

National Disability Insurance Agency

Consultation Paper: Access and Eligibility Policy with independent assessments

Occupational Therapy Australia submission

February 2021

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Executive summary

Occupational Therapy Australia (OTA) welcomes the opportunity to provide feedback to National Disability Insurance Agency (NDIA) regarding its Access and Eligibility Policy with independent assessments.

Occupational therapists work with participants to enhance their ability to engage in the occupations they want, need, or are expected to do; or by modifying the occupation or the environment to better support their occupational engagement. They have had a pivotal role in the NDIS since its inception and have long recognised the value of the scheme.

OTA is acutely aware of the need to determine a person's eligibility for NDIS in a timely manner and to do this both transparently and equitably. In principle, OTA supports the engagement of a core set of appropriately qualified, experienced and trained allied health clinicians to screen participants for their eligibility to enter the scheme.

However, OTA has major concerns about the relevance and scope of the proposed toolkit; the process for determining eligibility; the effectiveness of the tools being used to determine eligibility and, most importantly what impact this will have on participants, their families and caregivers.

Given these limitations, OTA has serious concerns about the IA being used as a proxy assessment for determining eligibility and proposes an alternative model for your consideration.

OTA would be happy to provide any further supporting evidence to substantiate this position.

Introduction

OTA is the professional association and peak representative body for occupational therapists in Australia. As of October 2020, there were more than 24,000 occupational therapists working across the government, non-government, private and community sectors in Australia. Occupational therapists are allied health professionals whose role is to enable their clients to engage in meaningful and productive activities.

Following extensive consultation with our membership, OTA is pleased to provide the following response to the NDIA's Independent Assessment (IA) Consultation Paper. OTA's response pertains to the issues and proposals specifically outlined in the consultation paper and to the consultation questions posed in the Consultation Paper (Appendix 1).

This submission should be considered in conjunction with OTA's response to the NDIA's Planning Policy for Personalised Budgets and Plan Flexibility with independent assessments submitted to NDIS under separate cover.

The role of occupational therapists in the NDIS

Occupational therapy is a person-centred health profession concerned with promoting health and wellbeing through participation in occupation. Occupational therapists achieve this by working with participants to enhance their ability to engage in the occupations they want, need, or are expected to do; or by modifying the occupation or the environment to better support their occupational engagement. Occupational therapists provide services across the lifespan and have a valuable role in supporting participants affected by developmental disorders; physical, intellectual, chronic and/or progressive disability; and mental health issues.

Given their expertise and area of practice, many occupational therapists deliver services funded by the NDIS (National Disability Insurance Scheme). Services focus on promoting independence in activities of daily living and enablement of social and economic participation. These services may include functional capacity assessment and intervention; disability-related chronic disease management; prescription and implementation of assistive technology and/or environmental modifications; mental health interventions; positive behaviour support; driving assessments (when specifically trained to do so); and targeted, goal-focussed rehabilitation.

Improving the NDIS

OTA is acutely aware of the need to determine eligibility for the NDIS in a timely manner and to do this both transparently and equitably. However, OTA has major reservations about how the defined independent assessment process and toolkit will achieve this (Appendix 2 & 3); particularly as the impact of disability on activity, participation and quality of life is so uniquely experienced and these interrelated and multifaceted factors are rarely detected in brief screening assessments or generic measurement tools (Madden et al., 2015; WHO, 2020). These factors are important considerations for determining eligibility and are core to

the spirit, purpose and scope of the NDIS (Australian Government, 2013a, 2013b & 2013c). We do not see any evidence that these factors have been considered in the recent pilot and we have serious concerns about the ethics, validity and implementation of the pilot project that underpins this significant change in practice (NDIS, 2020a & 2020b; Appendix 4).

OTA is particularly concerned that systemic safeguards protecting access to reasonable and necessary support for people with disabilities are not clearly articulated under the proposed NDIS reforms (Cummins 2021; Appendix 6). OTA is concerned that the solutions outlined in the Consultation Paper will further entrench inequity and lead to more harm than good (NDIS 2020a & 2020b; Barr et al., 2015; Cummins 2021). Equally, if the foundations and/or legislation of the NDIS are changed there is a serious risk that the economic gains the Productivity Commission anticipated may not eventuate (Australian Government Productivity Commission n.d). These concerns are elaborated on below.

NDIS Access and Eligibility

OTA recognises the value of NDIA utilising the International Classification of Functioning, Disability and Health (ICF) as a framework for the scheme. This framework aligns well to the core purpose and intent of the scheme and should underpin the rationale for determining eligibility (WHO 2020; NDIS 2020a & 2020b).

IAs were developed for the primary purpose of determining eligibility to the scheme. After close examination of the toolkit and the pilot program, OTA has concluded that the IA toolkit is not fit for this purpose (NDIS 2020a; DSS 2010; Madden 2015; Appendices 2, 3 & 4). OTA is concerned that this process impinges on the rights of people with disability and limits their choice and control (UN, 2007; Barr et al., 2015; Cummins 2021). The tools proposed for the IA are not designed to effectively identify functional needs related to the NDIS assessment domains and there is no clarity on how the data collected from these tools will be collated or analysed to determine eligibility (NDIS, 2020a & 2020b). This is of particular concern given that there is no scope for assessors to use their clinical reasoning; and that the ultimate decision makers, who may not even have a clinical background, will not know the applicant (NDIS, 2020b).

The proposed toolkit is predominantly based on self-report measures that are not designed as assessment tools or as tools to determine functional capacity. They were not designed to be used either individually or collectively to determine eligibility (NDIS 2020b; Appendices 2 & 3). Consequently, the terms and definitions used to describe the IAs are inaccurate and misleading to people with disability and to the people who have the serious responsibility of making the ultimate decision about someone's eligibility.

OTA questions the relevance and scope of the proposed toolkit; the process for determining eligibility; the effectiveness of the tools being used to determine eligibility and, most importantly, the impact this will have on participants, their families and caregivers (Barr et al., 2015, Cummins, 2021; Appendices 4, 5 & 6). We are deeply concerned that the person's first experience of the NDIS will be based on the use of predetermined self-report measurement tools, implemented in an impersonal way by an assessor who may not know

the client. While these issues affect NDIS applicants across the board, they are of particular concern to vulnerable client groups who may be experiencing loss, grief, mental health problems or post-traumatic stress (Fernández-Alcántara, 2016; Barr et al., 2015; Cummins, 2021; Appendices 5 & 6).

Furthermore, the proposed assessment tools are based on standardised self-report items linked to conceptual domains, as opposed to the nuances around the client's individual circumstances, needs and/or goals (WHO, 2020). This is particularly problematic when the client is not known to the assessor; they are unable to effectively engage in the process; and/or have limited capacity to complete self-report measures (Barr et al., 2015). It is important to note that the WHO themselves endorse the use of disability-specific assessments that are contextualised to the nuances of the individual circumstances of people with disability (WHO, 2020). OTA is seriously concerned that NDIA is attributing significant weight to the use of these tools, without the benefit of the assessor's clinical reasoning and without disclosing the criteria which will be used to guide decisions makers. Once again, this is particularly alarming given that the tools were not designed for this purpose and the ultimate decision maker may or may not have a clinical background.

Understanding the nuances and details of a person's situational context has a substantial bearing on their functional capacity, and ultimately their eligibility for NDIS. This includes their health, additional disabilities, education, work and life experiences, physical or built environment, community environment, family and social supports and economic situation. Generic measurement tools are limited in their capacity to detect and/or predict individual functional capacity and support needs because the characteristics and impact of disability are uniquely variable (WHO 2020; Madden et al., 2015). Occupational therapists are uniquely placed to carry out these assessments because they are trained in task analysis of cognitive, physical and psychosocial assessment components.

OTA does not believe the tools sufficiently target the needs of people eligible to access the NDIS. They lack sensitivity, specificity and, in many cases, relevance to a broad range of people that present with substantial and permanent disability (Madden, 2015; Appendix 3). Consequently, they have limited capacity to capture and/or accommodate for:

- The unique issues and needs of vulnerable client;
- The complex interplay of multiple disabilities and/or illnesses;
- Fluctuating capacity, and how this interacts with environmental factors;
- The needs of people with histories of homelessness and complex needs (Micah Projects, 2015);
- The experiences of disadvantage, abuse and trauma that many people with complex needs and/or psychosocial disability have experienced;
- The unique needs of people affected by psychosocial disability, particularly self-harm or behaviours of concern (Cummins, 2021; Appendix 5);
- The unique needs of culturally and linguistically diverse (CALD) clients and clients of Aboriginal and Torres Strait Islander (ATSI) descent; or
- The need for assistive technology and environmental modifications (Madden 2015; Appendices 3, 5 & 6).

The NDIA Independent Assessment document, which outlines the evaluation of all assessments, specifically states that assessments that require a person to “perform” or to be observed performing a task will not be included in the toolkit. Despite this, NDIA is requesting that the assessor does just this, without any means to document the analysis of these observations. OTA strongly objects to these observations being used in the IA as a proxy for a functional assessment. This type of observation is likely to have only limited usefulness in determining eligibility when it is based on a component activity that may or may not relate to the client’s typical daily routines. Moreover, if the assessor is not trained or qualified to functionally assess task performance, there is also the potential for harm due to inappropriate activity choice and/or failure to draw appropriate conclusions from the observation.

Functional assessments, as occupational therapists know them, require a distinct skillset that is core to occupational therapy practice. 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 reiterates that the proposed IA tool is not a functional assessment and should not be used as a proxy functional assessment to determine eligibility for the scheme.

Recommendations

- OTA strongly recommends the NDIS creates an approved, fit for purpose screening process which singularly focusses on determining eligibility for the scheme. We agree that this should be administered by allied health clinicians with relevant background, experience and training, with clear criteria and processes to ensure that decision making is supported by sound and objective clinical reasoning (Appendix 7).
- Clinical reasoning should be used to determine what, if any, measurement tools are relevant to use in the context of the person’s circumstances and to triage people who need more comprehensive clinical assessments to determine eligibility.
- Where a functional assessment of a person’s occupational performance is deemed necessary, OTA would strongly recommend referral specifically to an occupational therapist. Occupational therapists are uniquely qualified to conduct assessments to determine a client’s ability to effectively and safely carry out activities and tasks they want and need to do; and to determine their ability to participate in productive occupations and social and community activities. This model would provide a road map for improving the outcomes of clients with a disability, which is core to the intent and spirit of the NDIS (Appendix 7).
- OTA strongly recommends that an independent appeals process be established and that all those appealing are offered a comprehensive functional assessment by a suitably qualified occupational therapist or other allied health professional assessment as appropriate.

Personalised budgets and plan flexibility

OTA opposes the use of IAs for determining personalised budgets and plan flexibility as the tools are not designed for this purpose (Madden et al., 2015; Appendices 2 & 3). OTA members report substantial problems, disruption and delays in providing the relevant supports, services, assistive technology and/or home modifications when decisions for personalised budgets and plan flexibility are made without comprehensive assessment of the participant's needs. OTA elaborates on the reasons for this opposition in its submission to the NDIS Planning Policy for Budget Flexibility.

Recommendations

- OTA strongly recommends coordination of relevant allied health assessments to provide accurate estimates on the reasonable and necessary supports, services and/or assistive technology that is required to optimise participants' function.
- OTA strongly recommends referral to an occupational therapist to determine what is required to optimise participants' function and/or what interventions, modifications and/or assistive technology is needed to provide accurate estimates for personalised budgets.

Eligibility Reassessment

OTA understands the importance of reviewing the needs of participants and their NDIS plans to accommodate for superimposing fluctuation and/or deterioration of their condition. However, OTA does not understand why participants' eligibility for the scheme would be reassessed routinely if the initial assessor has already deemed them to have a permanent, ongoing disability. OTA considers this an unnecessary impost on participants and is concerned that this will cause participants a high degree of uncertainty about the viability of their future (UN, 2007).

OTA questions the circumstances and criteria for changing a participant's permanent disability status. If this does result in a participant being withdrawn from the scheme, we ask what mechanisms are in place to enable participants to re-enter the scheme as their needs change (UN, 2007).

Recommendations

- OTA recommends a regular review of the participant's needs and goals, in collaboration with the participant, their family and/or carers and health practitioners who know the client well, to inform modifications or changes to their NDIS plan.
- OTA recommends updated functional assessments to offer insight into the participant's current functional capacity to determine what reasonable and necessary measures are needed to sustain optimal functional capacity.

Independent Assessor Workforce

OTA is acutely aware of workforce shortages across the sector and the impact this has on a person's capacity to access the scheme. OTA supports a model of engaging allied health

providers with the relevant background, experience and training to improve timeliness of eligibility screening. However, OTA must emphasise that this model should only be used for eligibility screening, not for any type of assessment requiring discipline-specific expertise.

OTA is concerned that allied health clinicians will be recruited solely to carry out IAs. This will disrupt and erode the emerging allied health provider base which is already insufficient to manage the present demand.

OTA is also concerned that only a select number of organisations will be contracted out to provide IAs, limiting the pool of assessors available and ultimately limiting participant choice – supposedly a key tenet of the scheme. These assessors may or may not have the relevant background or experience to effectively assess all cohorts, particularly those who are vulnerable and/or those who have complex needs from an area of practice in which the assessor is not experienced (Barr et al., 2012).

OTA asks what processes will be put in place to ensure the tender process is equitable and transparent; that vested interests and/or conflicts of interest are identified; and that independent assessors receive sufficient orientation and training to carry out IAs before they commence. OTA would be happy to collaborate with NDIA to develop a model for training or endorsing assessors to carry out eligibility screens.

Recommendations

- Establish a standardised, regulated endorsement program to qualify suitably skilled and experienced existing providers to provide comprehensive functional assessment including support-needs identification.
- Ensure the independent assessors have relevant skills and experience with the cohort they are assessing. For example, only use mental health professionals to assess people with psychosocial disability. This could include psychologists, occupational therapists or social workers.
- Enable people with disability to access assessors with disability-specific expertise and the ability to accurately determine support needs.
- Implement a review process to ensure there is an equitable and transparent tender process in place.

Conclusion

OTA thanks the NDIA for the opportunity to comment on its Access and Eligibility Policy with independent assessments.

OTA recognises the need to determine a person's eligibility for NDIS in a timely manner and to do this both transparently and equitably. OTA supports the engagement of a core set of appropriately qualified, experienced and trained allied health clinicians to screen participants for their eligibility to enter the scheme. However, OTA has major concerns about the relevance and scope of the proposed toolkit; the process for determining eligibility; the effectiveness of the tools being used to determine eligibility and, most importantly what impact this will have on participants, their families and caregivers. Given these limitations,

OTA has serious concerns about the IA being used as a proxy assessment for determining eligibility and proposes an alternative model for your consideration (Appendix 7).

Please note that OTA clinicians would gladly meet with representatives of NDIA to expand on any of the matters raised in this submission.

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Appendix 1: OTA Response to Consultation Questions

OTA offers the following observations in response to the specific questions posed by the NDIA.

1. What will the people who apply for the NDIS need to know about the independent assessments process? How is this information best provided?

The NDIA should produce a visual flowchart outlining the process and expected timelines for gaining access to the NDIS. Applicants should also receive a simple form from a medical professional which includes the following information:

- a) Diagnosis/disability
- b) Date of diagnosis/start of disability
- c) Treatments/interventions attempted
- d) Permanent? Yes/no.

2. What should we consider in removing access lists?

Access lists have made access to the NDIS very straightforward for applicants with a diagnosis which clearly indicates permanent disability (e.g. a severe spinal injury). They have, however, been highly problematic for applicants with an unlisted disability. OTA members report that applicants are routinely rejected because their condition was not listed or known to the NDIS delegate.

If access lists are removed, they must be replaced by a comprehensive independent assessment model which accurately captures the extent of a person's functional impairment. If retained, the lists should be refined and the policies and procedures for unlisted conditions should be more transparent.

3. How can we clarify evidence and requirements from health professionals about a person's disability and whether or not it is, or is likely to be, permanent and lifelong?

OTA suggests that health professionals be required to complete a form, developed by the NDIA, which poses specific questions related to common elements of a permanent condition:

- a) Is there a cure for the condition?
- b) Will surgery resolve the condition?
- c) Is there a medication or treatment which would remedy the impairment?
- d) Is this a reasonable treatment expectation? Is it available and affordable for all Australians?
- e) Will any treatment improve the functional capacity of the individual to the point of being unimpaired?
- f) What is the expected trajectory of this type of condition/disability?

Example – Ehlers-Danlos Syndrome

- a) There is no cure.
- b) Surgery may be required for the management of joint dislocation but will not remove the impairment; it will simply make the joint less painful and more stable for a short period of time.
- c) Medication and treatments are supportive only; they are not curative or likely to remedy the impairment.
- d) Treatment is not widely accessible or affordable.
- e) There are no evidence-based treatments to cure or substantially treat the condition. Any intervention is supportive and capacity building; they are unlikely to improve the condition to the point of no longer being impaired.
- f) Disability often worsens with age due to the accumulation of injuries and joint instability. Pain adds to the disability burden and increases functional impairment.

Based on these questions, it is clear that a participant with Ehlers-Danlos Syndrome is likely to experience permanent and lifelong disability.

4. How should we make the distinction between disability and chronic, acute or palliative health conditions clearer?

A health condition is something which can likely be treated, resulting in a decrease of disease burden and impairment. A disability is a condition which diminishes a person's ability to engage in tasks, activities and roles in a typical way.

OTA notes that many disabilities are associated with health comorbidities, often directly linked to the cause or treatment of the disability. Those health conditions which can be directly linked to the disability should be funded by the NDIS. This matter is expanded upon in OTA's response to the NDIA's Planning Policy.

5. What are the traits and skills that you most want in an assessor?

Assessors should possess:

- Postgraduate clinical experience with complex disability;
- High level clinical reasoning and observational skills (e.g. noticing when an applicant is becoming overwhelmed and needs time);
- Demonstrable assessment interpretation skills, including the ability to analyse and synthesise complex information;
- Knowledge of their professional limits and scope, including when to refer to another health professional for more specialised advice;
- Communication and active listening skills; and
- An open and non-judgemental approach to all applicants.

6. What makes this process the most accessible that it can be?

Assessments should be as flexible as possible, enabling consumer choice and control regarding location, time and duration of assessments, as well as the communication method and who else can be present. OTA recommends that funding for a chosen provider to attend is incorporated into the cost of the assessment.

The NDIA must also ensure availability of interpreters to support access for CALD and ATSI applicants.

7. How can we ensure independent assessments are delivered in a way that considers and promotes cultural safety and inclusion?

All assessors should have cultural sensitivity training and a demonstrated understanding of Indigenous culture and barriers to accessing disability support, as well as engaging with the health sector more broadly. Similarly, LGBTQI+ awareness and training is essential for assessors working with an applicant who has identified as such. OTA notes that the option to choose a male or female assessor is also important for applicants of some religious backgrounds.

All assessors and interpreters should have a sound understanding of disability culture more broadly. Many people with disability strongly identify with their disability, seeing it as an enabler in life and something to be embraced rather than repaired. For example, a person with a hearing impairment may find it offensive for an assessor to suggest they should have their hearing corrected through surgery.

8. What are the limited circumstances which may lead to a person not needing to complete an independent assessment?

OTA believes a risk assessment should be conducted before requiring any applicant to undertake an independent assessment. In particular, people with trauma, PTSD, schizophrenia and Level 3 ASD may be at risk of adverse outcomes from participating.

Clients who might be exempted include those with psychosocial disability, ASD, communication disorders, traumatic brain injury, acquired brain injury or cognitive impairment; those experiencing homelessness; and those with severe pain or fatigue which precludes them from engaging in discussion for more than approximately 20 minutes, such as those with Lyme Disease, Chronic Fatigue Syndrome or migraines.

9. How can we best monitor the quality of independent assessments being delivered and ensure the process is meeting participant expectations?

To monitor the quality of assessments, the NDIA should consider the following options:

- Release of the NDIA's mapping and data analysis process for comment;
- External peer review of assessment results;
- Consumer and provider feedback forms;
- Compare results of an independent assessment with those of a comprehensive occupational therapy assessment; or
- Random Buddy Assessment – have two assessors attend an assessment and determine whether they draw the same conclusions from the data.

10. How should we provide the assessment results to the person applying for the NDIS?

The NDIA should provide a letter with the outcome and a copy of the assessment attached, followed by a phone call from the Planner or Local Area Coordinator (LAC). If the applicant is deemed ineligible, they should be provided with up to date advice about which alternative services are most appropriate to support their needs

Appendix 2 – Observations of the IA Model

Improving access

It is unclear how the proposed IA model will improve access to the NDIS. Rather, it involves a new layer of screening that risks excluding many potential participants from the scheme before a comprehensive assessment has been conducted.

Client experience

Under the proposed model, the client's first experience of the NDIS will be based on the objective collection of a substantial amount of data that by nature is impersonal. This is particularly so because the proposed assessment tools are primarily based on standardised self-report items linked to conceptual domains, as opposed to the nuances around the client's individual circumstances, needs and/or goals.

This is of particular concern when the client does not already know the assessor, and they are unable to effectively engage in the process and/or have limited capacity to complete self-report measures.

For example, OTA holds serious concerns for those clients who are particularly vulnerable because of the extent of their:

- Communication and comprehension difficulties;
- Psychosocial disability;
- Social disconnection, e.g. homelessness; and/or
- Culturally and Linguistically Diverse background.

Risk of further inequity

International evidence highlights the risk of inequity inherent in personalised and individualised social funding models, without an adequate policy response to address it. According to Inverse Care Law, people of higher socioeconomic status tend to benefit more from personalised approaches, as they typically have greater self-advocacy and negotiation skills to navigate complex systems.

Mandating that people with disability engage in an IA process which they do not have the functional capacity to complete creates a procedural and systemic barrier to access and participation in the NDIS. It is essential that people who cannot engage in an IA are offered an alternative pathway to access the NDIS.

OTA is also concerned that the applicant's right to appeal an IA is limited. In such instances, the NDIA proposes that the applicant completes a second IA, even though this style of assessment may have been the reason they were rejected for the scheme in the first case.

Potential for harm

NDIS Act 2013, Section 4 (3), states that people with disability and their families and carers should have certainty that they will receive the care and support they need over their lifetime. OTA would argue that the proposed introduction of the IA has resulted in uncertainty, fear and the loss of a sense of control for participants, families and carers.

There is a strong precedent for potential harm associated with large-scale benefit-eligibility assessment delivered through checklist-based assessment. For example, in England between 2010 and 2013, just over one million recipients of disability benefit had their eligibility reassessed using a new functional checklist. A study concluded that the program was independently associated with an increase in suicides, self-reported mental health problems and antidepressant prescribing (Barr et al., 2015). The reassessment process was associated with increases in adverse mental health outcomes, and these were greatest in the most deprived areas of the country, thereby widening health inequalities (Barr et al., 2015).

Given the limitations of the pilot study (see Appendix 3), OTA is concerned that the rollout of the proposed IA will result in similar outcomes.

Professional concerns

OTA holds grave concerns about the future of those smaller occupational therapy practices which have been involved in assessment processes to date and might lose that work as a result of the proposed reforms.

All too often, panels of approved providers comprise a few large, impersonal, multinational companies. And all too often, such arrangements – while bureaucratically convenient – result in the termination of longstanding and hugely beneficial clinical relationships between highly experienced clinicians working in small practices with often very complex clients.

The victims of this discernible trend in public policy are twofold. First there are those service providers who, while perfectly competent and conscientious, don't make the cut and, as a result, are denied access to a reliable source of work. Second, there are the consumers who, while being promised unprecedented choice in an age of consumer-driven care, are actually seeing their choice limited by public policy that is quite deliberately anti-competitive. Excluding qualified practitioners from whole fields of practice makes a mockery of all the rhetoric around consumer choice.

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Appendix 3 – Appraisal of the proposed IA toolkit

It is entirely inappropriate to determine a person's eligibility for NDIS supports using a set of tools which were neither designed nor validated for this purpose and population.

OTA has the following overarching concerns with the proposed toolkit:

1. **Construct validity:** There is a lack of evidence, in Australia or internationally, that the chosen toolkit can accurately measure a person's functional capacity and thereby determine their eligibility for disability supports.
2. **Disability-neutral approach:** There is a lack of evidence, in Australia or internationally, to support the assumption that functional capacity can be measured with a disability-neutral approach. Moreover, there is strong evidence to suggest this exacerbates inequity (expanded upon in Appendix 3).
3. **The full picture:** Even used cumulatively, the proposed tools will fail to capture a significant amount of information about an applicant's current and ongoing support needs. In particular, the tools do not effectively account for:
 - Upper limb impairment, fatigue, chronic pain or the need for assistive technology;
 - The functional impact of psychosocial disability, such as interpersonal and role functioning (e.g. parenting);
 - The fluctuating nature of some disabilities, including how this interacts with environmental factors;
 - Most situational variables (e.g. homelessness, unemployment and dual physical disability); or
 - The interface of diverse cultural perspectives and environmental factors that impact on activity, participation and community integration.

These limitations are demonstrated in **Case Study 1**.

OTA has also identified the following limitations associated with each specific tool.

CHIEF

- Intended to measure environmental factors, not functional capacity.

Vineland-3

- Intended to measure adaptive behaviour, not functional capacity.
- Inappropriate for people without cognitive or intellectual impairment and invalid for psychosocial disability where the impairment is due to mental health issues.
- Typically administered through a proxy, which some applicants may be uncomfortable with and/or unable to provide.

WHODAS-2

- Does not comprehensively assess functional capacity to engage in self-care activities (e.g. to wash; get dressed; plan, organise and prepare a meal).
- Does not address a person's capacity for economic participation, including work and study, if the person is not already engaged in these activities.
- Insufficiently addresses fluctuating nature of many disabilities, as it only considers experiences within the past thirty days.
- Questions are vague and can be hard for some applicants to understand.

LEFS

- Only useful for applicants with lower limb physical disability.

Case Study 1: Limitations of IA Toolkit

If I were to assess adult client X using the assessment tools only, the NDIA would not know that:

- *She can drive some of the time (i.e. in the mornings but not the afternoons or evenings);*
- *If she drives too far or for too long, her husband has to come and get her out of the car and carry her into the house;*
- *She needs help with dressing about fifty percent of the time. This is currently done by her husband who work full time and helps care for their two children, who are also NDIS participants.*
- *She has difficulties swallowing and sometimes aspirates;*
- *She has a lot of difficulty chewing; all of her food must be pureed, which she cannot do herself;*
- *She loses her voice when she is tired, emotional or has run out of energy;*
- *She has to have maintenance treatment (infusions) once every four weeks to give her body enough fuel to fight her autoimmune disorder;*
- *She uses her daughter's shower chair and other toilet aids on her really bad days which, depending on the point during her four-week treatment cycle, could be one per week or every day;*
- *Some days she struggles to wipe her own bottom after a bowel movement;*
- *She used to work full time but now struggles to do one hour every second day;*
- *She is responsible for her two children five days a week while they do distance education from home;*
- *She lives regionally and out of town, away from community supports;*
- *Her friends live too far away to provide "at the drop of a hat" support;*
- *She needs to hold her husband's hand when walking in town because she is unsteady on her feet and her legs sometimes give way;*
- *She has had multiple falls in the last twelve months;*
- *She doesn't have a wheelchair yet, though she desperately needs one;*
- *She cannot cook for herself or her children six out of seven days per week, relying on the freezer being stocked with meals prepared by her family who live 300 kilometres away; and*
- *She can sometimes put on a load of laundry but will struggle to get it out of the machine and could not hang it on the line.*

Use of IA Data

It is uncertain how the NDIA will use the data obtained in an IA to determine an applicant's eligibility for the scheme. OTA strongly believes the proposed tools and lack of scope for clinical reasoning mean that there will often not be enough information to make this decision. Certainly, no applicant should be excluded from the NDIS on the strength of an IA alone.

OTA is also deeply concerned by the proposal that IAs may inform a participant's current and future plan funding. The tools were not designed for this purpose and there is no evidence to support the assumption that they can be used as such. (This is expanded upon in OTA's submission to the NDIA's Planning Paper.)

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Appendix 4 –The IA pilot study: Ethical considerations

Informed consent

It is unclear how well-informed participants were of:

- The intended purpose of the pilots;
- Their right to refuse participation without negative ramifications; or
- How their personal data would be stored and used, including whether or not it would inform their current or future NDIS plan.

For example, the IA pilot consent form indicates that participants' data will be disclosed to a third party, without specifying what information will be shared or why. It also states that the IA pilot data will be stored in a Canadian server, without explaining the implications on participant privacy. This implies participants were not in a position to give informed consent.

Potential for harm

Anecdotal evidence suggests that confusion around the IA pilots – including their intended purpose, implications on plan funding and repeated requests for participation – has been highly distressing for participants and their families.

The IA itself involves a lengthy interview of up to 3.5 hours; observation by an assessor who is unknown to the participant; and completion of a series of standardised assessments which explore the highly sensitive subject of functional capacity and, by default, involve participant disclosure of functional deficits due to their disability. This is not routine care or process for NDIS participants. It is reasonable to assume this could be stressful or traumatic, especially given the uncertainty around whether the NDIA obtained informed consent from participants.

There is no publicly available information on what external supports or complaint avenues, if any, were available to participants of the pilot studies.

Transparency

The current pilot examines participant satisfaction with the proposed IA process, rather than satisfaction with – or accuracy of – the findings of an IA. It is difficult to understand how a national policy for accurately assessing eligibility for the scheme is to be developed based on these findings.

More broadly, there is a lack of clarity around how data from either of the pilots will be used to inform NDIA policies around eligibility and planning. This has caused significant uncertainty and distress for participants, families, carers and providers.

OTA also notes that the NDIA is yet to publish the full results of the first IA pilot. There is a perception that, to date, only positive responses have been published while negative ones have been withheld. The NDIA could alleviate these concerns by publishing the remaining results.

Generalisability

If the outcomes of the IA pilots are to be used to inform largescale policy reform, they should be based on a representative sample of NDIS participants. Instead, both pilots have relied

on individuals self-selecting to participate. This means the samples are likely to be biased towards participants with higher levels of functional capacity and self-advocacy skills.

OTA also notes that a very small percentage of participants in the first pilot study had a psychosocial disability. This, too, indicates that the pilot findings would not be generalisable to the wider NDIS population and should not be used in isolation to inform a national policy.

Conflict of interest

There is a potential conflict of interest if the organisation conducting the research has a vested interest, including financial interest, in the outcomes of the study. For this reason, OTA believes the IA pilot should have been overseen independently of the NDIA.

It would also be highly inappropriate for providers to have participated in the IA pilot whilst actively competing for the IA tender, as appears to have been the case.

HREC

Above all, an independent Human Research Ethics Committee (HREC) should have been engaged to oversee the ethical conduct of the IA pilots including: evaluation of risk to participants, informed consent, data record and management, publication of findings, potential conflicts of interests and allegations of research misconduct.

This assertion is based on strong evidence that the IA pilots do not reflect routine quality assurance undertakings but, rather, a piece of human research.

According to the National Statement on Ethical Conduct in Human Research (2007), human research is that which is conducted with or about people, including: taking part in surveys or interviews; undergoing psychological or other forms of assessment; and being observed by researchers. This aligns closely with the activities undertaken as part of the IA pilots.

OTA would also argue that the pilots were not necessarily low-risk for participants; that they did not reflect routine processes or data gathering; and that there was an intention to publish some or all of the results – all of which denotes research requiring ethical considerations.

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Appendix 5 – The impact of proposed independent assessments on people with psychosocial disability

The impact of proposed independent assessments on people with psychosocial disability

Updated 24/11/2020

THE NATIONAL DISABILITY INSURANCE AGENCY'S FOCUS ON EQUITY WITH THE NDIS IS WELCOMED. HOWEVER, THE INTRODUCTION OF THE PROPOSED INDEPENDENT ASSESSMENTS FRAMEWORK RAISES CONCEPTUAL AND PRACTICAL ISSUES REQUIRING URGENT ATTENTION. THIS DOCUMENT IS A DIRECT RESPONSE TO THE NDIS 'INDEPENDENT ASSESSMENT FRAMEWORK' AND 'SELECTION OF TOOLS' DOCUMENTS PUBLISHED BY THE NDIS, SEPTEMBER 2020.

Conceptual issue	Analysis of independent assessment (IA) process	Impact on people with psychosocial disability, their families and carers
<p>1. Australians with a disability, including psychosocial disability, have a right to expect an evidence-based, robust and safe process for assessment of functional capacity to determine access to, and reasonable and necessary supports from, the NDIS.</p>	<p>Robust empirical research is needed to ensure that independent assessment processes are fit for purpose; delivered by an independent party.</p> <p>There is a conflict of interest when organisations conducting the research and piloting the process have a vested interest, including financial interest, in the outcome of the pilot.</p> <p>Of the pilot scheme completed to date, only a small number (7%, 35-40 people) had a psychosocial disability [1]. Volunteers self-selected; therefore, this is not a representative sample of people with psychosocial disability, many of whom have reduced functional capacity that may have impacted on self-advocacy. These issues are likely to persist in second pilot as the selection methodology has not changed.</p>	<p>In the absence of an evidence base demonstrating the effectiveness and safety of IAs, there is the potential for causing harm.</p> <p>International studies evidence the potential for harmful outcomes when disability assessment is conducted via a point-in-time standardised checklist by a mandated assessor. These harmful outcomes include increased rates of suicide, increased mental health impacts and increased reliance on prescribed medication [2].</p>

2. There is an absence of evidence supporting the assumption that functional capacity can be measured in a ‘disability neutral’ manner, in Australia or internationally. Research highlights the global absence of a single assessment tool or suite of tools, proven to have the ability to do this [3].

WHO ICF research branch developed the ICF Core Sets in acknowledgement of functional variability between disability groups, including psychosocial disability, where the impairment is derived from mental health issues [4].

The subordinate rules under the NDIS Act 2013 Supports for Participants Rules (Australian Government, 2013a) acknowledge this by highlighting that assessment tools, should be **“specifically tailored to particular impairments”** (Part 4, point 4.5 b) [5]

It appears the combination of tools were selected based on constraints imposed by the NDIA [6]. There are significant issues with assessing functional capacity using assessment tools not researched as reliable or validated for this purpose, for people with psychosocial disability. These concerns are exacerbated when such tools are used in combination and in a novel context, such as the NDIS in Australia.

Two of the three IA tools proposed for psychosocial disability, the CHIEF and the Vineland-3, have not been researched or validated for use with people with psychosocial disability, and were designed for other populations and purposes [7] [8]. Vineland-3 invalidity for psychosocial disability where the impairment is due to mental health issues is also confirmed by the NDIS Quality and Safeguard Commission’s Compendium of Resources for Positive Behaviour Support (p182) [9].

Construct validity is the ability of the tool to actually measure what it is intended to measure. There are issues with construct validity in the Independent Assessment toolkit - the construct being measured with Vineland 3 and CHIEF are adaptive behaviour and environmental factors respectively, not functional capacity.

Interestingly, the inclusion of the Lower Extremity Function Scale (LEFS) administered “where applicable” appears to contradict the disability neutral approach outlined by the NDIA.

The impact of an Independent Assessment not fit for purpose is **insufficient assessment of substantially reduced functional capacity**, forming a restrictive barrier to accessing the NDIS, or an inappropriately funded support package.

Neither the Vineland-3 nor CHIEF is validated for psychosocial disability and the WHODAS-2 has limitations e.g. does not comprehensively assess functional capacity for self-care because it does not assess the **capacity or barriers to consistently wash; get dressed; plan, organise and prepare a meal; manage medication; implement daily routine.**

The WHODAS-2 only considers the past 30 days, not sufficient to capture **the fluctuating capacity** experienced by many people with psychosocial disability [10].

The WHODAS-2 does not consider capacity for work and study, when the person is not currently engaged in these activities. The WHODAS-2 does not provide insight into **the person with psychosocial disability’s capacity for economic participation.**

3. A fundamental principle of the NDIS Act (2013) is the identification of reasonable and necessary supports, that are individualised and goal-oriented.

Assessment Tools that focus on 'norm-referencing' people with disabilities with the general population, is contrary to individualised, tailored, goal-oriented support identification.

The subordinate rules under the *NDIS Act 2013* Supports for Participants Rules (Australian Government, 2013a) - state that the assessment tools **must ensure fair assessment of reasonable and necessary supports, and it should reference activity, social, and economic participation**, as identified in the WHO ICF (Part 4, point 4.6 a and b) (Australian Government 2013a) [11]. These rules were confirmed in the NDIS Becoming a Participant Rules (2016) under Part 7 (Australian Government, 2016)[12].

The proposed Independent assessment **does not include needs assessment, or a process to identify reasonable and necessary supports.**

Aspects of the assessment tools are contrary to the NDIS Act 2013 **concept of enabling social participation**. E.g. The CHIEF explicitly states social supports cannot be addressed through funded supports. Direct quote - "Social barriers can only be remedied by attitude change in others. Extra funding is not likely to solve these particular problems." (See P3 CHIEF User Manual version 3.0)[13].

Funding and support packages that do not address the, often invisible, individual reasonable and necessary support needs, may lead to **negative outcomes and harm** for people with psychosocial disability.

These include, but are not limited to, increased reliance on the acute mental health system through mental health decline; unnecessary, costly and distressing hospitalisations or crisis service engagement; further reduced capacity for social and economic participation; social isolation; difficulty completing personal care and daily living tasks.

4. 'Nothing About Us Without Us'

Choice and control for people with disabilities are cornerstone principles of the NDIS Act (2013)[14].

The United Nations Convention on the Rights of the Person with Disability (UNCRPD), which Australia signed in 2007, and the National Disability Strategy 2010-2020 (2010), emphasise the inclusion of people with disabilities in decision-making, **and active participation in designing systems that support them [15][16]**. There has been limited consultation with people with disabilities and other stakeholders, in the development of independent assessments.

Due to the inclusion of the Vineland 3, the IA toolkit for psychosocial disability **is weighted towards a carer or other support person** rating the person's functional capacity. This approach **undermines the person's place as the expert in their own disability**.

The Vineland-3 is fully rated by a carer or support person, not the NDIS applicant or participant. It includes an extensive interview with, and scoring by, the carer or support person [8]. It is unclear what the alternative process will be if person does not have a carer or support available to complete this assessment.

The CHIEF User Manual version 3.0 (p8) describes a discrepancy in scoring between client scoring and carer/support person scoring, which they attribute to "the unique barriers faced by these groups"[13]. This highlights that this tool is not reliable when scored by anyone other than the applicant or participant. It is unclear what the alternative process to gather environmental information will be if person does not have the capacity to respond to the CHIEF.

The proposed IA approach **is contrary to current mental health standards of service which emphasise trauma-informed care and recovery-oriented practice [17]**. The expectation that a person with a disability meet with a mandated assessor, a stranger, to complete a series of standardised tools to assess the impact of disability, for the purpose of making decisions around access to essential supports, has the potential to be a highly stressful experience. Many people with psychosocial disability have histories of mandatory treatment and involuntary hospitalisation, or experiences with assessments delivered by unknown professionals that have resulted in loss of freedom or self-determination.

NDIS Act 2013, Section 4 (3), states that people with disability and their families and carers **should have certainty that they will receive the care and support they need over their lifetime [14]**. IA at multiple points in the NDIS journey introduces uncertainty, loss of sense of control, and fear.

Inclusion of Vineland 3 is likely to cause distress to people with psychosocial disability who may have complex relationships with their family and carers (e.g. family violence situations).

5. The Social model of disability aims to reduce systemic and procedural barriers to participation for people with disabilities.

Mandating people with disabilities to engage in an IA process where they do not have the functional capacity to complete creates a **procedural and systemic barrier to access**, and participate in, the NDIS. It raises significant concerns regarding equity of access and equity of IA process. People without functional capacity to complete the IA will require an alternative process and pathway to assess eligibility for the NDIS.

The WHODAS-2 can be used to screen for substantially reduced capacity in the domains of communication, social interaction and cognition (self-management), **that indicate reduced functional capacity to engage in the IA process**. Specifically, those who rate 2 or higher (mild, moderate, severe or extreme difficulty) on the following items evidence reduced functional capacity to engage in the IA process: WHODAS item D1.1 - Concentrating on doing something for more than ten minutes; WHODAS item D1.5 - Generally understanding what people say; WHODAS item D1.6 - Starting and maintaining a conversation; WHODAS item D4.1 - Dealing with people you do not know.

If the person rates 2 or higher on the items D1.1, D1.5, D1.6, then continuation with the assessment is inappropriate – as they do not have capacity to engage in its completion. It is unreasonable and unethical to proceed with administering IA in these circumstances.

People with psychosocial disability currently represent approximately 12 per cent of participants accessing the NDIS [18]. These numbers continue to be lower than expected, at this stage of the Scheme development. Great care needs to be taken to ensure access pathways are accessible to people with psychosocial disability.

To minimise risk of the IA becoming a barrier, assessors are required to be mental health professionals who are very clear on the understanding of functional capacity as outlined in the NDIS Act 2013. Choice of provider to complete an IA must be preserved. Skilled, known providers, who are mental health professionals, minimise and offset the risk of non-standardised assessment tools through clinical reasoning and triangulation of information sources to build a clear picture of functioning for each individual.

6. The proposed IA process is wholly contradictory to recovery-oriented practice principles outlined in the national framework for recovery-oriented mental health services agreed by Australian government ministers, including recovery conceptualised as a unique, individual and personal journey (not ‘norm-referenced’); a non-linear journey interspersed with achievement and setback; and personal autonomy [17].

The NDIA has committed to the development of an NDIS Recovery Framework for people with psychosocial disability [19]. However, this approach will be contradictory to the disability neutral approach proposed by the NDIA regarding IAs.

People with psychosocial disability will question the NDIA’s stated commitment to develop an NDIS Recovery Framework, as it coincides with the introduction of an IA process that is not recovery-oriented and has potential to cause harm, as described above. **The conceptual contradiction between IA process and the NDIS Recovery Framework is substantial and requires addressing, with the reasonable and necessary support needs and the goals and aspirations of people with psychosocial disability central to this conversation.**

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Appendix 6 – Are the current Safeguards governing changes to National Disability Insurance Scheme (NDIS) policy and practice, sufficient to prevent contemporary systemic exploitation or neglect of people with disability?

Are the current Safeguards governing changes to National Disability Insurance Scheme (NDIS) policy and practice, sufficient to prevent contemporary systemic exploitation or neglect of people with disability?

1 February 2021

This Submission is a response to the Royal Commission into violence, abuse, neglect and exploitation of people with disabilities *Issues Paper on Safeguards and Quality*. Concerns are raised regarding the safeguards underpinning current policy and practice developments within the NDIS. Specifically, this Submission highlights concerns pertaining to reasonable, necessary, and safe access to funded disability supports; and the protections offered to NDIS participants when they are requested to engage in research or quality assurance initiatives.

Key points:

- Systemic safeguards protecting access to reasonable and necessary support for people with disabilities are not articulated under the current proposed NDIS reforms.
- The proposed NDIS Independent Assessment (IA) process appears to be underpinned by a need to establish numerical input into an actuarial modelling process to increase automation of NDIS funding decisions. Safeguarding processes focused on participants rights to access essential supports are not transparent using this approach.
- NDIS participants require clear safeguards when they are requested to engage in research or quality assurance initiatives, particularly when the investigating body holds the dual role of investigator and funder of essential disability supports.
- The current IA pilot raises ethical concerns, including risk of harm to participants.

1.0 Introduction

The Royal Commission into violence, abuse, neglect and exploitation of people with disabilities *Issues Paper on Safeguards and Quality* highlights the necessity for systemic safeguards to protect the safety of people with disabilities. As the primary governing body overseeing reasonable, necessary, and safe access to disability supports in Australia, the National Disability Insurance Agency has an obligation to provide exemplary practice in this regard. This Submission explores the limitations of current systemic safeguarding by examining two major developments in NDIS policy and practice. Firstly, policy reform in determining access to reasonable and necessary disability supports. Secondly, the engagement of NDIS participants in the Independent Assessment pilot.

2.0 Systemic safeguarding of access to reasonable and necessary support

Significant reforms to the way in which the NDIS will allocate funding to people with disability are planned [1]. These reforms will change the resources people with disability will be eligible for under the NDIS. The Submission queries whether there has been critical examination, both internal and external to the National Disability Insurance Agency (NDIA) of these reforms to understand their impact, prior to confirmation of intention to implement. Without economic modelling, comparison to alternatives, and a trial of the reforms enabling comparison to current routine resource allocation, have participants right to reasonable, safe and necessary disability supports, been safeguarded? And most pertinently, what are the risks of neglect and exploitation, if these safeguards have not been robust?

The resources available to people with disability via the NDIS, and the corresponding supports that people have access to, are critical to help to prevent violence, abuse, neglect and exploitation of people with disability. Adequate funding to ensure access to safe and quality, is preventative of harm [2]. Changes to the allocation process for NDIS funding will have impacts on supports and services that may prevent violence, abuse and neglect and exploitation of people with disability.¹

While legislative changes are required to enact the proposed reforms, a draft version of the legislation is yet to be made available for public review. It is likely that Section 34 of NDIS Act 2013, which relates to the funding of reasonable and necessary supports, will need to be amended, as the proposed changes to funding allocation are not possible under the current *NDIS Act 2013*. Public review, and disability sector and participant scrutiny and feedback, form an important step in maintaining transparency and safeguarding the rights of people with disability. The United Nations Convention on the Rights of the Person with Disability (UNCRPD), which Australia signed in 2007, and the National Disability Strategy 2010-2020 (2010), emphasise the inclusion of people with disabilities in decision-making and discourse, and in ensuring system design is fit for purpose [3] [4].

The NDIS reforms have been confirmed via policy documents [1], and significant elements of the reforms are being implemented via a pilot of the independent assessment process, prior to the release of draft legislation, with the assumption that legislation change will pass. Developing, communicating and confirming the implementation of a national policy reform determining access to essential disability support, based on an assumed and 'hoped-for' legislation change, is not consistent with a robust, planned, and quality-assured approach to systemic safeguarding.

¹ The Royal Commission defines exploitation as the improper use of another person or the improper use of, or withholding of, another person's assets, labour, employment or resources including taking physical, sexual, financial or economic advantage. (Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability 2019).

2.1 What Safeguards protect participants during the transition from reasonable and necessary support funding, to proposed standard funding packages based on an Independent Assessment?

There is a lack of transparent information about the “heart” of the proposed NDIS reforms to enable meaningful discussion. What is being proposed is a significant change to how the NDIS will allocate funding [1]. It will have a significant impact on what supports people with disability can access.

Currently, allocation of disability funding is based on identification of reasonable and necessary support needs, not a standard funding package tied to a predetermined dollar value, based on an Independent Assessment (IA). That is, the NDIS must fund supports that meet the reasonable and necessary criteria as outlined in the *NDIS Act 2013*. Current funding levels in NDIS plans are made up of an individualised, tailored package of specific supports, each meeting the reasonable and necessary criteria.

What is proposed is that the NDIA will fund standard dollar-value packages, rather than specific needs-based support **(Please refer to Table 1)**. Essentially, this means that the NDIS will determine a standard dollar value based on an Independent Assessment (IA), rather than funding specific needs-based supports that support people with disability to sustain and build functional capacity and work towards their goals.

It is important to mention that the proposed reforms break the link between goals and funding, and proposes that goals relate only to how the funding is spent i.e. the participant may choose to use the generic funding package to work towards their goals.

As outlines in Table 1, there is an absence of transparency on how the dollar-amount contained within the standard funding packages will be calculated – and how the NDIS can support the assumption that standard packages will meet disability support needs. Also, the avenue for participants to appeal a funding package that does not meet their needs has not been disclosed. Currently, if a person with a disability is not funded a specific support (including the frequency or intensity of a particular support) a person can seek a review of the decision based on the reasonable and necessary criteria outlined in the *NDIS Act 2013*. Under the new policy, it appears the route to appeal may be via another IA, repeating the flawed process – potentially trapping the participant in a cycle of inadequate support, and escalating risk of harm, and neglect of disability needs.

It is unclear how a person can challenge a decision if the amount of money allocated to the person is not sufficient to purchase essential disability supports. How can a standard dollar-amount be automatically deemed ‘reasonable and necessary’ if it is divorced from individual participant support need? The risk of unmet support needs is high, which sets the scene for neglect of individual support needs, and of participants not reaching their potential for social and economic participation.

The shift from a needs-based, tailored support package to a standard dollar amount based on IA, is a fundamental transformation of NDIS architecture. This critical change is not made sufficiently clear and transparent in the NDIS reform Consultation Papers, or information available to participants and the disability sector.

Another issue that merits greater transparency is the way that the NDIS reform Consultation Papers [1] has linked the ability to flexibly spend NDIS funds to the proposed reforms. That is, an impression is created that the introduction of IAs enable increased flexibility. However, increasing the level of flexibility appears already possible with relative minor policy changes, that do not require legislative change, or the introduction of IA.

	Current NDIS Funding	Proposed NDIS Funding based on reforms
	<p>Funding in NDIS plans is based on specific supports– based on individual goals support needs.</p> <p>For example a \$54 360.30 total NDIS plan value based on a collection of support funding including assistance with self-care activities, assistance to access the community, allied health service and home modifications (\$11 000)</p>	<p>Funding is based on a dollar value linked to Independent Assessment, not individual support needs, and not linked to goals.</p> <p>For example, \$50 000 total NDIS plan.</p>
Criteria for determining funding	<p>Reasonable and necessary funding criteria as outlines in the NDIS Act:</p> <p>(a) the support will assist the participant to pursue the goals, objectives and aspirations included in the participant’s statement of goals and aspirations;</p> <p>(b) the support will assist the participant to undertake activities, so as to facilitate the participant’s social and economic participation;</p> <p>(c) the support represents value for money in that the costs of the support are reasonable, relative to both the benefits achieved and the cost of alternative support;</p> <p>(d) the support will be, or is likely to be, effective and beneficial for the participant, having regard to current good practice;</p> <p>(e) the funding or provision of the support takes account of what it is reasonable to expect families, carers, informal networks and the community to provide;</p> <p>(f) the support is most appropriately funded or provided through the National Disability Insurance Scheme, and is not more appropriately funded or provided through other general systems of service delivery or support services offered by a person, agency or body, or systems of service delivery or support services offered:</p> <p>(i) as part of a universal service obligation; or</p> <p>(ii) in accordance with reasonable adjustments required under a law dealing with discrimination on the basis of disability.</p>	<p>Not disclosed.</p> <p>Likely to be standardised Independent Assessment results that are used as inputs that will automate a dollar value for NDIA delegates.</p>
Flexibility (Ability to choose which supports to purchase)	<p>Three categories of funds- Core, Capacity Building and Capital (Funding can be used flexibly within in Core, less flexibly in Capacity Building and Capital.</p> <p>Note- Flexibility in fund usage can be increased and the two ‘fixed’ and ‘flexible’ categories can be introduced without other reforms. This is an important point as increase in flexibility has been presented as intrinsically linked introduction of independent assessments.</p>	<p>Two categories of funds- ‘fixed’ or ‘flexible’.</p> <p>For example, \$39 000 in ‘flexible’ category and ‘\$11 000’ in ‘fixed’ category for home modifications</p>
The process of challenging funding decisions	<p>A person with a disability can challenge a funding decision if they have not received a support based on the reasonable and necessary criteria.</p> <p>For example, a person may require additional 4 hours of personal care per week. Currently, they will know how many hours of personal care is funded in their plan and challenge this decision.</p>	<p>Not disclosed.</p> <p>As specific supports are not funded, a person with a disability will need to challenge the total plan amount. It is unclear how this would occur.</p> <p>For example, a person may require additional 4 hours of personal care – however it is unclear how they will challenge this decision as the funding was not based on specific needs (rather based on a dollar value based on functional capacity on inputs from standardised assessment tools).</p> <p>If the NDIS legislation is changed so that the criteria for funding is primarily based on independent assessment inputs, it may become very difficult for people with disability to challenge funding decisions.</p> <p>The impact on the process for reviewing funding decisions is a concerning element of the proposed reforms.</p>

Table 1 – Comparison between current and proposed plan funding allocation processes

2.2 What Safeguards underpinned the development and pilot of Independent Assessments (IA)?

What criteria will be used to determine the standard dollar amount described above, given current reasonable and necessary criteria are applicable to individual support needs, not a standard, 'fixed dollar amount' funding package?

The proposed IA process offers a potential answer to this question. The features of the IA process, including the selected assessment tools, has confused many and has raised a number of concerns (See Appendix 1). It appears the purpose of the IA is to determine a numerical input to match the participant to a standard dollar-amount of NDIS funding.

It appears that the design of the IA process with the use of standardised assessments will provide a set of consistent inputs that will enable the NDIA to determine dollar values for NDIS plans based on actuarial modelling. This need for a consistent set of inputs is why the same assessment toolkit are used across all disability types.

However, allied health professional groups have raised concerns that the IA process results in an 'inaccurate' assessment of functional capacity, and that the IA does not have a supporting evidence base (Occupational Therapy Australia (OTA), OTA Virtual Exchange 2020, September 7th). These concerns have not yet been addressed. In addition, allied health professional groups have stated that their input to developing specific aspects of the IA, has been taken out-of-context and generalised for use with people with disabilities, in ways it was not intended to be (Speech Pathology Australia, 2020) [5].

The proposed introduction of IA caused much concern (See Appendix 1). For example, people with psychosocial disability have raised concerns that their functional capacity will be assessed using assessment tools that are not valid for psychosocial disability. IA assessors will not have access to previous disability, health and medical information to tailor the assessment process to individual circumstances. Critically, IA assessors will not have all relevant information to ensure a trauma-informed approach to assessment creating a significant risk of re-traumatisation of people with disability.

The NDIA has indicated that the use of the same assessment across all disability types is supported by the World Health Organization International Classification of Functioning, Health and Disability (ICF). This not the case. While the ICF does encourage disability-neutral conceptualisation of function, it *does not* support a disability neutral approach to assessing and measuring functioning and disability. Rather, it supports recognition of the variance of disability across a range of disability-types. This is most evident in the ICF Core Sets which are a set of assessments developed by the WHO that facilitate the description of functioning by providing lists of categories on *specific conditions*, including health conditions and specific disability types. (<https://www.icf-core-sets.org/en/page0.php>) The NDIA does not mention the ICF Core Sets in its policy documents relating to the proposed reforms [1], including the IA process. This is not surprising given the ICF Core Sets are disability type-specific assessments and would not be suitable for the proposed process that requires consistent numerical inputs to enable increased automation of funding decisions.

There is a lack of transparent information around the important details of the proposed reforms that will have the most significant impact people with disability, their families and carers (See Fig 1). There are limited details provided on how the IA tools and their results be used to determine access to the NDIS and how they will populate the amount of funds in a plan. What is of particular concern for existing participants is how IA results will be used to revoke access to the NDIS (more information on the proposed process for eligibility reassessment for current participants of the NDIS is available on p.22 of the NDIA’s Consultation Paper: Access and Eligibility Policy with independent assessments).

Figure 1: Proposed planning process for new and existing participants aged 7 to 65 (from late-2021)



Missing details

How will the results of a number of standardised assessment and an observation create a budget that will be considered by the delegate? What is the rationale and evidence for the proposed methodology?

For example: do all individual assessment scores have equal value or are they weighted differently? Are the scores combined? Do certain scores or a combination of scores correspond to a specific budget.

Figure 1: Proposed Access and eligibility process for people aged 7 to 65 (from mid-2021)



Missing details.

How will the results of the proposed standardised assessments inform a delegate?

For example, will the scores be compared to a normative population sample to inform access decisions?

Table 2 – Two examples of critical information missing from NDIA’s consultation papers on Access and Planning reforms. Without this information it is not possible for people with disability to engage meaningfully in the consultation process.

3.0 Safeguarding NDIS participants who are requested to engage in research and quality assurance initiatives

3.1 About the Independent Assessment pilot

According to NDIA communications, the pilot IA process is required to trial formal, standardised assessment tools, to explore the feasibility of including these in routine NDIS process in future, for both access eligibility and participant-planning purposes [6]. These tools are trialled with people with disabilities who are current NDIS participants, who are approached and given the choice to 'opt in' to the pilot IA.

NDIA aim to run two pilots to test how they would implement independent assessments. To date, the NDIA has trialled 6 assessment tools in the independent assessment toolkit, aiming to assess functional capacity. From November 2018 to April 2019, the NDIA ran the first independent assessment pilot. The pilot was held in nine metropolitan areas in NSW, with independent assessments offered on a voluntary, opt-in basis to people applying for the NDIS as well as existing participants aged between 7 and 64 years [5]. The pilot participants had a primary disability of Autism Spectrum Disorder (ASD), Intellectual Disability or Psychosocial Disability (PSD). These were chosen for the first pilot because they represent 63% of all NDIS participants [7]. The second pilot was postponed in March 2020 due to the coronavirus (COVID-19) pandemic, and recommenced in October 2020, with the stated aim of recruiting 4,000 existing NDIS participants across all disability types [6].

Participation involves the completion of a series of standardised assessment instruments, delivered by interview. The second pilot includes an observational assessment of the participant [8].

The pilot IA process then involves an interview, delivering a suite of assessment tools typically used in clinical practice by allied health professionals. It also requires the NDIS participant to undergo an observational assessment of a task, chosen by the assessor. The assessor, a contracted third-party employee, will have access to the participant's contact details as delivered to them from the NDIA. The process around informed consent, or the extent to which NDIS participant information is shared with the third party, has not been made publicly available.

In Australia and internationally, human research ethics principles and guidelines ensure research is safe, ethical, necessary, and that the benefits outweigh potential risks. The National Statement on Ethical Conduct in Human Research (2007, Updated 2018) outlines the responsibilities of researchers in the Australian context [9]. It sets down the broad principles of responsible and accountable research practice, and identifies the responsibilities of institutions and researchers in areas such as data and record management, publication of findings, authorship, conflict of interest, and the handling of allegations of research misconduct. It includes specific reference to the additional considerations required when conducting research with groups of people with disabilities, including people with a cognitive impairment, an intellectual disability, or a mental illness. It states that, for these cohorts, vulnerabilities as research participants must be taken into account, as the capacity of a person with any of these conditions to consent to research, and the ability to participate in it, can vary for many reasons, including the nature of the condition; the person's vulnerability to discomfort or distress; fluctuations in their condition; and the complexity of the research.

According to NMHRC (2018), human research is defined as research conducted with or about people, including:

- taking part in surveys, interviews or focus groups;
- undergoing psychological, physiological or medical assessment or treatment;
- being observed by researchers;
- researchers having access to their personal documents or other materials;
- access to their information (in individually identifiable, re-identifiable or non-identifiable form) as part of an existing published or unpublished source or database.

**National Statement on Ethical Conduct in Human Research (2007, Updated 2018), [9]
National Health and Medical Research Council (NMHRC)**

The IA pilot process meets all the human research criteria listed above, as per the National Statement on Ethical Conduct in Human Research (NMHRC, 2018).

The Independent Assessment Pilot Evaluation, a document published on the NDIS website, summarises the findings of the first NDIS IA pilot [10]. Alongside publication of pilot findings, it delivers detailed description of the characteristics of the research sample (See document, Appendix B) [10]. The language throughout this document pertains to research, for example:

- This document states “The aim of pilot is to understand how the person’s disability affects function in daily life”. This is reflective of a research question.
- This document states the first IA pilot “tested the use of 5 standardised instruments”.
- This document states the aim of the “second pilot to test the suitability and effectiveness of IAs.” (p.10)
- This document refers to the pilot as research (p.11);
- The first pilot is described as having a “robust sample size” (p.13)
- The document states “The NDIA’s Research and Evaluation Branch will oversee and quality assure all evaluation activities, and the NDIA will undertake all statistical analyses of IA results” (p.19)

Of note, these findings were **published**. In contrast, quality assurance activities, by their nature, are not intended to be published. The National Statement on Ethical Conduct in Human Research [9] highlights the need for formal research ethics process to be followed, if the intention is to publish findings, learnings or insights [11]. Publication is a privilege of a formal research process, overseen by an independent Human Research Ethics Committee (HREC).

The NDIS Data Sharing Policy states “Research-based projects are initially considered by the NDIA Research and Evaluation Office (REO). **The REO ensures that research is ethical** and is in the public interest. The Research and Evaluation Office will ensure that research conforms to the applicable National Health and Medical Research Council guidelines and regulatory requirements. Projects being considered for data sharing are assumed to have met the REO’s thresholds” [12].

As noted, for people with disabilities, participation in the IA pilot involves undergoing lengthy (up to 3hrs) engagement in an interview and assessor observation, that includes standardised assessments that were designed for use in clinical care, to explore the highly sensitive subject of functional capacity, which includes disclosure of functional deficits due to disability. This process is not routine care or process for an NDIS participant, and can be viewed as **an invasive process**.

Should **an external body** seek to complete a study using the same methodology as outlined in the IA pilot, researching NDIS participants, they would be required to adhere to the National Statement on Ethical Conduct in Human Research (NMHRC, 2018), and the study would be overseen by an independent Human Research Ethics Committee (HREC) [9]. Human Research Ethics Committees oversee ethical conduct in research practice, including, but not limited to: ethical research process; evaluation of risk of participants; informed consent; data and record management; publication of findings; conflict of interest; and the handling of allegations of research misconduct [9]. **Why do these research standards not apply to research undertaken by the NDIA?**

3.2 Ethical concerns regarding the Independent Assessment pilot

A number of ethical concerns have been raised, by participants in the pilot [8] [13], and other stakeholders. These pertain to the IA assessment process itself, in particular, issues caused by an organisation holding the dual role of investigator and funder of essential disability supports e.g. the lack of boundary between the pilot process, and the participants regular NDIS planning and funding decisions; lack of transparency around how pilot findings will be used in future; and potential conflict of interest. All four of these ethical concerns are described below, all contribute to the potential for confusion, distress and harm to pilot participants.

- **IA pilot participants** and those requested to participate, and their families and carers, are raising concerns regarding the potential for confusion, stress, inconvenience and harm. Anecdotally, many report receiving calls, phone calls and emails, or a combination of these, requesting their participation. Some report receiving requests by various media, having already declined participation. As described below, many feel unsure about if and how their participation in the pilot, or refusal to participate, may impact on their future NDIS plan. While the IA pilot is 'opt in', there appears to be confusion around whether this choice will have future consequences for the participant, and their NDIS funding. The pilot IA process itself involves a lengthy interview (up to 3 hours) and observation, and the disclosure of extremely sensitive information around functional capacity to an unknown assessor, has the potential to be traumatic and stressful for vulnerable individuals. There has not been any published information on how these risks are mitigated; what external supports are offered; and if there is an external complaints avenue offered to participants, which would be standard practice for research studies overseen by a HREC. There is anecdotal evidence that the pilot IA results in distress, and embarrassment [8].
- Professional groups have raised concerns that the IA process results in an 'inaccurate' assessment of functional capacity (Occupational Therapy Australia (OTA), OTA Virtual Exchange 2020, September 7th). The proposed IA may not be fit for purpose to determine substantially reduced functional capacity, a requirement under the NDIS Act 2013, to determine eligibility for the NDIS. There is an absence of evidence supporting the assumption that functional capacity can be measured in a 'disability neutral' manner, in Australia or internationally. Research highlights the global absence of a single assessment tool or suite of tools, proven to have the ability to do this [15]. WHO ICF research branch developed the ICF Core Sets in acknowledgement of the functional variability between disability groups, further indicating the disability-neutral approach is not valid [14].

- The use of a disability-neutral approach in the IA pilot, is contrary to the National Statement on Ethical Conduct in Human Research (NMHRC, 2018) which highlights the need for additional considerations required when conducting research with groups of people with disabilities, including people with a cognitive impairment, an intellectual disability, or a mental illness; and for people from culturally and linguistically diverse backgrounds, and ATSI groups. [9].
- Two of the three IA tools proposed for psychosocial disability, the CHIEF and the Vineland-3, have not been researched or validated for use with people with psychosocial disability, and were designed for other populations and purposes [16] [17]. Vineland-3 invalidity for psychosocial disability where the impairment is due to mental health issues is also confirmed by the NDIS Quality and Safeguard Commission’s Compendium of Resources for Positive Behaviour Support (p182) [18].
- Construct validity is the ability of the assessment tool to measure what it is intended to measure. There are issues with construct validity in the IA pilot, for example, the construct being measured with Vineland 3 and CHIEF are adaptive behaviour and environmental factors respectively, not functional capacity.
- Pilot participants undergoing a lengthy assessment process that may be flawed, invalid or inaccurate, raises concerns around the integrity of the IA pilot, and whether the benefits of completing the IA, outweigh the risks of harm and inconvenience to participants. The pilot IA process is likely to be a breach of the NDIS Code of Conduct [20] (which applies to NDIS providers). For example, if an NDIS service provider used a similar process to assess function including the use of invalid assessment tools to assess function, they would be in breach of the Code including the requirement to “provide supports and services in a safe and competent manner with care and skill”.
- There are ethical issues, and potential conflicts of interest, inherent in an organisation holding the dual roles of investigator, and funder of essential disability supports. A lack of boundary between the pilot process, and the participants regular planning and funding, creates uncertainty and often, fear and unsafety, for the participant, e.g. fear that their participation, or not, in the pilot, will impact future funding or access to disability support. There is ambiguity around this issue the in the Independent Assessment: Pilot Learnings and Ongoing Evaluation Plan document [10], which states the individual IA pilot assessment is “not used for any agency decisions at access or planning” and confusingly, also states the IA pilot includes “estimates of impact of IA on [participant] plan budget”. There is a lack of clarity around how the IA pilot results will be permanently stored, and if they will be added to existing participant files – or used in novel combinations with information already contained within the participant file, now or in future.

- A provider organisation described the lack of clarity around potential impacts on ‘routine NDIS process’ that was apparent for participants who were invited to participate in the pilot. They described the following questions raised by participants invited to partake in the pilot [13]:
 - How do you guarantee that if I join the pilot, my assessment results won’t be used or shared without my permission?
 - Will there be a black mark against my name if I say I don’t want to be part of the pilot?
 - Will the assessment results be provided in an accessible format (including easy English), and explained to me?
 - How will the NDIA get feedback about the process, and how will they use it to make things better?
 - Will people who are trying to get into the NDIS still have to use the NDIS’ Independent Assessment process, or can they just submit their own reports if they have them and want to?

The Growing Space [13]

3.3. Lack of transparency around how pilot findings will be used in future

Alongside the lack of clarity on how IA pilot findings may be used in future for individual participants, there is a lack of transparency around how pilot findings may inform future NDIS processes and policy developments. As the IA pilot utilises a self-selecting ‘opt in’ recruitment process, the pilot cohort will not be representative of the broader group of NDIS participants, many of whom do not have the capacity to engage in an IA. Therefore, IA pilot findings may not be generalisable to the broader group of NDIS participants, and not an appropriate foundation upon which to build a national policy. It is also unclear how or if participants will be informed if their data will be used to create models that will enable increased automation of funding decisions, or non-individualised funding packages.

There are also concerns about data storage as IA consent information states that the IA pilot data is stored outside of Australia, where Australian privacy laws do not apply. This appears to be a possible breach of NDIA policy that states: “When we use third parties, such as community partners and other contractors, to perform certain functions, the third parties are contractually required to work in accordance with the Privacy Act and the NDIS Act, and to access and store all personal information using our IT systems, not their own.” [19]

Finally, there will be a conflict of interest if organisations conducting the IA pilot have a vested interest, including financial interest, in the outcome of the pilot. For example, should they have engaged in a competitive tender to deliver the future Independent Assessment Panel Service.

4.0 Conclusion

The *Royal Commission into violence, abuse, neglect and exploitation of people with disabilities* is fundamental to establishing comprehensive safeguards to protect the future rights and welfare of people with disabilities. This Submission seeks that the Royal Commission consider steps to strengthen safeguards governing significant changes to NDIS policy and practice. For example, consideration of the following strategies:

- That the *Royal Commission* consider undertaking a detailed review of decision-making processes that led to the current suite of NDIS reforms, and analyse these decision-making processes from a quality and safeguards perspective.
- That proposed changes to NDIS policy and practice, particularly as they relate to access to reasonable and necessary disability supports, receive external scrutiny through clear and documented safeguarding processes.
- That the NDIS Parliamentary Joint Standing Committee review proposed changes to NDIS policy and practice, prior to implementation, and have capacity to pause implementation of changes and reforms until due discourse and diligence have occurred.
- That safeguarding processes around changes to the *NDIS Act 2013*, and associated rules and guidelines, are developed that enable public scrutiny; and participant, family and disability sector discourse PRIOR to implementing reforms related to the legislation change.
- That the participant voice is enabled through formal processes, in all aspects of decision-making related to changes to NDIS policy and practice.
- That all NDIS assessment and interventions are evidence-based, and adequate consultation occurs with peak bodies, including Occupational Therapy Australia. Occupational Therapy Australia were not consulted on the appropriateness or evidence base of IA, for use beyond an eligibility screen.
- That the NDIS Independent Advisory Council (IAC) plays a stronger role in safeguarding participants rights and safety, during instances of change to NDIS policy and practice. The writer submitted the documented included in Appendix 1 to the IAC in November 2020, and has not yet received a response.
- That the role of the NDIS Quality and Safeguards Commission be clarified, as it relates to oversight and complaints management regarding NDIS and NDIA interactions with participants and potential participants.
- **That immediate consideration be given to ceasing or suspending the current IA pilot, due to the likely risk of harm outweighing benefits to people with disability, and not resume without the oversight of an independent Human Research Ethics Committee (HREC).**
- That NDIS participants are protected when requested to engage in investigations, research and quality assurance activities instigated by governing and funding bodies, including the NDIS and NDIA. All investigations, research and quality assurance activities that fall outside routine care and 'usual' NDIS process need to be overseen by an independent Human Research Ethics Committee (HREC).

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APPENDIX 1

The impact of proposed IA on people with psychosocial disability

Updated 24/11/2020

THE NATIONAL DISABILITY INSURANCE AGENCY’S FOCUS ON EQUITY WITH THE NDIS IS WELCOMED. HOWEVER, THE INTRODUCTION OF THE PROPOSED INDEPENDENT ASSESSMENTS FRAMEWORK RAISES CONCEPTUAL AND PRACTICAL ISSUES REQUIRING URGENT ATTENTION. THIS DOCUMENT IS A DIRECT RESPONSE TO THE NDIS ‘INDEPENDENT ASSESSMENT FRAMEWORK’ AND ‘SELECTION OF TOOLS’ DOCUMENTS PUBLISHED BY THE NDIS, SEPTEMBER 2020.

Conceptual issue	Analysis of independent assessment (IA) process	Impact on people with psychosocial disability, their families and carers
<p>1. Australians with a disability, including psychosocial disability, have a right to expect an evidence-based, robust and safe process for assessment of functional capacity to determine access to, and reasonable and necessary supports from, the NDIS.</p>	<p>Robust empirical research is needed to ensure that independent assessment processes are fit for purpose; delivered by an independent party.</p> <p>There is a conflict of interest when organisations conducting the research and piloting the process have a vested interest, including financial interest, in the outcome of the pilot.</p> <p>Of the pilot scheme completed to date, only a small number (7%, 35-40 people) had a psychosocial disability [1]. Volunteers self-selected; therefore, this is not a representative sample of people with psychosocial disability, many of whom have reduced functional capacity that may have impacted on self-advocacy. These issues are likely to persist in second pilot as the selection methodology has not changed.</p>	<p>In the absence of an evidence base demonstrating the effectiveness and safety of IAs, there is the potential for causing harm.</p> <p>International studies evidence the potential for harmful outcomes when disability assessment is conducted via a point-in-time standardised checklist by a mandated assessor. These harmful outcomes include increased rates of suicide, increased mental health impacts and increased reliance on prescribed medication [2].</p>

2. There is an absence of evidence supporting the assumption that functional capacity can be measured in a ‘disability neutral’ manner, in Australia or internationally. Research highlights the global absence of a single assessment tool or suite of tools, proven to have the ability to do this [3].

WHO ICF research branch developed the ICF Core Sets in acknowledgement of functional variability between disability groups, including psychosocial disability, where the impairment is derived from mental health issues [4].

The subordinate rules under the NDIS Act 2013 Supports for Participants Rules (Australian Government, 2013a) acknowledge this by highlighting that assessment tools, should be **“specifically tailored to particular impairments”** (Part 4, point 4.5 b) [5]

It appears the combination of tools were selected based on constraints imposed by the NDIA [6]. There are significant issues with assessing functional capacity using assessment tools not researched as reliable or validated for this purpose, for people with psychosocial disability. These concerns are exacerbated when such tools are used in combination and in a novel context, such as the NDIS in Australia.

Two of the three IA tools proposed for psychosocial disability, the CHIEF and the Vineland-3, have not been researched or validated for use with people with psychosocial disability, and were designed for other populations and purposes [7] [8]. Vineland-3 invalidity for psychosocial disability where the impairment is due to mental health issues is also confirmed by the NDIS Quality and Safeguard Commission’s Compendium of Resources for Positive Behaviour Support (p182) [9].

Construct validity is the ability of the tool to actually measure what it is intended to measure. There are issues with construct validity in the Independent Assessment toolkit - the construct being measured with Vineland 3 and CHIEF are adaptive behaviour and environmental factors respectively, not functional capacity. Interestingly, the inclusion of the Lower Extremity Function Scale (LEFS) administered “where applicable” appears to contradict the disability neutral approach outlined by the NDIA.

The impact of an Independent Assessment not fit for purpose is **insufficient assessment of substantially reduced functional capacity**, forming a restrictive barrier to accessing the NDIS, or an inappropriately funded support package.

Neither the Vineland-3 nor CHIEF is validated for psychosocial disability and the WHODAS-2 has limitations e.g. does not comprehensively assess functional capacity for self-care because it does not assess the **capacity or barriers to consistently wash; get dressed; plan, organise and prepare a meal; manage medication; implement daily routine.**

The WHODAS-2 only considers the past 30 days, not sufficient to capture **the fluctuating capacity** experienced by many people with psychosocial disability [10].

The WHODAS-2 does not consider capacity for work and study, when the person is not currently engaged in these activities. The WHODAS-2 does not provide insight into **the person with psychosocial disability’s capacity for economic participation.**

3. A fundamental principle of the NDIS Act (2013) is the identification of reasonable and necessary supports, that are individualised and goal-oriented.

Assessment Tools that focus on ‘norm-referencing’ people with disabilities with the general population, is contrary to individualised, tailored, goal-oriented support identification.

The subordinate rules under the *NDIS Act 2013* Supports for Participants Rules (Australian Government, 2013a) - state that the assessment tools **must ensure fair assessment of reasonable and necessary supports, and it should reference activity, social, and economic participation**, as identified in the WHO ICF (Part 4, point 4.6 a and b) (Australian Government 2013a) [11]. These rules were confirmed in the NDIS Becoming a Participant Rules (2016) under Part 7 (Australian Government, 2016)[12].

The proposed Independent assessment **does not include needs assessment, or a process to identify reasonable and necessary supports.**

Aspects of the assessment tools are contrary to the NDIS Act 2013 **concept of enabling social participation**. E.g. The CHIEF explicitly states social supports cannot be addressed through funded supports. Direct quote - “Social barriers can only be remedied by attitude change in others. Extra funding is not likely to solve these particular problems.” (See P3 CHIEF User Manual version 3.0)[13].

Funding and support packages that do not address the, often invisible, individual reasonable and necessary support needs, may lead to **negative outcomes and harm** for people with psychosocial disability.

These include, but are not limited to, increased reliance on the acute mental health system through mental health decline; unnecessary, costly and distressing hospitalisations or crisis service engagement; further reduced capacity for social and economic participation; social isolation; difficulty completing personal care and daily living tasks.

4. 'Nothing About Us Without Us'

Choice and control for people with disabilities are cornerstone principles of the NDIS Act (2013)[14].

The United Nations Convention on the Rights of the Person with Disability (UNCRPD), which Australia signed in 2007, and the National Disability Strategy 2010-2020 (2010), emphasise the inclusion of people with disabilities in decision-making, **and active participation in designing systems that support them [15][16].** There has been limited consultation with people with disabilities and other stakeholders, in the development of independent assessments.

Due to the inclusion of the Vineland 3, the IA toolkit for psychosocial disability is **weighted towards a carer or other support person** rating the person's functional capacity. This approach **undermines the person's place as the expert in their own disability.**

The Vineland-3 is fully rated by a carer or support person, not the NDIS applicant or participant. It includes an extensive interview with, and scoring by, the carer or support person [8]. It is unclear what the alternative process will be if person does not have a carer or support available to complete this assessment.

The CHIEF User Manual version 3.0 (p8) describes a discrepancy in scoring between client scoring and carer/support person scoring, which they attribute to "the unique barriers faced by these groups"[13]. This highlights that this tool is not reliable when scored by anyone other than the applicant or participant. It is unclear what the alternative process to gather environmental information will be if person does not have the capacity to respond to the CHIEF.

The proposed IA approach is **contrary to current mental health standards of service which emphasise trauma-informed care and recovery-oriented practice [17].** The expectation that a person with a disability meet with a mandated assessor, a stranger, to complete a series of standardised tools to assess the impact of disability, for the purpose of making decisions around access to essential supports, has the potential to be a highly stressful experience. Many people with psychosocial disability have histories of mandatory treatment and involuntary hospitalisation, or experiences with assessments delivered by unknown professionals that have resulted in loss of freedom or self-determination. NDIS Act 2013, Section 4 (3), states that people with disability and their families and carers **should have certainty that they will receive the care and support they need over their lifetime [14].** IA at multiple points in the NDIS journey introduces uncertainty, loss of sense of control, and fear.

Inclusion of Vineland 3 is likely to cause distress to people with psychosocial disability who may have complex relationships with their family and carers (e.g. family violence situations).

5. The Social model of disability aims to reduce systemic and procedural barriers to participation for people with disabilities.

Mandating people with disabilities to engage in an IA process where they do not have the functional capacity to complete creates a **procedural and systemic barrier to access**, and participate in, the NDIS. It raises significant concerns regarding equity of access and equity of IA process. People without functional capacity to complete the IA will require an alternative process and pathway to assess eligibility for the NDIS.

The WHODAS-2 can be used to screen for substantially reduced capacity in the domains of communication, social interaction and cognition (self-management), **that indicate reduced functional capacity to engage in the IA process**. Specifically, those who rate 2 or higher (mild, moderate, severe or extreme difficulty) on the following items evidence reduced functional capacity to engage in the IA process: WHODAS item D1.1 - Concentrating on doing something for more than ten minutes; WHODAS item D1.5 - Generally understanding what people say; WHODAS item D1.6 - Starting and maintaining a conversation; WHODAS item D4.1 -Dealing with people you do not know.

If the person rates 2 or higher on the items D1.1, D1.5, D1.6, then continuation with the assessment is inappropriate – as they do not have capacity to engage in its completion. It is unreasonable and unethical to proceed with administering IA in these circumstances.

People with psychosocial disability currently represent approximately 12 per cent of participants accessing the NDIS [18]. These numbers continue to be lower than expected, at this stage of the Scheme development. Great care needs to be taken to ensure access pathways are accessible to people with psychosocial disability.

To minimise risk of the IA becoming a barrier, assessors are required to be mental health professionals who are very clear on the understanding of functional capacity as outlined in the NDIS Act 2013. Choice of provider to complete an IA must be preserved. Skilled, known providers, who are mental health professionals, minimise and offset the risk of non-standardised assessment tools through clinical reasoning and triangulation of information sources to build a clear picture of functioning for each individual.

<p>6. The proposed IA process is wholly contradictory to recovery-oriented practice principles outlined in the national framework for recovery-oriented mental health services agreed by Australian government ministers, including recovery conceptualised as a unique, individual and personal journey (not ‘norm-referenced’); a non-linear journey interspersed with achievement and setback; and personal autonomy [17].</p>	<p>The NDIA has committed to the development of an NDIS Recovery Framework for people with psychosocial disability [19]. However, this approach will be contradictory to the disability neutral approach proposed by the NDIA regarding IAs.</p>	<p>People with psychosocial disability will question the NDIA’s stated commitment to develop an NDIS Recovery Framework, as it coincides with the introduction of an IA process that is not recovery-oriented and has potential to cause harm, as described above. The conceptual contradiction between IA process and the NDIS Recovery Framework is substantial and requires addressing, with the reasonable and necessary support needs and the goals and aspirations of people with psychosocial disability central to this conversation.</p>
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Appendix 7 – NEAT: An alternative IA model

Rationale

Australians with disability have a right to best-practice assessment of their individual needs. The model should uphold principles of choice and control, trauma-informed care, inclusion of existing support providers and participant co-design. (Refer to Appendix 3 for further information regarding the limitations of the model proposed by the NDIA).

NEAT

OTA asks that the NDIA consider the National Endorsed Assessor Team (NEAT) as an alternative model for assessing eligibility for the NDIS.

The NDIA, in consultation with stakeholders, could develop a functional assessor endorsement program, which appropriately skilled and experienced allied health professionals could choose to undertake in order to qualify to assess eligibility for the NDIS.

The model would not require costly establishment of a new national service infrastructure, as it would use the existing provider base. This would ensure functional assessments are completed by experienced allied health professionals, including mental health professionals for people with psychosocial disability.

An assessor endorsement program would meet the NDIS requirements of a more consistent approach to assessment, while enabling participants and applicants to retain choice and control of provider. Assessors would be empowered to utilise their professional judgement and clinical reasoning skills.

This model would prevent costly duplication of assessment process, as the functional assessment would include tailored, needs-specific recommendations for supports. This is particularly important if the NDIA expects data obtained from IAs to inform plan funding. (Refer to OTA's submission to the Planning Consultation Paper for further discussion around plan funding).

Conflict of interest concerns could be mitigated by the assessor being prohibited from therapeutic support or services in the proceeding term of the NDIS-participant support plan.

Summary of IAP and NEAT Models

Independent Assessment Panel (IAP) Model	National Endorsed Assessor Team (NEAT) Model
Establishes a limited panel of government-contracted private organisations to provide a function/eligibility screen.	Establishes a standardised, regulated endorsement program to qualify suitably skilled and experienced existing providers to provide comprehensive functional assessment, including identification of support needs.

Creates a compliance/eligibility-focused institution with an emphasis on being 'disabled enough,' which may be stigmatising for participants.	Delivers an integrated community model with a focus on quality assessment and expert needs identification.
Generic, disability 'neutral', approach to function/eligibility screen.	People with disability can access assessors with disability-specific expertise and ability to accurately determine support needs.
Functional screen only – no support need identification, meaning support needs will require an additional assessment. This results in duplication and less person-centred	One functional capacity assessment, including support needs identification. To offset conflict-of-interest, assessors cannot provide further service to the participant for the term of future NDIS plan.
Limited choice of panel providers	Choice and control of provider preserved
Generic workforce, no minimum experience or disability specific experience required.	Skilled workforce, with defined standards of skills and experience required e.g. minimum 3 years disability-specific experience.
Disrupts and erodes emerging allied health provider base.	Builds the emerging allied health NDIS workforce, which is especially important in areas with thin markets.