Centre for Disability Law and Policy

Australian Capital Territory Law Reform Advisory Council inquiry into the terms and operation of the Guardianship and Management of Property Act 1991

Submission
July 2015
About Us

The Centre for Disability Law and Policy (CDLP) at the National University of Ireland Galway was formally established in 2008. The CDLP’s work is dedicated to producing research that informs national and international disability law reform, guided by the principles of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). The Centre’s Director, Professor Gerard Quinn, led the delegation of Rehabilitation International during the negotiations of the CRPD in New York. Since its establishment, the CDLP has organised and participated in a number of key events regarding disability law reform. Two members of CDLP staff provided support to the Secretariat of the UN Committee on the Rights of Persons with Disabilities in developing General Comment No. 1 on Article 12. The CDLP also co-ordinates a coalition of over 15 NGOs working on disability, ageing and mental health issues to advocate for human rights-based legislation on legal capacity in the Republic of Ireland in the development of the Assisted Decision-Making (Capacity) Bill 2013. The CDLP is also a regular contributor of legislative and policy submissions on issues regarding legal capacity and has made submissions to the United Nations Committee on the Rights of Persons with Disabilities, the Australian Law Reform Commission, the Department of Justice and the Irish parliamentary Committee on Justice, Defence and Equality.

1. The CDLP welcomes the opportunity to make this submission to the ACT Law Reform Advisory Council (LRAC) review of the Guardianship and Management of Property Act 1991 (hereinafter “the Act”). The CDLP has substantial expertise in this area of the law, and since its establishment, the CDLP continues to be a leading authority – nationally and internationally – on legal capacity and disability rights law. The CDLP has organised and participated in a number of key events regarding disability law reform and legal capacity. These include 3 national conferences in 2011, 2012 and 2013, held in conjunction with Amnesty Ireland, which explored how forthcoming Irish legislation can reflect the changes Article 12 of the Convention on the Rights of Persons with Disabilities demands. The Centre also participated in a Canadian conference titled ‘Taking Personhood Seriously: Legal Capacity Law Reform and the UN Disability Convention’ in 2011. For more information on our international engagement on the CRPD, including Article 12, please see out website at https://www.nuigalway.ie/cdlp/.

2. This submission should be read with reference to our previous submission to the Department of Justice and Equality, Republic of Ireland, on the Assisted Decision-Making (Capacity) Bill (October 2013), our submission to the Australian Law Reform Commission 'Issues Paper' regarding Equality before the Law in January 2014, and our submission to the House of Lords Select Committee on the Mental Capacity Act 2005 (September 2013).

Introduction

3. This submission will refer particularly to the first point of consideration of the Law Reform Advisory Council in its review, particularly:

4. The Act should move away from its current focus on substituted decision-making, ‘best interests’ and mental capacity. Instead, the Act should move toward a framework based on supporting individuals to exercise legal capacity on an equal basis with others. This ‘legal capacity support model’ would remove disability-based discrimination and build on existing protection against discrimination in the ACT and complement the Human Rights Act 2004.

5. The remainder of this submission outlines the mechanisms required to develop a support model of legal capacity, including: being responsive to the needs of any person who requires support to exercise his or her legal agency; replacing ‘best interests’ standards with a will and preferences framework; creating certainty in the application of the law; and applying uniformly to all people.

6. The model of legal capacity support advanced in this submission, is being developed to some extent in law in the Republic of Ireland in the Assisted Decision-Making (Capacity) Bill 2013 (ADM Bill). The ADM Bill has been developed specifically according to the jurisprudence of the CRPD, and could be used to enhance law reform efforts in the ACT.

**Equal Recognition Before the Law and Support Model for Legal Capacity**

7. This submission outlines an alternative support model for legal capacity which is in harmony with Article 12 of the CRPD, and can be applied coherently across the scope of the Act.

8. The interpretation of CRPD Article 12 underlying the formulation of the proposed legal capacity support model outlined below is that:
   - every person has a right to recognition before the law and support to exercise that legal standing irrespective of whether or not they have a disability;
   - this is a non-derogable civil and political right requiring immediate implementation;¹
   - some people require assistance to exercise their legal capacity and governments are required to support individuals who need assistance and safeguard against abuse within that support system - as equality before the law is a civil and political right there is no limit to the level of support that must be provided to achieve this;²
   - the ‘best interests’ standard, and substituted decision-making generally, should be replaced with an adherence to the rights, will and preferences of the individual;
   - legal agency is exercised when will and preference is expressed;
   - the State is obliged to provide the support necessary for a person to express his or her will and preference;
   - failure to provide adequate support, including the inadequate resourcing of support options, may constitute discrimination; and

¹ By virtue of Article 5 and 12 of the CRPD.
exceptional instances will occur where no formulation of support that can determine will and preferences. In this circumstance a representative may be appointed to make decisions based on the ‘best interpretation of the will and preference’ of the individual,\(^3\) including consideration of previously expressed will and preference of the person, and/or also with regard to his or her human rights as applicable to the situation.

9. These features make up the core of the ‘support model’ of legal capacity, and will be elaborated throughout this submission with specific reference to the Act, as well as practical examples of domestic law reform around the world.

The Need to Clearly Distinguish Mental Capacity from Legal Capacity

10. Article 12 of the CRPD indicates the need to distinguish mental capacity and legal capacity. These concepts are distinguished in the Australian Law Reform Commission (ALRC) enquiry into legal capacity, equality and disability in commonwealth law, where the ALRC distinguish ‘legal capacity’ from ‘decision-making capacity.’ Distinguishing the two concepts is crucial to realising the support model of the CRPD in practice, and for the sake of clarity will be elaborated below.

11. ‘Legal capacity’ refers to both a person’s legal standing (legal personality) but also his or her ability to act on such legal standing (legal agency).\(^4\) The exercise of legal capacity in relation to voting helps illustrate this distinction. A person may hold a formal right to vote on an equal basis with others (in which her legal personality is upheld). Yet a lack of reasonable accommodation – such as ramps to enter polling stations, or plain language guides – may mean that a person cannot exercise his or her right to vote on an equal basis with others (her legal agency is denied). Both elements – legal personality and legal agency – are required in order that a person has legal capacity on an equal basis with others.

12. ‘Mental capacity’ (or ‘decision-making capacity’ as the ALRC describe it) is a concept used in ethics and law which asks that someone demonstrates independent capacity to consider a range of options when deciding, to consider the consequences of different options, and to communicate a choice.\(^5\) When a person is deemed to lack mental capacity following a assessment of their cognitive functioning, a substituted decision-maker is authorised to make decisions on his or her behalf — typically according to a ‘best interests’ standard. In this sense, where the person fails to meet the functional assessment for a specific issue, his or her legal capacity is curtailed. Such tests were introduced to replace outdated and extreme forms of legal capacity denial – usually where a person was found to be ‘wholly’ incapable of making any decisions about his or her life.\(^6\)

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\(^{3}\) Committee on the Rights of Persons with Disabilities, General Comment No. 1 – Article 12: Equal Recognition Before the Law, Paragraph 18bis, UN Doc. No. CRPD/C/GC/1, adopted at the 11th Session (April 2014).


\(^{5}\) ‘Understand and appreciate’ tests for capacity are advanced by Beauchamp and Childress who argue that competent decision-making occurs where an individual has capacity to understand relevant information, can cast judgement on the information according to their values, envisage an outcome, and freely communicate her or his ultimate wishes. See TL Beauchamp and JF Childress, Principles of Biomedical Ethics (Oxford University Press, 4th Ed. 1994) 135.

13. Yet functional assessments of mental capacity can now be seen to violate the human right to equal recognition before the law. The CRPD Committee, which provides guidance on Article 12 in its first General Comment which states that functional assessments of mental capacity are prohibited because they are ‘discriminatorily applied to people with disabilities.’

14. Under the current Act, assessments of decision-making ability may appear to be prima facie disability-neutral (i.e. where no diagnostic threshold is required). However, in practice people with disabilities – and those with intellectual, cognitive and psychosocial disabilities in particular – are disproportionately more likely to be considered for, and to fail such assessments.

15. Further, functional assessments of mental capacity impose a higher threshold for decision-making than is imposed on the majority of citizens. This makes functional assessments of decision-making ability discriminatory against persons with disabilities in effect, which is contrary to the provisions of the CRPD, where Article 12 operates in conjunction with Article 2 to prohibit discrimination in ‘purpose or effect.’ The CRPD Committee elaborates on the violation of Article 12 that occurs with functional assessments of mental capacity in its first General Comment:

The functional approach attempts to assess mental capacity and deny legal capacity accordingly. (Often based on whether an individual can understand the nature and consequences of a decision and/or whether she/he can use or weigh the relevant information.) This functional approach is flawed for two key reasons. The first is that it is discriminatorily applied to people with disabilities. The second is that it presumes to be able to accurately assess the inner-workings of the human mind and to then deny a core human right – the right to equal recognition before the law – when an individual does not pass the assessment. In all these approaches, a person’s disability and/or decision-making skills are taken as legitimate grounds for denying his or her legal capacity and lowering his or her status as a person before the law. Article 12 does not permit such discriminatory denial of legal capacity, but rather requires that support be provided in the exercise of legal capacity.

RECOMMENDATION: Any statutory materials developed by the LRAC should clearly differentiate the concepts of legal and mental capacity. At a minimum, a definition of ‘legal capacity’ should be added to the Act, to avoid confusion and to ensure the consistent interpretation and application of the Act in light of human rights principles. According the UN Committee on the Rights of Persons with Disabilities’ General Comment 1 on Article 12, legal capacity should be understood as the ability both to hold rights and to exercise them. Insert definition of ‘legal capacity’ into Part 1, as follows:

“Legal capacity’ means the ability to hold rights and duties and to exercise these rights and duties.”

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8 Committee on the Rights of Persons with Disabilities, General Comment No. 1 – Article 12: Equal Recognition Before the Law, Paragraph 13, UN Doc. No. CRPD/C/GC/1, adopted at the 11th Session (April 2014).
Support Model of Legal Capacity and Supported Decision-Making

16. Once legal capacity has been clearly defined, support measures to assist people to exercise legal capacity on an equal basis with others can be strengthened.

17. In determining whether measures meet the criteria set down in the General Comment for ‘supported decision-making’ the CRPD Committee has set out the following criteria in paragraph 25:

- (a) Supported decision-making must be available to all. A person’s level of support needs (especially where these are high) should not be a barrier to obtaining support in decision-making;
- (b) All forms of support in the exercise of legal capacity (including more intensive forms of support) must be based on the will and preference of the person, not on what is perceived as being in his or her objective best interests;
- (c) A person’s mode of communication must not be a barrier to obtaining support in decision-making, even where this communication is non-conventional, or understood by very few people;
- (d) Legal recognition of the support person(s) formally chosen by a person must be available and accessible, and the State has an obligation to facilitate the creation of support, particularly for people who are isolated and may not have access to naturally occurring supports in the community. This must include a mechanism for third parties to verify the identity of a support person as well as a mechanism for third parties to challenge the decision of a support person if they believe that the support person is not acting based on the will and preference of the person concerned;
- (e) In order to comply with the requirement set out in Article 12, paragraph 3, of the Convention that States parties must take measures to “provide access” to the support required, States parties must ensure that support is available at nominal or no cost to persons with disabilities and that lack of financial resources is not a barrier to accessing support in the exercise of legal capacity;
- (f) Support in decision-making must not be used as justification for limiting other fundamental rights of persons with disabilities, especially the right to vote, the right to marry (or establish a civil partnership) and found a family, reproductive rights, parental rights, the right to give consent for intimate relationships and medical treatment, and the right to liberty;
- (g) The person must have the right to refuse support and terminate or change the support relationship at any time;
- (h) Safeguards must be set up for all processes relating to legal capacity and support in exercising legal capacity. The goal of safeguards is to ensure that the person’s will and preferences are respected.’

The General Comment has set forth these key provisions based on the belief that a supported decision-making regime should allow for primacy of a person’s rights, will and preferences.

18. These criteria should be more fully reflected in the Act, where support measures could be strengthened and expanded. Even cautious interpretations of the CRPD acknowledge that the CRPD directs States

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9 CRPD/C/11/4 (25).
Parties to strengthen provision of ‘positive rights’ to people with disabilities (for example where resources are provided to assist a person to exercise his or her right) as compared to traditional guardianship laws which focus on ‘negative rights’ (such as freedom from state intervention and the point at which that freedom is denied). Positive rights with regard to the Act entail resources being provided to assist people to exercise their legal capacity, especially via decision-making support, but also via personal advocacy services, plain language information, and so on.

RECOMMENDATION: Introduce specific decision-making support arrangements, which assist people to hold and exercise their legal capacity on an equal basis with others without requiring an assessment of mental capacity. The essential questions for a new framework remain: Are a person’s will and preference known? If so, and it is legal to do so, how can his or her will and preference be given effect?

RECOMMENDATION: The Guardianship Tribunal should refer people to supported decision-making training and resources in the community (as opposed to the Tribunal doing the training) so that there is an ability for skill-development in supported decision-making outside the guardianship realm, and that decision makers and their supporters have somewhere to go to get confident in practicing supported decision-making. An example of such an organisation is Advocacy for Inclusion, or ADACAS.

PRACTICAL EXAMPLES OF SUPPORT:

Canadian law provides for a ‘representative agreement’ in which an ‘assistant’ can be appointed to assist a person to exercise his or her legal capacity, including by providing support to the relevant person to make decisions and live a self-directed life. The Representation Agreement Act 1996 in British Columbia provides a specific means of appointing assistants on the basis of their relationship being characterised as being one of trust (including where there is no sign of abuse or coercion). Similarly, the Victorian Law Reform Commission has advanced a spectrum of support that includes ‘decision-making assistants,’ and ‘co-decision-makers’ being statutorily appointed, again, to help a person live a self-directed life. In Ireland, the Assisted Decision-Making (Capacity) Bill 2013 will introduce a number of decision-making categories for assisting people to exercise their legal capacity, including decision-making assistance agreements, co-decision-making agreements, the appointment of decision-making representatives. These concrete, practical examples of statutory support designed to help people exercise their legal capacity can inform the development of statutory categories of decision-making and legal capacity support.

RECOMMENDATION: The Act should include a principle of providing support in line with the legal capacity model, such as the following: 10

1(a) A person who requires support should be able to appoint a supporter or supporters at any time:
   a. where a supporter is appointed, ultimate decision making authority remains with the supported person;
   b. any decision made with the assistance of a supporter should be recognised as the decision of the supported person; and

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c. a person should be able to revoke the appointment of a supporter at any time, for any reason.

(b) Support may include:
   d. support to obtain, receive or understand information relevant to a decision and the effect of a decision;
   e. support to retain information necessary to the extent necessary to make a decision;
   f. support to use or weigh information as part of the process of making a decision;
   g. support to communicate a decision to third parties;

(c) Support persons may also:
   h. provide advice;
   i. handle the relevant personal information of the person;
   j. endeavour to ensure the decisions of the person are given effect; and
   k. assist the person to develop their use of decision making supports.

(d) In addition to formal support providers, the role of families, carers, and other significant persons in supporting persons to exercise their legal capacity should be acknowledged and respected.

Reasonable Accommodation

19. Providing support to exercise legal capacity relies on the concept of ‘reasonable accommodation.’ ‘Reasonable accommodation’ means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.11 Further, according to the terms of the CRPD, “discrimination on the basis of disability” (...) includes all forms of discrimination, including denial of reasonable accommodation.”12

20. Many people will simply require a specific reasonable accommodation to enable them to exercise legal capacity in respect of a relevant decision – such as the availability of information in an accessible format. If trusted relationships exist, and such lines of communication are open, there is no need for substitute decision-making arrangements.

21. The addition of a definition of ‘reasonable accommodation’ to the Act, will help clarify the duties of third parties (including disability service providers, local authorities, healthcare professionals, and other figures) towards the relevant persons.

RECOMMENDATION: Insert definition of ‘reasonable accommodation’ into the Act’s definitions, based on the following:

11 CRPD, Article 2.
12 Ibid.
‘Reasonable accommodation’ means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.\(^\text{13}\)

**Replace ‘Best Interests’ with the Will and Preferences Approach**

22. The ‘interests’ standard should be discarded. Instead, the will, preferences and rights of persons who may require decision-making support can direct decisions affecting their lives, as long as respecting persons will and preferences is possible within the bounds of the current law. Even where a person’s will and preferences are unclear, the person can be supported to exercise his or her legal capacity without recourse to a ‘best interests’ framework.

23. The General Comment on Article 12 by the CRPD Committee states that “(a)ll forms of support in the exercise of legal capacity (including more intensive forms of support) must be based on the will and preference of the person, not on what is perceived as being in his or her objective best interests.”\(^\text{14}\)

24. The ‘best interests’ standard is problematic not simply from a human rights perspective. Laurie and Mason summarise a prominent critique, arguing that the ‘essentially paternalistic [‘best interests’ test is] inappropriate when applied to adults.’\(^\text{15}\) The Victorian Law Reform Commission criticises the ‘best interests’ standard as being overly vague,\(^\text{16}\) endorsing the view that ‘best interests’ ‘has come to constitute somewhat of a euphemism for overriding free will.’\(^\text{17}\) The drafters of the original Act have clearly sought to transform the ‘best interests’ standard to discard its negative connotations, and prioritise the will and preference of the person compared to older, more paternalistic approaches.

25. However, the Act should join other law reform efforts which have sought to discard the ‘best interests’ standard altogether. For example, the Australian Law Reform Commission proposed the replacement of the ‘best interests’ test with a paramount consideration of the rights, will and preferences of the person (including the ‘best interpretation of the persons will and preference’).\(^\text{18}\)

**RECOMMENDATION:** Replace ‘interests’ standard with a preference for adhering to the rights, will and preference of the person.

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\(^\text{13}\) Ibid.

\(^\text{14}\) CRPD/C/GC/1 (25(b)).


\(^\text{17}\) The Victoria Public Advocate argues: ‘In common usage, ‘best interests’ has come to be associated negatively with paternalism which itself is perceived negatively as being antithetical to individual rights.’ Ibid s 17.120.

Recognition of ways Legal Capacity can be Recognised

26. Once legal capacity is defined and support mechanisms provided for, practical steps can be taken to replace the ‘best interests’ and mental capacity model with recognition in law that individuals can exercise legal capacity in a wide variety of ways – including through the use of support measures.

**PRACTICAL EXAMPLE:**

The text proposed by the CDLP for inclusion in the ADM Bill in Ireland, provides an example of legislative text for gaining equal recognition before the law:

“(1) Legal capacity may be exercised:

a) by the relevant person with decision-making supports as needed (including a decision-making assistant*) and/or reasonable accommodation; or

b) by the relevant person and their co-decision maker,* acting jointly; or

c) in a situation of last resort, where all efforts to ascertain the relevant person’s will and preferences have been made and the relevant person’s will and preferences remain not known, legal capacity may be exercised by the relevant person’s legal capacity (i.e. decision-making representative, attorney, or patient-designated healthcare representative in advance healthcare directive*).

(2) Where legal capacity is exercised with the support of a decision-making assistant, co-decision-maker, or is being made by a person selected to represent the relevant person (decision-making representative, attorney, or patient-designated healthcare representative)*, and where the relevant person’s will and preferences are not known, the decision shall be guided by the individual’s best interpretation of the relevant person’s will or preferences and how these are to be applied to a specific decision(s).

(3) In applying subsection (2), decision-making assistants, co-decision-makers and persons selected to represent the relevant person must be able to provide a reasonable account of how this interpretation was arrived at.

* These categories refer to the legislative mechanisms for exercising legal capacity proposed under the ADM Bill.

‘Hard Cases’ under the Support Model for Legal Capacity – Defining ‘Best Interpretation’

27. Following the release of the first General Comment of the CRPD Committee, it is possible to address how decisions can be made as a last resort by outside decision-makers in ways that provide for necessary safeguards without violating the individual’s human rights.

28. While intervention in some exceptional cases which conflict with the individual’s will and preferences should be permissible, such interventions should be disability-neutral and not justified on the basis of an individual’s decision-making ability. This is challenging, as there must be scope to allow for tolerated risk-taking under law (for example, people playing extreme sports, people abusing alcohol, and those living in abusive relationships). There must also exist sufficient safeguards to ensure people are afforded protection by the government on an equal basis with others.

29. The support model for legal capacity can be implemented in law and policy in such a way that strikes this balance. Where a decision needs to be made and an individual is non-communicative or minimally communicative after significant attempts have been made to facilitate communication, an outside decision-maker can make a decision on her or his behalf in accordance with the ‘best
interpretation’ of her or his will and preference, taking into account past expressed preferences, where available, knowledge gained from family and friends and any other evidence that is available.\textsuperscript{19}

30. In this situation, the individual must be closely consulted to discover who she or he would like to appoint as a representative decision-maker. If she or he is communicating but not clearly expressing who she or he would like to make a decision on her or his behalf, then an outside decision-maker could be appointed, but again, could only make decisions that were in accordance with the best interpretation of her or his will and preference. This will rarely be an easy task, however ‘best interest’ determinations that are currently used are similarly difficult in these situations. Article 12 is merely shifting these difficult decisions from focusing on judgment existing outside the individual to the individual’s own will and preference.

31. Where an individual is communicative but is expressing conflicting wishes, after all efforts have been made to clarify and reconcile P’s will and preferences, an outside decision-maker can make a decision based on the best interpretation of her will and preference at that particular time. This may be one of the most difficult situations in which to apply Article 12. These situations will always be difficult – they are difficult under ‘best interests’ determinations and they will continue to be difficult under an approach that prioritises will and preference.

32. Where an individual’s will and preferences are clear but impracticable, the law should ask nothing more than it already asks. If an individual’s will and preference are to undertake an illegal action, no one can be forced to support or realise that will and preference and the individual can be held responsible for the decision if the crime or illegal action is committed.

33. This explanation of what to do in the ‘hard cases’ should not be equated to substitute decision-making systems that currently exist. There are clear distinctions which characterize the support model of legal capacity, which are 1) using ‘rights, will and preference’ as the guiding paradigm as opposed to ‘best interest,’ 2) not denying legal capacity to individuals with disabilities on a different basis, and 3) not imposing outside decision-makers against the will of the individual.\textsuperscript{20}

34. However, there are times in which a decision needs to be made and the relevant individual is not able to make a decision or needs assistance in making the decision. Article 12 can and does address these situations without the need for substituted decision-making.

35. For example, in a situation in which an individual is displaying behaviours of serious self-harm, the support paradigm does not leave the individual to perish. Instead, it asks support people around the person to closely examine what is happening and to support the individual by taking actions that will facilitate her or his decision-making ability to a point at which she or he can clearly express her or his will and preferences. This could mean a variety of things, including but not limited to assisting the individual in stopping the self-harming behaviour and interacting with the individual in a caring

\textsuperscript{19} CRPD/C/GC/1.
\textsuperscript{20} CRPD/C/GC/1.
and understanding manner and/or attempting to create an environment that the individual feels safe and comfortable in to allow her or him to be in an optimal decision-making scenario. Throughout any interaction, the goal remains of arriving at the will and preference of the individual. Further, according to the terms of the CRPD, any emergency interventions must adhere to the principle of non-discrimination by ensuring that criteria for crisis interventions do not discriminate on the basis of disability (as is the case with mental health diagnosis or mental capacity assessments).

36. The need of emergency intervention at a certain point will always be required in every society – and the point at which intervention can be justified has to be reached by consensus and dialogue with civil society, including disability people’s organisations. But that intervention should not be justified on the basis of disability. Instead, it should be based on the level of unacceptable risk which an individual is subjecting themselves or someone else to. Once again, disability-neutral criteria must be developed, such as extreme self-harm, and so on. Currently, s5 of the Act is specifically based on ‘the person’s decision-making ability [being] impaired because of a physical, mental, psychological or intellectual condition or state, whether or not the condition or state is a diagnosable illness.’ This would seem to contradict the non-discriminatory provisions of the CRPD as it specifically identifies ‘physical, mental, psychological or intellectual conditions or states’.

37. The duty of care is likely to arise in ‘hard cases’. While there is not space in this submission for a full analysis of the duty of care in relation to Article 12, it will be important to re-examine practices that are currently justified as falling under a ‘duty of care,’ but may be unduly restricting the lives of people with disabilities. The gravity of these issues highlights the importance of exerting great efforts to discover the will and preference of an individual and to help realise that will and preference to the greatest degree possible.

38. These solutions are only intended to apply to the ‘hard cases’, and should not encroach into cases where an individual is expressing a will and preference – even where the will and preference of the individual is contrary to medical advice or to advice of mental health professionals. It should also not be used to impose an outside decision-maker on a person who is expressing an unpopular or unorthodox decision. The solutions proposed for these ‘hard cases’ only apply at the end of a process where there is a genuine inability to understand a person’s will and preference or where it is impossible to realise the person’s will and preferences without breaching some other aspect of the law.

RECOMMENDATION: The Act should define the notion of ‘best interpretation of will and preferences,’ which may have to guide decisions in situations where the will and preferences of the individual are unclear or unknown, as follows:

‘Best interpretation’ means ‘the interpretation of the relevant person’s past and present communication (using all forms of communication, including, where relevant, total
communication, augmented or alternative communication, and non-verbal communication, such as gestures and actions) that seems most reasonably justified in the circumstances.  

This language could be used to guide the ministries in their development of the Act in responding to situations of last resort. (More extensive rationale and textual amendment suggestions developed for the ADM Bill are available on request).

The Right to Refuse Support

39. Support should be readily available but should never be imposed upon someone against his or her wishes. Safeguards must ensure individuals can refuse offers of assistance regardless of whether a third party considers that they require, or would benefit from support. Such safeguards will help to ensure full respect for the individual’s will and preferences.

40. The CRPD Committee has made clear that the individual has the option to not exercise his or her right to support in accordance to Article 12, Paragraph 3. In the General Comment, the CRPD Committee specified that “the person must have the right to refuse support and terminate or change the support relationship at any time.”

41. As a practical example, in Ireland’s ADM Bill, it is clear that if a relevant person exercises the right to use available support, P retains the ability to change his or her mind at any point in time. For example, with respect to the provisions on the creation of decision-making assistance agreements between a relevant person and a support person, the Irish Bill states that “Nothing in this section shall be construed to prevent the appointer of a decision-making assistant from revoking or varying the decision-making assistance agreement which appointed the decision-making assistant.” This is particularly important, as it does not require the relevant person to reach a particular standard of decision-making ability (i.e. mental capacity) prior to revoking or changing a decision-making assistance agreement.

RECOMMENDATION: The safeguards of the decision-making model should be set out, including establishing clear duties for supporters and recognising the ability of the supported person to revoke the support.

Safeguards to Prevent Undue Influence and Coercion

42. In order to prevent “undue influence”, the CRPD Committee has called for safeguards for the exercise of legal capacity while respecting “the rights, will and preferences of the person, including the right to take risks and make mistakes.”

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21 Centre for Disability Law and Policy, From Mental Capacity to Legal Capacity (Amendment) (No 2) Assisted Decision-Making (Capacity) Bill 2013 2.1.5. (Available on request).
22 Ibid.
23 CRPD/C/GC/1 (19)
24 CRPD/C/GC/1 (29(g)).
25 CRPD/C/GC/1 (22)
26 Assisted Decision-Making (Capacity) Bill 2013, s 10(11).
27 CRPD/C/GC/1 (22)
43. Where there is a suspicion an individual is being unduly influenced by another, Article 12 of CRPD directs that the law must treat people with disabilities the same as it does people without disabilities. For example, contract law provides for the invalidation of a contract where undue influence is found based on the nature of the relationship between the parties, not the existence of the label of disability. Where there is suspicion that a person with a disability may be experiencing undue influence, the law must only be allowed to intervene to the same extent as it would for a person without a disability. People without disabilities are permitted, under the law, to choose to live in settings that may seem unorthodox to outsiders. Some may even be in abusive households or under the oppressive control of a friend or family member. People with disabilities must be given the same freedom. However, there is an obligation to provide services that help reduce dependence and guarantee an alternative to abusive or dangerous settings; for example, supported living funding, domestic violence services, affordable housing and supported employment.

44. The term ‘undue influence’ must be carefully defined so as not to impose a degree of influence which is discriminatorily applied to persons with disabilities. After all, all adults are subject to some degree of influence and manipulation by those around them. When defining duties, or responsibilities, it can be useful to draw on terms advanced by the CRPD Committee, such as where the ‘quality of the interaction between the support person and the person being supported includes signs of fear, aggression, threat, deception or manipulation.’

Ensuring Nominated Persons and other Support Persons

45. As noted, the ADM Bill includes provisions on the creation of decision-making assistance agreements between a relevant person and a support person. The Irish Bill states that “Nothing in this section shall be construed to prevent the appointer of a decision-making assistant from revoking or varying the decision-making assistance agreement which appointed the decision-making assistant.” This is particularly important, as it does not require the relevant person to reach a particular standard of decision-making ability (i.e. mental capacity) prior to revoking or changing a decision-making assistance agreement.

RECOMMENDATION: if a relevant person is indicating a wish to involve a second person with whom they are in a relationship characterised by trust, the involvement of this second person should be granted, regardless of the relevant person’s decision-making ability (mental capacity), though with adequate safeguards to prevent against abuse.

RECOMMENDATION: Adequate safeguards must include duties or functions placed on nominated persons and other support persons which include, for example, the following:

(a) to advise the relevant person by explaining relevant information and considerations relating to a relevant decision in a manner the appointer can understand,
(b) to ascertain the will and preferences of the relevant person on a matter the subject or to be the subject of a relevant decision and to assist the appointer to communicate them,
(c) to assist the relevant person to obtain any information or personal records (in this section referred to as “relevant information”) that the relevant person is entitled to and that is or are required in relation to a relevant decision,
(d) to assist the relevant person to make and express a relevant decision,
(e) to endeavour to ensure that the relevant person’s relevant decisions are implemented,
(f) to make all reasonable efforts to attempt to build a relationship with the relevant person in order to fully understand the relevant person’s will and preferences,
(g) to assist the relevant person to explore options for each decision to be made, including, where possible, giving the relevant person the opportunity to try different options before making a final decision, and
(h) to support the relevant person to exercise his or her legal capacity and not to supplant the exercise of the P’s legal capacity.

These duties will necessarily differ. For example, those undertaking to make a ‘best interpretation’ judgment will require more stringent duties, such as making a reasonable justification to courts or other authoritative bodies upon request as to how they arrived at a particular decision.

As a final note, we have attached an article by Dr. Piers Gooding, Research Associate at the Centre for Disability Law and Policy (CDLP), which was written for the Human Rights Law Review. The article, ‘Navigating the Flashing Amber Lights of the Right to Legal Capacity in the United Nations Convention on the Rights of Persons with Disabilities: Responding to Major Concerns’ responds to the common criticisms of the UNCRPD approach to guardianship law reform. The CDLP thank the ACT LRAC for the opportunity to contribute to this Inquiry, and would be happy to participate in further consultation on any of the matters raised in this submission.

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Submission to the Department of Justice and Equality on the Assisted
Decision-Making (Capacity) Bill

1st November 2013

The Centre for Disability Law and Policy welcomes the opportunity to make this submission on the Assisted Decision-Making (Capacity) Bill to the Department of Justice and Equality. The Centre for Disability Law and Policy (CDLP) at the National University of Ireland Galway was formally established in 2008. The Centre’s work is dedicated to producing research that informs national and international disability law reform, guided by the principles of the UN Convention on the Rights of Persons with Disabilities (CRPD). The Centre’s Director, Professor Gerard Quinn, led the delegation of Rehabilitation International during the negotiations of the CRPD in New York. Since its establishment, the CDLP has organised and participated in a number of key events regarding disability law reform and legal capacity. These include 3 national conferences in 2011, 2012 and 2013, held in conjunction with Amnesty Ireland, which explored how forthcoming Irish legislation can reflect the changes Article 12 of the Convention on the Rights of Persons with Disabilities demands. The Centre also participated in a Canadian conference titled ‘Taking Personhood Seriously: Legal Capacity Law Reform and the UN Disability Convention’ in 2011. The Centre is also a regular contributor of legislative and policy submissions on issues regarding legal capacity and made a submission on Legal Capacity to the Oireachtas Committee on Justice, Defence & Equality (2011).
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Executive Summary

The Centre for Disability Law and Policy welcomes the publication of the draft Assisted Decision-Making (Capacity) Bill, which introduces many important reforms, such as the opportunity for individuals to make legally binding agreements with others to assist and support them in making their own decisions. While the Bill is a significant improvement on the Scheme of the Mental Capacity Bill published in 2008, further changes are required for it to fully respect the human rights of persons with disabilities, people with mental health problems and older people.

This submission identifies the key areas for reform in order for the Bill to fully reflect the vision of equality, dignity and respect for human rights contained in international human rights generally, and in the UN Convention on the Rights of Persons with Disabilities (CRPD) in particular.

The submission is divided into two parts. The first part aims to provide clarity on the emerging international consensus as to how to operationalize the right to legal capacity in domestic law. This part comprises an in depth analysis of Article 12 of the CRPD, drawing in part from the draft general comment on Article 12 issued by the Committee on the Rights of Persons with Disabilities. Of note is the distinction made by the CRPD Committee between legal capacity and mental capacity, affirming that deficits in mental capacity cannot be used as justification for denying legal capacity. This part also delves into what support means, illuminating how supported decision-making differs from substituted decision-making.

The second part aims at making concrete proposals for amendments to the bill to bring it in line with Article 12 of the UN Convention. Our key proposals include first, the need to define legal capacity in the Bill as including both the capacity to hold rights and to exercise them. Second, the need to replace the presumption of mental capacity with the presumption that people will exercise legal capacity independently, or with supports and accommodations. Third, recommendations aimed at ensuring that assisted decision-making, co-decision-making, representative decision-making and informal decision-making respect the will and preferences of the individual. Underlying these recommendations is the idea that supports for making decisions should be flexible and accessible to all. Fourth, we examine how the provisions in the Bill on enduring powers of attorney and wards of court can be amended to bring them more in line with Article 12. Fifth, we propose the introduction of new parts in the Bill including on advocacy, chemical restraint, detention safeguards and legal aid.

This submission is to be read together with the ‘Textual Amendments to the Assisted Decision-Making (Capacity) Bill’ developed by the Centre for Disability Law and Policy together with a group of civil society organisations.

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1 Draft General Comment on Article 12: Advance Unedited Version, Committee on the Rights of Persons with Disabilities (CRPD), 10th Sess., (September 2-13 2013)
1. Introduction

Article 12 of the UN Convention on the Rights of Persons with Disabilities represents a paradigm shift in understanding the right to legal capacity. Prior to the entry into force of the Convention, there was no international human rights standard that guaranteed to persons with disabilities the enjoyment of legal capacity on an equal basis with non-disabled people. As a result, in many countries around the world, people with disabilities were deprived of their legal capacity – meaning that they were denied the right to make many legally binding decisions – including entering contracts, voting, getting married, and consenting to (or refusing) medical treatment. In many liberal democracies today, it is still considered acceptable to deny people with disabilities the right to exercise their legal capacity, based on the person’s ‘mental capacity’ or decision-making ability. This particularly affects those with intellectual disabilities, psycho-social disabilities, dementia, autism, and other neurological or cognitive disabilities.

The Assisted Decision-Making (Capacity) Bill has been eagerly awaited by many, both in Ireland and abroad, who are anxious to see how Ireland will interpret the emerging international consensus on the right to legal capacity for persons with disabilities and the right to support in the exercise of legal capacity. While the Bill represents an important step forward and provides a number of options for those who wish to use support to exercise their legal capacity, it does so based on a model of mental capacity – meaning that the kind of support a person can use is still based on how the courts view their decision-making ability – rather than giving full recognition to the individual’s will and preferences to choose the type of support they desire. For example, according to the Bill as currently drafted, a person may wish to use a decision-making assistant, but may be found by the court not to have sufficient ‘mental capacity’ to make decisions on their own even with the support of an assistant, and may be appointed a co decision-maker or decision-making representative instead, even if this is not the kind of support the individual really wants.

The focus of this submission is to provide clarity on the emerging international consensus as to how to operationalise the right to legal capacity in domestic law. Many countries worldwide are introducing new legislation in this field, and there is much to be learned from in comparative countries’ experiences. Importantly, the UN Committee on the Rights of Persons with Disabilities has recently published its Draft General Comment on Article 12, which provides a more expansive account than ever before on what the right to legal capacity means and how it should be realised. The key aspects of this Draft General Comment are discussed in further detail below.

For clarity, it is worth setting out the key elements of Article 12 here, before examining the Assisted Decision Making (Capacity) Bill’s compliance with these provisions of the Convention.
Article 12 states as follows:

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.

2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person’s rights and interests.

5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

The first paragraph reaffirms the status of persons with disabilities as persons before the law, i.e. as individuals possessing legal personality, with legal status and agency. This is confirmed by paragraph two, which extends the right to enjoy legal capacity on an equal basis with others to all aspects of life. Some might argue that functional assessments of mental capacity (which result in the removal of an individual’s legal capacity in respect of a particular decision) conform with Article 12.2, since all adults, regardless of whether or not they have a disability, could, in theory, be subject to a functional assessment of their mental capacity, and have their legal capacity removed for a particular decision if they fail to meet a certain standard of decision-making ability.

However, the Draft General Comment on Article 12 clarifies that where functional assessments of mental capacity exist, they are disproportionately applied to people with disabilities. The Committee argues that Article 12 must be read in conjunction with Article 5 (Equality and Non-Discrimination), and that this reading prohibits the use of functional assessment of mental capacity.
to justify substitute decision-making, as the functional test is discriminatory (in both purpose and effect) towards persons with disabilities. ²

The Draft General Comment also clearly states, for the first time, that an individual’s mental capacity cannot be used as a reason to deprive that person of legal capacity, even if the deprivation of legal capacity relates to a single decision.

Legal capacity and mental capacity are distinct concepts. Legal capacity is the ability to hold rights and duties (legal standing) and to exercise these rights and duties (legal agency). It is the key to accessing meaningful participation in society. Mental capacity refers to the decision-making skills of an individual, which naturally vary among individuals and may be different for a given individual depending on many factors, including environmental and social factors. Article 12 does not permit perceived or actual deficits in mental capacity to be used as justification for denying legal capacity.³

Paragraph three contains one of the more novel additions to Article 12 – a state obligation to provide the supports required to exercise legal capacity. This support can take many forms, including, but not limited to, formal agreements with supporters who assist in certain areas of decision-making. Further explanation of the types of measures which constitute support to exercise legal capacity is provided in the Draft General Comment, which states:

‘Support’ is a broad term capable of encompassing both informal and formal support arrangements, and arrangements of varying type and intensity. For example, persons with disabilities may choose one or more trusted support persons to assist them in exercising their legal capacity for various types of decisions, or may use other forms of support, such as peer support, advocacy (including self advocacy support), or assistance in communication. Support for the legal capacity of persons with disabilities might include measures encompassing universal design and

accessibility, for example, the burden of providing understandable information from private and public actors such as banks and financial institutions in order to enable persons with disabilities to perform the legal acts required to open a bank account, enter into contracts, or other social transactions. (Support can also constitute the development and recognition of diverse and unconventional methods of communication, especially for those who use non-verbal communication to express their will and preferences.)

Paragraph four of Article 12 addresses the safeguards required for all measures regarding the exercise of legal capacity. Some argue that this provision allows for some limited forms of guardianship to remain if the appropriate safeguards are in place; however, the Committee on the Rights of Persons with Disabilities has not accepted this argument from any of the countries it has examined to date – even those countries which have interpretative declarations on Article 12, setting out interpretations that Article 12 permits some limited forms of substituted decision-making.

The key phrase in Article 12(4), and one which has been used repeatedly by the Committee on the Rights of Persons with Disabilities in its concluding observations on the countries examined to date, is that safeguards should be designed to respect the ‘rights, will and preferences’ of the person. The term ‘best interests’ does not appear in paragraph four, or in Article 12 at all. Therefore, it is clear that safeguards which are paternalistic in nature, or which envisage the use of substitute decision-making, are not permitted under Article 12. Finally, paragraph five refers specifically to the need to respect legal capacity with regard to financial affairs and property – an issue which was subject to extensive debates during the negotiation of the CRPD.

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5 See Canada’s Reservation to the CRPD, Article 12 (11 March 2010). However, the United Nations Committee on the Rights of Persons with Disabilities (CRPD) has recently noted in several of its concluding observations that steps should be taken to replace substituted decision-making with supported decision-making. Consideration of reports submitted by States parties under article 35 of the Convention: concluding observations, Tunisia, Committee on the Rights of Persons with Disabilities (CRPD), 5th Sess., at 4, UN Doc CRPD/C/TUN/CO/1 (April 11-15 2011); Consideration of reports submitted by States parties under article 35 of the Convention: concluding observations, Spain, Committee on the Rights of Persons with Disabilities (CRPD), 6th Sess, at 5, UN Doc CRPD/C/ESP/CO/1 (September 19-23, 2011).
6 See for example Consideration of reports submitted by States parties under article 35 of the Convention: concluding observations, Australia, Committee on the Rights of Persons with Disabilities (CRPD), 10th Sess., UN Doc CRPD/C/AUS/CO/1 (September 2-13 2013).
The Committee has repeatedly called for the abolition of regimes of substitute decision-making and their replacement with systems of supported decision-making in each of the seven concluding observations it has issued to date.\(^7\) In each of its Concluding Observations on these countries, the Committee expressed concern “that no measures have been undertaken to replace substitute decision-making by supported decision-making in the exercise of legal capacity”.\(^8\) With respect to all countries, the Committee recommended that the states “review the laws allowing for guardianship and trusteeship, and take action to develop laws and policies to replace regimes of substitute decision-making by supported decision-making, which respects the person’s autonomy, will and preferences.”\(^9\) This approach demonstrates the Committee’s acceptance of the need for a support model of legal capacity to be implemented in States Parties to the Convention; and following the publication of the Committee’s Draft General Comment more guidance has been provided on the definitions of ‘substitute decision-making regimes’ and ‘supported decision-making’ respectively. Substitute decision-making is defined as follows:

where 1) legal capacity is removed from the individual, even if this is just in respect of a single decision, 2) a substituted decision-maker can be appointed by someone other than the individual, and 3) any decision made is bound by what is believed to be in the objective ‘best interests’ of the individual – as opposed to the individual’s own will and preferences.\(^10\)

By contrast, the Committee provides a broad interpretation of ‘supported decision-making’, as ‘a cluster of various support options which give primacy to a person’s will and preferences and respect human rights norms.’\(^11\) A non-exhaustive list of support options is provided in the draft General Comment,

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7 See for example Consideration of reports submitted by States parties under article 35 of the Convention: concluding observations, Tunisia, Committee on the Rights of Persons with Disabilities (CRPD), 5th Sess., at 4, UN Doc CRPD/C/TUN/CO/1 (April 11-15 2011); Consideration of reports submitted by States parties under article 35 of the Convention: concluding observations, Spain, Committee on the Rights of Persons with Disabilities (CRPD), 6th Sess, at 5, UN Doc CRPD/C/ESP/CO/1 (September 19-23, 2011).


from relatively minor accommodations, such as accessible information, to more formal measures such as supported decision-making agreements nominating one or more supporters to assist the individual in making and communicating certain decisions to others.\textsuperscript{12}

A supported decision-making regime is a cluster of various support options which give primacy to a person’s will and preferences and respect human rights norms. It should provide protection for all rights, including those related to autonomy (right to legal capacity, right to equal recognition before the law, right to choose where to live, etc.) and rights related to freedom from abuse and ill-treatment (right to life, right to bodily integrity, etc.). While supported decision-making regimes can take many forms, they should all incorporate some key provisions to ensure compliance with Article 12. These conditions include the following:

(a) Supported decision-making must be available to all. An individual’s level of support needs (especially where these are high), should not be a barrier to obtaining support in decision-making.

(b) All forms of support to exercise legal capacity (including more intensive forms of support) must be based on the will and preference of the individual, not on the perceived/objective best interests of the person.

(c) An individual’s mode of communication must not be a barrier to obtaining support in decision-making, even where this communication is unconventional, or understood by very few people.

(d) Legal recognition of the supporter(s) formally chosen by the individual must be available and accessible, and the State has an obligation to facilitate the creation of these supports, particularly for people who are isolated and may not have access to naturally-occurring supports in the community. This must include a mechanism for third parties to verify the identity of a support person as well as a mechanism for third parties to challenge a decision of a supporter if s/he believes the supporter is not acting based on the will and preference of the individual.

\textsuperscript{12} Draft General Comment on Article 12: Advance Unedited Version, Committee on the Rights of Persons with Disabilities (CRPD), 10th Sess., (September 2-13 2013), at para 15.
(e) In order to comply with the Article 12(3) requirement that States Parties take measures to ‘provide access’ to support, States Parties must ensure support measures are available at nominal or no cost to persons with disabilities and that a lack of financial resources is not a barrier to accessing support for the exercise of legal capacity.

(f) The use of support in decision-making must not be used as a justification for limiting other fundamental rights of persons with disabilities. This is especially so for the right to vote, right to marry (or establish a civil partnership) and found a family, reproductive rights, parental rights, the right to give consent for intimate relationships and medical treatment and the right to liberty.

(g) The person must have the right to refuse support and end or change the support relationship at any time they choose.

(h) There must be safeguards for all processes connected to legal capacity and supports to exercise legal capacity. The goal of these safeguards must be to ensure that the person’s will and preferences are being respected.13

Finally, the Draft General Comment provides the following guidance to countries developing legislation on support to exercise legal capacity:

The obligation to replace regimes of substitute decision-making by supported decision-making requires both the abolishment of substitute decision-making regimes, and the development of supported decision-making alternatives. The development of supported decision-making systems in parallel with the retention of substitute decision-making regimes is not sufficient to comply with Article 12. 14

Further to the Committee’s interpretation, and building on the work of Bach and Kerzner, Arstein-Kerslake and Flynn have suggested some additional

components of the support model of legal capacity as enshrined in Article 12. They argue that it is crucial that supports for exercising legal capacity can only be offered to the individual, but not imposed.\footnote{Flynn, E. and Arstein-Kerslake, A. ‘The Support Model of Legal Capacity: Fact, Fiction, or Fantasy?’ (2013) 30(4) Berkeley Journal of International Law (forthcoming) at p. 5.} In situations where the person’s will and preferences remain unknown after significant efforts to discover these have been made, ‘facilitated’ decision-making\footnote{The concept of facilitated decision-making was conceptualized by Michael Bach and Lana Kerzner in “A New Paradigm for Protecting Autonomy and the Right to Legal Capacity” prepared for the Law Commission of Ontario (October 2010) available at <http://www.lco-cdo.org/disabilities/bach-kerzner.pdf> (last accessed 17 May 2013).} could be available, where someone could be appointed to make a decision on behalf of another individual as a last resort. In all situations where support is provided, the most important safeguard, as has been emphasised by the Committee, is the need for decisions to reflect the rights, will and preferences of the individual receiving support.\footnote{Draft General Comment on Article 12: Advance Unedited Version, Committee on the Rights of Persons with Disabilities (CRPD), 10th Sess., (September 2-13 2013), at para 15.}
2. Suggested Amendments to Bill Based on International Human Rights Law

1. Definition of Capacity
The definition of capacity in section 3 of the bill is based on the concept of mental capacity. There is no definition of legal capacity in the bill, nor does the bill contain recognition of universal legal capacity. To be in line with the CRPD, the Bill should replace the definition of mental capacity in the bill with a definition of legal capacity as the capacity both to hold rights and to exercise them (either independently, or with supports and accommodations). It should also contain a statement that all natural persons have legal capacity and that this cannot be removed, reduced or restricted based on mental capacity/disability. The bill should not make support options contingent on a test of mental capacity. Instead, the bill should make it clear that the exercise of legal capacity may be achieved either:

(1) by the relevant person, acting legally independently, and with decision-making supports and accommodations as needed; or
(2) by the person(s) appointed to support the relevant person in exercising his or her legal capacity; and
(3) Where a person is exercising legal capacity with support, there should be a requirement that the decision be guided by the decision-making assistant, co-decision-maker, decision-making representative or attorney’s best interpretation of the adult's will or preferences and how these are to be applied to a specific decision(s);
(4) In applying no. 3 above, “best interpretation” means the interpretation an adult's behaviour and/or communication that seems most reasonably justified in the circumstances; and decision-making assistants, co decision-makers and decision-making representatives must be able to provide a reasonable account of how this interpretation was arrived at.

Assisted decision-making agreements and co-decision-making agreements should be available to anyone to enter into, based on a relationship of trust between the parties and an understanding of the nature of the agreement, rather than a high level of mental capacity (including understanding the consequences of decisions) currently set out in section 3.

2. Assisted Decision-Making
Section 10 of the bill outlines assisted decision-making agreements, allowing appointers to create agreements with assistants if they consider that their capacity is, or shortly may be, in question.
Assisted decision-making provisions should ensure that assisted decision-making appointers should not have to pass a test of functional mental capacity as outlined under section 3. Second, assisted decision-making appointers should have flexibility to appoint more than one assistant for each type of decision, taking into account the fact that at present, by law, a person can appoint more than one attorney to make whichever decisions the person would like. The Bill also envisages the appointment of more than one decision-making representative for each area of decision-making, so should equally give this flexibility to the less restrictive support options. Third, the bill should make it clear that assisted decision-making agreements are legally binding in nature, and as such should place an obligation on third parties to respect decisions made using an agreement.

The following are general guidelines comprising the essential elements of assisted decision-making agreements in line with the CRPD:

a) No front-end test of mental capacity to enter agreement
b) Burden of proof on third parties to demonstrate the agreement is invalid by proving the person did not have the ability to make an agreement
c) Low threshold for ability to make an agreement – e.g. British Columbia model for representation agreements, i.e. agreement is valid if the relationship between the parties can be characterized as one of trust, and the assistant has not breached their duties under the agreement, acted in good faith in accordance with the person’s will and preferences, etc.
d) Ensure that decision-making assistance agreements survive the Mental Health Act, even if the person is involuntarily detained
e) Ensure that decision-making assistance agreements can continue to be amended and will remain valid for the whole length of a person’s life if they so choose, even where the individual’s decision-making ability fluctuates or deteriorates through time

In addition, decision-making assistants should be bound by the following duties:

(a) to build a relationship with the appointer over time in order to fully understand the appointer’s will and preferences, recognizing that this may be a long-term process
(b) to ascertain the will and preferences of the appointer on a matter the subject of a relevant decision, using all forms of communication, including, where relevant, total communication, augmented or alternative communication, and non-verbal communication or gestures
(c) to assist the appointer to communicate his or her will and preferences to third parties,
(d) to assist the relevant person to explore options for each decision to be made, including giving the person the opportunity to try different options before making a final decision
(e) to advise the appointer by explaining relevant information and considerations relating to a relevant decision in a manner the appointer can understand,
(f) to assist the appointer to obtain any information or personal records (in this section referred to as “relevant information”) that the appointer is entitled to and that is or are required in relation to a relevant decision,
(g) to assist the appointer to make and express a relevant decision,
(h) to adhere to the appointer’s will and preferences as communicated and to endeavour to ensure that the appointer’s relevant decisions are implemented.
(i) to abide by the terms of the agreement and not to act beyond the scope of their powers or in breach of their duties
(j) to remain a support for the exercise of the appointer’s legal capacity and not to act as a substitute decision-maker

The Bill should contain consequences for breach of duties.

3. Co-Decision-Making

Section 16 of the Bill sets out how individuals can make co decision-making agreements, the powers of courts to make co-decision-making orders and safeguards.

More safeguards are needed for co-decision-making; as currently framed, the provisions on co-decision-making run the risk of being coercive. In the first place, co-decision-making agreements should be entered into based on the free and informed consent of the relevant person and the co decision-maker.

Individuals should be able to appoint more than one co decision-maker for each area of decision-making, taking into account the fact that at present, by law, a person can appoint more than one attorney to make whichever decisions the person would like. The Bill also envisages the appointment of more than one decision-making representative for each area of decision-making, so should equally give this flexibility to the co-decision-making option.

Further, agreements should be legally binding once appropriate notice and conditions are met – and a court order should not be necessary to give these legal effect.

Strict scrutiny must be applied by the relevant state bodies to investigate possible abuses.

In addition, stronger obligations should be imposed on co decision-makers to support the will and preferences of the person, and more control must be vested in the appointer (rather than the court) in terms of varying, revoking, or discharging agreements.

Co-decision makers should have the following duties:

(a) to continue to build a relationship with the appointer over time in order to fully understand the appointer’s will and preferences, recognizing that this may be a long-term process;
(b) to ascertain the will and preferences of the appointer on a matter the
subject of a relevant decision, using all forms of communication, including, where relevant, total communication, augmented or alternative communication, and non-verbal communication or gestures);
(c) to assist the appointer to communicate his or her will and preferences to third parties;
(d) to assist the relevant person to explore options for each decision to be made, including giving the person the opportunity to try different options before making a final decision;
(e) to support the person to connect with and build a network of naturally-occurring community supports, with a view to transitioning out of co decision-making back to less intrusive options like the decision-making assistance agreement;
(f) to advise the appointer by explaining relevant information and considerations relating to a relevant decision in a manner the appointer can understand;
(g) to assist the appointer to obtain any information or personal records (in this section referred to as “relevant information”) that the appointer is entitled to and that is or are required in relation to a relevant decision;
(h) to assist the appointer to make and express a relevant decision;
(i) to adhere to the appointer’s will and preferences as communicated and to endeavour to ensure that the appointer’s relevant decisions are implemented.
(j) to abide by the terms of the agreement and not to act beyond the scope of their powers or in breach of their duties;
(k) to remain a support for the exercise of the appointer’s legal capacity and not to act as a substitute decision-maker.

The Bill should contain consequences for breach of duties.

4. Representative Decision-Making

Section 23 allows the court to appoint decision-making representatives where a person is found to lack mental capacity for a decision, and either the court is unable to appoint a co-decision maker, or the person would not have mental capacity for that decision even with a co-decision maker.

In the first place, less restrictive measures, such as the use of an assisted decision-making agreement, should be fully explored before the last resort of a representative. Representative decision-makers should be seen as decision-makers of last resort and should only be appointed where the will and preferences of the person are unknown, and their role should only be to act in a manner that represents their best understanding of the person’s will and preferences.

Represented persons should have more choice and control to determine who should or shouldn’t be their representative, as well as the scope of any decisions made.

Decision-making representatives should be under the following duties:
(a) to build a relationship with the relevant person over time in order to fully understand the relevant person’s will and preferences, recognizing that this may be a long-term process
(b) to ascertain the will and preferences of the relevant person on a matter the subject of a relevant decision, using all forms of communication, including, where relevant, total communication, augmented or alternative communication, and non-verbal communication or gestures
(c) to consult those who know the relevant person well, including friends, family members, and others, in order to formulate the best interpretation of the relevant person’s will and preferences
(d) to assist the relevant person to explore options for each decision to be made, including giving the person the opportunity to try different options before making a final decision
(e) to support the person to connect with and build a network of naturally-occurring community supports, with a view to transitioning out of representative decision-making back to less intrusive options like the decision-making assistance agreement
(f) to assist, where possible, the appointer to communicate his or her will and preferences to third parties,
(g) to make concerted efforts to advise the relevant person by explaining relevant information and considerations relating to a relevant decision in a manner the relevant person can understand,
(h) to assist the appointer to obtain any information or personal records (in this section referred to as "relevant information") that the relevant person is entitled to and that is or are required in relation to a relevant decision,
(i) to assist the appointer to make and express a relevant decision,
(j) to make the decision based on his or her best interpretation of the relevant person’s will and preferences as communicated and to endeavour to ensure that the relevant decisions are implemented,
(k) to explain to the relevant person, his or her duties as a representative in a manner the relevant person can understand
(l) to investigate and pursue any opportunities for the relevant person to develop natural and community supports, and to support the relevant person to make decision-making assistance agreements or co decision-making agreements with other supporters if applicable,
(m) to abide by the terms of the agreement and not to act beyond the scope of their powers or in breach of their duties
(n) to remain a support for the exercise of the relevant person’s legal capacity and not to act as a substitute decision-maker

The Bill should contain consequences for breach of duties.

5. Enduring Powers of Attorney

Section 40 allows individuals to create enduring powers of attorney (amending the 1996 Act) to come into effect where they ‘lack or consider that they will shortly lack’ capacity.
Several amendments need to be made to ensure that the provisions on enduring powers of attorney are in line with the CRPD. As currently framed, the enduring powers of attorney section in the Bill is very much based on a deficits model of mental capacity, which assumes that a person loses all decision-making skills at a certain point and that these cannot be regained. Provisions on enduring powers of attorney should not commence based on a person ‘lacking capacity’ as this conflicts with Article 12 of the CRPD. Instead, powers of attorney should be activated on more neutral terms, for example, when an individual is no longer able to clearly articulate their will and preferences or is in crisis, or communicates the desire to activate a power of attorney. In addition, there should be clear way to exit power of attorney; a lower threshold is needed for donor capability to revoke the power under section 49(4).

Second, the interaction between powers of attorney and other forms of advance planning, such as the proposed advance care directives to be introduced at committee stage, must be clarified in the Bill.

Third, while the Bill makes reference to the guiding principles in Section 40(4)(d)(i), it is not advisable to retain the language of ‘act in the interests of the donor’ as this runs the risk of running counter to the will and preferences of the person, which should be the guiding principle in the Bill.

Fourth, the person appointed should be under obligation to minimise conflict of interest.

Fifth, in cases where an attorney wishes to authorise a deprivation of liberty for a relevant person, the attorney should be under obligation to seek specific authorisation from the Court via an application under Part 4 of the Act.

Sixth, the bill should provide for clear consequences for breach of duties of attorney.

Finally, under Section 40 is a typo, where it states ‘donor’ instead of ‘donee’; the word donor refers to the person granting the power so it needs to replace donee as appropriate in Section 40.

6. Wards of Court

Part 5 sets out how the Act will apply to wards of court.

The provisions relating to Wards of Court require review to ensure that all Wards exit wardship, and have the benefit of the provisions of the capacity legislation. In conducting the review of persons currently under wardship, the Court must consider what supports would enable that person to exercise legal capacity, and take steps to avoid imposition of other forms of substitute decision-making on people who were formerly wards.

Confusion regarding wards under 18 years of age remains. Children aged 16 and 17 should be recognized by the Bill as being capable of entering into
decision-making assistance agreements as well as co-decision-making agreements. The Bill needs to address respect for the evolving capacity of children.

7. **Informal Decision-Making**

Part 7 of the Act allows for informal decision-making on personal welfare matters. Part 7 should be significantly amended, at an absolute minimum to provide more safeguards in situations where informal decision-making may arise. The Bill should be amended to ensure standard practice in informal decision-making should be supported decision-making, not substituted decision-making. It is important to remove substitute decision-making powers, particularly for decisions with significant consequences, from informal decision-makers.

Carers, family members, professionals acting in good faith and other third parties should be obligated to support individuals to create an assisted decision-making agreements, rather than resorting to informal substitute decision-making.

There is a need to develop guidelines which could include: establishing a relationship with the person, commitment of time, skills in supporting people with complex communication needs, appropriate consultation with relevant others, and an onus to support development of natural supports. The informal supporter should be under an obligation to minimize conflict of interest.

8. **Advocacy**

People subject to the Bill should have the right to independent advocacy, and the Bill should recognise the role of advocacy in all processes provided for there under. In particular, people who are subject to more restrictive measures under the Bill must have a real ability to challenge the appointment of substitute decision-makers, as well as the decisions they make. In this regard, access to independent advocates is critical. This calls for the immediate and full commencement of the Personal Advocacy Service provided for in the Citizens Information Act 2007, as well as the recognition of different types of advocacy (e.g. self advocacy, peer advocacy and citizen advocacy) and the roles these could play in the Bill.

The Bill should create linkages between the Office of Legal Capacity and Support and the National Advocacy Service; the Office of Legal Capacity and Support shall, where relevant, make referrals to the National Advocacy Service where a relevant person requires professional representative advocacy to develop and communicate his or her will and preferences.
9. Chemical restraint
Sections 27 and 41 set out instances in which decision-making representatives, informal decision-makers and attorneys under enduring powers of attorneys can restrain the relevant person.

The bill does not explicitly identify chemical restraint as restraint – a significant omission. The Bill should explicitly state that chemical restraints fall within the definition of restraint.

The Bill must provide a clear mechanism for people who have been restrained under the Act to challenge this treatment. It should also provide clarity on whether third parties apart from those listed can legally restrain an individual, and if so, what the process is for obtaining court approval for such restraint. The Bill must demand a review of the person’s situation to ameliorate the cause of the behaviour rather than simply permitting others to manage the symptom of the person’s unmet needs through restraints.

10. Detention safeguards
Part 9 covers detention orders and safeguards for persons with a mental disorder (where Mental Health Act 2001 applies) or persons who were placed in an institution by order of a wardship court.

The Bill must be changed to reflect the broad spectrum of individuals who are currently de facto detained. This is more than former wards of court and patients under the Mental Health Act and includes persons who have been placed in social care homes, group homes, or nursing homes against their will. Both the ECHR and the CRPD require a remedy for this detention.

The provisions on de facto detention and safeguards should address the following. First, such provisions should contain a definition of de facto detention where person is placed in a residential setting (e.g. social care institution, nursing home, etc.) against their will and are not free to leave. Second, the principle that detention cannot be based on the person’s disability. Third, there should be an oversight mechanism from which those seeking to place a person in a setting against their will must seek approval for detention. Fourth, provisions on detention should contain clear safeguards to prevent the person from being detained against their will, and a right to challenge or appeal the decision to be detained. Finally, such provisions should recognize that decisions made by a substitute decision-maker to place a person in a particular setting is not the same as the person’s informed consent to be placed there, and should trigger immediate safeguards/monitoring.

Ideally, the Assisted Decision Making (Capacity) Bill should not address detention. However, should the provisions on detention be maintained, at a

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18 Article 14 CRPD
minimum, any system of detention safeguards should incorporate the following principles:

1. Include a clear definition of deprivation of liberty, based upon the recent ECHR authorities. It is preferable that any such definition overshoots and provides safeguards for ‘borderline cases’\(^{19}\), than people who are detained go without protection. Involuntary placement is in any case engages important Article 8 rights to respect for home, family and private life. Increasingly the European Court has emphasised the importance for procedural safeguards in matters where a person’s legal capacity is at stake.\(^{20}\)

2. Principles for detention in any setting must comply with the ECHR and the CRPD.\(^{21}\)

3. There should be a clear procedure which those making decisions, or acting in a way, which results in a deprivation of liberty can follow to engage the appropriate scrutiny and safeguards. There must be mandatory requirements to follow these procedures.

4. Safeguards must provide for accessible individual redress, to seek review of any possible unauthorised or authorised deprivation of liberty in accordance with Article 5(4) ECHR, with provisions for compensation in the event of unlawful deprivation of liberty in accordance with Article 5(5) ECHR.

5. The state must ensure that any places where people may be deprived of their liberty are subject to independent monitoring in accordance with OPCAT and Article 16 CRPD.

6. Any bodies charged with commissioning or funding institutional placements, or with monitoring institutions, must be under a general obligation to alert the appropriate authorities to any possible unauthorised deprivation of liberty. It is suggested that the Office of Legal Capacity and Support should be charged with investigating such cases and bringing them to the attention of the courts.

7. In recognition of the difficulty people who do not have access to detention safeguards may have in seeking individual redress, the

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\(^{19}\) There will always be borderline cases when it comes to deprivation of liberty, Guzzardi v Italy (App no 7367/76) [1980] 3 EHRR 333 [93]. In the case A Local Authority v PB & Anor [2011] EWHC 2675 (CoP) (England and Wales), Charles J acknowledged that ‘there will always be borderline cases on the question whether a person is being deprived of his liberty’, and recommended that ‘in those cases it would be prudent and in accordance with a best interests approach for P, a self interest approach for the care provider and an approach that has regard to the relevant Convention rights to ensure that (i) there is no breach of Article 5, and (ii) the regime of care is reviewed to check that it remains in P’s best interests and is the least restrictive available regime to bring about that result’ and recommended that ‘the [MCA deprivation of liberty safeguards] regime can be applied in such cases of doubt and thus to cover those cases’ [64].

\(^{20}\) e.g. MS v Croatia (App no 36337/10) [2013] ECHR 378; AK and L v Croatia (App no 37956/11) [2013] ECHR 8; Sýkora v The Czech Republic (App no 23419/07) [2012] ECHR 1960; D.D. v Lithuania (App no 13469/06) [2012] ECHR 254; Stanev v Bulgaria (App no 36760/06) [2012] ECHR 46.

relevant regulatory bodies should be empowered to impose fines against services for unlawful any deprivation of liberty. This would act as a deterrent against failure to apply the safeguards appropriately.

The Deprivation of Liberty Standards under the UK Mental Capacity Act 2007 should not guide the Bill on how to proceed regarding deprivation of liberty, in light of the fact that the UK Parliamentary Health Committee has described the situation regarding the deprivation of liberty safeguards as ‘profoundly depressing and complacent’.22

11. Legal Aid
Section 14(6) states that for applications to court under Part 4, each party is responsible for the costs of his own legal representation. If an applicant to court fails to qualify for legal aid due to financial reasons, the court can require that all or part of the costs incurred be paid out of the relevant person’s assets.

The legal aid provisions of the Bill must be strengthened to ensure that there is an automatic right to legal representation, regardless of means, when an application is made to court for a declaration of an individual’s mental capacity for a decision. This is essential to ensure effective access to justice for people affected by the Bill. For applications under Part 4, relevant persons should be entitled to free independent legal representation in the same manner as involuntary patients under the Mental Health Act 2001.

The costs of court applications and expenses of decision-making assistants, co-decision makers, and decision-making representatives, should not be automatically taken from the individual’s estate. This will pose a significant financial barrier to people seeking to realise their rights under the Bill. The Bill should provide people with meaningful access to legal aid, in light of the fact that fundamental human rights are at stake.

The Bill should provide clarity on ability to appeal/challenge the appointment of a co decision-maker or decision-making representative through the courts, including greater access to legal aid for relevant persons who wish to challenge the appointment of, or decisions made by, their substitute decision-makers.

12. Costs
For applications under Part 4, relevant persons should be entitled to free independent legal representation in the same manner as involuntary patients under the Mental Health Act 2001.

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The possibility of awarding costs to other parties from the relevant person’s assets should be removed from the Bill. Otherwise, the relevant person may be paying for their rights to be restricted if they are found not to have the mental capacity to make a decision.

If a court system is used in the Bill, it must be flexible and accessible, which require amendments to legal aid and costs.

13. Office of Legal Capacity and Support (and clarity on interaction with other agencies)

Part 8 establishes an Office of Public Guardian. Functions include registering agreements, appointing and supervising co-decision makers, decision-making representatives and attorneys and reporting to the Court.

All reference to a ‘Public Guardian’ should be removed from the Bill as this has connotations of substituted decision-making. The Bill should re-name this the Office of Legal Capacity and Support to reflect the true purpose of the Bill, which is to enable individuals to have greater autonomy in decision-making. The Bill should also clarify how it will interact with existing agencies such as HIQA, NDA and NAS.

The functions of the Office of Legal Capacity and Support should be:
(a) to receive and consider representations, including complaints, in relation to the way in which a decision-making assistant, co-decision-maker, decision-making representative or attorney for a relevant person is performing his or her functions as decision-making assistant, co-decision maker, decision-making representative or attorney, as the case may be, and

(b) to act on complaints referred to in paragraph (l) which the Office of Legal Capacity and Support is satisfied have substance, including by directing a special visitor or general visitor to conduct an investigation and meet with the complainant, relevant person and decision-making assistant, co-decision maker, decision-making representative or attorney, as the case may be, and to report to the Office of Legal Capacity and Support on any findings; and/or making an application to the court or High Court under this Act.

As an additional safeguards for relevant person who has a decision-making assistant, co decision-maker or decision-making representative, the Bill should provide for easy recourse to the OPG/Office of Legal Capacity and Support for anyone who suspects a person to be failing in their duties under the Act. It should also give the Office of Legal Capacity and Support strong powers for the Office to investigate cases where complaints are made.

The Office should have the power to direct a special visitor or general visitor to act as a monitor for any decision-making assistant, co decision-maker,

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decision-making representative or attorney where the Office is satisfied that there significant concerns that the will and preference of the relevant person is not being fully adhered to in accordance with the duties set out under the Act.
Conclusion

The Programme for Government commitment from Fine Gael and labour is unambiguous. It unequivocally commits to introducing capacity legislation in line with the Convention on the Rights of People with Disabilities. This commitment is to be welcomed and commended.

The reforms called for in this submission are based on best international practice and the guiding ethos of the UNCRPD. Underpinning all the suggested amendments is the core idea of respecting a person’s choices and the need to restore decision-making autonomy to the individual. Introducing these changes to the Bill would enable the government to honour its Programme for Government commitment to introduce capacity legislation which is compliant with the UN Convention on the Rights of Persons with Disabilities, and thus to move steadily towards ratification of the UN Convention. It would also mean a huge and very real improvement to people’s lives.

The CDLP looks forward to continued engagement with the Department of Justice and Equality as the Department continues to develop the Bill.

Figure 1 Signature of Prof. Gerard Quinn

Professor Gerard Quinn,
Director, Centre for Disability Law and Policy, NUI Galway
The Centre for Disability Law and Policy welcomes the opportunity to make this submission to the Australian Law Reform Commission. The Centre for Disability Law and Policy (CDLP) at the National University of Ireland Galway was formally established in 2008. The Centre’s work is dedicated to producing research that informs national and international disability law reform, guided by the principles of the UN Convention on the Rights of Persons with Disabilities (CRPD). The Centre’s Director, Professor Gerard Quinn, led the delegation of Rehabilitation International during the negotiations of the CRPD in New York. Since its establishment, the CDLP has organised and participated in a number of key events regarding disability law reform and legal capacity. These include 3 national conferences in 2011, 2012 and 2013, held in conjunction with Amnesty Ireland, which explored how forthcoming Irish legislation can reflect the changes Article 12 of the Convention on the Rights of Persons with Disabilities demands. The Centre also participated in a Canadian conference titled 'Taking Personhood Seriously: Legal Capacity Law Reform and the UN Disability Convention' in 2011. The Centre co-ordinates a civil society coalition on legal capacity reform in Ireland, which has a membership of over 15 NGOs in the fields of disability, mental health and ageing. The Centre is also a regular contributor of legislative and policy submissions on issues regarding legal capacity and has made submissions to the Department of Justice and the Irish parliamentary committee on Justice, Defence and Equality to draft amendments for Ireland’s Assisted Decision-Making (Capacity) Bill.
Introduction

The Centre for Disability Law and Policy (CDLP) welcomes the opportunity to make this submission in response to the Australian Law Reform Commission’s Discussion Paper on Equality, Capacity and Disability in Commonwealth Laws. Since its establishment in 2008, the Centre continues to be a leading authority – nationally and internationally – on legal capacity and disability rights law, and will focus on these issues in its submission.

This submission does not address all the questions posed by the ALRC in its consultation, but rather focuses on providing responses to Proposals 2-1 to 3-9, as these proposals form the core principles for the further, more detailed, recommendations in the Discussion Paper. The submission focuses on how to address the challenge posed by the General Comment on Article 12 adopted by the UN Committee on the Rights of Persons with Disabilities in April 2014. Specifically, it focuses on how to move away from legal frameworks which require individuals to pass a functional assessments of mental capacity or decision-making ability before recognising the individual’s legal capacity in respect of specific decisions. Also, given the new definition of ‘substituted decision-making’ provided by the UN Committee in its General Comment, this submission addresses how decisions can be made as a last resort by ‘outside decision-makers’ which do not violate the individual’s human rights as provided in the CRPD.

To provide concrete examples of how the goals of the General Comment can be achieved in a domestic legislative framework, this submission will draw on amendments prepared by the Centre, as the co-ordinator of a civil society coalition on legal capacity reform for Ireland’s Assisted Decision-Making (Capacity) Bill. The core provisions of the legislative framework which will be explored include the development of a decision-making support framework which complies with Article 12 – by allowing individuals to enter into support frameworks based on choice and the existence of a relationship of trust between the individual and supporter(s), with no front-end test of mental capacity, once supporters agree to adhere to their duties – primarily, to support the individual to express will and preferences, to communicate those wishes to third parties, and endeavour to ensure they are acted upon within the boundaries of the law.

The submission also explores what legislative options should exist where a person has no supporters, and will and preferences are unknown, drawing on the guidance of the UN Committee that the principle of ‘best interpretation’ of will and preferences should apply. It will also set out how situations of risk can be addressed within an Article 12 compliant framework – where a person expresses will and preferences, which, if acted upon, would result in grave harm to that person and others.

1 Examples of the coalitions submissions and publications can be viewed at the following links http://www.nuigalway.ie/cdlp/documents/principles_web.pdf and http://www.nuigalway.ie/cdlp/documents/amendments_to_bill.pdf
Proposal 2-1:

Proposal 2-1 is an excellent example of Australia’s willingness to comply with the United Nations Convention on Rights of Peoples with Disabilities (UNCRPD). The Centre agrees that Australian Government should withdraw the Interpretative Declaration as it now clearly diverges from the UN Committee’s interpretation of Article 12 of the UNCRPD. When Australia appeared before the 10th session of the Committee on Rights of Persons with Disabilities (the Committee) in 2013, the Committee recommended that Australia review its Interpretative Declaration in order to withdraw. The Committee has made it clear, in their General Comment (GC), that Article 12 should be interpreted in a way that calls for the abolition of substituted decision-making regimes. Furthermore, the Committee has emphasized that there is a difference between mental capacity and legal capacity in Paragraph 12 of the GC, and that perceived or actual deficits in mental capacity (decision-making ability) cannot be used to justify restrictions on legal capacity.

Upon Australia’s ratification of the UNCRPD, Professor Ron McCallum, former Chairman of the Committee, saw the lodging of Australia’s Interpretative Declaration as an example of ‘overabundant legislative caution’. Similarly, at the adoption of the GC on Article 12, Professor McCallum indicated his desire for Australia to review its declaration with a view to withdrawing it. In this discussion paper, the ALRC has shown its understanding of the UNCRPD with its conclusion that the retention of the Interpretative Declaration would hinder Australia’s reform efforts and its continued leadership in the field of promoting equal recognition before the law for persons with disabilities.

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 3-2 is another example of the ALRC’s willingness to comply with the UNCRPD, but could be further strengthened by the introduction of an emphasis that the standards which guarantee that these rights exist for all adults should be

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5 Professor Ron McCallum AO, Committee Hansard, Sydney, 12 November 2010, p. 12.
the same regardless of whether the adult has a disability or not. Article 12 of the UNCRPD has made it clear that there is a difference between mental capacity and legal capacity and that a lack of decision-making ability cannot be used to deny a person the right to legal capacity. It states “The concept of mental capacity is highly controversial in and of itself. Mental capacity is not, as is commonly presented, an objective, scientific and naturally occurring phenomenon. Mental capacity is contingent on social and political contexts, as are the disciplines, professions and practices which play a dominant role in assessing mental capacity.”6 The Committee has made it clear, in the GC, that the decision-making ability cannot be the basis for granting, denying, or restricting legal capacity.

In amendments proposed for the Irish Assisted Decision-Making (Capacity) Bill 2013, the Centre for Disability Law and Policy has called for legal capacity in Ireland to be exercised in several different ways. Our proposed amendment to the Irish Bill aims to shift away from the use of decision-making ability as the key eligibility criteria for determining the use of supports, towards recognizing that individuals can exercise legal capacity in a wide variety of ways – including through the use of support measures. The text of the amendment we propose is included here as it may provide useful guidance to the ALRC in developing its final recommendations:

“(1) Legal capacity may be exercised:
(a) by the relevant person with decision-making supports as needed (including a decision-making assistant) and/or reasonable accommodation; or
(b) by the relevant person and their co-decision maker, acting jointly; or
(c) in a situation of last resort, where all efforts to ascertain the relevant person’s will and preferences have been made and the relevant person’s will and preferences remain not known, legal capacity may be exercised by the relevant person’s legal capacity (i.e. decision-making representative, attorney, or patient-designated healthcare representative in advance healthcare directive).

(2) Where legal capacity is exercised with the support of a decision-making assistant, co-decision-maker, or is being made by a person selected to represent the relevant person (decision-making representative, attorney, or patient-designated healthcare representative), and where the relevant person’s will and preferences are not known, the decision shall be guided by the individual’s best interpretation of the relevant person’s will or preferences and how these are to be applied to a specific decision(s).

(3) In applying subsection (2), decision-making assistants, co-decision-makers and persons selected to represent the relevant person must be

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6 CRPD/C/GC/1 (14).
able to provide a reasonable account of how this interpretation was arrived at."\textsuperscript{7}

The amendment was based on the principle set forth by the Committee, which expressly forbids a functional assessment of mental capacity from being used to restrict or deny a person's legal capacity, even in respect of a single decision.\textsuperscript{8}

**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 3-3 seeks to realise the Committee’s declaration that “supported decision-making must be available to all.”\textsuperscript{9} While it is good to ensure that support is readily available, provisions must be added in order to allow for the relevant person to reject support if they do not want it. Even if others believe them to require support, the relevant person should have the right to choose whether or not they wish to avail themselves of such a support.\textsuperscript{10}

While the Committee has recognized that support for people with disabilities may come in different forms, it has been made clear that the individual has the option to not exercise their right to support in accordance to Article 12, Paragraph 3.\textsuperscript{11} In the GC, the Committee specified that "the person must have the right to refuse support and terminate or change the support relationship at any time.”\textsuperscript{12}

Furthermore, according to the Committee “A person’s level of support needs, especially where these are high, should not be a barrier to obtaining support in decision-making.”\textsuperscript{13}

In Ireland’s Assisted Decision-Making (Capacity) Bill 2013, it is clear that if a relevant person exercises the right to use available support, the relevant person retains the ability to change their mind at any point in time. For example, with respect to the provisions on the creation of decision-making assistance agreements between a relevant person and a support person, the Irish Bill states that "Nothing in this section shall be construed to prevent the appointer of a decision-making assistant from revoking or varying the decision-making assistance agreement which appointed the decision-making assistant.”\textsuperscript{14} This is particularly important, as it does not require the relevant person to reach a particular standard of decision-making ability prior to revoking or changing a

\textsuperscript{7} From Mental Capacity to Legal Capacity (Amendment) (No 2) Assisted Decision-Making (Capacity) Bill (2013) 2.1.1.

\textsuperscript{8} From Mental Capacity to Legal Capacity (Amendment) (No 2) Assisted Decision-Making (Capacity) Bill (2013) 2.1.1.

\textsuperscript{9} CRPD/C/GC/1 (29(a)).

\textsuperscript{10} General Comment 1

\textsuperscript{11} CRPD/C/GC/1 (19)

\textsuperscript{12} CRPD/C/GC/1 (29(g)).

\textsuperscript{13} CRPD/C/GC/1 (29(a)).

\textsuperscript{14} Assisted Decision-Making (Capacity) Bill 2013, s 10(11).
decision-making assistance agreement. Similar options could be considered by the ALRC in making its final recommendations.

**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.

Proposal 3-4’s inclusion of reference to ‘all aspects of life’ is especially important. It is important that decision-making support extend to all decisions a person may wish to make and not be limited to a specific type of decision-making, such as property or financial affairs.

As with Proposal 3-3, support should be readily available to those who wish to avail themselves of such support, but this support should never be imposed upon someone against their wishes. Safeguards must be in place to allow individuals to refuse offers of assistance regardless of whether a third party considers that the individual in question requires, or would even benefit from support. Such safeguards will help to ensure full respect for the individual’s will and preferences, in keeping with Article 12 UNCRPD.

b. Persons who may require decision-making support should be supported in making decisions.

As with Proposal 3-3 and 3-4(a), support should be available and accessible but never imposed upon an individual. The decision as to whether a person ‘requires support’ should be one which the individual makes – not one which can be made by third parties, as this could coerce the individual to enter into supported decision-making arrangements which the individual does not want or need.

c. The role of families, carers and other significant persons in supporting persons who may require decision-making support should be acknowledged and respected.

It is vital to recognize the role of the family as a natural support system, and the crucial role of carers and others in supporting persons who may require decision-making support. However, this principle must always be accompanied by safeguards in order to minimize conflicts of interest which inevitably arise. While the family should be recognized as a natural support system, they should only be assigned the role of the support in cases where the person gives consent to family members assuming such a role.

In order to prevent “undue influence”, the Committee has called for safeguards for the exercise of legal capacity while respecting “the rights, will and preferences of the person, including the right to take risks and make mistakes.”

Where there is a suspicion that an individual is being unduly influenced by another individual, Article 12 of CRPD directs that the law must treat people with disabilities the same as it does people without disabilities. For example,

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15 CRPD/C/GC/1 (22)
contract law provides for the invalidation of a contract where undue influence is found based on the nature of the relationship between the parties, not the existence of the label of disability. Where there is suspicion that a person with a disability may be experiencing undue influence, the law must only be allowed to intervene to the same extent as it would for a person without a disability. People without disabilities are permitted, under the law, to choose to live in settings that may seem unorthodox to outsiders. Some may even be in abusive households or under the oppressive control of a friend or family member. People with disabilities must be given the same freedom. However, there is an obligation to provide services that help reduce dependence and guarantee an alternative to abusive or dangerous settings; for example, supported living funding, affordable housing and supported employment.

It is important to acknowledge that the role of supporting an individual to make a decision may require different skills and that, depending on the decision in question, it may be extremely difficult for a family member to take on a new role as a person’s ‘supporter’ – where this may mean supporting decisions that the family member does not agree with. Another issue that arises here is that, under the support model, the outside decision-maker may be asked to make, or support, a decision that she or he does not agree with. This can be extremely difficult, especially where the outside decision-maker also plays another role in the person’s life, such as a family member might do. Where this kind of dispute arises, there should be a process for the outside decision-maker to step down from the role of providing this kind of support to exercise legal capacity, if she or he so desires. The autonomy of the outside decision-maker must also be respected and she or he should not be forced to realise a decision of the individual that is morally repugnant to her or him or causes her or him great harm or distress. However, there must equally be another mechanism for providing a different outside decision-maker who will, in fact, realise the will and preference of the individual.

The ALRC has rightfully recognized the difficulty of protecting people when exercising their use of support. The safeguards of the Commonwealth decision-making model include establishing clear duties for the supporter and recognising the ability of the supported person to revoke the support.

Existing critiques of Ireland’s Assisted Decision-Making (Capacity) Bill have pointed to the lack of recognition for families in the current text of the Bill. The Bill does recognise that those engaged in the ‘care or treatment’ of relevant persons should be consulted by decision-making assistants, co decision-makers, decision-making representatives, and other intervenors under the legislation. However, this does not fully include many family members who may not be actively involved in care or treatment but may have detailed knowledge of the person’s will and preferences which should be taken into consideration. The ALRC should consider how best to reflect the role of families as providers of knowledge on the individual’s will and preferences in its final recommendations.

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16 Assisted Decision-Making (Capacity) Bill 2013, s 8(8)a.
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.

Proposal 3-5 clearly reflects the spirit and purpose of Article 12 UNCRPD. This could be further strengthened by acknowledging that not only should will and preferences direct decisions affecting the individual’s life but that there should be no other basis for decisions to be made about a person if will and preferences are clear, as long as respecting the individual’s will and preferences is possible within the bounds of the current law. Additionally, there should be no distinction between decisions made by those who require decision-making support and those who do not require such support. This reflects the previous recommendation on Proposal 3-4(b) which is to ensure that the determination of the need for support can only come from the individual herself.

The guiding principle behind the UNCRPD is not only that people who may require decision-making support have decisions made based on their will or preference, but that all people have equal rights to exercise their legal capacity in making decisions based on their will and preference. As with Proposal 3-4, the Committee has recognized in its GC “the rights, will and preferences of the person, including the right to take risks and make mistakes.” 17 The UNCRPD has not laid out any other basis on which decisions may be made about a person. If the person’s will or preference may be ascertained, it should always be used as the only basis for making a decision when exercising their legal capacity.

Proposal 3-5 could also be strengthened by reinforcing the notion of ‘best interpretation’ of will and preferences which may have to guide decisions in situations where the will and preferences of the individual are unknown, as in the Irish amendments to the Assisted Decision-Making (Capacity) Bill 2013. 18 The proposed amendment will insert a definition of ‘best interpretation’ into the Irish Bill, as follows: “the interpretation of the relevant person’s past and present communication (using all forms of communication, including, where relevant, total communication, augmented or alternative communication, and non-verbal communication, such as gestures and actions) that seems most reasonably justified in the circumstances.” 19 This language could be used to guide the ALRC in its development of final recommendations on how will and preferences may be determined in situations of last resort.

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.

17 CRPD/C/GC/1 (22)
18 From Mental Capacity to Legal Capacity (Amendment) (No 2) Assisted Decision-Making (Capacity) Bill (2013) 2.1.5.
19 From Mental Capacity to Legal Capacity (Amendment) (No 2) Assisted Decision-Making (Capacity) Bill (2013) 2.1.5.
This threshold is an important starting point, but could be further substantiated by making clear that a representative decision-maker can not be imposed if the person’s will and preferences are known, rather than imposing a representative decision-maker where the person is deemed to not possess a certain level of decision-making ability. As with Proposal 3-5, the emphasis should remain on the will and preference of the relevant person. While we agree with Proposal 3-6, there needs to be further guidelines to ensure that not only is representative decision-making a last resort, but that the appointment should not be made in cases where a person is deemed to lack decision-making ability, but where the relevant person’s will and preferences remain unknown even after significant efforts to discover them.

Ireland is basing the proposed Decision-Making Representative amendment to its Assisted Decision-Making (Capacity) Bill 2013 on the belief that the representative can make decisions using the 'best interpretation' principle, and through all forms of communication and consultation with the relevant person and those who know them well. The proposed Decision-Making Representative amendment to the Bill will seek to ensure that the will and preference of the relevant person is adhered to in the case that such a will and preference is unclear. This may be done in the following way:

“15(1): the court, on application to it by a person entitled by virtue of section 14 to make the application, may make one of the following declarations:

(a) a declaration that the will and preference of the relevant person who is the subject of the application is unclear in relation to one or more decisions, and that
   (i) the assistance of a suitable person as a decision-making assistant or co-decision-maker, should be made available to him or her, and/or
   (ii) reasonable accommodation should be provided to him or her, to make one or more than one decision specified in the application relating to his or her personal welfare or property or affairs, or both;

or

(b) a declaration that the will and preference of the relevant person who is the subject of the application is not known in relation to one or more decisions relating to his or her personal welfare or property or affairs, and that following
   (i) the provision of reasonable accommodation, and
   (ii) the efforts of a decision-making assistant or co-decision-maker to discover will and preferences of the relevant person, the will and preferences of the relevant person remain not known.”

20 From Mental Capacity to Legal Capacity (Amendment) (No 2) Assisted Decision-Making (Capacity) Bill (2013) 2.2.14.
It is only, therefore, where the court makes a declaration under section 15(b) that a representative can be appointed. Where this occurs, proposed amendments to the Irish Bill aim to ensure that the representatives duties to act on 'best interpretation' of will and preferences are clear.

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

While this proposal calls for implementation of an important safeguard, there should be something to distinguish it from the already existing safeguards in the antiquated substituted decision-making regimes. As defined by the Committee in its GC, the most important safeguard for a decision-making regime is respect for the right, will, and preferences of the relevant person.

(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.

While the Centre agrees with the general principle of this Proposal, its impact could be further strengthened by the inclusion of the requirement that a person's will and preferences must be given effect as long as these are within the boundaries of the law. While support must be available for those who wish to use such support, appointed supporters do not have to support the relevant in making any decisions that will constitute an illegal act. As with the previous Proposal on Threshold, any support based on an unclear will or preference of the relevant person should hold to the standards stated in the above Proposal and remain in line with the 'best interpretation' principle set forth in the GC.

Whereas good efforts should be made to determine the will and preference of the relevant person, where the 'best interpretation' arrived at leads to a conflict of human rights (e.g. right to health in conflict with right to self-determination), it may be better for outside decision-makers to adhere to subjective guidance and follow the principle of 'best interpretation' rather than setting forth 'objective' rules which would allow the representative to decide which balance of human rights to achieve.

In determining whether measures meet the criteria set down in the GC for 'supported decision-making' the Committee has set out the following criteria in paragraph 25:

"(a) Supported decision-making must be available to all. A person's level of support needs (especially where these are
high) should not be a barrier to obtaining support in decision-making;
(b) All forms of support in the exercise of legal capacity (including more intensive forms of support) must be based on the will and preference of the person, not on what is perceived as being in his or her objective best interests;
(c) A person’s mode of communication must not be a barrier to obtaining support in decision-making, even where this communication is non-conventional, or understood by very few people;
(d) Legal recognition of the support person(s) formally chosen by a person must be available and accessible, and the State has an obligation to facilitate the creation of support, particularly for people who are isolated and may not have access to naturally occurring supports in the community. This must include a mechanism for third parties to verify the identity of a support person as well as a mechanism for third parties to challenge the decision of a support person if they believe that the support person is not acting based on the will and preference of the person concerned;
(e) In order to comply with the requirement set out in article 12, paragraph 3, of the Convention that States parties must take measures to “provide access” to the support required, States parties must ensure that support is available at nominal or no cost to persons with disabilities and that lack of financial resources is not a barrier to accessing support in the exercise of legal capacity;
(f) Support in decision-making must not be used as justification for limiting other fundamental rights of persons with disabilities, especially the right to vote, the right to marry (or establish a civil partnership) and found a family, reproductive rights, parental rights, the right to give consent for intimate relationships and medical treatment, and the right to liberty;
(g) The person must have the right to refuse support and terminate or change the support relationship at any time;
(h) Safeguards must be set up for all processes relating to legal capacity and support in exercising legal capacity. The goal of safeguards is to ensure that the person’s will and preferences are respected.” 21

The GC has set forth these key provisions based on the belief that a supported decision-making regime should allow for primacy of a person’s will and preferences. These criteria could be more fully reflected in the ALRC’s final recommendations.

21 CRPD/C/11/4 (25).
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 recognized and respected

Proposal 3–7 describes a functional test of decision-making ability (also known as ‘mental capacity’). However, the Committee has specifically stated in its GC that such a test cannot be used to determine the type of support a person may need.

The provision of support to exercise legal capacity should not hinge on mental capacity assessments; new non-discriminatory indicators of support needs are required in the provision of support to exercise legal capacity.22

Although the ALRC proposal is to only use this assessment of decision-making ability to determine the point at which a representative should be appointed to take the decision on an individual's behalf, this would also conflict with the Committee’s interpretation of Article 12, since the Committee has stated that perceived or actual deficits in mental capacity (or decision-making ability) cannot lead to the restriction or denial of an individual’s legal capacity. The removal of the individual's legal ability to make a particular decision and the vesting of the power to make such a decision in a third party on the basis of functional assessments of decision-making ability, such as the one the ALRC proposes, constitutes a conflict with the Committee’s interpretation of Article

22 From Mental Capacity to Legal Capacity (Amendment) (No 2) Assisted Decision-Making (Capacity) Bill (2013) 2.
Some assessments of decision-making ability currently enshrined in legislative frameworks explicitly discriminate against persons with disabilities, as they include a diagnostic threshold, which means that they only apply to those deemed to have an impairment in the functioning of the mind or brain. Even where assessments of decision-making ability may appear prima facie to be disability-neutral (i.e. where no diagnostic threshold is required) the reality is that people with disabilities (and those with cognitive disabilities in particular) are disproportionately more likely to fail such assessments. This makes functional assessments of decision-making ability discriminatory against persons with disabilities ‘in effect’ contrary to the provisions of the Committee’s GC.

This functional approach is flawed for two key reasons. The first is that it is discriminatorily applied to people with disabilities. The second is that it presumes to be able to accurately assess the inner-workings of the human mind and to then deny a core human right – the right to equal recognition before the law – when an individual does not pass the assessment. In all these approaches, a person’s disability and/or decision-making skills are taken as legitimate grounds for denying his or her legal capacity and lowering his or her status as a person before the law. Article 12 does not permit such discriminatory denial of legal capacity, but rather requires that support be provided in the exercise of legal capacity.  

In a seminar organized by Mencap Northern Ireland and the Northern Irish Association for Mental Health, Michael Bach and Oliver Lewis defined a functional test as one where a person’s functioning is labeled as ‘impaired’ depending on whether or not they meet certain criteria. They further point out that ‘a presumption of mental capacity (decision-making ability) is meaningless’ and does not help protect the individual’s human rights. Further, according to the Committee’s interpretation of Article 12 – all individuals, by virtue of their humanity, possess legal capacity – therefore, legal capacity (in contrast with decision-making ability) is not something which can be presumed, it simply exists in all persons, regardless of that individual’s decision-making skills. The Centre strongly urges the ALRC not to include a final recommendation that an individual’s decision-making ability should determine the exercise of his or her legal capacity.

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23 From Mental Capacity to Legal Capacity (Amendment) (No 2) Assisted Decision-Making (Capacity) Bill (2013) 2.
24 CRPD/C/11/4 (13).
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.

While intervention in some exceptional cases which conflicts with the individual’s will and preferences should be permissible, such interventions should be disability-neutral and not justified on the basis of an individual’s decision-making ability.

As discussed above, where a decision needs to be made and an individual is non-communicative or minimally communicative, after significant attempts have been made to facilitate communication, an outside decision-maker can make a decision on her or his behalf in accordance with the ‘best interpretation’ of her or his will and preference, taking into account past expressed preferences, where available, knowledge gained from family and friends and any other evidence that is available.\(^{26}\) In this situation, the individual must be closely consulted to discover who she or he would like to appoint as a representative decision-maker. If she or he is communicating but not clearly expressing who she or he would like to make a decision on her or his behalf, then an outside decision-maker could be appointed, but again, could only make decisions that were in accordance with the best interpretation of her or his will and preference. This will rarely be an easy task, however ‘best interest’ determinations that are currently used are similarly difficult in these situations. Article 12 is merely shifting these difficult decisions from focusing on judgment existing outside the individual to the individual’s own will and preference.

Where an individual is communicative but is expressing conflicting wishes, after all efforts have been made to clarify and reconcile her will and preferences, an outside decision-maker can make a decision based on the best interpretation of her will and preference at that particular time. This may be one of the most difficult situations in which to apply Article 12. A commonly used example of conflicting will and preferences is that of anorexia. Many people with anorexia express a will to live, but a preference to not eat.\(^{27}\) In these cases, an outside decision-maker may be involved, but would still be restricted from making a decision that was contrary to the individual’s expressed will and preference. PEG feeding, for example, would only be allowed if the individual agreed to it. These situations will always be difficult – they are difficult under ‘best interests’ determinations and they will continue to be difficult under an approach that prioritises will and preference.

Where an individual’s will and preferences are clear but impracticable, the law should ask nothing more than it already asks. If an individual’s will and preference is an illegal action, no one can be forced to support or realise that will

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\(^{26}\) General Comment No.1, Article 12: Equal Recognition Before the Law, Paragraph 18bis, UN Doc No. CRPD/C/GC/1, Committee on the Rights of Persons with Disabilities, 11th session (31 March – 11 April 2014).

\(^{27}\) See, for example, Re E (Medical treatment: Anorexia) (Rev 1) [2012] EWCOP 1639 (15 June 2012).
and preference and the individual can be held responsible for the decision if the crime or illegal action is committed. This raises larger questions of the functioning of criminal justice systems. As it currently exists, people with cognitive disabilities are disproportionately represented in criminal justice systems. This requires significant further study to explore how to remedy this problem while simultaneously respecting the autonomy of people with cognitive disabilities and their right to equal recognition before the law. If it is civil penalties that are at risk, the individual could potentially be held responsible for these. This then also begs an examination of the civil legal system, including contract law, civil responsibility, and others – however, there is not space in this submission to explore those areas.

This explanation of what to do in the ‘hard cases’ should NOT be equated to substitute decision-making systems that currently exist. There are clear distinctions, which are 1) using ‘will and preference’ as the guiding paradigm as opposed to ‘best interest,’ 2) not denying legal capacity to individuals with disabilities on a different basis, and 3) not imposing outside decision-makers against the will of the individual.

However, there are times in which a decision needs to be made and the relevant individual is not able to make a decision or needs assistance in making the decision. The foregoing explanation is meant to show that Article 12 can and does address these situations without the need for substituted decision-making. However, it is also important to stress that these solutions are ONLY intended to apply to the ‘hard cases’, and should not encroach into cases where an individual is expressing a will and preference – even where the will and preference of the individual is contrary to medical advice or to advice of mental health professionals. It should also not be used to impose an outside decision-maker on a person who is expressing an unpopular or unorthodox decision. The solutions proposed for these ‘hard cases’ only apply at the end of a process where there is a genuine inability to understand a person’s will and preference or where it is impossible to realise the person’s will and preferences without breaching some other aspect of the law.

Realising the right to legal capacity and the support paradigm of Article 12 requires that the will and preference of the individual is always paramount. However, this does not mean that vulnerable individuals who are having difficulty expressing their will and preference are going to be left by the wayside in emergency situations.

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28 Research has found that 90% of the prison population have mental health issues. Kimmett Edgar and Dora Rickford, Too Little, Too Late: an independent review of unmet mental health need in prison, Page 7, Prison Reform Trust (2009). It is estimated that around 30% of people in the criminal justice system have learning difficulties or disabilities. “A joint inspection of the treatment of offenders with learning disabilities within the criminal justice system - phase 1 from arrest to sentence,” Page 2, Joint Inspection by HMI Probation, HMI Constabulary, HM Crown Prosecution Inspectorate and the Care Quality Commission (January 2014).

29 General Comment No.1, Article 12: Equal Recognition Before the Law, Paragraph 23, UN Doc No. CRPD/C/GC/1, Committee on the Rights of Persons with Disabilities, 11th session (31 March – 11 April 2014).
For example, in a situation in which an individual is displaying behaviours of serious self-harm, the support paradigm does not leave the individual to perish. Instead, it asks support people around the person to closely examine what is happening and to support the individual by taking actions that will facilitate her or his decision-making ability to a point at which she or he can clearly express her or his will and preferences. This could mean a variety of things, including but not limited to assisting the individual in stopping the self-harming behaviour and interacting with the individual in a caring and understanding manner and/or attempting to create an environment that the individual feels safe and comfortable in to allow her or him to be in an optimal decision-making scenario. Throughout any interaction, the goal remains of arriving at the will and preference of the individual. Further, according to the terms of the CRPD, any emergency interventions must adhere to the principle of non-discrimination by ensuring that criteria for crisis interventions do not discriminate on the basis of disability (for example, by using mental health diagnosis or mental capacity assessments).

The duty of care is likely to arise in these situations. While there is not space in this submission for a full analysis of the duty of care in relation to Article 12, it will be important to re-examine practices that are currently justified as falling under a ‘duty of care,’ but may be unduly restricting the lives of people with disabilities. The gravity of these issues highlights the importance of exerting great efforts to discover the will and preference of an individual and to help realise that will and preference to the greatest degree possible.

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.

The key safeguard for laws and legal frameworks should remain a respect for the will and preferences of the relevant person. Safeguards should not just respect due process or judicial review of the interventions that restrict legal capacity. There is a need for checks and balances in order to respect the process as well as the autonomy of the relevant person. For example, monitors could be appointed in certain support agreements to ensure that significant decisions are made on the basis of the relevant person’s will and preference. Also, the infrastructure at Commonwealth and State or Territory levels established to oversee and implement new legislation in this arena will be crucial, and accessible complaints mechanisms must be established within the implementing bodies to ensure ease of access for those using support to exercise legal capacity, as well as the usual recourse to the courts. Similar to the amendments proposed for the Irish Bill, criminal offences can be introduced to specifically prohibit abuses of power by
those appointed to assist or make decisions on behalf of the relevant person.\textsuperscript{30} Additionally, there should be training and support for the supporters to ensure that they fully understand their role and the scope of their powers. Lastly, there should be an appeal process to an independent and impartial tribunal or court for instances when the relevant person is unable to choose his or her own representative and where an outside decision-maker is appointed to make particular decisions. In the ALRC’s final recommendations, it could be further emphasized that all safeguards should focus on ensuring that the will and preference of the relevant person are respected in decisions made in all aspects of life.

Conclusion

This submission addresses the broad principles set out by the ALRC which should guide legislative reform in the field of equality, capacity and disability, and provides guidance and insight into how these principles could be further strengthened to achieve the full realisation of Article 12 UNCRPD. It draws on the detailed guidance now provided by the Committee in its GC on Article 12, as well as Ireland’s experience with its Assisted Decision-Making (Capacity) Bill 2013, drawing from amendments which are currently being proposed to that Bill by a civil society coalition on legal capacity reform (with member organizations working in the fields of disability, mental health and older persons). The ALRC’s comprehensive discussion paper provides detailed insight into the current Australian legal framework (particularly at Commonwealth level) and will be an extremely useful tool for commencing reform in this area. With the suggestions we propose, the Centre believes that the ALRC’s final recommendations can be further enhanced to ensure that Australia provides global leadership in securing the rights of persons with disabilities to equal recognition before the law.

\textsuperscript{30} From Mental Capacity to Legal Capacity (Amendment) (No 2) Assisted Decision-Making (Capacity) Bill (2013) 2.
Centre for Disability Law and Policy
NUI Galway

Submission to the House of Lords Select Committee on the Mental Capacity Act (2013)

The Centre for Disability Law and Policy welcomes the opportunity to make this submission on the Mental Capacity Act to the House of Lords Select Committee. The Centre for Disability Law and Policy (CDLP) at the National University of Ireland Galway was formally established in 2008. The Centre’s work is dedicated to producing research that informs national and international disability law reform, guided by the principles of the UN Convention on the Rights of Persons with Disabilities (CRPD). The Centre’s Director, Professor Gerard Quinn, led the delegation of Rehabilitation International during the negotiations of the CRPD in New York. Since its establishment, the CDLP has organised and participated in a number of key events regarding disability law reform and legal capacity. These include 3 national conferences in 2011, 2012 and 2013, held in conjunction with Amnesty Ireland, which explored how forthcoming Irish legislation can reflect the changes Article 12 of the Convention on the Rights of Persons with Disabilities demands. The Centre also participated in a Canadian conference titled 'Taking Personhood Seriously: Legal Capacity Law Reform and the UN Disability Convention’ in 2011. The Centre is also a regular contributor of legislative and policy submissions on issues regarding legal capacity and made a submission on Legal Capacity to the Oireachtas Committee on Justice, Defence & Equality (2011).
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EXECUTIVE SUMMARY

The Centre for Disability Law and Policy (CDLP) welcomes the opportunity to make this submission in response to the Select Committee’s call for evidence on the Mental Capacity Act 2005 (MCA). The work of the CDLP is dedicated to producing research that informs national and international disability law reform, guided by the principles of the UN Convention on the Rights of Persons with Disabilities (CRPD). Since its establishment in 2008, the Centre continues to be a leading authority – nationally and internationally – on legal capacity and disability rights law, and will focus on these issues in its submission.

This submission aims to provide evidence for two key questions in the Select Committee’s call for evidence in the subsection on ‘Devolved administration and international context.’ It will first address question 27 by providing an analysis of the requirements of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and examine areas that the Mental Capacity Act 2005 may need reform in order to comply with the CRPD. In particular, this submission will focus on Article 12 CRPD, which sets out the right to equal recognition before the law, the right to recognition of legal capacity of persons with disabilities on an equal basis with others, and the right to support for the exercise of legal capacity. Further detail on the scope and application of this right will be provided with reference to the Concluding Observations of the Committee on the Rights of Persons with Disabilities. The application of these human rights norms to the content of the Mental Capacity Act is considered in this section.

This submission will then address question 26 by providing lessons learned from recent legal capacity reform efforts as well as good practices around the world. Particular emphasis is placed on the Assisted Decision-Making (Capacity) Bill published in Ireland in July 2013, as an example of one attempt to legislate for systems of support to exercise legal capacity, in light of Article 12 CRPD. Other legislative examples are provided from the Representation Agreement Act of British Columbia, Canada, and the Persons with Disabilities Bill and National Trust Amendment Bill in India. Practical examples of good practice in developing support to exercise legal capacity are briefly considered, including supported decision-making pilot projects undertaken in a number of Australian States such as South Australia and Victoria.
INTRODUCTION

Since the entry into force of the UN Convention on the Rights of Persons with Disabilities (CRPD) in 2008, many countries around the world have struggled with the implementation of one of the Convention’s key articles – Article 12. This article recognises equality before the law, but also provides for the recognition of legal capacity of persons with disabilities in all aspects of life on an equal basis with others, and places an obligation on States Parties to provide persons with disabilities with the supports they may require to exercise their legal capacity.

Ireland is currently in the process of reforming its legal capacity legislation with a view to being able to ratify the UN CRPD. The CDLP led a coalition of NGOs in producing the Essential Principles for legal capacity law reform in Ireland,¹ and gave evidence to the Houses of the Oireachtas Committee on Justice Defence and Equality in relation to the Scheme of the Mental Capacity Bill 2008.² That submission provided evidence on legal capacity law reform from the perspective of the CRPD, and based on the CDLP’s experience of this process in Ireland and other jurisdictions.

The CDLP has been involved in numerous publications and projects worldwide related to the right to legal capacity, which are used to inform the present submission. For example, the CDLP co-ordinates the PERSON project to advocate for the reform of legal capacity and guardianship laws in several Balkan states.³ It also contributed to a series of recent reports by the European Union Agency for Fundamental Rights on legal capacity⁴ and independent living.⁵ Given this breadth of experience, the CDLP is well-placed to provide evidence to the House of Lords Select Committee on the compliance of the Mental Capacity Act with the CRPD, possible reforms which could enhance supports to exercise legal capacity for persons with disabilities in England and Wales, and other legal capacity.

³ See www.eu-person.com for more information.
reform processes around the world which may be relevant as the Committee considers possible amendments which could be tabled to the MCA.

**Part I: UN CRPD Compliance**

**The requirements of the UN CRPD**

The United Kingdom ratified the CRPD on June 8, 2009 and its Optional Protocol on August 7, 2009. The UK has the potential to be a leader in implementing the Convention both because of its international obligations and because of its strong history of human rights protection.

**ARTICLE 12: THE RIGHT TO LEGAL CAPACITY ON AN EQUAL BASIS**

Article 12 of the CRPD protects the right to Equal Recognition Before the Law for people with disabilities. This right has its roots in both the Universal Declaration of Human Rights (Article 6) and the International Covenant on Civil and Political Rights (Article 16). The CRPD was the first international human rights instrument to enumerate the essential elements of this right for people with disabilities.

**Article 12, CRPD**

*Equal recognition before the law*

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person’s rights and interests.
5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own...

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or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

The right to legal capacity in Article 12 refers both to the recognition of the individual as a holder of rights, as well as an actor under the law in “all aspects of life”. Article 12(3) mandates that States “take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity”. Therefore, States must respect the legal agency and legal standing of people with disabilities on an equal basis with others and must provide access to support for the exercise of that agency and standing.

Article 12 of the CRPD demands a shift from substituted decision-making to supported decision-making mechanisms. While the UN Committee on the Rights of Persons with Disabilities has not yet provided a concrete definition of substituted decision-making regimes, it has found systems of adult guardianship, trusteeship, curatorship and judicial interdiction in the seven countries it has examined at the time of writing, to constitute substitute decision-making regimes which must be abolished in order to ensure compliance with Article 12. Drawing on these concluding observations, it can be surmised that impermissible substituted decision-making includes any system where 1) legal capacity is denied (even where this is only in respect of a single decision and based on an assessment of mental capacity), 2) a substituted decision-maker can be imposed on the individual against her will, and 3) any decision made is bound by what is believed to be in the objective ‘best interests’ of the individual – as opposed to the individual’s own will and preferences. This can happen through legislation, such as under the MCA, or through informal norms that allow others to make decisions using their judgment of what is best for the individual. In contrast, supported decision-making mechanisms for the exercise of legal capacity must respect the rights, will and preference of the individual. The aim of Article 12 is to guarantee the right to legal capacity and support for the exercise of legal capacity and thereby enable the realization of the right to equal recognition before the law for people with disabilities.

The support paradigm of Article 12 recognises that some people with disabilities will need access to informal or formal supported decision-making in order to

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9 Ibid.
exercise legal capacity. Supported decision-making models can vary greatly, and include practices such as setting up a specific decision-making agreement with chosen support people\(^\text{10}\) or receiving support from a community-based organization.\(^\text{11}\) A support paradigm demands that the people around the individual work hard to communicate with the individual and to provide the support necessary for the individual to express their will and preference and to act on it.

**MCA Compliance with the UN CRPD**

England and Wales has been lauded for having a robust system of rights protections for people with disabilities.\(^\text{12}\) At the time of drafting\(^\text{13}\) the 2005 Mental Capacity Act (MCA),\(^\text{14}\) it was on the forefront of progressive legal capacity legislation. However, in recent years, since the adoption of the CRPD, there have been major advancements in the understanding of the rights of persons with disabilities. In particular, it has become clear that respecting equal legal personhood and ensuring the right to choice in decision-making is essential for human flourishing. Unfortunately, people with disabilities are often denied these opportunities and the MCA does not sufficiently protect against this. The MCA falls short in several aspects when compared with the standards established in Article 12 CRPD. The key problems with the legislation from the perspective of the CRPD are: the conflation of mental capacity and legal capacity in a functional test; the ‘best interests’ standard for substitute decision-making; and the legislative sanctioning of informal capacity assessments by third parties.

The MCA’s functional test of ‘capacity’ conflates the concepts of ‘legal capacity’ and ‘mental capacity.’ It is important for legislation to distinguish between decision-making ability (mental capacity) and legal capacity. All individuals have varying levels of decision-making ability. The right to legal capacity on an equal basis in Article 12 asks that regardless of an individual’s disability – which may include a decision-making impairment – his/her legal capacity is respected to the

\(^{10}\) Canada, British Columbia, Representation Agreement Act, RSBC 1996, c. 405.

\(^{11}\) Swedish user-run service with Personal Ombud (PO) for psychiatric patients, PO-Skane, available at http://www.po-skane.org.

\(^{12}\) The United Kingdom has been listed as one of the countries with the most comprehensive definitions of disability discrimination. Theresia Degener and Gerard Quinn, *A Survey of International, Comparative and Regional Disability Law Reform*, Disability Rights Law and Policy International and National Perspectives, Mary Lou Breslin and Silvia Yee (eds.), Disability Rights Education and Defense Fund (2002).

\(^{13}\) The England and Wales Mental Capacity Act was created in 2005 in response to a finding by the Law Society’s Mental Health Sub-Committee that legislation was lacking in this area. Gordon R Ashton, *Preface to the First Edition*, Gordon Ashton (ed.), *Court of Protection Practice 2012*, Page ix, Jordan Publishing (2012).

\(^{14}\) The Mental Capacity Act (2005), Ch. 9, UK Public General Acts (England and Wales)
same degree as individuals without such disability or impairment.\textsuperscript{15} According to Article 12, every person has an inherent right to legal capacity and equal recognition before the law.\textsuperscript{16} It requires that states never deny legal capacity on the basis of disability, and instead provide appropriate assessments limited to what type of supports a particular individual needs in order to be able to exercise her legal capacity.

The MCA requires a two-stage test of mental capacity, which begins with determining whether the person has an impairment of the mind or brain.\textsuperscript{17} This automatically places individuals with cognitive disabilities (including learning disabilities, dementia, mental health issues, or neurological conditions) on unequal standing with all others being assessed for legal capacity, violating Article 12(2) of the Convention which states that persons with disabilities shall enjoy legal capacity on the same basis as others and in all aspects of life.\textsuperscript{18} The second step of the capacity test in the MCA is to ask whether the person is able to make the specific decision in question at the time it needs to be made.\textsuperscript{19} However, in order to recognize legal capacity for all, there should not be an assumption that they can and an effort to determine their wishes. By contrast, under Article 12, the more appropriate approach is to support the person to express their will and preferences, and use the individual’s will and preferences as the sole basis for the exercise of legal capacity. It is only where the will and preferences of the individual cannot be determined, after significant efforts to communicate with and support that person, that any other options, such as the introduction of a third party decision-maker, can be considered.

The MCA places the power to assess capacity in the hands of almost any third party who needs a decision to be made – without significant procedural protections.\textsuperscript{20} Article 12(4) requires that any assistance provided in decision-

\textsuperscript{15} UN Convention on the Rights of Persons with Disabilities, Article 12(3) 46 I.L.M. 443 (Dec. 13, 2006).
\textsuperscript{17} Mental Capacity Act 2005 Code of Practice, issued by Lord Falconer, Secretary of State for Constitutional Affairs and Lord Chancellor, Department for Constitutional Affairs, Page 41 (23 April 2007); The Mental Capacity Jurisdiction, Gordon Ashton (ed.), Court of Protection Practice 2012, Section 2.58, Page 113, Jordan Publishing (2012).
\textsuperscript{20} The Mental Capacity Jurisdiction, Gordon Ashton (ed.), Court of Protection Practice 2012, Section 2.100, Page 126, Jordan Publishing (2012).
making must be accompanied with appropriate procedural safeguards,\textsuperscript{21} which are lacking when doctors, lawyers, and others are permitted to make ad hoc determinations of whether an individual has sufficient decision-making skills, and if they find that s/he does not, to make a substitute decision in that person's 'best interests.'

Finally, while the MCA does mention the importance of giving weight to the wishes of the individual,\textsuperscript{22} it still maintains the best interest standard as the primary means for decision-making. Article 12 makes no mention of best interests, and instead requires States to "respect the rights, will and preferences" of the individual.\textsuperscript{23} This is an important paradigm shift in decision-making assistance. It is putting the power back in the hands of the individual using the assistance. 'Giving weight' to wishes, beliefs and values, is a much lesser standard than the imperative to 'respect' the rights, will and preferences of the individual. In the best interest standard, it is judgment from outside the individual that substitutes the judgment of the individual him/herself. In a will and preference standard, the goal is to assist the individual to develop and/or express long and short term desires. This is an essential component of respecting the right to legal capacity. It ensures that people who need assistance in decision-making are able to receive that assistance, be respected as persons before the law, and have their will and preferences realized on the same basis as others.

The MCA is a substituted decision making model – whereby legal capacity is disproportionately denied to people with disabilities; the law validates third parties substituting their decision-making; and decision-making is based on the 'best interest' principle.\textsuperscript{24} Article 12 requires a move to supported decision-making where legal capacity is not disproportionately denied to people with disabilities and assistance with decision-making is based on the will and preference of the individual. While the principles underlying the MCA do require support for the individual prior to removing his or her capacity,\textsuperscript{25} the ultimate removal of legal capacity undermines the requirement of support. This does not fulfil the Article 12 requirement of support because support should occur in replace of, not merely as a supplement to, the removal of decision-making power from the individual. The UN Committee on the Rights of Persons with Disabilities


\textsuperscript{22}The Mental Capacity Act (2005), Ch. 9, UK Public General Acts, Part 1 (3)(6)(a) (England and Wales).


has been extremely clear on this point – it is not appropriate to simply introduce supports to exercise legal capacity along with the maintenance of substituted decision-making systems.²⁶

The Mental Capacity Act of 2005 was a step in the right direction and is a distinct improvement upon the prior guardianship system in England and Wales.²⁷ However, with the UK’s ratification of the CRPD, England and Wales must modify its system further to come into compliance with the Convention and to uphold the human rights of individuals with disabilities. This requires the eradication of substituted decision making under the MCA and its replacement with the supported decision making system required by the CRPD. This should include shifting of resources from the old system to a new system that is premised on support.

**Part II: Learning from Other Jurisdictions**

**The Irish Law Reform Process**

The Scheme of the Mental Capacity Bill published in Ireland in 2008 closely mirrored the MCA of England and Wales in several respects. However, in hearings on the Scheme held by the Oireachtas (Parliamentary) Committee on Justice, Defence and Equality in 2012, evidence was heard suggesting that the ‘best interests’ standard was inappropriately paternalistic, and its inclusion in the legislation was contrary to the UN CRPD. The Oireachtas Committee also heard evidence that ‘legislation must be based on supported decision making’ in accordance with the UN CRPD. The House of Lords Select Committee may find it instructive to look at the changes adopted under the new Assisted Decision-Making (Capacity) Bill in Ireland, in response to these concerns.²⁸

*A ‘functional’ approach to capacity*

Disappointingly, the Irish Bill continues to retain a functional approach to ‘mental capacity’, which is very similar to the MCA (§3). Unlike the MCA, the Bill does not include a ‘diagnostic threshold’. This might be thought to reduce any discriminatory application of the functional approach to capacity, and therefore be more in accordance with the CRPD. We would caution against that view, as

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²⁷ Gordon R. Ashton, *Mental Capacity: The New Law*, 5 P.C.B. 299-302 (2006). Gordon R. Ashton describes how the previous guardianship system was more restrictive, provided the individual with very little control, and did not provide an assumption of capacity.
the functional test is still likely to be disproportionately applied to people with disabilities. Expanding the category of people potentially subject to substituted decisions would not help legislation better comply with the CRPD requirement that regimes of substituted decision making be replaced with supported decision making.

‘Best interests’
The new Bill does not include a single reference to ‘best interests’. The Bill does, however, permit some ‘interventions’ on the basis of functional incapacity. Since these ‘interventions’ may constitute a form of substituted decision-making, which has been prohibited by the Committee for the Rights of Persons with Disabilities, this is problematic from the perspective of the CRPD. Nevertheless, these interventions still differ in important respects from the ‘best interests’ approach of the MCA.

The MCA uses an ‘objective’ test of best interests, where a person’s wishes and preferences are one factor among many to be considered – neither are they necessarily the most important factor (ITW v Z & Ors [2009] EWHC 2525 (Fam)). By contrast, §8(7)(b) of the Irish legislation specifies that those ‘intervening’ in respect of a person shall ‘give effect, in so far as is practicable, to the past and present will and preferences of the relevant person, in so far as that will and those preferences are reasonably ascertainable’. This accords respecting and fulfilling a person’s will and preference a much higher priority than under the MCA.

The ‘least restriction’ principle
The MCA requires that before any act is done in a person’s best interests, ‘regard must be had’ for whether it can be done in a way which is less restrictive of a person’s rights and freedom of action. As noted in Re P [2009] EWHC 163 (Ch) §41, this is merely an obligation to consider not to follow that course of action. By contrast the Irish Bill specifies that:

(6) An intervention in respect of a relevant person shall—
(a) be made in a manner that minimises—
(i) the restriction of the relevant person’s rights, and
(ii) the restriction of the relevant person’s freedom of action, and
(b) have due regard to the need to respect the right of the relevant person to his or her dignity, bodily integrity, privacy and autonomy

This is a much higher threshold for any interventions which contravene a person’s will and preference or which otherwise restrict their autonomy, or interfere with their privacy or bodily integrity.
Assisted Decision-Making and Co Decision Making

The Bill includes two specific statutory regimes of supported decision making: Assisted Decision-Making (§9-§12) and Co Decision-Making (§16-§22). Both types of support arrangements must be made with the consent of the relevant person, who may nominate a suitable person of their choice to act as an Assisted Decision-Maker or Co Decision-Maker. This person will very often be a relative or friend. An agreement sets out the duties of the Assisted Decision-Maker or the Co Decision-Maker. In the case of Co Decision Makers, this agreement only becomes valid when a court order has been made confirming that the agreement is in accordance with the relevant person’s will and preference. Both these arrangements reflect provisions in Canadian legislation, discussed below.

The functions of Assistants (under Assisted Decision-Making Agreements) are:

(a) to advise the appointer by explaining relevant information and considerations relating to a relevant decision,
(b) to ascertain the will and preferences of the appointer on a matter the subject or to be the subject of a relevant decision and to assist the appointer to communicate them,
(c) to assist the appointer to obtain any information or personal records (in this section referred to as “relevant information”) that the appointer is entitled to and that is or are required in relation to a relevant decision,
(d) to assist the appointer to make and express a relevant decision, and
(e) to endeavour to ensure that the appointer’s relevant decisions are implemented

In accordance with their role, Assistants may access the relevant information to help a person to understand the relevant decision. Although many people with impairments affecting communication and understanding may informally benefit from somebody playing such a role, giving the relationship statutory footing may help many difficulties they can experience. The agreement may help friends, carers or non-statutory advocates acting as Assistants to access the relevant information to support a person. Often health and social care professionals are unfamiliar with a person’s mode of communication, and this can help to formalise the role of an Assistant in understanding and facilitating their communication. The role of the Assistant in endeavouring to ensure that a person’s decisions are implemented is also important from an advocacy perspective, where people may struggle to follow up on their decisions without support.

Although the MCA does say ‘A person is not to be treated as unable to make a decision unless all practicable steps to help’ have been made (§1(3)) and ‘A person is not to be regarded as unable to understand the information relevant to a decision if he is able to understand an explanation of it given to him in a way
that is appropriate to his circumstances (using simple language, visual aids or any other means)’ (§3(2)), this is framed in the passive voice. This is problematic, as those assessing capacity may not be familiar with a person’s communication method, and they may not have the time or a relationship of trust with the relevant person which enables them to provide appropriate support. Whilst these general provisions for support are retained under the Irish Bill, Assistant Decision-Makers are much more sensitive to the importance of recognising relationships which underpin support.

Co Decision Making Agreements, when they have the force of a court order, mean that any decisions within the scope of the agreement (and any relevant documentation signed) are only valid if both a person and their co decision maker have signed them. In effect, both the relevant person and the co-decision maker retain a veto for decisions which will affect a person. This is advantageous for (at least) two groups. Some people may find it difficult to make some decisions, enter into contracts and so on for themselves, but may have a trusted person in their lives who they would like to do so on their behalf. These agreements would enable them to nominate that person but – unlike a Lasting or Enduring Power of Attorney – they can still exercise a veto over any decisions that person makes which they disagree with. Secondly, people who consider that their ability to make good decisions fluctuates, or they are prone to making impulsive decisions which they later regret, may think that requiring a person whose judgment they trust to sign off on any decisions, would be desirable. Co decision-makers must acquiesce to their decisions if it is clear that ‘a reasonable person could have made that relevant decision’ and ‘no harm to the appointee or any other person is likely to result from that relevant decision’. Although some questions remain about how easily a person may be able to extricate themselves from co decision-making if they find it does not work for them, this measure provides much more concrete requirements for collaborative and consensual working with people than frameworks like §4 MCA which merely require that they are ‘involved’ in, and consulted about, decisions about their lives.

Court procedure
Many jurisdictions, including England and Wales under the Court of Protection Rules 2007, do not require judges making major decisions relating to a person’s legal capacity to meet the person him or herself. Insofar as this relates to a failure to facilitate a person’s attendance in court, this is not in accordance with the requirement of Article 13 CRPD on access to justice (and Article 9, on accessibility). If the failure to facilitate the person’s attendance at court is premised on a person’s alleged ‘incapacity’, it will also fall afoul of Article 12 CRPD and the enjoyment of equal recognition before the law. Given the centrality of the principle of inclusion, and respect for a person’s will and preferences for the exercise of their legal capacity, under the UN CRPD, it is not tenable for
courts to fail to meet parties to proceedings on disability-related grounds. It is also increasingly unacceptable under the European Convention on Human Rights for them to fail to do so (e.g. X and Y v Croatia (App no 5193/09) [2011] ECHR 1835; Lashin v Russia (Application no. 33117/02) [2012] ECHR 63). Under §107 of the Assisted Decision-Making (Capacity) Bill, there is a presumption in favour of any applications under the Bill being heard in the presence of the relevant person.

Advocacy

One important element missing from the Irish Bill is the provision of independent advocacy to support people in exercising their legal capacity. We note that the MCA does provide for ‘Independent Mental Capacity Advocates’, for which England and Wales is to be applauded. However, we are concerned that this form of ‘best interests’ advocacy may not be effective in ensuring that people’s will and preferences are given centrality, nor that people are entitled to statutory support in making decisions for themselves and avoiding ‘best interests’ decisions. It is also concerning that it is unclear whether IMCAs are required to support a person to challenge decisions which do not accord with their will and preferences if the IMCA themselves does not regard this as being in their best interests. We submit that whilst non-instructed advocacy is very important for people with communication impairments, this does not reflect best practice where a person is able to communicate their will and preferences.

Legal capacity in India, Canada and Australia

In light of the requirements of the CRPD as well as a decades-long push from civil society, several other jurisdictions are currently in the process of reforming their legal capacity laws. Much can be gained from examining these processes and their successes. While there is still some question about whether Canadian jurisdictions are fully compliant with Article 12, some provinces have made significant progress on instigating supported decision-making mechanisms within their substituted decision-making regimes. For example, in 1996, after a groundswell of civil-society advocacy, British Columbia enacted the Representation Agreement Act (RAA). The RAA allows an individual to nominate one or more people to act as their supporters or representatives in making legally binding decisions and exercising legal capacity. Importantly, the diagnostic threshold to determine who is permitted to create a representation agreement is flexible enough to allow a person with a diversity of decision-making skills to enter into agreements.
Similar to Ireland, India currently has a new legal capacity bill that will shortly be put before the parliament.\textsuperscript{29} It also has a separate bill that proposes amendments to its National Trust Act,\textsuperscript{30} which would provide the structure for the blossoming of a new supported decision-making mechanism. Interestingly, the Indian bill reforming legal capacity law proposes to maintain a substituted decision-making partial guardianship regime for those that are currently under guardianship. However, all individuals in the future who are in need of decision-making assistance, will be provided with access to the support system set up in the National Trust Act.

There are several pilot programs on supported decision-making happening around the globe. Some of the most successful and well developed are in Australia. The South Australia Office of the Public Advocate successfully completed a supported decision-making pilot in 2012 and continues to expand activities in this area.\textsuperscript{31} The Victoria Office of the Public Advocate is currently undertaking a similar pilot program and has received a sizable grant to do so.\textsuperscript{32}

Finally, it is worth noting that the Good Friday/Belfast Agreement contained a commitment to ensure that “equivalence” of human rights protection (in particular related to equality of opportunity) would be ensured in Northern Ireland and in the Republic.\textsuperscript{33} Northern Ireland is currently developing new legislation on mental capacity and mental health, and meetings of officials from the Departments of Justice in both Northern Ireland and the Republic have been held, to discuss the proposed legislative reforms in both jurisdictions. Developments in Northern Ireland are therefore also worth following, especially as the new legislation on capacity purports to implement Article 12 CRPD.

Conclusion: ‘Nothing About us Without Us’

‘Nothing about us without us’ is a common refrain within the disability rights movement, meaning that policy decisions which affect people with disabilities should be made in close consultation with them. This concept animates several elements of the UN CRPD, in particular Article 33 (on monitoring the CRPD) and Article 4(4):

In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

We note in passing that this call for evidence was drafted in language which may be inaccessible to many people directly affected by the MCA. We hope that the Committee will take steps to capture their voices, views and experiences in other ways.

There is a wealth of research evidence which suggests that people with disabilities, and older people, experience considerable frustration and distress by the denial of choices about their lives which are available to others, and that this can lead to mental health problems in its own right. Yet there is a paucity of evidence about the experiences of those said to ‘lack capacity’ under the MCA. To the best of our knowledge, not a single published research project has explored capacity assessments and best interests decisions from their perspective. Consequently, the literature on the MCA is generally informed by the perspectives of those empowered to make substituted decisions under the Act: caregivers, and health and social care practitioners. The Committee must be very cautious of accepting their views at face value. The empirical research by the European Union Agency for Fundamental Rights did collect the views of

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citizens denied legal capacity within the EU; here is the only available quote from the UK:

‘My mum is my guardian and I can’t say ‘no’ to her. If she wants me she can phone up the house. And the house phones her. Everything is controlled by her. And I can’t breathe. Because she’s there – in my face. In this. In that. And you know she’s everywhere. [...] I know she’s my mum but I’ve tried to move away from her slowly but it’s not working.’

We suggest that the Committee work with user-led organisations for people with disabilities and older adults to explore the experiences of those directly affected by the MCA.

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Piers Gooding*

ABSTRACT
In recent years, the enumeration of the right to legal capacity in the United Nations Convention on the Rights of Persons with Disabilities (CRPD) has caused considerable controversy. The adoption of General Comment No 1 by the United Nations Committee on the Rights of Persons with Disabilities in April 2014 sheds new light on major debates in the field, particularly regarding implementation measures to fulfil the obligation of States Parties to provide people with disabilities with ‘support to exercise legal capacity’ on an equal basis with others. This interpretative guidance builds upon the CRPD framework for achieving equal recognition before the law for people with disabilities. Yet commentators have criticized both the CRPD Committee’s interpretation and the enumeration of Article 12 in the CRPD itself as wanting in key respects. This article draws on General Comment No 1 to list and respond to major concerns raised about the obligation of States Parties to provide people with disabilities with the support they may require in exercising their legal capacity. The list of concerns and counterarguments are set against a broad range of implementation measures from domestic law and policy from around the world.

KEYWORDS: disability, right to legal capacity, mental capacity law, mental health law, guardianship law, supported decision-making, United Nations Convention on the Rights of Persons with Disabilities

1. INTRODUCTION
In this article, I will examine major concerns raised about the enumeration of legal capacity in the United Nations (UN) Convention on the Rights of Persons with Disabilities...
Disabilities (CRPD). I will set out a list of questions raised by scholars and other commentators regarding the obligation of States Parties to provide people with disabilities with the ‘support they may require in exercising their legal capacity’, pinpointing controversies and highlighting ongoing practical and conceptual issues. These questions will be considered with specific regard to General Comment No 1 (‘General Comment’) of the UN Committee on the Rights of Persons with Disabilities (‘CRPD Committee’), which was adopted on 11 April 2014 and provides specific interpretative guidance on Article 12 of the CRPD.

Article 12 aims to ensure that all persons are recognized as equal before the law, regardless of disability, and their legal capacity is promoted and respected on an equal basis with others. Article 12 establishes that all people have legal capacity regardless of disability (and regardless of mental functioning) and includes the obligation on States Parties to the CRPD to ensure equality before the law for people with disabilities and to provide them with the ‘support they may require in exercising their legal capacity’ on an equal basis with others.

According to the General Comment of the CRPD Committee, ‘support to exercise legal capacity’ includes a broad spectrum of support, some of which may engage legal mechanisms, some of which may not. Such support might include, for example, personal advocacy, plain language aids, decision-making assistance and in exceptional circumstances—when it is necessary to make a decision where a person’s wishes are unknown or unclear—using the ‘best interpretation of a person’s will and preference’ to guide decisions. The term ‘supported decision-making regime’ is used in the General Comment to refer to the broad elements required to implement this system of support. Supported decision-making is contrasted with ‘substituted decision-making’, a term defined by the CRPD Committee as having three common characteristics: the removal of legal capacity ‘even if this is just in respect of a single decision’; authorization for appointing a substituted decision-maker by someone other than the person concerned ‘against his or her will’; or the making of substituted decisions ‘based on what is believed to be in the objective “best interests” of the person concerned as opposed to being based on the person’s own will and preferences’.

It is important to note at the outset that Article 12 of the CRPD does not introduce a ‘new model’ of legal capacity per se. Instead, while the scope and content of the right to legal capacity in Article 12 is not new, its application is unique—reiterated as it is for the context of disability. The obligation of States Parties under Article

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2 Article 12(3) CRPD.
3 CRPD Committee, General Comment No 1: Equal recognition before the law (art. 12), 11 April 2014. The CRPD Committee is authorized under Article 34 of the CRPD to review the compliance reports of States Parties.
4 Article 12(3) CRPD.
5 CRPD Committee, supra n 3 at para 25.
6 Ibid. at para 23.
7 Kayess and French pointed out that the aim of drafters was not to introduce new rights but instead to restate existing rights as applied to people with disability; they also note the somewhat paradoxical aim to address the failure of existing human rights formulations to ensure the rights of persons with disabilities: see Kayess and French, ‘Out of Darkness into Light? Introducing the Convention on the Rights of

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12(3) to provide ‘support to exercise legal capacity’ to people with disabilities on an equal basis with others is seemingly novel in this respect. CRPD directives for realizing ‘universal’ legal capacity in accordance with Article 12 are purported to produce a number of benefits. These benefits include the promotion of personal autonomy, authority and control for people over their own lives;8 the use of a more realistic account of autonomy and decision-making that takes into account a person’s social context and interdependence;9 providing a clear structure for addressing decision-making by people who may require support to make decisions, or whose will and preference is unclear;10 and even realizing a ‘frontier of justice’ by extending core civil rights to people with disabilities.11

Yet despite these apparent benefits, the terms of Article 12 and the CRPD Committee’s compliance directives have been seen by diverse commentators as wanting in key respects.12 The increasing number of conceptual studies on Article 12 of the CRPD have identified numerous concerns—so many as to make it difficult to locate key issues. As such, the list presented here is by no means exhaustive.13 Instead, the concerns were chosen for having been raised repeatedly in scholarship and law reform materials, or where issues appear to present significant risks or ambiguities.

The scope of analysis will extend beyond a human rights focus to include pragmatic arguments, including matters of resourcing, conceptual coherence and the weighing of evidence with respect to the successes and shortcomings of proposed implementation measures. The purpose of articulating these issues is to assist in

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13 A fuller range of concerns raised about the CRPD formulation of Article 12 can be found among the 73 submissions to the CRPD Committee in response to its draft General Comment on Article 12: see UN Office for the High Commission for Human Rights, ‘Submissions to the Draft General Comment on Article 12 of the Convention - Equal Recognition before the Law and Draft General Comment on Article 9 of the Convention – Accessibility’ CRPD Committee Website, February 2014, available at: www.ohchr.org/EN/HRBodies/CRPD/Pages/DGCArticles12And9.aspx [last accessed 10 January 2015].
weighing the costs and benefits of various interpretations of Article 12 and to tease out some of the major practical and conceptual concerns. The intention is to raise a range of critical issues and to present possible counterarguments so as to better examine which issues the various implementation strategies may or may not address.

Finally, in assessing the costs and benefits of a particular interpretation of Article 12 and subsequent implementation measures for realizing the right to legal capacity on an equal basis, it is perhaps as easy to give the law too much credit for solving personal and social maladies, as it is to give it too much blame for causing them.\(^4\) One possibility is that any benefits of using the law for social justice in this way are overwhelmed by other powerful forces in society, such as resource allocation or wealth disparity.\(^5\) Nevertheless, it is generally agreed that the law authoritatively creates the power structures, institutions and incentives of disability service ‘systems’, which directly shape the lives of people with disabilities, their families and others. Further, the issues listed in this article concern the intersection of law and practice and are relevant not just to persons with disabilities, but also families and other informal supporters, legal and medical professionals, and service providers—all of whom will be impacted by, and may influence developments in current law and policy. The core significance of these issues to persons with intellectual, cognitive and psychosocial (mental health) disabilities rests on their being among the last groups to hold and exercise decision-making rights on an equal basis with others.

### 2. THE RIGHT TO LEGAL CAPACITY

Article 12 of the CRPD sets out the right to legal capacity on an equal basis as a subsidiary to the right to equal recognition before the law.\(^6\) The right to legal capacity on an equal basis with others was first advanced in 1979 in the Convention to Eliminate all Forms of Discrimination Against Women.\(^7\) The right to equal recognition before the law can be found in the earlier Universal Declaration of Human Rights\(^8\) and the International Covenant on Civil and Political Rights (ICCPR).\(^9\)

Under the CRPD, Article 12(1) establishes that persons with disabilities have the right to be recognized everywhere as persons before the law—applying the existing right to equal recognition before the law to the specific context of persons

\(^{14}\) McSherry makes this point with regards to mental health law: see McSherry (ed.), *International Trends in Mental Health Laws* (2008) at 1.


\(^{16}\) Article 12 CRPD.


\(^{19}\) Article 16(1) ICCPR 1966, 999 UNTS 171 simply states: ‘Everyone shall have the right to recognition everywhere as a person before the law.’
The right to legal capacity on an equal basis in Article 12(2) of the CRPD draws on a formulation of legal capacity that has two constitutive elements: a person’s legal standing (legal personality) but also his or her ability to act on such legal standing (legal agency). Article 12(3) sets out the obligations on States Parties to ‘take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity’ and is often regarded as the locus situs of the obligation of states to provide ‘supported decision-making’ (a term that will be elaborated upon shortly). Article 12(4) sets out safeguards required for all measures related to the exercise of legal capacity. These include the principle of proportionality, freedom from conflict of interest and undue influence and respect for the rights, will and preference of the person. These safeguards should ensure that legal capacity support measures ‘apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body.’ Finally, Article 12(5) contains explicit recognition of the importance of the right to legal capacity for persons with disabilities in respect of financial and property matters. Overall, Article 12 sets out a commitment by States Parties to uphold the legal standing of people with disabilities and to ensure they may act on such legal standing on an equal basis with others.

A. Article 12 Convention on the Rights of Persons with Disabilities: Key Concepts

Theoretical questions in current debates about Article 12 of the CRPD and legal capacity have been closely considered in the literature. These concerns include the historical evolution of the concept of legal capacity in international human rights law; the challenges of cognitive disability to moral philosophy; the regulation of personhood in constructions of legal capacity; typologies of support in line with Article 12; and supported decision-making in the context of extreme self-harm and

22 Article 12(3) CRPD.
24 Article 12(4) CRPD.
25 Ibid.
26 Article 12(5) CRPD.
27 McSherry, supra n 21.
29 Quinn, supra n 23 at 16.
suicide, mental health law and elder law. As noted, the recently published General Comment of the CRPD Committee on Article 12 provides an important resource for navigating the expanding literature (though little scholarly analysis of the General Comment has emerged at the time of writing). Before proceeding to list the major practical and theoretical questions about Article 12, it is useful to review this literature to outline key elements of the CRPD’s enumeration of legal capacity.

Flynn and Arstein-Kerslake have argued that Article 12 of the CRPD ‘identifies that an individual has a right to legal capacity irrespective of whether or not they have a disability, and simultaneously recognizes that some people require assistance to exercise their legal capacity.’ States are, therefore, required to provide support for individuals who may need assistance and to safeguard against neglect, abuse and exploitation. Key elements of the CRPD Committee’s recommendations for implementing legal capacity on an equal basis in domestic law include replacing the ‘best interests’ standard for substituted decision-making with an adherence to the will and preference of the individual. Where it is not possible to discern a person’s will and preference, according to the General Comment, supporters are to make decisions based on the supporter’s ‘best interpretation of the will and preference’ of the individual where necessary.

A number of key concepts within this model require brief elaboration. Defining core terms helps to avoid a situation where participants in conceptual debates misunderstand one another and offer arguments that do not meet. The brevity of the following definitions can be justified on the grounds that the literature has progressed a great deal in clarifying conceptual questions about what constitutes support to exercise legal capacity.

As noted, ‘support to exercise legal capacity’ refers to the broad obligation set out in Article 12(3) of the CRPD by which States Parties must provide support to persons with disabilities on an equal basis with others. ‘Support’ is not specified in Article 12(3) but ‘encompasses both informal and formal support arrangements, of varying types and intensity’. Hence, support to exercise legal capacity is considerably broad, and could include personal advocacy, accessible education, plain language aids and so on. The CRPD Committee’s General Comment states that support to

34 The term ‘support model of legal capacity’ is used by Flynn and Arstein-Kerslake to describe the conditions for achieving universal legal capacity in practice: see Flynn and Arstein-Kerslake, ‘Legislating Personhood: Realising the Right to Support in Exercising Legal Capacity’ (2014) 10 International Journal of Law in Context 81 at 85.
35 Articles 12(4) and 16 CRPD.
36 CRPD Committee, supra n 3 at para 25.
37 Ibid. at para 21.
40 CRPD Committee, supra n 3 at para 15.
exercise legal capacity ‘must respect the rights, will and preferences of persons with disabilities and should never amount to substitute decision-making’. In contrast, the term ‘substitute decision-making’ is defined by the CRPD Committee as follows:

Substitute decision-making regimes can take many different forms, including plenary guardianship, judicial interdiction and partial guardianship. However, these regimes have certain common characteristics: they can be defined as systems where (i) legal capacity is removed from a person, even if this is just in respect of a single decision; (ii) a substitute decision-maker can be appointed by someone other than the person concerned, and this can be done against his or her will; or (iii) any decision made by a substitute decision-maker is based on what is believed to be in the objective “best interests” of the person concerned, as opposed to being based on the person’s own will and preferences.

Substituted decision-making may be contrasted with ‘supported decision-making’, which is one type of support to exercise legal capacity. Supported decision-making refers to a decision made by a person, on his or her own behalf, with support from others to exercise legal capacity. There is some disagreement in the literature as to whether ‘supported decision-making’ should refer to statutory arrangements alone, such as those found in British Columbia’s Representation Agreement Act 1986, in which formal supporters are authorized as ‘associates’ with specific legal powers. Others draw on the term to refer to informal support arrangements for decision-making to exercise legal capacity as well. These conceptual ambiguities will be discussed later in the article.

A further conceptual distinction is advanced by Browning, Bigby and Douglas who differentiate supported decision-making from ‘support with decision-making’. The term ‘Support with decision-making’, they argue, could refer to broader measures to assist people who may require assistance to make decisions outside the context of directly exercising legal capacity—for example, through accommodations such as plain language information, decision-making aids or self-advocacy training. Such efforts may indirectly influence the exercise of legal capacity (for example, by giving people the confidence and skills to engage in legal transactions), but its scope is less targeted.

A definition of ‘supported decision-making regime’ is provided in the General Comment to outline the core elements of what is required to apply CRPD compliant

41 Ibid.
42 Ibid. at para 23.
44 Bach and Kerzner, supra n 10 at 84.
45 Representation Agreement Act B.C. 1996 (Canada) c 405.
47 Browning, Bigby and Douglas, supra n 30.
48 Ibid.
support to exercise legal capacity in law, policy and practice. This includes providing ‘protection for all rights’, including upholding autonomy (for example, the right to legal capacity, the right to equal recognition before the law and the right to choose where to live) as well as rights related to freedom from abuse and ill-treatment (right to life, right to physical integrity and so on). Such a regime could take various forms, but should incorporate key features, including being available to all, even those with complex communication and intensive support needs, and being ‘based on the will and preference of the person, not on what is perceived as being in his or her objective best interests’. The regime should include readily available and accessible supports, including facilitating support for ‘people who are isolated and may not have access to naturally occurring supports in the community’, as well as the right to refuse such supports. Based on this definition, a supported decision-making regime includes supported decision-making, support with decision-making and broader support to exercise legal capacity, across a range of law, policy and practice.

The term ‘supported decision-making regime’ arguably causes confusion by giving the impression that the CRPD Committee interprets Article 12 to preclude some decisions being ‘made for’ a person. Instead, the CRPD Committee invites States Parties to rethink how decisions are ‘made for’ people in exceptional circumstances, such as where a person’s will and preference are unclear or unknown. As previously noted, the CRPD Committee interprets Article 12 to include the use of standards such as the ‘best interpretation of a person’s wishes and preference’, as well as other proposals for non-discriminatory ‘support’ to exercise legal capacity in exceptional circumstances. These points will be elaborated upon in the following section.

The above terms and concepts are useful for policymakers and practitioners wishing to implement support to exercise legal capacity on an equal basis. For the purposes of legal research, these distinctions help to clarify some of the conceptual ambiguities of Article 12. The analytical distinctions are not meant to be conclusive, nor will they provide an unfalsifiable judgement of being the ‘right’ or ‘true’ approach to all conceptual questions. But they can help avoid confusion, and can help to affirm when an analysis (particularly a human rights-based analysis) is good, or comparably better, for a particular purpose.

3. MAJOR ISSUES IN DEBATES ABOUT SUPPORT TO EXERCISE LEGAL CAPACITY

The purpose of this article is to elaborate on the limitations, conceptual tensions and ambiguities raised in the literature on the application of the right to legal capacity and the CRPD, to which I will now turn. The intention is to outline the concerns as clearly as possible, including a number of possible counterarguments, to provide a more complete analysis of CRPD Committee directives for achieving universal legal capacity in practice.

49 CRPD Committee, supra n 3 at para 29.
50 Ibid.
51 Ibid. at para 29(d).
52 Ibid.
53 Ibid. at para 21.
54 This approach to linguistic issues is adapted from a discussion by Bix: see supra n 38 at 29.
A. ‘What about the Person in a Coma?’ Are there Exceptions in the Provision of Support to Exercise Legal Capacity?

The most common critique of the CRPD Committee directive to replace substituted decision-making with supported decision-making is captured in the following questions: ‘What about a person in a coma? How can Article 12 apply when a person is incapable of expressing any will or preference in the strict sense, or cannot consistently express a sense of “yes” and “no”? ’ Undoubtedly, there will always be situations where even a person’s closest supporters cannot evince a sense of his or her will and preference. This may also include someone who has been institutionalized for decades or who is socially isolated and has no connection to others from whom to gain support.

In part, proponents who reject the view that some form of substituted decision-making should be retained have argued against acknowledging decision-making ‘in-capacity’ or ‘incompetency’, as it risks fixing such a status without any countervailing incentive to accommodate residual expressions of a person’s will and preference. This risk is particularly pointed to people with disabilities given a long history of their being considered to have limitations that are ‘natural’ and fateful, but which are, in fact, socially engineered, born from low expectations or a lack of accommodations due to underdeveloped or unavailable assistive technology. In a recent iteration of this pattern, Naci and Owen have produced some evidence suggesting that it is possible to open up communication with a small but significant proportion of people in a so-called ‘persistent vegetative state’. Naci and Owen used functional magnetic resonance imaging data to establish a form of brain-communication with comatose persons. ‘[D]espite the apparent absence of external signs of consciousness’, they have reported that ‘a significant small proportion of patients with disorders of consciousness can respond to commands by wilfully modulating their brain activity, even respond to yes or no questions, by performing mental imagery tasks’. Such studies add a pragmatic dimension to queries as to whether there is any justification for ‘locking in’ a categorical notion of incapacity.

Nevertheless, there will remain individuals for whom no relationships of trust exist and for whom not enough intention is expressed to guide decision-making. There are clear risks to stretching the meaning of the term ‘supported decision-making’ to cover situations where decisions are being made ‘for’ a person, rather than ‘by’ a person. Quinn has argued:

[W]hat’s worse: stretching a fiction (100% support) to the point that it is visibly at odds with reality – a factor that is only likely to be seized on by States acting out of abundant caution and enter declarations or reservations ring-fencing substitute decision-making – or, admitting the obvious and then

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55 Dhanda, supra n 10.
58 Ibid.
using our talents to lock in the exception and transform how decisions are ‘made for’ people?  

More decisively, he concludes, ‘[w]e cannot trade-off the reality that decisions will be “made for” some people under the carpet in the hope of cementing into place the paradigm shift only for the majority.’ Acknowledging that decisions will be ‘made for’ some people, particularly in times of emergency, immediately raises difficult questions. Certain types of psychosis and extreme self-harm, for example, raise particularly challenging issues (as will be considered shortly).

The CRPD Committee’s General Comment offers some interpretative guidance on this point. The CRPD Committee indicates that Article 12 requires discarding the term ‘substituted decision-making’, even as some of the practices currently seen to operate under the term may be retained. The CRPD Committee refers to the use of an interpretation by a third party based on the perceived wishes of the person as a way out of many of the difficulties described in the coma scenario and like situations. For the comatose patient, the use of the ‘best interpretation’ by friends or family, or even by public officials who seek to identify the wishes and preference of an individual based on his or her life story, values and beliefs, would conform with the concept of support advanced in Article 12 of the CRPD. In the terms of the CRPD Committee:

Where, after significant efforts have been made, it is not practicable to determine the will and preference of an individual, ‘best interpretation of will and preference’ must replace ‘best interests’ determinations. This respects the rights, will and preferences of the individual, according to Article 12 (4). The ‘best interests’ principle is not a safeguard which complies with article 12 in relation to adults. The ‘will and preference’ paradigm must replace the ‘best interests’ paradigm to ensure that persons with disabilities enjoy the right to legal capacity on an equal basis with others.

States wishing to realize this interpretation will be confronted with the challenge of situations in which the ‘best interpretation’ approach would not appear to quite fit. This could include a person who is non-verbal, requires intensive support and has no financial experience or apparent preference regarding her personal finances. On what basis should a supporter make investment choices with her money? The Victorian Law Reform Commission (VLRC) has suggested the guiding principle in these exceptional instances should be an overarching goal of ‘promoting the personal and social wellbeing’ of the supported person, with other principles applied in certain circumstances, such as the ‘prudent person principle’, in administering a person’s finances. It would seem difficult to apply support to exercise legal capacity in

59 Quinn, supra n 23 at 16.
60 Ibid. at 18.
61 CRPD Committee, supra n 3 at para 21.
62 For example, when making financial decisions, the VLRC proposed that ‘financial decision makers should be required to apply the prudent person principle in managing a person’s finances to the extent this promotes their personal and social wellbeing’. See VLRC, Guardianship: Final Report 24 (2012) at 398, section
accordance with the CRPD, when at first glance these approaches seem indistinguishable from the 'best interests' standard.

But while it might be impossible to stretch the fiction that the person is being supported to ‘make’ a decision in these exceptional scenarios, it is not inconceivable to suggest that the best interpretation of the person’s will and preference by the supporters could be the principal driver in a decision, even as other guiding principles such as those advanced by the VLRC are applied. For example, supporters wishing to make an investment decision for a person who is non-communicative, aside from a small number of physical and verbal cues known only to the supporters, could reasonably presume that the person wishes to be free from harm and vulnerability, and would, therefore, prefer secure and stable investments. Although robust mechanisms for addressing financial exploitation would be required (as they are under ‘best interests’ frameworks), as well as arbitration procedures to resolve possible disputes about the ‘best’ interpretation of a person’s will and preference, this framework could conceivably extend to the exceptional cases that are often advanced in debates about disability and legal capacity.

The CRPD Committee also included ‘rights’ as a third element of the ‘best interpretation of will and preference’ determination, stating that any such determination must respect ‘the rights, will and preferences of the individual, according to Article 12 (4)’. Although the ‘rights’ element is neither specifically emphasized nor elaborated upon by the CRPD Committee, it is likely to receive attention by states wishing to address ambiguities in ‘best interpretation’ determinations. In very recent law reform activity in Australia, for example, the Australian Law Reform Commission (ALRC) has recommended that ‘if it is not possible to determine what the person would likely want, the representative must act to promote and uphold the person’s human rights and act in the way least restrictive of those rights’. An important issue to resolve under such a scheme then becomes determining the point at which it is ‘not possible to determine what the person would likely want’. Identifying such a point will pose challenges, including questions as to who decides, how they decide and the extent of support that must be provided before such a decision is made. Another challenge will arise in instances where a person’s ‘rights’ are seen to conflict with a representative’s ‘best interpretation’ (or indeed the person’s own will and preference, as discussed later in the article). States wishing to heed the General Comment will be required to set boundaries as to how far the best interpretation of will and preference might stretch, and in giving due consideration to ‘rights, will and preference’ in establishing such boundaries.

B. Manipulation and Undue Influence by Supporters

The scenarios discussed in the previous section raise another common critique in proposals for implementing Article 12—support mechanisms such as supported decision-making open the possibility of manipulation and unchecked abuse against people with disabilities. Adrian Ward argues that Article 12 was the result of

63 CRPD Committee, supra n 3 at para 21 (emphasis added).
‘inept drafting’ where the definition of capacity is confused and confusing, leading to the potential for unbridled manipulation of people by so-called supporters.\textsuperscript{65} He argues that a ‘lack of clarity on this issue means that any reference to supported decision-making should be viewed as a flashing amber light requiring vigilance to distinguish between the adult’s own competent decision, made without undue influence, on the one hand, and on the other a decision more truly reflective of the views and values of the supporter, masquerading as the supported decision of the adult, but in fact straying into the area of de facto substituted decision-making.’\textsuperscript{66} Certainly, evidence is required to measure the incidence of undue influence, coercion or abuse in supported decision-making arrangements, including identifying factors that may encourage or discourage subtle coercion and substituted decision-making.

As a starting point, it is important to note that all adults are subject to influence, pressure, manipulation and subtle coercion by those close to them. This (almost banal) point remains important so as to avoid lowering standards for state intrusion into the decision-making of people with disabilities compared to the general population. Avoiding such exceptions is important, according to Dhanda, in the light of the historical overuse by governments of protectionism and paternalism based on the alleged incapacity of persons with disabilities.\textsuperscript{67}

From this view, an important question then becomes to what extent it is possible to ‘draw a bright line in law’ as a safeguard against ‘undue’ influence and manipulation in general.\textsuperscript{68} It is difficult to see how any such bright line exists for the majority of people making life decisions.\textsuperscript{69} The notion of supported decision-making (even prior to the CRPD) was designed in recognition that autonomy is a relational phenomenon.\textsuperscript{70} This view of autonomy as interdependent is contrasted with individualistic and rationalistic conceptions of the self which have dominated law and policy based on assessments of mental capacity.\textsuperscript{71} The notion of ‘relational autonomy’ casts some doubt on a claim for it to be possible to categorically distinguish between the ‘competent decision, made without undue influence, on the one hand’, from ‘a decision more truly reflective of the views and values of the supporter’. Resolving this line of enquiry requires a clearer definition of ‘undue influence’.

Indeed, the draft General Comment of the CRPD Committee was criticized for being unclear on this point.\textsuperscript{72} In response, the final draft of the General Comment included elaboration on what is meant by ‘undue influence’. The CRPD Committee notes that undue influence is characterized ‘where the quality of the interaction


\textsuperscript{66} Ibid.

\textsuperscript{67} See generally, Dhanda, supra n 10.

\textsuperscript{68} Quinn, supra n 23 at 19.

\textsuperscript{69} Ibid.

\textsuperscript{70} Gordon, supra n 9 at 62.

\textsuperscript{71} Ibid.

\textsuperscript{72} See, for example, Series, Submission to the UN CRPD, ‘Comments on Draft General Comment on Article 12: The Right to Equal Recognition before the Law’, Submission 25 to the UN CRPD, 21 February 2014, at 3, available at: www.ohchr.org/Documents/HRBodies/CRPD/GC/LucySeriesArt12.doc [last accessed 17 December 2014].
between the support person and the person being supported includes signs of fear, aggression, threat, deception or manipulation'.73 Clarifying these definitions at the domestic level, as well as designing measures to assess the ‘quality of the interaction’ between supporter and supported if need be, will help develop adequate safeguards, including placing duties on supporters to refrain from undue influence. Thresholds for undue influence in contract and probate law—which are broader than mental capacity determinations—may also provide guidance on this point, including tests as to whether a relationship is characterized by trust and confidence, power imbalance and so on. Further research is required to identify how these kinds of abuses can be identified and addressed, including identifying the limits of the law in entering interpersonal spheres of decision-making.

Another concern raised by Kohn, Blumenthal and Campbell, is that manipulation may arise not just in the form of deliberate coercion or unconscious influence from supporters, but also from ‘deliberate deference by the principal decision-maker’.74 This may include elderly people who prefer a decision-making proxy rather than making such decisions themselves as some research indicates is the case.75 Such deference can subvert the goals of supported decision-making, though again there is little evidence to support how or when this happens.76

Yet, although deference to others is a serious issue requiring concerted efforts to encourage maximal autonomy, this is an issue—again—that all adult people must grapple with at an interpersonal level. All people are likely to defer some decisions about themselves to those whom they trust. This may be magnified if expert advice is given. Indeed, there is some neuroscientific evidence showing that expert advice may, for those receiving it, shut down areas of the brain seemingly responsible for decision-making processes, particularly when individuals are trying to evaluate a situation involving risk.77 Nonetheless, manipulation by ‘supporters’ remains a concern, particularly given the long history of people with disabilities having their abilities devalued and suffering abuse in the private sphere. Further, some people with disabilities—such as those whose disabilities mean that they cannot communicate meaningfully with more than one or two people—would seemingly be vulnerable to abuse in substantially different ways, as will be discussed in the next section.

Finally, it is important to acknowledge the ongoing difficulty of safeguarding against abuse under current substituted decision-making models. The prevention of abuse and the application of adequate safeguards that balance freedom and protection remains an issue of significant (and possibly equal) difficulty under current substituted decision-making laws.78

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73 CRPD Committee, supra n 3 at para 22.
74 Kohn, Blumenthal and Campbell, supra n 43 at 1123.
75 Ibid. at fn 108.
76 Ibid. at 1123.
C. The Need for Boundaries Between Different Support Arrangements

Establishing comprehensive support to exercise legal capacity in law and policy would seemingly still require ‘dividing lines’ between different categories of support and safeguarding. This includes separating those categories in which a legislative mechanism is required where a decision must be ‘made for’ someone, rather than by that person, including where a person’s wishes and preference are unclear or unknown, or are only discernible to a small number of people.

Various categories of support for exercising legal capacity in these situations have been advanced. 79 For example, Bach and Kerzner have suggested three categories for legal models of support in line with Article 12 of the CRPD: autonomous (or ‘legally independent’) decision-making, supported decision-making and facilitated decision-making. 80 Each category in the model would be accompanied by a corresponding level of legal oversight. This would span from non-intervention with decision-making assistance, the provision of support mechanisms designed to help the person develop ‘decision-making capabilities’, and facilitation whereby a supporter is appointed to make decisions ‘for’ another person using (in general) the ‘best interpretation of his or her will and preference’. 81 Ireland’s Assisted Decision-Making (Capacity) Bill 2013 is set to introduce similar categories of support. 82

The challenge arises in setting out criteria for the application of these types of categories in ways that do not discriminate against persons with disabilities—including practices that do not discriminate in effect. 83 As Richardson has observed, supported decision-making seemingly requires the creation of new boundaries that ‘determine when support is to be offered and/or imposed and to provide for cases where decision-making powers are severely impaired and, despite all support, a decision with drastic consequences is maintained’. 84 Richardson notes that creating such boundaries would conceivably require some form of functional mental capacity testing and would, therefore, run counter to the spirit of the CRPD, 85 and more recently to the explicit interpretation of the CRPD Committee. 86 Indeed, Bach and Kerzner deemed it necessary to include functional assessments of ‘decision-making ability’ with

80 Bach and Kerzner, supra n 10.
81 Bach and Kerzner use the term ‘decision-making capability’ in a very specific way, to refer not to individual abilities or capacities but instead to ‘capabilities to function’ where function refers to the getting of things done or making things happen that are important to individuals or communities. Further, capabilities for decision-making are ‘a combination of . . . individual decision-making “abilities” and of decision-making “supports” and accommodations.’ They use these terms ‘as a way to conceptually integrate recognition of the functional diversity of individuals with an understanding of the array of supports and accommodations a person might need to enjoy and exercise his or her legal capacity’. See ibid. at 20–2.
82 These supports categories are: decision-making assistance, co-decision-making and representative decision-making: see An Bille um Chínnteoireacht Chuidithe (Cumas), 2013, Assisted Decision-Making (Capacity) Bill (No 83) 2013 (Ireland).
83 CRPD Committee, supra n 3 at para 25; and Articles 2 and 5 CRPD.
84 Richardson, supra n 31 at 103.
85 Ibid.
86 CRPD Committee, supra n 3.
regards to the boundaries between their proposed categories of support, as did the drafters of Ireland’s Assisted Decision-Making (Capacity) 2013.

The Canadian Association of Community Living (CACL) echo Bach and Kerzner and argue that functional assessments of mental capacity can help to identify those who exercise their legal capacity in ‘substantially different’ ways. In particular, CACL refers to people with more profound disabilities who require supporters to interpret their unique forms of communication, assist them to develop their will and preference, and translate those wishes into ‘particular actions and decisions which enable the person to exercise legal capacity’. For CACL, functional assessments of mental capacity help determine those who require such arrangements and can, therefore, be made non-discriminatory:

To recognize that people have different decisional [sic] abilities is not in itself discriminatory; just as it is not discriminatory to recognize that people have different mobility abilities. The issue is how those different abilities are recognized and supported, and how to ensure equal access and outcomes are not dependent on those differences.

CACL criticized the CRPD Committee’s rejection of assessments of decision-making ability, warning that a ‘principle of proportional support is not the answer to these challenges, except at the highest and most abstract level of principle’. Similar arguments have been advanced elsewhere, and lawmakers are struggling to find alternative, non-discriminatory mechanisms of support with accompanying safeguards.

The final draft of the General Comment did not heed CACL’s suggestion to endorse ability tests in defined circumstances. Indeed, the CRPD Committee expanded on its view that mental capacity tests were prohibited by the CRPD by stating explicitly that ‘the provision of support to exercise legal capacity should not hinge on mental capacity assessments; new, non-discriminatory indicators of support needs are required’. The CRPD Committee also abstained from specifying categories of support that were conceivably viewed as being too complex and specific and hence the domain of States Parties. However, the CRPD Committee did add to the final draft the ‘best interpretation of will and preference’ standard that CACL

87 Bach and Kerzner, supra n 10.
88 Section 3 An Bille um Chinníeireacht Chuidithe.
90 Ibid.
91 Ibid.
92 CACL, supra n 89.
94 CRPD Committee, supra n 3 at para 29(i).
recommended as a tool for navigating between the more challenging categories of support to exercise legal capacity.95

Those wishing to pursue the CRPD Committee’s call to discard decision-making ability tests will need to investigate alternative indicators for triggering support—or for indicating the limits of such support. Only a very small number of commentators have explored this possibility beyond the abstract.96 For example, a coalition of Australian non-government organizations has advanced a national framework to discard ‘ability tests’.97 The coalition describes such functional assessments of mental capacity as providing an ‘overarching exception to the right to equal capacity before the law, [which] embed[s] discrimination against people with disability’.98 Instead, a determination as to whether the will, preference or decision of a person is recognized by the law should focus on ‘the integrity of the support process’ used to express that decision.99 This, in turn, requires the testing of supports based on the ‘functional ability [of those supports] to meet the requirements of a person to make and/or communicate a decision to a third party’.100 In practice, this would mean that

[a]ny test of a person’s ability to exercise their legal agency is actually a test of whether the supports provided to the person are adequate and appropriate to the task in hand. If not they should be altered until will and preference can be expressed, or it becomes apparent that this is not possible.101

Researchers at the Centre for Disability Policy and Law have advanced similar proposals, including proposed legislative amendments which would focus on determining a ‘dividing line’ on whether a person’s will and preference is unknown or unclear.102 Such proposals are in the early stages of conceptual development and their practical application to legislation would constitute a profound shift away from centuries of capacity jurisprudence. Perhaps unsurprisingly then, no state has expressed a willingness to remove entirely functional assessments of mental capacity in the light of the CRPD. Yet, conceptual alternatives have developed considerably in recent years and the search for ‘dividing lines’ between categories of support in line with Article 12, while challenging, appears to promote a more explicit consideration

95 CACL, supra n 89.
97 Ibid.
98 Ibid. at para 5.
99 Ibid. at para 7.
100 Ibid.
101 Ibid. at para 11.
of the moral dilemmas at stake in fraught decision-making scenarios, and in a way the binary division of mental capacity/incapacity cannot.103

D. Risk Where the Person is Unaware of Harm Caused
Despite supported decision-making and broader support to exercise legal capacity under Article 12 challenging the high priority given to risk aversion, there remains a distinct challenge where individuals are not aware of the consequences of certain decisions that carry grave danger. This point is illustrated in Farr’s account of her own experience of psychosis.104 After many years of visual and aural hallucinations, Farr felt that she had to perform a dangerous act:

I thought I was approaching some kind of horrible Enlightenment about which I felt quite ambivalent... The voices told me that in order to reach this Enlightened [sic] state I would have, at the appropriate moment, to jump from the seventh floor of a building and land on my head in a certain way. This would put me in a cosmic junction whereupon... I would be able to enlighten all mankind to all the full scope of reality that lay beyond.105

Farr’s account brings into sharp relief a troubling moral dilemma to which Article 12 of the CRPD offers no easy answers. Bach and Kerzner’s legislative proposal for a framework for law and policy in line with Article 12 leaves some ambiguity on this point, where ‘facilitated decision-making’ is seemingly permitted under their proposal when a person was not able to express intention in ways that would direct reasonable consequential action—hence retaining a ‘reasonableness’ criteria from the functional assessment of mental capacity.106 They also use a concept of ‘serious adverse effects’ as a trigger for emergency safeguarding schemes aimed at maximizing autonomy, yet simultaneously limiting legal agency to address issues of self-harm and the ‘unacceptably high rates of abuse and neglect of older adults and people with disabilities’.107

Webb has (tentatively) suggested that states insisting on the need for emergency powers to intervene when someone poses a grave risk of suicide may consider generic suicide prevention legislation.108 The term ‘generic’ is used here in the sense of remaining non-discriminatory on the grounds of disability. In contrast, typical civil

103 Richardson, supra n 31 at 95, 103.
105 Ibid. at 4.
106 Bach and Kerzner, supra n 10 at 144.
107 CACL, supra n 89 at Part 2, section VI.
commitment laws require a diagnosis of mental disorder in certain circumstances before coercive intervention can lawfully occur.109

Richardson and others have pointed to another type of exceptional scenario in which a person’s will and preference are conflicting following efforts to clarify and reconcile his or her wishes.110 Anorexia provides a commonly used example of such a bind, where persons with anorexia commonly express a preference not to eat, but a will to live.111 Again, a ‘best interpretation of will and preference’ could be used to guide a decision but adjudicating its application would be fraught indeed (as it is under current substituted decision-making and ‘best interests’ approaches). The issue of conflicting will and preference has been described rightly as perhaps ‘one of the most difficult situations in which to apply Article 12’.112

It is clearly outside the scope of this article to consider the specific concern of conflicted will and preference in detail, or to discuss relative merits and drawbacks of generic suicide prevention legislation and other such proposals. The more important point here is the apparent need to explicitly define the emergency instances in which legal agency can be overridden and in which coercion can occur in ways that do not discriminate on the basis of disability (if this is indeed possible in substantive terms).113 In international human rights law ‘public order’ (‘ordre public’) may be invoked under the terms of the ICCPR to impose restrictions on the exercise of certain human rights, including freedom of movement,114 that may help set the boundary between the individual right to legal capacity and countervailing collective interests. However, the General Comment directs that the right to legal capacity (on an equal basis) is non-derogable even in emergencies.115 It will be useful to seek guidance in international human rights law on this point. Indeed, discovering more suitable alternatives that comply with human rights standards yet provide suitable means for emergency intervention remains an ongoing endeavour for governments and others wishing to advance the provision of support to exercise legal capacity on an equal basis with others.


110 Richardson, supra n 31.

111 See, for example, Re E (Medical treatment: Anorexia) (Rev 1) [2012] EWCOP 1639, 15 June 2012 (UK).


113 See the references in supra n 109.


115 CRPD Committee, supra n 3 at para 5.
E. The Limits of Legislative Mechanisms in Garnering Resources

Carney has argued that the success of supported decision-making can be measured by its ability to draw in resources,116 which would apply equally to measuring the success of broader efforts to provide support for exercising legal capacity. He emphasizes the limited role of legal mechanisms for addressing issues in service provision or civil society, and argues that legislative mechanisms for supported decision-making can ‘only be judged by how well [they] mobilize...public or private resources (such as informal supports of civil society) in accordance with peoples’ individual set of values and preference (in this and other respects); but the point here is that agency is realised only to the extent that resources exist in the external environment.”117 The South Australian Office of the Public Advocate, reported at the conclusion of its supported decision-making trial that Carney’s warning ‘turned out to be very much the case in our trial, particularly when people made accommodation or support decisions...that then had to be resourced.”118

Importantly, this argument is not directly concerned with cost-effectiveness, but rather concerns the acknowledgement that implementing supported decision-making and broader support to exercise legal capacity is dependent on material conditions. Flynn and Arstein-Kerslake argue that from a human rights perspective equality before the law is a civil and political right, for which there is arguably no limit to the level of support that must be provided to achieve this.119 Further, it should be noted that it would be crucial that in any cost-effectiveness analysis—that this article will not engage directly—the comparative costs of the existing systems of substituted decision-making would need to be considered.

In fiscal terms, attracting sufficient resources for people requiring support to exercise legal capacity will continue to challenge. A number of governments around the world are transitioning to funding schemes for disability services that are self-directed by those receiving support. These schemes clearly dovetail with the emphasis on ‘choice’ in the application of Article 12 and may address certain deficits that currently limit the reasonable expectations of people with disabilities in making decisions about their lives.120 But the evidence varies on self-directed funding schemes121 and inevitably the issue of the most effective use of government spending to best realize support ‘ramps’ for exercising legal capacity will need to be carefully considered by reformers or others interested in implementation.

Interestingly, the PO Skåne model, a Swedish personal advocacy service for people with psychosocial disabilities—which was described by the European Commissioner for Human Rights as ’decision-making support in line with

117 Ibid. at 17.
118 South Australian Office of the Public Advocate, supra n 116.
119 Flynn and Arstein-Kerslake, supra n 34 at 85.
120 See, for example, Part 2 National Disability Insurance Scheme Act (No 20) 2013 (Cth). See generally, the National Disability Insurance Scheme Website, available at: www.ndis.gov.au [last accessed 17 December 2014]; and Ungerson and Yeandle (eds), Cash for Care in Developed Welfare States (2006).
121 See, for example, Glasby and Littlechild, Direct Payments and Personal Budgets: Putting Personalisation Into Practice, 2nd edn (2009).
Article 12 has a specific function for demanding resources. A report by the Swedish National Board of Health and Welfare indicates that a key role of the personal advocate is as a ‘care demander’. The advocate, or ‘PO’, ‘make[s] demands on the public authorities that are responsible for people with serious psychiatric disabilities, to ensure that they are receiving the help and service to which they are entitled’. Policymakers facing fiscal restraint may be deterred by such a function. Yet the same report claims the scheme produces savings up to 17 times the cost of the service itself. The saving is explained in the report by a reduction in the number of mental health crises, and by the POs facilitative role in coordinating between services and highlighting weaknesses in service provision.

‘Informal resources’, or ‘natural supports’, will be just as important in measuring the application of a supported decision-making regime in practice. It is worth reiterating that concepts such as supported decision-making were developed from relationships between people with disabilities and their (mostly) informal support networks. Such ideas were progressed within peer groups, families and advocacy groups, often alongside the development of theory, and applied only later to law and policy. This trajectory of advocacy would seem important to retain so as to guard against the appropriation of support practices solely into the specialized realm of service provision, or law, or any other area of expertise. At the same time, it will be important to ensure that informal efforts by people with disabilities, their families and other supporters, do not replace government resourcing. (The potential risks for informal supporters in this equation has an important gendered dimension, where informal support is typically provided by mothers, and women more generally.) An innovative effort to strike this balance in policy terms, can be found in a supported decision-making trial in Victoria, Australia, by the Office of the Public Advocate. The trial aims to mobilize citizen volunteers, using a paid facilitator, to develop freely-given relationships around socially isolated persons who may benefit from decision-making support.

124 Ibid.
125 Ibid. at 23–4.
126 Ibid.
127 See Gordon, supra n 9 at 64. Gordon argues that theory underpinning the concept of supported decision-making includes that of Wolf Wolfensberger: see Wolfensberger, A Brief Introduction to Social Role Valorization: A High-Order Concept for Addressing the Plight of Societally Devalued People, and for Structuring Human Services, 3rd edn (1998).
128 Ibid.
130 For more information, see: www.publicadvocate.vic.gov.au/research [last accessed 10 January 2015].
131 Ibid.
F. ‘Responsibilisation’—Governments Placing Risks on Citizens

One risk arising from added emphasis on informal supports noted in the previous section is that governments may abrogate their duty to provide support to citizens by transferring various risks to individuals. In a more general critique, Foucault argues that the government may discard its duties under the guise of increasing the rights and responsibilities of citizens. This ‘responsibilisation’, as Foucault terms it, occurs where citizens view social risks, such as illness, unemployment and poverty as existing in the domain of individual responsibility and ‘self-care’, rather than being addressed by the state’s duty to provide services.

A key function of mental capacity-based laws in this respect, such as guardianship legislation and unfitness to plead provisions in criminal law, has been the recognition at law that people cannot be held responsible for decisions for which they lack mental capacity. Carter and Chesterman have argued that ‘[o]ne of the most positive features of (the) guardianship system, is the acceptance of responsibility by the guardian and/or the administrator for the decisions s/he makes at a time in history when many professionals are increasingly reluctant to accept such responsibility.’

From this view, the implementation of supported decision-making has the potential to draw credibility from the ideas and language of individual human rights, autonomy and self-determination, though it may result in the unreasonable transfer of risk and uncertainty by the state to persons with disabilities.

One counterargument is that the CRPD framework for realizing legal capacity on an equal basis explicitly aims to counterbalance the possibility of ‘responsibilisation’ by re-directing state duties and resources in strategic ways. An example would be the provision of support and ‘reasonable accommodation’. Another would be efforts in law and policy to prevent abuse, exploitation and neglect by decoupling substituted decision-making from protection against abuse, exploitation and neglect.

A second counterargument is that from a broader, structural perspective, the CRPD promotes a theory of change that rests on boosting the advocacy capacity of representative organizations of people with disabilities. The increasing power of these groups, in combination with independent monitoring processes, could conceivably serve as a countervailing power against ‘responsibilisation’ by pressuring governments to adhere to human rights directives, including the provision of

133 Ibid. Foucault coined the term ‘governmentality’ to describe the mentality, taken on by citizens, which is most accommodating to systems of power, particularly within the logic of the prevailing economic ideology. Hence, with ‘neoliberal governmentality’ the ends of reducing the scope of government—particularly the provision of welfare—can be realized by means of techniques that lead and control individuals without the state taking responsibility for them: see Foucault, ‘Security, Territory, and Population’ in Rabinow (ed.), Ethics: Subjectivity and Truth (1997) at 67.
134 Lemke, ‘“The Birth of Bio-Politics” – Michel Foucault’s Lecture at the Collège de France on Neo-Liberal Governmentality’ (2001) 30 Economy and Society 190 at 201.
135 Carter and Chesterman, supra n 132 at 19.
136 Ibid.
137 Articles 2 and 5 CRPD.
138 Article 16 CRPD.
139 Article 33(3) CRPD.
goods to enjoy the human rights set out in the CRPD. Finally, bolstering disability representative organizations will be important given such organizations would be well-placed to negotiate the extent of acceptable risk of ‘responsibleisation’ taking place. The re-orientation of state responsibilities in this way may be sound in theory but will require careful evaluation and monitoring to ensure its realization in practice.

G. ‘Net Widening’

Most commentators on supported decision-making see its potential for introducing a spectrum to what has heretofore been a crude binary division between those considered capable and those considered incapable of decision-making. A more nuanced spectrum of legislative intervention would help people avoid this binary system. However, Carney has raised the concern that such a spectrum may not help keep people out of adult capacity law arrangements, but will potentially ‘widen the net’ and capture more people into prescriptive decision-making structures:

One possible unintended consequence of any additional legal avenue is that of ‘net widening’ – where supported decision-making orders extend to an additional population rather than apply to those otherwise liable to a guardianship order; a phenomenon that may variously be both a risk (via unnecessary incursions on autonomy and privacy) or a benefit (in facilitating the provision of necessary support and the recognition of such support by third parties).140

‘Net widening’ may be especially likely to emerge from efforts to make capacity tests facially non-discriminatory.141 Series reiterated this point with reference to UK case authority, which ‘held that unless mental capacity assessors can show that a person failed the “functional test” because of a “disturbance in the functioning of the mind or brain” (as set out in the Mental Capacity Act 2005 [England and Wales]) then they should be treated as having legal capacity’.142 In other words, without a causative correlation between the decision and this ‘diagnostic criterion’ the person cannot be found to lack mental capacity. The removal of the criterion, paradoxically, would result in its application to more people generally (and more people with disabilities, who are more likely to have their mental capacity called into question).

Similarly, though in a different context, mental capacity law reform efforts in Northern Ireland have included expanded criteria for assessing mental capacity in an effort to remain non-discriminatory against persons with disability.143 The Draft Mental Capacity Bill 2014 is designed to ‘fuse’ mental health law and mental capacity law so as to avoid relying on a diagnosis of mental illness as a criterion for detention and involuntary treatment under current mental health legislation.144 The Draft

140 Carney and Beaupert, supra n 12 at 195.
141 Ibid.
142 Series, supra n 72 at 3. For relevant case law, see PC and Anor v City of York Council [2013] EWCA Civ 478.
143 Section 3(1)(c) Draft Mental Capacity Bill (Northern Ireland).
Mental Capacity Bill 2014 would see an additional criterion in assessments of mental capacity which goes further than the typical functional assessment of mental capacity (the so-called ‘understand-and-appreciate’ test). The accompanying policy material states, ‘[i]t will not be sufficient for a person to have a cognitive understanding of the information relevant to the decision.’\(^{145}\) Instead, a ‘person whose insight is distorted by their illness or a person suffering from delusional thinking as a result of their illness, may not . . . meet this element of the test.’\(^{146}\) Such a measure explicitly widens the interpretative flexibility of mental capacity assessors and may indeed result in ‘net-widening’.\(^{147}\)

The CRPD Committee did not explicitly respond to concerns raised about ‘net-widening’ in its General Comment. This is perhaps unsurprising given its mandate to monitor human rights violations against persons with disabilities specifically (and not all vulnerable individuals who may be affected by ‘net-widening’). Further, the General Comment repeatedly emphasizes the need for non-discriminatory measures of support in both form and effect and appears to reject mental capacity assessments as a discriminatory practice, citing them as a barrier to equal recognition before the law. Hence, the concern raised about net-widening rests not on a criticism of the model itself but rather on its implementation. Given the inchoate nature of the application of support to exercise legal capacity in practice, the issue of ‘net-widening’ demands careful attention by reformers wishing to apply the directives of Article 12. It is not clear how pilot programmes or empirical evidence could solve this particular problem in a way that law reform, which closely considers this potential pitfall, could not.

**H. Gaps in Evidence on the ‘Success’ of Support to Exercise Legal Capacity**

This last point raises a final issue of note. A major gap in the literature on implementing a supported decision-making regime is the lack of empirical research. Kohn, Blumenthal and Campbell describe this gap regarding supported decision-making (again, which is only one aspect of support to exercise legal capacity):

Supported decision-making holds promise . . . as an alternative to guardianship . . . . If it empowers persons with cognitive and intellectual disabilities to make decisions for themselves, as advocates of supported decision-making claim, it has the potential to advance the interests and human rights of persons with disabilities. However, without more evidence as to how supported decision-making functions in practice, it is too early to rule out the possibility that it may have the opposite effect.\(^ {148}\)

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145 Ibid. at 2.22.
146 Ibid.
147 It is important to note that the use of ‘insight’ as a criteria for mental capacity is likely to be implicit in other mental capacity schemes, as Emmett and colleagues found was the case under the Mental Capacity Act 2005 (England and Wales). See, for example, Emmett et al., ‘Homeward Bound or Bound for a Home? Assessing the Capacity of Dementia Patients to Make Decisions about Hospital Discharge: Comparing Practice with Legal Standards’ (2013) 36 International Journal of Law and Psychiatry 73.
148 Kohn, Blumenthal and Campbell, supra n 43 at 1157.
Indeed, there have been extensive discussions of the benefits and possible drawbacks of supported decision-making, most of which ‘provide little or no empirical support for their claims’. Carney and Beapert have stated that ‘current proposals are confused and may well invite potential for use and even abuse to the detriment of the disabled person’. Similarly, Mason argues that ‘proposals for supported decision-making (in legislation) must be based on empirical evidence-based research and pilot programmes which are presently lacking’. More decisively, Mason concludes that, ‘[a]s things currently stand, the proposals seem to reflect little more than ideals that have not been carefully thought through, with the risk that they will result in experimental law-making.’ Certainly, the gap in the empirical and social science literature on how to effectively realize a supported decision-making regime does little to assuage the concerns of policymakers, academics, families and others, about the concept.

However, the paucity of empirical literature is not unique to supported decision-making. As Kohn, Blumenthal and Campbell acknowledge, ‘there is also surprisingly little evaluative empirical literature on guardianship’. Donnelly has raised similar concerns about the ‘best interests’ approach, observing of the literature that, ‘the conceptual basis for the [“best interests”] standard has remained, for the most part, unexplored’, despite its widespread use. The lack of evidence to support the efficacy of involuntary outpatient treatment under mental health law, such as ‘community treatment orders’ and ‘assisted outpatient treatment’, provides another example of substituted decision-making mechanisms in law that lack a strong evidence base to indicate its success.

It is noteworthy that governments are willing to implement such under-researched coercive measures, the success of which is unproven. The reason for retaining ‘experimental law-making’ in these cases can only be speculated at, though it is not unreasonable to hypothesize that risk aversion drives government priorities with regards to substituted decision-making measures. Substituted decision-making approaches may be also strongly supported by some service providers and professionals. Light and colleagues produced evidence indicating that many service

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151 Ibid.

152 Ibid.

153 Kohn, Blumenthal and Campbell, supra n 43.

154 Ibid. at 1111.


156 See Burns et al., ‘Community Treatment Orders for Patients with Psychosis (OCTET): A Randomised Controlled Trial’ (2013) 381 The Lancet 1627; and Johnson, ‘Can We Reverse the Rising Tide of Compulsory Admissions?’ (2013) 381 The Lancet 1603.
providers are convinced about the effectiveness of community treatment orders, despite large-scale, randomized control trials failing to support such a view. Such conviction may, in turn, drive service delivery culture and entrench policy, which adapts to using and relying upon forms of coercive intervention.

It is also worth throwing caution to the wind as to claims about ‘evidence-based law’ more generally. Undoubtedly, empirical research is useful to debunk false myths that are advanced in legal debates. However, ‘evidence-based law’ is a relatively new field of enquiry compared to empirical testing in other disciplines, such as medicine or business, to which it is seeming better suited. Rachlinski has argued that empirical testing for medicine, with its uniform mission to treat patients, is more straightforward than law—by contrast, ‘law is often politics by other means’. A useful legal and public policy issue to illustrate this point is the death penalty. The abandonment of the death penalty in most jurisdictions to have done so cannot be explained by the accumulation of empirical evidence highlighting its ineffectiveness in preventing crime; instead, change was driven by evolving ideas as to what is moral and unjust. Rachlinski argues that law often ‘sorts winners and losers, rather than right and wrong’, and the imposition of empirical legal testing can cloud normative claims.

The call for ‘evidence’ regarding support to exercise legal capacity must be weighed against the qualitative criteria for justifying reform of substituted decision-making law and policy. Arstein-Kerslake argues that ‘as a moral imperative...equality of people with cognitive disabilities is “right,” and is the proper aim of law reform processes’. She further argues that ‘the prima facie inequality enshrined in legislation is sufficient evidence to demonstrate a need for reform to reach equality and compliance with human rights law’. From this view it can be reasonably asked why advocates for supported decision-making regimes are being asked to ‘prove’ whether such a model works.

Yet even if human rights are set aside in favour of pragmatic concerns, there are well-documented problems in converting empirical legal studies into evidence-based law. Again, the death penalty issue is illustrative. Donohue and Wolfs have undertaken a meta-analysis of research examining whether or not the death penalty deters crime in the USA. They conclude that despite decades of concerted social-scientific inquiry there has been a consistent failure to demonstrate that the death penalty is more effective than long prison sentences at deterring crime—yet neither have studies proven that the death penalty is less effective than long-term prison

158 Ibid.
160 Ibid.
161 Ibid. 905.
162 Ibid. 901.
164 Ibid. at 12.
165 Rachlinski, supra n 159 at 912.
sentences at deterring crime.\textsuperscript{166} The methodological complexity of drawing a direct causative link between the death penalty and preventing crime seems comparable to the challenge of measuring the ‘success’ of replacing substituted decision-making with supported decision-making in law and policy. What measurements could be used for such a comparison? The ‘well-being’ of subjects is one option; another might be the rate of reported abuse before and after legal change. Yet in both these cases it would be extremely difficult to indicate direct causality between the conceptual basis for legal change and subsequent events. Again, even if human rights concerns are set aside, it is questionable to hinge the basis for implementing the universal legal capacity model as enunciated by the CRPD Committee on empirical evidence.

4. CONCLUSION
The issues listed in this article revealed a number of areas requiring further attention. These include accommodating the substantially different ways people exercise legal capacity, arbitrating what it means to do so on an equal basis with others, and operationalizing support and safeguards in such a way that they do not create discriminatory toe-holds for historic patterns of abuse, neglect and exploitation. Addressing these concerns would require, among other things, tighter definitions of exceptional circumstances to justify overriding legal agency in emergency crises. If the right to legal capacity were to be applied as it is advanced in the CRPD, these exceptions would need to be non-discriminatory and defined \textit{within} a human rights framework rather than being balanced against human rights considerations. Such reform efforts would need to be developed in ways that facilitate disabled people’s organizations and independent human rights bodies to collaborate in deliberative processes to conceive and implement alternatives.

Other concerns, not raised in this article, are also worthy of attention. Distinct challenges are likely to arise, for example, if previously informal relationships are formalized under supported decision-making schemes.\textsuperscript{167} Determining the legal responsibility of supporters and representatives, including consequences where duties are breached, will also require attention. Clearly, research is required on a number of fronts.

Yet, despite these gaps, the issues raised in this article provide no plausible reasons as to why domestic law, policy and practice could not be generally reshaped according to the CRPD Committee’s elucidation of the right to legal capacity in international human rights law. The concerns and counterarguments listed here help to resolve certain ambiguities raised in current debates about Article 12 of the CRPD. The issues were listed to provide a more complete analysis of an idea being increasingly applied in law, policy and informal and formal support practices for persons with disabilities and others. Although certain tenets of a supported decision-making regime can be set, some of its boundaries will remain fluid—and necessarily so.


This flexibility is required given complex tensions inherent in the right to legal capacity itself, and to the CRPD generally, which concerns intersections between individual needs and broader social and legal change, informal and formal support, and state and civil society, and in competing accounts of equality and other core rights.\(^{168}\)

The findings, I have presented, raise important questions about how governments and civil society organizations can navigate these tensions to set the boundaries of support to exercise legal capacity on an equal basis for all citizens.

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\(^{168}\) Carney and Beaupert, supra n 12 at 180–1.