



Submission: NDIS Access and Eligibility Policy for Independent Assessments - Consultation Paper

The Mental Health Coordinating Council (MHCC) is the peak body for community based mental health organisations (CMOs) in New South Wales. The purpose of the Council is to support a strong and sustainable community-managed mental health sector that delivers effective health, psychosocial and wellbeing programs, and services to the people of NSW. MHCC provides its membership and the sector with policy leadership, promotes legislative and systemic reform, and offers resources and training to assist community-based organisations to deliver quality and effective services. The MHCC Learning and Development arm is a widely respected registered training organisation delivering nationally accredited mental health training and professional development courses.

The National Disability Insurance Agency (NDIA) has released a [Consultation paper: Access and Eligibility Policy for independent assessments](#). The new NDIS Policy for Independent Assessment focuses on the individual, their function and support needs. Independent Assessments (IAs) will be used for prospective participants to assess the impact of their disability on their day-to-day life (functional capacity). The policy, and independent assessments, will come into effect in the middle of 2021 for all applicants over 7 years of age.

General summary comment

MHCC welcomes the opportunity to comment on the questions posed in the NDIS consultation paper. Additionally, we provide comment having consulted with member organisations and other state peak bodies on several issues identified in the following commentary. We are also able to report on feedback gathered via a survey which MHCC distributed more broadly to our membership.

Pilot studies

From 2018, the NDIA piloted independent assessments (IAs) of functional capacity on a voluntary opt-in basis to NDIS applicants and participants aged 7 to 64 years participating in NSW service delivery regions. The pilot was initiated based on evidence that the current approach to assessing a person's functional capacity is inadequate leading to inconsistent and inequitable eligibility and plan budgeting decisions.¹ There continues to be a particular concern about the over-use of assessment tools by health professionals that rely solely on diagnosis of disability and impairment, rather than describes a participant's functional capacity; which requires subjective judgement by NDIS staff.

¹ NDIS 2020, *Independent Assessments: Pilot learnings and ongoing evaluation plan*. Available: <https://www.ndis.gov.au/participants/independent-assessments/independent-assessment-pilot>

The NDIA set out to gather holistic, consistent and standardised information on a participant's functional capacity (including environmental factors which effect an individual's support needs) as required under the NDIS Act to inform decision-making on what is 'reasonable and necessary'.

However, the initial pilot of 513 assessments, and the second pilot of 99 assessments (conducted in four NDIS service delivery areas in NSW) only drew upon data from 7% and 9% assessments respectively of participants with psychosocial disability as their primary disability. This was too low a number to determine any statistical relevance for this group.² Unfortunately, the impact of COVID-19 reduced the number of IAs completed in the second pilot, and 'social distancing' rules directly impacted on the completion of IAs. MHCC understand that the second pilot has recommenced to better support the operationalisation of IAs. Evaluation following the second pilot's completion will help enhance implementation and allow for further opportunities to test and learn, and further consult the sector. At this point in time while supportive in principle of IAs, community mental health organisations consulted by MHCC are reluctant to wholeheartedly endorse them until further questions have been clarified and evaluation and outcome studies have been conducted.

MHCC broadly supports IAs provided that, they are conducted by appropriately trained staff, supported by adequate resources who have a good understanding of mental illness and its potential psychosocial impact on individuals, their families and support networks. This understanding must also include knowledge and expertise concerning what constitutes a trauma-informed recovery-oriented practice approach to assessment and planning, which can benefit the participant during the assessment, and when planning and developing the scope of their package.

Cultural competence is a key skill set for assessors which should include an appreciation of diversity across the community. As a corollary to this, it is necessary to ensure that staff conducting IAs receive ongoing education and supervision; and that people undergoing assessments in rural and regional locations are not disadvantaged because of a lack of suitably qualified assessors.

In conversation with the sector, it was made clear that IAs should not be mandated, and need to be flexible enough to meet the individual needs of participants. Likewise, that IAs should be conducted as part of a comprehensive assessment process that takes into account reports and discussions with existing service providers, families and support persons, with a view to establishing the broadest possible perspective on what a person will need to enhance their recovery.

Reservations concerning methodology

Whilst MHCC understand that there is a degree of flexibility around the 3-5 hour assessment timeframe, many participants may experience a degree of stress in relation the assessment process itself; and may be unable to take part in a process that takes some time to complete. They may also experience considerable difficulty in participating because of episodic illness; or may be disadvantaged if assessed when well or unwilling to share their experiences of functionality when they are unwell. The importance of input from family and support persons in conducting IAs is vital to establishing a true picture of functionality across time and context.

² Ibid, NDIS 2020.

Flexibility around splitting up assessments into shorter sessions may also need to consider lengthier timeframes; and involve reviews over several months to assess episodic variations. In this regard, concerns were expressed about the potential for participant disengagement if the process of conducting IAs did not establish the trust and the development of the rapport necessary for a person to share their perspectives with a stranger.

Some MHCC member organisations are very concerned that the use of IAs would further entrench an insurance-based cost control approach where assessors might likely be influenced by limited funds available in the scheme and biased towards reducing supports. This may particularly disadvantage participants lacking the social supports to assist them advocate for themselves. They felt that this was not a person-centred approach and was one that would offer less transparency and accountability about decision-making. They also proposed that this method would not necessarily include strategies suitable for engaging people with cognitive impairment and complex needs; and might undermine existing professional helping relationships.

Independent assessment

A question was raised as to the degree to which assessors could be independent; especially if they work for and represent the NDIS. It was suggested that the assessment process, if mandatory is likely to pose a barrier to many people who may be eligible but refuse to participate in a process with an unknown assessor.

MHCC strongly urge the NDIS to ensure a degree of flexibility surrounding assessments so that people can engage in ways that they feel comfortable with. This includes a person being able to have a trusted worker or support person with them during the assessment, and that the assessment process be framed in terms of therapeutic engagement which positively impacts the psychological well-being of the subject person; and that the outcome will benefit the participant in terms of improved service planning.

Those consulted asked whether independent assessors would have the skills to manage distress if the process of assessment has a triggering impact on the person being assessed, and what debriefing process would be available if this were to arise, for both the person and the assessor.

Assessment tools and quality assurance

MHCC understand that quality assurance processes have increased the NDIA knowledge base and contributed to continuing improvements, and that recent procedural reviews indicated a level of inconsistency and subjectivity in assessment information. This led to an overarching approach to the assessment of functional capacity. Nevertheless, MHCC is concerned that the tools identified are limited and will be unable to identify the nuances underlying a person's responses that may better reflect their experience and goals.

Several tools have been identified for assessment. The question arises as to who will determine which tools are most appropriate for a particular individual and what would happen during and after an assessment if the assessor considers that the wrong tool/s have been selected? MHCC are concerned that there is limited opportunity for a robust questioning of the methodology utilised or available, especially concerning that which reflects recovery orientation.

MHCC ask how assessment will be conducted if for example, the WHODAS 2.0 is used, since this is a self-administered tool? Some participants may need to be supported through the process for various reasons including literacy or language difficulties.

Since the best assessment will reflect the participant's views and goals, it would be valuable to understand how participant and clinician rated assessments will be reconciled.

Concerns were raised as the validity of the assessment tools which would be characteristically be used in rather different contexts. It is unclear as to how the assessment will translate into participant eligibility or into the development of a package or its size. Some of the tools provide scores, and as mentioned earlier, the subtleties of a person's experience can easily be missed, especially since the assessor is a stranger to the consumer. For example, a question in the CHIEF tool relates to the availability of medical services, and whether that represents a problem or not to the individual. Some consumers, who might benefit from improved access to a range of medical services may be reluctant to engage with them for a number of reasons including: a disinclination to interact with professionals who they feel might judge their mental health; that they are concerned about the cost of some services not necessarily bulk billable; or that they do not recognise they have a physical health problem that needs attention; or that they experience difficulties waiting in waiting rooms because this provokes anxiety. This are just a few potential issues that would not be picked up by a scoring methodology.

What seems absent from the choice of assessment tools is one that asks about a person's strengths, goals and aspirations, and demonstrates how this relates to their functionality and how the assessment might translate into planning for recovery outcomes.

Outcomes and evaluation

MHCC would like more information about what structures would be in place to evaluate the process of conducting IAs and outcomes as experienced by participants, carers and support persons, and service delivery providers. MHCC are keen to know what data and qualitative evidence will be collected and how quickly the findings might translate into individual quality improvements to plans and packages. It is important that we can see how this assessment process has improved people's lives and how the assessment tools translate into plans that meaningfully incorporate participant goals and aspirations for their own recovery. The tools are primarily a way of assessing what adaptive or remedial assistance might be necessary that meets their level of functionality. What it doesn't seem to incorporate is an expression of choice and control that will be interpretable into planning processes.

MHCC is also interested to better understand how outcomes and evaluations will be built into the system to ascertain the impact of IAs on quality of life for participants and their families; and whether this model of assessment is an improvement on what went before. Apart from participant/carer experience, how will the NDIA be gathering evidence and reporting on outcomes, both in the short term and longitudinally?

We also ask what monitoring and safeguarding mechanisms will be in place to oversight the assessment process and how accountability will be reported and evaluated.

Independent Assessments of forensic and correctional patients

MHCC is interested to better understand how IAs will apply to forensic or correctional patients and whether IAs will be conducted prior to release; and if so, what supports these patients will have access to, and where we can access more information about the process for this group of potential participants.

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The Consultation Paper Survey Questions

The following sections represent responses to the questions posed in the survey:

Learning about the NDIS

1. What will people who apply for the NDIS need to know about the independent assessments process?
 - Whether there are any out-of-pocket expenses that will apply to the consumer?
 - Who else can attend assessments with the consumer (e.g. carer, friend, support worker, advocate etc)?
 - Can a consumer ask for the assessment to take place over several meeting dates over a what period of time? How might this be accommodated?
 - What qualifications and experience does the independent assessor have in relation to psychosocial disability?
 - Can a consumer elect to be seen in a place of their choosing (e.g. their home, a friend's home, a culturally appropriate community setting, etc)?
 - Will a consumer be prepared beforehand for the type of questions they will be asked; what kind of information will be available (e.g. FAQs; about dress; are they expected to bring other documents, etc)?
 - Will a consumer be supported to attend an assessment appropriately in terms of transport, and any other issues?
 - What are consumers' rights in relation to the IAs?
 - What avenues for appeal exist if a consumer is assessed in a way that they disagree with or that they feel was unfairly or unprofessionally conducted?
 - Who gets to see the assessment results/scores?
 - How long will they have to wait to know the outcome?
2. How is this information is best provided?
 - A range of communication alternatives should be available: e.g. in conversation with support workers, telephone help lines, printed brochures, videos, YouTube, online app, website FAQs, – available at community mental health public and community-based services, through GP clinics and health centres, through mental health facilities, correctional and hospital contexts such as EDs, public libraries, etc.
 - Materials should be also available in plain English and pictographs.

Accessing the NDIS

3. What should we consider in removing the access lists?

- List A – Conditions, which are those likely to meet the disability requirements in section 24 of the NDIS Act, should be removed. This list provides for diagnostic assessment for people with some conditions based on the DSM V, which we consider to be an undesirable requirement in the context of the assessment process, and contrary to recovery principles.
- What is not discussed anywhere is the issue of people living with personality disorders that may seriously impact their ability to function. For example, people with Borderline Personality Disorder characteristically have great difficulty in interpersonal relationships and may be socially isolated, be unable to manage their levels of distress, lead chaotic and disorganised lives and cannot maintain employment. Their ability to engage in an assessment process will likely disadvantage them and they are likely as they usually do fall through the service access gap.

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

- This information will be qualitative; based on professional judgement of the person, their psychosocial disability and lived experience. The “evidence” will be subjective based on the assessment of case notes, as well as personal and professional knowledge acquired over time.
- MHCC are aware that for some people with a psychosocial disability, there have been significant issues in gathering the necessary evidence for their NDIS application. Not all people have an ongoing relationship with a GP or health professional and some health professionals have struggled to understand and provide what is required for an NDIS application. It is important the commitments made by the NDIA to make it simpler and easier for health professionals and prospective participants to provide information on evidence of a disability and whether it is likely to be permanent (p.14 of the discussion paper) are introduced before IA's are implemented, otherwise one of the promised benefits of IAs, e.g., a smoother and more consistent assessment process, will not be realised.

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

These terms refer to quite different things, so the distinction between these terms is necessary in the context of people living with psychosocial disability. MHCC provides the following examples:

- **Disability.** A person with a mental health condition experiencing psychosocial disability may experience different degrees of disability according to where they are in their recovery journey; whether they are in an active stage of their illness or have a continuing condition which is stable or at base—line. Their condition may affect their thought processes, perception of reality, emotions or judgment or results in behaviour that affects social interactions and their functionality all the time or episodically.

- **Chronic** disability refers to conditions with persistently debilitating psychiatric symptoms and severely impaired functionality. Individuals with chronic mental illness suffer from symptoms that may interfere with their ability to perform activities of daily living (ADLs) and to participate in work, school, and interpersonal relationships. In other words, they may have a disability that is enduring and severe, which limits social inclusion and quality of life.
- **Acute disability** is characterised by significant and distressing symptoms of a mental illness requiring immediate care and treatment. This may be the person's first experience of mental illness, or a relapse or deterioration resulting in the worsening of symptoms of a continuing condition and/or severe disability, which leads to psychosocial difficulties that must be addressed immediately.
- **Psychosocial difficulties** refer to the psychological and social factors that influence mental health. Social influences including peer pressure, parental support, cultural and religious background, socioeconomic status, and interpersonal relationships all help to shape personality and influence psychological makeup, that also influences outcomes for the individual. People with psychosocial disorders may have difficulty functioning in social situations and have problems effectively communicating with others.
- **Palliative health conditions** require treatment, care and support for people living with a life-limiting illness. A life-limiting illness is one that can't be cured and that is likely to cause death. Life-limiting illnesses can include for example dementia and other degenerative illnesses of the brain that affect functioning and physical health.

Undertaking an independent assessment

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

An ability to:

- Ensure that the person being assessed feels safe and comfortable to proceed
- Ability to listen and be empathic
- Be respectful and non-judgemental
- Understand and be able to apply a trauma-informed recovery-oriented practice approach to the assessment process
- Demonstrate expert knowledge and experience of mental health and coexisting conditions, as well as the diversity of the lived experience of those they will be assessing
- Give time for a person to convey their answers
- Be inclusive of other people invited to attend
- Be prepared to answer questions even if not strictly relevant to the assessment process, but important to the person being assessed
- Be capable of managing distress and be able to diffuse a situation if it occurs
- Be able to use the tools in a non-formulaic way.

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

- Consumers must be contacted in a private and confidential way prior to the assessment meeting to ensure that a home visit will afford them the privacy and confidentiality they need and want.

- Where a home environment is not appropriate assessors must be able to work with the participant to identify reasonable alternatives that they can easily access.
 - A home environment must be a safe environment for both consumer and assessor. This must be checked appropriately prior.
 - Allow the person being assessed to identify who they would like to participate or support them during the assessment, or who they don't want involved.
 - Ensure that a debriefing process is available if the person being assessed would like to be supported in this way.
8. How can we ensure independent assessments are delivered in a way that considers and promotes cultural safety and inclusion?
- Cultural context is paramount. A consumer must be offered the various alternative ways they can undertake the assessment; asked beforehand what would be the most comfortable environment for them? An explanation as to why their desired option may not be available, should also be explained.
 - Assessors should be selected where possible from the same cultural and language group. Where this is not possible assessors should demonstrate cultural competence and have undergone appropriate training.

Exemptions

9. What are the limited circumstances which may lead to a person not needing to complete an independent assessment?
- Where a person is experiencing symptoms that make it impossible to engage them in rational conversation (such as paranoia and delusional experiences); or where safety is a concern.
 - When a person is too unwell to process the questions or answer them, or when they feel they will be disadvantaged in any way.
 - Where a Guardian or substitute decision maker has been appointed because the person is unable to participate in the activity or refuses to attend.

Quality assurance

10. How can we best monitor the quality of independent assessments being delivered and ensure the process is meeting participant expectations?
- A participant evaluation process must be established (e.g., something like the Yes/CMO survey) that asks the participant to share their experience of the assessment (e.g., were you treated with respect? Did you feel safe whilst being asked questions during the assessment? Etc.)

- An evaluation process should be conducted by someone other than the assessor who completed the assessment. This could be done over the phone or online, as well as given in paper form at the end of the assessment with a stamped addressed envelope.
- Independent advocates sitting in assessments and reporting on the process in some accountable format.
- Implementing an audit process that assesses outcomes against stated objectives and criteria.
- The validity of the assessment needs some clarification. Assumptions about assessment as expert led in the context of such a brief process needs further exploration. MHCC would like to see some research evidence that demonstrates the tools and the process is fit for purpose, and evaluation of accountability mechanisms in place.

Communications and accessibility of information

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

- It is unclear what is meant by providing assessment results. Does this mean that the scores or expert interpretation would be shared? Or that this refers to the result of the assessment in terms of eligibility or supports recommended?
- The question arises in this context as to what right a person has to see their scores and detailed interpretation.
- A person applying should be advised at the end of the assessment how long the process of confirmation or ineligibility will take; how they will be advised and who will be contacting them.
- They should also be provided with contact numbers for follow up questions or queries.
- A consumer should be advised in writing by registered mail, after they have been advised in person or at the very least telephoned with the outcome of the application.
- No applicant should be advised of a negative outcome via a letter only. A consumer should be personally contacted by someone who will explain why the outcome was decided in that way.
- Where a consumer is likely to experience a difficulty or distress in understanding a negative outcome, an appropriate support person should be made available to them.
- If the outcome was negative, the consumer should be advised of the appeal processes available to them through the NDIS review and AAT as appropriate thereafter. The letter of rejection should also include that information as to their rights of appeal, links to forms requesting a review, or making a complaint.

- We assume that staff meeting with consumers to advise them about their assessment or writing communications about this matter, will be well versed in recovery-oriented language and ways of communicating. MHCC are concerned that the language of written communications conveying assessment results may be difficult for a person to hear, and that disappointing news, will be appropriately expressed.
- MHCC suggest that the NDIS Q&S Commission should be considered as the appropriate body to investigate complaints in relation to professional conduct about conducting IA assessments.

MHCC wish to acknowledge all the organisations and individuals who contributed to this submission. We thank them for collaborating with us in this important consultation process.

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