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Subject: Submission to the Select Council on Disability Reform

The Mental Health Coordinating Council (MHCC) is the peak body for mental health community managed organisations in NSW. We thank you for the opportunity to provide feedback concerning proposals from the Select Council on Disability Reform as to how *eligibility and reasonable and necessary support* under an NDIS might be defined, building on the work of the Productivity Commission (PC) and developed to describe in more detail how the scheme might work in practice.

MHCC have undertaken work over the past year investigating the existing evidence and development of self-directed funding models and considered issues relevant to this submission process. We therefore direct the Select Council to our Discussion Paper: *Self Directed Funding in the Community Managed Mental Health Sector* (2011) which discusses and builds on the recommendations of the PC report and reviews current international and Australian literature, which may be of interest. We attach this paper which can also be accessed via this link: [http://www.mhcc.org.au/documents/Research%20and%20Position%20Papers/Self%20Directed%20Funding%20and%20the%20Community%20Managed%20Mental%20Health%20Sector%20Opportunities%20and%20Challenges%20-%20Discussion%20Paper%20FINAL%2014%2011%2011.pdf]

MHCC respond specifically to the two sets of questions posed in the draft definition document. The first two relate to **Description of eligibility** developed by the Select Council as follows:

> 1. Does this description of eligibility cover all the things that you think a National Disability Insurance Scheme would need to know about you to determine whether you should be eligible to receive support under an NDIS?
> 2. Are there additional questions that an NDIS should ask people before deciding if they are eligible to receive support?

MHCC propose that the draft eligibility statement makes a good start in attempting to describe the people in scope to receive support funded under a NDIS. However, Item 4: *The impairment /s: a) is permanent or likely to be permanent* – sits uncomfortably in terms of the language favoured by the mental health sector in the context of the person centred recovery orientated approach in mental health service delivery which is considered best practice. We propose the terminology" severe and persistent" in preference, and comment that 'permanence' is not a defining characteristic.

In a paper by Rosen, Rosen and McGorry (2011) they propose that: *"severe and persistent mental illness (SPMI) is not a unitary construct. It is not confined to DSM Axis I psychiatric conditions, nor should it be defined centrally in terms of diagnosis. Rather it should be defined in terms of the six Ds: Disability, Distress, Duration (and severity) of symptoms, Disorganization, Danger (to self and others), and 'De family' or Disaffiliation (lack of family support or social isolation)."* [i]

It is clear that the NDIS sets out to maximise autonomy and self-determination for people with mental illness in scope. However, one of the difficulties that MHCC has with the description of eligibility is that it has no context or statement of the principles of equity under which assessment of the individual takes place. If the overarching principle is 'an equitable system' then the risk is that when and if resources become scarce, whilst criteria remain in place, packages may be reduced, as has happened in the UK model of the NDIS.

If the principle of access to the NDIS is equitable across the board, then a statement needs to be made that clearly says that every person in Australia within the scope of the disability eligibility criteria is entitled to the NDIS irrespective of other factor/s such as:

- whether the assessable person has private assets or lives entirely on a Disability Support Pension
- whether assessable person has family and carer support or is totally isolated in the community
- whether the assessable person has responsibilities such as childcare or aged care that need to be taken into account
- whether the package of funds allocated to the accessible person will be taken into consideration as taxable income
- whether the assessable person has been deemed eligible for existing services provided by other systems, but has been on waiting lists and unable to access the service
- whether the service the consumer has been offered is rejected by the consumer, who would like an alternative service of his/her own choosing

MHCC propose that the Item 5 statement is too general and unclear a description: *The support needs will persist for the foreseeable future and are not more appropriately met by other systems including education, health, and/or palliative care.* A consumer may be closely connected to mental health services because under the *NSW Mental Health Act* 2007, they are obliged to comply with a treatment plan. This may provide support needs but from their perspective these do not match the support needs they want in terms of self-directed services. A consumer may have a case manager from community mental health or a PHAMS worker from a CMO allocated but want additional support that this worker cannot provide. Our query is how gaps that exist will be met by other services without a perception of duplication. Similarly, a consumer may prefer a service of their choosing to one offered as part of the care plan combining clinical and psychosocial services they may already be receiving in the community. They may want to access someone outside of the mental health system to take them to appointments or assist them undertake other tasks - how will their preferences be assessed?

We are also keen to ensure that people are not refused access to coordinated services across systems, and that if it is assessed that they already have access to a service and are inappropriately referred out of the NDIS system, that their preferences to receive a service from an alternative supplier is considered.

One factor not addressed in the definition of eligibility is the issue of a person's financial means to access services outside the NDIS. This is a particular issue for people with psychiatric disability. It is well known that episodic illness and other factors associated with the disability have led to a very low level of participation in the workforce by people with psychiatric disability, and the financial means of people with mental health problems and disorders is often extremely limited. This characteristic is of course not limited to people with psychiatric disability.

If an individual with a disability were to be assessed as ineligible for service within the NDIS, then there should be a question asked as to the individual's ability to access support services outside the NDIS. If such a service were only available at a cost that might be beyond the person's financial means, then this could be another criterion under which the individual's case might be assessed. There is no desire to see any form of means testing applied to the NDIS. However we already have situations where people requiring psychiatric and psychological care have limits placed upon their access to this service, and this is seen by mental health consumers as a major barrier to their wellbeing. Given the objective of appropriate and seamless support, it would be unfortunate if the NDIS repeated any of the shortcomings which have been built into the medical care system.

It is a lengthy process, moving from a block funded system to one of personal budgets. The descriptions provided for our consideration are about **who** not **what**. Our question is - Is the system planning to adopt the UK system that financially attributes 'occasions of care', which is moving more towards an Activity Based Funding Model? . In discussing these matters and presenting a position, we need to know the role the community managed sector might play in providing occasions of care or other services. If this system is supposedly smart, what do we envisage will be the levels of accountability against the services provided – for example in measuring the outcomes or accountability of leisure activities, education, sports and activities like massage, meditation etc.

In both the definitions of eligibility and reasonable and necessary supports, Item 5 states: *The support needs will persist for the foreseeable future and are not more appropriately met by other systems including education, health and/or palliative services.* Similarly in f - *are best provided through the NDIS and are not more appropriately provided through other systems of service and support, including services that are offered by mainstream agencies as part of its universal service obligation to all citizens.* Our query is what will the NDIS consider to be Mainstream Services? Following on from that, how will the system take into account poor access to entitlements where they are just not available (for example in rural and remote areas)?

MHCC ask what bits of the service delivery mix outside of hospital care belongs to the NGO/CMO sectors and what belongs to state/ Commonwealth health departments and all those responsible for providing mental health services? Without such information finalising definitions of eligibility and reasonable and necessary support remains problematic.

MHCC propose that what is necessary is to undertake modelling of diversity of needs - perhaps using the Mental Health Clinical Care and Prevention (MHCCP) Planning Process. MHCC is currently modelling the types of community programs that should be available to people with severe mental illness in each local area. A taxonomy of seven core community-managed mental health service areas (functions) have already been identified in the *Final Report of the New South Wales Mental Health Community Managed Organisation (CMO) Sector Mapping Project* 2008-2010 (MHCC).

- Accommodation Support & Outreach;
- Employment & Education;
- Leisure & Recreation;
- Family Support & Carer Programs;
- Self-help & Peer Support;
- Helpline & Counselling Services; and,
- Information, Advocacy & Promotion.

The amount of support available is population-based with needs based variation parameters. In this modelling we need to consider what is available such as the access to psychological services through the Medicare Benefits Scheme or ATAAPS and consider if a consumer requires ongoing long-term therapy/counselling and would this be something they could get access to over and above the allocated 10 sessions available? Similarly could a consumer select their own provider from a different discipline outside of the Medicare Benefits Scheme.

In terms of additional questions that an NDIS should ask people before deciding if they are eligible to receive support, we suggest that the issue of adjustment to fee for service for CMOs, and the impact on grants funding arrangements for those not eligible must be considered at this point.

MHCC respond to the three focus questions regarding the **Description of reasonable and necessary support** developed by the Select Council which are:

1. Are there supports that you think are important to include in an NDIS that would be excluded by this description?
2. Are there additional points that are needed to make sure that the support provided under an NDIS meets the reasonable and necessary support needs of people with disability?
3. Does this description of reasonable and necessary supports, combined with the eligibility statement, help you to understand who will be supported in an NDIS and what supports might be provided to them? If not, how do you suggest that the description be made clearer?

MHCC propose that the reasonable and necessary support require greater clarity concerning a number of questions across the 6 statements (a-f):

- How will eligibility be assessed against other packages of care that people may be receiving and including Disability Support Pensions?
- To what extent will people eligible under the NDIS be able to choose private providers as suppliers?
- How will private providers be assessed for value for money, and quality assurance?
- How will community managed organisations be identified and what criteria would put a CMO into the category of being a mainstream provider?
- Who will manage the funding?
- How much discretion will the person with the package have?
- Where is the overlap between 'mainstream' services and the community managed sector
- How will costing occasions of care in different setting and circumstances be allocated? e.g. discharge packages
- How will marketing costs be attributed for service advertising
- How will services currently offered at a program level be offered as an 'event of care'?

Similarly, it is unclear to MHCC as to how supporting self-directed funding will interact with the clinical service providers that sit outside of the NDIS. Importantly, we need to understand what role families and carers are likely to play in substituted decision making if the consumer is lacking capacity for supported decision making. How are people without capacity to be assessed in a self-directed model – how will appointed guardians or substitute decision makers be included in the process?

Finally, MHCC wish to advise the Select Council that we have provided a proposal to the Practical Design Fund to undertake a research and development project to meet the imminent needs of mental health community managed organisations (CMO) under the NDIS. It aims to provide an analysis of the factors that support sector sustainability, workforce development and improved organisational capacity under the NDIS.

The proposed project is entitled: **NDIS Mental Health CMO Development and Sustainability Project.** Briefly, working on the assumption that the mental health consumers eligible under the NDIS will be consumers already receiving disability support pensions and engaging with mental health services - a staged process to the project envisages at a minimum a number of essential outcomes:

- Build on the literature reviewed in the 2011 MHCC discussion paper
- Further analyse international evidence against the Productivity Commission's recommendations
- Provide a short discussion paper to the sector in order to conduct consultations/ forums and targeted interviews with consumers, carers and the community mental health and human service sectors
- Evaluate how information gathered from consultations sits alongside the international evidence base and review its relevance in an Australian context with particular reference to the Partners in Recovery Program (PIR)
- Evaluate potential of the NDIS to provide access for people not engaging with mental health services and access how gaps in service delivery are likely to affect equity and consumer/carer outcomes
- Investigate ineligibility criteria across the NDIS & PIR programs and make recommendations concerning cross program collaboration and service delivery coordination
- Identify the framework and strategies necessary to establish and implement policy for a model of a service delivery and flexible packages that meet the diverse needs of people with complex psychosocial disability(identified from consultative processes)
- Provide a report which articulates the findings and makes recommendations to government as to how best to meet stated objectives in terms of:
    - a person-centred recovery oriented approach to the NDIS
    - the interface with the Partners in Recovery (PIR) programs and alignment of two models, one primarily self-directed utilising an array of service types including for-profits complementing services offered by the not-for- profits under Medicare Local governance
    - meeting the needs of Aboriginal and culturally diverse people with mental illness as well as individuals and groups experiencing co-existing difficulties (e.g. ID, ABI, physical disability)
    - identifying assessment tools and processes for eligibility criteria
    - CMO sector development, sustainability and organisational capability
    - establishing the necessary workforce competencies, training frameworks (and qualifications)required and organisational tools to support sector development and organisational capability, and
    - identifying models for delivery(e.g. brokerage) and cross sectoral partnerships
    - feedback loops, quality improvement and complaints mechanisms
    - community awareness strategies
    - investigate data collection/ evaluative processes of consumer outcomes against program costs

MHCC recommend that before finalising definitions of eligibility and reasonable and necessary support under the NDIS that more evidence is necessary to inform the model with specific reference to people with severe and persistent mental health problems.

We thank you your interest and look forward to further discussion in the near future. For more information on this submission please contact Corinne Henderson, Senior Policy Officer

Jenna Bateman
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[i] Rosen, A., Rosen, T. & McGorry, P. (2011). *The Human Rights of People with Severe and Persistent Mental Illness Can Conflicts between Dominant and Non-Dominant Paradigms be reconciled?* PART 2: HUMAN RIGHTS ABUSES, PSYCHIATRY, NATION STATES, AND MARKETS Chapter 16. 297-320