18 February 2014

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The Hon John Ajaka MLC
Minister for Ageing
Minister for Disability Services

E:disbilityinclusionbill@facs.nsw.gov.au

Dear Minister,

Subject: The *NSW Disability Inclusion Bill 2014* (The DIB)

The Mental Health Coordinating Council (MHCC) thanks the Government for providing an opportunity to respond to the *Disability Inclusion Bill 2014*: Consultation Draft.

MHCC is the peak body representing mental health community managed organisations (CMOs)[1] in NSW. Our members provide a range of psychosocial and clinical services, and support programs, as well as advocacy, education, training and information services with a focus on recovery-oriented practice. MHCC's membership consists of over 200 organisations whose business or activity is wholly or in part related to the promotion and/or delivery of services for the wellbeing and recovery of people living with mental health conditions. We work in partnership with both State and Commonwealth Governments to promote recovery and social inclusion, participate extensively in policy and sector development and facilitate linkages between government, community and private sectors in order to affect systemic change. MHCC manages and conducts research projects and develops collaborative projects on behalf of the sector. MHCC is also a registered training organisation (MHCC Learning & Development) delivering nationally accredited mental health training and professional development to the community managed workforce across all human services.

MHCC is a founding member of Community Mental Health Australia (CMHA) the alliance of all eight State and territory community sector mental health (MH) peak bodies. Together we represent more than 800 CMOs delivering mental health services nationally.

MHCC has been working in partnership with the NSW Mental Health Commission since July 2013 monitoring the role out of the NDIS. A senior MHCC Policy Advisor has been seconded to the Hunter as NDIS Launch Site Mental Health Analyst. She is analysing the launch process, as well as exploring the increasing opportunities for the inclusion of mental health/psychosocial disability within the Hunter NDIS site. This work has been funded for a year and the work will conclude with a report describing activities undertaken, findings and

[1] Also known as NGOs (non-government organisations)

making recommendations to strengthen the situation for people affected by mental illness through the NDIS. In the interim, we attach the most recent update overview.

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General Comments

1. MHCC propose that the DIB is a substantial improvement on the NSW *Disability Services Act 1993* (DSA) in terms of its attempt to better meet Australia's commitment to its ratification of the UN Convention of the Rights of Persons with a Disability (UNCRPD). However, its relationship to the UNCRPD is not clearly articulated and needs to match the 'Objects' as described in the *National Disability Insurance Scheme Act 2013* No. 20, 2013 (NDIS Act), which states that the Objects of the Act, should "give effect to Australia's obligations under the UNCRPD" (Section 3, Part 2—Objects and principles).

2. We also propose that the DIB fails in some contexts to demonstrate how it will interface with the NSW *Mental Health Act 2007* (MHA), or how it will operate in relation to, for example:
    - National Practice Standards for the Mental Health Workforce 2002 [i]
    - The National Mental Health Standards 2010: Recovery Principles [ii]
    - And give effect to Australia's obligations under the United Nations Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care 1991, which is the Optional Protocol of the CRPD [iii]

The legislation needs to clearly articulate where the MHA takes precedence over the DIB so that it is clear where service providers' obligations are situated. The legislation likewise needs to demonstrate an understanding of the different operational context, practice cultures including the different language/ terminology and understandings that dominate the two sectors - disability and mental health.

3. MHCC applaud the enabling of people with disability to exercise choice and control, highlighted in the Objects Clause 3(c) and General Principles 4(4) "in the pursuit of their goals and the planning and delivery of supports and services". Nevertheless, the issue raised in point 2 above is pertinent, in that the issue regarding how this might play out for people under community treatment orders (CTOs). The Bill makes no reference to:

- Supported decision making and advocacy
- People with substitute decision making roles such as guardians
- Carers and families who have informal decision-making roles or are nominated carers.

The NDIS Act provides a good model of what should be replicated in the DIB; that is as described in Section 4(9) and 4(13) and in the DSA 1993, Schedule 1, Principles and application 2(l).

4. MHCC note that the DIB does not include a Statement or Charter of Consumer or Carer Rights. We recommend that elements of Chapter 4, Part 1 – Rights of patients or detained persons and primary carers, Division 1 – General 68 Principles for care and treatment (MHA) have elements appropriate for inclusion in the DIB.

5. Whilst we recognise that there are occasions when restrictive practices are necessary, the language used in the DIB, Division 3: Clauses 43 - 52 is not in keeping with 'Recovery Principles' and the National Mental Health Service Standards 2010. We are optimistic that these Principles will be appropriately reflected in the forthcoming amendments to the NSW *Mental Health Act 2007,* and advocate that the DIB, needs to be more closely aligned to this, if it is to cover people with mental health conditions as part of the NDIS target group. We attach Appendix 1, outlining Recovery Principles and Standards.

6. References in the DIB to Disability planning, Division 1: Part 2, State Disability Inclusion Plan (SDIB), Clause 8 Requirement for a SDIB, Clause 9 Review of Plan, and Division 2,Section 10, Requirement for Disability action plans, weakly describe the relationship between agencies to provide the services across sectors and systems. In order to address a broader disability demographic to include people with disability with lived experience of mental illness with complex psychosocial needs: MHCC recommend that the government review the MOU between Housing and Mental Health Agreement (HMHA) to articulate how cooperation can be fostered across agencies.

This agreement between NSW Health and the NSW Department of Family and Community Services (FACS) – encompasses all its agencies: Housing NSW, Aboriginal Housing Office, Ageing, Disability & Home Care and Community Services. The agreement recognises that NGOs are key providers of services to people with psychosocial disability and signatory departments committed to working in partnership with community managed organisations and their peak organisations, to improve outcomes for this group of people. The Agreement provides: an overarching framework including aims and objectives, principles, commitments, elements of good practice and governance and a high level Action Plan to support the implementation of the Agreement which outlines the actions signatory agencies agree to progress.[iv]

7. MHCC highlights concerns about monitoring and safeguard mechanisms under the NDIS. *The National Disability Insurance Scheme (NSW Enabling) Act 2013*, assented on 27/11/2013 - Act No 104 of 2013 (GG. No. 168, 6/12/2013, p. 5647) has a technical role primarily dealing with the transfer of ownership from one entity to another – that is ADHC to an NGO, NFP or FP for the purposes of the transition of services under the NDIS.

Our understanding is that the DIB would deal with the matters of oversight and monitoring safeguards, however the Bilateral Agreement between the Commonwealth and the State which was to enable the Ombudsman to have jurisdiction for the launch sites, is incapable of guaranteeing safeguards because CS CRAMA (*The Community Services (Complaints, Reviews and Monitoring) Act 1993*) is dependent on the funding agreement between ADHC and the provider e.g. an NGO. However, in a new system where the funding may go direct to an individual who is responsible for paying the service provider, the Ombudsman's ability to track those exchanges is much more difficult, and outside of their jurisdiction.

What has thus far been proposed is that all complaints will go to the Ombudsman as a 'Clearing House'. The matter will then be referred to the appropriate authority (e.g. the HCCC). When the Ombudsman has identified difficulties arising during this initial period of experience with the NDIS launch site, they will be able to identify gaps and problems, and report back on how the monitoring safeguards mechanisms might best be designed.

MHCC express particular interest in this matter and suggest that a research study and scoping of international models be undertaken in order to recommend a best practice model for monitoring safeguards for people with psychosocial disability, in the context of the NDIS. As it stands, the Ombudsman does not have the expertise or a workforce with the knowledge and competences to oversight mental health services providing support under the NDIS.

We refer in some more detail to several of these matters in the items following.

Comment directly related to DIB Clauses

i. Division 2: Part 1, Clause 4 General Principles (6) - We note that privacy and confidentially are inadequately dealt with both in the DSA and the DIB. MHCC recommend that this is well articulated in the MHA, Clause 189, Disclosure of information: 1 (a) – (e).[v]

We alert the Government to Chapter 4, General matters Part 1: Other persons, Division 2, Section 55 - *Power to obtain information from other persons to ensure the integrity of the National Disability Insurance Scheme* (NDIS Act 2013). MHCC are reliably informed that this section is being used as a loophole for providing information between services, without the permission of the participant in the scheme. This is contrary to what we would regard as appropriate practice in mental health services, and we would query how the two pieces of legislation will interface in the context of disclosure of information.[vi] We note that the important principles protecting privacy and confidentiality must also be reflected in Part 5: Division 6: Clause 35 – *Giving information*, and we are deeply concerned about the lack of protection demonstrated in Clause 36 – *Protection from liability for giving information*, where in (b) "a person cannot be held to have breached any code of professional etiquette or ethics or departed from any accepted standards of professional conduct as a result of giving information or document". 'Good faith' in accordance with Clause 36 is one thing, but the matter of consumer consent for others to pass on information to the Director General or how that information is protected, must be more appropriately and fully addressed.

We therefore recommend that there be a further element to this clause that speaks to the requirement that all avenues for supported decision-making and substitute decision making (where applicable) have been initiated. Hence, information sharing without consumer consent must be understood as a last resort.

ii. Division 2: Part 1, Clause 5, *Principles recognising the needs of particular groups*. The DIB clearly recognises the responsibility to provide necessary supports to groups with particular needs. However, the concept of supported decision-making is not articulated, or expressed adequately in a way that embeds 'Recovery Principles' in the legislation, and which we expect will be clearly identified in the amendments to the MHA.

iii. Likewise, Division 2: Part 1, Clause 6, having regard to the application of disability principles to services and support, we would also propose that Recovery Principles are applied where relevant.

iv. Part 3: Refers to the role of the Disability Council (DC) of NSW. Whilst MHCC support the role of the DC having special functions and reporting arrangements, we question how the DC will adequately reflect, represent and advocate for people with mental illness and psychosocial disability. MHCC suggest that the Council Members and Secretariat are not well informed about consumer issues and that it would be necessary to substantially involve the expertise of the Consumer Advisory Group NSW (CAG), the NSW Health funded NGO consumer peak in order to fairly represent mental health consumer issues.

v. Part 4: Clause 19 – The meaning of "supported accommodation" does not include some understandings of the term as used in the context of mental health services. This includes a diversity of step-up and step- down programs according to levels of need, which may fluctuate at certain times, across the life-span.

vi. Part 4: Clause 20 – We propose that this clause should also include the National Mental Health Service Standards and reflect Recovery Principles. The Disability Service Standards do not appropriately cover the standards necessary for working with people with mental health conditions.

vii. Part 4: Clause 21 – Similarly this clause needs to refer to, and make publically available the mental health service standards in addition to general disability standards.

viii. Part 5: Division 1: Clause 23 – This clause is the only place in the DIB that clearly refers to people under the *NSW Mental Health Act 2007*. Elsewhere the DIB fails to provide the necessary interface between it and the MHA, articulating how the Objects and Principles may co-exist in harmony, and stating when the MHA takes precedence over the DIB.

ix. Part 5: Division 1: Clause 24 (2) – Does not deal with situations in which a person who lacks capacity to nominate another to receive financial assistance on their behalf might be supported to make that decision.

x. Part 5: Division 2: Clause 24 (4) – It is unclear how consumers may be able to exercise choice under this clause. If a consumer wishes to access a commercial or other service provider, e.g. a gym, cleaning service or family carer who does not have an arrangement with the government, how will this be accommodated? We are of the view that Clause 24 (5) – (8) deals with this question, however, the reading of these clauses for a lay-person is (in our view) vague and unclear.

xi. Part 5: Division 2: Clause 25 (3) (b) - We suggest that with regards to review of a decision concerning financial assistance, that this clause specify whether it relates to: eligibility criteria; a condition surrounding financial assistance on behalf of a target person instead of directly provided; or a condition surrounding nature of service support agreed to.

xii. Part 5: Division 3: Clauses 27, 28 and 29 –similar to Clause 24, these clauses fail to address the matter of support services that may come outside an 'eligible organisation' categorisation; for example where a service is provided by an individual carer, or is an education/ recreational activity (e.g. pottery classes) or a commercial transport service. Where these anomalies are dealt with in the legislation is unclear.

xiii. Part 5: Division 3: Clause 30 – Likewise, regarding probity checks on workers in organisations, we question how this will apply to family members, and suppliers of commercial services, e.g., cleaning services?

xiv. Part 5: Division 4: Clause 31 – With regards to suspension of financial assistance, it is unclear as to how the matter of episodic illness is dealt with. People with continuing mental health conditions may have long periods of wellness, where they need fewer or no supports, but when unwell need quickly to have access to services.

We note that 31 (1) (a) (i) specifically refers to people "no longer requiring supports and services because the person is hospitalised". However, a person may still require some services whilst hospitalised, e.g. to maintain their home, garden, look after pets etc., and we are concerned that the re-instatement of supports and maintenance of ongoing supports requires sensitive handling. Whilst this aspect is loosely dealt with in Clause 31 (4) as 'alternative support' while financial assistance is suspended, we suggest that the matter of ongoing supports requires attention.

xv. Part 5: Division 4: Clause 32 - With regards to termination of financial assistance, and (2) (iii) - *Invitation for participant to make a submission concerning termination*, and Division 5: Clause 33, *Review of decisions*, we strongly urge that the legislation acknowledge the support that many people with disability might need in order to make such a submission. A major concern that MHCC highlight here is clearly articulated in the recently launched report from the Australian Human Rights Commission, 2014, *Equal before the law: Towards disability justice strategies*.[vii]

xvi. Part 5: Division 6: Clause 34 – To some extent the question raised in this submission item (xii) above is dealt with in Clause 34 as "another entity". However, we urge greater clarity in defining what 'another entity' might represent.

xvii. Part 6: *Restrictive Interventions* Division 1, Preliminary, Clause 37 – *Definitions*. We reiterate our concerns expressed in item 5 of this submission which also relates to Clause 37 and Clause 38 *Definitions*, which need to be reflected upon in the light of the work currently in progress under the auspices of the National Mental Health Commission investigating Seclusion and Restraint practices.

With respect to Clauses 43-52, MHCC are deeply concerned that these clauses assume the inclusion of seclusion and restraint in a management plan is accepted practice. In fact people with mental health conditions are only subject to seclusion and restraint in the most extreme circumstances (as an involuntary patient under the MHA or when brought into a facility by police under s22 of the MHA). The assumption and intention of Clauses 43-52 suggest that seclusion and restraint are acceptable

elements of behaviour management plans, rather than rare and undesirable interventions of last resort that have been shown to be traumatising and detrimental to recovery.

We are also concerned about the way in which the legislation seeks to address the matter of "chemical restraint". There is no clear distinction between the use of medication to 'manage behaviour' or 'treat a mental disorder'. The issue of medication use for people with co-occurring intellectual disability and mental illness is highly problematic, since the presentation often represents reactions to a range of factors including circumstance and environment. It is simplistic to assume that it might be possible to specify the primary purpose for prescribing medication. The safeguards do not focus on medical justification and appropriateness, but on offering behaviour management together with medication.

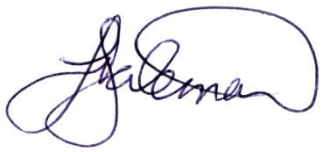
Because of the complexity of 'diagnosis' in these circumstances, it is necessary to foster a close collaboration between disability and mental health services to explore whether alternative positive behavioural approaches might be utilised. Unfortunately, the expertise and skills necessary to bring about better long term outcomes are often absent, and psychotropic medication is the 'quick fix' used in many instances, determined by practitioners lacking the appropriate expertise to implement other interventions.

The use of medication outside of the PBS is expensive. This further complicates the matter when doctors use a psychiatric diagnosis in order to prescribe to the person in a way that minimises the cost for them. Whilst this may be 'well-intentioned' it is absolutely critical that all restrictive practices are registered and reviewed by a Practice Authorisation Panel.

The panel must be satisfied that prescription is based on sound medical evidence, and with the consent of a guardian/ advocate or 'person responsible', in the case of a person with intellectual disability. Such a prescription must take into account other contributing health issues or diagnoses that may be contributing to behavioural problems.

MHCC thanks the Minister for considering our perspectives on the Draft *Disability Inclusion Bill 2014*, and express our willingness to discuss any matters surrounding this consultation and the contents of this submission at any time. If such a need arises, please contact Corinne Henderson, Senior Policy Advisor at corinne@mhcc.org.au or telephone: 02 9555 8388 # 101.

Yours sincerely,



Jenna Bateman
Chief Executive Officer
Attached: Hunter launch-site news update January 2014

Appendix 1

Principles of recovery-oriented mental health practice

From the perspective of the individual with mental illness, recovery means 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. It is important to remember that recovery is not synonymous with cure. Recovery refers to both internal conditions experienced by persons who describe themselves as being in recovery—hope, healing, empowerment and connection—and external conditions that facilitate recovery—implementation of human rights, a positive culture of healing, and recovery-oriented services, (Jacobson & Greenley, 2001, p. 482).[viii]

The purpose of principles of recovery-oriented mental health practice is to ensure that mental health services are being delivered in a way that supports the recovery of mental health consumers.

1. Uniqueness of the individual

Recovery oriented mental health practice:

- recognises that recovery is not necessarily about cure but is about having opportunities for choices and living a meaningful, satisfying and purposeful life, and being a valued member of the community
- accepts that recovery outcomes are personal and unique for each individual and go beyond an exclusive health focus to include an emphasis on social inclusion and quality of life
- empowers individuals so they recognise that they are at the centre of the care they receive.

2. Real choices

Recovery oriented mental health practice:

- supports and empowers individuals to make their own choices about how they want to lead their lives and acknowledges choices need to be meaningful and creatively explored
- supports individuals to build on their strengths and take as much responsibility for their lives as they can at any given time
- ensures that there is a balance between duty of care and support for individuals to take positive risks and make the most of new opportunities.

3. Attitudes and rights

Recovery oriented mental health practice:

- involves listening to, learning from and acting upon communications from the individual and their carers about what is important to each individual
- promotes and protects individual's legal, citizenship and human rights
- supports individuals to maintain and develop social, recreational, occupational and vocational activities which are meaningful to the individual
- instils hope in an individual's future and ability to live a meaningful life.

4. Dignity and respect

Recovery oriented mental health practice:

- consists of being courteous, respectful and honest in all interactions
- involves sensitivity and respect for each individual, particularly for their values, beliefs and culture
- challenges discrimination and stigma wherever it exists within our own services or the broader community

5. Partnership and communication
Recovery oriented mental health practice:

- acknowledges each individual is an expert on their own life and that recovery involves working in partnership with individuals and their carers to provide support in a way that makes sense to them
- values the importance of sharing relevant information and the need to communicate clearly to enable effective engagement
- involves working in positive and realistic ways with individuals and their carers to help them realise their own hopes, goals and aspirations.

6. Evaluating recovery
Recovery oriented mental health practice:

- ensures and enables continuous evaluation of recovery based practice at several levels
- enables individuals and their carers to track their own progress
- ensures that services demonstrate that they use the individual's experiences of care to inform quality improvement activities
- require that the mental health system reports on key outcomes that indicate recovery including (but not limited to) housing, employment, education and social and family relationships as well as health and well- being measures

Reference: Recovery Principles have been adapted from the Hertfordshire Partnership NHS Foundation Trust Recovery Principles in the UK.

Delivery of care – Standards

It is necessary that that the principles are supported by the mental health standards that 'incorporate recovery principles into service delivery, culture and practice providing consumers with access and referral to a range of programs that will support sustainable recovery'.

National Mental Health Standards: Standard 10

10.1 Supporting recovery
Criteria

10.1.1 The MHS actively supports and promotes recovery oriented values and principles in its policies and practices.
10.1.2 The MHS treats consumers and carers with respect and dignity.
10.1.3 The MHS recognises the lived experience of consumers and carers and supports their personal resourcefulness, individuality, strengths and abilities.
10.1.4 The MHS encourages and supports the self-determination and autonomy of consumers and carers.
10.1.5 The MHS promotes the social inclusion of consumers and advocates for their rights of citizenship and freedom from discrimination.
10.1.6 The MHS provides education that supports consumer and carer participation in goal setting, treatment, care and recovery planning, including the development of advance directives.
10.1.7 The MHS supports and promotes opportunities to enhance consumers' positive social connections with family, children, friends and their valued community.
10.1.8 The MHS demonstrates systems and processes for consumer and carer participation in the development, delivery and evaluation of the services.
10.1.9 The MHS has a comprehensive knowledge of community services and resources and collaborates with consumers and carers to assist them to identify and access relevant services.

10.1.10 The MHS provides access for consumers and their carer(s) to a range of carer-inclusive approaches to service delivery and support.

RERERENCES

[i] National Practice Standards for the Mental Health Workforce September 2002, Available: http://www.health.gov.au/internet/main/publishing.nsf/content/CFA833CB8C1AA178CA257BF0001E7520/$File/servst10v2.pdf

[ii] The National Mental Health Standards 2010: Recovery Principles, Available: http://www.health.gov.au/internet/main/publishing.nsf/Content/CFA833CB8C1AA178CA257BF0001E7520/$File/servpri.pdf

[iii] United Nations Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care http://www.un.org/documents/ga/res/46/a46r119.htm

[iv] NSW Health, 2011, 'Housing & Mental Health Agreement', Available: http://www.housing.nsw.gov.au/NR/rdonlyres/2CA35546-A3D4-455A-AAF5-78A51AF3186D/0/HousingandMentalHealthAgreement.pdf

[v] (1) A person must not disclose any information obtained in connection with the administration or execution of this Act or the *Mental Health (Forensic Provisions) Act 1990* or the regulations unless the disclosure is made:

(a) with the consent of the person from whom the information was obtained, or
(b) in connection with the administration or execution of this Act or the *Mental Health (Forensic Provisions) Act 1990*, or
(c) without limiting paragraph (b), to a primary carer of a person in connection with the provision of care or treatment to the person under this Act or the *Mental Health (Forensic Provisions) Act 1990*, or
(d) for the purposes of any legal proceedings arising out of this Act or the *Mental Health (Forensic Provisions) Act 1990* or the regulations or of any report of any such proceedings, or
(d1) for a purpose referred to in health privacy principle 10 (1) (f) (research) under the *Health Records and Information Privacy Act 2002*, or
(e) with other lawful excuse.

[vi] (1) If the CEO has reasonable grounds to believe that a person other than a participant or a prospective participant has information, or has custody or control of a document, that may be relevant to one or more of the matters mentioned in subsection (2), the CEO may require the person to give the information, or produce the document, to the Agency.
(2) The matters are as follows:
(a) whether a prospective participant meets the access criteria;
(b) whether a participant continues to meet the access criteria;
(c) whether a person purporting to act on a person's behalf for the purposes of this Act has the authority to do so;
(d) the preparation or review of a participant's plan; (e) the monitoring of supports funded for, or provided to, a participant;
(f) whether NDIS amounts paid to the participant or to another person have been spent in accordance with the participant's plan;
(g) whether a participant or other person has complied with section 46;
(h) whether a participant receives:
(i) supports or funding through a statutory compensation scheme or a statutory care or support scheme; or
(ii) any other disability support;
(i) whether an applicant for approval as a registered provider of supports meets the criteria for approval;
(j) whether a registered provider of supports continues to meet the criteria for approval;
(k) the functions of the Agency.

[vii] Australian Human Rights Commission,2014, *Equal before the law: Towards disability justice strategies,* Available: http://www.humanrights.gov.au/publications/equal-law

[viii] Jacobson, N & Greenley, D. 2001, 'What Is Recovery? A Conceptual Model and Explication,' Psychiatric Services 2001; doi: 10.1176/appi.ps.52.4.482. Available: http://ps.psychiatryonline.org/article.aspx?articleID=85752