



NUI Galway

**CENTRE *for* DISABILITY
LAW & POLICY**

Submission from the Centre for Disability Law and Policy,
NUI Galway to the Oireachtas Committee on Children,
Equality, Disability, Integration and Youth on the Assisted
Decision-Making (Capacity) (Amendment) Bill 2021: Draft
General Scheme and Heads of Bill

20 January 2022

The Centre for Disability Law and Policy (CDLP) welcomes the opportunity to make this submission on the General Scheme of the Assisted Decision-Making (Capacity) (Amendment) Bill 2021. This Bill includes a number of amendments to enable full commencement of the ADM and significant pieces of legislative reform which have been identified as a necessary step to bring Ireland's laws into conformity with the UN Convention on the Rights of Persons with Disabilities (CRPD). While we welcome many of the proposals made in the General Scheme there are some issues we feel must be addressed to uphold disabled people's human rights and ensure the spirit of the 2015 Act is respected and maintained.

Heads 3, 38 and 60

The CDLP does not support the proposal to remove the opportunity to include decisions about healthcare treatment in Enduring Powers of Attorney. We consider that this creates an additional bureaucratic burden on the relevant person if they are required to draft two separate instruments, with different requirements for supporting evidence, witnessing, etc – an EPA and an AHCD. This is especially burdensome if the relevant person wishes to authorise the same person who holds the EPA as their designated healthcare representative to consent or refuse to treatment on their behalf in accordance with their will and preference. It would also be inconsistent with the approach in the rest of the Act to exclude healthcare treatment from EPAs when decisions about healthcare treatment can be included in any other decision support arrangement under the Act – including decision-making assistance agreements and co decision-making agreements.

Heads 5, 6, 12, 13, 16, 17, 18, 21, 22, 36, 38, 50, 52, 57, 58

In principle, the CDLP has no objection to the transfer of these administrative functions from the Minister for Children, Equality, Disability, Integration and Youth to the Director of the Decision Support Service. However, the ongoing consultations by the Decision Support Service on the Codes of Practice for different actors (including decision supporters) has brought to light a number of concerns.

These are that

- The Codes of Practice include significant differences of interpretation of the Act by the Decision Support Service as compared to spirit and letter of the Act.
- The manner in which the Decision Support Service has conducted its consultation on the Codes of Practice has not, to date, been meaningfully inclusive of disabled people.

We are particularly concerned that the Decision Support Service is putting forward an interpretation of the Act – especially with regard to assessments of capacity – which contradicts the letter and spirit of the Act. In effect, the Decision Support Service is proposing in its draft Codes, that a wide range of actors – including legal practitioners, financial professionals, and healthcare professionals – can carry out assessments of capacity as they see fit. These individuals can then make decisions about whether or not to respect the relevant person's decision based on their own assessments without any recourse to or oversight by the courts. If this inconsistency in interpretation continues, we would be gravely concerned about the appropriateness of the transfer of these powers to the Director of the Decision Support Service, as this would mean that the regulations to be made

regarding the format and content of various decision support arrangements may not reflect the Act as drafted.

Disabled people and their allies who campaigned for this legislation categorically did not want a system where their decisions could be disregarded on the basis that a particular professional interacting with them believed them to lack capacity. This is why, in contrast to the Mental Capacity Act 2005 in England and Wales, the 2015 Act does not provide a general power to third parties to assess capacity and decide whether or not to respect the person's decision on this basis.

Disabled people, older people, people with experience of mental health services are likely to be those who are most directly impacted by the Act. Ireland has an obligation under the UNCRPD to 'closely consult with and actively involve persons with disabilities' in decision making processes. Unfortunately, the consultation on the Codes of Practice by Decision Support Service has not to date been meaningfully inclusive of disabled people. The draft codes were not made available in Easy to Read formats, and no alternative methods of submission, beyond a written form, were provided for. Further, no draft Code is planned aimed specifically at disabled people or others likely to be the subject of this Act. While the Director of the Decision Support Service has a number of functions in relation to the development of guidance, raising awareness of the Act and the UNCRPD they do not have a clear obligation to meaningfully consult in an accessible manner. Should all the amendments listed above be successful the Director will be central to the development and reviewing of many other key instruments which disabled people or others wishing to create support arrangements will use.

Therefore, in order to guard against the reinterpretation outlined above and in line with Ireland's obligations under the UNCRPD, we recommend that these Heads be further amended. This amendment must ensure that the Director of the Decision Support Service has an obligation to consult with and ensure the meaningful participation of all those who are likely to be impacted by the Act or create support arrangements, in the development and review of all guidance, regulations etc. related to the Act.

Head 10, 20, 30

We understand and support the need to provide for more flexible and perhaps informal methods of complaint or dispute resolution under the Act. This is evidenced elsewhere in the Act by the removal of the requirement of wigs and gowns during hearings. However, we feel it is imperative that provisions regarding will and preferences and consent are retained here to ensure that the alternative process is in keeping with the relevant person's wishes. Further, such proceedings will relate to a decision supporters' role and may in certain circumstances leave the relevant person without any support mechanism while it is resolved. Therefore, we recommend that a further amendment is included here to ensure that an independent advocate or other supports can be made available to the relevant person if required.

Finally, if the initial complaint is dealt with by the Director in this manner, the onus would be on the relevant person to apply to court to challenge the outcome if they are not satisfied.

We ask for clarity here that legal aid will be available to individuals appealing a decision of the Director in relation to such complaints.

Head 19

Under the provisions of the 2015 Act, decision support arrangements, including who supports a person and how they support them, should be based on person's will and preferences. In this section it is proposed that a person must not only notify the Director of the Decision Support Service and provide evidence of capacity to revoke an agreement but also provide a reason for revocation. This places too many requirements on an individual who wishes to revoke an arrangement. It also suggests that the Director of the Decision Support Service could deny the revocation if they believe the reason provided is not sufficient. We recommend that the requirement to provide a reason for revocation is removed.

Head 21 & 57

Creating, amending, or revoking decision support arrangements under the Act should be accessible to all. The existence of a fee, even a nominal fee, could pose a barrier to those with a limited income. Therefore, we recommend the removal of references to regulations for fees regarding the registration, amendment, objection to or revocation of a co-decision making agreement or Enduring Power of Attorney under these heads. We understand that a nominal fee for obtaining authenticated copy may be required.

Head 23

The CDLP is unclear as to rationale for removing the requirement for most cases to be held otherwise than in public except for those relating to Advance Healthcare Directives. We recognise the importance here of striking an appropriate balance between individuals' privacy and legal principles such as justice being administered in public. However, issues which are deeply personal in nature are just as likely to be discussed in hearings under Part 4 as in cases relating to Advance Healthcare Directives in our view. Therefore, we feel a clear and consistent approach is required which both ensures dignity and privacy of the individual and ensures transparency and promotion of the public's understanding of this new law. We suggest an amendment which allows for judicial discretion regarding which cases are held otherwise than in public which applies to all cases related to the Act as a whole and drawing on existing legislation ensures representatives of bona fide press, researchers and legal professionals can still attend and report on cases subject to reasonable restrictions.

To achieve this, we suggest the introduction of a provision which states that 'all cases under the Act **may** be heard otherwise than in public'. A clear distinction between this and the current provisions is that cases 'may' be held rather than 'shall' or must be held. Additionally, any amendments should clearly state that, subject to reasonable restrictions regarding the publication of sensitive information, the hearing of a case otherwise than in public shall not preclude the reporting of such cases.

Head 25

The CDLP rejects the distinction made in this proposed amendment between decision making representatives appointed from the panel operated by the Decision Support Service and others (such as family and friends of the relevant person). Representatives appointed from a panel should be treated in the same manner as those who opt into the role having a pre-existing relationship with a person. These expenses must be met by the Decision Support Service regardless of a person's financial situation.

Financing decision making representatives out of a person's personal estate, mirrors the operation of wardship, which this Act is to replace. It is inappropriate that this Act would operate in a manner which is to the detriment of person's personal estate, and provision should be made for all of these expenses to be met by the state.

Head 27

The CDLP supports an amendment to the provisions regarding restraint under the Act. The removal of provision of restraint is a welcome development in bringing the Act in line with the UNCRPD. However, the Act cannot be silent on the issue of restraint. A failure to include an explicit prohibition could be interpreted by decision making representatives or other individuals as conferring a power to restrain. It is vital therefore that this Head is amended to include an explicit prohibition on chemical and mechanical restraint by all forms of decision supporters.

Head 32

The CDLP objects to the proposal in this Head to place the power to make an application under Section 55 within the discretion of the High Court. In order to better reflect the spirit of the Act, applications under Section 55 should be on the basis of the consent of the ward, or on the basis of the will and preferences of the ward.

Head 37

We are concerned that the wording proposed in this amendment, and copied below, is misleading. We believe it could be interpreted to mean that the trust corporation, if granted approval, can make decisions for the donor prior to the loss of decision-making capacity.

“A trust corporation shall apply to the High Court before the donor loses his or her decision-making capacity for approval to act as such in order to take on the duties of attorney in an enduring power of attorney under this Act.”

We recommend that this is rephrased for clarity and the rationale for these additional provisions explored in more detail.

Head 39 (and Heads 8, 14, 24, 40, 43, 44, 45, 46, 47, 48, 49, 50, 51, 52, 54, 56, 58, 59)

The CDLP has no objection in principle to the creation of a new two step process for registering and notifying an EPA. However, we do object to the approach in this and subsequent heads which would grant the Director of the Decision Support Service the authority (albeit on application by the attorney with accompanying statements from medical and other healthcare practitioners) to determine that the EPA should enter into

force without court oversight. Instead, we recommend maintaining court oversight of the decision to bring the EPA into effect, rather than delegating this power to the Director of the Decision Support Service. This is because under the Act, the court is the only body empowered to make a declaration that the relevant person lacks capacity – and because this declaration has such significant legal consequences for the individual, the full due process afforded by the courts should be in place.

Head 62

The CDLP objects to the approach in this Head which would allow the Director of the Decision Support Service to share sensitive information about a relevant person with other bodies due to safeguarding concerns without that person's express consent and/or where such sharing is not in keeping with the person's will and preferences. The proposed amendment allows for sharing without consent with 'relevant organisations' which is not further defined, and this approach runs contrary to the stated purpose of the Act, to ensure respect for the person's will and preferences. We firmly believe that safeguarding concerns can be addressed in a manner which is more compliant with human rights norms and respectful of the individual's autonomy, than the sharing of sensitive personal information without consent.

Head 64

While the CDLP acknowledges the need for a new provision in the Act to allow for temporary prohibition orders, we are concerned that the relevant person may be left without any support while a temporary prohibition order on a decision supporter is in place. This head as currently drafted provides for the appointment of a replacement decision-making representative while the temporary order is in effect – but not for the appointment of a replacement decision-making assistant or co-decision maker for example. It is vital that this is amended to ensure that the Director of the Decision Support Service has an obligation to support the relevant person while the temporary order is in force, or to make arrangements to ensure the person in this position is provided with additional support in accordance with her will and preferences. In order to ensure consistency with other provisions in the Act, (e.g. section 19(5)), the CDLP also propose amending this Head to refer to an 'immediate risk of **serious** harm' rather than simply a risk of 'harm'.

Head 66

The CDLP objects to the proposed amendment to allow special visitors and general visitors to dispense with the requirement of consent of the relevant person to inspect documents without court oversight. The amendment provides that the Director does not have to apply for court approval to dispense with consent of relevant person if those visitors are assisting the Director in an investigation. This should not occur as it would be contrary to the spirit and letter of the Act to allow for a dispensal of the relevant person's consent without any court oversight. We recommend changing the provision to ensure that the consent of the relevant person can only be dispensed with following approval of the court.

Head 67

Similarly, to Head 66, the CDLP objects to the proposed amendment to allow court friends to dispense with the consent of the relevant person, as being incompatible with the spirit

and letter of the Act. The purpose of a court friend is to assist the relevant person during the course of court proceedings. Therefore, it is not possible for a court friend to truly assist the relevant person without their full consent, including consent to access information and documents relevant to the proceedings. We suggest this proposed amendment is removed.

Head 71

As this head purports to amend the section of the 2015 relating to the development of Codes of Practice, the CDLP wishes to suggest additional items for inclusion in this section. In particular, it would be useful to add specific reference to the need for the Decision Support Service to develop the following additional guidance on the operation of the Act:

- Guidance for relevant persons, donors, directive-makers;
- Guidance for family members;
- Guidance for young people who will be able to create a support arrangement once they turn 18.

The CDLP further recommends the introduction of obligations under this Head on the Director of the Decision Support Service to develop codes of practice and guidance on interpretation and application of the Act through consultation with and the meaningful participation of all those who are likely to be impacted by the Act or create support arrangements. This includes the need for all guidance documents, codes of practice, and consultation processes to be fully accessible and subject to regular and ongoing review.

Head 79

The CDLP objects to the language proposed in this head which would introduce the term 'mental or intellectual capacity' into the Juries Act. Such language inconsistent with the 2015 Act which deliberately does not include any reference to specific cognitive impairments. In accordance with the approach proposed in the Law Reform Commission's 2013 report, the CDLP suggests the following alternative wording: "a person is eligible for jury service unless, arising from the person's ill health, he or she is resident in a hospital or other similar health care facility or is otherwise (with permissible and practicable assisted decision-making supports and accommodation that are consistent with the right to a trial in due course of law) unable to perform the duties of a juror."

Head 81

The CDLP considers that it is unnecessary to add specific recognition of the NDA in supporting IHREC to perform its functions as proposed in this Head. NDA's existing legislative functions already allow for the sharing of information including statistical data with public bodies such as IHREC. Furthermore, the CDLP views that it would be more appropriate to amend the IHREC Act to create an obligation on IHREC to meaningfully engage with disabled people directly – rather than the NDA as a public body – in order to obtain information and advice on how the rights of disabled people are being impacted at grassroots level. IHREC has already taken steps to achieve this including through the creation of its Disability Advisory Committee, but the CDLP views that further direct engagement with disabled people would be more appropriate in this context than providing legal recognition for the role of the NDA.

Head 85

The CDLP welcomes the introduction of new clarity on the role of advisory committees to IHREC and would further suggest amending this head to ensure that the membership of this committee has a two-thirds majority of disabled people, rather than a simple majority. Furthermore, the CDLP recommends changing the definition of disability used to establish eligibility for this Committee from that contained in the Disability Act 2005 to the approach of the CRPD which is that “persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.” This approach is preferable as it allows for greater flexibility in who can be considered to come within the meaning of ‘person with disability’ and it is more consistent with the human rights model of disability enshrined in the CRPD.

Head 86

The CDLP recommends that this Head be revised to provide clarity on whether the decision-making assistant, co decision-maker, or decision-making representative can also be the relevant person’s agent for the purpose of social welfare payments. If that individual is supporting the person to appoint an agent, it may be viewed as a conflict of interest for the same person to then act as that person’s agent, but the person may want their decision supporter to act in this role and may have no one else that they could nominate to act as agent. This issue needs to be clarified in the final text of the Bill.

Head 87

The CDLP suggests a further provision be added to this Head to amend section 47(7)(e) of the Nursing Home Support Scheme Act to remove the authority for any relative over 18 to act on behalf of another person including in arranging their admission to a nursing home or making applications to the Fair Deal Scheme for the person without obtaining their express consent.

Head 88

The CDLP does not support the proposal in this Head to change the requirement for a full review of the functioning of this Act from 5 years after enactment to 5 years after commencement of all the sections of the Act. Those who campaigned for this legislation specifically argued that a comprehensive review clause was necessary to ensure that the Act remained under ongoing review at regular intervals, given the pace of change in this area globally and advances in practice on the ground. Therefore, the CDLP recommends retention the original approach in the Act which was to ensure a review of the Act’s functioning no later than the 5th anniversary of its enactment, and add further provision to ensure that the Act is reviewed thereafter at least every 3 years.

Further amendments

Finally, we believe that a number of areas, which would serve to advance the human rights of those impacted by the Act and strengthen its functioning, have been omitted from the current proposals. These include the extension of the provisions of the Act to those aged 16 and 17 years of age, the extension of Advanced Healthcare Directives to the Mental Health

Act and their full application during pregnancy, and the introduction the concept of best interpretation of will and preferences.

Extend the provisions of the entire Act to young people aged 16 and 17

Currently, the provisions of the Assisted Decision – Making (Capacity) Act 2015 only apply to those aged over 18. This is despite young people aged 16 and 17 being understood to be able to participate in a number of legally binding decisions such as consent to medical treatment, applications for assessments of need and applications for and management of social protection payments such as Disability Allowance. There is the possibility that in undertaking of any of these tasks a young person could have their capacity questioned or may require support.

A Law Reform Commission report in 2011 recommended further clarity and certainty on a young person’s right to consent to and refuse medical treatment. Extending the provisions of the Assisted Decision – Making (Capacity) Act 2015 would go some way to addressing this issue. It would provide also provide a clear legal framework for the assessment of capacity, recognition of support and the standards and safeguards that should be applied.

Advance Healthcare Directives

It is important that advanced health care directives are available to all persons accessing mental health care. Activists have campaigned both during the drafting of the Act and since it was signed into law to ensure that they were included. Under the Act, currently, someone’s express refusal of treatment in an Advance Healthcare Directive can be overridden if the person is subsequently detained under the Mental Health Act 2001. In order to ensure that persons are not subject to treatment they previously refused it is necessary to delete section 85(7) of the 2015 Act.

When the 2015 Act was passed, section 85(6) provided that an Advance Healthcare Directive would not be valid or applicable insofar as it contained a refusal of treatment which would have a deleterious effect on the unborn. We propose the deletion of section 85(6) in order to ensure that all pregnant people can avail of advance healthcare directives. Section 85(6) was inserted prior to the Repeal of the Eighth Amendment of the Constitution and the enactment of the Health Regulation (Termination of Pregnancy) Act 2018.

Interpretation & Guiding Principles

The Assisted Decision – Making (Capacity) Act 2015 was drafted to enable Ireland to ratify the UNCRPD. Ireland has since ratified the Convention and the CDLP believes embedding an explicit reference to the UNCRPD in the Guiding Principles of the Act would strengthen the potential for the Act to be interpreted in a manner compatible with the human rights obligations in that Convention. It would also signal Ireland’s commitment to a progressive interpretation of this law.

Decision making representatives and other intervenors under the Act must act in manner that is consistent with the past and present will and preferences of the relevant person, in

so far as they are reasonably ascertainable. To support intervenors to fulfil their obligations and uphold the rights of the relevant person we recommend the introduction of the concept of 'best interpretation of will and preferences' to the Act. General Comment No. 1 of the UNCRPD states that 'where, after significant efforts have been made, it is not practicable to determine the will and preferences of an individual, the "best interpretation of will and preferences" must replace the "best interests" determinations.' The introduction of this concept would cement the cultural shift required by the Act and ensure supporters understand what their duty is when the person's will and preferences are not ascertainable due to the circumstances.