Response to the Council of Australian Governments and the Select Council on Disability Reform on the *Draft Eligibility Statement and Description of Reasonable and Necessary Support,* 28 September 2012

The MHCA is committed to ensuring the development of appropriate eligibility and assessment criteria for the NDIS that is consistent with the United Nations *Convention on the Rights of Persons with Disabilities*[1] and the World Health Organisation *International Classification of Disability and Functioning* (ICF).[2] This is the most appropriate way to approach meeting the needs of people with psychosocial disability.[3]

The *Draft Eligibility Statement* and the description of *Reasonable and Necessary Support* proposed by COAG do not yet contain enough information to help understand who will be supported under the NDIS and what supports may be provided. The MHCA has also proposed some changes to the criteria to ensure that the needs of people with psychosocial disability are effectively met. The following specific points highlight what must be considered in developing the final definitions and guidelines.

Who is being targeted in this statement?
It is unclear which groups of people with disabilities are being targeted by the document. The description of eligibility and support does not seem reflect the Productivity Commission's proposal that different parts of the NDIS would target the needs of people with disabilities under a tiered system of supports. This means that while the document notes that "in one sense, the NDIS is for all Australians" it does only really appear to address eligibility issues related to tier 3.

For example, under the tiered support arrangement, the Productivity Commission proposed that people in tier 2 would receive referral to appropriate support services. For these referrals to be effective they would need to include follow up, advocacy and capacity for the NDIS to work with agencies to improve their accessibility for people with disabilities. Therefore to effectively provide services under tier 2, the NDIS would have a very important role in contributing to policy development,

[1] United Nations. (2008). *Convention on the Rights of Persons with Disabilities.* United Nations, Geneva.
[2] World Health Organisation. (2002). *Towards a common language for functioning and disability and health, ICF*. World Health Organisation, Geneva.
[3] National Mental Health Consumer & Carer Forum. (2011). *Unravelling Psychosocial Disability*. National Mental Health Consumer & Carer Forum, Canberra.

community education and development to ensure that services for people with disabilities are accessible and available.

Yet this important role has not been acknowledged in the document.

The document needs to articulate who is included in the NDIS and the process for eligibility for different tiers.

This issue is directly related to the criteria 2 and 5 and will be discussed under those headings.

NDIS eligibility should be based on need
The MHCA already accepts that in a world of finite resources, not all people with disabilities will be able to access individually funded tier 3 supports under the NDIS. The real challenge for the scheme in determining eligibility will be to delineate on a carefully developed scale of need, according to which the person will be eligible or ineligible for services in tier 3, prioritising those in most need first.

The description of eligibility and support should be focussed more on

- identifying an appropriate eligibility assessment process
- discussing the parameters that will define the appropriate level of support to ensure effective community participation for eligible participants
- proposing guidelines about who will be eligible for the NDIS based on these parameters.

Eligibility assessment process
Ideally an eligibility assessment process would be streamlined to ensure that people already in receipt of disability supports would be easily identified as eligible and transition seamlessly to the NDIS.

However for some applicants it will not be immediately clear which level of support is required and the eligibility assessment process may be longer and more complex, requiring skilled oversight of the process to establish validity and reliability. Eligibility assessment for people with psychosocial disability may need to include the use of tools and a guided needs-based assessment conversation to assist in determining functioning and support needs. A flow chart should be included to better depict the process envisaged by the NDIS.

Appropriate assessment tools will need to be informed by the ICF framework and be selected in consultation with mental health consumers and carers. It is not clear that there is a comprehensive ICF based assessment process currently in use for mental health consumers in Australia. Therefore tools to supplement this process such as a guided needs based conversation with the consumer and carer could be developed. For example, the Job Capacity Assessment (JCA) used by the Department of Education Employment and Workplace Relations is purported to be ICF based, but regularly fails to detect the support needs of mental health consumers. In this regard the JCA tool needs further input and refinement to work effectively.

The term *activities of daily living* needs to be defined

The term "activities of daily living" needs to be defined for this statement to encompass instrumental activities of daily living. Narrow and inflexible interpretations of the activities of daily living domains of self-care, mobility and communication have traditionally disadvantaged many people with psychosocial disability who would benefit greatly from support with activities of daily living. The concept of "instrumental activities of daily living" more is more effective in describing the needs of people with psychosocial disability.

Instrumental activities of daily living include the ability to undertake food preparation, laundry, transport, housekeeping, manage one's own medication, finances and keep appointments. Lack of support in these areas marginalises and disadvantages mental health consumers with a psychosocial disability and can contribute to ongoing social exclusion, stress, exacerbation of illness and exploitation.

The definition of "activities of daily living" should also be informed by the ICF framework.

Eligibility for and support for early intervention

The role of early intervention needs to be considered both in terms of eligibility and type and level of support as it plays a key role in preventing psychosocial disability.

While some early intervention is undertaken through mental health rehabilitation services, these services are not they widely available. This probably contributes to a greater level of disability amongst mental health consumers.

Mental health consumers with a psychosocial disability may be ineligible for NDIS support for extensive periods, but without early intervention at crucial times in their lives, their illness and or functioning may deteriorate to such an extent that they become eligible. It is tragic and ultimately costly that the NDIS will probably not be able to provide for services to prevent this from happening. In such cases the NDIS will have a key role in highlighting areas of service need for urgent development.

This relates to the broader issue of episodic mental health conditions discussed under criterion 4 of the *Definition of Eligibility*. However the MHCA also proposes that guidelines will need to be developed to target services for people with psychosocial disability who, without support, are at significantly increased risk of functional impairment.

Role of carers in determining eligibility and need for support

Carers can play a significant role in the support of mental health consumers and this also needs to be reflected in the development of policy around eligibility and support.

The significant and often unsustainable role that carers play has been documented widely.[4] The final report of the Productivity Commission Inquiry into Disability Support advised that:

---

[4] Mental Health Council of Australia. (2009). *Adversity to Advocacy, the lives and hopes of mental health carers.* Mental Health Council of Australia, Canberra.

> *...there should be greater assistance for (unpaid) carers through properly funded training and counselling services.*[5]

The Productivity Commission also noted there was general consensus amongst submissions to the *Inquiry into Disability Support*, around the need for carer support needs to be assessed because they have a direct impact on the lives of the consumers they support.[6] The ability of carers to provide effective care for consumers or themselves is compromised if their own critical health, mental health and financial needs are neglected. The NDIS will need to play a role in maximising consumer support by assessing carer support needs and identifying ways of meeting these.

However it is unclear from the *Draft Eligibility Statement* or the description of *Reasonable and Necessary Support* how carers needs will be considered under the NDIS. Nor is it clear how the sustainability of carer support will be assessed including identifying acceptable community standards for young or ageing carers providing round the clock support for people with disabilities. These key points should be clarified before definitions are finalised.

Further, carer input must inform any processes that determine consumer support needs. Some consumers do not have the capacity or knowledge to articulate the important role that carers play in providing supports to them and this information will play a key role determining support needs. Ideally this conversation should take place with the consent of consumers but if this consent is not given there will need to be clear guidelines on how to manage assessment where significant carer supports are being provided to consumers who do not see the need for their carers needs or input to be considered.

Confidentiality of consumer information and consumer relationships with NDIS personnel should remain paramount in this process. While this may preclude the assessor or other NDIS personnel discussing or disclosing any information about the consumer to carers, it should not preclude the gathering of information from carers to inform the assessment process about consumer needs. This information would include describing the role that carers currently play and the risks to the sustainability of their caring role.

These issues will need to be addressed as part of both eligibility and support assessment processes.

Psychosocial disability

The diagnosis based term *psychiatric disability* should be replaced with the mental health consumer and carer nominated term: *psychosocial disability.*[7] Given that diagnosis is often not an effective criterion for disability (see 3 below), it is unclear why the term psychiatric disability continues to be used.

---

[5] Australian Government Productivity Commission. (2011). Disability Care and Support. Productivity Commission, Canberra, p331.

[6] ibid

[7] National Mental Health Consumer and Carer Forum. (2011). *Unravelling Psychosocial Disability.* NMHCCF, Canberra.

If there is a concern that the term psychosocial disability is too broad for the NDIS, exceptions should be advised as part of the eligibility guidelines.

Comments on specific elements of the *Draft Eligibility Statement*

1. The individual resides in Australia

The word "resides" needs to be defined and should not exclude the possibility of people with disabilities pursuing reasonable opportunities for travel or employment overseas.

2. The individual is less than 65 years of age on entry to a NDIS

It is unclear if the NDIS will be taking up the Productivity Commission's recommendation that people with a disability who turn 65 will need to choose between the NDIS or aged care services. This needs to be clarified.

However the MHCA is also disappointed that there is no proposed role for the NDIS in improving the disability support needs of people whose disability occurs after age 65. This role should include working with the aged care sector to ensure that best practice disability support is a feature of aged care services. This would also go some way to ensuring that the support needs of people with disabilities who choose to use aged care services are not discriminated against. It would also cover the needs of people with a disability over 65 who were not eligible for individually funded support under tier 3.

Further comment on this issue is included under 5.

3. The individual has a disability that is attributable to an intellectual, psychiatric, cognitive, neurological, sensory or physical impairment or a combination of impairments.

The MHCA strongly disagrees with this criterion in its current form. The use of the medical descriptor "psychiatric" is diagnosis based and is not in consistent with the framework provided by the ICF and definition of disability provided by the *Convention on the Rights of Persons with Disabilities*. While a medical diagnosis may provide some information about a person's medical condition, it does not describe their disability or level of need. Further the use of diagnosis is often the cause of stigmatised or stereotyped views of the impairments and support needs of people with that diagnosis. This is particularly the case in mental health.

There are also a significant proportion of mental health consumers who, for a range of reasons, may not have sought or obtained a satisfactory diagnosis. Many of these people still have severe functional impairments and are consequently disabled. For example, some people with psychosocial disability are unaware of their mental health condition. Anosognosia, is the term which is used to describe this medical condition which is characterised by a lack of insight into one's own illness.[8] It is often associated with severe mental health conditions and results in a reduced capacity to seek help or treatment, which in turn restricts the treatment and support

[8] David A and Amador X. (2004). *Insight and Psychosis: awareness of illness in schizophrenia and related disorders*, Oxford University Press, Oxfordshire.

available. The role of carers is extremely important in determining the support needs of people with anosognosia.

Nor is diagnosis a reasonable guide to severity. While low prevalence disorders such as schizophrenia have been recognised by the Productivity Commission as potentially resulting in severe psychosocial disability, it is also the case that many people with schizophrenia achieve effective community participation, including employment, with little or only episodic support. However other disorders such as anxiety and depression, which are higher prevalence disorders and frequently considered less severe, can also result in severe functional impairments. Consumers with such conditions must not be excluded for eligibility under the NDIS on the grounds of their diagnosis.

If the wording of this criterion is not changed, there is a real possibility that some of these consumers, whose psychosocial disability may otherwise give them eligibility, would not be eligible for the NDIS.

For these reasons the MHCA supports the approach to disability which is described in the *Convention on the Rights of Persons with Disabilities.* The Convention defines disability as:

> *An evolving concept ….disability results from the interactions between persons with impairments and the attitudinal and environmental barriers that hinder full and effective participation in society on an equal basis.*[9]

The importance of this sort of approach was recognised by the Productivity Commission who outlined in their final report that a feasible approach to assessing functional impairment would be:

> *The use of functional criteria with examples of those likely to be captured: …This approach is equitable and also provides potential scheme users with some certainty without being unduly prescriptive. However, the NDIS would still need to manage the risk of false positives. Accompanying guidelines, which clearly spell out the scheme's boundaries, would help minimise this risk.*[10]

Therefore diagnosis should be deleted as a criterion and this criterion should describe the level of functional impairment that identifies eligibility for different levels of support under the NDIS.

4. The impairment is permanent or likely to be permanent ~~and~~ [insert] or may be of a chronic episodic nature ~~and~~ [insert] or result in the need for ongoing or long term episodic support

The MHCA is concerned that the use of the word "permanent" is in direct conflict with the important notion of recovery from a mental health condition. Recovery is described in the National Standards for Mental Health Services[11] and is recognised

---

[9] United Nations. (2008). Op cit.

[10] Australian Government Productivity Commission. (2011). *Productivity Inquiry Report Disability Care and Support*. Australian Government Productivity Commission, Canberra, p174.

[11] Australian Government. (2010). *National Standards for Mental Health Services 2010*. Commonwealth of Australia, Canberra.

as an important element of psychosocial rehabilitation.[12] While recovery does not necessarily encompass a cure for mental illness, it does mean:

> *Gaining and retaining hope, understanding of ones abilities and disabilities, engagement in an active life, personal autonomy, social identity meaning and purpose in life, and a positive sense of self.*[13]

Thus recovery approaches to policy development and service delivery are consistent with the General Principles of the UN Convention of the Rights of Persons with Disabilities which seek to ensure a quality of life for people with disabilities that is equal to that of all citizens.[14]

Guidelines around recovery and psychosocial disability will need to be developed for the NDIS. The MHCA also proposes that in recognition of the importance of recovery, the wording of this criterion be changed:

> *The impairment is permanent or likely to be permanent ~~and~~ [insert] or may be of a chronic episodic nature…*

The eligibility definition will also need to be flexible enough to able to accommodate people with psychosocial disability whose support needs fluctuate such that they require little support apart from pro-active monitoring for extensive periods. Many people with psychosocial disability and long term or chronic mental health conditions can maintain extensive periods with minimal support, if that support is appropriate. The MHCA is concerned that this would exclude them from eligibility for support under tier 3 of the NDIS. However, the nature of mental illness is such that it can become severe very quickly, potentially leading to severe and potentially long term psychosocial disability. It would be short-sighted if the NDIS was not able to accommodate the needs of such people before their disability had become more severe, when maintenance support could prevent more serious illness and disability.

Careful guidelines around this area will need to be developed in consultation with mental health consumers and carers and the MHCA proposes the following change to this criterion will assist in reflecting these requirements:

> *The impairment is permanent or likely to be permanent ~~and~~ [insert] or may be of a chronic episodic nature ~~and~~ [insert] or result in the need for ongoing or long term episodic support.*

5. The support needs will persist for the foreseeable future and are not more appropriately met by other systems inducing education, health and or palliative care

In an ideal world, many of the support needs of people with disabilities would be met through existing service systems. Yet it is the inability of these existing systems to provide adequate support that forms part of the "attitudinal and environmental barriers that hinder full and effective participation"[15] and contribute to the definition of disability.

---

[12] Australian Health Ministers. (2009). *Fourth National Mental Health Plan*. Commonwealth of Australia, Canberra.
[13] Australian Government, (2010). Ibid.
[14] United Nations. (2008) Op cit.
[15] Ibid.

It is acknowledged that the need for disability supports is required and it is well known that the health, aged care, employment and education sectors struggle to meet the needs of people with disability. While it may not be the role of the NDIS to make up for shortfalls in these systems it would be counterproductive for the NDIS not to have some role in assisting these systems to improve their performance.

The MHCA would be extremely concerned if the intent of the NDIS was not to play a role in working with other service systems to ensure that they provide appropriate disability support. The role would include enhancing community awareness about disability, providing support (such as referral to appropriate education and training) for employers, and involvement at a local and national strategic level in contributing to policy development. This role would be particularly relevant for those people with disabilities who are will be targeted by in tier 1 and tier 2 supports as well as those people in tier 3 who may be accessing supports in the general community.

This criterion needs to be clarified and guidelines will need to be developed to explain its application to the eligibility process for supports in tiers 1, 2 and 3. These guidelines would take into account the important role that would be played by the NDIS in the interface between people with disabilities and those service sectors that are not fulfilling their obligations in providing appropriate support.

Comments on specific elements of *Reasonable and necessary support*

a. Reasonable and necessary supports are designed to support the individual to achieve their goals and maximise their independence.

The identification of reasonable and necessary support must include a process to work with individual consumers on their own terms. Anosognosia, and other impairments such as low mood, social withdrawal and decreased motivation for physical activity, can all affect an individual's willingness to engage with an assessment and goal setting process. In many disability service settings these characteristics disadvantage mental health consumers because busy services are reluctant to pursue the long term relationship building that working with these impairments requires. Further the input of people who are close to the consumer (such as family carers, friends nominated by the consumer) should also be sought to inform process.

It is proposed that the following additional wording should be added to this criterion:

Reasonable and necessary supports are designed to support the individual to achieve their goals and maximise their independence.

[Insert the following]

Support requirements will be indicated by a combination of:

- *an appropriate functional needs assessment (based on the ICF framework)*
- *an identification of the individual consumer's goals and desires for support, undertaken with the input of family and carers*
- *the NDIS guidelines on reasonable and necessary support (what is and is not covered by the NDIS).*

b. Reasonable and necessary supports, support the individuals capacity to undertake activities of daily living to enable them to participate in the community and or employment

See comments under *activities of daily living* above.

c. Reasonable and necessary supports are effective and evidence informed

Clear guidelines will also need to be developed for this criterion, in consultation with mental health consumer and carer experts. They will need to be regularly reviewed as improved service types develop under the NDIS over time.

For example mental health consumers and carers are very likely to favour peer run services. While the evidence and effectiveness of peer run services may be very clear to many in the mental health sector, there is still resistance to these service types, for a range of reasons. Clear guidelines what on what supports are acceptable consumers and carers to identify what is most appropriate for them and what is acceptable under the NDIS.

d. Reasonable and necessary supports are value for money

Flexible guidelines on this area will need to be developed. Some activities may be value for money for particular consumers, despite being expensive.

Again these guidelines must be developed in consultation with mental health consumers and carers.

e. Reasonable and necessary supports reflect community expectations including what is realistic to expect from the individual families and carers

Guidelines around this criterion will be required to ensure consistent and transparent decision making and will need to be developed in collaboration with mental health consumers and carers.

f. Reasonable and necessary supports are best provided through a NDIS and are not more appropriately provided through other systems of service delivery and support, including services that are offered by mainstream agencies as a part of its universal service obligation to all citizens

This criterion has the same disadvantages outlined above in response to criterion 5. Given the Productivity Commission's description of a tiered arrangement of supports for the NDIS it would seem reasonable that the NDIS would have a key role in community liaison, education and development for all three tiers of support.

The NDIS will also be in a key position to identify service gaps in mainstream services and while it should not be expected to make up the shortfall in mainstream service delivery it should play a role in highlighting needs and advising on how they are best met in collaboration with those mainstream services.

The MHCA also proposes that in the case of grave areas of need and lack of service availability, exceptions to the strict application of this criterion must also be possible.