National Disability Insurance Agency

Consultation Paper: Planning Policy for Personalised Budgets and Plan Flexibility

Occupational Therapy Australia submission

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Executive Summary

Occupational Therapy Australia (OTA) welcomes the opportunity to provide feedback to the National Disability Insurance Agency (NDIA) regarding its Planning Policy for Personalised Budgets and Plan Flexibility.

Occupational therapists work with clients 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 National Disability Insurance Scheme (NDIS) since its inception and have long recognised the value of the scheme.

OTA endorses NDIA's commitment to giving people choice and control over how their disability-related services and supports are delivered. OTA also recognises the need for a planning policy that ensures personalised plans and budgets are consistent and fair for all participants.

However, OTA is deeply concerned that the proposed changes described in the planning policy for personalised budgets and plan flexibility will disadvantage and disenfranchise participants, particularly as the proposed changes centre around the use of a generic independent assessment (IA) toolkit to inform personalised budgets and plans. The toolkit lacks sensitivity, specificity and, in many cases, relevance to a broad range of people that live with substantial and permanent disability.

OTA strongly refutes the claim that the implementation of the IA tool for determining personalised budgets and plans will benefit participants. OTA's rationale for taking this position is outlined in this submission.

OTA recommends robust and independent research is carried out using consumer co-design methods in line with international standards. OTA believes this is the only way to ensure redesign and policy reform is appropriate, viable and sustainable.

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.

A substantial proportion of occupational therapists work in the NDIS sector and are acutely aware of the need for a consistent and fairer experience for all participants receiving supports through the NDIS.

OTA welcomes the opportunity to respond to NDIA's Planning Policy for Personalised Budgets and Plan Flexibility Consultation Paper. Following extensive consultation with our membership, OTA is pleased to provide the following response to the issues and proposals specifically outlined in the Consultation Paper.

This submission should be considered in conjunction with OTA's response to the NDIA's Access and Eligibility Policy 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 are allied health professionals who enable people to engage in the occupations that bring meaning and purpose to their lives. They 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 NDIS-funded services to participants. 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 disability 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 has long recognised the value of NDIS and welcomes any initiatives that will improve the experience and outcomes of participants. OTA fundamentally supports NDIA's commitment to giving people choice and control over how their disability-related services and supports are delivered.

However, the proposed changes outlined in the Consultation Paper imply radical reform of the scheme. These reforms demonstrate a clear shift away from the social model of disability, upon which the NDIS was founded, to a deficit-focussed model (WHO n.d; Pfeiffer 2002). OTA is concerned that this shift accentuates disablement rather than enablement and does not put much store into supporting individuals to reach their full potential (Pfeiffer 2002).

Independent Assessments

OTA has major concerns about the relevance, scope, and effectiveness of the proposed toolkit, the process for informing personalised budgets and plans, and most importantly the anticipated impact this will have on participants, their families, or caregivers (Barr et al., 2015; Cummins, 2021; Appendices 3, 4 and 5). OTA is deeply concerned that a person's experience with NDIS will be based on the use of predetermined self-report measurement tools and implemented in an impersonal way by an assessor who may not know the participant. While these issues affect NDIS applicants across the board they are of particular concern to vulnerable participants (Barr et al., 2015; Cummins, 2021; Appendices 4 & 5).

These tools have not been properly evaluated for their intended purpose and there are serious flaws with the ethics and nature of the trial currently underway (Appendix 3). OTA is deeply concerned that the proposed tools are being used as a proxy for functional assessments and strongly objects to the proposed observation of a participant interaction being used in the tool. This type of observation is likely to have only limited usefulness when it is carried out by an independent assessor not trained or qualified to functionally assess task performance. Moreover, potential harm can be caused by 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 opposes the use of the proposed independent assessment tools for informing participants' personalised budgets and plans. The tools are not designed to be used as assessment tools or as tools to determine functional capacity (NDIS 2020a & 2020b; Appendices 1 & 2). The terms which have been used to define the initial assessment are inaccurate and misleading, both to people with disability and to those who have the serious responsibility of determining what access supports and services participants receive (Madden et al 2015; Appendices 1 & 2).

Independent Assessments and Access

OTA does not believe the independent assessment tools sufficiently target the needs of people requiring access to 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 2).

Understanding the nuances and details of a person's situational context is extremely important as it has a substantial bearing on their functional capacity such as, for example, their health, additional disabilities, education, work and life experiences, physical or built environment, community environment, family and social supports and economic situation. These are important factors to consider when determining access to NDIS and developing personalised budgets.

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 n.d; Madden et al., 2015). This is particularly problematic when the participant does not already know 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 World Health Organisation (WHO, 2020) stipulates the importance of contextualising disability-specific assessments within the nuances of the individual circumstances of people with disability.

OTA is seriously concerned that NDIS is attributing significant weight to the use of these generic measurement tools with no transparency regarding how the information will be used to inform decision making. This is particularly alarming given that the tools were not designed for this purpose and that the decision makers may or may not have a clinical background. If NDIA proceeds with the proposed toolkit, this non-standard, unvalidated use of the tools is likely to require disclosure to the authors of the tools.

Independent Assessments, Personalised Budgets and Plan Flexibility

OTA opposes the use of the independent assessment tool for determining personalised budgets and plan flexibility as they have not been designed for this purpose (Madden et al., 2015; Appendices 1 & 2). They are based on standardised self-report items linked to broad conceptual domains, not the client's individual circumstances, needs and/or goals purported to be core to the intent of the scheme (WHO n.d; NDIS 2020 a, 2020b & 2020d). This disparity is extremely concerning when there seems to be such heavy weighting towards the independent assessment informing personalised budgets and plan flexibility.

To date, OTA has not been able to determine how the raw assessment scores from these tools will be collated and/or interpreted in a meaningful way to inform a realistic personalised budget estimate. OTA is deeply concerned that these estimates will rely on the use of arbitrary criteria aligned to "scores" generated from the independent assessment tools and matched to predetermined budgets, rather than being determined by the participant's support needs and goals. OTA strongly recommends referral to an occupational therapist to determine what is required to optimise participants' function and what interventions, modifications and/or assistive technology is needed, in order to provide accurate estimates for personalised budgets.

The proposed assessments do not document in any real way a description of the disability, related comorbidities or risks for disability-related health needs. It is difficult to understand how this information could be used in isolation to inform a participant's budget.

As noted by an OTA member,

> *"If a person on the autism spectrum received a particular 'score' because they needed a carer for ADLs, and a person with tetraplegia received a particular 'score' because they needed a carer for ADLs, this actually tells you nothing about the*

> *budget for care supports for either of them. They certainly are unlikely to require the same budget. The person on the spectrum may just require someone for one hour for prompting and timekeeping or, if they have challenging behaviour, may require two people for 2 hours. Conversely, the person with tetraplegia may have specific continence and skin care requirements; they may need two-person manual handling. This could take 2-3 hours. Or they may just need assistance of 1 with set up in the environment and bowel care but be independent in transfers and other tasks. None of that is recorded anywhere, so I cannot begin to imagine how you could generate a budget."*

Proposed Planning Process

OTA remains deeply concerned that there is not sufficient scaffolding in the proposed access and planning process to ensure participants' basic support needs or personal goals are identified (WHO n.d; Madden et al., 2015). It seems that the assessment tools are driving the agenda rather than the participants. OTA believes that too much weight has been placed on the initial assessment tools and not enough on the participants' needs, goals and/or aspirations. This process could be improved by using a comprehensive needs assessment and sound clinical reasoning from an experienced clinician.

Planning Policy for Personalised Budgets and Plan Flexibility

OTA understands the need for accountability and transparency in the way government funds are spent and recognises the need for a planning policy that ensures personalised plans and budgets are consistent and fair for all participants (DSS, 2010; Royal Commission, 2019).

Principles

OTA recognises the value of the principles underpinning the policy on personalised budgets and plan flexibility. However, the operational and decision-making processes for determining budgets and plan flexibility appear to be at odds with the principles. Namely, the principles are based on the premise that adequate funding is provided and yet the tools being used to inform budgets are not designed to achieve this. Adequate funding processes are the cornerstone feature of a safe disability service system in providing reasonable and necessary supports to people with a disability (Royal Commission, 2019). Furthermore, adequate funding is considered critical in helping to prevent violence, abuse, neglect and exploitation of people with disability (Royal Commission, 2019).

OTA is concerned that the proposed changes will result in people with disability receiving inadequate funding. There seems to be a de-emphasis on participants' goals and aspirations, as well as their social and economic participation. OTA is deeply concerned by this overreliance on independent assessments in determining and/or changing personal budgets. It appears that people with disability, particularly those with psychosocial disability and/or complex, fluctuating needs, are the most likely to be disadvantaged by this process. This will exacerbate existing inequities as these cohorts are also less likely to be able to engage in the independent assessment process or advocate for themselves (Barr et al., 2015; Carey, 2017; Cummins, 2021; Appendix 4).

Personalised budgets

The independent assessment tools predominantly focus on what people with disability cannot do as opposed to what they have the potential to do with the necessary supports. OTA is concerned that budgets will be inadvertently aligned to a deficit-focused model which emphasises disablement and does not place the same emphasis on participant goals or individual supports to enable social and economic participation. This would be a clear departure from the principles stated in the policy and in the United Nations Convention on the Rights of People with Disability (Mannan, 2012; UN, 2007; Appendices 4 & 5).

OTA is concerned that when funding is inadequate, participants will have to use available funds to sustain basic, daily core supports, to cope and survive. There may not be sufficient funds for capacity building to reduce the need for core support or to transition from coping to active social participation.

Determining reasonable and necessary funding

OTA recognises the importance of having clear criteria across the sector to ensure there is consistency and transparency in the way personal budgets are set. However, OTA is concerned that the criteria for determining what is reasonable and necessary has shifted from what is ‘reasonable and necessary support’ to what is ‘reasonable and necessary funding’. While this may appear to be a subtle shift in language, it reflects a profound shift in policy; from a personal budget being determined by a participant’s needs to it being predetermined by a standardised funding model. OTA has serious misgivings about this shift of focus. This is particularly concerning if the personal budget is informed by the proposed independent assessment tools in the absence of a comprehensive needs assessment; if a draft budget is likely to be determined before there has been any real engagement with the participant; and if there are limited options for the draft budget to be changed once it has been determined.

Planning

OTA has serious misgivings about participants’ personal budgets being informed predominantly by impartial assessments based on inadequate tools. Of particular concern is the lack of guidance around how the information from the assessments will be collated and interpreted to inform planning. OTA doubts whether individual assessments will capture participants’ support needs, goals and aspirations, or their future social and economic participation. To provide accurate estimates for personalised budgets, OTA strongly recommends referral to an occupational therapist to determine what is required to optimise participants’ function, including what interventions, modifications and/or assistive technology may be needed.

OTA recommends that NDIA seek allied health assessments and/or reports from relevant health and community sectors in the early phases of planning. This will help provide more useful estimates on the reasonable and necessary supports, services and/or assistive technology that is required to optimise participants’ function. It will also allow for better coordination of their services and supports so that participants do not fall through the gaps.

OTA strongly supports the proposal for participants to be able to review a draft of their plan before their planning meeting. OTA agrees that participants may benefit from having support available to them when they review the draft. OTA is concerned that some participants may be disadvantaged if they are unable to access support from NDIS and suggest participants are given the opportunity to engage an allied health professional involved in their care.

OTA recommends that the planning meeting is facilitated by a properly trained case manager and that participants are encouraged to bring a support person of their choice. To avoid any misunderstanding, OTA recommends that participant plans are written in plain and consistent language with a glossary of terms. OTA strongly recommend that participants receive a clear set of plain language guidelines on what NDIA considers reasonable and necessary services and supports. OTA also recommends goals are discussed in the planning meeting and participants receive help, if they need it, to map out what supports, resources and/or funding will be required to achieve their specific goals. OTA strongly recommends a specific timeframe is set after the draft budget for relevant clinical assessments to be carried out to better inform budget estimates. OTA is concerned that if these assessments are not incorporated early in the planning process, plans will need to be altered. OTA would be deeply concerned if these alterations triggered the need for another initial assessment, particularly if this did not provide sufficient detail to support the development of the draft budget in the first place. OTA is concerned about the impact this may have on the participant (Barr et al., 2015).

Flexible and Fixed Budgets

OTA believes participants' choice and control over their personal budgets should be maintained wherever possible, and suggests that participants are given support to manage their budgets effectively when they need it (Carey et al., 2017). This support is essential for participants who do not have the understanding or ability manage a budget or the capacity to advocate for themselves and what they need. Otherwise, there is a risk that the implementation of flexible budgets will amplify the inequity between participants who have greater self-advocacy and management skills compared with those who do not (Carey et al ., 2017).

OTA supports the notion of flexible budgets and sees them working well in some instances. However, OTA is concerned that a flexible budget will be more difficult for a participant to manage and track if their supports are not itemised. For this reason, OTA recommends a separate assessment process for determining funded support needs using purpose-built tools. OTA also recommends a separate budget for capital items (e.g. assistive technology, home modifications, specialist disability housing) and sees value in having a fixed budget for capacity building when this funding needs to be ringfenced to enable participants to achieve their chosen goals. For example, funds for therapeutic support and behaviour support services that are ringfenced to give participants who have difficulty managing behaviour, essential daily tasks and decisions, and psychosocial issues of concern greater capacity to genuinely work towards their goals. Without this, the most disadvantaged groups who have the greatest need for capacity building and therapeutic support, may not have access to it.

Genuine choice and control can only be achieved with an adequate budget that covers the necessary costs and does not require a participant to have to choose one support over another. OTA would be extremely concerned if a flexible budget put core support and capacity building funding in competition with each other. This is essentially asking a participant to choose whether they want to exist or whether they want to improve their independence, quality of life and chance of independent social and economic participation. NDIA must either ensure there is sufficient funding for both or put safeguards around capacity building to ensure it is retained (Royal Commission, 2019).

Plan Implementation

OTA recommends participants on self-managed plans have a nominated support person to consult about any budget issues as they arise. Some participants may also benefit from specific training on budget management (Carey et al, 2017). Participants would most likely benefit from having clear, plain language guidelines on how to manage their plan and how to determine what would be considered a reasonable and necessary support. OTA suggests participants be given options to manage their budget to meet their needs and that there be mechanisms in place for them to track of their expenditure (Carey et al., 2017).

Making Changes to the Plan

OTA understands the importance of reviewing NDIS plans to accommodate participants with changing needs and goals, particularly when many people with a disability experience superimposing fluctuation and/or deterioration in their condition. However, OTA recognises the impact that reviews can have on participants, particularly if there is no transparency about the purpose or requirements of the review.

The *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 (Commonwealth of Australia, 2013). OTA is concerned that the impartial nature of an independent assessment and its failure to capture this type of vital information will impact on participants' sense of security in the scheme (Barr et al., 2015). This is particularly concerning when the proposed initial assessments may be used as a trigger for increasing costs or for a retest of eligibility.

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 it will cause participants a high degree of uncertainty about the viability of their future (Barr et al., 2015; UN 2007). This is most alarming when the reassessment is based on generic tools that have limited capacity to discern individual needs or circumstances.

OTA also questions the circumstances and criteria for changing participants' 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 (Mannan, 2012; UN, 2007).

If reassessment is required to determine eligibility, OTA strongly recommends the participant be offered a comprehensive needs assessment with an experienced clinician who can use their clinical reasoning and problem-solving skills to understand the discrepancy between the assessed need and actual need.

Starting the new planning process

OTA appreciates the need to have a fair and transparent process for all participants in the scheme and acknowledges that it should apply to both new and existing participants equally. OTA agrees that there needs to be a period of time for any new changes to be phased in, with some safeguards in place to ensure existing participants are not unduly disadvantaged.

However, OTA is extremely concerned that the proposed model will disadvantage both new and existing participants. This is primarily because the initial assessment tools are unlikely to capture participants' support needs, goals and aspirations or future social and economic participation. We sincerely hope this does not lead to participants becoming more disadvantaged and disenfranchised, in a scheme which was established to redress such disadvantage (Barr 2016; Australian Government, 2013 a & 2013b; NDIS n.d).

Exemptions from IAs

OTA does not believe the independent assessment tools are suitable for informing personal budgets and plans. OTA is extremely concerned that the independent assessment tools have limited capacity to capture and/or accommodate for:

- The unique issues and needs of vulnerable client cohorts;
- 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 psychosocial disability have experienced;
- The unique needs of people affected by psychosocial disability (Cummins, 2021; Appendix 5);
- The unique needs of culturally and linguistically diverse (CALD) clients and clients of Aboriginal and Torres Strait Islanders (ATSI) descent; or
- The need for assistive technology (Madden, 2015; Appendices 2, 4 & 5).

OTA is also acutely aware that participants who have substantially reduced capacity in the domains of communication, social interaction and cognition (self-management) would not be able to participate in the proposed independent assessment.

Appeal Rights and Complaints

OTA is extremely concerned that NDIA has placed such a heavy weighting on the use of independent assessments for determining participants budgets and plans. This is evident throughout the policy and yet there does not appear to be any facility for participants to seek recourse if they are unhappy with the outcome. It seems the only route of appeal is through another independent assessment and this makes it extremely difficult for people with disability to challenge funding decisions. OTA is particularly concerned NDIA has taken the position that the initial assessments will not be directly reviewable by the Administrative Appeals Tribunal.

If NDIA is confident of the fairness and efficacy of its proposed arrangements, it should not fear being held accountable for them.

OTA strongly recommends that an independent appeals process be established and that all participants seeking an appeal are offered a comprehensive functional assessment by a suitably qualified occupational therapist and/or any other allied health professional to provide a thorough profile of the participants' capacity and needs (Appendix 6; WHO n.d; UN 2007).

Conclusion

OTA thanks NDIA for the opportunity to comment on its Planning Policy for Personalised Budgets and Plan Flexibility.

OTA appreciates the need for accountability and transparency in the way government funds are spent and recognises the need for a planning policy that ensures personalised plans and budgets are consistent and fair for all participants (Royal Commission, 2019).

However, OTA is deeply concerned that the proposed changes in the planning policy for personalised budgets and plan flexibility will further disadvantage participants. The changes centre around the use of a generic independent assessment toolkit for informing personalised budgets and plans. The toolkit lacks sensitivity, specificity and, in many cases, relevance to a broad range of people that live with substantial and permanent disability (Madden, 2015; Appendix 2). OTA is fundamentally opposed to using this toolkit to determine participants' budgets as it has limited capacity to detect and/or predict individual functional capacity and support needs.

Given the significance of these changes on participants, OTA recommends robust and independent research is carried out using consumer co-design methods in line with international standards. OTA believes this is the only way to ensure redesign and policy reform is appropriate, viable and sustainable.

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– 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 loss of 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 the greatest increases in adverse mental health outcomes in the most deprived areas of the country, widening health inequalities (Barr et al., 2015).

Given the limitations of the pilot study (see Appendix 1), OTA is concerned that the rollout of the proposed IA could 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 2 – 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 3 –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 4 - 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
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.	**Robust empirical research** is needed to ensure that independent assessment processes are fit for purpose; delivered by an independent party. 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. 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.	In the absence of an evidence base demonstrating the effectiveness and safety of IAs, there **is the potential for causing harm.** 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].

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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.

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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 5 –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.

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[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
	Funding in NDIS plans is based on specific supports– based on individual goals support needs. 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)	Funding is based on a dollar value linked to Independent Assessment, not individual support needs, and not linked to goals. For example, $50 000 total NDIS plan.
Criteria for determining funding	Reasonable and necessary funding criteria as outlines in the NDIS Act: (a) the support will assist the participant to pursue the goals, objectives and aspirations included in the participant's statement of goals and aspirations; (b) the support will assist the participant to undertake activities, so as to facilitate the participant's social and economic participation; (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; (d) the support will be, or is likely to be, effective and beneficial for the participant, having regard to current good practice; (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; (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: (i) as part of a universal service obligation; or (ii) in accordance with reasonable adjustments required under a law dealing with discrimination on the basis of disability.	**Not disclosed.** Likely to be standardised Independent Assessment results that are used as inputs that will automate a dollar value for NDIA delegates.
Flexibility (Ability to choose which supports to purchase)	Three categories of funds- Core, Capacity Building and Capital (Funding can be used flexibly within in Core, less flexibly in Capacity Building and Capital. 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.	Two categories of funds- 'fixed' or 'flexible'. For example, $39 000 in 'flexible' category and '$11 000' in 'fixed' category for home modifications
The process of challenging funding decisions	A person with a disability can challenge a funding decision if they have not received a support based on the reasonable and necessary criteria. 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.	**Not disclosed.** 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. 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). 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. The impact on the process for reviewing funding decisions is a concerning element of the proposed reforms.

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).

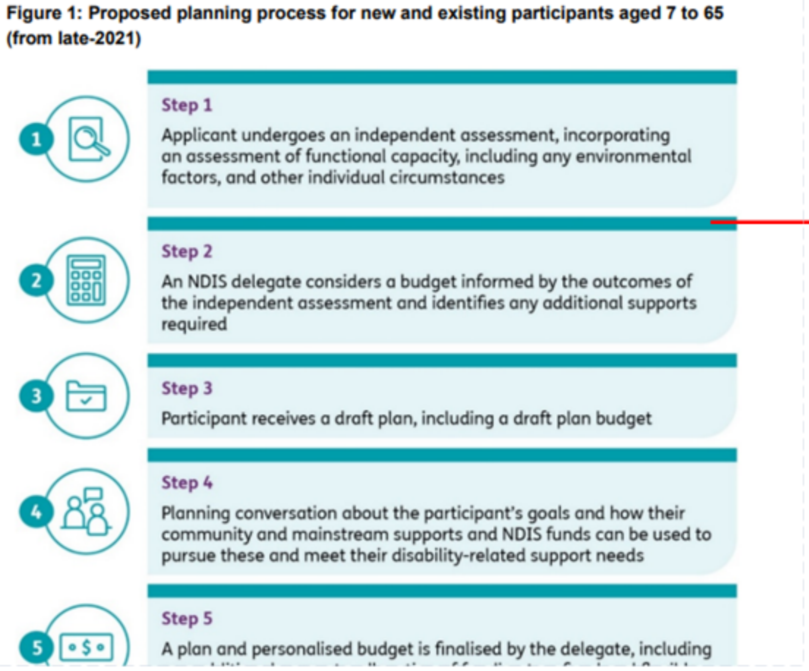

Figure 1: Proposed planning process for new and existing participants aged 7 to 65 (from late-2021)

1. **Step 1** Applicant undergoes an independent assessment, incorporating an assessment of functional capacity, including any environmental factors, and other individual circumstances
2. **Step 2** An NDIS delegate considers a budget informed by the outcomes of the independent assessment and identifies any additional supports required
3. **Step 3** Participant receives a draft plan, including a draft plan budget
4. **Step 4** Planning conversation about the participant's goals and how their community and mainstream supports and NDIS funds can be used to pursue these and meet their disability-related support needs
5. **Step 5** A plan and personalised budget is finalised by the delegate, including

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 has equal value or are they weighted differently? Are the scores combined? Do certain scores or a combination of scores correspond to a specific budget.

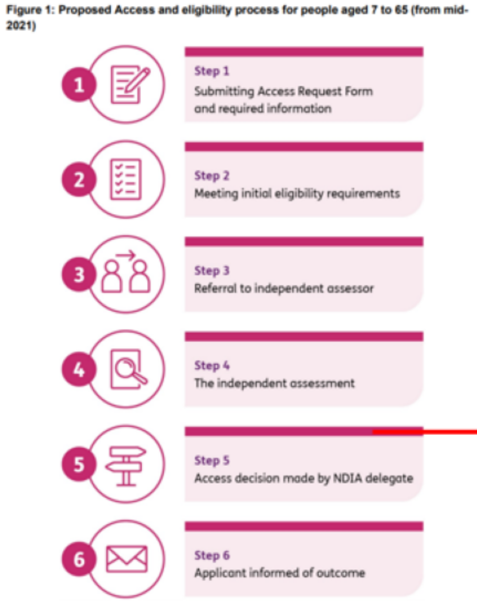

Figure 1: Proposed Access and eligibility process for people aged 7 to 65 (from mid-2021)

1. **Step 1** Submitting Access Request Form and required information
2. **Step 2** Meeting initial eligibility requirements
3. **Step 3** Referral to independent assessor
4. **Step 4** The independent assessment
5. **Step 5** Access decision made by NDIA delegate
6. **Step 6** Applicant informed of outcome

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 form 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
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.	**Robust empirical research** is needed to ensure that independent assessment processes are fit for purpose; delivered by an independent party. 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. 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.	In the absence of an evidence base demonstrating the effectiveness and safety of IAs, there **is the potential for causing harm.** 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].

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 – 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.