

30 June 2014

**Australian Law Reform Commission
Equality, Capacity & Disability in Commonwealth Laws: Discussion Paper 81**

The Mental Health Coordinating Council (MHCC) is the peak body representing community managed organisations (CMOs) in NSW. Our members deliver a range of psychosocial disability support programs and services including housing, employment and social inclusion activities, as well as clinical and peer supported services with a focus on recovery orientated practice. MHCC members also include organisations that provide advocacy, education, training and professional development and information services. Our membership in NSW 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 affected by mental health conditions. We work in partnership with both State and Commonwealth Governments to promote recovery and social inclusion for people affected by mental health conditions, participate extensively in policy and sector development and facilitate linkages between government, community and private sectors in order to effect systemic change. MHCC also manage and conduct collaborative research and sector development 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 mental health and human services workforce. MHCC is also 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 and related services nationally.

MHCC thank the Australian Law Reform Commission (ALRC) for inviting us to comment on this discussion paper which was made public on 22 May 2014. We congratulate the ALRC on both this and their earlier Discussion Paper (44); both which clearly take into account contemporary thinking with regards to people with disability maximising their autonomy and incorporating “recovery” principles by adopting a strengths based approach. However, we are concerned that (whilst understanding the pressures from Government to present final recommendations) the tight time frame for submissions has made it hard for us to consult broadly with our membership. Therefore, the comments we provide are based on our views and those shared with us by stakeholders we have managed to consult with, who have experience in these matters. However, we cannot claim to have consulted to the extent that we normally would in order to provide feedback on such important matters raised in this paper. This unfortunately ‘flies in the face’ of the inclusive approach that the DP81 presents. MHCC also note that they provided a submission to the earlier Discussion Paper 44, which was released 31 November 2013, with a deadline for submissions 16 December 2013. This deadline also made it difficult for us to consult our members and interested stakeholders.

MHCC also note that having provided comment on many of the questions raised in the earlier paper, we have tried to focus on the specific proposals and areas that we previously did not address.

In order that our members reading this submission can make sense of the context of our comments, we present them following the ALRC's proposals and questions:

Proposals and Questions

2. Conceptual Landscape—the Context for Reform

Proposal 2–1 The Australian Government should review the Interpretative Declaration in relation to art 12 of the *United Nations Convention on the Rights of Persons with Disabilities* with a view to withdrawing it.

MHCC strongly believe that the interpretive declarations lodged by the Australian government under the UNCRPD should not be in place, and should be rescinded immediately. It is our view that the interpretative declaration evokes a 'deficits' model of disability incompatible with a rights based model of disability which we consider the objective of the CRPD .

3. National Decision-Making Principles

Proposal 3–1 Reform of Commonwealth, state and territory laws and legal frameworks concerning decision-making by persons who may require support in making decisions should be guided by the National Decision-Making Principles and Guidelines, set out in Proposals 3–2 to 3–9.

Proposal 3–2 National Decision-Making Principle 1

Every adult has the right to make decisions that affect their life and to have those decisions respected.

Proposal 3–3 National Decision-Making Principle 2

Persons who may require support in decision-making must be provided with the support necessary for them to make, communicate and participate in decisions that affect their lives.

Proposal 3–4 Support Guidelines

- (a) Persons who may require decision-making support should be supported to participate in and contribute to all aspects of life.
- (b) Persons who may require decision-making support should be supported in making decisions.
- (c) The role of families, carers and other significant persons in supporting persons who may require decision-making support should be acknowledged and respected.

Proposal 3–5 National Decision-Making Principle 3

The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.

Decision making is about expressing choice and preference and being able to act upon that choice. For people with disability this particularly relates to being able to choose the supports they need to enable them to lead the lifestyle of their choosing. MHCC endorse the four general principles that reflect the key ideas and values upon which the ALRC's approach in relation to legal capacity is based. We understand that they are distinct from the framing principles for the inquiry as a whole (dignity, equality, autonomy, inclusion and participation, and accountability), but reflect and are informed by those principles and act as an overlay for general application.

Proposal 3–6 Will, Preferences and Rights Guidelines

(a) *Threshold*: The appointment of a representative decision-maker should be a last resort and not as a substitute for appropriate support.

(b) *Appointment*: The appointment of a representative decision-maker should be limited in scope, be proportionate, and apply for the minimum time.

(c) *Supporting decision-making*:

(i) a person's will and preferences, so far as they can be determined, must be given effect;

(ii) where the person's will and preferences are not known, the representative must give effect to what the person would likely want, based on all the information available, including communicating with supporters; and

(iii) if it is not possible to determine what the person would likely want, the representative must act to promote and safeguard the person's human rights and act in the way least restrictive of those rights.

Whilst we agree that there needs to be a consistent approach to the assessment of capacity in the context of representative decision making, promoting individual autonomy as circumstances require, it is important that the process does not become too proscriptive and therefore run the risk of leading to for example, harm or neglect. At the end of the day the legislation must have an underpinning code of practice that provides the key framework and principles of best practice.¹

Proposal 3–7 Representative Decision-Making Guidelines

Any determinations about a person's decision-making ability and any appointment of a representative decision-maker should be informed by the following guidelines:

(a) An adult must be presumed to have ability to make decisions that affect their life.

(b) A person has ability to make a decision if they are able to:

(i) understand the information relevant to the decision and the effect of the decision;

(ii) retain that information to the extent necessary to make the decision;

(iii) use or weigh that information as part of the process of making the decision; and

(iv) communicate the decision.

(c) A person must not be assumed to lack decision-making ability on the basis of having a disability.

(d) A person's decision-making ability is to be assessed, not the outcome of the decision they wish to make.

(e) A person's decision-making ability will depend on the kinds of decision to be made.

(f) A person's decision-making ability may evolve or fluctuate over time.

(g) A person's decision-making ability must be considered in the context of available supports.

(h) In communicating decisions, a person is entitled to:

(i) communicate by any means that enables them to be understood; and

(ii) have their cultural and linguistic circumstances recognised and respected.

In principle MHCC agree with the guidelines in Proposal 3-7. However, in relation to (f) we propose that advance directives should also be included in the guidelines, with particular reference to medical treatment. This would allow people to make decisions when well as to what treatment they would or would not like to have in circumstances when they lose capacity due to mental illness.

¹ Information, Mental Health Capacity Act 2005, United Kingdom, Available: <http://www.mentalhealth.org.uk/help-information/mental-health-a-z/M/mental-capacity-act-2005/>

Proposal 3–8 National Decision-Making Principle 4

Decisions, arrangements and interventions for persons who may require decision-making support must respect their human rights.

As Donnelly (2010) describes, a key principle of the UNCRPD is autonomy, but that a human rights approach places autonomy in a wider context. It “provides a mechanism within which to deal with questions of limitations on the right of autonomy.”² The principle must be supported by the Safeguards Guidelines outlined below in 3-9, which we thoroughly endorse.

Proposal 3–9 Safeguards Guidelines

Laws and legal frameworks must contain appropriate safeguards in relation to decisions and interventions in relation to persons who may require decision-making support to ensure that such decisions and interventions are:

- (a) the least restrictive of the person’s human rights;
- (b) subject to appeal; and
- (c) subject to regular, independent and impartial monitoring and review.

Whilst these guidelines are general, and it is suggested that they be incorporated in Commonwealth Laws and legal frameworks, it is critical that these be consistent across state, territory and Commonwealth legislation.

4. Supported Decision-Making in Commonwealth Laws

Proposal 4–1 Commonwealth laws and legal frameworks should encourage supported decision-making by adopting a model for individual decision-making consistent with the National Decision-Making Principles and Proposals 4–2 to 4–9 (the ‘Commonwealth decision-making model’).

MHCC agree that the “Commonwealth decision-making model represents a significant shift” (p.76) which would require reconfiguration of decision-making approaches across state and territory law. Unfortunately, a number of jurisdictions have reviews of mental health and disability legislation (particularly in the context of the NDIS) either recently assented or currently passing through parliament with capacity and decision making approaches as elements under consideration. We are concerned that there will be (albeit, possibly temporary) inconsistencies across these instruments.

Question 4–1 In what areas of Commonwealth law, aside from the National Disability Insurance Scheme, social security, aged care, eHealth and privacy law, should the Commonwealth decision-making model apply?

MHCC recommend that the ALRC consider the Commonwealth Decision making model to also apply to Medicare, pensions and taxation particularly in relation to superannuation.

Question 4–2 Are the terms ‘supporter’ and ‘representative’ the most appropriate to use in the Commonwealth decision-making model? If not, what are the most appropriate terms?

² Donnelly, M 2010, ‘Healthcare Decision-Making and the Law—Autonomy, Capacity and the Limits of Liberalism’, Cambridge University Press, 2010, 2.

MHCC prefer the word 'representative' which we consider to be a much less patronising and respectful term to use than 'supporter'.

Proposal 4–2 The objects or principles provisions in Commonwealth legislation that involves decision-making by people who may require decision-making support should reflect the National Decision-Making Principles.

MHCC agree that the existing objects and provisions contained in relevant legislation be amended to reflect the National Decision-Making Principles (NDMPs). Where no such provisions exist, they should be included so as to guide the application and interpretation of the Act as a whole.

Proposal 4–3 Relevant Commonwealth laws and legal frameworks should include the concept of a 'supporter' and provide that an agency, body or organisation may establish supporter arrangements. In particular, laws and legal frameworks should reflect the National Decision-Making Principles and provide that:

- (a) a person who requires decision-making support should be able to appoint a supporter or supporters at any time;
- (b) where a supporter is appointed, ultimate decision-making authority remains with the person who requires decision-making support;
- (c) any decision made with the assistance of a supporter should be recognised as the decision of the person who requires decision-making support; and
- (d) a person should be able to revoke the appointment of a supporter at any time, for any reason.

MHCC agree that where a 'representative' is appointed, ultimate decision making remains with the person requiring support. However, we are aware that some people will require, at certain times or when their impairment is enduring and permanent, support with day to day living decisions and not just surrounding major decisions in their lives.

Nevertheless, the concept of 'dignity of risk' must always be at the forefront of decision making and the necessity for representatives to maximise self-determination. A person requiring a representative should always be able to exercise choice and control, and revoke appointment, even if the person is a close family member or appointed guardian.

Question 4–3 In the Commonwealth decision-making model, should the relationship of supporter to the person who requires support be regarded as a fiduciary one?

We recognise the problem with regards to the potential liability of representatives, which will vary according to the specific support needs that led to appointment. We propose that this should be explored further in the light of some particular duties, and the unintended consequences of the potential reluctance of people to take on these roles if they feel the personal risk of liability is too high, especially if they feel they are supporting a person's choice which could be considered by others in a different light.

Proposal 4–4 A Commonwealth supporter may perform the following functions:

- (a) assist the person who requires decision-making support to make decisions;
- (b) handle the relevant personal information of the person;
- (c) obtain or receive information on behalf of the person and assist the person to understand information;
- (d) communicate, or assist the person to communicate, decisions to third parties;
- (e) provide advice to the person about the decisions they might make; and
- (f) endeavour to ensure the decisions of the person are given effect.

Whilst we support the proposal in 4-4, we are concerned about safeguards and monitoring of representatives, where a person being supported has difficulty communicating their preferences. We urge that the particular Commonwealth agencies have safeguard mechanisms in place to monitor practices and undertake reviews from time to time to ensure that there is no abuse of the supporter's role or duties.

Question 4–4 What safeguards in relation to supporters should be incorporated into the Commonwealth decision-making model?

We recognise the complexity of ensuring safeguards both for the person requiring support and the representative. However we endorse the suggestion of the key safeguards as outlined (4.63, p.90) in the proposed duties of supporters to include:

- the ability of the person who requires decision-making support to revoke the appointment at any time;
- provision for appointment of more than one supporter; and
- the provision of guidance and training to people who require decision-making support, supporters and Commonwealth departments and agencies interacting with supporters.

Proposal 4–5 Relevant Commonwealth laws and legal frameworks should provide that Commonwealth supporters must:

- (a) support the person requiring decision-making support to make the decision or decisions in relation to which they were appointed;
- (b) support the person requiring decision-making support to express their will and preferences in making a decision or decisions;
- (c) act in a manner promoting the personal, social, financial, and cultural wellbeing of the person who requires decision-making support;
- (d) act honestly, diligently and in good faith;
- (e) support the person requiring decision-making support to consult with 'existing appointees', family members, carers and other significant people in their life in making a decision; and
- (f) assist the person requiring support to develop their own decision-making ability.

For the purposes of paragraph (e), 'existing appointee' should be defined to include existing Commonwealth supporters and representatives and a person or organisation who, under Commonwealth, state or territory law, has guardianship of the person, or is a person appointed formally with power to make decisions for the person.

We agree that the duties of representatives should be set out in the legislation relevant to the area of Commonwealth law, and that the manner in which representatives should act should reflect the duty imposed on 'nominees' under the *National Insurance Scheme Act 2013* (Cth) but include elements relating to financial and cultural wellbeing.

Question 4–5 What mechanisms should there be at a Commonwealth level to appoint a representative for a person who requires full decision-making support?

The best mechanism for appointing a representative is when a person appoints their own representative. We suggest that other mechanisms are the usual ones of the court, tribunal or other body, always with the understanding that the person can refuse the representative appointed, unless they require full decision-making support. We do not agree with the suggestion of a nominee by the Commonwealth agency or department as currently occurs under the *Social Security Act 1999* (Cth) or the NDIS Act.

Proposal 4–6 Relevant Commonwealth legislation should include the concept of a 'representative' and provide that an agency, body or organisation may establish representative arrangements. In particular, legislation should contain consistent provisions for the appointment, role and duties of representatives, and associated safeguards, and reflect the National Decision-Making Principles.

We agree that a body may establish representative arrangements, but not the agency providing the funds or services such as Social Security or the National Disability Insurance Agency (NDIA). Only an independent tribunal, body or court should be able to fulfil this function. The legislation should contain the consistent provisions for appointment as suggested in Proposal 4-6 above.

Proposal 4–7 A Commonwealth representative may perform the following functions:

- (a) assist the person who requires decision-making support to make decisions;
- (b) handle the relevant personal information of the person;
- (c) obtain or receive information on behalf of the person and assist the person to understand information;
- (d) communicate, or assist the person to communicate, decisions to third parties;
- (e) provide advice to the person about the decision they might make; and
- (f) endeavour to ensure the decisions of the person are given effect.

We agree with the functions outlined in Proposal 4-7 expanded in more detail in Proposal 4-8.

Proposal 4–8 Relevant Commonwealth laws and legal frameworks should provide that Commonwealth representatives must:

- (a) support the person requiring decision-making support to express their will and preferences in making decisions;
 - (b) where it is not possible to determine the wishes of the person who requires decision-making support, determine what the person would likely want based on all the information available;
 - (c) where (a) and (b) are not possible, consider the human rights relevant to the situation;
 - (d) act in a manner promoting the personal, social, financial and cultural wellbeing of the person who requires decision-making support;
 - (e) support the person who requires decision-making support to consult with ‘existing appointees’, family members, carers and other significant people in their life when making a decision; and
 - (f) assist the person who requires support to develop their own decision-making ability.
- For the purposes of paragraph (e), ‘existing appointee’ should be defined to include existing Commonwealth supporters and representatives and a person or organisation who, under Commonwealth, state or territory law, has guardianship of the person, or is a person appointed formally with power to make decisions for the person.

MHCC agree with the suggestion that the obligation exists for a representative to support a person to express their ‘will, preferences and rights’. This corresponds more effectively with the NDMPs and is preferable to the objective ‘best interests’ test, which currently applies to nominees under Commonwealth legislation.

Proposal 4–9 The appointment and conduct of Commonwealth representatives should be subject to appropriate and effective safeguards.

We agree that consistent with NDMPs (Principle 4) and Article 12(4) of the UNCRPD that all representatives are subject to the stated safeguards. Where there is overlap between areas of decision making, and where the decisions have been made, the authority of the appointee must be recognised under the Commonwealth law, but not automatically (for example if the decision maker’s role in this context is inappropriate). Where a state appointee has a function under Commonwealth law, this role should be subject to all the associated safeguards.

Proposal 4–10 The Australian Government should develop mechanisms for sharing information about appointments of supporters and representatives, including to avoid duplication in appointments.

In the effort to develop mechanisms for sharing information, we express our concerns about matters of information sharing as has been reflected for example in the development of legislation in NSW: in the *NSW Disability Services Act 1993* (DSA) which is to be replaced by the *NSW Disability Inclusion Bill 2014* (The DIB).

In Division 2: Part 1, Clause 4 General Principles (6) - Privacy and confidentiality are inadequately dealt with both in the DSA and the DIB. We recommended that this is well articulated in the *NSW Mental Health Act 2007* (MHA), Clause 189, Disclosure of information: 1 (a) – (e).

We alert the ALRC 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). We 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 regard as best practice in mental health services, and we queried as to how the two pieces of legislation would interface in the context of disclosure of information in our discussions concerning the DIB, earlier in 2014.

We also noted that important principles protecting privacy and confidentiality must be reflected in the DIB in Part 5: Division 6: Clause 35 – Giving information, which demonstrated a lack of protection 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 recommended that there be a further element to this clause that speaks to the requirement that all avenues for representative decision-making have been initiated. Hence, information sharing without consumer consent must be understood as a last resort. We raise these matters as we consider them relevant to Proposal 4-10 in this DP.

Proposal 4–11 The Australian Government should ensure that people who may require decision-making support, and supporters and representatives (or potential supporters and representatives) are provided with information and advice to enable them to understand their roles and duties.

Proposal 4–12 The Australian Government should ensure that Australian Public Service employees who engage with supporters and representatives are provided with regular, ongoing and consistent training in relation to the roles of supporters and representatives.

We agree with the sentiments presented above, that consistent information and advice, and targeted training and support for all people involved in decision making is vital. We are also in agreement with all the comments expressed from 4.105 – 4.112

5. The National Disability Insurance Scheme

Proposal 5–1 The objects and principles in the National Disability Insurance Scheme Act 2013 (Cth) should be amended to ensure consistency with the National Decision-Making Principles.

Proposal 5–2 The National Disability Insurance Scheme Act 2013 (Cth) and NDIS Rules should be amended to include supporter provisions consistent with the Commonwealth decision-making model.

Proposal 5–3 The National Disability Insurance Scheme Act 2013 (Cth) and NDIS Rules should be amended to include representative provisions consistent with the Commonwealth decision-making model.

MHCC endorse Proposal 5-1; 5-2 & 5-3.

Question 5–2 In what ways should the National Disability Insurance Scheme Act 2013 (Cth) and NDIS Rules in relation to managing the funding for supports under a participant's plan be amended to:

- (a) maximise the opportunity for participants to manage their own funds, or be provided with support to manage their own funds; and
- (b) clarify the interaction between a person appointed to manage NDIS funds and a state or territory appointed decision-maker?

The ALRC may be interested to read MHCC submissions presented during 2013 and in early 2014.

NDIS Rules Consultation paper

<http://www.mhcc.org.au/media/7343/sub-ndis-rulesv.f040313.pdf>

Reforming NSW Disability Support: Legislative Structure and Content: Discussion Paper

http://www.mhcc.org.au/media/33220/disability_services_act_review_15.02.13f.pdf

The NSW Disability Inclusion Bill 2014 (The DIB)

http://www.mhcc.org.au/media/40422/disability_inclusion_bill_2014_nsw_v.f_13.02.14.pdf

Whilst we consider the matter raised in sections 6, 7 and 9 of great importance we feel that there will be others more appropriately placed to respond to the proposals and questions.

8. Restrictive Practices

Proposal 8–1 The Australian Government and the Council of Australian Governments should facilitate the development of a national or nationally consistent approach to the regulation of restrictive practices. In developing such an approach, the following should be considered:

- (a) the need for regulation in relation to the use of restrictive practices in a range of sectors, including disability services and aged care;
- (b) the application of the National Decision-Making Principles; and
- (c) the provision of mechanisms for supported decision-making in relation to consent to the use of restrictive practices.

The National Mental Health Seclusion and Restraint Project was a collaborative initiative between the Australian Government and State and Territory Governments. In line with the 'National Safety Priorities in Mental Health: a National Plan for Reducing Harm' the project aimed to reduce and, where possible, eliminate the use of seclusion and restraint in public mental health services. MHCC propose that the key principles for seclusion and reduction practice be clearly reflected in the legislation as principles, outlined in the National Plan for Reducing Harm.³

MHCC endorse the need for a nationally consistent approach to seclusion and restraint. Principles must be reflected in statements that services undertake to ensure restrictive interventions may only be used as a last resort, and after all other less restrictive options reasonably available have been tried or considered and found unsuitable in the circumstances.

Safeguards including a register should be mandatory in all service delivery contexts and monitoring mechanisms and accountability reporting. Any event must be followed up by appropriate trauma-informed counselling, debriefing etc., to minimise re-traumatisation.

The National Consumer & Carer Forum published an important document: Ending Seclusion and Restraint in Australian Mental Health Services.⁴

MHCC thank the ALRC for all their endeavours in promoting equality and human rights in Commonwealth laws, and we express our willingness to be consulted further regarding any matters raised in this submission.

Please feel free to contact me to discuss the contents of this paper or the review in general.



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³ Reference: National Mental Health Working Group, 2005, 'National safety priorities in mental health: a national plan for reducing harm, Health Priorities and Suicide Prevention Branch', Department of Health and Ageing, Commonwealth of Australia, Canberra. Available: <http://www.health.gov.au/internet/main/publishing.nsf/content/mental-pubs-n-safety>

⁴ The National Consumer & Carer Forum, 2009, 'Ending Seclusion and Restraint in Australian Mental Health Services' Available: <http://www.nmhccf.org.au/documents/Seclusion%20&%20Restraint.pdf>