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Centre for Disability Law and Policy

Ad Hoc Joint Committee to Consider the Mental Capacity Bill in Northern Ireland

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.

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1. **The CDLP** welcomes the opportunity to make this submission to the Ad Hoc Joint Committee to Consider the Mental Capacity Bill in response to the *Mental Capacity Bill (NI)* (hereinafter referred to as 'the Mental Capacity Bill'). For more information on our engagement with related issues please see our website at https://www.nuigalway.ie/cdlp/.

2. This submission is intended to be read with reference to previous CDLP submissions, particularly: the submission to the Department of Health, Social Services and Public Safety in Northern Ireland and the Department of Justice Northern Ireland (September 2014), submission to the Department of Justice and Equality, Republic of Ireland, on the Assisted Decision-Making

(Capacity) Bill (October 2013), the submission to the Australian Law Reform Commission 'Issues Paper' regarding Equality before the Law in January 2014, and the submission to the House of Lords Select Committee on the Mental Capacity Act 2005 (September 2013).

Introduction

3. The CDLP has previously discussed the contentious inclusion of the issues of best interest and mental capacity in Northern Ireland legislation and we are concerned that it continues to be a primary feature of the current Bill. In our previous submission of September 2014 we provided several examples of how this could be achieved, including through replacing the principle of 'best interests' with respect for the person's will and preferences, and replacing the current definition of mental capacity with a recognition of the various ways in which an individual might exercise his or her legal capacity. We will not repeat our previous recommendations in full in this submission but would encourage the members of the Ad Hoc Joint Committee to read those recommendations for a more detailed explanation of our approach.

4. Northern Ireland, as part of the UK, is due to be examined by the Committee on the Rights of Persons with Disabilities during 2015.[1] The Committee adopted General Comment 1 in April 2014 which makes clear that 'best interests' is not an appropriate safeguard for the right to legal capacity, and that perceived or actual deficits in an individual's mental capacity should never be used to deny that person's legal capacity.[2] Since this Bill continues to use both 'best interests' and 'mental capacity' as its guiding principles, it is likely to be criticised by the Committee during its forthcoming dialogue with the UK.

Overarching Principles

5. The two principles of the Bill in its current form are 'mental capacity' and 'best interests'. Given the historical abuses of people with disabilities and others for whom this Bill is intended (which often occurred within the parameters of law), we would argue that any Bill designed to support and safeguard decision-making for this group ought to reflect principles of human rights, including equality and dignity, as well as the *substantive* rights (sometimes referred to as 'positive rights', in acknowledgement of the needs of persons for whom the legislation is intended. Further, the Bill should explicitly recognise different forms of support which people with disabilities might use in the exercise of their legal capacity. This should include the option of making formal, legally-binding support agreements and advance directives, where individuals set out the support they intend to use in exercising their legal capacity in various areas of their lives.

[1] Equality and Human Rights Commission, http://www.equalityhumanrights.com/about-us/our-work/human-rights/international-framework/monitoring-and-promoting-un-treaties, last accessed 2 July 2015.

[2] 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).

6. An example of such considerations was advanced by the Australian Law Reform Commission,[3] which clearly articulated four key national decision making principles that capture a rights perspective to support for decision-making. The principles reflect developments in international human rights law regarding the issues to which the Bill seeks to address and we strongly recommend that some form of these principles are used in the Bill. We outline these principles below as an alternative set of principles for this Bill.

Recommended Amendments: Principles

Replace clause 1 and 2 with:

1) Principle 1: The equal right to make decisions
All adults have an equal right to make decisions that affect their lives and to have those decisions respected.

2) Principle 2: Support
Persons who may require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.

3) Principle 3: Will, preference and rights
The will, preference and rights of persons who may require decision-making support must direct decisions that affect their lives.

4) Principle 4: Safeguards
Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for persons who may require decision-making support, including to prevent abuse and undue influence.

Recommended Amendments: From Mental Capacity to Legal Capacity

7. The Bill retains 'functional assessments of mental capacity' which can be used to restrict or deny legal capacity – where the result can be the imposition of substituted decision-making. The replacement of a best interests approach that uses mental capacity assessments is possible with strategic amendments. We include some examples of how such amendments could be made. Although these small changes early on in the Bill would require changes to be made throughout the Bill as a whole (for example, where 'best interests' and mental capacity are referred to) the CDLP would be able to provide more detailed explanations, upon requests, as to how this transition is possible.

Replace Section 3 in its entirety with the following

[3] 'Equality, Capacity and Disability in Commonwealth Laws Final Report' Australian Law Reform Commission Report 124, August 2014, Chapter 3 from page 63, https://www.alrc.gov.au/sites/default/files/pdfs/publications/alrc_124_whole_pdf_file.pdf, accessed 2 July 2015.

5) "'Legal capacity' means the ability to hold rights and duties and to exercise these rights and duties

6) Legal capacity may be exercised:

(a) by the relevant person with decision-making supports and/or reasonable accommodation; or
(b) by the relevant person and his or her nominated person, acting jointly; or
(c) in a situation of last resort, where all efforts to ascertain the relevant person's will and preference have been made and the relevant person's will and preference remain not known, legal capacity may be exercised by the person(s) selected to represent the relevant person in exercising the relevant person's legal capacity (i.e. decision-making representative, attorney, or nominated person in advance healthcare directive).

(2) Where legal capacity is exercised with the support of a decision-making assistant or is being made by a person selected to represent the relevant person, and where the relevant person's will and preference are not known, the decision shall be guided by the individual's best interpretation of the relevant person's will or preference 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."

Recommended Amendments: 'Best interpretation' of will and preference

8. Where a person's will and preferences remain unknown after significant efforts to discover them, then the only option where a decision must be made is for an appointed person to take this decision. To remain human rights compliant, the appointed person would make this decision based on the 'best interpretation of will and preferences.' This novel provision is included in the proposed amendment below and reflected in the CRPD Committee's General Comment 1 on Article 12.

Amend Section 4 as follows

Meaning of "~~unable to make a decision~~ will and preference are not known"

~~4.—(~~**7.—**1) For the purposes of this Part a ~~person is "unable to make a decision~~ person's "will and preference are not known" ~~for himself or herself~~ about a matter if the person—

~~(a) is not able to understand the information relevant to the decision; or~~

~~(b) is not able to retain that information for the time required to make the decision; or~~

~~(c) is not able to appreciate the relevance of that information and to use and weigh that information as part of the process of making the decision; or~~

~~(d) is not able to communicate his or her decision (whether by talking, using sign language or any other means).~~

~~(2) In subsection (1) "the information relevant to the decision" includes~~

~~information about the reasonably foreseeable consequences of—~~

~~(a) deciding one way or another; or~~
~~(b) failing to make the decision.~~

~~(3) For the purposes of subsection (1)(a) the person is not to be regarded as "not able to understand the information relevant to the decision" if the person is able to understand an appropriate explanation of the information.~~

~~(4) An appropriate explanation means an explanation of the information given to the person in a way appropriate to the person's circumstances (using simple language, visual aids or any other means).~~

all practicable steps have been taken, without success, to help discover his or her will and preference.

2) In the case of an intervention in respect of a person whose will and preference are unknown, regard shall be had to –

(a) the likelihood of the recovery of the person's ability to express his or her will and preferences in respect of the matter concerned, and
(b) the urgency of making an intervention prior to such recovery.

(3) The court, on application to it by a person entitled 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 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 unknown."

(4) For the purposes of this Part a '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.

Recommended Amendments: Decision-Making Support

9. In helping to determine a person's will and preferences it is crucial that he or she is provided with the support that may be required to exercise legal capacity. If legislation simply provides legal recognition for this support, and provides for arbitration to resolve any disputes about the provision of support or about the person's will and preferences, then assessments of mental capacity will be no longer necessary. Dispute resolution mechanisms could be provided for in the first instance by a statutory body, with a right of review by the courts where necessary. This could provide a more cost-effective solution by limiting the caseload of the court, as well as providing more flexible, timely and accessible mechanisms for people who wish to use the provisions of the Bill.

Supporting person to make decision

8.—(1) A person is not to be regarded for the purposes of section 1(4) as having been given all practicable help and support to ~~enable him or her to make a decision~~ exercise his or her legal capacity, unless in particular, the steps required by this section have been taken so far as practicable.

(2) Those steps are—

(a) the provision to the person, in a way appropriate to his or her circumstances, of all the information relevant to the decision (or, where it is more likely to help the person to make a decision, of an explanation of that information);

(b) ensuring that the matter in question is raised with the person—

(i) at a time or times likely to help the person to make a decision; and

(ii) in an environment likely to help the person to make a decision;

(c) ensuring that persons whose involvement is likely to help the person to make a decision are involved in helping and supporting the person.

(3) The information referred to in subsection (2)(a) includes information about the reasonably foreseeable consequences of—

(a) deciding one way or another; or

(b) failing to make the decision.

~~(4) Nothing in this section is to be taken as in any way limiting the effect of section 1(4).~~

Recommended Amendments: 'Best interpretation' of will and preference

10. Section 7 currently provides for a best interests framework. This is clearly incompatible with the Committee on the Rights of Persons with Disabilities' interpretation of Article 12 CRPD as set out in General Comment 1. In order to achieve compliance with this interpretation of the CRPD, we suggest deleting section 7 in its entirety, and replacing it with the aforementioned concept of the 'best interpretation' of the individual's will and preferences, as described below.

Compliance with section ~~1(2)~~ 1-4

9.—(1) In proceedings under this Act or any other statutory provision, any question whether a person ~~who is 16 or over lacks capacity in relation~~ 's will and preferences are unknown in relation to a matter (within the meaning of this Act) is to be decided on the balance of probabilities.

(2) Subsection (3) applies where, other than in such proceedings, it falls to a person to determine for any purpose of this Act whether ~~another persona~~ person's will and preferences are not known who is 16 or over ("P") ~~lacks capacity~~ in relation to a matter.

(3) If—

(a) the person making the determination has taken reasonable steps to establish whether ~~P lacks capacity~~the relevant person's will and preferences is known in relation to the matter,

(b) the person reasonably believes that ~~P lacks capacity~~the relevant person's will and preferences are unknown in relation to the

matter, and

(c) the principles ~~in section 1(3) to (5) and section 5~~of this Act have been complied with,

for the purposes of section 1(2) the person is to be taken to have sufficiently "established" that ~~P lacks capacity~~the relevant person's will and preferences are unknown in relation to the matter.

(4) In this section "proceedings" includes proceedings before a tribunal and proceedings of any panel constituted under Schedule 1 or 3.

Compliance with section 2

10.—(1) This section applies where a person other than the court ("third party")—

(a) does an act for or on behalf of another person who is 16 or over ~~and lacks capacity~~where the person's will and preferences are unknown in relation to whether the act should be done; or

(b) makes a decision based on the 'best interpretation of will and preferences' for or on behalf of another person who is 16 or over in which the person's will and preferences are unknown~~and lacks capacity to make the decision~~.

(2) The relevant person is to be taken to have sufficiently complied with the 4 principles of the Act ~~in section 2(2) (act or decision must be in best interests)~~ if that person—

(a) reasonably believes that the act or decision is ~~in the other person's best interests~~being undertaken based on the person's rights, will and preferences; and

(b) in determining whether the act or decision is made ~~in~~ according to the other person's ~~best interests~~rights, will and preferences, has complied with section 7.

Recommended Amendments: Support to Exercise Legal Capacity where Person's Will and Preference are Unknown

11. The Bill currently provides for safeguards for those who are deemed to lack capacity, and introduces protection from liability for third parties who make 'best interests' decisions on behalf of those who are deemed to lack capacity. If the Bill is to be reoriented in accordance with the support paradigm of legal capacity, the safeguards need to be reframed as safeguards for the exercise (rather than the denial) of legal capacity, and liability protection should be introduced for third parties who in good faith make decisions that they believe reflect the will and preferences of the person. Given that sections 13 and 14 relate to formal assessments of mental capacity, we recommend that these sections are deleted in their entirety.

PART 2

~~LACK OF CAPACITY:~~SUPPORT FOR LEGAL CAPACITY: PROTECTION FROM LIABILITY, AND SAFEGUARDS

CHAPTER 1
PROTECTION FROM LIABILITY, AND GENERAL SAFEGUARDS

Protection from liability for acts in best interests of person lacking capacity

11~~9~~.—(1) This section applies where—

(a) a person ("P") is 16 or over;

(b) another person ("D") does an act in connection with the care, treatment or personal welfare of P;

(c) before doing the act, D takes reasonable steps to establish whether P's will and preference are unknown ~~lacks capacity~~ in relation to the matter, including those steps identified in section 5;

(d) when doing the act, D reasonably believes—

(i) that P's will and preference are unknown ~~lacks capacity~~ in relation to the matter; and

(ii) that it will be ~~in P's best interests~~according to the best interpretation of the person's will and preference ~~for~~that the act ~~to~~will be done; and

~~(e) D would have been liable in relation to the act if P had had capacity in relation to the matter and D had done the act without P's consent.~~

(2) D does not incur any liability in relation to the act, apart from such liability, if any, as D would have incurred in relation to it even if P—

(a) had had ~~capacity to consent~~clear will and preference in relation to the matter; and

(b) had consented to D's doing the act.

(3) But subsection (2) has effect subject to the additional safeguard provisions (each of which imposes a safeguard, additional to those in subsection (1)(c) and (d), and more than one of which may apply in a given case).

(4) The additional safeguard provisions are—

(a) section 12 (conditions for any act of restraint);

(b) sections ~~13 and~~ 15 (~~formal assessment of capacity, and~~ consultation of nominated person, required for serious interventions);

(c) sections 16 and 17 (second opinion required for certain treatment);

(d) sections 19, 22, 24, 26, 28 and 30 (authorisation required for serious treatment where there is objection from P's nominated person ~~or compulsion, and for deprivations of liberty~~ and certain other measures);

(e)section 35 (independent advocate required for certain serious interventions).

~~(5) The principles in sections 1(3) to (5) and 5 (P not to be treated as lacking capacity on irrelevant grounds, or where practicable help and support not given) and section 7 (best interests) apply in particular for the purposes of determining whether a belief mentioned in subsection (1)(d) is reasonable.~~

~~(6) Where P is under 18, in subsection (1)(e) "without P's consent" is to be read as "without P's consent and without any consent that could be given by a parent or guardian of P".~~

General Comments

12. It is beyond the scope of this submission to provide detail on harmonising the entire Bill based with the recommended changes above Bill. We offer the above recommendations to give practical examples of how amendments can be made which help transition laws based on 'mental capacity' and 'best interests' to laws that are based on human rights and the will and preferences paradigm. The remainder of the submission will refer to more general comments that the CDLP would like to advance in relation to the Bill.

Community Residence Requirement

13. Sections 30 – 34 relate to 'community residence requirements' under the Bill. The explanatory document provides detail of this order as being made by a HSC trust to ensure access to an individual by a health professional or to avail of training, education, occupation or treatment.

14. These sections may mean that a person can be forced to live somewhere against his or her will and preferences if she is found to lack mental capacity. If the changes that the CDLP set out above, regarding section 9, are adopted, Section 30 would seemingly pose no issue as the community residence requirements would apply where a person's wishes and preferences are not known. However, where the requirements rest on a mental incapacity finding – even if a person is expressing a clear will and preference not to reside somewhere – then this provision would appear to run counter to Article 19 of the CRPD.

15. Article 19 states that:

> *'States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:*
>
> *a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;*
> *b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;*

c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.'

16. By requiring a person to reside at a certain place against his will or preferences, he or she is being denied his right to have choice and control over where and with whom he or she lives on an equal basis with others in the community. The proviso that the residence requirement must be a 'proportionate response' within section 30 has the potential to be abused especially in situations of lack of staff and resources which prevent D from availing of alternative, less restrictive courses of action.

17. The CDLP recommends that sections 30-34 are amended to place a stronger emphasis on the 'will and preference' of the individual to ensure that a person is not forced to live in an institution, or any other residence, against their will, on an equal basis with others. If a person's will and preference remains unknown, then, as with all interventions based on this standard, periodic efforts must be taken to 'spark' the will and preference of the person concerned.

The CDLP thank the Ad Hoc Joint Committee to Consider the Mental Capacity Bill in Northern Ireland for the opportunity to contribute to this legislation, and would be happy to provide more detailed amendments on how the Bill can be framed in accordance with the support paradigm of legal capacity advanced in Article 12 CRPD.

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Northern Ireland Department of Justice Department of Health and the Social Services and Public Safety in Northern Ireland

Submission
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About Us

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1. **The CDLP** welcomes the opportunity to make this submission to the Department of Health, Social Services and Public Safety in Northern Ireland, and the Northern Ireland Department of Justice in response to the *Mental Capacity Bill (NI)* (hereinafter referred to as 'the Mental Capacity Bill'). 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. In response to the Draft *Mental Capacity Bill (NI)* Consultation Document ('Consultation Document') this submission aims to contribute to law and policy to uphold the human rights of persons with disabilities.

4. The Bamford Review made important inroads – both in Northern Ireland and internationally – to addressing the discriminatory nature of mental health legislation. The report highlighted how civil commitment legislation imposes discriminatory standards of rights to liberty and consent in

healthcare for people diagnosed with mental disorder/illness compared to other citizens. The proposed Mental Capacity Bill, which provides for a single framework for substituted decision-making using functional assessments of mental capacity has been designed to remedy this discrimination. We applaud the Department of Health, Social Services and Public Safety in Northern Ireland, and the Northern Ireland Department of Justice for these efforts. No other jurisdiction in the world can be seen to have taken such steps toward removing this (often unacknowledged) form of disability-based discrimination. We further commend the relevant ministries of Northern Ireland for their ongoing consultation with civil society organisations regarding the Mental Capacity Bill, including disability people's organisations, family groups and human rights organisations. It is perhaps for these reasons, that the 'Consultation Document' states that '(i)t is widely acknowledged that the draft Bill is a significant and progressive piece of legislation in human rights terms.' (5.5)

5. Notwithstanding these advances, the CDLP is concerned that crucial developments in contemporary international human rights law do not appear to have informed the Mental Capacity Bill.[1] Since the Bamford Review, the adoption of the CRPD by the United Nations in 2006, and its coming into force in 2008, have generated new ideas and standards in law, policy and practice governing the provision of disability support and safeguards.

6. Based on these developments the CDLP is concerned that the Mental Capacity Bill rests on a foundational conceptual confusion, which risks undermining efforts of drafters to overcome disability-based discrimination. The Mental Capacity Bill should move away from its current focus on substituted decision-making, 'best interests' and mental capacity. The functional assessment of mental capacity in the Mental Capacity Bill, even as it appears *prima facie* to be non-discriminatory, continues to impose substantive discrimination against people with disabilities — particularly persons with intellectual, cognitive and psychosocial (mental health) disabilities.

   Instead, the Mental Capacity Bill 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 Northern Ireland and complement existing UK and ECHR case law.

7. 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. It also addresses specific features of the Mental Capacity Bill with reference to the broad alternative being proposed, in particular: using 'insight' as a criterion for a functional assessment of mental capacity; the risks of codifying the doctrine of necessity; recognising family, friends and other supporters; and ensuring an implementation review.

[1] For example, the Consultation Document refers to the CRPD only two times. The first reference is made in general terms, regarding the 'best interests principle' in relation to mental health orders for children (pg 43). The second reference regards a statement of compatibility which will be provided to the Assembly when the Bill is introduced (pg. 71) – though basis for this compatibility statement is not provided.

8. Finally, the CDLP wishes to offer this submission with regard to the Good Friday Agreement, in which the Irish Government is directed to pursue 'at least an equivalent level of protection of human rights' with Northern Ireland. As O'Cinneide notes, "There are also substantial policy considerations that would support a common equivalence approach on both sides of the border, which might be given concrete form in the proposed charter of rights and in parallel legislation on both sides of the border."[2] He also suggests that there may be 'new' areas of discrimination where a common equivalence approach might need to be pursued on a cross-border basis. Arguably, since the emergence of the CRPD and the development of the jurisprudence of the CRPD Committee represents new perspectives on the discrimination facing persons with disabilities, including those with psycho-social (mental health) disabilities, this area of legislative change is a particularly pertinent one for ensuring cross-border equivalence in protection of human rights.

9. The model of legal capacity support advanced in this submission, is being developed 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 Northern Ireland.

Equal Recognition Before the Law and Support Model for Legal Capacity

10. 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 Mental Capacity Bill.

11. With regards to regional human rights activity, the European Court of Human Rights has already indicated that it is prepared to interpret the rights contained in the European Convention on Human Rights (ECHR) in the light of the CRPD, including with regard to legal capacity. In *Glor v Switzerland*[3] the Court specifically referred to the CRPD as representing European and universal consensus on the need to prevent discriminatory treatment of, and ensure equality for, persons with disabilities.[4] And in this respect the European Court of Human Rights has already significantly expanded its jurisprudence related to persons with disabilities in such cases as *Shtukaturov v. Russia* (App no 44009/05)*, Stanev v. Bulgaria* (App no 36760/06) (2012) ECHR 46*, DD v. Lithuania* (App no 13469/06) [2012] ECHR 254*, X and Y v. Croatia* (App no 5193/09), *Sykora v. Czech Republic* (App no 23419/07*), Mihailovs v. Latvia* (App no 35939/10) and *Lashin v. Russia* (App no 33117/02)*.*

12. 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;[5]
    - 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 -

[2] C O'Cineidde, 'Equivalence in Promoting Equality: Implications of the Multi-Party Agreement for the Further Development of Equality Measures for Northern Ireland and Ireland' Equality Commission of Northern Ireland http://www.equality.ie/Files/Equivalence%20in%20Promoting%20Equality.pdf viewed 1 August 2014.
[3] (App.no. 13444/04) Chamber judgment of April 30, 2009.
[4] Ibid §53.
[5] By virtue of Article 5 and 12 of the CRPD.

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;[6]

- the 'best interests' standard, and substituted decision-making generally, should be replaced with an adherence to the 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
- 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,[7] 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.

13. 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 Mental Capacity Bill, as well as practical examples of domestic law reform around the world.

The Need to Clearly Distinguish *Mental* Capacity from *Legal* Capacity

14. Article 12 of the CRPD indicates the need to distinguish mental capacity and legal 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.

15. '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).[8] The exercise of legal capacity in relation to voting helps illustrate this distinction. A person (P) may hold a formal right to vote on an equal basis with others (in which P's 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 (P's 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.

16. 'Mental capacity' 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.[9] When a person is deemed to lack mental capacity

[6] E Flynn & A Arstein-Kerslake, 'Legislating personhood: realising the right to support in exercising legal capacity,' (2014) 10(1) *International Journal of Law in Context* 81 at 85.

[7] 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).

[8] B McSherry, 'Legal capacity under the Convention on the Rights of Persons with Disabilities' (2012) 20(1) *Journal of Law and Medicine* 22.

[9] '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.

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 out-dated 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.[10]

17. 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.'[11]

18. Under the draft Mental Capacity Bill, 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. In a recent series of roundtables hosted by the Essex Autonomy Project with the UK Ministry for Justice, the question of the discriminatory nature of the functional test of mental capacity was discussed, and the outcome of these roundtables was the consensus that 'at least in its current form, the MCA is not compliant with the requirements of the CRPD.'[12] Since many aspects of the Mental Capacity Bill in Northern Ireland mirror similar provisions of the MCA in England and Wales, it is important to acknowledge that this finding of incompatibility between the MCA and the CRPD has now been made. Given that Northern Ireland is at the beginning of reforming its laws on legal capacity post CRPD, it has the unique opportunity to remedy the defects in mental capacity legislation, such as the MCA, and to ensure greater compatibility with the CRPD.

19. 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*

[10] KG Booth, 'Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond' (2012) 44(93) *Columbia Human Rights Law Review* 115.
[11] Committee on the Rights of Persons with Disabilities, General Comment No. 1 – Article 12: Equal Recognition Before the Law, Paragraph 23, UN Doc. No. CRPD/C/GC/1, adopted at the 11th Session (April 2014), Paragraph 13.
[12] Wayne Martin, 'Mental Capacity Law Discussion Paper: Consensus Emerges in Consultation Roundtables: The MCA is Not Compliant with the CRPD' *ThirtyNine Essex Street Mental Capacity Law Newsletter* http://www.39essex.com/docs/newsletters/uncrpd_mca_compatibility_discussion_paper.pdf viewed 2 August 2014.

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.[13]

20. The CRPD Committee also specifies that the functional assessment of mental capacity cannot be used to determine what supports a person might need in exercising his or her legal capacity in this General Comment:

> *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.*[14]

This directive refutes any suggestion that functional mental capacity assessments and substituted decision-making could be considered 'reasonable accommodation' (defined below). The CRPD Committee has made it clear that the decision-making ability cannot be the basis for granting, denying, or restricting legal capacity.

21. From this view, the notion of 'presumption of mental capacity' is no longer valid. Under s1 of the current draft Mental Capacity Bill, a person is to be 'assumed to have capacity in relation to a matter unless it is established that the person lacks capacity in relation to the matter.'[15] This presumption of capacity is meant to prevent a person being deemed to lack mental capacity on the basis of a disability or diagnosis. 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.[16] They further stated that "a presumption of mental capacity is meaningless" as it does not help to protect the individual's human rights.[17] Bach and Lewis argue that the right to equal recognition before the law, from which the right to legal capacity stems, is a guarantee, not a presumption. A presumption can be rebutted if evidence is provided to demonstrate that a certain individual is not worthy of equal recognition before the law. Further, according to the CRPD Committee's interpretation of Article 12, all individuals, by virtue of their humanity, possess legal capacity. Hence, legal capacity – in contrast with decision-making ability – is not something which can be presumed, it simply exists in all persons, regardless of an individual's decision-making skills.

22. To achieve the transition to a support model of legal capacity, therefore, the Mental Capacity Bill requires a range of amendments. Detailing such amendments – which would require replacing the use of mental capacity assessments – is outside the scope of this submission. An indication of a

[13] 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).
[14] Ibid, Para 25(i).
[15] MC Bill, s1(1).
[16] Oliver Lewis and Michael Bach, 'How Northern Ireland can avoid making a big "mental capacity law" mistake' (MDAC: Oliver talks, 23 April 2014) http://www.mdac.info/en/olivertalks/2014/04/23/how-northern-ireland-can-avoid-making-big-mental-capacity-law-mistake viewed 1 July 2014.
[17] Ibid.

comprehensive application of the support model to statute law has been elaborated by the CDLP elsewhere.[18] However, there are a number of amendments that should be included in the Mental Capacity Bill to more immediately contribute to harmonizing the Mental Capacity Bill with the CRPD.

RECOMMENDATION: Any statutory materials developed by the ministries should clearly differentiate the concepts of legal and mental capacity. At a minimum, a definition of 'legal capacity' should be added to the Bill, to avoid confusion and to ensure the consistent interpretation and application of the Bill 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."

Support Model of Legal Capacity and Supported Decision-Making

23. 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.

24. 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

[18] For a more comprehensive overview of proposed changes, see the CDLP's previous submissions referred to above on page 2.

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.' [19]

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.

25. These criteria should be more fully reflected in the Mental Capacity Bill, where support measures could be strengthened and expanded. The Mental Capacity Bill currently makes clear that no one may conclude that a person is unable to make a particular decision that needs to be taken 'unless all practicable help and support has been given to them to make the decision themselves without success' (s4).

26. From a human rights perspective, the provision of substituted decision-making 'unless all practicable help and support has been given' is insufficient to provide for the positive rights necessary for supported decision-making. First, the CRPD Committee has called for substituted decision-making to be 'replaced' by supported decision-making. Second, even cautious interpretations of the CRPD acknowledge that the CRPD directs States 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 mental health and mental capacity laws which focus on 'negative rights' (such as freedom from state intervention and the point at which that freedom is lifted). Positive rights with regard to the Mental Capacity Bill 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. The 'last resort' approach used in the Mental Capacity Bill has been taken in typical mental health legislation in many common law jurisdictions which asks for 'least restrictive alternatives' to be exhausted before civil commitment powers are used. Yet a key criticism of this type of mental health legislation – to which a wide range of commentators agree[20] – is the persistent failure of mental health law to garner resources to allow a person to *access* support services.[21]

[19] CRPD/C/11/4 (25).
[20] Ibid.
[21] B McSherry and P Weller (eds), *Rethinking Rights-Based Mental Health Laws* (Hart Publishing 2010) 6; G Quinn, 'Rethinking Personhood: New Directions in Legal Capacity Law and Policy' (Ideas Paper) New Foundations for Personhood and Legal Capacity in the 21st Century Conference, University of British Columbia, April 29 2011, 11 http://www.arts.ubc.ca/fileadmin/user_upload/CIC/July_2011/Gerard_Quinn_s_Keynote_-_April_29__2011.pdf viewed 20 September 2011.

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 a 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? Local jurisdictions will have to determine support measures in consultation with people with disabilities, families, service providers, and others.

> ***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 Mental Capacity Bill should include a principle of providing support in line with the legal capacity model, such as the following:[22]

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
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

[22] This principle is drawn from the submission to the Australian Law Reform Commission enquiry into equality before the law, by People with Disabilities Australia, The Australian Centre for Disability Law, and the Australian Human Rights Centre. www.alrc.gov.au/sites/default/files/subs/136._org_people_with_disability_australia_pwda__the_australian_centre_for_disability_law_acdl_and_australian_human_rights_centre_.pdf (viewed August 14 2014).

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

27. 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.[23] Further, according to the terms of the CRPD, '"discrimination on the basis of disability" (…) includes all forms of discrimination, including *denial* of reasonable accommodation.'[24]

28. 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. The Mental Capacity Bill should explicitly require the provision of reasonable accommodations such as consultation with family and trusted supporters to P, in order to gain a sense of P's will and preference. If trusted relationships exist, and such lines of communication are open, there is no need for substitute decision-making arrangements. As the Mental Capacity Bill currently stands, the only reference to family and other supporters with regards to decision-making support appears to be 'nominated persons', and provisions in s4 related to including 'persons whose involvement is likely to help the person to make a decision.'

29. The addition of a definition of 'reasonable accommodation' to s2 of the Mental Capacity Bill, 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 part 1 on definitions, based on the following:

'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.[25]

Replace 'Best Interests' with the Will and Preferences Approach

30. The 'best 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

[23] CRPD, Article 2.
[24] Ibid.
[25] Ibid.

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.

31. 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."[26]

32. 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.'[27] The Victorian Law Reform Commission criticises the 'best interests' standard as being overly vague,[28] endorsing the view that 'best interests' 'has come to constitute somewhat of a euphemism for overriding free will.'[29] In Ireland, the Minister for Justice, Equality and Defense has stated that "international good practice advises that it is better to enable a person to take his or her own decisions than to have a third party decide what is best" and that therefore the ADM Bill "moves away from the more paternalistic focus on best interests."[30] The drafters of the Mental Capacity Bill 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.

33. However, the Mental Capacity Bill should join other law reform efforts which have sought to discard the 'best interests' standard altogether. For example, the Victorian Law Reform Commission proposed the replacement of the 'best interests' test with a paramount consideration of the will and preferences of the person.[31] Similarly, proposed new mental health legislation in the Republic of Ireland, as well as the ADM Bill, shall see 'best interests' discarded.[32]

RECOMMENDATION: Replace 'best interests' standard in ss6-7 with a preference for adhering to the will and preference of P. Drawing on the practical examples noted above, the drafters of the NI Bill should re-orient the Mental Capacity Bill away from a 'best interests' framework.

Recognition of ways Legal Capacity can be Recognised

34. 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

[26] CRPD/C/GC/1 (25(b)).
[27] GM Laurie and JK Mason, 'Negative treatment of vulnerable patients: Euthanasia by any other name' (2000) 3 *The Juridical Review* 176. See also, M Donnelly, 'Decision-making for Mentally Incompetent People: The Empty Formula of Best Interests?' (2001) 20(1) *Medicine and Law* 405.
[28] Victorian Law Reform Commission 'Guardianship: Final Report 24' (Author, Melbourne 2012) 92 s 6.93-96 http://www.lawreform.vic.gov.au/sites/default/files/Guardianship_FinalReport_Full%20text.pdf viewed 7 May 2012.
[29] 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.
[30] Speech by Minister for Justice, Equality & Defence at the Assisted Decision – Making (Capacity) Bill 2013: Consultation Symposium, Printworks Conference Centre, Dublin Castle, 25 September 2013 http://www.justice.ie/en/JELR/Pages/SP13000341 viewed 3 August 2014.
[31] Victorian Law Reform Commission (VLRC), *Guardianship: Final Report 24* (Author 2012) xxiv, s 36 http://www.lawreform.vic.gov.au/sites/default/files/Guardianship_FinalReport_Full%20text.pdf viewed 7 May 2012.
[32] For example, the proposed new mental health act in Ireland has sought to discard the use of a best interests standard. Department of Health (Ireland), *Interim Report of the Steering Group on the Review of the Mental Health Act 2001* (author 2012) 11 http://www.dohc.ie/publications/pdf/int_report_sg_reviewMHA_new.pdf?direct=1 viewed 27 July 2012.

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'

35. 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.

36. 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.

37. 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.[33]

38. 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.

39. 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. 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.[34] 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 under the support model of legal capacity 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.

40. 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. 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.[35] 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.

41. 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 'will and preference' as the guiding paradigm as

[33] CRPD/C/GC/1.
[34] See, for example, *Re E* (Medical treatment: Anorexia) (Rev 1) [2012] EWCOP 1639 (15 June 2012).
[35] 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).

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.[36]

42. 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.

43. 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 (as is the case with mental health diagnosis or mental capacity assessments).

44. 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.

45. 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.

46. 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

[36] CRPD/C/GC/1.

is impossible to realise the person's will and preferences without breaching some other aspect of the law.

RECOMMENDATION: The Mental Capacity Bill 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.'[37]

This language could be used to guide the ministries in their development of the Mental Capacity Bill in responding to situations of last resort. (More extensive rationale and textual amendment suggestions developed for the ADM Bill are available on request).[38]

Family and other supporters

47. The intention behind s8 is clearly a good one — providing immunity to third parties such as family members who make informal day-to-day decisions to support and protect P. However, it is actually the practice and habit of a person making these small decisions – and being supported to do so – that is crucial to growing a person's capacity, competence and confidence: using a bus, taking money out from an ATM, making tea according to one's preference. Formal legal powers to make informal substituted decisions will undermine the individual's ability to grow and learn and to make his or her own decisions, and can result in learned passivity. Second, for people with disabilities, the private sphere – including in care homes – continues to be a site where people with disabilities have experienced significant abuse. Such abuse is more likely to occur where family and other supporters are not recognized and supported in their role.

48. There is currently very little in the Mental Capacity Bill which recognizes family and other informal supporters. For the Mental Capacity Bill, the term 'family' is only referred to in s149 with regard to decisions related to a person and his or her 'family relationships', such as consent to marriage and consent to sex; in s29 regarding a person posing a 'serious threat to the liberty or life of a member of the adult's family'. The role of specific family members and other informal supporters is referred to in relation to 'nominated persons' in Part 3 of the Bill. This lack of reference to family fails to frame the vast majority of people with disabilities as persons living in a network of relationships.

49. In order to uphold the intention of s8, without providing for 'powers' of informal substituted decision-making, the Mental Capacity Bill should acknowledge the valuable support given by family and other supporters in informal arrangements. This includes recognising the knowledge by

[37] 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).
[38] Ibid.

family members and other supporters of P's values and beliefs from their years of experience. Further, such recognition could include the provision of additional support and guidance for those who are working tirelessly with their family members and those they support to discover the person's will and preferences and support him or her to live a self-directed life.

50. A role for the officials designated in the Mental Capacity Bill (currently 'public guardians') should be to provide resources to assist families and other supporters. This role could be included explicitly in the mandate and remit of official figures in part 7 of the Mental Capacity Bill.

51. The principle of recognising the role of the family as a natural support system must 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 which meet with P's will and preferences, including the 'best interpretation of P's will and preferences'.

RECOMMENDATION X: Section 4 (2)(c) of the Mental Capacity Bill should be amended as follows:

c) ensuring that ~~persons whose involvement is likely to help the person to make a decision~~ <u>family members, carers, friends and other informal supporters,</u> are involved in helping and supporting the person.

RECOMMENDATION X: The role of families, carers and other significant persons in supporting persons who may require decision-making support should be acknowledged and respected. Part 7 of the Mental Capacity Bill should direct that the office overseeing public guardians must "provide advice and guidance to family members, informal carers and healthcare professionals who support relevant persons in exercising their legal capacity."

The Right to Refuse Support

52. 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.[39]

53. 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.[40] 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]

[39] CRPD/C/GC/1
[40] CRPD/C/GC/1 (19)
[41] CRPD/C/GC/1 (29(g)).

54. 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."[42] 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. Similar options could be considered by the ministries in amending the provisions for 'nominated persons'.

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.

For example, Section 72 should include a clause whereby the appointer can revoke the role of their previously appointed 'nominated person' according to their will and preference, regardless of P's mental capacity. The revocation of a nominated person appointment – for example by someone experiencing psychosis – should not mean the blanket exclusion by professionals who may still seek relevant information from family members, loved ones, and so on. Information of a general nature can be shared according to law to assist with the support and care of a person and the views of family and other informal supporters can be respected without compromising the confidentiality of P.[43]

Safeguards to Prevent Undue Influence and Coercion

55. 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."[44]

56. 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,

[42] Assisted Decision-Making (Capacity) Bill 2013, s 10(11).
[43] See e.g. New South Wales Consumer Advisory Group, 'Issues Paper: Privacy and Confidentiality' (1 June 2004).
[44] CRPD/C/GC/1 (22)

supported living funding, domestic violence services, affordable housing and supported employment.

57. 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.'[45]

Ensuring Nominated Persons and other Support Persons

58. Regarding supported decision-making, s4(2)(c) of the Mental Capacity Bill indicates that public officials must 'ensur(e) that persons whose involvement is likely to help the person to make a decision are involved in helping and supporting the person.' This provision leaves a number of open questions. Who decides on whether or not involving a trusted supporter 'is likely to help' a person make a decision? If a person expresses a desire for assistance from a specific person, on what basis should the supporter be disallowed from providing assistance?

59. s79(3) gives some indication as to the criteria for making such a determination, specifically in relation to nominated persons, where the subsection states that '(t)he factors that may be taken into account in determining whether a person is not suitable to be P's nominated person include whether the person has behaved, is behaving or proposes to behave in a way that is not in P's best interests.'

60. We have already noted the need to discard the 'best interests' framework in accordance with international human rights norms, as well as international trends in mental capacity law. The vague nature of the criteria for determining whether a nominated person 'has behaved, is behaving or proposes to behave in a way that is not in P's best interests' leaves much uncertainty. Will a 'nominated person' who disagrees with a medical practitioner about treatment plans be considered to be not working in P's 'best interests'?

61. While the CDLP agrees that the range of 'qualifying persons' noted in s79(4) should have power to apply to the Tribunal to highlight inappropriate conduct by the nominated person, the 'best interests' standard neither provides an adequate support principle nor an adequate safeguard in this respect. Instead, there should be duties placed on nominated persons and other people in support roles whereby any exertion of undue influence, abuse, coercion, or the like, should disqualify them from the role, or make them subject to liability.

62. 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-

[45] CRPD/C/GC/1 (18ter).

making assistant."[46] 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. A similar option is required in amending the provision for 'nominated persons' under the terms of the Mental Capacity Bill.

RECOMMENDATION: if a person is indicating a wish to involve a person with whom they are in a relationship characterised by trust, the involvement of this person should be granted, regardless of P'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 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.

Codifying the Doctrine of Necessity

63. Informal substituted decision-making is undoubtedly widespread basis in homes, hospitals and care services in Northern Ireland (as it is throughout the UK, in Ireland and elsewhere). Codifying the common law position on necessity into legislation – as proposed in s8 of the Mental Capacity Bill – makes the status quo explicit.

64. However, as noted previously, human rights and anti-discrimination standards indicate that this status quo is unacceptable. Coercion, or the granting of legal powers to third parties to make

[46] Assisted Decision-Making (Capacity) Bill 2013, s 10(11).

decisions for others, without any oversight or scrutiny, is a clear violation of the rights to self-determination and personal autonomy.

65. Further, the codification of the doctrine of necessity would *strengthen* 'powers' for informal substituted decision-making that currently exist under common law. Case law is rarely taken which demonstrate the limits of a third party's power to make decisions for others, or interventions on them without their consent, in situations where they believe the individual 'lacks mental capacity' solely under the common law doctrine of necessity – and so few judgments are available on these points, and little jurisprudence has developed. Often this may be because those who are subject to such interventions are not in a position to exercise their rights and bring these cases to court, and these issues go unnoticed by others who could bring cases on their behalf. Therefore, little is known about how far the scope of the existing common law doctrine of necessity would extend, were it not codified in this area. However, from the case law that does exist,[47] the common law doctrine of necessity only justifies intervention in very serious circumstances, such as where necessary to preserve the person's life – rather than to justify minor interventions on a daily basis. Therefore, s8 represents a widening of the scope of the common law doctrine of necessity in a manner which gravely risks undermining the human rights to self determination and autonomy.

66. The protection from liability powers proposed under s8 of the Mental Capacity Bill has precedent elsewhere in the region. In the Republic of Ireland, for example, informal decision-making 'powers' are proposed under s53 of the ADM Bill. Codifying the doctrine of necessity in this way appears to be based on ss5-6 of the *Mental Capacity Act 2005* (England and Wales) (MCA). However, unlike the MCA, the Mental Capacity Bill – to the credit of drafters – explicitly limits where the protection from liability can be used.[48]

67. Under the terms of the Mental Capacity Bill, 'serious interventions' require a formal assessment that the person lacks capacity. The meaning of 'serious intervention' appears to be based on English common law authorities and is described as including an intervention which: 'consists of or involves major surgery'; 'causes P serious pain, serious distress, or serious side-effects'; 'affects seriously the options that will be available to P in the future, or has a serious impact on P's day-to-day life'; 'in any other way has serious consequences for P, whether physical or nonphysical'.

68. However, there is a lack of clarity in the Mental Capacity Bill indicating that if a person objects, or those close to him or her object, then authority has to be sought from the court, *even if* the person is formally found to lack mental capacity.[49] It is not explicitly clear based on the Mental Capacity Bill or the Consultation Document whether these interventions would cover placing somebody in an institution (even if they're objecting), restricting his or her contact with others, preventing him or her from having sex, and so on.

[47] See e.g. *Re F (Mental Patient: Sterilisation) [1990] 2 AC 1*; *Airedale NHS Trust v Bland* [1993] AC 789, 869; H.L. v. THE UNITED KINGDOM - 45508/99 [2004] ECHR 471 (5 October 2004).
[48] E.g. psychosurgery (s9), and 'serious interventions' (s8(4)(b)), and 'serious treatment' where P objects (s8(4)(d)).
[49] See e.g. Mental Capacity Bill, s 17(1)(b) and 20.

69. England and Wales has had a number of common law cases to resolve disputes along these lines. UK common law authorities found that care providers or public bodies which seek to 'regulate, control, compel, restrain, confine or coerce' P, outside of an emergency situation, where a person or his or her family are objecting, are first required to seek authority from the court (see A Local Authority v A (A Child)& Anor [2010] EWHC 978 (Fam) , paras. 66-76; London Borough of Hillingdon v Neary & Anor [2011] EWCOP 1377, paras 20-23). However, reports suggest that these judgments have come too late.[50] A significant number of health and care authorities reportedly use the MCA to drive through treatment and care plans in the face of objections, and if a person or their family and other supporters object then they have to go to court. According to the UK House of Lords Select Committee on the MCA, neither the MCA, nor its code of practice, was specific enough to make it clear that public authorities were not meant to use informal substitute decision-making 'powers' when a person or his/her family are objecting, without first going to court.[51]

70. Paragraphs 98, 235-6 of the House of Lords' report are informative and for a more complete analysis are worth citing in full:

    a) *(98.) There were also concerns that a decision-maker could assume too much power, and sometimes on the basis of questionable legal authority. Sheffield Safeguarding Adults Board pointed out that "once a person has been deemed to lack capacity to make a decision they become vulnerable to the opinion of the decision-maker and when those decisions are not reflective of their best interests it often leaves them powerless to challenge". This was echoed by other witnesses who expressed concern over the use of the 'general defence'—the term often used to describe sections 5 and 6 of the Act (Acts in connection with care or treatment and Section 5 Acts: limitations)—which provides protection from liability for carers and others to carry out acts in relation to a person who lacks capacity. The pre-legislative scrutiny committee foresaw problems with these sections, which were at the time entitled 'the general authority'. They worried that it would wrongly give the "impression that the general authority would be assumed by a single individual who would then take all decisions on behalf of an incapacitated individual". In response, the Government removed the term 'general authority' from the Mental Capacity Bill, but concerns have persisted since implementation. Professor Phil Fennell and Dr Lucy Series described the general defence as providing "tremendous discretionary power" which was "not subject to any routine monitoring". Liberty expressed concern about the very wide range of decisions which could be made under these sections, combined with a "worrying lack of oversight".*[52]

    …

    b) *(235.) Professor Fennell and Dr Series raised a further concern about access to the Court in relation to "situations where professionals and family are in agreement as to a person's capacity and best interests, but where the person themselves is not." In such a situation the person was unlikely to have an independent mental capacity advocate, and the ruling in Neary appeared not to require the public authority to refer such a case to court. They argued that "surely, under the ECHR, a person's rights to access justice to assert their capacity cannot*

[50] House of Lords Select Committee on the Mental Capacity Act 2005, *Mental Capacity Act 2005: Post-Legislative Scrutiny*, Report of Session 2013-14, HL Paper 139, paras 98, 235-7 http://www.parliament.uk/business/committees/committees-a-z/lords-select/mental-capacity-act-2005/news/mca-press-release---13-march-2014/ viewed 2 August 2014.
[51] Ibid.
[52] (footnotes removed).

hinge on something so arbitrary as whether or not their relations and professionals have fallen out?"

c) *(236.) We are concerned that the responsibility of public authorities to initiate proceedings in cases of dispute is not widely known or adhered to. We also share the concerns of Professor Fennell and Dr Series regarding the ability of the person concerned to challenge decision-making when all others are in agreement.*

71. Further, the HOL enquiry made the following recommendation:

a) *(237.) We recommend that the Government, and in future the independent oversight body, provide clearer guidance to public authorities regarding which disputes under the Act must be proactively referred to the Court by local authorities. This should include situations in which it is the person who is alleged to lack capacity who disagrees with the proposed course of action. Efforts must be made to disseminate this guidance to families and carers as well as to local authorities.*

72. We ask the ministries responsible for the Mental Capacity Bill if they agree with the statements in *Neary and A Local Authority v A*, that if either the person or those close to him or her are objecting to some intervention, authority must be sought from the court? If so, this provision must be clearly provided for in the Mental Capacity Bill, with an accompanying commitment to disseminate guidance to people with disabilities, families, and other supporters, as well as local authorities.

RECOMMENDATION: All references to protection from liability in the Mental Capacity Bill, which have the effect of giving formal legal authority to third parties to make substituted decisions without any external scrutiny, should be removed. Any public authority wishing to take any measure to 'regulate, control, compel, restrain, confine or coerce' a person when he or she, or any of his or her family and/or supporters objects to such measures, regardless of whether he or she is presumed or deemed to lack mental capacity, are first required to seek authority from the court. Further, efforts must be made to disseminate this guidance to people with disabilities, families, and other supporters, as well as to local authorities.

Using 'Insight' as a Criterion for Assessing Mental Capacity

73. The Consultation Document makes clear that assessment criteria will extend beyond 'cognitive understanding of the information relevant to the decision' to include instances in which a person's 'insight is distorted by their illness,' including where he or she is 'suffering from delusional thinking as a result of (his or her) illness.' (2.22)

74. We are concerned about the implicit use of the term 'insight' as a criterion for assessing mental capacity in s3(1)(c) of the Mental Capacity Bill, which raises a number of concerns.

75. First, 'insight' is a notoriously slippery term that is difficult if not impossible to substantiate in relation to a person because it refers to a ''subjective report of his or her internal state''.[53] Second,

[53] R Keefe, 'The neurobiology of disturbances of the self: Autonoetic agnosia in schizophrenia' in XF Amador & AS David (Eds.), *Insight and psychosis* (Oxford University Press, 1998) 159.

it is difficult for any external review mechanism to evaluate claims about the *absence* of a characteristic, rather than the existence of a characteristic, such as self-harming actions.[54] Diesfeld and Sjostrom investigated how the term 'insight' was employed in 25 decisions from mental health review proceedings in Victoria, Australia, and found the application of the term to be "problematic".[55] While they did find the term provided 'interpretative flexibility' to usefully resolve complex issues, they concluded that there was little clarity as to how the term was used, confused logic in its application, and 'frequent allusions to an implicit and undefined scale of insight, offering the appearance of objectivity'.[56] Sullivan and Ferrell describe the application of 'insight' as a 'stigmatizing prelude' to continued detention.[57]

76. There is evidence to suggest 'insight' is being used under the MCA, as a criterion for mental capacity, by public authorities in England and Wales.[58] Emmett and colleagues found that '(w)here assessors did not agree with patients' decisions, they were prone to interpret the decision as lacking insight and, thus, the decision maker as lacking capacity'.[59] In Williams and colleagues' analysis of the application of capacity testing under the MCA, they found the following:

> *…there was a dilemma about the difference between someone with capacity who made an 'unwise decision' and someone who lacked capacity, as also found by Willner et al. The two matters were often confusingly conflated within the notion of 'lack of insight' which was a commonly cited reason for assessing a lack of capacity.*[60]

77. One of the principles underpinning the Mental Capacity Bill, as set out in Clause 1, is the need to decouple capacity from 'unwise decisions.' The research of Emmett and colleagues indicate that the 'insight' criterion in assessments of mental capacity – from a purely pragmatic perspective – would likely undermine this key principle of the Mental Capacity Bill. Further, the sheer interpretive flexibility of the term may 'widen the net' of people who are deemed to lack mental capacity.

RECOMMENDATION: Remove the implict use of 'insight' as a criterion for mental capacity. Instead, define specific exceptional circumstances for overriding a person's legal agency, which do not discriminate on the basis of disability. (This recommendation should be read in conjunction with previous recommendations for establishing a support model of legal capacity to replace the mental capacity).

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[54] K Diesfeld & S Sjöström, 'Interpretive flexibility: why doesn't insight incite controversy in mental health law?' (2007) 25(1) *Behavioral Sciences & the Law* 85–101.
[55] Ibid.
[56] Ibid 85.
[57] M Sullivan & B Ferrell, 'Ethical challenges in the management of chronic nonmalignant pain: Negotiating through the cloud of doubt' (2005) 6(1) *The Journal of Pain* 2, at 5.
[58] See e.g. C 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(1) *International Journal of Law and Psychiatry* 73–82.
[59] C 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(1) *International Journal of Law and Psychiatry* 73, at 78.
[60] V Williams et al. *'Making Best Interests Decisions: People and Processes'* January 2012, 159 http://www.mentalhealth.org.uk/content/assets/PDF/publications/best_interests_report_FINAL1.pdf?view=Standard viewed 2 august 2014.

Implementation Review

78. The concepts of equal recognition for legal capacity and support for the exercise of legal capacity are relatively new, and various legislative reforms are underway throughout the world to implement Article 12 of the CRPD. At the regional level, significant issues have been raised by the UK House of Lords regarding the implementation of MCA. Further, the UK Ministry of Justice recently commissioned a panel of distinguished experts, which established that 'at least in its current form, the MCA is not compliant with the requirements of the CRPD.'[61]

79. Hence, the Bill should include a 2-year review mechanism. The scope of the review should include reflection on both international developments and practical experience at the ground level in Northern Ireland.

80. A mechanism for comprehensive review will ensure amendments can be made to fully embed the progressive approach of Article 12 of the CRPD in Northern Ireland. In keeping with the spirit of the CRPD – and building upon the ministries record for consultation with civil society – this review must be designed and carried out with the full participation of those affected by the legislation, especially persons with disabilities and their representative organisations.

RECOMMENDATION: Add the following text to the Mental Capacity Bill:

> "The Minister shall cause a comprehensive review of the functioning of this Act to be carried out before the 2nd anniversary of the date of enactment of this Act. The design and implementation should consider developments in relevant law, including Northern Ireland's international human rights obligations, and should be carried out with the full participation of those affected by the legislation, in particular, persons with disabilities and their family members."

The CDLP thank the Northern Ireland Department of Justice Department of Health and the Social Services and Public Safety in Northern Ireland 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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[61] Wayne Martin, 'Mental Capacity Law Discussion Paper: Consensus Emerges in Consultation Roundtables: The MCA is Not Compliant with the CRPD' *ThirtyNine Essex Street Mental Capacity Law Newsletter* http://www.39essex.com/docs/newsletters/uncrpd_mca_compatibility_discussion_paper.pdf viewed 2 August 2014.