Mental Health
Council of Australia

# Submission to the Senate Community Affairs Legislation Committee Inquiry into the National Disability Insurance Scheme Bill 2012, January 2013.

The Mental Health Council of Australia (MHCA) is the peak, national non-government organisation representing and promoting the interests of the Australian mental health sector. The membership of the MHCA includes national organisations of mental health services, consumers, carers, special needs groups, clinical service providers, community and private mental health service providers, national research institutions and state/territory peak bodies.

## Introduction

The MHCA strongly supports the development of a social insurance scheme for disability long term support in Australia and is pleased to be involved in consultation for the National Disability Insurance Scheme (NDIS) Bill. The MHCA is pleased that the Bill takes a broad approach to ensuring that the needs of consumers are at the centre of support arrangements. Also important is that the Bill addresses the early intervention needs of people with disabilities and acknowledges the need to consider the sustainability of carer roles. However, there are also a number of ways that the Bill also needs to be significantly strengthened, particularly around supported decision making arrangements for consumers.

Further, the Bill does not yet contain enough information to describe specifically who will be eligible to be supported under the NDIS and it is missing important references to or detail on safeguards around the interests of people with disabilities on a number of issues. While some of this missing information may be outlined in the NDIS Rules in the future, the MHCA proposes that the following key issues will need to be incorporated into the legislation either as changes to the Bill or be reflected in the NDIS Rules to ensure that the NDIS can provide the best possible support to people with disabilities.

## Consumer control

The Bill needs to better acknowledge that all participants have their own decision making capacity. This will ensure that the Bill more closely reflects the intent of the UN Convention on the Rights of People with Disabilities, particularly the following articles:

> *Article 3 General Principle (a):*
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> > *Respect for the inherent dignity, individual autonomy including the freedom to make one's own choices and independence of persons; and*

> *Article 12 (3) States Parties shall take appropriate measure to provide access by persons with disabilities to the support they may require in exercising their legal capacity.* [1]

These articles incorporate an acknowledgement the decision making capacity of people with disabilities and, if required, specify the provision of support to make decisions (supported decision making). Under this model substitute decision making is only used after maximising consumer choice and control and as a last resort. However, many of the processes described in the Bill, including nominee arrangements, are not consistent with this approach.

For example in *Clauses 86-88* participants should be allowed choose and appoint their own nominee. CEO appointments should only be made in the case where participants are themselves unable to make appointments and then only with regard to the choices of the participant.

Further, *Clause 88* specifies that a CEO may only appoint a plan or correspondence nominee if they receive the written consent of the people being appointed and

> *(b) after taking into consideration the wishes (if any) of the 26 participant regarding the making of the appointment.*[2]

This clause gives the nominees the dignity of giving consent but not the participant. This must be amended to ensure that gaining the consent of participants is at least if not more important than gaining the consent of nominees.

Regarding *Clause 44* and *Subclause 44.3,* relating to the determination of reasonable risk under plan activities, the NDIS will need to ensure that reasonable risk is guided by the participant's views. This process will also need to include input from the participant's carer – see *Recognition of the mental health carer role* below.

Further, where supported or substitute decision making arrangements are used, they need to include activities that build the capacity of participants. This should be integral to the role of nominees.

## Nominee arrangements

There are a number of other concerns around nominee arrangements as they are currently described.

The MHCA is pleased to note that *Clause 80,* addressing the duty of nominee towards the participant, outlines:

> *(1) It is the duty of a nominee of a participant to ascertain the wishes of the participant and to act in a manner that promotes the personal and social wellbeing of the participant…*[3]

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[1] United Nations. (2006). Convention on the Rights of Persons with Disabilities. http://www.un.org/disabilities/convention/conventionfull.shtml.

[2] National Disability Insurance Scheme Bill 2012 No. , 2012, *(Families, Housing, Community Services and Indigenous Affairs),* A Bill for an Act to establish the National Disability Insurance Scheme, and for related purposes.

[3] Ibid.

However much more information is required to ensure that supported decision making, which can be complex and time consuming, is key role for nominees that that substitute decision making is only used as a last resort. An assumption of decision making capacity for participants throughout the Bill would logically support this.

Safeguards also need to be put into place to ensure that any nominee or CEO decisions on participants' choices are subject to scrutiny to ensure that effective supported decision making practice has been used. This could be achieved by a number of mechanisms, for example: the oversight of decisions by a committee which has suitable expertise in supported decision making. Statistics on the use of supported and substitute decision making should also be reviewed to monitor improvements in supported decision making practice, capacity building and the expanded decision making capacity of participants.

Potential conflict of interest for a range of roles in the NDIS is not adequately addressed. For example, it would appear that nominees may also be plan management providers and, or service providers. This situation is currently unacceptable due to the potential for a significant conflict of interest to occur and work against the interests of participants. It is probably too difficult to mitigate this potential conflict of interest except by specifying that these roles should not be held by the same person or organisation.

Where nominees are not the participant's carer, provision for ongoing consultation with carers about their support role must be made under all descriptions of nominee arrangements. This is in recognition of the importance of the carer role in the lives of participants outlined below in *Recognition of the mental health carer role*.

*Clause 89*, regarding cancellation of nominees, should include provision for carers to propose cancellation of nominee arrangements if they have reason to believe that the wellbeing or wishes of the participant are being compromised. Carers are well placed to provide information about the quality of life of the person that they care for and how this is impacted by nominee arrangements.

Nominee arrangements should take into account the use of Advance Directives for participants of the scheme with a mental illness. Advance Directives are used to ensure that if mental health consumers become unwell and unable to make decisions about their support arrangements, then these have previously been specified as a plan of action under an Advance Directive. The participant's wishes regarding Nominee arrangements should be specified as part of an Advance Directive and would provide guidance for nominees at these times.

### Review of decisions

*Clause 99* lists the CEO decisions that are reviewable. However a clear description of the participants rights in this instance, including a description of the process and an indication of who will be reviewing the matter, needs to be described.

*Clause 100* sets out the process for internal review of decisions which comprises an internal review, followed by an application to the Administrative Appeals Tribunal (AAT) if internal review is not satisfactory.

Given that the process of making an appeal to the AAT would be intimidating for most people, another review process should be provided as an option before approaching the ATT. The process would be more independent than the internal review process but not as burdensome for participants as the AAT process. The Productivity Commission proposed the establishment of an Office of the Inspector–General as an independent body within the proposed National Disability Insurance Agency to undertake review processes.[4] This would seem to be a more accessible option for participants than the AAT.

Provision should also be made for the support for participants pursuing a review. Supports may be in the form of reasonable access to an independent advocate to assist with mediation and resolution.

### Recognition of mental health carer role

Involvement by carers in the assessment and planning phases for participants also needs to be strengthened. This involvement is not intended to overshadow the provisions to ensure that consumer's preferences and goals are at the centre of their support, but that assessments and plans reflect the participant's day to day needs and carers are able to continue to provide effective support to participants if that is what the participant wants.

Mental health carers play a key role in the lives of many people with long-term disability including people with psychosocial disability related to mental illness. There is well recognised evidence that involvement by families and carers improves the mental health outcomes of people with a mental illness.[5] This includes the impact of psychosocial disability. Because carer input is increasingly recognised as playing a critical role in recovery and relapse prevention it is essential that the carers' role is acknowledged as a key support mechanism for consumers who choose or rely on it and that it is supported.

The following specific areas of the Bill need to be changed to reflect this.

- The role of mental health carers in the participant's life must be understood by assessors and planners and mechanisms need to be put in place to ensure that a carer's input on a consumer's needs are factored into assessment and planning processes where that carer plays a key role.

- Carers may or may not fill the role of either plan or correspondence nominee so mechanisms must be in place to ensure that nominees are aware of the carer role and take carer input into consideration when supporting participants to make decisions. Again, it is worth emphasising, that this information would be used only to inform the support needs and goals of the consumer. Effectively trained assessors, nominees and disability workers are able to utilise this information without compromising the centrality of consumer

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[4] Australian Government Productivity Commission. (2011). *Disability Care and Support Inquiry Report.* Australian Government Productivity Commission, Canberra, Vol 1, page 453.

[5] Falloon I. (2003). *Family Interventions for mental disorders: efficacy and effectiveness.* Work Psychiatry, 2(1):20-8.

control. A good example of the importance of carer input is described in the following paragraph.

Anosognosia is a condition that causes a lack of insight into one's own illness, the extent of one's their impairment and the role that a carer may play in support. It is often associated with severe mental health conditions but also occurs in other conditions such as stroke and acquired brain injury. It results in a reduced capacity for help seeking with the consequence that consumer's needs can be overlooked or misunderstood in assessment processes and by health and support services. Where anosognosia is present, the input of carers provides important information about a person's needs that may not be otherwise available. For NDIS services to access and support people with anosognosia, input from carers will be necessary. It will need to be obtained privately and separately from the consumer so that they do not have to be subject to the humiliation or distress that may occur by listening to this carer input.

- The Bill needs to provide safeguards in assessing the sustainability of carers' roles. While *Clause 34* on reasonable and necessary supports state that:

  > *e) the funding or provision of the support takes account of what it is reasonable to expect families, carers, informal networks and the community to provide;*[6]

  there must be more detail on who will decide and how the sustainability of carers roles will be decided. This includes consideration of the age and wellbeing of carers to sustainably carry out their role in supporting a person with a disability. Currently many carers, particularly those who are young, ageing or have health issues, currently feel they provide more support than they can realistically manage and their needs must be acknowledged. Principles to adequately determine the sustainability of carer support must be described and mechanisms for appeal of these decisions by carers need to be put in place.

**Determining access and eligibility issues**

A number of provisions in the Bill allow for the CEO to make requests that the prospective participant undergo an assessment or a medical, psychiatric or psychological examination in relation to making determinations. This includes, for example, *Clause 26*, in determining whether a person meets the access criteria, and *Clause 50*, for the purpose of reviewing a plan.

As highlighted in the MHCA's submission to the Productivity Commission, it is extremely unclear whether conventional medical, psychiatric or psychological assessments are able to determine disability support requirements for people with a psychosocial disability related to a mental illness.[7] Therefore assessment processes for people with a psychosocial disability related to a mental illness must

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[6] National Disability Insurance Scheme Bill 2012 No. , 2012.

[7] Mental Health Council of Australia. 2010. *Mental Health Council of Australia Submission to: The Productivity Commission Inquiry into Disability Long Term Care and Support April 2011.* Mental Health Council of Australia Website www.mhca.org.au.

follow, as closely as possible, the principles of the International Classification of Functioning.

While the Bill's Explanatory Memorandum, Statement of Compatibility with Human Rights states that:

> *Eligibility and assessment of need will be based on the World Health Organisation's International Classification of Functioning, Disability and Health (ICF);*[8]

this is not yet specified in the Bill.

There will need to be safeguards around this process to ensure that the ICF framework or whatever best practice disability assessment framework succeeds it, is followed.

The Bill will also need to outline who is to pay for such examinations or assessment so that consumers are not excluded due to their inability to pay  Provision on who should be able to conduct such assessments will need to be made, including flexible approaches for people in rural and remote areas where professionals and services can be difficult to access.

**Early Intervention requirements**

Early intervention needs to be better defined so that requirements under *Clause 25* can be clarified. Without a definition, early intervention can mean both intervention for a person with a

- recently acquired impairment (or for example if they are young) and
- chronic episodic condition who is in the early stages of a relapse or recovery.

Both of these situations would respond effectively to the early intervention currently described in *Clause 25*.

Therefore, people with chronic episodic ongoing mental health conditions who may intermittently need support to continue to manage their independence and health would appear to meet the early intervention requirements outlined in this Clause as well as the Disability Requirements outlined in Clause 26 below. If this is not the case, this needs to be clarified.

The population eligible for early intervention would include people, often young adults, experiencing their first episode of mental illness. ORYGEN Youth Health has significant experience in providing support to young adults who experiencing their first episode of mental illness and in identifying and addressing their disability support needs. It will be important to engage with stakeholders such as ORYGEN Youth Health to determine how their client group will be eligible for early intervention under the NDIS.

There is also a small population of people who are disabled by their first episode of mental illness and who are not in the young adult population target group of

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[8] The Parliament of the Commonwealth of Australia House of Representatives National Disability Insurance Scheme Bill 2012 Explanatory Memorandum.

ORYGEN Youth Health. The disability support needs of these people will also be a target for the NDIS.

### Disability Requirements

*Clause 26* states that:

> 2. *For the purposes of subsection (1) impairment or impairments that vary in intensity may be permanent, and the person's support needs in relation to such an impairment or impairments may be likely to continue for the person's lifetime, despite the variation.* [9]

This clause needs be identify the circumstances under which an impairment may or may not be considered permanent. This will provide clarity around the eligibility of a person with a psychosocial disability related to mental illness whose impairment may change due to the episodic nature of their illness. If any such impairment is not considered permanent for the purpose of *subsection 1* this may exclude people with who experience significant psychosocial disability for extended periods of time and whose impairments are likely to be exacerbated if appropriate treatment and or disability supports are not received. The MHCA is keen to ensure that needs of this group are not excluded from access to appropriate disability support under the NDIS.

### Advocacy

There needs to be a provision for arrangements to provide assistance to people accessing the NDIS. Some participants eligible for funded supports will need advocacy support to work with agencies specified as part of their plan, for example educational institutions. Others will need assistance and possibly advocacy to access services to which they are referred under Tier 2. Those people who exit the NDIS for the Aged Care System may also require advocacy support to ensure that their needs will be met under Aged Care arrangements. It is not clear how this assistance would be provided.

### Monitoring arrangements

There is no detail on provisions for monitoring arrangements for the NDIS. *Clause 73* outlines that the NDIS rules will make provision for monitoring of registered service providers. However the Productivity Commission made recommendations for the development of a quality framework and a range of monitoring arrangements for assessing performance including use of community visitors. It would seem appropriate to make provision for the robustness of these sorts of arrangements in the Bill.

### Launch Transition Agency governance

It will be very important that the Board of the Launch Transition Agency includes appropriately qualified people with a lived experience of disability and caring. It is not enough that under *Subclause 127(2)*, a person may has skills in

> *(a) the provision* **or** *use of disability services.*[10] *(*Emphasis added*).*

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[9] National Disability Insurance Scheme Bill 2012 No. , 2012.

[10] Ibid.

It is essential that a minimum number of appropriately skilled people with a lived experience of disability are represented on the Board to assist in providing a strategic direction for the Organisation that will ensure consumers are at the centre of their support arrangements.