

Submission on proposed legislative changes to the National Disability Insurance Scheme

Mental Health Carers NSW Inc. Submission

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MHCN
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About MHCN

Mental health carers are people who support friends, partners, members of their family, kinship groups or communities, when they experience mental illness. **Mental Health Carers NSW Inc.** is the peak body in NSW for mental health carers, advocating for a vision of safe and competent mental health services and systems that recognise and respect carers as partners in care planning and delivery, to achieve recovery. **MHCN's** Mission is to support, empower, capacity build, and advocate with mental health carers to ensure their voices and experiences are heard.

Summary of Recommendations:

- In the proposed “Becoming a Participant Rules”, Rule 8 and Rule 12 should define the terms “*appropriate treatment*”, “*reasonably available*” treatment and provide further guidance as to what constitutes a “*reasonable period of time*” for a person to receive treatment in order for their disability to be considered permanent.
- In the proposed “Becoming a Participant Rules”, Rule 8 and Rule 12 should remove the term “*substantial improvement*” and instead require that “*after undergoing treatment the person continues to experience substantially reduced functional capacity to undertake an activity mentioned in 24c of the Act*”.
- In the proposed changes to the NDIS Act, section 47A would give the CEO power to vary a participants plan on their own initiative without conducting a full plan reassessment. This is strongly opposed by MHCN.
- In the proposed changes to the NDIS Act, section 100 allows participants to request an explanation of decisions made by the NDIA prior to any internal review application. Instead, the Act should be amended so that participants receive an explanation of all access, planning and plan review decisions made by the NDIA. An explanation of reviewable decisions should be delivered before the review can proceed.

Positive Legislative Changes to the NDIS Act and Rules

MHCN welcomes reform to areas of the National Disability Insurance Scheme (NDIS) Act 2013 and the NDIS rules in line with the recommendations 2019 Tune Review. Many of the proposed changes to the legislation are positive, in particular:

- Changes outlined in Schedule 2 – Flexibility Measures of the draft amendment recognize co-design principles, gender diversity and should allow for greater recognition and inclusion of family members and carers in the NDIS.
- Recognition of the importance of relationships with family and carers to people with a disability as outlined in the proposed addition of subsection 4(12A) provides clear logic for the inclusion of family members and carers in assessment and planning processes.
- The proposed changes to paragraph 14(a) allows the NDIS to fund services for family and carers that build their capacity and enable family and carers to participate in social and economic life. Funding family and carer supports has positive impacts for both family members, carers and people with a psychosocial disability.

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- The addition of timeframes in the NDIS act and NDIS rules for access, planning and plan reviews which should ensure timely responses for people with a disability and their families and carers when they interact with the NDIS.
 - The addition of section 204A to the NDIS which provides for annual reporting by the Commonwealth Ombudsman. This should allow for greater oversight of the NDISs performance against the participant service guarantee.

Psychosocial Disability and the “Becoming a Participant Rule”

Additional clarification around the definition of permanent impairment and functional capacity for people with a psychosocial disability in the proposed “Becoming a Participant Rule” is welcome. Previous consultations with carers and the sector have found that experiences of access to the NDIS for people with a psychosocial disability are variable and often appear to be based on a subjective interpretation of the Act and the Rules. Clear guidance should reduce the variability and subjectivity in access decisions for people with a psychosocial disability and improve the transparency and fairness of the NDIS. Positively rule 8 and rule 12 recognise that a permanent disability may fluctuate in severity, effectively functioning as a permanent vulnerability to disability which may vary in intensity of experience. This should address long standing access issues for people with an episodic condition to some degree. Positively rule 11 recognises that the type of assistance required for people with psychosocial disability includes prompting, supervision and guidance.

However, further guidance is needed around the terms used in rule 8 and rule 12. As the rules are currently written the rules lack clarity around what constitutes; *‘appropriate treatment’* for people with a psychosocial disability, *‘substantial improvement’* in the persons condition and a *‘period of time that is reasonable considering the nature of the impairment.’* Without further clarification, access decisions will continue to be based on a subjective interpretation of the legislation and rules, most likely with variable results in access for people with a psychosocial disability.

Rule 8 (2) and rule 12 (2) require that a person has either undergone *‘appropriate treatment’* for their psychosocial disability or that treatment is not accessible to the person. With regards to these rules, it should be noted that the symptoms of psychosocial disability often interfere with an individual’s capacity to access treatment and comply with treatment regimens. In the instance that a person cannot access or comply with treatment due to a psychosocial impairment, it should be considered that no appropriate treatment is reasonably available to that person. Access to *‘appropriate treatment’* may also be hindered by a range of issues including; affordability of treatment, inadequate housing, lack of appropriate transport, lack of appropriate treatment options for people with a dual diagnosis (e.g. alcohol or drug addition), literacy or lack of culturally appropriate options for treatment. The rules should outline that for a treatment to be *‘reasonably accessible’*, it must be in a format that addresses individuals specific needs.

Further guidance should also be provided around what constitutes a reasonable period of time for the person to undergo treatment before it can be determined that the persons impairment is permanent. This is of particular importance in the context of early intervention (rule 12). The logic of early intervention holds that intervening immediately when a person first develops a disability can reduce the impact of that disability on functional capacity in the long term. The concept that a person must have already undergone treatment for a period of time, prior to accessing early intervention supports is clearly contradictory. People with a psychosocial disability have very limited

access to early intervention through the NDIS because there is often significant uncertainty around whether mental illness will cause permanent impairment prior to treatment.

Rule 8 paragraph 2ai and rule 12 paragraph 2ai require that *'the treatment has not led to a substantial improvement in the person's functional capacity'* in order for a disability to be considered permanent. The term *'substantial improvement'* is highly subjective, and it is possible for a person to have improved substantially while still experiencing substantially reduced functional capacity in core life areas, e.g. they may maintain good health until expected to return to the stresses of the workplace. Instead, this section of the act should cite section 24c of the NDIS act which sets out the eligibility requirements for substantially reduced functional capacity to access the NDIS. For example this section could state that *'after undergoing treatment the person continues to experience substantially reduced functional capacity to undertake an activity mentioned in 24c of the Act, or a permanent vulnerability to such disability which may fluctuate but can be triggered by stressors or other factors.'*

Psychosocial Disability and Plan Variation

Positively the proposed changes to the NDIS Act clarify the term 'review' and instead use the language of 'plan variation' for less significant changes and 'plan reassessment' for more significant changes. It also includes timeframes for the NDIA to conduct an assessments and variations. The addition of plan variation should allow for participants to make minor changes to their plan without needing to undergo a full reassessment process. This flexibility is especially important in the context of fluctuating mental ill health so that minor changes can be made in a timely fashion to individuals plans on their request to reflect changed circumstances.

Concerningly, section 47A of the act gives the CEO unilateral powers to vary a participants plan on their own initiative without conducting a full reassessment. This is strongly opposed by MHCN as this change allows for plans to be varied without the consent, consultation or involvement of the participant. In contrast to plan variation, plan reassessment, as it is set out in the proposed changes to section 48 (3ii) of the act, would require the CEO to "prepare a new plan *with the participant* in accordance with Division 2 and approve, under subsection 33(2), the statement of participant supports in the new plan."

The power given to the CEO in section 48 is adequate and reflects the powers that the CEO has under the current Act. Consultations with mental health carers and mental health organisations conducted by MHCN in 2018 found that many participants had supports which they did not use removed upon plan review. This was of deep concern for carers of people with a fluctuating psychosocial disability who may only need to access all the supports in their plan occasionally at times when they are most unwell. Ideally plans for individuals experiencing fluctuating psychosocial disability should include the full range of supports that the individual might need when they experience changes to their functional capacity due to fluctuations in their mental health. Different degrees of support should be triggered as the person experiences different levels of incapacity.

MHCN sees no reason to give additional powers which allow the CEO to vary participants plans without their involvement. In line with the principles of choice and control, participants and their family and carers should be able to discuss what they want and provide evidence of their needs to the NDIA before their plan is altered. If there are some narrow circumstances in which variation of an individual's plan by the CEO without their involvement would be necessary, then these should be set out in the act. For example, an emergency situation when the person is not immediately contactable. But it would be far

preferable, for the plan to be agreed after review of relevant medical and other evidence with the consent of all parties.

Explanation of NDIA decisions

The proposed section 100 (1B and 1C) of the Act allows for a participant to request the reasons for a reviewable decision by the NDIA. While this change is positive, it does not fully implement the recommendations of the 2019 Tune Review. The Tune Review States that:

“People with disability have the right to understand the reasons why a particular decision was made, and how it was made, including what information was taken into account in making that decision”, that “Failure on the part of the NDIA to provide an explanation of the basis for its decisions disempowers participants and impedes their capacity to exercise informed choice and control” and that “Providing people with disability with an explanation of a decision should be a routine operational process for the NDIA when making access, planning and plan review decisions.”

Rather than require participants to make a formal request in order to be informed about the reasons for NDIA decisions, section 100 should be amended so that the NDIA provides the reasons for their decisions to all participants. Many people with a disability and their family and carers experience significant barriers in navigating NDIS processes which are complex and time-consuming. Impairments due to disability, limited literacy and limited energy or time to engage with NDIA processes are common barriers to participation. The onus should therefore be on the NDIA to explain decisions to participants, their family and carers. Furthermore, the NDIA should be required to provide an explanation of decisions once a review has been made under section 100(6).

Concluding Remarks

Thankyou for the opportunity to comment on the proposed amendments to the NDIS Act. Many of the changes proposed are positive and should improve accessibility, transparency and flexibility of the scheme and provide greater choice and control to participants. However, there are a few areas of concern, outlined above, which MHCN feels do not reflect the spirit of the recommendations of the 2019 Tune Review. Expanded powers of the CEO to vary the plans of participants without their involvement are of particular concern. The intention of simplifying the review process for minor changes to NDIS plans was to allow greater flexibility, choice and control for participants, rather than to give additional power to the CEO to make changes to plans that might not be supported by participants, family or carers. MHCN believes that the minor changes to the proposed legislation outlined above would help to improve the accessibility, transparency and flexibility of the NDIS for people with a psychosocial disability, their carers and family members. The alternate suggestions made by MHCN also provide a way of recognising the fluctuating experience of psychosocial disability, and therefore the support which needs to be provided. It recognises that the *vulnerability* to acute experience of such disability may be permanent, even if its realisation in the capacity of the participant may fluctuate over time.

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