



Centre for Disability Law and Policy NUI Galway

Submission to the Australian Law Reform Commission Discussion Paper on Equality, Capacity and Disability in Commonwealth Laws (2014)

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

Introduction

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

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

To provide concrete examples of how the goals of the General Comment can be achieved in a domestic legislative framework, this submission will draw on amendments prepared by the Centre, as the co-ordinator of a civil society coalition on legal capacity reform¹ for Ireland's Assisted Decision-Making (Capacity) Bill. The core provisions of the legislative framework which will be explored include the development of a decision-making support framework which complies with Article 12 – by allowing individuals to enter into support frameworks based on choice and the existence of a relationship of trust between the individual and supporter(s), with no front-end test of mental capacity, once supporters agree to adhere to their duties – primarily, to support the individual to express will and preferences, to communicate those wishes to third parties, and endeavour to ensure they are acted upon within the boundaries of the law.

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

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

Proposal 2-1:

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

Proposal 2-1 is an excellent example of Australia's willingness to comply with the United Nations Convention on Rights of Peoples with Disabilities (UNCRPD). The Centre agrees that Australian Government should withdraw the Interpretative Declaration as it now clearly diverges from the UN Committee's interpretation of Article 12 of the UNCRPD. When Australia appeared before the 10th session of the Committee on Rights of Persons with Disabilities (the Committee) in 2013, the Committee recommended that Australia review its Interpretative Declaration in order to withdraw.² The Committee has made it clear, in their General Comment (GC), that Article 12 should be interpreted in a way that calls for the abolition of substituted decision-making regimes.³ Furthermore, the Committee has emphasized that there is a difference between mental capacity and legal capacity in Paragraph 12 of the GC, and that perceived or actual deficits in mental capacity (decision-making ability) cannot be used to justify restrictions on legal capacity.⁴

Upon Australia's ratification of the UNCRPD, Professor Ron McCallum, former Chairman of the Committee, saw the lodging of Australia's Interpretative Declaration as an example of 'overabundant legislative caution.'⁵ Similarly, at the adoption of the GC on Article 12, Professor McCallum indicated his desire for Australia to review its declaration with a view to withdrawing it. In this discussion paper, the ALRC has shown its understanding of the UNCRPD with its conclusion that the retention of the Interpretative Declaration would hinder Australia's reform efforts and its continued leadership in the field of promoting equal recognition before the law for persons with disabilities.

Proposal 3-2 National Decision-Making Principle 1:

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

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

² Committee on the Rights of Persons with Disability, 'Concluding Observations on the Initial Report of Australia, Adopted by the Committee at Its Tenth Session (2-13 September 2013)' (United Nations, 4 October 2013) 9, [24] <<http://www.ncid.org.au/index.php/docman-documents/reports/30-un-report-on-australia-2013/file>>.

³ Committee on the Rights of Persons with Disability, 'Concluding Observations on the Initial Report of Australia, Adopted by the Committee at Its Tenth Session (2-13 September 2013)' (United Nations, 4 October 2013) 9, [24] <<http://www.ncid.org.au/index.php/docman-documents/reports/30-un-report-on-australia-2013/file>>.

⁴ Committee on the Rights of Persons with Disability, 'Concluding Observations on the Initial Report of Australia, Adopted by the Committee at Its Tenth Session (2-13 September 2013)' (United Nations, 4 October 2013) 9, [24] <<http://www.ncid.org.au/index.php/docman-documents/reports/30-un-report-on-australia-2013/file>>.

⁵ Professor Ron McCallum AO, *Committee Hansard*, Sydney, 12 November 2010, p. 12.

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

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

“(1) Legal capacity may be exercised:

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

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

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

⁶ CRPD/C/GC/1 (14).

able to provide a reasonable account of how this interpretation was arrived at.”⁷

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

Proposal 3-3 National Decision-Making Principle 2:

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

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

While the Committee has recognized that support for people with disabilities may come in different forms, it has been made clear that the individual has the option to not exercise their right to support in accordance to Article 12, Paragraph 3.¹¹ In the GC, the Committee specified that “the person must have the right to refuse support and terminate or change the support relationship at any time.”¹²

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

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

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

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

⁹ CRPD/C/GC/1 (29(a)).

¹⁰ General Comment 1

¹¹ CRPD/C/GC/1 (19)

¹² CRPD/C/GC/1 (29(g)).

¹³ CRPD/C/GC/1 (29(a)).

¹⁴ Assisted Decision-Making (Capacity) Bill 2013, s 10(11).

decision-making assistance agreement. Similar options could be considered by the ALRC in making its final recommendations.

Proposal 3-4 Support Guidelines:

- a. Persons who may require decision-making support should be supported to participate in and contribute to all aspects of life.

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

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

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

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

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

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

In order to prevent "undue influence", the Committee has called for safeguards for the exercise of legal capacity while respecting "the rights, will and preferences of the person, including the right to take risks and make mistakes."¹⁵ Where there is a suspicion that an individual is being unduly influenced by another individual, Article 12 of CRPD directs that the law must treat people with disabilities the same as it does people without disabilities. For example,

¹⁵ CRPD/C/GC/1 (22)

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

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

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

Existing critiques of Ireland's Assisted Decision-Making (Capacity) Bill have pointed to the lack of recognition for families in the current text of the Bill. The Bill does recognise that those engaged in the 'care or treatment' of relevant persons¹⁶ should be consulted by decision-making assistants, co decision-makers, decision-making representatives, and other intervenors under the legislation. However, this does not fully include many family members who may not be actively involved in care or treatment but may have detailed knowledge of the person's will and preferences which should be taken into consideration. The ALRC should consider how best to reflect the role of families as providers of knowledge on the individual's will and preferences in its final recommendations.

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

Proposal 3-5 National Decision-Making Principle 3:

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

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

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

Proposal 3-5 could also be strengthened by reinforcing the notion of 'best interpretation' of will and preferences which may have to guide decisions in situations where the will and preferences of the individual are unknown, as in the Irish amendments to the Assisted Decision-Making (Capacity) Bill 2013.¹⁸ The proposed amendment will insert a definition of 'best interpretation' into the Irish Bill, as follows: "the interpretation of the relevant person's past and present communication (using all forms of communication, including, where relevant, total communication, augmented or alternative communication, and non-verbal communication, such as gestures and actions) that seems most reasonably justified in the circumstances."¹⁹ This language could be used to guide the ALRC in its development of final recommendations on how will and preferences may be determined in situations of last resort.

Proposal 3-6 Will, Preferences and Rights Guidelines:

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

¹⁷ CRPD/C/GC/1 (22)

¹⁸ From Mental Capacity to Legal Capacity (Amendment) (No 2) Assisted Decision-Making (Capacity) Bill (2013) 2.1.5.

¹⁹ From Mental Capacity to Legal Capacity (Amendment) (No 2) Assisted Decision-Making (Capacity) Bill (2013) 2.1.5.

This threshold is an important starting point, but could be further substantiated by making clear that a representative decision-maker can not be imposed if the person's will and preferences are known, rather than imposing a representative decision-maker where the person is deemed to not possess a certain level of decision-making ability. As with Proposal 3-5, the emphasis should remain on the will and preference of the relevant person. While we agree with Proposal 3-6, there needs to be further guidelines to ensure that not only is representative decision-making a last resort, but that the appointment should not be made in cases where a person is deemed to lack decision-making ability, but where the relevant person's will and preferences remain unknown even after significant efforts to discover them.

Ireland is basing the proposed Decision-Making Representative amendment to its Assisted Decision-Making (Capacity) Bill 2013 on the belief that the representative can make decisions using the 'best interpretation' principle, and through all forms of communication and consultation with the relevant person and those who know them well. The proposed Decision-Making Representative amendment to the Bill will seek to ensure that the will and preference of the relevant person is adhered to in the case that such a will and preference is unclear.²⁰ This may be done in the following way:

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

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

or

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

²⁰ From Mental Capacity to Legal Capacity (Amendment) (No 2) Assisted Decision-Making (Capacity) Bill (2013) 2.2.14.

It is only, therefore, where the court makes a declaration under section 15(b) that a representative can be appointed. Where this occurs, proposed amendments to the Irish Bill aim to ensure that the representatives' duties to act on 'best interpretation' of will and preferences are clear.

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

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

(c) Supporting decision-making:

- i. a person's will and preferences, so far as they can be determined, must be given effect;
- ii. where the person's will and preferences are not known, the representative must give effect to what the person would likely want, based on all the information available, including communicating with supporters; and
- iii. if it is not possible to determine what the person would likely want, the representative must act to promote and safeguard the person's human rights and act in the way least restrictive of those rights.

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

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

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

"(a) Supported decision-making must be available to all. A person's level of support needs (especially where these are

high) should not be a barrier to obtaining support in decision-making;

(b) All forms of support in the exercise of legal capacity (including more intensive forms of support) must be based on the will and preference of the person, not on what is perceived as being in his or her objective best interests;

(c) A person's mode of communication must not be a barrier to obtaining support in decision-making, even where this communication is non-conventional, or understood by very few people;

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

(e) In order to comply with the requirement set out in article 12, paragraph 3, of the Convention that States parties must take measures to "provide access" to the support required, States parties must ensure that support is available at nominal or no cost to persons with disabilities and that lack of financial resources is not a barrier to accessing support in the exercise of legal capacity;

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

(g) The person must have the right to refuse support and terminate or change the support relationship at any time;

(h) Safeguards must be set up for all processes relating to legal capacity and support in exercising legal capacity. The goal of safeguards is to ensure that the person's will and preferences are respected."²¹

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

²¹ CRPD/C/11/4 (25).

Proposal 3-7 Representative Decision-Making Guidelines:

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

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

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

- i. understand the information relevant to the decision and the effect of the decision;
- ii. retain that information to the extent necessary to make the decision;
- iii. use or weigh that information as part of the process of making the decision; and
- iv. communicate the decision.

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

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

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

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

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

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

- i. communicate by any means that enables them to be understood; and
- ii. have their cultural and linguistic circumstances recognized and respected

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

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

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

²² From Mental Capacity to Legal Capacity (Amendment) (No 2) Assisted Decision-Making (Capacity) Bill (2013) 2.

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

This functional approach is flawed for two key reasons. The first is that it is discriminatorily applied to people with disabilities. The second is that it presumes to be able to accurately assess the inner-workings of the human mind and to then deny a core human right – the right to equal recognition before the law – when an individual does not pass the assessment. In all these approaches, a person's disability and/or decision-making skills are taken as legitimate grounds for denying his or her legal capacity and lowering his or her status as a person before the law. Article 12 does not permit such discriminatory denial of legal capacity, but rather requires that support be provided in the exercise of legal capacity.²⁴

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.²⁵ They further point out that 'a presumption of mental capacity (decision-making ability) is meaningless' and does not help protect the individual's human rights. Further, according to the Committee's interpretation of Article 12 – all individuals, by virtue of their humanity, possess legal capacity – therefore, legal capacity (in contrast with decision-making ability) is not something which can be presumed, it simply exists in all persons, regardless of that individual's decision-making skills. The Centre strongly urges the ALRC not to include a final recommendation that an individual's decision-making ability should determine the exercise of his or her legal capacity.

²³ From Mental Capacity to Legal Capacity (Amendment) (No 2) Assisted Decision-Making (Capacity) Bill (2013) 2.

²⁴ CRPD/C/11/4 (13).

²⁵ 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>> accessed 1 July 2014.

Proposal 3–8 National Decision-Making Principle 4:

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

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

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

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

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

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

²⁷ See, for example, *Re E (Medical treatment: Anorexia)* (Rev 1) [2012] EWCOP 1639 (15 June 2012).

and preference and the individual can be held responsible for the decision if the crime or illegal action is committed. This raises larger questions of the functioning of criminal justice systems. As it currently exists, people with cognitive disabilities are disproportionately represented in criminal justice systems.²⁸ This requires significant further study to explore how to remedy this problem while simultaneously respecting the autonomy of people with cognitive disabilities and their right to equal recognition before the law. If it is civil penalties that are at risk, the individual could potentially be held responsible for these. This then also begs an examination of the civil legal system, including contract law, civil responsibility, and others – however, there is not space in this submission to explore those areas.

This explanation of what to do in the ‘hard cases’ should NOT be equated to substitute decision-making systems that currently exist. There are clear distinctions, which are 1) using ‘will and preference’ as the guiding paradigm as opposed to ‘best interest,’ 2) not denying legal capacity to individuals with disabilities on a different basis, and 3) not imposing outside decision-makers against the will of the individual.²⁹

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

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

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

²⁹ General Comment No.1, Article 12: Equal Recognition Before the Law, Paragraph 23, UN Doc No. CRPD/C/GC/1, Committee on the Rights of Persons with Disabilities, 11th session (31 March – 11 April 2014).

For example, in a situation in which an individual is displaying behaviours of serious self-harm, the support paradigm does not leave the individual to perish. Instead, it asks support people around the person to closely examine what is happening and to support the individual by taking actions that will facilitate her or his decision-making ability to a point at which she or he can clearly express her or his will and preferences. This could mean a variety of things, including but not limited to assisting the individual in stopping the self-harming behaviour and interacting with the individual in a caring and understanding manner and/or attempting to create an environment that the individual feels safe and comfortable in to allow her or him to be in an optimal decision-making scenario. Throughout any interaction, the goal remains of arriving at the will and preference of the individual. Further, according to the terms of the CRPD, any emergency interventions must adhere to the principle of non-discrimination by ensuring that criteria for crisis interventions do not discriminate on the basis of disability (for example, by using mental health diagnosis or mental capacity assessments).

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

Proposal 3–9 Safeguards Guidelines:

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

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

The key safeguard for laws and legal frameworks should remain a respect for the will and preferences of the relevant person. Safeguards should not just respect due process or judicial review of the interventions that restrict legal capacity. There is a need for checks and balances in order to respect the process as well as the autonomy of the relevant person. For example, monitors could be appointed in certain support agreements to ensure that significant decisions are made on the basis of the relevant person's will and preference. Also, the infrastructure at Commonwealth and State or Territory levels established to oversee and implement new legislation in this arena will be crucial, and accessible complaints mechanisms must be established within the implementing bodies to ensure ease of access for those using support to exercise legal capacity, as well as the usual recourse to the courts. Similar to the amendments proposed for the Irish Bill, criminal offences can be introduced to specifically prohibit abuses of power by

those appointed to assist or make decisions on behalf of the relevant person.³⁰ Additionally, there should be training and support for the supporters to ensure that they fully understand their role and the scope of their powers. Lastly, there should be an appeal process to an independent and impartial tribunal or court for instances when the relevant person is unable to choose his or her own representative and where an outside decision-maker is appointed to make particular decisions. In the ALRC's final recommendations, it could be further emphasized that all safeguards should focus on ensuring that the will and preference of the relevant person are respected in decisions made in all aspects of life.

Conclusion

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

³⁰ From Mental Capacity to Legal Capacity (Amendment) (No 2) Assisted Decision-Making (Capacity) Bill (2013) 2.