidence

The NDIA have argued that their new approach is recommended in the Productivity Commission's 2011 *Disability Care and Support* Inquiry Report. VALID disagrees. The Productivity Commission *did* recommend independent assessments, but it proposed something very different to the model the NDIA is currently trialling.

The NDIA has said that using 'independent' contracted assessors for all participants, rather than relying on the participant's own treating professionals, will reduce "sympathy bias"^{ix}. It is true that the Productivity Commission referred to the potential for sympathy bias, however, it was specifically pointing to situations where doctors are put in the unfair position (the report uses the word "invidious") of filling out application forms so that a patient can access benefits (e.g. Centrelink; worker compensation schemes).

Bias can go either way – for or against you. Many NDIS participants have had extremely negative experiences of being forced to see a 'government doctor' by a Centrelink-appointed Job Capacity Assessor or compensation schemes like Workcover. VALID understands that the assessors will be paid per assessment. This means that the more assessments they complete, and the faster they complete them, the more money the NDIA-appointed assessors will make. As long as the NDIA is in charge of appointing the organisations undertaking the assessments and setting their pay and Key Performance Indicators, we cannot be confident that the contracted assessors are not holding sympathy bias for the NDIA itself.

"My son was ordered to have an assessment when he applied for a Centrelink Disability Support Pension. The assessor was an unfamiliar psychologist who asked my son questions that he didn't feel comfortable answering. He became visibly distressed and asked to wait in the waiting room while I answered the questions. The psychologist told me he was functioning "like an 8-year-old". I was amazed then that his application was refused. Apparently, the psychologist was advised by Centrelink to reject the application. I appealed and after many distressing months and was told by a Centrelink appeals consultant that it should never have been denied. The whole thing was such a traumatic experience for our family. It took some time for both my son and I to recover from this assessment."

VALID has noticed that GPs find the NDIS Access Request Form difficult to understand and use, and that they too have not been given clear guidance by the NDIA on how to fill in the

form. There is also no Medicare rebate for assisting with an NDIS application so little incentive to spend the time needed to fill out every detail comprehensively. This has led to many unnecessary rejections of applications for access to the NDIS and for some people, years wasted on appeals that should never have been needed. VALID has heard from some advocacy organisations that they have resorted to ghost-writing applications for doctors because they know the tricks to use on the form that the doctors don't. VALID has found that some doctors now simply refuse to complete the forms altogether.

2.5 A list of other big problems that need to be solved

- Some people with intellectual disabilities need assistance to map out what they want their life to look like independent of their families, services and the NDIA itself. Every request VALID advocates have made for independent person-centred planning has been refused by the NDIA, even where the person is unable to communicate their support needs, has only one service provider and no family involved.
- Lack of individualised and community-based support for decision-making: while the NDIA is working on a framework for supported decision-making, we have seen no commitment to allocating any funding to a participant (e.g. to start a circle of support), or to community and advocacy organisations (e.g. peer support, volunteer decision supporters). Without support for decision-making informing what people want and need, the NDIA continues to produce purposeless plans.
- Lack of training for NDIA planners and delegates on working with people with intellectual disabilities resulting in underfunded and cookie-cutter plans, and forcing people into review after review. This is a key reason why advocacy organisations across Australia are overwhelmed with demand and have long or closed waiting lists. While advocates are busy solving problems the NDIS creates, they are not attending to cases involving abuse and neglect and other discrimination.
- Low quality support coordination and widespread confusion about what support coordinators must do and cannot do for participants.
- Unbalanced incentives for Specialist Disability Accommodation property developers who are rushing ahead with building congregate housing instead of a home for every participant. Meanwhile, the NDIA raises concerns about the increasing cost of Supported Independent Living funding, most of which is used in congregate settings.
- The Information Linkages and Capacity Building Program is not achieving the vision set out for it, leaving eligible people without access to the Scheme and ineligible people without supports in the community.
- Extremely limited opportunities for people with intellectual disabilities and people with other cognitive disabilities to have meaningful and accessible co-design opportunities with the NDIA that would help identify where the problems are and how they could be fixed.

“Results are very hit and miss. Planners vary greatly. Many have very little understanding of what it means to require support to do basic tasks. Any requests that are not the standard 'cookie cutter' type seem to have bewildered the planners, requiring lengthy, time-wasting reviews, and advocacy from health professionals, MPs, media, etc.”

3 MISSING EVIDENCE

The NDIA has failed to produce the evidence that would convince us that compulsory assessments will improve fairness and consistency in planning as they say it will, or that people with intellectual disability will not be worse off. We don't know if the evidence is missing because the NDIA has simply not sought it out or because they are withholding important information.

3.1 Scheme sustainability

The NDIA have linked the need for compulsory assessments with the problem of 'Scheme sustainability'. In fact, the Australian Government Actuary estimated in 2012 that the NDIS would cost \$22 billion per year when it was fully established, and in the last financial year, NDIS spending was at \$21.72 billion – right on track. We have not seen evidence that a cost blowout is imminent, and if it is, the NDIA should explain why and invite public examination of the issues and possible solutions.

The NDIA have also said that they want to make major changes to the way that funding for Supported Independent Living (SIL) works; it is more expensive than they expected it would be. It is possible that SIL costs are higher than anticipated because they were previously underfunded by state systems and that the real costs are only now becoming clear. Research also tells us that the cost of congregating people escalates over time: it's less expensive in the long term to support people to live in a home of their own^x. Capping SIL costs through compulsory assessments will be dire for people with intellectual disability who want and deserve more independent lives.

VALID is also concerned about the implications for Scheme sustainability – not to mention the sustainability of participants' lives – if compulsory assessments go wrong. We predict the eviction of people with intellectual disability by SIL providers where the result of compulsory assessments leaves them with less than it costs to live in their current arrangement. In a market-based system, providers have no duty of care to work with a person who cannot pay. We have not seen evidence that future SIL costs will break the NDIA's budget.

And we haven't seen a comprehensive analysis of the costs and benefits of properly investing in the social and economic participation of people with intellectual disability since the Productivity Commission's 2011 report. Why not? If there is a real problem with Scheme sustainability, VALID is not aware of any evidence that demonstrates that compulsory assessments will solve it.

There are other reasons that may be causing problems with Scheme sustainability, including:

- changes to the Social, Community, Home Care and Disability Services Industry Award
- the cost of engaging lawyers and barristers to represent the NDIA at the AAT
- the double-handling of planning involving both LACs and delegates
- the cost of unnecessary plan reviews due to inadequate internal decision-making
- the ongoing cost of the NDIA staffing cap.

3.2 The postcode premise

Former Minister for the NDIS, Stuart Robert, has repeatedly stated publicly that compulsory assessments will make the NDIS fairer and more equitable. Minister Robert has said that it is unfair that people from more affluent postcodes receive more funding on average than people living in socio-economically disadvantaged areas^{xi}.

There are many reasons why average funding packages might differ between postcodes, other than lack of access to allied health assessments, including that:

- people who have had better access to education are more likely to live in certain postcodes and are more able to navigate NDIA's extremely complex systems
- some postcodes have more services available to assist them with NDIS planning and better access to advocacy
- people with Supported Independent Living funding, who have the highest packages on average, usually live closer to cities (e.g. most people who lived in Kew Cottages now live in Melbourne's affluent inner east).

It is unclear whether the aim of compulsory assessments is to bring people with lower-than-average packages up to the higher amount currently allocated to people from wealthier postcodes, or most worryingly, the opposite. It is also predictable that participants and families who have more financial resources will be more able to dispute the results of a compulsory assessment at the AAT, including privately commissioning detailed allied health therapy reports, because they will be the only ones able to afford it.

3.3 "Sympathy bias"

The NDIA's Independent Assessment Framework, released in August 2020, quotes a 2006 study to justify their claim that professionals known to the participant may overreport

support needs: “This risk may be amplified if the ‘rater’ or assessor has a professional relationship with the person being assessed.”^{xii} It should be noted, however, that the study involved disability support workers using the Special Needs Assessment Profile (SNAP) assessment tool with 29 people with intellectual disabilities. This is not evidence that allied health therapists are misrepresenting the needs of their clients to the NDIA in current access applications or in allied health reports.

VALID has not seen any evidence that the NDIA has taken steps to test the accuracy of current trial assessments given there will be no comparison data available to test it against. The NDIA will not make a second assessment available if a participant disputes the accuracy of the report data in their compulsory assessment. If the NDIA believe that allied health therapists are producing flawed reports under the current system, they must ensure that contracted assessments produce accurate results. The NDIA has not shown us if or how they will.

“I understand wanting to make sure that they have a consistent, controllable process, but they are effectively questioning the validity of every single medical professional other than the ones they deem trustworthy, as though every other medical professional and specialist is corrupt EXCEPT FOR THEIRS.”

3.4 Disability, not functional impairment

The introduction of compulsory assessments will provide the Agency with unprecedented information about the functional impairment of each participant. The tests that have been chosen are typically used for population research and in compensation schemes for workplaces and traffic accidents. The tests focus on what the participant cannot do, rather than what they would be able to do if they had the right support in the right environment. It is possible that the test results will mean that people with similar impairment scores receive similar funding – that is the NDIA’s goal – but that they will ignore the individual’s goals and aspirations – and their entitlement – to reasonable and necessary supports.

The UNCRPD asks more of the NDIA than to focus on functional impairment. It recognises that “disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others”^{xiii}. In other words, the environments people live, work and play in directly affects how much their disability impacts their life.

VALID is extremely concerned about whether compulsory assessments will take into account how the participant's situation or environment impacts on their current functioning. VALID has witnessed example after example of people who previously had been considered as having extreme behaviours of concern who relax and thrive when they have moved out of inappropriate congregate living situations and into a home of their own. Conversely, we have also seen many people who are no longer displaying behaviours of concern due to the supports in place around them, who have had funding cut and support removed because the planner failed to understand the ongoing need for them. The NDIA must ensure that any assessment it commissions or is funded through a participant's NDIS plan measures whether the person's rights are being realised in the context of the vision of the UNCRPD.

“My daughter took part in the pilot assessment last week. As they were all closed questions, the assessor missed out on crucial information. The questions are deficit-based and didn't cover any of my daughter's strengths or likes. The assessor misinterpreted information we provided so that near the end of the assessment she thought my daughter was verbal when she's totally non-verbal.”

3.5 Data, data, data

Given the assessment tools the NDIA has chosen are not designed to provide an accurate estimate of the cost of supports, VALID has questions about what the data will be used for over the long term. For instance:

- What benefit will the data be to the participant?
- How else will the data be used other than to determine the amount of funding in the plan?
- How will participants be kept informed about how their data is being used?
- Does the NDIA have plans to use the data to cap the funding of participants who are not 'making improvements' or 'building capacity'?
- Will the data be used to classify some participants as suitable only for congregate care?

VALID understands that the NDIA and Federal government are working on a range of projects simultaneously that raise serious questions about the way that data collected through compulsory assessments could be used. These projects include the National Disability Data Asset, digitalisation of NDIS invoices via Services Australia^{xiv}, an NDIS payment card, New Payments Platform ('blockchaining')^{xv}, Digital Partnership Program (DPP)^{xvi}, and others. VALID has also heard from NDIS participants who are concerned about

why Centrelink now requires them to report the total value of their NDIS package. We are also aware that the signing of an Access Request Form for NDIS now requires consent be given to the Agency to freely use information provided to them, with few exceptions.

VALID is concerned that the chosen tools will collect considerable data about Australian citizens who have disabilities and that it is unclear how or if this data will be used by other government agencies. VALID believes the NDIA should be transparent in everything it does and we do not have confidence that people with disabilities have been told the whole truth about how the data collected by compulsory assessments will be used and the benefits and risks to participants.

4 UNINTENDED CONSEQUENCES

VALID is extremely concerned that the NDIA is focussing only on the benefits of introducing compulsory assessments without regard for the possible negative impacts on, and unintended consequences for, people with intellectual disabilities and their families.

4.1 The domino effect

VALID anticipates that many people with intellectual disability will be worse off because the tests are not fit-for-purpose and will leave participants with inadequate funding, resulting in:

- Disability services refusing to work with underfunded participants
- Increased self-harm and harm towards others because people are forced to live in unsuitable environments with inadequate support
- Adults with intellectual disability moving back in with elderly parents
- Reduced access to specialist disability services including support coordination
- The closure of small and medium service providers who cannot operate on slimmer margins
- Participants and families putting up with underfunded plans for long periods just to avoid having a compulsory assessment
- Massive pressure on state systems who remain the last resort for people who have their NDIS funding reduced or are exited from the Scheme after a compulsory assessment – this will mean people returning to prison, people evicted into hospitals, more children in out-of-home care, homelessness and even preventable death.

4.2 Failing the test

People with disabilities, families and supporting professionals are at risk of overreporting or underreporting support needs during a compulsory assessment. This is predictable because the proposed compulsory assessment resembles a test that a participant must pass: failure

will have profound life-altering consequences. The assessment questions that are asked in the tools that have been chosen can be difficult to understand because they lack context and the yes/no questions leave no room for subtlety or error. The current trial does not allow participants to choose assessors that have expertise in intellectual disability even though this would be essential to success, and there have been no indications from the NDIA that the future brand of Independent Assessments would do this either.

Self-reporting

It is highly likely that people with intellectual disability will fare worse than others on the tests because they will:

- overreport what they can do, and/or
- underreport what they can't do, and/or
- refuse to engage with the assessor because they are fearful of strangers, are uninterested in, or object to, being tested and/or
- be unable to provide any answers to the questions due to the severity of their cognitive disability and other people will be relied on to speak on their behalf.

VALID has supported thousands of people with intellectual disability in their NDIS planning meetings since 2013. Advocates assist in NDIS planning meetings by rewording the questions asked by the planner because they are not in plain language and lack context, and they ask additional questions to get the context right.

For example, LACs and NDIS planners currently administer the WHODAS questionnaire in planning meetings. One of the questions is: *In the past 30 days, how much difficulty did you have in walking a long distance such as a kilometre?* If the person does not have any physical difficulty walking, they usually answer 'None', and most often, others present who know the person give the same answer. But VALID advocates ask more questions to get a clearer picture of the support the person needs while walking, such as

- Do you usually have someone with you when you go for a walk?
- Do you choose when you're going for a walk or do you need some help with that?
- Can you decide where you're going for a walk without any assistance?
- Can you easily plan by yourself where you're going?
- Can you choose the clothes you need for the walk that are right for the weather or do you staff to give you advice?
- Can you cross the road safely without someone you know there with you?
- If something went wrong while you were out walking, would you need support to be safe?
- Could you do all of those things without any help from anyone at all?

After the follow up questions, the answer usually changes from 'None' to a higher rating because even though the person can walk a long way, they cannot walk alone. In one case,

the participant walked up to 50 kilometres on some days, but requires two support staff travelling near him in a vehicle at all times. If the tests applied ask questions that do not make sense to the participant or their supporters, or do not properly measure the support the person needs in their lives, the results will be inaccurate, invalid, dangerous, and a waste of taxpayers' money.

“My children have high anxiety. This is especially true when meeting new people. They are unable to speak in stressful situations and take months to interact in any meaningful way with a new therapist. Ultimately, these assessments will have the combined effect of increasing their support needs on the day and, due to inaccurate results, they could lose much needed supports. Overall, I fear they will be worse off.”

Families and disability support staff

Some families and disability support staff have many years of experience navigating service systems to obtain adequate funding for people with intellectual disabilities. Many do not. The introduction of the NDIS has revealed that many people with intellectual disability do not have the support they need from family or paid staff to find their way through the system. Case managers used to do this work for many people with intellectual disability, but this has been lost in the transition from state systems to the NDIS. For many reasons, NDIS support coordinators have not filled the gap.

The NDIA believe that compulsory assessments will create a fairer system, but the NDIS has never been fair to people with intellectual disability because it has never been made accessible to them. The Access Request Form is inaccessible. NDIS plans are full of jargon. The portal is unusable for people who have low literacy or no access to a computer. This means that NDIS participants with intellectual disability rely on others just to access the basics from a system that should have been designed around their needs. This will be true for compulsory assessments too.

For many participants with intellectual disability, arranging an independent assessment will be a job left to families and disability support staff – they will choose the assessor, make the appointment, seek an exemption, request the report, and lodge reviews as needed. They are also likely to be the support person who attends the compulsory assessment and answer questions with the person, on their behalf, and, as required by some of the NDIA's chosen tests, give answers without the person present. Families and disability support workers will know that the compulsory assessment is a do-or-die appointment and that if they fail the test, they will have even more work to do.

“We are extremely worried about the introduction of independent assessments. Our daughter is in her own place on her own with 24/7 support. The whole idea of the NDIS is to individualise supports and the introduction of independent assessments will be a huge step backwards to the bad old days. We are ageing and thought we were doing the right thing getting her established before anything happens to us.”

We expect that many families and disability support staff will underreport the person’s support needs because they do not want to humiliate the person by disagreeing with their answers or reveal sensitive personal details to a stranger. Some families and staff will overreport because they fear a return to the bad old days of state system lotteries where painting the worst possible picture was the only way to get the funding needed or any funding at all.

Allied Health Therapists

Instead of fixing their own problems, the NDIA blame allied health therapists for bias: “real or perceived inconsistency and uncertainty around the process of decision making by the NDIS...may lead to assessors overstating, whether intentionally or not, the need for funding for supports for the people with whom they have developed a professional relationship.”^{xvii}

VALID does not accept that the involvement of a contracted assessor will solve the problem the NDIA has with its own internal decision-making processes that frustrate allied health therapists. The proposed process will make an NDIA delegate’s work even more complex than it already is because it will require sharp judgement to determine whether the assessment results compared with other information including the risks of reducing funding.

“Employ planners who actually have qualifications and experience with the disabilities they are making decisions about. Their ignorance is the reason that so many NDIS plans need fixing. The current planners make extensive mistakes which won't be fixed by independent assessors.”

4.3 Judging a fish on how it climbs a tree

People with intellectual disabilities are at a significant disadvantage in standardised tests because their needs are often about assistance with planning, prompting and safety than their capacity to physically do the task. It is VALID’s experience that most disability

professionals – including NDIA planners and allied health therapists – are unable to assess the support needs of people with intellectual disabilities unless it is their chosen specialty.

People without experience in working with people with intellectual disability typically overestimate them or underestimate them. Many NDIS-funded allied health professionals and NDIA staff lack key knowledge of the impact on an individual of long-term institutionalisation – including acquiescence with assessors – common practices including Active Support and Systematic Instruction, supported decision-making, and communication support needs. Without a human rights approach that values community living, it is easy enough for an inexperienced assessor to assume that a congregate life is what people with intellectual disability want and deserve. This confirmation bias is widespread, and it keeps people with intellectual disability in their place: VALID advocates are accustomed to hearing NDIA planners ask group home staff “She likes it here, doesn’t she?”

It is also highly likely that a person with intellectual disability will perform better on the test at home, than in an unfamiliar place. Asking a person with intellectual disability to make a cup of tea as the observational component of a compulsory assessment proves only that the person can make a cup of tea in their own home. The assessor will not see that that same person is unable to make a cup of tea in an unfamiliar kitchen. This will skew test results and potentially disastrous for people who need highly tailored, active individualised support.

“My family member has an intellectual disability, and when people who don't know her ask her questions, she does not always understand them or answer truthfully. She doesn't understand, or doesn't want to be embarrassed. She often appears much more capable than she is. A past assessor had not bothered to look into her history or ask her family or care team about her needs. She didn't get the funding she needed.”

VALID has closely observed various disability funding systems over 30 years. In each iteration, people with disabilities, their families, advocates and service providers have had to figure out tricks and workarounds to access the funding they need. The spectre of compulsory assessments for each review request will mean that participants are likely to overreport their needs to get a bigger package so that they can avoid future assessments for as long as possible.

In the same way that the NDIA are concerned about the potential for professional bias, they should also be clear that many people with disabilities and their families will do what they

can to paint the worst possible picture of their needs because they know that everything is at stake. Forcing people to speak to a stranger about their lives and support needs guarantees inaccurate assessment results. Worse, it risks creating an NDIS where nobody trusts anybody.

5 WHAT IS AN INDEPENDENT ASSESSMENT?

VALID agrees that some people may need an assessment from an allied health therapist to get access to the NDIS for the first time because they do not have the evidence they need. We agree with the NDIA that participants should not have to pay for the reports they need to get access to the Scheme. But we also believe that participants should have the right to choose a professional who understands their disabilities, their support needs, and who can provide tailored support throughout the process. This is particularly important for people with severe intellectual disability, people with multiple disabilities, people without any informal supporters, and people with complex behaviour and/or communication support needs.

VALID believes that for an assessment to be independent it should be independent from government and the NDIA itself. The current proposal, where the NDIA contracts the providers directly, raises serious questions about the integrity of the process and removes choice and control from the participant. This is why the 2019 Tune Review (*Review of the National Disability Insurance Scheme Act 2013*) recommended against it:

Therefore, this review considers that, in at least the short term, the NDIA should not implement a closed or deliberately limited panel of providers to undertake functional capacity assessments...the panel of approved providers should be dynamic and evolve to ensure the new approach does not drive disengagement...there may be particular individual circumstances where it is more appropriate for non-NDIA approved providers to undertake the assessments. In addition, functional capacity assessments would not always be required, for instance if a participant's functional capacity is stable.^{xviii}

VALID believes that the tools selected for assessments should be chosen and evaluated by an independent body and must include academics with specialist knowledge on various disabilities and a diverse range of assessment tools. Governance processes should involve national Disability Representative Organisations. Participants can only be confident that assessments are independent if they are independent of the NDIA – this would align with the principles in the NDIA's Participant Service Charter:

Transparent

We will make it easy to access and understand our information and decisions.

Responsive

We will respond to individual needs and circumstances.

Respectful

We will recognise your individual experience and acknowledge you are an expert in your own life.

Empowering

We will make it easy to access information and be supported by the NDIS to lead your life.

Connected

We will support you to access the services and supports you need.^{xix}

5.1 What did the Productivity Commission say?

The NDIA has ignored some of the Productivity Commission’s other recommendations about how an independent assessment process should work. The Productivity Commission said these things about how the NDIA should proceed:

- “...the assessment process would draw upon existing medical reports”
- “As in New Zealand, assessors would be mentored in their first six months of assessments, and all assessors would be regularly assessed to ensure comparability of outcomes. This would prevent assessors from developing their own criteria for assessment, and avoid outcomes such as ‘sympathetic bracket creep’.”
- “Assessors...approaches to assessment would have to be aligned with the objectives of the NDIS”
- Assessors would be properly trained in...listening to the input of participants.”^{xx}

The Productivity Commission was also clear that assessments must keep the person with the disability front and centre:

Assessment should be carried out as a collaborative process, and in a way that is understandable for the person seeking support so that they are able to:

- *gain a better understanding of the purpose of assessment and its implications for their situation*
- *actively participate in the process*
- *identify and articulate the outcomes they wish to achieve (a support plan will also be key here)*
- *identify the options that are available to meet these outcomes and to support their independence and well being*
- *understand the basis on which decisions are reached.^{xxi}*

VALID considers that the above measures should have been put in place with the contracted assessors *before* the NDIA trials the proposed process to demonstrate a reliable result. They have not.

5.2 What else did the Tune Review say?

The NDIA says that the rollout of compulsory assessments is in line with the recommendations of the Tune Review:

The NDIS Act Review...recommended the NDIA introduce assessments for new and existing participants for the purposes of decision-making, using NDIA-approved providers in a form set by the NDIA.^{xxii}

The Tune Review recommended that changes should be made to the NDIS Act (2013) so that, a) the NDIA can use information from professionals about participants for access as well as for developing the person's NDIS plan (which is not currently how it works), and b) that the NDIA can require a person applying to the NDIS for the first time to have an assessment with a provider that the NDIS approves:

Recommendation 7: The NDIS Act is amended to:

- a. allow evidence provided to the NDIA about a prospective participant or participant to be used for multiple purposes under the NDIS Act, including access, planning and plan review processes*
- b. provide discretionary powers for the NDIA to require a prospective participant or participant undergo an assessment for the purposes of decision-making under the NDIS Act, using NDIA-approved providers and in a form set by the NDIA.^{xxiii}*

The Tune Review did not recommend that Independent Assessments should be compulsory. The *Australian Government response to the 2019 Review of the National Disability Insurance Scheme Act 2013* stated that, "The Government supports or supports in principle all 29 recommendations made in the [Tune] Report"^{xxiv}, but just ten days later, on 7 September 2020, the NDIA published on their website that "participants will need to complete an independent assessment from time to time...to ensure they continue to get additional funding." (Note: This statement is no longer available on the NDIA's website).

The NDIA have also either misinterpreted the Tune Review's recommendations, or have ignored Tune's caution that the introduction of independent assessments, should involve: "...extensive consultation with participants, the disability sector, service providers and the NDIA workforce"^{xxv}. The consultation the NDIA have done on independent assessments so far is asking how their proposal can best be implemented, not if we accept the premise that cost-savings are necessary, or if the tools are the right ones, or choice of assessor, the budget calculator or the governance. The NDIA have cherry-picked the recommendations that suit their agenda on Independent Assessments, while ignoring key safeguards that both Tune and the Productivity Commission recommended.

5.3 Independence and allied health therapists

It is insulting for the NDIA to suggest that allied health therapists currently working with NDIS participants are producing inflated accounts of the needs of participants - we have seen no evidence that this is true. Allied health therapists are required to take a clinical, objective and unbiased approach to their work with all clients. This is required by the regulator, the Australian Health Practitioner Regulation Agency, and by each profession's National Board (e.g. Occupational Therapy Australia), under the Health Practitioner Regulation National Law, and various codes of conduct.

Good Practice

The NDIA rely on therapy reports to assist with determining the allocation of funding for therapies, equipment, identifying risks (including the risk of having inadequate funding), as well as ratios of support. It is currently expected by the NDIA that an allied health therapist will work directly with the participant to complete assessments on functional impairment, work collaboratively with other treating professionals, monitor progress against goals, recommend supports and equipment that will improve the person's independence over time (or at a minimum, prevent further decline in their current functioning)^{xxvi}. This is the NDIA's own view of what constitutes good practice by allied health therapists.

It is VALID's understanding that the NDIA-contracted assessors will:

- Meet with the person at their home for a minimum of 20 minutes
- Will complete 4-5 of the prescribed assessment tools for each participant
- Write a report to the NDIA and that the report will generate a functional impairment score indicating which 'level' or 'band' of funding the NDIA delegate will allocate.

The NDIA-contracted assessors will not be required to make recommendations about how much funding a participant requires – this will be left to NDIA delegates. Contracted assessors will not be required to take into account what other professionals have previously reported. The NDIA is carving up widely accepted professional practices into unrecognisable pieces. This is irresponsible. If the NDIA have evidence that allied health therapists are acting improperly, they should release the information publicly.

“Our son does not respond to people he doesn't know. It would not be possible for anyone, no matter how experienced, to ascertain his needs in just a few hours. It takes months and months of knowing him and witnessing him on different days and different environments.”

Assessing Individuals

The Productivity Commission acknowledged that selecting assessment tools that will work for all participants is an extremely difficult task. The diversity among NDIS participants means that the tools must be carefully chosen for each individual situation, taking into account that some participants have multiple disabilities, health conditions and that make assessment a highly complex.

VALID does not dispute that the assessment tools currently being used in the trial are valid and reliable for the purpose for which they were designed. VALID objects to the way that the tools are being misused to calculate the cost of support for participants. If Independent Assessments are to have any reliability and credibility, VALID believes that the tools chosen must be verified for assessing support needs from a person-centred and strengths-based approach. Allied health therapists working with an individual are in the best position to determine which tools are needed at the time for the purpose they are being used.

The Right Tools for the Job

We have consulted with leading academics in intellectual disability who have confirmed that:

- there is no precedent for using these assessment tools in the way that the NDIA intends to and that it will not work;
- there is no available evidence that would suggest that the tools can accurately determine an individual's support needs;
- only tools specifically designed and tested for projecting support costs should be used.

“Budgets should not be based on independent assessments. The tools were not designed for that. The NDIA is stating they will pay for the commissioned independent assessments. Let people decide who does their assessment, from a therapist that is not beholden to the NDIA. A government-contracted assessor is not independent.”

Academics and practitioners VALID spoke with suggested that the I-CAN (Instrument for the Classification and Assessment of Support Needs), an Australian-designed tool that assesses support needs for people with a broad range of disabilities, is ideal for the job. We understand that, the NDIA did consider the I-CAN when selecting the tools for the trials, but ruled it out because it requires additional training and takes slightly longer to complete than some of the chosen tools. We would argue a job worth doing is worth doing properly. The NDIA also evaluated an old version of the I-CAN but it is now in Version 6. VALID recommends that the NDIA reconsider the choice of assessment tools by engaging research

by an independent body employing experts in developing and using tools that can accurately assess for support needs for different disabilities.

6 OVERWHELMING OPPOSITION

Many people with disabilities, families, advocacy organisations, peak bodies, allied health associations, and independent statutory agencies have publicly opposed the NDIA's proposal for compulsory assessments. This should matter to the Federal government and the NDIA. It is unacceptable that the views of people with disabilities and their supporters are being ignored by decision-makers.

6.1 People with disabilities and their families oppose it

VALID surveyed its members and subscribers about their views on NDIS Independent Assessments. We received more than 200 responses in two weeks. This is a snapshot of what they told us:

“ Offer assessments to people who choose to have them because they have no supports in place yet or cannot afford them. Do NOT make them compulsory. Listen to the qualified therapists who already know and understand the people they work with and are qualified to give recommendations. ”

“ Independent Assessments should not be used unless rigorous academic research delivers evidence that they are a fair solution for disabled Australians. Then if so, they should be optional. If people want to use an independent assessor, they can choose to do so. Other people may choose to get assessments and supply reports from other providers. After all, they are the same international assessment tools, aren't they? ”

“ Ensure NDIS staff are trained, capable and governed by duty of care. Refine the current system but don't replace it with a system of don't-know-don't-care-don't-take-responsibility staff like they have now. ”

“ For the most vulnerable like my son who has a severe developmental disability with incredibly high and challenging needs there must be a combination of assessments by experienced professionals who know him. If not, the resulting plan is likely to be inadequate and inappropriate. The consequences for my son would be devastating and potentially lead to an early death. ”

“ Our family member will not cope with the assessment process as he has an intellectual disability and autism. He will probably have a meltdown which will make the process impossible. Where that leaves him if he won't participate is anyone's guess. ”

“ My daughter always tries to guess at the answer that she thinks the person will want to hear. So the question may be ‘Can you make a cup of tea,’ and she will answer ‘Yes,’ because she thinks that it is the right answer rather than the correct answer. She can't make a cup of tea. If they asked ‘Can you tie your shoe laces?’, she will say yes, but it took her 20 years to learn how. She will say she can hang the washing but we only give her a handful of socks. We do this to encourage her but she doesn't realise she is only doing 1% of the task. An independent, unfamiliar allied health therapist is going to get an incorrect picture of my daughter. ”

“ My family member speaks in metaphors, so only someone who knows him well has half a chance of understanding him. He exhibits institutionalised behaviour where he answers in agreement just to end the experience. My family member has a significant phobia to inclement weather and if the assessment is taking place on such a day, he most likely will not participate. ”

“ My daughter can't read or write or tell time yet her language skills of talking are her strongest points. She can come across quite good in an initial chat but as the conversation continues or over time people realize what is missing. An assessment with someone who doesn't know her would probably result in a much closer to normal and not requiring as much support than if someone took the time to really understand her issues. ”

“ Richard is a non-verbal autistic 30-year-old with AHHD and no impulse control. He may go into the interview room if we promise to buy him chips later but he won't speak and is incapable of communicating any needs or any other information. He will not stay in an interview room for more than a few minutes. ”

“ Our 27 year old son has multiple complex disabilities with over 30 allied health and disability health specialists. A majority are based 180 km away as there are no local therapists or specialists in our area. There is NO possible way an independent assessor can come into my son's life without evidence from his village of specialists and therapists. We live in a regional area of Victoria and there is a real and current thin market of therapists. No doubt those services who have secured the NDIS Independent Assessments will take away the much needed therapists who are available locally. The NDIS Independent Assessment process will NOT work, especially for those with multiple - complex disabilities. THE NDIA MUST LISTEN TO US!!!! ”

6.2 Disability Representative Organisations oppose it

On 11 March 2021, national disability advocacy peak organisations released a joint statement opposing the plan for compulsory assessments. There are now more than 100 organisations who have endorsed the statement. The statement says:

The introduction of mandatory assessments is the biggest change to the NDIS since it began. Despite the scale and cost of the changes, they have not been rigorously tested or undergone an independent evaluation. Consultation has been rushed and the questions and concerns of people with disability, their families and the organisations that support and represent them have not been addressed. Based on the information released by the NDIA, we are concerned that a desire to cut costs is the main motivation for the hurried introduction of these reforms.^{xxvii}

Disabled People's Organisations and Disability Representative Organisations, who represent NDIS participants, as well as Australians with disabilities who are not eligible for the Scheme, should be considered as a legitimate and credible source of information for the NDIA and the Federal government when making critical changes to the NDIS. It is entirely unacceptable for their concerns to be ignored or excluded from genuine co-design processes.

6.3 Allied health associations oppose it

Key allied health associations have publicly opposed the NDIA's compulsory assessment proposal. It is also important to note that while the NDIA claim that they consulted with allied health professionals in the development of the compulsory assessments, their professional bodies have been critical of the transparency of the NDIA during the consultations. They say that they were told that they were involved in developing a model for assessing eligibility access only, and that the use of the tools to determine funding levels was never discussed.^{xxviii}

The Occupational Therapy Association has stated their strong opposition to NDIA's current plan:

These tools have not been properly evaluated for their intended purpose and there are serious flaws with the ethics and nature of the trial currently underway...OTA is deeply concerned that the proposed tools are being used as a proxy for functional assessments and strongly objects to the proposed observation of a participant interaction being used in the tool...Observation of a participant carrying out a task cannot be reliably interpreted as a valid method for determining functional capacity unless the independent assessor is a qualified occupational therapist using specific professional reasoning, detailed task analysis, risk management and assessment

tools. OTA opposes the use of the proposed independent assessment tools for informing participants' personalised budgets and plans. The tools are not designed to be used as assessment tools or as tools to determine functional capacity...The terms which have been used to define the initial assessment are inaccurate and misleading...^{xxix}

On 8 March 2021, the Australian Association of Psychologists Inc. (AAPi) made a public statement that said:

AAPi rejects the claims made by the NDIA that providers have 'compassion bias' leading to inflated requests for funding and supports. It is the position of AAPi that professionals working directly with participants would have the best information and assessment about what supports are needed for the participant to improve their functional capacity and live an 'ordinary life'.^{xxx}

On 26 March 2021, the Australian Physiotherapy Association published a media release opposing the NDIA's proposal:

The Australian Physiotherapy Association (APA) is calling on the federal government to immediately cease plans to introduce independent assessments...This is an unfair and untested measure which is being introduced solely as a tool to reduce the number of participants accessing the NDIS. This isn't about giving people what they most need to live the lives they deserve with dignity and independence, it's about minimising costs by reducing choice and individual control...It represents the largest backflip to the scheme since its introduction. Surely it warrants closer attention to the lessons learnt elsewhere, particularly where similar policy experiments have failed so miserably.^{xxxi}

6.4 Service providers oppose it

National Disability Services released a statement on 11 March 2021 criticising the proposal, and calling for an immediate stop to the plan:

NDS is calling on the government to:

- *Immediately cease the rollout of compulsory assessments as currently planned*
- *Undertake robust, independent and transparent trials of alternative approaches to improving consistency in access and planning—such as allowing a person's existing health professionals to complete assessments using the same tools*

- *Once the trials and evaluations are complete, engage in a meaningful co-design process with people with disability*
- *Allow a participant to invite a support person of their choice to attend planning meetings (or independent assessment, if it is implemented)*
- *When information from an independent assessment paints a picture of support needs which is quite different from that of others, a review should be triggered (which follows a process developed with the broader sector)^{xxxii}*

6.5 Critical figures oppose it

Professor Bruce Bonyhady AM, Executive Chair and Director of the Melbourne Disability Institute (University of Melbourne) released a submission in mid-March 2021 opposing the proposal. Professor Bonyhady was the inaugural Chair of the NDIA from 2013 to 2016, and integral to the developed of the NDIS in the years leading up to its launch. He said:

It is difficult to understand why administrative 'efficiency' is being prioritised over accuracy, especially given that the accurate determination of both eligibility and reasonable and necessary supports are foundational to the success of the NDIS. Fairness and consistency can only be achieved through accurate, valid assessments and governments need both accurate and consistent assessments for funding to be predictable and sustainable.^{xxxiii}

David Bowen, inaugural CEO of the NDIS spoke out against Independent Assessments on 25 March 2021:

I think the government's doing this to save money...It's a way of controlling the amount of funds that go into each plan, through determining that plan value through an assessment tool, rather than through a personalised plan...This was never a one-size-fits-all model. This was about personalised plans, recognising the individual circumstances of people. Now they're introducing an assessment where you see someone who has no knowledge of your history [and] no personal relationship with you. I think that's woeful.^{xxxiv}

Australia's Disability Discrimination Commissioner, Ben Gauntlett, has also raised concerns:

...[the new policy] might undermine the effectiveness of the National Disability Insurance Scheme and not have the intended effect, particularly for individuals with complex support needs. What I'm hopeful is that there will be some material amendments to the approach taken. The practical operation of these independent assessments is critical and their implementation has caused widespread concern and

comment from people with disability, disabled persons organisations, advocates, academics, carers, and health and medical professionals.^{xxxv}

7 CONCLUSION

VALID strongly opposes the NDIA's current proposal for compulsory assessments. VALID believes that the proposal is not aligned with the UNCRPD, the NDIS Act and its General Principles, and does not meet the expectations of NDIS participants, their families and supporters. As always, VALID will work with decision-makers to get it right for people with intellectual disabilities and their families. However, VALID will continue to campaign against Independent Assessments unless there is a major overhaul of the principles, design and implementation of the proposal. We thank the Joint Standing Committee on the National Disability Insurance Scheme for the opportunity to make this submission. We hope that the Committee will make the recommendations that are needed to ensure the NDIS is the best it can be – an NDIS that works for everyone.

VALID CEO STATEMENT OF CONCERN

NDIS Independent Assessments

9 September, 2020

VALID is deeply concerned that people with intellectual disabilities will be much worse off if the NDIA goes ahead with its plans for compulsory Independent Assessments. The information the NDIA has released so far tells us that there is a lack of evidence that Independent Assessments will produce the outcomes that NDIA wants, and that people will be put at serious risk if it fails.

We know that this approach has not been properly trialled with people with intellectual disabilities who have complex support needs. Also, that the assessment tools the NDIA has chosen are not likely to give information that is a true reflection of the wishes and needs of a person with intellectual disability. Experts tell us that people with intellectual disability typically need a sustained, multi-disciplinary approach to put together a reliable, ethical, evidence-based assessment of need. Unless the NDIA's proposed Independent Assessments have been proven effective for people with intellectual disability, they cannot go ahead in any way.

We know that Independent Assessments rely on interviewing the participant, as well as speaking with people who know the person well ('informants'). We don't know yet how the NDIA will decide whether a participant can accurately report their wishes and needs, how families will be involved, who the right informants should be, how conflicts of interest will be managed where services are the only available informant, the role of independent advocacy and supported decision-making and much more. These questions must be properly resolved before Independent Assessments are operating.

Inclusion Australia, with VALID's support, worked hard to show the NDIA that people with complex support needs had to have a different approach to planning. The standard pathway didn't work for some people - that's why the NDIA has a Complex Support Needs Branch now. Independent Assessments is just one more initiative that hasn't been tested or endorsed by the participants who use the NDIS the most. We don't want one more parallel system - we want a system that works for everyone.

The NDIA must hold people with the most complex support needs at the heart of the design of any new initiative. This means co-designing with

people with intellectual disabilities, their families and advocates – people with intellectual disability with communication support needs, people with behaviours of concern, people formerly institutionalised, and people who have no family or friends they can rely on. We are talking to the NDIA at every level, and working with Inclusion Australia and other advocacy organisations, to speak up about the problems with Independent Assessments. We will keep raising your questions too, and keep you updated about what we find out.

Kevin Stone AM
CEO

VALID CEO OPEN LETTER

VALID stands against independent assessments

19 November, 2020

VALID made a statement in September this year about the NDIA introducing mandatory independent assessments. Since then, we have read the information that the NDIA has published and we have worked hard to consult with people with intellectual disabilities, families and professionals about the changes.

We have presented our concerns in many forums and consultations over the past few months and we have met with the NDIA CEO, too. We appreciate the effort that the NDIA has made to engage with us to resolve the problems we and others have identified, and we acknowledge the good will and genuine commitment of many people working at the NDIA who are grappling with how to make sure that the scheme is sustainable, flexible and individualised.

VALID is not opposed to the idea of independent assessments. We believe they will be helpful for people who want and need them, and they might save people money on buying expensive therapy reports. But we also believe there is no evidence that the NDIA's proposed tools and process will achieve the outcomes that the NDIA wants them to.

The Productivity Commission said in 2011 that independent assessments should only be used when the right assessment tools become available. Those tools still do not exist. The 2019 Tune Review also said that independent assessments should be optional. We agree. We believe that the unintended consequences of the current proposal will be potentially devastating for people with intellectual disabilities and their families.

Yet, the NDIA have already decided that independent assessments will go ahead and that they will be mandatory. They have not done the research or evaluation necessary to prove that independent assessments will work for people with intellectual disability, particularly for people with multiple disabilities and people with complex support needs. The NDIA have not answered our questions about how independent assessments will be used to determine an individual's support needs.

The NDIS was designed to support the individual goals and aspirations of people with disabilities so that they can have great lives. NDIS planning

was supposed to be about getting to know the participant and involving other people who know them well so that each plan is a custom-build for the individual.

VALID always looks to collaborate with decision-makers on issues important to people with intellectual disabilities and their families. But when it becomes clear that we are not being listened to, or that decisions are being made without a good evidence base, or when we are being asked to agree with something that is against our fundamental principles, we will take strong action. In relation to the NDIA's agenda on Independent Assessments, VALID is aggrieved on all three counts. We firmly believe the unintended consequences of their approach will be harmful to people with intellectual disabilities and detrimental to the success of the NDIS itself.

VALID therefore advises of its withdrawal from any further consultation processes on independent assessments. Instead, we will be working with our members and advocacy allies to actively campaign against independent assessments to ensure that the NDIS we have in the future is the one we fought so hard for. Stay tuned!

Kevin Stone AM
CEO



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NDIA Response to VALID's Open Letter re Independent Assessments

The NDIA notes with regret VALID's open letter stating its opposition to independent assessments and intention to withdraw from further consultation with the NDIA.

We appreciate the acknowledgement by VALID of the good will and genuine commitment of NDIA staff working on the introduction of these reforms. Similarly the NDIA records its deep respect for the work of VALID over many years, and of its CEO, Mr Kevin Stone AM, and all other staff members, on behalf of people with intellectual disability.

We do not agree with the position taken by VALID on the introduction of independent assessments, and consider VALID to be mistaken in its understanding of both the Productivity Commission and Tune Review reports.

The Productivity Commission (PC) did not say independent assessments should not be used until the right assessment tools become available. Quite the reverse. The PC report noted that *"assessment tools are needed to determine the level of needs and funding for a person covered by the scheme"*. It then stated *"There is currently no ideal tool to use in the NDIS, but governments should not delay implementation of the scheme in the absence of 'perfect' tools. Accordingly, the NDIS would use the best available tools in its initial implementation phase, with the ongoing development of best practice approaches"*.

The Tune Report did not state that independent assessments should be optional. Recommendation 7 was that *"The NDIS Act is amended to b. provide discretionary powers for the NDIA to require a prospective participant or participant undergo an assessment for the purposes of decision-making under the NDIS Act, using NDIA-approved providers and in a form set by the NDIA."* It noted at para 4.29 *"The benefits that have arisen from this pilot indicate it is worth implementing nationally for every person with disability who would like to test their access for the NDIS or who require further evidence to support decision-making about the supports in their plan"*.

The approach the NDIA is taking is backed by deep research and evaluation. The proposed tools have been validated over multiple years in multiple countries, including specifically with people with intellectual disability, as providing a reliable assessment of functional capacity. The approach the NDIA is taking is set out in two detailed academic papers we released on both the [Assessment Framework](#) and the [Tools selection](#).

The NDIA's approach has been endorsed by leading Australian academics in the field. Professor Andrew Whitehouse from the Autism CRC and Telethon Kids Institute and Professor of Autism Research at The University of Western Australia states *"The [independent assessment] framework is consistent with international best practice. It has great potential to increase the accuracy of assessment, which is a critical foundation in determining the most appropriate supports for each individual."*

University of Sydney's Dr Ros Madden AM, Honorary Research Fellow and Nick Glozier, Professor of Psychological Medicine state *"[The NDIA] have outlined a framework on which to build a fairer and more consistent disability assessment – to enable the rights of people with disability to participate"*

Delivered by the

National Disability
 Insurance Agency

across society. This diagnosis-neutral framework combines both the need to evaluate capacity and the determining role of the environment in helping or hindering participation.”

Professor and Chair of Infant, Child and Adolescent Psychiatry at the University of New South Wales and Head of the Academic Unit of Child Psychiatry, South West Sydney, Valsamma Eapen said *“The new functional capacity assessment framework by NDIS aligned to the International Classification of Functioning will undoubtedly enhance the development of effective programs matching each individual’s functional level and needs, thereby optimising outcomes.”*

We agree with VALID that planning is meant to be about getting to know the participant and involving other people who know them well so that each plan is a custom-build for the individual. In too many cases it is not that today. The NDIA’s new approach, as set out in the [Policy Consultation paper](#), enables exactly those sort of conversations, with planning being about how best to use a fair and reasonable flexible budget to pursue the participant’s individual goals and aspirations.

The fair and reasonable flexible budget will be derived from a consistent measure of functional capacity and environmental factors. We have pointed to significant evidence that the current approach to line by line negotiation of funded supports is leading to unfair and inconsistent plan budgeting decisions, including favouring those with higher socio-economic status.

Participants with similar functional capacity in similar life situations will receive a similar overall budget amount. We will use the experience and data gained over the past seven years, together with the large volume of pilot assessments currently being undertaken, to formulate those consistent budget amounts. Planning will then be about how best to use those funds by, with and for the individual participant so they can indeed pursue their goals and have great lives.

Lastly, the NDIA notes that the October 2020 Budget shows annually increasing expenditure on funded supports in the NDIS, and a \$3.75 billion increase for 2020-21 to 2022-23 compared to the prior Budget. Independent assessments are not a cost-cutting exercise.

The NDIA will continue to work openly and in good faith on the implementation of the independent assessment-based approach to access and planning. There is still much joint work to be done. We will be delighted to re-engage with VALID on this work at any time.



Martin Hoffman
Chief Executive Officer
National Disability Insurance Agency

3 December 2020

END NOTES

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