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MHCC ACT Response to the NDIA on Independent Assessment

Mental Health Community Coalition ACT

Peak Body in the ACT for the Community Mental Health Sector

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About MHCC ACT

The Mental Health Community Coalition of the ACT (MHCC ACT) is a membership-based organisation which was established in 2004 as a peak agency. It provides vital advocacy, representational and capacity building roles for the Not for Profit (NFP) community-managed mental health sector in the ACT. This sector covers the range of non-government organisations (NGO) that offer recovery, early intervention, prevention, health promotion and community support services for people with a mental illness.

The MHCC ACT vision is to be the voice for quality mental health services shaped by lived experience. Our purpose is to foster the capacity of the ACT community managed mental health services to support people to live a meaningful and dignified life.

Our strategic goals are:

- To support providers to deliver quality, sustainable, recovery-oriented services
- To represent our members and provide advice that is valued and respected
- To showcase the role of community-managed services in supporting peoples' recovery
- To ensure MHCC ACT is well-governed, ethical and has good employment practices.

Preamble

The Mental Health Community Coalition of the ACT (MHCC ACT) welcomes the opportunity to respond to the consultation on the Independent Assessment IA). We will frame our response around the IA meeting the needs of people with psychosocial disability within the NDIS framework. MHCC ACT has contributed extensively to the consultation on the proposed changes to the access procedures of the NDIS, especially around the IA. We contributed to the Community Mental Health Australia (CMHA) submission to the NDIA in August 2020, the Mental Health Australia (MHA) recommendation paper, and various online sessions with NIDA representatives and service providers, participants carers commenting on the consultation paper's questions. This submission is complementary to that work.

MHCC ACT's overarching concern is that the structure of IA's and the mandatory nature will negatively impact people with psychosocial disabilities. The needs and capacity of people with psychosocial disability can fluctuate depending on the cyclical nature of mental illness and where they are in their recovery journey. The proposed design of IA does not seem to reflect an understanding of this which leaves people with psychosocial disability in danger of not receiving the support they need to reach their goals and live a meaningful life

Executive summary/conclusions

MHCC ACT agrees with the objective to improve the NDIS intake process to make it simpler and more equitable. It sees merit in moving away from diagnosis to a functional assessment consistent with the initial objectives of the NDIS.

However, MHCC ACT has many concerns regarding the way the NDIA is shaping the IA. Our concerns are around the following aspects of the IA:

- independence and impartiality
- mandatory nature
- speed and scale of the rollout
- lack of evidence regarding how it works for participants
- nature and quality of assessments
- qualification, capability and appropriateness of the assessors

MHCC ACT's overarching recommendation is that the IA as currently proposed should be abandoned. It needs to be revised, and robust evidence produced which shows that the revised IA is genuinely independent and will be implemented in a way that gives participants choice and control, is consistent with their human rights and produces better outcomes for participants, including by doing no harm. These must be the guiding principles to change the system to give equity of access.

The nature of this consultation

We acknowledge the NDIA's consultations over the last few months, but we want to point out that according to the NDIA, the IA are a fact, and the rollout is happening no matter the feedback. The consultations were around finetuning the IA to make them less offensive.

MHCC ACT's view on Independent Assessment

Where we agree

MHCC ACT accepts the premise of the need to ensure everyone has the same opportunity to enter the NDIS regardless of socioeconomic background. We understand and support the NDIA's desire to address the inequality created by the appropriateness of the plan of NDIS participants depending more on affluence, the level of education/administration skills of the participants and/or their support network than their actual need.

It is well known that the complicated access process of the NDIS is deterring people from entering the Scheme because it is "too hard and expensive". It's is especially an issue for people with severe psychosocial disabilities (PSD) who are often socially isolated and have negative experiences with institutions and administrations. MHCC ACT understands the desire to make sure vulnerable people are not disadvantaged and support this wholeheartedly.

MHCC ACT supports the NDIA's attempt to move away from the diagnostic approach and focus on a participant's functional capacity. This has been advocated for a long time by people with lived experience.

Concerns

Independent nature of IA

MHCC ACT has concerns regarding the implementation and effectiveness of the IA. One of the most significant issues is the premise that the assessments are independent. MHCC ACT strongly objects to that notion; these assessments cannot be seen as "independent" when the assessors are on the NDIA payroll. Independent means no vested interest or receiving benefits.

To quote the meaning of independence from the dictionary[1]:

> *free from outside control; not subject to another's authority.*
>
> *not depending on another for livelihood or subsistence.*

No amount of quality assurance frameworks nor professional body standards can detract from the fact that the agency that employs the assessors to determine whether a person will have access to the Scheme is also the authority that decides on people's access to the Scheme. It is a fraught model causing a conflict of interest for the assessors and the agency and can lead to undue hardship for the participant.

MHCC ACT at no point insinuates that the NIDA purposely will abuse the system, but this is not a new model, and one cannot claim that the perverse outcomes of such a model are not well known. Many are the stories of people being traumatised by so-called independent assessors in areas like compensation and insurance claims and worse, "doctor shopping" by the ruling authority. A recent investigation by the ABC showed how Comcare engaged

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[1] Definition from Oxford languages

independent assessors for a favourable outcome[2], causing trauma. Why would the NDIA pursue such a process, given their participants are already some of the most vulnerable in our society?

In their current form, these assessments are not independent. MHCC ACT, therefore, recommends that the design of the IA be revisited to guarantee true independence. For example, a more effective way to make IA independent would be to introduce a medicare item number for them so that assessors don't have a direct relationship with the NDIA.

Why mandatory?

A second issue MHCC ACT has is the mandatory feature of the IA. We accept that the agency is now considering exceptions to this rule, but MHCC ACT wonders why the onus, once again, has to be on the participant to prove that the assessment will cause damage and or trauma? It would be much better to step away from this mandatory requirement and make it optional so people have choice and control in keeping with the NDIS objectives.

MHCC ACT also questions why IA will be made mandatory for people already accepted in the Scheme and that such people only have access to a limited list of assessors? It is not the approach recommended by Tune review[3] despite claims to the contrary from the Government and the NDIA.

The Tune Review recommended that the Act be amended to require prospective participants to undergo assessments using NDIA-approved providers (recommendation 7, p 67). That is not the same thing as what the NDIA is doing. On the contrary, on page 67 of the Tune Review it explicitly states:

"NDIA should not implement a closed or deliberatively limited panel of providers to undertake functional capacity assessments."

MHCC ACT recommends that if IA is introduced, it be optional and that assessors are independent to the NDIS, accessible to all and that IA is structured in keeping with the true recommendations of the Tune review

Where is the evidence?

MHCC ACT questions why the rush to roll out this contentious process and at such a large scale? It is quite clear that the NDIA does not have the data to back up IA's merit in the proposed form. From Senate Estimates[4], in December 2020, we know that the introduction of IA is based on 145 respondents to a survey, of which only 35 were participants. The number of people with PSD who responded to this pilot is even lower; a rough calculation

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[2] Federal Government workers compensation authority Comcare accused of unethical behaviour, 5 February 2021

[3] Tune review,

[4] https://everyaustraliancounts.com.au/tag/independent-assessments/ and https://www.smh.com.au/politics/federal/just-not-ok-only-6-per-cent-of-ndis-trial-participants-completed-survey-20201221-p56pbc.html#comments

brings us to about 2[5]. Hardly enough data to roll out a new high impact process at such a large scale and making it mandatory.

Our question to the NDIA is why the rush to implement the IA and make them mandatory, given the lack of evidence on how it could work and doesn't cause harm? The NDIA claims to listen to people with disability and wants to make sure their experience with the NDIS is positive and empowering. MHCC ACT urges the NDIA to note the loud voices of protest against the NDIA from people with disability[6] , questioning the NDIA's motives and the appropriateness of IA.

We are not convinced that so-called 'sympathy-bias' is corrupting decision making as to participant eligibility and plan outcomes. Even if it does exist, it is no reason to introduce a system with an opposite type of bias – that being toward the NDIA as the employer of assessors.

One approach to improve equity of access and ensure independence could be to use Medicare. There have long been calls for a medicare item to be introduced associated with the costs of entry to the NDIS.

The NDIA needs to provide a lot more transparency around its processes and the evidence it uses as the basis for its decisions. For example, a system should be used similar to that used for submissions to government enquiries whereby they are available for the public to read.

MHCC ACT recommends that the NDIA slow down the rollout of IA and instead build it in a more robust, considered, transparent and trusting partnership with stakeholders – consumers, carers and providers - to ensure it produces outcomes appropriate to participants' needs and the objectives of the NDIS.

Human rights framework

This brings us to how the mandatory IA sits within the Human rights of people with disability. As clearly stated in the Convention on the Right of People with Disability, people with disabilities have the same rights to self-determination as everyone else. Already, participants of the Scheme go through many scrutinies, and often very intimate and private details are used to assess their eligibility.

MHCC ACT understands the need for assessment, but we believe there needs to be a balance and if in doubt, the participant's rights and wellbeing takes priority. Within that framework making anything mandatory needs to be approached with caution as by doing so, you take away a person's right to choice and control. This is not only a violation of the HR act but also contradictory to the NDIS ACT. Additionally, NDIA appointed assessors further limit the choice and control of participants.

MHCC ACT understands that the NDIA has been consulting widely to ensure the IA is done safely and appropriately. We sincerely hope that the feedback from the various stakeholders

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[5] NDIA data on first pilot, shows 7% people with PSD

[6] https://probonoaustralia.com.au/news/2020/09/fight-against-ndis-independent-assessments-ramps-up/, https://probonoaustralia.com.au/news/2020/09/new-ndis-independent-assessments-slammed-by-disability-activists/, Funding concerns as more Aussies join NDIS | The Canberra Times | Canberra, ACT

is taken into account. It is very important that if the NDIA goes ahead with an IA that no harm is done to the participant as a result of the process.

MHCC ACT recommends that procedures are put into place to ensure that people going through an IA process will not be inadvertently harmed or made worse off. These must,

- Be made clear to all stakeholders and publicly reported against
- Clear, accessible and appropriately resourced avenues for raising and promptly addressing issues must be available for all stakeholders

Quality of the assessment

MHCC ACT, together with many others, have raised concerns regarding the quality of the assessment. One of the issues that came up a lot was how people with disability could be sure that the assessment is fit for purpose? How will it be able to capture the idiosyncrasies of each participant? A recent Administrative Appeal Tribunal decision[7] seems to justify those concerns.

The AAT compared the evidence of the independent assessor and Mrs Ray's treating psychologist, Teana Barry, stating:

"*The Tribunal considers the observations made by Ms Barry are more reliable than those made by (the independent assessor), as Ms Barry has seen Mrs Ray on approximately 50 to 60 occasions, including out of the comfort and familiarity of her home environment, whereas (the Independent Assessor) had only seen Mrs Ray once for a period of three hours in her home environment."*

The Tribunal noted that the opinions of the Independent Assessor were at odds with those allied health professionals who knew Mrs Ray and had carried out multiple assessments over an extended period, concluding that the Tribunal had:

"(lost) confidence that (the Independent Assessor's) opinions were based on an accurate understanding of Mrs Ray's background, past achievements and her current state".

It begs the question of how can an independent assessor, based on one relatively short meeting with a participant, come to conclusions and make recommendations which will produce optimal outcomes for the participants? If the above Tribunal ruling is indicative of the outcomes of IA, then it suggests that very little weight be given to IA in the overall process of eligibility and planning/plan review outcomes. This begs the question of why have IA at all?

Some other things to consider:

- The IA has to be culturally appropriate to make sure CALD and ATSI people are not disadvantaged.
- The IA has to be relevant for people with PSD with an assessment tool(s) that works for people with PSD
- The IA has to place great weight on the existing evidence and history of the participant

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[7] Ray and National Disability Insurance Agency [2020] AATA 3452 (8 September 2020)

- The IA needs to allow adequate time for an assessment and processing - three hours is not enough to assess the often complex needs of people with PSD and other severe disabilities
- The place where the IA will be conducted has to be up to the participant
- Skilled assessors must be made available in all parts of Australia, including in remote and rural areas
- Procedures need to be put in place in case the pressure of the significance of the IA triggers the participant, and leads to an inability to engage.

MHCC ACT recommends the NDIA investigate a different approach to achieving equity in access to the NDIS and optimising outcomes for participants. This new process must respect a participants' choice and control and take account of the points in this section – particularly the evidence provided by health professionals and the participant's life history. Any disregard by the NDIA of such evidence must be able to be justified by qualified independent experts.

Quality Of The Assessor

A lot of concerns have been raised regarding the quality of the assessors. Rightfully, people have asked how a stranger will be able to assess often very complex cases and how this assessment compares to years of assessment by accredited professionals? MHCC ACT refers to the AAT decision mentioned earlier that goes to the very heart of these issues.

Given the significant impact assessors will have on a participant's future, all assessors must, as a basic requirement, be highly skilled and experienced professionals with relevant (tertiary) qualifications. Due to the prevalence of trauma in people with PSD and the nature of psychosocial disability, trust is a big thing. It can take a lot of time before a trust relationship is established. Without it, people with PSD might be hesitant to disclose and, more worrying, it increases the risk of triggering distress and trauma.

Plenty has been said and raised around the quality of the assessor in the consultations, but here are a few things to consider, especially in relation to people with PSD:

- All assessors need to be trauma-informed and recognise signs of distress and be able to keep a person safe until other support is available.
- All assessors need to have relevant experience in recovery-focused principles of care
- The assessor must establish a trust relationship before doing an IA.
- Assessors have to be well-versed in cultural awareness to make sure people with minority backgrounds are not disadvantaged.
- They need to be trained in unconscious bias, to prevent stereotyping and assumptions

MHCC ACT recommends that all assessors are experienced professionals, in line with the points made in this section.

Exemptions

MHCC ACT was pleased to see that the Agency is considering exemptions to the mandatory rule, indicating it realises that IA is not an appropriate tool for everyone. While we continue to argue the case to remove IA's mandatory aspect completely, we want the Agency to consider including all people with PSD on the exemption list.

Forcing people who already have a higher prevalence of anxiety, emotional distress, and trauma to undergo an IA with someone they don't know/hardly know, is inviting complications. There is a high risk that people will become unwell, just contemplating an IA, thus negatively impacting their recovery. Furthermore, it can also cause people to withdraw from the Scheme or never even engage with it, potentially missing out on life-changing supports.

MHCC ACT recommends that as a minimum, people with PSD are exempt from compulsory IA.

Continuing participants

MHCC ACT questions why existing participants will have to go through a mandatory IA? This mandatory condition leaves a bitter taste and is cause for stress and anxiety. Participants with PSD have already had to go through a rigorous and stressful lot of additional assessment to be accepted into the Scheme. It is unreasonable to ask them to do so again. Where is the evidence that this is necessary and will improve outcomes? Forcing existing participants to undertake an IA further erodes their self-determination and agency and is cause for stress and anxiety.

As raised, earlier, submitting existing participants to IA is not part of the Tune Review recommendation and takes away the participant's choice and control.

MHCC ACT recommends that existing NDIS participants not be required to undertake another eligibility process in the form of IA unless there is strong evidence that this will improve outcomes for individuals and it is their choice to do so.

Conclusion

MHCC ACT understands the NDIA's need to reform and simplify processes to make sure no one is excluded. However, we do not believe that the proposed IA, in its current form, is the answer to that problem. We have not seen the evidence and neither are we convinced that the IA as planned, will reduce inequality and improve outcomes for participants as the Agency predicts.

MHCC ACT is concerned about the scale and speed of implementing the IA based on such a small sample and without any other robust evidence on the impact of participants. Our primary concern is regarding participants' wellbeing and outcomes. We are especially concerned for people with trauma and PSD having to undergo an AI without real choice or control on who will perform it, how the assessment will happen, and the weight given to existing evidence provided by professionals with a long history of working with an individual.

MHCC ACT does not agree with the so-called sympathy-bias argument to introduce strangers to assess people. There is no evidence to support this. Furthermore, treating professionals are better placed to assess the needs and functionality of their patients. It can take months before a person with PSD feels comfortable enough to disclose, so how will that work under the proposed IA? On the flip side, if assessors are employed by the NDIA, they can not be called independent.

We urge the NDIA to reconsider the mass rollout and the mandatory nature of the IA. The structure of the proposed IA needs to be completely overhauled. Robust evidence must be gathered to show that any sort of IA is consistent with the intent of the NDIS, is in keeping with people’s human rights and produces better outcomes for participants. Until this evidence is available and transparent, the mass rollout of IA should not be contemplated.

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