

SUBMISSION TO THE JOINT STANDING COMMITTEE ON THE NATIONAL DISABILITY INSURANCE SCHEME

1. Introduction

Mental Health Carers Australia (MHCA) is a national peak body focussed solely on the needs of families and carers supporting people living with mental ill health. We are made up of seven state and territory organisations, including one national. More information about MHCA is accessible at: mentalhealthcarersaustralia.org.au.

Our aim is to work constructively with governments and the community sector to improve policies and programs that directly and indirectly impact mental health families and carers.

For the purposes of this submission, mental health families and carers can be defined as everyday Australians providing significant emotional, practical and financial support to their family member or friend living with a mental illness.

There are significant, well documented impacts on mental health families and carers associated with the caring role, including but not limited to: emotional distress, depression, financial insecurity, employment insecurity and loss of connections with their own family, friends and community.

Mental health carers are extraordinarily diverse, ranging from ageing parent carers, parents supporting an adolescent with emerging mental illness, to young people caring for a parent with mental ill health. They have their own stories to tell and have differing needs. These carers have the same right to live a good life as do all Australians.

An estimated 240,000 Australians care for an adult with mental illness, providing 102 million hours of care, at a cost of \$13.2B to replace informal mental health care with formal support services¹.

MHCA welcomes this inquiry into independent functional assessments. The specific focus of our submission is the impact of independent functional assessments on NDIS participants with psychosocial disability, their families and carers. Our areas of concern include lack of consultation around implementation, and the appropriateness of these assessments for people with psychosocial disability (including workforce suitability issues).

¹ Diminic S, Hielscher E, Lee Y, Harris M, Schess J, Kealton J, & Whiteford H, (2016) The economic value of informal mental health caring in Australia: technical report

2. NDIS Families and Carers Project

In 2019 MHCA undertook a project in partnership with the NDIA to identify strategies to improve the experience of families and carers of NDIS participants with psychosocial disability. As part of the project, a number of consultation workshops were held with families and carers across Australia to identify the pain points of the NDIS, the positive aspects, and strategies for improvement.

Of particular relevance to this inquiry, the project found:

- the assessment and planning process caused significant distress to participants with psychosocial disability, with many describing it as a re-traumatising experience. Families and carers reported that participants were reluctant or lacked trust to engage in the process, in some instances discarding correspondence from the NDIA before opening it.
- participants with psychosocial disability, their families and carers find it challenging to translate their experience of mental distress into a list of functional impairments and lack awareness of how this informs their NDIS plan leading to poor and inconsistent outcomes
- planners' lack of understanding about psychosocial disability has led to inconsistent planning outcomes, particularly when planning meetings were held when participants were unwell or where their families and carers weren't invited to the meeting, or in fact didn't know it was happening at all.

While MHCA agrees in principle of the need for a fair, transparent and consistent planning process to ensure consistent plan outcomes, we fear that the above issues will continue to occur with the roll-out of mandatory independent functional assessments.

3. Our concerns

1. Lack of consultation and engagement

MHCA is concerned about the lack of consultation with the sector leading up to and following the announcement of mandatory independent assessments in late 2020.

In particular the announcement undermines the integrity of the scheme, which was founded on the principles of choice and control. While we acknowledge that participants can choose their assessors, we have concerns about the appropriateness of the tools, the nature of the workforce (including their skills and experience in psychosocial disability), and the reliability of the process given the episodic nature of psychosocial disability.

In relation to the benefits of consultation and co-design, there is a growing evidence-base for positive outcomes from engaging consumers, their families and carers in the design of services, including outcomes relating to individual agency and autonomy, connectedness and skills development. Co-design should be considered a value proposition for government

with benefits including reduction in the usage of crisis care services and positive employment outcomes².

We do not believe that we have been appropriately engaged in the implementation and roll-out of these assessments.

2. The appropriateness of mandatory independent assessments for people with psychosocial disability

As noted above, in principle MHCA supports the concept of a consistent process to capture the supports required by people with disability in order for them to participate fully in social and economic life.

However, we share the concerns of other disability advocacy groups³, and Professor Bruce Bonyhady AM⁴ about the validity of the chosen tools, in particular their validity and reliability in assessing the needs of people with psychosocial disability, the importance of capturing goals and aspirations as part of determining reasonable and necessary supports, the time allocated to conducting the assessments and concerns about the experience, skills and knowledge of the assessors.

The announcement in August 2020 of the Australian Government's plan to implement the independent functional assessments blindsided families and carers, and the people whom they support. Trust has been broken meaning that the goodwill held by people with disability their families and carers towards the NDIS has dissipated.

Trust and goodwill are the foundation stones upon whether independent assessments will succeed or fail. Concerns about the processes and outcomes of the tender processes (including that former NDIA employees will directly benefit financially from these decisions) have only served to further undermine this trust across the sector.

The success of independent assessments will be highly reliant on the willingness and confidence of people with disability, their families and carers to engage in the process. Families and carers of people with psychosocial disability are concerned that three hours is insufficient to build the relationship that is needed to disclose their personal history (given many people will have a background of significant trauma), and discuss the support they require to carrying out functional tasks of daily life.

In addition, the lack of focus on personal goals and aspirations is reductive and will leave people feeling that they are no more than a set of functional activities. Additionally, we are

² Slay J, Stephens, L, (2013) *Co-production in mental health: A literature review*

³ <https://www.abc.net.au/news/2021-03-11/disability-organisations-against-ndis-independent-assessments/13233838>

⁴ https://disability.unimelb.edu.au/_data/assets/pdf_file/0011/3623987/Independent-Functional-Assessment-An-Analysis-of-the-Proposed-Approach-by-the-NDIA-Final-22-February-2021.pdf

not confident that an assessment of functional capacity, without conversations about social and economic aspirations, will result in any improvement to NDIS plans and outcomes for participants.

Along with other disability peaks, we are concerned that the successful organisations will employ allied health care workers with minimal experience, skills or knowledge in disability (and of particular concern psychosocial disability) in order to reduce costs. Gaining an understanding of a person's true needs associated with their specific disability and taking into account their unique abilities and challenges takes more than three hours and a brief questionnaire delivered by a worker with minimal knowledge.

Applying assessment instruments to people with psychosocial disability requires deep understanding of the episodic nature of mental ill health in order to fully understand the functional impacts, including how they can vary greatly on a day to day, and week to week basis. It also requires knowledge of trauma-informed and recovery-oriented principles and practices.

We are also concerned that if a participant with psychosocial disability is mentally unwell at the time of the assessment, or does not want to engage at all, that punitive responses may include a reduction in their supports or being deemed ineligible for the scheme. MHCA has been advised that a participant with psychosocial disability was recently deemed ineligible for the NDIS in NSW as they were unwell at the time of the assessment and did not participate in the process. This is an appalling dereliction of duty on the part of the NDIA.

Equally, if a participant is in a 'well-phase', their responses to the functional assessment questions could reflect a greater positive emphasis on their capacity rather than reflect their capacity over a period of time. Point in time assessments do not provide a sound evidence base from which to make funding decisions.

We also share concerns with the sector in relation to the validity of the generic assessment tools as they are applied to people with psychosocial disability. In this regard, we support the concerns raised by Prof. Bonyhady regarding the assumptions made by the NDIA in relation to their use. We also note that these are the same tools that have been used by NDIA planners and local area coordinators with such poor results in terms of consistency and fairness of funding decisions.

Finally, the critical role of families and carers in the process needs to be acknowledged. With the person's agreement and consent, families should be closely involved in assessment processes to ensure that the needs of the person are adequately captured, particularly when they are unwell.

The assessment process should also include an assessment of family and carer needs. MHCA would like to see better operationalisation of the NDIS legislation that requires funding

decisions to consider what is reasonable for families and carers to provide. It is not clear to us as to how these decisions are currently made.

It is impossible to develop NDIS plans without assessing whether families and carers can sustain their caring role without support in their own right, or indeed wish to continue their caring role at the same level. We note that this is a particular issue for ageing parent carers, young carers and carers who wish to re-engage with the workforce or pursue a social life of their own.

MHCA would welcome the opportunity to discuss this submission in greater detail.

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