

**Response from the Centre for Disability Research and Policy, Centre for Disability Studies, University of Sydney combined feedback to the NDIS *Consultation paper: Access and Eligibility Policy with independent assessments***

Background: Thank you for this opportunity to respond This is a collaborative submission on behalf of multiple members of the Centres, including people with lived experience of disability. The messages in this document reflect these different perspectives on the scheme.

For further discussion please contact: Jennifer Smith-Merry [Jennifer.smith-merry@sydney.edu.au](mailto:Jennifer.smith-merry@sydney.edu.au)

**Learning about the NDIS**

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

Accessible information offered as much as possible by people with lived experience of disability.

Independent assessment can understandably be a very frightening or intimidating process for people with disability because so much is at stake in the assessment (their access to the scheme). For some people this may be even more intimidating if, for example, they have invisible disability and may feel that this is yet another circumstance in which they need to 'prove' their disability to others. People with invisible disability already receive lower access to disability accommodations and supports, for example in education (Venville et al 2016).

Psychosocial disability, or mental illness, is often fluctuating, so people will have periods of relative wellness and periods where they are very 'disabled' by the symptoms of their condition. People with psychosocial disability who are relatively well at the time of the assessment may also worry that they are not 'disabled' enough on the day of the assessment to be eligible. The same can be said for individuals on the autism spectrum who may fluctuate with natural transitions that occur throughout the life stages. An IA conducted at a single point in time prior to these transitions without any input or history from supporting professionals may have a significantly different outcome than during or after these transitions. For example, the transition from early childhood supports to school entry.

People may be worried that their disability is being assessed by people they don't know when they have established and trusting relationships with existing clinicians. This may mean that they have to disclose their disability, which may make them uncomfortable if they have been in situations where they have been ridiculed for their disability in the past, or not believed. The person being assessed should be able to bring in reports/recommendations from others (clinicians they have established relationships with, family, and friends). Individuals and their caregivers may also have just received a diagnosis for themselves or their child and may be in different stages of understanding, processing and accepting that diagnosis. This may have a marked impact on their ability or willingness to advocate for their support needs or those of their child.

Some people who are very socially marginalised may not readily have anyone to support them with the independent assessment process, so this needs to be available to them.

Many people who have cognitive, intellectual and developmental disabilities can have difficulties making ratings and many are acquiescent so they are likely to agree they can do activities and tasks they cannot do without support, while a small percentage are “nay-sayers” who will typically disagree to everything. Additionally, the desire to please can be very strong so they will answer however they think the assessor wants. These responses will give false ratings regarding actual functioning level across multiple items and domains.

In addition, health professionals with established and enduring relationships, understand the complete presentation of conditions, subsequent support needs and the role of informal care in the individual's life. This holistic picture of the individual's needs may not be sufficiently captured by someone unknown to the person with disability and if assessment occurs at one point in time. People with intellectual disability who are non-verbal and those who live with or are supported by family carers would be at risk of incomplete assessments. Assessment is an individualized process by its very nature and therefore, a one size fits all approach is inherently problematic. It is also a relational process as needs evolve and vary over time...the devil is in the detail. A one off assessment is not going to adequately capture the support needs of many people with disability.

For these reasons the following information is essential:

1. There should be clear information on what to expect of the process that is provided by people with disability based on how the process was for them.
2. They should have access to peer support and psychological support (Who have training and back up themselves, especially if they are peers) at the time of the assessment so that they can debrief afterwards if needed. Funding should be available for this peer worker to meet with the person prior to the assessment meeting in order to build some level of rapport and understanding of the person.
3. There should be independent peer workers available to be with someone if they feel that they need support during the process.
4. Information should be culturally accessible for Aboriginal and Torres Strait Islander people with disability. It should also be accessible for people who do not speak English as their first language or who use augmentative and alternative communication (AAC) or have other communication needs.
5. Carers and support people should be invited to support people in the process as standard and helped to understand their role and its purpose and parameters. including the use of multiple proxy respondents for people with intellectual, cognitive or developmental disability when self-report is unlikely to yield accurate responses

Individuals should also be aware of what information about them is being shared by and with other services and have the ability to specifically consent to their information being discussed.

People with disability and their supports people require clear information about the options for how an assessment may be carried out using stories and examples from people with disability who have gone through the process. Short videos may be an option to provide this. Aggregated data should be readily available in accessible formats so that people with disability can understand trends/ patterns in outcomes of assessment processes.

The potential for involvement of carers/support workers/allied health professionals who have an established relationship with the person with a disability should be made clear to the person with disability.

It is essential to ensure the engagement of the person with a disability in a meaningful way, particularly if they have cognitive limitations or communication issues, avoiding tokenism that may lead to an incomplete understanding of support needs.

## **Accessing the NDIS**

### What should we consider in removing the access lists?

The access list C should not be removed unless the NDIA is certain that every person who uses one of the services on the list has had the opportunity to test their eligibility for the NDIS.

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

There are many conditions that are of a lifelong nature, but it seems that the independent assessment process is not about conditions, but about function which may well be variable. This is a significant conflict in the independent assessment process which is attempting to predict something which is variable.

The life-long permanence criteria is a difficult one to enact and determine particularly for people with psychosocial disability whose level of disability may fluctuate with their symptoms. If they were assessed at a time when they were comparatively well then this could lead to people whose disability is significant and permanent being denied access to the scheme.

It would hopefully be the case that people already in the scheme have their functioning improved because of their access to the services that have been funded and provided. That could conceivably mean that if people were to be assessed at a later date, short-sighted assessments without contextual insights regarding the supports that had enabled or supported functioning, might deem people no longer eligible for the scheme. Without access to the scheme and the supports, the person's situation may deteriorate rapidly.

People with intellectual disability are living longer, with the onset of ageing and related conditions occurring earlier than for the general population. Thus, the impact of longevity and ageing needs to be acknowledged and that review of needs seeks to identify where a person may need a change in level or type of support and not a review focused on no longer being eligible.

For these reasons it is important that a longer-term view of disability is taken which allows for functioning to be assessed over a significant time period. In these circumstances engagement and information provided by health professionals to assess the permanence of the disability is essential. It would be significantly problematic if the assessment were made on a single assessment visit. There should be formal acknowledgment of the limitations of the assessment process. Clear and consistent guidelines are needed for professionals around what the NDIA require. This would include documentation, training and consistent communication for health professionals.

For people with a disability who are still engaging in understanding the impact of their disability, predictive estimations of support needs will be difficult. The timing of assessments is an essential consideration for someone with an acquired disability.

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

The clinical judgement of the individual's regular clinical team is essential to making a judgement on this within the definitional boundaries set by the NDIS Act.

Chronic conditions should be defined as ongoing but allow for fluctuations in functioning. An individual with a chronic condition may or may not experience disability relative to their level of functioning and the barriers (and facilitators) in their social, physical and cultural environment. Acute is short term and although may occur more than once, by definition it is not ongoing impact on/ reduced functioning. Palliative is not a good term because it can either be short term or relatively so and synonymous with acute, or longer term and due to impact on functioning over time be classified as a disability.

In order to assess how an individual fits into one of these categories there needs to be a professional conversation between the independent assessor and the clinical team that usually cares for the individual. It may be perceived that the independent assessment process actually undermines belief and trust in the professionalism of the clinical teams that work with individuals on a day-to-day basis. It should be assumed that their professional judgement is correct, and processes put in place to address this where there is poor practice, rather than designing a whole system of independent assessments because of doubts about the ethics of and ability for health and social care professionals to make evidence-informed judgements about an individual's level of disability.

Clinicians should be supported via written (online) and verbal information (via telephone support) which they can draw on easily so that they understand the NDIS definitions of each of these terms. The definitions should be revised as new evidence to support assessment practice emerges.

The focus of assessments should be on the supports needed, rather than the deficits in functioning experienced solely. A functional deficit model does not equate or translate with a support needs assessment. While research has shown positive moderate correlations between the two assessment types, there is a significant gap of around 40 percent of support need unaccounted for by functional assessments. Clear and realistic budget allocations to resource the supports is needed and should be transparent as part of the assessment process.

In the interests of promoting diversity and inclusion, the NDIS needs to recognise that some neurodivergent people (who still require supports for their neurological differences) would prefer to disclose their neurodivergence as opposed to disability (Rothstein et al 2012).

The real question should be how can we ensure that no one falls through the cracks between health and disability and how can we ensure that when making this distinction that systems are in place to transition or provide immediate supports as needed? Health and Disability need to work together to make this a cohesive and clear process for individuals and professionals.

## **Undertaking an independent assessment**

General comments:

This process must include information from relevant others nominated by the PWD; carers, family members, support workers, allied health professionals who have an ongoing relationship with the person with disability.

There is a statement that the panel of assessors are independent of the NDIS but it is not clear when they are being paid by the NDIA. A truly independent assessment panel should be run by another agency.

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

Experience with and empathy for people with disability and the likely consequent social marginalisation. Respect for different forms of knowledge and the expertise of people with lived experience, clinicians and family and support personnel, including advocates and friends.

Because of the problems with the implementation of the NDIS for people with psychosocial disability, intellectual disability and Autism Spectrum Disorder, it is essential that the independent assessors understand the context of mental illness and the specific challenges associated with assessing specific disabilities including intellectual disability and ASD. For example, the WHODAS 2.0 items are very broad overarching levels of functioning that require a level of prompting and further exploration before a person with Intellectual disability could answer correctly and does not account for challenging behaviour or behaviours of concern that can significantly impact on functioning but may be ignored unless the assessor knows how to probe and check if the person can and does perform at a certain level. This skill set involves effective communication with people who use AAC and the ability to ascertain when multi-source proxy response may be required.

We need to grow a significant workforce in the sector that is capable of completing high quality assessment and support. Splitting the workforce into assessors and support providers will reduce the availability of a high quality workforce, particularly in rural and remote locations.

It is critical that assessors understand the impact of complex needs, intersectional needs (e.g. those of First Nations people with disability, women, young people, traumatic stress), poverty, trauma and social marginalisation, which can further disable the individual and lead individuals to be wary of interactions with public services and assessment processes.

A routines based interviewing approach (McWilliam 2009) may be an option to consider to ensure that the relevant informal information is captured to supplement the standardised tools.

The independent assessor needs to be employed by an independent department, such as Health, so they are not reliant on funding from the NDIS directly which may influence the culture of the independent assessment process.

The primary aim of the independent assessment is to determine the supports required for the individual, which may necessitate a broader suite of assessment approaches, both standardised and informal/observational.

There is a significant shortage of allied health professionals in rural and remote areas in the disability and health sector, leading to concerns about timely access to independent assessors for people with disability in these locations.

An unintended consequence for rural and remote people with disability may be that allied health professionals have to choose whether to become an assessor or a provider, further reducing access to allied health supports in rural and remote locations.

Detailed description of functioning is a key part of the skills of an assessor. You must understand and clearly document what supports are required in the environment to support the person with a disability. That includes structural and informal supports that are essential eg. Guidance and advice with personal care activities; travel training for new routes; advice re dressing for the weather or the occasion. A sweeping statement about capacity to undertake activities without exploring the detail will lead to a mismatch of supports and potential exclusion from funded supports.

What makes this process the most accessible that it can be? For example, is it by holding the assessment in your home?

The assessment process should be individualised so that people are genuinely able to choose where an assessment takes place and who they need or want to be supported by during the assessment. Access to an in-home assessment or other location chosen by the individual, needs to extend to people who live in rural and remote Australia, including remote Aboriginal and Torres Strait Islander communities.

Allocation of sufficient assessment time for some participants is essential. Additional time may be required for people who use AAC, or require additional time to understand certain terms, or take breaks throughout the assessment process.

Standardised assessment tools offer a consistent approach but may not be suitable for all people with disability. It is important that any assessment approach and tools used have been adapted, tested and validated for use with people with intellectual disability. All information should be available in a range of accessible formats including easy read, audio, visual recordings.

Accessibility for people in rural and remote areas is a very important consideration. There is a potential for timely assessments to be problematic in rural and remote areas.

Involvement of others to help the person with disability feel comfortable and confident in the process is essential. That may require interpreters or other support people that are familiar with cultural practices.

The independent assessment process must be a collaborative process that is about matching the person with disability with the supports they require, not an adversarial process.

Individuals and their families should be shown visually a range of ways in which the assessment can take place using videos or pictures. This will help participants know what to expect if they are conducting the assessment in their home, via video conferencing, in an office etc. By showing what to expect, this can increase predictability and reduce anxiety for many individuals.

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

Assessments are based on a western model of functioning and medicine. These models are not culturally respectful for Aboriginal people. Relationships between professionals and Aboriginal people take years to evolve. As such, Aboriginal people often do not disclose personal issues to strangers.

Assessments should as standard be completed by people with knowledge, expertise and skill in working with people from different cultural backgrounds. In some communities, assessors will need to be people who are trusted and accepted by the local community. Interpreters will need to be funded as standard for anyone who requires this support.

Assessors will require an understanding of cultural sensitivities for individuals. In relation to the Vineland 3, the only tool appropriate for use for most adults with intellectual disability (the CHIEF only has a very small dataset in reliability and validity for people with developmental disability and the WHODAS 2.0 presents many challenge in its use with people with intellectual disability, as noted above). The Vineland 3 allows for some contextualisation in the terms used in the assessment, however the assessor will need to understand the cultural sensitivities to then make these contextualisations.

Including people from a diverse background as assessors or being part of the assessment process is essential to ensuring cultural safety.

The assessment process has potential to be tainted if the purpose of the assessment is diluted. The determination of support needs is a key part of the process, however a determination that another organisation is responsible for providing supports is not clearly outlined by this process as there are no other departments involved in the process. This process must include a support pathway for those who are not deemed eligible for NDIS packages to ensure they do not slip through the gaps.

Independent assessors should have professional (tertiary level) qualifications with evidence disability study, practice in the field and/or lived experience. As in Aged Care, independent assessor need to be appropriately qualified. Not just people who are trained in house to complete form. Some workers use titles for which they do not hold qualifications. An example of this was a behavioural support planner whose qualification was an *Advanced Diploma of Therapeutic Yoga Teaching*.

### **Exemptions**

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

Independent assessments are not necessary for most people coming into the scheme. They should only be used where people are not able to access their own clinical support teams for assessments, for example in the case of people who may have been for a long period without the provision of any services (e.g. homeless people, or those that have otherwise been severely underserved in the past).

### **Quality assurance**

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

This should be done in multiple ways and include:

- You should ask whether the service is fit-for purpose and has clear rigour and is fully independent (if that is its purpose). This needs to be monitored and evaluated
- You should determine whether the assessment meets the expectations of people with disability.
- A process of following up each assessment to determine the acceptability of the assessment process to the person with disability and, where relevant, their families. There should be mechanisms for providing this information anonymously.
- If the goal is for an equitable process for accessing the NDIS, there must be a consistent system of administering IA's. How can this be done with such significant variation in support needs for individuals in the IA process, as well as levels of experience and training of assessors.
- The NDIA should undertake an open and independent evaluation of the services offered by independent assessors. This should be commissioned by the government (rather than the NDIA, who has a vested interest in the outcome) and publicly released so that the results can be scrutinised.
- There should be data on the assessment processes collected and made publicly available on a quarterly basis. This should be compared to practices prior to the independent assessment process being implemented.
- There must be a longer horizon on outcomes for people with disability who undertake the assessment process, both those who are included in the NDIS and those that are not. At least a 5 year evaluation should be undertaken to follow up on all independent assessments with a focus on outcomes for people with disability. We need long term data (at least one plan period) to understand whether the IA process was accurate at identifying support needs for the individual at that point in time.

## **Communications and accessibility of information**

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

The results should be available in a timely way, with timing monitored to ensure that people are able to have their assessment received in a clear timeframe. People should know ahead of time when they will receive the results so that they can be prepared with supports in place when they receive them.

They should be provided in person where possible and on the phone where not so that information provided can be immediately followed up and people's questions answered. Peer and other support should be made available for people to receive at the time of receiving the results or afterwards. These peer support workers should be paid. Where the person with disability wants this, they should have a support person with them at the time of receiving the results.

Similar to the assessment process, results should be presented in a communication format that suits the individual. There should be a clear outline of next steps and actions so that the person with disability and their supporters/ advocates know what to expect in terms of follow on and access to the necessary supports. There should also be a very open and transparent



mechanism to contest the assessment findings if the individual and/or their supporters feel the results do not reflect the true need.

The person with disability should be linked immediately with a support person or LAC to ensure that the next step in their pathway is clear. This may require engagement with other organisations and main stream services particularly if the person is not accepted into the NDIS.

### **Additional Points**

- The desire to provide an equitable system using independent valid and reliable assessments is noteworthy, especially when funds are limited and costs across the scheme have been escalating. What is unclear however, is how level of functioning will be tied to funding and lack of transparency around this process suggests a return to standard packages based on Functional scores. There are critical risks here:
  - Funding based on functioning level alone is insufficient and does not include other key factors such as support to achieve goals a person wants (a premise of the NDIS) and adjustment required for presence of challenging behaviour. The assessment suite for adults (18 years+) includes the Vineland 3 Domain version but does not include a measure of behaviour of concern or challenging behaviour. It is well known that the presence of behaviour of concern can significantly and adversely affect functioning level on a day-to-day basis so failure to acknowledge or include any rating of this a number of individuals with disability is flawed.
  - In Supported independent Living settings including group homes, few if any informal supports are available. Reductions in funding to recipients in these situations may have significant unintended consequences including underfunding of participants in group home settings. This may result in the inability of organizations continuing their support to underfunded individuals leading to group home closures and/or evictions of individuals with high support needs. The result will be people with disability becoming homeless, or being inappropriately housed in nursing homes, hospitals and aged care facilities – a problem we are already trying to reduce and prevent.

Rothstein, A. (2012). 'Mental disorder or neurodiversity?' *The New Atlantis*, pp.99-115.