National Disability Insurance Scheme Bill 2012

Submission to the Senate Standing Committee on Community Affairs

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About WAAMH

WAAMH is the peak body for over 80 community managed mental health organisations in Western Australia.

WAAMH's vision is that Western Australian community organisations will lead the way in supporting and including people with mental illness and their carers, providing innovative, well-governed community-based services focused on recovery.

WAAMH's core role is to support the development of the community-based mental health sector, provide systemic advocacy and representation, and influence public opinion for the benefit of people with mental illness and their carers.

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Summary

The NDIS is a landmark step towards progressing better outcomes for some our most disadvantaged community members.

WAAMH applauds the efforts of all people involved in the journey towards an NDIS for Australia. For far too long, many people with disability and mental illness, as well as their carers and family members, have had to define their personal aspirations around unreasonably complex, fragmented and often inadequately resourced support systems, resulting in people facing unfair barriers when doing their best to live a good life. The NDIS has the potential to overcome many of these barriers by empowering our most disadvantaged community members to exercise control over how they live their life and the services they want to access. WAAMH's submission draws on the lived experiences of consumers of mental health care, their family members and carers, as well as community based mental health services, to identify key measures for realising the strong potential of the NDIS to enhance the mental health and wellbeing of all Australians. This submission makes the following observations and recommendations:

1. **The eligibility requirements should be amended to better reflect the real-life experiences of mental illness.**

Recommendation 1: Eligibility for NDIS participation should be guaranteed for people whose level of impairment places them in need of NDIS support, regardless of the likelihood of permanency of impairment or likelihood of future needs. The complexity of mental illness makes 'permanency' an inappropriate framework for determining eligibility and goes against a Recovery based approach.

2. **The eligibility requirements should be amended to avoid a diagnostic approach.**

Recommendation 2: Clauses 24 and 25 be amended to extend potential eligibility to a person experiencing any form of mental illness, dependent on their level of functional capacity.

3. **The eligibility requirements should be amended to align with recovery principles.**

Recommendation 3: Clauses 24(1)(b) and (e) should be removed from the Bill in order to guarantee the right of all people to seek NDIS support for the purpose of seeking recovery.

4. **The role of carers should be properly reflected in the scheme.**

Recommendation 4: specific provision be made to ensure the role and needs of carers are adequately included in the NDIS. WAAMH refers the committee to the submission of its member organisation, Carers Association of WA, for specific recommendations on these issues.

1. The eligibility requirements should be amended to reflect real-life experiences of mental illness

Currently, the access criteria require applicants to satisfy:

(a) age requirements;
(b) residence requirements
(c) either
    i. **Disability requirements** – which among other things, require a person to demonstrate the permanence or likely permanence of their impairment; or

    ii. **Early intervention requirements** – which, among other things, require that the CEO be satisfied that the provision of early intervention supports is likely to reduce a person's future needs.[1]

The disability and early intervention requirements do not reflect the real-world situations of people experiencing mental illness who need NDIS support. Due to the complexity of mental illness, it is difficult to state with certainty whether a person's mental illness is likely to be permanent or whether early intervention will reduce the likelihood of further support being needed. For example, many people experiencing significant mental illness can and do recover. This includes people experiencing psychoses – a mental illness which is commonly assumed to be permanent. Every person's experience of mental illness and their recovery journey is both complex and unique, and the NDIS should address this by taking a recovery approach to eligibility. We elaborate on the concept of recovery at section 3 below.

Recommendation 1: Eligibility for NDIS participation should be guaranteed for people whose level of impairment places them in need of NDIS support, regardless of the likelihood of permanency of impairment or likelihood of future needs. The complexity of mental illness makes 'permanency' an inappropriate framework for determining eligibility and goes against a Recovery based approach.

2. The eligibility criteria should avoid a diagnostic approach.

WAAMH emphasises the importance of avoiding a diagnostic approach to eligibility. In particular, the term "psychiatric condition" in clause 24(1)(a) should be removed for the following reasons:[2]

(a) Limiting eligibility of people with mental illness to those with a psychiatric diagnosis will unfairly result in people who would otherwise satisfy the impairment criteria contained in section 24(1)(c) being ineligible for the scheme. This is because diagnosis of any mental health issue does not provide a reasonable guide to severity of impairment. A medical diagnosis may provide some information about a person's medical condition; however, it does not describe their disability or level of need.[3] For example:

- It is the case that many people with a psychiatric diagnosis experience severe impairment; however, it is also the case that many people with conditions such as psychoses achieve effective community participation, with little or only episodic support.

- At the same time, many disorders such as anxiety or depression can result in severe functional impairments, despite the fact that they are higher prevalence disorders that are commonly assumed to be less severe.

(b) A diagnosis is often the cause of stigmatised or stereotyped views of the impairments or support needs of people with that diagnosis. This is particularly the case with mental health diagnoses.[4]

(c) There is a significant proportion of people experiencing mental illness who, for a range of reasons, may not have sought or obtained a diagnosis. Some people with psychosocial disability are unaware of their disability and lack capacity to gain insight into their disability.[5]

WAAMH recommends extending potential eligibility to a person experiencing any form of mental illness, dependent on their level of functional capacity.

Recommendation 2: Clauses 24 and 25 be amended to extend potential eligibility to a person experiencing any form of mental illness, dependent on their level of functional capacity.

3. The eligibility requirements should align with Recovery principles.

3.1 'Recovery' in the context of mental health

"Recovery" refers to a fundamental and widely accepted philosophy of practice underpinning activities aimed at mental health enhancement. In the context of mental health, the term recovery does not simply refer to overcoming personal physical or mental illness. Rather, recovery generally refers to an individual's personal journey towards wellbeing. Each person's recovery journey is unique and each person will have different personal aspirations and goals. The core principles underpinning recovery include hope, empowerment and choice and high importance is placed on focusing on a person's strengths and potential.

The Commonwealth Government has a clear vision for the mental health system that reflects and actively puts recovery into practice. The Government's vision aims to integrate recovery approaches within the mental health sector, promote mental health and wellbeing, and protect the rights of people, families and communities living with mental health issues.[6] Recovery is endorsed in the *National Standards for Mental Health Services 2010* which identify recovery as an individual process involving empowerment through real choices and building on strengths. Also highlighted are the principles of dignity and respect, partnership and sharing and a continuous process of evaluating recovery based practice.[7] The Australian Health Ministers Advisory Council, Safety and Quality Partnerships Sub-committee, is currently overseeing the development of a National Mental Health Recovery Framework, which flows from a commitment arising from the Fourth National Mental Health Plan.

It is widely accepted, including by the Commonwealth and State and Territory Governments, that recovery principles are crucial to the enhancement of mental health and wellbeing of people experiencing mental illness, as well as their carers and family members. It is therefore essential that the NDIS operates in a way that aligns with the principles of recovery.

WAAMH's recommendations are aimed at improving the NDIS access criteria so that they:

- more realistically reflect the experiences of people experiencing mental illness; and
- better align with recovery principles .

3.2 Recovery and the NDIS Bill

Clauses 24(1)(b) and (e) counter-act recovery principles for a number of reasons, including the following:

- They require prospective scheme participants to focus on their personal deficits rather than their strengths and potential. A strengths based approach to addressing social disadvantage is well supported by evidence and is included in the Australian Government's social inclusion agenda;[8] and

- They require prospective scheme participants to focus on the reasons why their circumstances are likely to remain the same, as opposed to focusing on opportunities for improved wellbeing.

The consequences of taking a non-recovery approach to eligibility may prove significant for many individuals seeking to access the scheme. For example:

- Requiring people to prove permanency of their disability inhibits the potential for hope and optimism – personal attitudes that are fundamental to a person's wellbeing. Considering the complexity and sense of personal despair often arising from mental illness, there is a real risk that requiring people to focus on the likely permanence of their mental illness will inhibit their journey towards wellbeing.

- It may exclude some people experiencing significant mental illness from being eligible to participate in the scheme. Due to the complexity of mental illness, it is difficult to state with certainty whether a person's mental illness is likely to be permanent or not. The important point is that people experiencing mental illness can and do recover, but usually only with self-directed support.

The inclusion of an alternative, early intervention eligibility option does not sufficiently address the potentially negative consequences of taking a non-recovery approach within the disability requirement. This is because, no matter how significant or debilitating a person's physical disability or mental illness, all people should maintain the right to identify recovery as a personal aspiration. The eligibility criteria itself therefore inhibit some of the core principles and objectives behind the NDIS, including that:

- people with disability have the same right as other members of Australian society to realise their potential for physical, social, emotional and intellectual development;[9] and

- people with disability have the same right as other members of Australian society to be able to determine their own best interests.[10]

WAAMH recommends removing clauses 24(1)(b) and (e) from the Bill for the purpose of guaranteeing the right of all people to indentify recovery as a personal aspiration related to their NDIS support. The following clauses are adequate to ensure that NDIS individualised support is available to people most in need:

- clause 24(1)(c) (a requirement that the impairment or impairments result in substantially reduced functioning in specified areas); and
- clause 25(1)(i) and (ii) (early intervention requirements to demonstrate specific disability or developmental delay).

Recommendation 3: Clauses 24(1)(b) and (e) should be removed from the Bill, in order to guarantee the right of all people to seek NDIS support for the purpose of seeking recovery

4. The role and needs of carers should be properly reflected in the scheme

WAAMH has identified the following issues as centrally important to the role of carers of participants engaged in the NDIS.

(a) Carer involvement in NDIS participation, including eligibility determination and developing plans. WAAMH recognises that relationships between people experiencing mental illness and their family member carers can involve complexity arising from the nature of a person's particular mental health issues. For example:

- a person experiencing mental illness may exhibit mistrust of their family member carer, and decisions often need to be made by service providers as to whether the mistrust is a symptom of or relates to their mental illness; or
- a person experiencing mental illness may only place trust in their family member carer, and may be unwilling to communicate with service providers or other decision makers.

Due to these potential complexities in consumer-carer relationships, the NDIS Act and Rules need to put processes in place to achieve an outcome where the rights and privacy of consumers are respected, while at the same time ensuring that carers are able to communicate with NDIS decision makers on information that is key to prospective participants' eligibility and their care needs.

While the NDIS Bill is expressly underpinned by the object of acknowledging and respecting the role of families and carers, more specific provision needs to be made to ensure that balanced processes are in place for carer involvement in NDIS participation.

(b) Family member/ carers as recognised providers of care.
There are likely to be participants who want to have their core support needs met by family member carers. Examples of where a formalised caring relationship might be appropriate include where:

- A person experiencing paranoia places a particular level of trust in their family member and few others; and
- Where a person has physical disability resulting in reliance on others to provide intimate care related to personal hygiene. Some participants who receive this care from family members may have a strong preference for it to continue. This is particularly relevant to the objective of the Bill in reflecting a person's right to respect for their dignity.[11]

With respect to the role of carers, the NDIS Bill currently places most focus on the level of unfunded care that can reasonably be provided by family as a consideration relevant to determining the level of care that that the scheme should provide.[12] This needs to be accompanied by express provision for family members to become recognised (and therefore funded) providers of care for participants where appropriate.

(c) The NDIS Bill should adequately provide for carer and family member support.
Evidence strongly suggests that the wellbeing of family members and carers is key to the wellbeing of people experiencing mental illness.[13] Put another way, having family members and carers who are well supported and resourced is a key factor contributing to better outcomes for people experiencing or at risk of mental illness. The NDIS Bill inadequately reflects the support needs of family members and carers.

Recommendation 4: That specific provisions be made to ensure the role and needs of carers are adequately included in the NDIS.

WAAMH refers the committee to the submission of its member organisation, Carers Association of WA, for specific recommendations on these issues.

[1] NDIS Bill, see clauses 21, 24 (disability) and 25 (early intervention).
[2] Mental Health Council of Australia, *Response to the COAG and the Select Council on Disability Reform on the Draft Eligibility Statement and Description of Reasonable and Necessary Support (28 September 2012),* p 5-6.
[3] Ibid.
[4] Ibid, 5.
[5] Ibid.
[6]See the Commonwealth of Australia, *Fourth National Mental Health Plan – An Agenda for Collaborative Government Action in Mental Health* 2009 – 2015, Priority Area 1.
[7] National Standards for Mental Health Services (2010). See in particular, Standard 10.1 ("Supporting Recovery") and the *Principles of Recovery oriented mental health practice*. Retrieved 1 Novemeber,2012 from http:www.health.gov.au
[8] See the Australian Government, Social Inclusion Principles, available at <http://www.socialinclusion.gov.au/what-social-inclusion/social-inclusion-principles>
[9] NDIS Bill, clause 4(1).
[10] NDIS Bill, clause 4(8).
[11] NDIS Bill, clause 4(6).
[12] NDIS Bill, clause 34.
[13] Productivity Commission, *Disability Care and Support* (No 54, 31 July 2011) Box 15.5, p 727.