



**Tithe an
Oireachtais
Houses of the
Oireachtas**

An Coiste um Leanaí, Comhionannas, Míchumas, Lánpháirtíocht agus Óige
Tuarascáil ar an nGrinnscrúdú Réamhreachtach ar Scém Ghinearálta an
Bhille um Chinnteoireacht Chuidithe (Cumas) (Leasú), 2021

Aibreán 2022

Joint Committee on Children, Equality, Disability, Integration and Youth
Report on Pre-legislative Scrutiny of the General Scheme of the Assisted
Decision-Making (Capacity) (Amendment) Bill 2021

April 2022



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INTEGRATION AND YOUTH**

**Report on pre-legislative scrutiny of the General Scheme of the Assisted
Decision-Making (Capacity) (Amendment) Bill 2021**

April 2022

CDEI 33 008

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Joint Committee on Children, Equality, Disability, Integration and Youth



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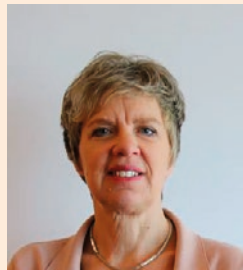
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Senator Mary Seery
Kearney
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Senator Ned O'Sullivan
Fianna Fáil



FOREWORD

The reforms this Bill will provide are both urgent and overdue. For far too long the wardship system has deprived people of their human rights and caused harm. The Bill will also crucially bring significant progress in terms of our responsibilities under the UNCPRD. There must now be no more delays in ratifying the Optional Protocol.

The Committee commends the Minister and his team for their action on progressing this historic piece of legislation. On the other hand, the Committee hopes that the failure to meaningfully consult with stakeholders during its development will be an important lesson learnt going forward. The Committee were tied to very tight timelines in producing this pre-legislative report and acknowledge that for some stakeholders this was inaccessible. We are extremely grateful to everyone who contributed to this report, either through submissions or the public meetings. A special thanks goes to the Disabled Persons Organisations whose input was vital.

The Committee's engagement with relevant persons and other stakeholders cannot be seen as a job done in terms of consultation and collaboration with those directly affected by the legislation. Ongoing opportunities for input will be essential to its success. As such, several of the recommendations in this report are aimed at strengthening that input.

Another key element to ensuring this progressive and potentially transformative Bill delivers is resources. The health, social care and disability sectors it centres on have a long legacy of being under-resourced. Staff working in these sectors and family carers do incredible work with limited resources and the State owes them a debt of gratitude. Far more important though, is that they are properly resourced to contribute to making the legislation a success. For people who will be supported under the Bill to have real decision-making opportunities available to them, as promised by the legislation, the resources to make various choices a reality must be provided.

The Committee has made 64 recommendations about how the Bill could be improved. We implore the Minister and all those involved in progressing the legislation to give the recommendations provided in this report serious consideration.

A handwritten signature in blue ink that reads "Kathleen Funchion".

Kathleen Funchion T.D.
Cathaoirleach
5th April 2022

Table of Contents

MEMBERSHIP	2
FOREWORD	5
INTRODUCTION AND WITNESSES.....	8
KEY ISSUES.....	13
1. Presumption of Capacity and Protecting Will and Preference	13
The Assisted Decision-Making legislation and the UNCRPD	14
Medical versus Social model of disability	14
Intersectionality	15
Substitute Decision-Making	16
Functional Assessments of Capacity	17
Safeguarding Will and Preference	18
Privacy and Consent.....	20
2. Consultation, Language and Accessibility.....	26
Engagement and Consultation.....	26
Language and Accessibility	28
3. Costs, Capacity Building and Resources	31
Living arrangements	32
Capacity Building and Resources	33
Independent Advocates	35
Family Carers	35
Costs and Fees	36
4. Mental Health.....	39
5. People who are Involuntarily Detained, Protection of Liberty Safeguards and Restraint.....	41
People who are Involuntarily Detained	41
Protection of Liberty Safeguards	42
Restraint.....	43
6. Advance Healthcare Directives and Enduring Power of Attorneys	45
7. Accountability, Appeals, Complaints	48
8. Wards	50
9. IHREC	52
RECOMMENDATIONS.....	53
APPENDIX 1 - ORDERS OF REFERENCE.....	62
APPENDIX 2 – LINKS TO MEETING TRANSCRIPTS	66
APPENDIX 3 – LINKS TO SUBMISSIONS & OPENING STATEMENTS	66

INTRODUCTION AND WITNESSES

The proposed Bill will amend the Assisted Decision-Making (Capacity) Act 2015 ('the Act'). Although the Act was signed into law in 2015, it is not yet fully commenced. The Act will replace the Wards of Court system and introduce a graduated supported decision-making framework. It is intended to support a range of people, some examples include wards, those with disabilities, older people with degenerative cognitive conditions and people with mental health issues. The Act also repeals the Marriage of Lunatics Act 1811 and the Lunacy Regulation (Ireland) Act 1871.

The rationale provided for drafting an amending piece of legislation to change a Bill not yet fully commenced is to improve processes and safeguards for those who will make use of the new decision-making supports¹. Further, the amending Bill "includes measures to further realise the United Nations Convention on the Rights of Persons with Disabilities in Ireland, including legislating for the Irish Human Rights and Equality Commission's (IHREC) position as the national monitoring body for the United Nations Convention on the Rights of Persons with Disabilities, and increasing the public sector duty regarding the employment of persons with disabilities from 3% to 6%.²"

As per the 2015 Act, the term 'relevant person', which is used throughout this report means—

- (a) a person whose capacity is in question or may shortly be in question in respect of one or more than one matter,
- (b) a person who lacks capacity in respect of one or more than one matter, or
- (c) a person who falls within paragraphs (a) and (b) at the same time but in respect of different matters.

The Decision Support Service has been set up within the Mental Health Commission to oversee the implementation and operations of the legislation. The three levels of decision

¹ [gov.ie](http://www.gov.ie) - Cabinet approves General Scheme of the Assisted Decision-Making (Capacity) (Amendment) Bill (www.gov.ie)

² [gov.ie](http://www.gov.ie) - Cabinet approves General Scheme of the Assisted Decision-Making (Capacity) (Amendment) Bill (www.gov.ie)

support available for people who currently, or may shortly, require support when making certain decisions are:

1. Decision-making assistance agreement: the person makes their own decision with support from their decision-making assistant. Their decision-making assistant helps them to access and to understand information and to communicate their decision.
2. Co-decision-making agreement: the person makes specified decisions jointly with a co-decision-maker.
3. Decision-making representation order: the court appoints a decision-making representative to make certain decisions on the person's behalf³.

The Government has committed to commencing the legislation by June 2022. A common theme almost unanimous to all the submissions the Committee received and testimony it heard was that there was no meaningful or accessible consultation process carried out during its development. The Committee too came under time pressure in delivering this pre-legislative scrutiny report. This is a complex and ground-breaking piece of legislation amending another complex piece of legislation, that is yet to be fully commenced. The submissions the Committee received contain detailed analyses of, and suggestions about the legislation and potential unintended consequences. The time-pressure the Committee came under necessitated that it focused in on a limited number of key issues. As such, given the lack of meaningful and accessible consultation undertaken by the Department, the Committee makes an initial general recommendation as follows:

The Minister, the DSS and those involved in progressing this legislation should examine, in depth, all the submissions and testimony received during the Committee's public call for submissions and two public hearings, as well as scrutinising this report. This should be done with an open mind to working with stakeholders and bringing forward collaborative amendments at Committee stage.

³ DSS online FAQs.

WITNESS DETAILS

Tuesday 15th February 2022

National Platform of Self Advocates

- Mr Joe McGrath
- Mr Dermot Lowndes

Independent Living Movement Ireland

- Mr Peter Kearns, ONSIDE Project Coordinator

National Federation of Voluntary Service Providers

- Ms Alison Harnett, Chief Executive
- Ms Teresa Mallon, Chair of the Assisted Decision-Making Reference Group

Mental Health Reform

- Ms Fiona Coyle, Chief Executive
- Ms Ber Grogan Policy and Research Manager

Family Carers Ireland

- Mr John Dunne, Chief Executive

Wednesday 16th February 2022

Centre for Disability, Law and Policy NUI Galway

- Professor Eilionóir Flynn
- Ms Clóna de Bhailís, PhD Candidate

The Department of Children, Equality, Disability, Integration and Youth

- Ms Carol Baxter, Assistant Secretary
- Mr Niall Brunell, Principal Officer

Decision Support Service

- Ms Áine Flynn, Director
- Mr John Farrelly, Chief Executive of the Mental Health Commission

Irish Human Rights and Equality Commission

- Mr Adam Harris, Commission Member
- Dr. Iris Elliott, Head of Policy and Research

GLOSSARY/ABBREVIATIONS

UNCRPD: United Nations Convention on the Rights of Persons with Disabilities

General Comment: A general comment is a treaty body's interpretation of human rights treaty provisions, thematic issues or its methods of work. General comments often seek to clarify the reporting duties of State parties with respect to certain provisions and suggest approaches to implementing treaty provisions.

DPO: DPO is a precisely defined term under General Comment 7 of the UN CRPD Rights Committee as an organisation led, directed and governed by a clear majority of disabled people and whose primary focus is to directly represent and advocate for the rights of its members in line with the principles of the UNCRPD.

Substitute Decision-Making: substitute decision-making is when a person makes a decision on behalf of a person who has lost decision-making capacity.

Optional Protocol: The Optional Protocol to the Convention on the Rights of Persons with Disabilities is a side-agreement to the Convention on the Rights of Persons with Disabilities. The Optional Protocol establishes an individual complaints mechanism for the Convention, similar to those of other conventions. Ireland has not yet ratified the Optional Protocol.

The Act: The Assisted Decision-Making (Capacity) Act 2015

The Bill: The General Scheme of the Assisted Decision-Making (Capacity) (Amendment) Bill 2021

IHREC: Irish Human Rights and Equality Commission

Public sector duty: All public bodies in Ireland have responsibility, under the Public Sector Equality and Human Rights Duty or Public Sector Duty, to promote equality, prevent discrimination and protect the human rights of their employees, customers, service users, and everyone affected by their policies and plans. This is a legal obligation and is contained in Section 42 of the Irish Human Rights and Equality Act 2014.

DSS: Decision Support Service

Functional Assessments of Capacity: capacity is assessed in a time and issue specific manner rather than an all or nothing medical-status focused process.

CDLP: Centre for Disability Law and Policy

EPA: Enduring Power of Attorney

AHD: Advance Healthcare Directive

HSE: Health Service Executive

MyGovID: A single secure online identity used to access a range of government services
www.mygovid.ie

HIQA: Health Information and Quality Authority

MHC: Mental Health Commission

ECHR: European Convention on Human Rights

KEY ISSUES

Following a public call for submissions and two public hearings with stakeholders the Committee have identified eight key areas of concern in the proposed Bill and have made a number of recommendations. The Committee notes that this call was over the Christmas period and that Disabled Persons' Organisations (DPOs) felt that adequate time and possibility was not given for them to participate in the consultation.

1. Presumption of Capacity and Protecting Will and Preference

The presumption of capacity and the importance of will and preference are central to this legislation. If its provisions are implemented effectively it offers a potentially transformational policy and culture shift. This would bring Ireland into line with our obligations under the UN Convention on the Rights of Persons with Disabilities (UNCPRD).

The focus on supporting people, or as they are referred to in the legislation 'relevant persons', to make decisions based on their will and preference is welcome. This Amendment Bill will finally allow for the long-awaited full commencement of the Assisted Decision-Making (Capacity) Act 2015. While this policy and culture shift is to be commended, it is long overdue, and the Bill needs to be strong in terms of embedding the presumption of capacity and the importance of will and preference into law. The Committee heard wide ranging concerns as to how these aspects of the Bill need strengthening. At all stages relevant persons should be presumed to have capacity unless a court decides otherwise. The obligation must be on other parties to establish a lack of capacity rather than the relevant person having to prove their capacity.

The Committee heard from Disabled Persons Organisations about how important that autonomy is. These progressive provisions will need to be carefully matched with equally progressive supports for family carers who the Committee recognise will be both challenged by the legislation and crucial to its success. The issue of supporting and resourcing carers is explored further in key issue three. Family Carers Ireland consistently raised the issue of family carers having to deal with the consequences of bad decisions taken by relevant persons. The aim of the legislation is to support decision-making and maximising a person's

capacity to make decisions. There may be occasions where relevant persons may take what appear to someone else to be unwise decisions. However, despite disagreement, under the legislation they will have the right to make that decision unless a lack of capacity is established.

The Assisted Decision-Making legislation and the UNCRPD

The Assisted Decision-making Capacity legislation offers significant progress towards recognising that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life, as per Article 12 of the UNCRPD⁴.

Medical versus Social model of disability

The UNCRPD and best practice in the area of disability mandates a shift in culture and policy away from the medical model of disability and its focus on 'best interests' and 'duty of care' concepts, using a human rights-based approach and social model of disability. The social model of disability centres on will and preference and enabling equal recognition before the law as well as the removal of barriers to legal capacity, including tests of capacity. It also recognises that disability is created by society when obstacles, including physical infrastructure, bureaucratic systems, and social attitudes, limit the capacity of individuals to live full independent lives. This approach seeks to explore the range of environmental issues disabled people face and better resource and support them accordingly. The Decision Support Service will, in this vein, be accessed based on need not diagnosis. The UNCRPD conceptualisation of disability is broader and in line with the social and human rights models of disability. As such the Committee recommends the adoption of that understanding of disability⁵.

⁴ [Article 12 – Equal recognition before the law | United Nations Enable](#)

⁵ Article 1 of the UNCRPD states: "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."

Intersectionality

Several stakeholders stressed the importance of intersectionality in terms of the Act and more generally in how we consider disabled persons and understand the need to build their capacity in terms of will and preference. The social model of disability offers more scope for this than the medical model, which can focus too much on one factor, the medical disability or impairment. As Mr. Peter Kearns of Independent Living Movement Ireland (ILMI) said:

“The medical model is so inherent and big that it is easy to fall back into impairment label narratives and identifying disabled people with their impairment label baggage... We start out by recognising class, gender and ethnic backgrounds. Those elements are very important to take into account. If a person is a working-class woman who has spent 20 years in an institution, where does that person get the confidence to really appreciate that will and preference? ... Will and preference also has a capacity-building nature and framework behind it. It is not just saying, ‘Here you go, you have your will and preference, go for it.’ There is a need to recognise that disabled adults have to have capacity-building for that will and preference.”⁶

Many stakeholders recommended that this model be explicitly referenced in the ADMC legislation, possibly within its Guiding Principles, so that it takes account of the intersection of disability, gender and gender identity, sexual orientation, socioeconomic status, family status, ethnicity marital status, religion and age. Then, stakeholders suggest, it can deliver more in terms of enabling individuals to make their own choices by building decision-making capacity and resourcing them with the supports necessary to their personal situation. The Committee is cognisant that a seeming lack of capacity is often actually a shortage of resources or the presence of inappropriate supports. In these cases, there is a need to dig deeper into the interlinked issues affecting a particular individual’s ability to develop capacity to make decisions. As such, the Committee recommends imbedding the social/human rights-

⁶ 15th February meeting

based model of disability into the ADMC legislation, including the Act, Amendment Bill and codes.

During the Committees public hearings on the Bill and in the submissions received, it was perhaps unsurprisingly the DPOs who most effectively tied together everything needed to make this legislation work, from an intersectional perspective. They have much to offer by way of wisdom and building capacity which will be key to making this legislation work. Their involvement should not be limited to a tick box or storytelling exercise, individuals deserve so much more, and have much more to offer, than that. This is explored more in Key issue three.

Substitute Decision-Making

If a relevant person has been declared to lack capacity, then the Bill permits substitute decision-making. In General Comment 1, the UNCRPD took Article 12 to prohibit substitute decision-making. When Ireland ratified the Convention in 2018, the State entered a declaration permitting the retention of substitute decision-making subject to safeguards and in appropriate circumstances. A declaration is a formal submission, whereby a State agrees with the Convention in the main but reserves the right to take its own interpretation of what a rule means. Substitute decision-making diverges from Article 12 as interpreted by the UNCRPD, and the Committee heard calls from some stakeholders for it to be removed⁷. Others cautioned that it should only be used when absolutely necessary and robust safeguards must be in place where will and preference may be overruled. The Committee considers that capacity building and significant supports and resources will be key to enabling people to realise their human right to decision-making; minimising substitute decision-making and prioritising the will and preference of relevant persons and alleviating the pressures of family carers' experiences.

⁷In a declaration made in respect of Article 12, Ireland has declared its understanding that the Convention permits supported and substituted decision-making arrangements which provide for decisions to be made on behalf of a person, where such arrangements are necessary, in accordance with the law, and subject to appropriate and effective safeguards. To the extent Article 12 may be interpreted as requiring the elimination of all substitute decision-making arrangements, Ireland reserves the right to permit such arrangements in appropriate circumstances and subject to appropriate and effective safeguards. See Initial report for Ireland: [99830_c15d2ebb-6f3f-4d0f-bd97-4aeb0dc69148.pdf](https://www.ohchr.org/en/huridocda/huridoca/doc.aspx?docid=99830_c15d2ebb-6f3f-4d0f-bd97-4aeb0dc69148.pdf)

Functional Assessments of Capacity

Stakeholders raised concerns that although this Bill is progressive in that it centres on the presumption of capacity, ultimately, the legislation still relies on a functional assessment of mental capacity, which contrasts with Article 12 of the UNCRPD. If the functional assessment of mental capacity is to remain in the Act, they underlined the need for strong guiding principles and safeguards to develop a culture of support and empowerment, rather than one of capacity assessments.

Stakeholders raised issues with the way in which 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.

Head 31 seeks to amend section 50 of the 2015 Act. This Head provides for the deletion of the term 'cognitive ability' from section 50 of the Act. This is a welcome step in the right direction, whereby capacity is assessed in a time and issue specific manner rather than an all or nothing medical-status focused process.

The Act's main provisions around presumed capacity in Part 3 are summarised as follows:

A person lacks the capacity to make a decision if they are unable:

- To understand the information relevant to the decision
- To retain that information long enough to make a voluntary choice
- To use or weigh that information as part of the process of making the decision, or
- To communicate their decision

However, a person should not be said to lack capacity if they:

- Require information to be explained to them in a way that is appropriate to their circumstances
- Can only retain the relevant information for a short period of time

- Did lack capacity for a particular decision at one time but may no longer lack capacity to make that decision
- Lack capacity for some decisions but have capacity to make decisions on other matters⁸

Safeguarding Will and Preference

The Committee also heard some alarming concerns about potential misinterpretations of the Act in terms of who can assess capacity or make decisions. It is important that the Act and the codes developed by the DSS make clear that an individual is presumed to have capacity until a court decides otherwise, and that the obligation is on another party to establish a lack of capacity rather than the individual having to defend themselves. At the moment there are fears that the DSS draft Codes imply that third parties can decide someone lacks capacity, when in fact, the Act says it is only the courts that have the power to declare that someone lacks capacity (Part 5, Chapter 3 of the Act). A range of detailed training supports, and example scenarios will need to be provided to anyone who may interact with relevant persons. This will be an important safeguard in terms of protecting will and preference. The need for resources and training is further explored in Key issue three.

The CDLP sounded a note of caution about an approach to assessment of capacity that suggests that assessments of capacity can be conducted by a person who encounters the individual in a bank or a doctor's office or any other community setting. This carries risks, such as people making assessments who lack the required expertise. This echoed fears, expressed by DPOs that they could come up against people in a community setting who either don't have the time, expertise or perhaps the inclination, in that moment, to learn about and implement the Bill's provisions. The reality is that, apart from investigations into complaints regarding decision support arrangements and processes around EPAs or co-decision-making agreements, whereby capacity assessments must be undertaken by a doctor and another healthcare professional, that is the direction the legislation is going in. The draft codes state:

⁸ Source: [Citizens Information Board](#)

“no specific person or professional is required to undertake the assessment. Because it is not a medical assessment, it is not a requirement that the person undertaking the assessment be a doctor or healthcare professional. The most appropriate person to assess capacity will often be the person with the best understanding of the specific decision that needs to be made. This includes an understanding of the choices available to the relevant person, the likely consequences of each option, and the consequences of taking no action. It is usually the person who is most directly concerned with the relevant person in regard to the decision that needs to be made. This may be a solicitor, bank official, social housing agent, or care provider, among other.”⁹

The importance of countering the risks this system entails with sufficient resources, clear codes, guidelines and training cannot be underestimated. A potential safeguard against these issues would be to make abundantly clear relevant persons’ rights of recourse to the courts following refusal to consent to a capacity assessment or following dispute of the findings of a capacity assessment.

Another safeguard of will and preference the Committee heard calls for is the application of the Guiding Principles to everybody interacting with a relevant person. At present, under section 8 of the Act, only these named interveners are obliged to apply the guiding principles. However, they are a progressive toolset and widening their application aligns better with the UNCRPD. The Director of the DSS, Mental Health Reform and Safeguarding Ireland, among others, are supportive of this recommendation, with the DSS draft Code of Practice stating: *“this code of practice promotes the adoption of the guiding principles more generally, intervention is used throughout this code in its ordinary, broader sense unless otherwise specified, as any engagement with or action taken in respect of a relevant person in the context of the Act¹⁰”*. In their submission, the HSE¹¹, flag that limitations in terms of who is considered an intervener could be problematic. They recommend that the definition of

⁹ [Draft code of practice on supporting decision-making and assessing capacity](#)

¹⁰ [Draft code of practice on supporting decision-making and assessing capacity](#)

¹¹ ‘HSE’ is used in this report as shorthand. The submission was made by the HSE Assisted Decision-Making Implementation Steering Group with support from the HSE National Office for Human Rights and Equality Policy.

intervener should be further broadened to widen the applicability of the Guiding Principles and to remove uncertainty regarding the scope of the application of the Act.

Those not legally recognised as decision-making supporters must be fully informed that they are not being empowered to make decisions relevant persons stand. The rules around interveners, decision supporters and court ordered decision-making representatives must be clearly communicated so that relevant persons will and preference is adhered to. Resources and communication will be key to ensuring that individuals aren't inadvertently pushed further up the scale of supports into more restrictive arrangements than are necessary, such as being assigned a decision-making representative rather than assistant simply because of a lack of resources, including the time and personnel required to build capacity and act as an assistant. The use of alternative and augmentative modes of communications (AAC) should be better incorporated in the codes and the Bill.

Independent Advocacy could also have an important role to play in safeguarding will and preference and reducing the need to resort to substitute decision-making, with the important caveat that advocacy is no replacement for seeking the input of relevant persons themselves. This is explored in more detail in key issue three.

Privacy and Consent

The Committee heard compelling testimony from stakeholders and in the submissions received about the importance of privacy and consent to the persons affected by the Bill. Parts of the Bill give discretion to waive relevant persons' privacy or consent in certain circumstances. This is seen to contrast with the emphasis that both the Act and the UNCRPD place on the presumption of capacity and the importance of will and preference. These issues were also widely flagged in the submissions received. Heads 23, 62, 66 and 67 were the main areas of concern raised and warrant further consideration.

The sharing of information without consent – Heads 62, 66 & 67

These Heads each contain provisions that allow the consent of the relevant person to be overridden and information about them shared in certain circumstances. Disabled Women

Ireland were among those who expressed concerns with these Heads, stating in their submission:

“While we want to ensure that there are protections within these systems to avoid abuse, it should be done in a manner which centres the person, their will and preferences and rights.... Nothing in the act should grant anybody the power to negate the consent of the person without oversight from the court.”¹²

The Bill in its current form would allow investigators under the DSS to access private data without an individual’s consent and without court oversight. This impacts on disabled people’s right to privacy (Article 22 of the UNCRPD).

Head 62 allows for this in the case of safeguarding concerns. It proposes to insert into the Act that one of the Director’s functions is *“to promote the safeguarding and welfare of relevant persons by sharing information, including sensitive personal information where appropriate, with relevant organisations and bodies where such concerns arise”*. While the Committee understands that the Bill needs to create effective pathways for safeguarding issues to be communicated, given the feedback it received in relation to Head 62, these circumstances should be limited and further defined. The Bill should include an explicit commitment to take all relevant steps to obtain informed consent before information is shared or privacy compromised. Consideration should be given to further defining *‘relevant organisations’*.

Head 66 allows the Director to dispense with the relevant person’s consent, and a need for court approval to share certain documents about them with special and general visitors, for the purposes of carrying out certain investigations. The explanatory note reads *“the intention behind the inclusion of the amended section 99(8)(b) is to provide that court approval is not required in order to allow a special or general visitor to obtain access to documents when that visitor is assisting the Director in carrying out an investigation.”* In line with the observations on Head 62, an explicit commitment to take all relevant steps to obtain informed consent

¹² Disabled Women Ireland submission.

before information is shared or privacy compromised and the circumstances when this step will be taken should be further defined.

Head 67 allows the Director to “*dispense with the requirement for consent of the relevant person to be sought before a court friend can access personal welfare or financial records in circumstances where it would be impracticable to obtain such consent, such as, for example, where the relevant person was in a coma or otherwise unable to communicate.*” Unlike Head 66, it mandates the approval of the Court. Concerns still arise though, in relation to ‘*otherwise unable to communicate*’. DPOs understandably expressed concerns around communication to the Committee, sharing their experience of people being considered non-verbal or unable to communicate, when, with the right supports, communication abilities exist. As Mr. Peter Kearns of Independent Living Movement Ireland informed the Committee:

“In my experience ... I have not come across any cases, having worked with disabled people for 30 years, where one cannot find that point of communication and a bit of that will and preference.”¹³

The DSS and Safeguarding Ireland are supportive of these Heads, with the DSS having sought an even more liberal amendment to consent requirements around visitors. The Committee understand the intention here is to be able to safeguard relevant persons effectively. However, these Heads raise serious privacy and consent concerns among DPOs especially. If DPOs had been meaningfully consulted during the drafting of these sections initially, then some of these fears may have been alleviated. The Committee recommend that engagement takes place now and an opportunity for input is provided. This is explored further in key issue two.

The requirement for cases to be heard in public – Head 23

The 2021 Bill proposes to amend the Act to remove the requirement for some cases in court to be heard otherwise than in public. The Committee heard concerns about relevant persons

¹³ 15th February meeting.

and privacy at court from a wide variety of stakeholders. A number of alternative provisions were suggested, with the common theme being that more privacy can be afforded to relevant persons without compromising transparency or public confidence. Consideration could be given to publishing determinations in court anonymously and permitting representatives of bona fide press, researchers and legal professionals to attend and report on cases subject to reasonable restrictions that protect relevant persons. Often, under various parts of the Bill, vulnerable persons' health, welfare, finance, family and property information will be discussed in court, which brings about potential safeguarding risks. The safety, dignity and privacy of relevant persons in court must be paramount. As such the Committee recommends giving relevant persons primary input into whether cases are to be heard in public or private. The Committee heard from Mr. Joe McGrath of the National Platform of Self Advocates on this:

*"I think the decision about whether a court case is heard in private or not should depend on what the person with a disability wants."*¹⁴

Head 23 and provisions in relation to hearings in court being in public or private generally, is another area of the Bill that should be revisited with the will and preference of relevant persons front and centre.

RECOMMENDATIONS

The Committee recommends:

1. There should be statutory requirement in the Bill which places a duty on the Decision Support Service to meaningfully consult and actively engage with disabled people and increases accountability. This should include:

- an obligation for a meaningfully inclusive consultation process on all Codes of Practice, guidance documents, forms etc.

¹⁴ 15th February meeting.

- the creation of an advisory group for Decision Support Service made up of disabled people and others likely to be affected by the Act and their representation on the Mental Health Commission Board.
 - creation of paid roles within the Decision Support Service for community engagement.
2. The Department and the DSS should arrange for meaningful engagement with relevant persons on Heads 62, 66 and 67 with a view to redrafting them with clearer privacy and consent protections, to align them with the UNCRPD.
3. People should have the option to have hearings heard in camera under all parts of the Act in line with their will and preferences. This should not prevent bona fide reporting on hearings by journalists and researchers, if anonymity is preserved, as occurs in comparable situations.
4. There should be some judicial discretion given to the judge to have an input into determining whether cases are heard in public or private.
5. The guiding principles should always apply to everybody interacting with a relevant person, especially the principle that only a court should have the right to remove decision-making capacity.
6. The definition of intervener should be broadened so as to widen the applicability of the guiding principles and to remove uncertainty regarding the scope of the application of the Act.
7. The Bill should explicitly reference the UNCRPD and specific articles therein, especially Article 12 and General Comment No. 1 of the UNCRPD.
8. The Bill should adopt the UNCRPD understanding of disability, especially concerning eligibility for jury service and in the appointment of the advisory committee to assist and advise IHREC.

9. The Bill should be based on a human rights-based approach and should adopt the social model of disability.

10. The draft codes need to be revised before commencement to reflect it is only the courts that have the power to declare that someone lacks capacity.

11. The Bill should remove the functional test of capacity and replace this with an obligation to acknowledge, interpret and act upon the relevant person's will and preferences, in line with the UN Convention on the Rights of Persons with Disabilities.

12. The Bill should explicitly reference the need for resources to enable individuals exercise their 'will and preference' and free-of-charge supports to empower disabled people to make decisions, such as Irish Sign Language, independent living Personal Assistance Services (PAS), peer advocates and collective disabled person-led spaces.

13. Relevant persons' rights of recourse to the courts following refusal to consent to a capacity assessment or following dispute of the findings of a capacity assessment need to be made very clear.

14. The Bill should remove substitute decision-making.

15. Removal of the Act's reliance on the functional assessment of mental capacity.

16. The ADMC Bill needs to recognise the intersection of impairment label, gender and gender identity, sexual orientation, socioeconomic status, family status, ethnicity, marital status, religion and age, especially in the function of the DSS and concerning the appointment of the advisory committee to assist and advise IHREC.

17. The use of alternative and augmentative modes of communications (AAC), total communication, and other recognised forms of non-traditional communication should be better incorporated in the codes and the Bill.

2. Consultation, Language and Accessibility

Engagement and Consultation

A significant number of stakeholders highlighted that there was no public process organised by the Department to engage with DPOs, family carers or other relevant persons and that there is no plain English or easy-to-read version of the Bill. Furthermore, the 2015 Act is not available in an easy-to-read format. Comparably, the lack of sufficient consultation by the DSS in drawing up the draft codes of practice was criticised¹⁵. Unfortunately, the consultation on the Codes of Practice by the 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.

The difficulties around the scrutiny of a Bill amending an Act that has not yet commenced were well vented, as well as the challenging timelines to meet what some considered an arbitrary June deadline. Stakeholders urged the Committee to try to address these issues in relation to this Bill, but also as a broader issue in terms of the accessibility of legislation, and legislative development generally.

In response to these issues, the Department said they view the consultation the Committee undertook with DPOs as part of its pre-legislative scrutiny as important, are willing to answer queries on the Bill and see this legislation as part of a long-standing consultation process. The original consultation on the initial draft capacity legislation was undertaken a decade ago¹⁶.

It was consistently highlighted during pre-legislative scrutiny that, under Article 4 of the UNCRPD, the State has an obligation to proactively engage with the disability representative

¹⁵ See for example Dr. Alison Harnett, 15th February meeting.

¹⁶ From Oireachtas Library & Research Service [Bills Digest](#): “In late 2011 the Joint Committee on Justice, Defence and Equality received over 70 submissions from stakeholders on the mental capacity legislation, in an initiative to inform the drafting of the Bill. On 22nd and 29th February 2012, the Committee also met with a number of stakeholders. Some of the content of these submissions, as well as the input from these meetings, is included in this Bills Digest. The Committee published their report on the Bill in May 2012.”

organisations and disabled people. This means meaningfully involving them throughout the process. IHREC cautioned that:

“the committee’s pre-legislative scrutiny with disability rights groups and disabled people’s organisations... must not be seen as job done... It is critical that this process is in line with general comment No. 7, directly and in an accessible way to engage disabled people and our organisations, and also recognising that under general comment No. 7 there is a role for family voices as well.”¹⁷

The Committee extended the deadline for submissions twice in an effort to get the voices of relevant persons and others heard during the pre-legislative scrutiny process. Timelines for stakeholders and for the Committee were none-the-less extremely tight. In the context of the voluminous piece of legislation at hand, the profound impact it will have on people’s lives and our obligations under the UNCRPD, meaningful opportunities for input are essential. Legislation of this kind requires a collaborative approach to succeed, that involves relevant persons, families, carers, service providers and any other groups in wider society, as needed. As such, the Committee makes several recommendations aimed at including these voices in the process going forward. If implemented, these recommendations will help to implement lessons learnt, remedy any unintended consequences and ensure the legislation is effective.

Another obstacle both the Committee and stakeholders encountered, when considering this legislation, was that key elements are not yet ready or resolved. Valid concerns were raised about the lack of accessible resources, the sparsity of examples in the draft codes, the absence of deprivation of liberty safeguards, inconsistencies with the reform of the Mental Health Act and outdated references to deleterious effect on the unborn. The responses received were that these items are being looked at, receiving attention, in development, or are the responsibility of another department. It is difficult to scrutinise and strengthen a legislative framework with these kinds of gaps. It also creates nervousness among those who may be affected by the as-of-yet unresolved issues.

¹⁷ 16th February meeting.

Going forward, with legislation of this kind, more needs to be done to better coordinate inputs and actions across relevant departments and bodies. This will enable more meaningful input into the process and the formation of more robust legislation. As regards this Bill, these outstanding issues need to be addressed as a priority and well in advance of the June deadline for commencement. Furthermore, stakeholders should be kept informed on progress in these areas, as the earlier opportunities for engagement and consultation appear to have been missed. This process has given an opportunity for learning on how to ensure disabled people are enabled to actively take part in consultative processes on legislation. The Committee recommends linking with the Disability Matters Committee and Sub-Committee on Mental Health to see how best to ensure accessible and inclusive processes of consultation (as per our obligations under Article 4.3 of the UNCRPD).

Language and Accessibility

The importance of recognising different forms of communication, particularly in the case of those sometimes referred to as non-verbal, was discussed in the section on the presumption of capacity and protecting will and preference. Communication is at the heart of this Bill. Recognition of various ways different people communicate, learn and take in information will be key to its success. Unfortunately, accessible resources about the Bill are lacking. While commitments have now been made by the Department and the DSS to provide more accessible resources going forward, it is too late for many who would have wished to engage with the relevant submissions processes or get a sense of the forthcoming legislation early on.

The Committee heard from several individuals and organisations that the development of this Bill has not been an accessible process, which has further hampered meaningful engagement. The timing and nature of consultations can impact accessibility. Mr. Joe McGrath of the National Platform of Self Advocates explained how relevant persons have been impacted by this as follows:

“we were in lockdown for two years and some of us do not have Internet in our homes. How can we get on to the website of a support service or whatever other website is available to us when we do not have Internet in our houses or anything like that? Some of us need to meet face to face and if some members have access to technology, they can educate others about the Bill. There needs to be proper consultation with advocates, parents and a good number of others who have a stake in this. There is no point in people debating in the Dáil what should be in the law if they do not consult the groups. They would be wasting their time and would have to rewrite the legislation in ten years’ time, even if I have retired from advocacy work.”¹⁸

The digital divide and the need for alternatives to computer-based interaction with the DSS was a recurring theme during the pre-legislative scrutiny hearings and in the submissions received. The CDLP, for example, suggested that even a requirement for an online registration or a MyGovID could cause many to abandon efforts to engage with the DSS. Many stakeholders cautioned that computer-based systems won’t work for everybody. The DSS acknowledged these potential issues and committed to providing manual or paper-based alternatives where needed. This is welcome.

The Committee heard, and supports, calls for a selection of explanatory videos, easy-to-read, Irish Sign Language and Plain English resources, FAQ documents and a large body of examples or vignettes that take account of the diverse and complex situations those affected by the legislation may encounter. It is important that the Decision Support Service has ample resources to make these available. This issue is explored in Key issue three.

A number of specific examples of language within the Bill that needs attention were flagged in submissions to the Committee. The section which proposes to bring the Juries Act in line with the 2015 Act, for example, includes references to ‘mental or intellectual capacity’. This is inconsistent with the 2015 Act. The language throughout the Bill should be consistent with

¹⁸ 15th February meeting.

the initial presumption of everyone's capacity and the understanding that capacity can vary over time, in line with its core principles. Safeguarding Ireland suggested that 'lacks capacity' may better align with the conception of capacity as time specific than 'has lost capacity' which does appear in the Bill a number of times.

RECOMMENDATIONS

The Committee recommends:

18. Linking with the Disability Matters Committee and Sub-Committee on Mental Health to see how best to ensure accessible and inclusive processes of consultation (as per our obligations under Article 4.3 of the UNCRPD).

19. The outstanding issues flagged in this section need to be addressed as a priority and well in advance of the June deadline for commencement.

20. An accessible, multi-stakeholder revision of the draft Codes must occur before commencement. This process must be carried out in conjunction with DPOs.

21. All Bills published should be accompanied by an easy-to-read, Irish Sign Language and Plain English summary.

22. Every effort should be made by Government Departments, in compliance with the Public Sector Equality and Human Rights Duty, to carry out meaningful engagement with those directly affected by legislation prior to publication. In the case of legislation impacting disabled people, it should be developed in line with the UNCRPD.

23. Reliance on a decade old public consultation for this Bill or another piece of legislation is inappropriate.

24. Accessibility and ease of use must be central to the Bill's provisions and interacting with the DSS, including the provision of non-digital routes and the removal of the requirement to

have a MyGovID to register with and use DSS. The Department and DSS should work with DPOs in developing these routes and accessibilities.

25. The Bill must reflect the approach in the 2015 Act that only the court is empowered to declare a person to lack capacity. The 2015 Act does not confer this authority on anyone else, and the Bill must not allow for third parties to conduct assessments of capacity on individuals which lead to a restriction of their rights, or a refusal to respect a decision the individual has made.

26. The Bill should place a duty on the Minister to meaningfully consult and actively engage with disabled people and DPOs in the implementation and monitoring of the Act.

27. The Bill should amend the proposed language on eligibility for jury service in line with the recommendations of the Law Reform Commission report to be inclusive of a broader range of disabled people and to avoid the use of impairment-based language such as “mental or intellectual capacity” which is discriminatory and inconsistent with the 2015 Act.

3. Costs, Capacity Building and Resources

The previous two sections underlined the centrality of will and preference to this legislation and the need to involve relevant stakeholders meaningfully and accessibly. When such involvement is in place it leads to stronger legislation and better use of resources. The transformational potential of the Bill will only be fully realised, however, if it is sufficiently resourced from the outset. Given the scale of resources required to firstly build awareness of the legislation, secondly build relevant persons capacity to engage in decision-making and thirdly make their choices a reality on the ground, the Committee recommends an impact assessment is carried out at the outset.

Two areas in need of resourcing that initially come to mind when considering capacity assessments are the health service and the courts. Some stakeholders, such as the HSE and Safeguarding Ireland, see the requirement for two capacity assessments in some instances as

potentially unworkable and suggest an amendment to allow either a doctor or another healthcare professional to undertake one assessment.

Living arrangements

Choices about where to live were cited as perhaps the most important to relevant persons during pre-legislative scrutiny, but also as an example of the need to match the provisions of the ADMCA Bill with resources on the ground. A report entitled *“Time to Move on from Congregated Settings”* was published in 2011 by the Working Group on Congregated Settings and provided an ambitious roadmap for giving people living in congregated settings opportunities to live as independently as possible within communities. It made community living a reality for many, yet, in 2019 HIQA reported that 2914 people were resident in congregated settings¹⁹. On the need for resources to make choice a reality, Dr. Alison Harnett, of the National Federation of Voluntary Service Providers informed the Committee:

*“Without access to options, choice cannot be meaningful. For instance, the choice of where and with whom we live is a fundamental life decision. It is an area in which access to will and preference is essential, as set out in Article 19 of the UNCRPD. Today, more than 2,000 people with intellectual disability remain living in institutional or congregated settings and more than 1,000 people under the age of 65 are inappropriately living in nursing homes for elderly people. There are many more people with intellectual disabilities who have not chosen where or with whom they live, and many express significant distress on a daily basis due to the incompatibility of those living together. The funding and resourcing of the required supports to meaningfully address the rights-based approach to providing choice to people with disabilities across living, education, employment and other areas must be considered in the planning for the implementation of this Act, as this will be a key driver of access to will and preference for people with intellectual disabilities.”*²⁰

¹⁹ HIQA News, Issue 35 February 2020

²⁰ 15th February meeting.

These issues were explored in depth in a recent report by the Joint Committee on Disability Matters on the UNCRPD and ensuring independent living²¹.

Capacity Building and Resources

Providing real options about where to live shows somewhat the scale of investment that will be needed to realise the choices this legislation aims to enable. First though, all stakeholders will need to be made aware of the new provisions under the legislation and how to empower relevant persons to avail of them, which will require a campaign of awareness-raising, support, training, and education for relevant persons, their families and carers and service providers. This will need to have national reach and be resourced accordingly. The Committee heard worrying examples of those who will be interacting with the Bill not understanding its implications. This will risk leaving all involved, but especially relevant persons, open to misinterpretations of the law and the unintended consequence of disempowerment. Safeguarding against these risks by providing really good supports and information to those operating under the Bill is crucial. The DSS draft codes will be one important resource in this regard, and the Committee supports calls for these to be strengthened to include more numerous and detailed examples for those operating under the Bill to refer to.

Despite these risks, the Committee heard some great examples of knowledge building around the Bill already underway and a great willingness generally to embrace the culture change it involves. The DSS told the Committee they had recently engaged with 78 different organisations including many who came before the Committee. The National Office for Human Rights and Equality Policy within the HSE has delivered information and briefing sessions on the Act to over 10,000 staff since 2016, despite not receiving any resources for this additional work. During the Committee's call for submissions, the Irish Penal Reform Trust and the Irish Banking Culture Board made submissions to the Committee regarding the Bill's provisions for their service users in the prison and banking arenas, respectively. Dialog and training on the legislation with these sectors, and others as appropriate, should begin prior to commencement of the legislation.

²¹ [Joint Committee on Disability Matters – Ensuring Independent Living and the United Nations Convention on the Rights of Persons with Disabilities – March 2022 \(oireachtas.ie\)](https://www.oireachtas.ie/en/jointcommittees/disabilitymatters/reports/2022/03/01/joint-committee-on-disability-matters-ensuring-independent-living-and-the-united-nations-convention-on-the-rights-of-persons-with-disabilities-march-2022/)

As discussed in Key issue one, capacity building will be key to centring will and preference in decision-making by relevant persons. The Bill creates an onus on those interacting with a relevant person to be aware of their responsibilities under the legislation, to support the relevant person as much as possible to make their own decisions and to assess capacity on an issue and time-specific basis only where necessary. Everybody who interacts with a relevant person in this regard will need to be resourced appropriately in terms of having the time and information needed to engage in building capacity and in implementing the Bill. The impact assessment must take account of the breadth of resources required to give those working with relevant persons, for example in day centres, the time and know-how for this important work. Those working in the care and disability sectors are already dealing with a lack of resources and this legislation must not add to those challenges.

Paid staff, such as those working in day centres or residential units, cannot take on decision supporter roles under the legislation. Many of those who may seek decision support live in institutional settings where they mainly interact with paid staff. A DSS panel of decision-making representatives is provided for, which the court can appoint a decision-making representative from, for someone who does not have a suitable person known to them who can undertake that role. There is no such panel provided for the two lower scale decision supporters, namely decision-making assistants or co-decision-makers. The Committee heard well-placed fears that individuals, especially in residential settings, lacking traditional contacts such as friends and family, may be pushed further up the scale of decision supporters as a consequence. This would be more restrictive than the spirit of the Act. It is possible that for many other reasons, a relevant person may not have a contact available to them for decision support, but that they would not require as restrictive a support arrangement as a decision-making representative. The Committee therefore recommends that panels are established for the two other levels of decision-making support also or that the Bill be amended to allow certain staff be decision-supporters, only in instances where the relevant person has no other supports and has already built up a relationship of trust and effective communication with the worker.

Independent Advocates

The need for statutory recognition of independent advocates was a common thread in the submissions the Committee received. The DSS acknowledges that advocates have an important capacity building and safeguarding role to play. This role is also acknowledged elsewhere by HIQA. Independent advocates are to be provided with a code of practice under the Act, and a draft of this was published by the DSS in January. In their submission, the National Advocacy Service propose several amendments necessary if they are to provide this service, which they say England and Wales have established to support people who are availing of decision-making supports. Mental Health Reform, the HSE, and multiple advocacy organisations who made submissions to the Committee favour an explicit right of access to an independent advocate on a statutory footing. The Committee recommends including a definition of advocacy within the Bill and a provision establishing a general right of relevant persons to an independent advocate. This role will have to be carefully defined, with consideration given to the access to information advocates would require. Their work should be guided by quality standards, robust policies and guidelines.

Family Carers

While the Bill offers a sea-change for relevant persons, it is important that family carers do not get left behind. Tailored supports for family carers, financial and otherwise, should be made available. Family Carers Ireland highlighted that Head 25 provides for the payment of expenses and remuneration of decision-making representatives appointed by the court from the DSS panel, in cases where the court orders that these cannot be met from the assets of the relevant person. The Committee heard the challenges carers face in terms of how little support is offered by carer's allowance, and the conditions around qualifying. A study on the cost of caring was suggested. The Committee supports a review of the carers allowance and innovations that reduce the bureaucratic barriers carers face.

Family Carers Ireland expressed deep apprehensions about how to potentially deal with unwise decisions those they care for make and sought a transitional arrangement within which to implement the Bill's provisions. Some of these worries may stem from an impression that as soon as the Bill is enacted everybody will be mandated to go to court and formalise

their family care arrangement immediately. The DSS provided some reassurances to the contrary at the second public hearing on the Bill and aims to provide better reassurance to family carers on this going forward. Supportive engagement with family carers, which provides spaces for them to express their concerns and opportunities to thoroughly inform them about the Bill's implications will be crucial.

The Committee heard that many family carers are themselves elderly, which poses challenges in terms of the administrative burden of a formalised decision support arrangement and the potential need to interact with services such as the DSS online. The DSS has expressed a willingness to provide paper-based workarounds where needed. Furthermore, the Committee's recommendation for a panel of each three tiers of decision supporters to be made available, as opposed to just decision-making representatives, should help alleviate some of these fears, if implemented. The legislation may make it easier for elderly family carers to ask another contact to act as a decision-making support to them or a relevant person, as it provides a framework for doing so. Family carers of all ages and abilities are an invaluable resource. Their importance in the lives of relevant persons cannot be underestimated and they too must be minded. Supports for family carers should be advertised in all publicity and awareness campaigns around the Bill.

Costs and Fees

A wide variety of stakeholders emphasised the need to keep costs and fees for those operating under the Bill to an absolute minimum. The financial challenges faced by many stakeholders in this field are well known. Even nominal fees could deter interactions with the legislation. Fees for creating, amending, or revoking decision support arrangements, for example, should be avoided, as they could have the unintended consequence of keeping people in inappropriate decision support arrangements. Similarly, the provisions of legal aid should also be extended to as many parts of the Act as possible. Minimising costs and fees will act as an important safeguard for people who may need access to the Bills provisions. As discussed in relation to family carers, the distinction made between decision-making representatives appointed from the DSS panel and those known to relevant persons

personally may be counterproductive. It may deter people whom relevant persons know and are comfortable with from taking on decision supporter roles.

RECOMMENDATIONS

The Committee recommends:

28. An impact assessment on the resources required to fund and staff all aspects of the Bill should be carried out immediately.

29. Further legislative and programmatic reforms are required to ensure that the decisions made under the 2015 Act and the 2021 Bill (including decisions about where and with whom to live) are appropriately resourced so that the person's will and preferences are respected in practice.

30. The Department of Children, Equality, Disability, Integration and Youth and the Decision Support Service must engage meaningfully with DPOs and those most impacted by the 2015 Act, in the roll-out of a national campaign of awareness-raising, support, training, and education for all relevant stakeholders. Such a campaign must not be restricted to the commencement of the 2015 Act but must include a long-term commitment to public legal education on supported decision-making and human rights.

31. Supports for carers, family members, and potential supporters should be advertised in all publicity and awareness campaigns around the Bill.

32. The DSS must progress and intensify meaningful engagement with DPOs and other stakeholders in the development of guidance resources and must assign the necessary resources to achieve this in a timely manner.

33. The DSS must be sufficiently resourced to develop, in conjunction with DPOs, a wide range of resources for those seeking to understand the Bill, including a selection of explainer videos, easy-to-read, Irish Sign Language and Plain English resources, FAQ documents and a large

body of examples or vignettes that take account of the diverse and complex situations those affected by the legislation may encounter.

34. The Bill should amend the 2015 Act to provide for the development of panels of decision-making assistants and co-decision-makers. In so doing, it is crucial to broaden the criteria for panel membership, in contrast with the current approach which restricts panel membership to members of specified professional bodies with independent access to professional indemnity insurance. Such a restrictive approach excludes many qualified individuals who have deep understanding and extensive skills in interpreting an individual's will and preference. To address concerns about indemnity, the Bill could include a further amendment to the 2015 Act to extend liability protection to interveners who in good faith respect the relevant person's will and preferences.

35. Independent advocacy should be defined in the Bill and a provision should be inserted establishing a general right of relevant persons to independent advocates, whose work should be guided by quality standards, robust policies and guidelines which are centred on respecting a relevant person's will and preferences. This must include legislative powers for advocates to carry out their role in line with the person's will and preferences. Further legislation will be required to extend a right to advocacy to all disabled people and not just relevant persons within the meaning of the 2015 Act.

36. Supportive engagement with individuals affected by the bill, carers, family members, and potential supporters should continue, and resources must be made available for these individuals and groups to discuss their concerns and become thoroughly informed about the Bill's implications.

37. The provision of legal aid should also be extended to as many parts of the Act as possible. Supports should be available as part of all alternative dispute resolution processes.

38. There should be no cost to create, amend or revoke a decision support arrangement under the Act. Costs and fees for other areas should be kept to an absolute minimum and the

Decision Support Service should have the discretion to waive fees for relevant persons to access documents or records where necessary.

4. Mental Health

Those with long-term mental health difficulties, also known as psychosocial disabilities, are protected under the UNCRPD and will need access to the Bill's provisions. It is important to remember this cohort in the development and implementation of the legislation. Resources such as the DSS codes or guides will need to include comprehensive and different scenarios which take account of those experiencing mental health difficulties.

Reform of the Mental Health Acts is ongoing. Mental Health Reform, along with many other stakeholders, highlighted the need for alignment between this Bill and the Mental Health Acts to ensure that there are no contradictions between the two and that access to the supports available under the 2015 Act cannot be withheld from persons in mental health settings. The Committee was told this is currently being worked on. In their submission, the DSS summarise some of the key changes required for that alignment to work and provide reassurance that "the General Scheme to amend the Mental Health Acts, to which the MHC has made detailed contributions envisages that decision supports under the 2015 Act will be available on an equal basis to all persons in the mental health setting."²²

There is a possibility that while the Mental Health Act 2001 is being reformed a lacuna will exist for those in need of decision-making supports. There is a need to amend Sections 85(7) and 136 of the 2015 Act to extend provisions of the 2015 Act to people involuntarily detained under the Mental Health Act and under the Criminal Law (Insanity) Act. The amendment Bill to amend the 2015 Assisted Decision-Making (Capacity) Act 2015 does not currently apply to people involuntarily detained under Part 4 of the Mental Health Act.

Another issue raised frequently in relation to aligning these two Bills was their treatment of 16- and 17-year-olds. The Mental Health (Amendment) Bill 2021 will provide for the

²² DSS Submission

presumption of capacity for 16- and 17-year-olds to consent to mental health treatment²³. This will bring parity between mental health and physical health on consent, as the Non-Fatal Offences against the Person Act provides for people of those ages to consent to medical treatment. Stakeholders recommended that the Bill under discussion here should be amended to reflect this also. Mental Health Reform suggested “either amending section 84 of Part 8 of the amendment Bill to provide that 16- and 17-year-olds could make those decisions or including in the amendment Bill an amendment to the Non-Fatal Offences Against the Person Act, given that it provides for small technical amendments to five or six Acts.”²⁴ The ISPCC submitted to the Committee that it is imperative, in the context of this Bill, that the rights of children and young people (16- & 17-year-olds) to consent to or refuse treatment for their mental health are vindicated. The Committee recommends that these issues are addressed as a priority.

RECOMMENDATIONS

The Committee recommends:

39. The DSS codes or guides will need to include comprehensive and different scenarios which take account of those experiencing mental health difficulties.

40. There must be careful alignment between the Assisted Decision-Making (Capacity) (Amendment) Bill 2021 and the Mental Health Acts which upholds the person’s human rights, respects their will and preferences and ensures access to support in accordance with the UNCRPD including when involuntarily detained. The Committee recommends amending Sections 85(7) and 136 of the 2015 Act to extend provisions of the 2015 Act to people involuntarily detained under Part 4 of the Mental Health Act 2001 and the Criminal Law (Insanity) Act.

²³ [Joint Sub-Committee on Mental Health debate - Tuesday, 2 Nov 2021 \(oireachtas.ie\)](https://www.oireachtas.ie/en/debates/joint-sub-committee-on-mental-health-debate-tuesday-2-nov-2021/)

²⁴ 15th February meeting.

41. The Bill should include provisions for 16- and 17-year-olds to make decisions about their healthcare treatment, including mental health treatment, which align with those in development as part of the reform of the Mental Health Act.

5. People who are Involuntarily Detained, Protection of Liberty Safeguards and Restraint

People who are Involuntarily Detained

Three main issues associated with people who are involuntarily detained arose during pre-legislative scrutiny. Firstly, concerns were raised that the decision-making supports the Bill provides may not be provided to persons detained under the Mental Health Acts. This was discussed in key issue four.

Secondly, concerns were raised in relation to Advance Healthcare Directives (AHDs) and the involuntarily detained. Currently, under section 85(7) of the 2015 Act, an AHD will not be complied with insofar as it relates to the refusal of mental health treatment if the directive-maker is detained under the Mental Health Acts. As pointed out by several stakeholders, this exception does not take account of parity between physical and mental health. The Department informed that Committee that, if possible, it will also be addressed during Committee Stage consideration of the Bill. It is absolutely necessary that this is rectified.

Thirdly, issues were raised in relation to Part 10 of the 2015 Act, which deals with detention matters, including the detention of wards. IHREC flagged that there is a lack of clarity around legal representation, time frames and the right to appeal. The Mental Health Act 2001 was referenced as an example of strong provisions on these fronts, which could be drawn on. The DSS informed the Committee that those parts of the Act are still under review and that they expect to see them improved.

In their submission to the Committee, the Irish Penal Reform Trust (IPRT) outlined the prevalence of disabilities among those detained in prison. It is estimated that almost one in three prisoners have intellectual disabilities, for example. The prevalence of severe mental health difficulties among the prison population is estimated to be four times that of the

general population. On consideration of this data, it becomes clear that people detained in prison are potentially some of the most likely to need to draw on the provisions of this Bill. Many prisoners go on to be transferred to the Central Mental Hospital. The overlap, in terms of stays in multiple institutions, by those seeking asylum, experiencing mental health issues, in homelessness, with disabilities and with a history of interaction with the criminal justice system is well documented²⁵. This taps into some of the broader challenges around efforts to decongregate vulnerable people from institutions, and the potential framework this Bill can provide, with its focus on choice, support and participation.

These issues will be key to determining not only how effectively the act works, but also how vulnerable people are treated while involuntarily detained. Their development should have been coordinated across Departments to the June deadline. As highlighted in key issue two, the fact that they are not yet available hampers effective scrutiny and input by the Committee and other stakeholders. They need to be prioritised so that there are no legislative gaps or lacunas and no one who should be protected by the legislation gets left behind.

Protection of Liberty Safeguards

The right to liberty has strong high-level protections, including in the Constitution, the European Convention of Human Rights (ECHR) and the UNCRPD. However, national legislation relating to vulnerable adults and their personal freedom is lacking. The Courts have pointed out the urgent need for protection of liberty legislation to be passed by the Oireachtas²⁶. In 2018, priority drafting was approved for a Bill to deal with the protection of liberty. The Department of Health carried out an initial consultation, which they published a report on²⁷. Progress has since stalled. Several stakeholders cautioned that, in the context the Bill under discussion here, actual protection of liberty legislation is urgently needed. In their submission, the HSE provides detail on the implications of this legal gap, the potential breaches of Constitutional and ECHR rights it entails and how this could worsen once this Bill is enacted.

²⁵ See for example Professor Gulati on trans-institutionalisation here: [Joint Committee on Disability Matters debate - Thursday, 1 Jul 2021 \(oireachtas.ie\)](#)

²⁶ [notes-on-ac-v-cork-university-hospital.pdf \(sageadvocacy.ie\)](#)

²⁷ [gov.ie - The Deprivation of Liberty Safeguard Proposals: Report on the Public Consultation \(www.gov.ie\)](#)

Restraint

Heads 27 and 41 delete provisions relating to the use of restraint by decision supporters in private settings. This will not include the use of restraint in institutional settings, which will continue to be governed by relevant legislation and guidelines. However, recommendation 92 of the national mental health policy, *Sharing the Vision*, states that Ireland will move towards a ‘zero restraint, zero seclusion’ model of care. Multiple DPOs and several other stakeholders cautioned against having nothing there in place of these Heads. They propose that a clear ban on restraint is required, as, if the Bill says nothing about restraint, it could be perceived as authorised. The CDLP described the issue as follows:

“one of the issues with removing all reference to restraint from the legislation, as proposed in the Heads, is that if the Act is silent on restraint people may interpret a power to restrain where there is, in fact, none. One option that should be given consideration would be to say that nothing in this Act provides any authority for an intervener under the legislation to authorise restraint, whether mechanical or chemical on a relevant person. While we are waiting, as a placeholder for further legislation in respect of protection of the right to liberty, having such a placeholder statement in the amendment to the legislation would be helpful in terms of guidance on the ground.”²⁸

There was a discussion of current practices around the use of restraint on relevant persons by family carers and others. The Committee has concerns that insufficient support and expenditure is currently available for the roll-out and development of alternatives to restraint, which are necessary in the context of human rights compliance and our obligations under the UNCRPD.

The Committee recognises all individuals’ equal right to liberty and the importance of the Assisted Decision-Making Capacity Act in upholding these fundamental human rights by ensuring that no additional powers of restraint are granted for use on relevant persons

²⁸ 16th February meeting.

beyond those which already exist in common law for all persons, without discrimination on the basis of disability.

However, it is essential that sufficient resources be made available to ensure that these rights can be meaningfully realised and that safe and appropriate alternatives to restraint can be used when necessary to ensure the safety of the relevant person, their family members and their carers. For example, mechanical devices such as motion sensors or alarms that go off when someone exits their bed at night may be required in certain situations to ensure the safety of a relevant person without infringing on their fundamental right to liberty and freedom from degrading treatment. Relevant persons have a right to dignity and any discourse around the use of restraints or deprivation of liberty should be cognisant of that.

It is vital that the UNCRPD is central to this legislation. The UNCRPD places an obligation on States to ensure that disabled people have an equal right to liberty/freedom from restraint as anyone else and states clearly that "the existence of a disability shall in no case justify a deprivation of liberty" (Article 14 – Liberty and security of person). Granting or allowing additional powers of restraint under the law, against certain individuals, on the grounds of disability, may also be in breach of several other Articles of the UNCRPD as well as having implications in relation to Articles 3, 8 & 14 of the European Convention on Human Rights.

RECOMMENDATIONS

The Committee recommends:

42. Advance healthcare directives should be extended to people in all healthcare settings including those detained in hospital for mental health treatment and all pregnant people.

43. The provisions around legal representation, time frames and the right to appeal under part 10 of the Act need to be strengthened, including for wards.

44. Arrangements must be made for those in prison and other institutions to access the Bill's provisions.

45. Protection of liberty legislation which respects a person's right to liberty under Article 14 UNCRPD must be urgently progressed. A person's liberty must never be denied on the basis of an assessment of their capacity.

46. Explicit prohibition of chemical and mechanical restraint is necessary to meet our obligations under the UNCRPD and other human right's instruments.

47. The Bill should clarify that nothing in this act shall permit interveners to use either chemical or mechanical restraint. No one should be subject to the use of chemical or mechanical restraint on the basis of an assessment of their capacity.

48. No additional powers of restraint for use in order to ensure equal right to liberty.

49. Sufficient resources need to be made available so that this right can be meaningfully realised while ensuring the safety of the relevant person, their family and carer.

50. Family carers and others interacting with relevant persons should have access to appropriate training on avoiding the use of restraint and be properly resourced, supported and provided with alternatives to restraint.

6. Advance Healthcare Directives and Enduring Power of Attorneys

As discussed in key issue four, the issue most widely flagged by stakeholders about Advance Healthcare Directives (AHDs) was the need to enable them to apply to people who are detained in hospital for mental health treatment. There was widespread support for a register of AHDs, which the DSS are ready and willing to maintain, once regulations are put in place.

Another issue raised frequently by stakeholders in relation to AHDs are the provisions in the 2015 Act which limit the applicability of AHDs to pregnant women. These provisions pre-date the repeal of the eighth amendment and must be deleted. The CDLP outlined the areas in need of attention as follows:

“Section 85(6)...states ‘Where a directive-maker lacks capacity and is pregnant, but...does not specifically state whether or not she intended a specific refusal of treatment set out in the directive to apply if she were pregnant...the refusal of treatment would have a deleterious effect on the unborn, there shall be a presumption that treatment shall be provided or continued.’ Similarly, there is a provision that even where the directive-maker has explicitly said he or she wants the refusal to apply where they are pregnant, even if it “would have a deleterious effect on the unborn”, that cannot be respected without further application to the High Court to determine the validity of the refusal of treatment.”²⁹

The most widely opposed measure in relation to Enduring Power of Attorneys (EPAs) was the proposed removal of treatment decisions. This proposal received widespread criticism. DPOs, legal experts, advocacy organisations and others argued that this would be less accessible, more complex and inefficient. It was put that it will discourage people from using EPAs and increase costs, as those who wish to have the full range of their advance wishes protected will have to make two arrangements: an EPA and an AHD. The Committee was informed that EPAs are efficient, in that they have been found to save the state money and time, and so should be encouraged. On this basis the Committee heard calls for legal aid to be made available for EPAs.

The Committee was informed that the intention of the measure was to make things easier for those creating the instruments, and, currently in the Bill, EPAs cannot extend to a refusal of life-sustaining treatment, whereas AHDs can. The CDLP suggested that a

²⁹ 16th February meeting.

preferable fix, would be to amend the provisions on EPAs, to clarify that if a person gives that explicit power to individuals, they are free to carry out their wishes, including decisions around refusal of life-sustaining treatment.

Similar concerns to those raised about the removal of treatment decisions arose in relation to the new two-step process for registering an EPA, whereby an EPA is to be registered with the DSS while the donor has capacity (stage one) and then comes into effect when the attorney notifies the DSS that the donor lacks capacity (stage two). Legal experts advised against discussions about EPAs with the DSS, stating that this would breach solicitor client confidentiality.

The Committee heard concerns about the need for two statements of capacity - one by a registered medical professional, and one by a healthcare professional - for the creation, registration, revocation and variation of an EPA. Some stakeholders argued this is excessive and likely to be more costly to both the State and the relevant person. The HSE, in their submission, detail some of the difficulties this requirement creates. They caution that the requirement will make it unnecessarily difficult for people to put in place EPAs due to the lack of staff available to undertake these assessments on top of their day-to-day work, which could create a legal limbo for staff and people who are awaiting such an assessment. They warn that private groups of healthcare professionals could potentially emerge, at extra expense to the health service, to conduct assessments and that staff could be caught up doing assessments rather than interventions, as seen with the Assessment of Need processes. As discussed in key issue three, adequate resourcing of the courts and health service will be key to the Bill's success.

The Committee is aware that the need for two assessments is currently under review by the Department. However, other stakeholders have highlighted the need to diversify the power dynamics and that having two people assessing capacity will create greater safeguards for the relevant person. Legislation should be made for the need that exists

and not hindered by lack of resources. We should be making laws which put the need on the State to provide the necessary resources.

RECOMMENDATIONS

The Committee recommends:

51. There should be a provision in the Bill that gives responsibility and resources to maintain a register of AHDs to the DSS.

52. Health and medical treatment decisions should be retained in the scope of an Enduring Power of Attorney.

53. Removal of the two-step process for registering an EPA. Alternative approaches should be developed in conjunction with DPOs and other stakeholders, including those who made submissions to the Committee on this matter.

54. A repeal of section 85(6) is necessary to ensure that the rights of pregnant women/people are respected under this act.

55. Legal aid should be provided to those who create EPAs.

7. Accountability, Appeals, Complaints

Although assisted decision-making arrangements and an end to wardship have been discussed for some time, this legislation is a new and complex departure and is likely to profoundly change many lives. Safeguards in the form of strong accountability, appeals and complaints mechanisms are crucial in any legislation, but even more so in this context. In their submissions, IHREC and AsIAM detail some of the areas of the legislation that need strengthening in this regard and make some suggestions about how that could be achieved. IHREC informed the Committee:

“The 2015 Act and this general scheme only allows for a limited appeal on the many decisions that can be made on capacity and related issues, and on a point of law only. This compares unfavourably, for example, to the full right of appeal provided by section 19 of the Mental Health Act 2010.”³⁰

The importance of aligning this Bill with the ongoing reform of the Mental Health Acts has been discussed. The safeguards in this Bill should be equally robust as those in the mental health legislation.

Multiple stakeholders recommended that the provisions in relation to complaints should be strengthened by adding an option to avail of an alternative dispute resolution process, such as mediation. Others emphasised the importance of both independent advocacy and full legal aid being made available to those making complaints, especially during proceedings relating to a decision supporters’ role, or when a relevant person is applying to court to challenge the outcome of a complaint that the Director of the DSS dealt with.

There are provisions that build accountability into the Bill via changes to IHREC’s role. Head 85 will enable IHREC to act as *amicus curiae* (“friend of the court”) before the Court of Appeal, as well as before the High and Supreme Courts, as already provided for. It also creates a statutory basis for IHREC’s role in the monitoring framework in relation to the UNCRPD. While this is welcome, IHREC suggested that this could be further strengthened, as some of the language around monitoring has been weakened compared to that in the 2016 version of the Bill. The Committee was advised that:

“This Bill for example does not make explicit provision for the commission “to keep under review the adequacy and effectiveness of law and practice in the State relating to the protection of persons with disabilities”, whereas the previous amendment did. This Bill has deleted the word “protect” in the outlined tasks of the independent monitoring mechanism, compared to the previous amendment.

³⁰ 16th February meeting.

These proposed changes require further consideration to ensure that they do not give rise to a narrowing of the commission's independent monitoring mechanism role.”³¹

RECOMMENDATIONS

The Committee recommends:

56. The safeguards in this Bill, especially concerning the relevant person's will and preference, including accountability, appeals and complaints mechanisms should be strengthened.

57. An alternative dispute resolution process, such as mediation, should be made available at no cost for the relevant person.

58. Independent advocacy and legal aid should be made available to those making complaints relating to a decision supporters' role or when a relevant person is applying to court to challenge the outcome of a complaint that the Director of the DSS dealt with.

59. The provisions IHREC outlined from the 2016 version of the Bill, which provided a broader basis for its independent monitoring mechanism role, should be restored.

8. Wards

The abolition of wardship is long overdue. The Committee and those it engaged with welcome the end to this system, which is at odds with human rights norms. It is appreciated that, in large part, the drive to get this legislation commenced urgently stems from a want to spare those in wardship more time in that system. To this end, there has also been almost unanimous calls to shorten the period provided for all wards to transition out of wardship. Three years, as currently provided for, is a very long time.

³¹ 16th February meeting.

The Committee too, recommend that this is shortened. Innovative ways of resourcing and delivering this in a shorter period should be explored.

The need for better safeguards for wards under part 10 of the 2015 Act, in terms of clearer timeframes, rights to appeal and legal representation was discussed in key issue five.

Stakeholders stressed the importance of early, accessible and ongoing communication with wards as they go through the process set out under the Bill. The Committee was informed that the Office of Wards of Court has begun this communications process. It is also essential that wards have access to supports such as legal aid and independent advocacy³². It was brought to the Committee's attention that the Department of Justice has yet to finalise amendments relating to the Civil Legal Aid Act. It is important that the outstanding issue of legal aid for wards is resolved prior to commencement.

IHREC commented on the importance of ensuring that there is no residual wardship power through section nine of the Courts (Supplemental Provisions) Act 1961. They proposed that a sunset clause is introduced to the Bill "to ensure that the ending of wardship is entirely copper fastened and that there is no way back by any other route into a wardship system."³³

RECOMMENDATIONS

The Committee recommends:

60. The period provided for all wards to transition out of wardship should be shortened.

61. There must be early, accessible and ongoing communication with wards as they go through the process set out under the Bill and all efforts must be made to support them to build their decision-making capacity and explore options for support.

³² For more on wards and advocacy please see submission from the National Advocacy Service.

³³ 16th February meeting.

62. The provision of legal aid for wards must be addressed prior to commencement.

63. Alongside the existing sunset clause in the 2015 Act, a review of other legislation is required to ensure that all entry routes to wardship are removed.

9. IHREC

Several stakeholders expressed an opinion that it was unnecessary to add specific recognition of the National Disability Authority (NDA) in supporting IHREC to perform its functions, as proposed in this Head 81. There was a preference for creating an obligation on IHREC to meaningfully engage with disabled people directly and DPOs for this function.

RECOMMENDATIONS

The Committee recommends:

64. The Bill should oblige the Irish Human Rights and Equality Commission to engage with disabled people and DPOs in its monitoring role of the UNCRPD, rather than with the NDA exclusively.

RECOMMENDATIONS

1. There should be statutory requirement in the Bill which places a duty on the Decision Support Service to meaningfully consult and actively engage with disabled people and increases accountability. This should include:

- an obligation for a meaningfully inclusive consultation process on all Codes of Practice, guidance documents, forms etc.
- the creation of an advisory group for Decision Support Service made up of disabled people and others likely to be affected by the Act and their representation on the Mental Health Commission Board.
- creation of paid roles within the Decision Support Service for community engagement.

2. The Department and the DSS should arrange for meaningful engagement with relevant persons on Heads 62, 66 and 67 with a view to redrafting them with clearer privacy and consent protections, to align them with the UNCRPD.

3. People should have the option to have hearings heard in camera under all parts of the Act in line with their will and preferences. This should not prevent bona fide reporting on hearings by journalists and researchers, if anonymity is preserved, as occurs in comparable situations.

4. There should be some judicial discretion given to the judge to have an input into determining whether cases are heard in public or private.

5. The guiding principles should always apply to everybody interacting with a relevant person, especially the principle that only a court should have the right to remove decision making capacity.

6. The definition of intervener should be broadened so as to widen the applicability of the guiding principles and to remove uncertainty regarding the scope of the application of the Act.

7. The Bill should explicitly reference the UNCRPD and specific articles therein, especially Article 12 and General Comment No. 1 of the UNCRPD.
8. The Bill should adopt the UNCRPD understanding of disability, especially concerning eligibility for jury service and in the appointment of the advisory committee to assist and advise IHREC.
9. The Bill should be based on a human rights-based approach and should adopt the social model of disability.
10. The draft codes need to be revised before commencement to reflect it is only the courts that have the power to declare that someone lacks capacity.
11. The Bill should remove the functional test of capacity and replace this with an obligation to acknowledge, interpret and act upon the relevant person's will and preferences, in line with the UN Convention on the Rights of Persons with Disabilities.
12. The Bill should explicitly reference the need for resources to enable individuals exercise their 'will and preference' and free-of-charge supports to empower disabled people to make decisions, such as Irish Sign Language, independent living Personal Assistance Services (PAS), peer advocates and collective disabled person-led spaces.
13. Relevant persons' rights of recourse to the courts following refusal to consent to a capacity assessment or following dispute of the findings of a capacity assessment need to be made very clear.
14. The Bill should remove substitute decision-making.
15. Removal of the Act's reliance on the functional assessment of mental capacity.

16. The ADMC Bill needs to recognise the intersection of impairment label, gender and gender identity, sexual orientation, socioeconomic status, family status, ethnicity, marital status, religion and age, especially in the function of the DSS and concerning the appointment of the advisory committee to assist and advise IHREC.

17. The use of alternative and augmentative modes of communications (AAC), total communication, and other recognised forms of non-traditional communication should be better incorporated in the codes and the Bill.

18. Linking with the Disability Matters Committee and Sub-Committee on Mental Health to see how best to ensure accessible and inclusive processes of consultation (as per our obligations under Article 4.3 of the UNCRPD).

19. The outstanding issues flagged in this section need to be addressed as a priority and well in advance of the June deadline for commencement.

20. An accessible, multi-stakeholder revision of the draft Codes must occur before commencement. This process must be carried out in conjunction with DPOs.

21. All Bills published should be accompanied by an easy-to-read, Irish Sign Language and Plain English summary.

22. Every effort should be made by Government Departments, in compliance with the Public Sector Equality and Human Rights Duty, to carry out meaningful engagement with those directly affected by legislation prior to publication. In the case of legislation impacting disabled people, it should be developed in line with the UNCRPD.

23. Reliance on a decade old public consultation for this Bill or another piece of legislation is inappropriate.

24. Accessibility and ease of use must be central to the Bill's provisions and interacting with the DSS, including the provision of non-digital routes and the removal of the requirement to have a MyGovID to register with and use DSS. The Department and DSS should work with DPOs in developing these routes and accessibilities.

25. The Bill must reflect the approach in the 2015 Act that only the court is empowered to declare a person to lack capacity. The 2015 Act does not confer this authority on anyone else, and the Bill must not allow for third parties to conduct assessments of capacity on individuals which lead to a restriction of their rights, or a refusal to respect a decision the individual has made.

26. The Bill should place a duty on the Minister to meaningfully consult and actively engage with disabled people and DPOs in the implementation and monitoring of the Act.

27. The Bill should amend the proposed language on eligibility for jury service in line with the recommendations of the Law Reform Commission report to be inclusive of a broader range of disabled people and to avoid the use of impairment-based language such as "mental or intellectual capacity" which is discriminatory and inconsistent with the 2015 Act.

28. An impact assessment on the resources required to fund and staff all aspects of the Bill should be carried out immediately.

29. Further legislative and programmatic reforms are required to ensure that the decisions made under the 2015 Act and the 2021 Bill (including decisions about where and with whom to live) are appropriately resourced so that the person's will and preferences are respected in practice.

30. The Department of Children, Equality, Disability, Integration and Youth and the Decision Support Service must engage meaningfully with DPOs and those most impacted by the 2015 Act, in the roll-out of a national campaign of awareness-raising, support, training, and education for all relevant stakeholders. Such a campaign must not be restricted to the

commencement of the 2015 Act but must include a long-term commitment to public legal education on supported decision-making and human rights.

31. Supports for carers, family members, and potential supporters should be advertised in all publicity and awareness campaigns around the Bill.

32. The DSS must progress and intensify meaningful engagement with DPOs and other stakeholders in the development of guidance resources and must assign the necessary resources to achieve this in a timely manner.

33. The DSS must be sufficiently resourced to develop, in conjunction with DPOs, a wide range of resources for those seeking to understand the Bill, including a selection of explainer videos, easy-to-read, Irish Sign Language and Plain English resources, FAQ documents and a large body of examples or vignettes that take account of the diverse and complex situations those affected by the legislation may encounter.

34. The Bill should amend the 2015 Act to provide for the development of panels of decision-making assistants and co-decision-makers. In so doing, it is crucial to broaden the criteria for panel membership, in contrast with the current approach which restricts panel membership to members of specified professional bodies with independent access to professional indemnity insurance. Such a restrictive approach excludes many qualified individuals who have deep understanding and extensive skills in interpreting an individual's will and preference. To address concerns about indemnity, the Bill could include a further amendment to the 2015 Act to extend liability protection to interveners who in good faith respect the relevant person's will and preferences.

35. Independent advocacy should be defined in the Bill and a provision should be inserted establishing a general right of relevant persons to independent advocates, whose work should be guided by quality standards, robust policies and guidelines which are centred on respecting a relevant person's will and preferences. This must include legislative powers for advocates to carry out their role in line with the person's will and preferences. Further legislation will be

required to extend a right to advocacy to all disabled people and not just relevant persons within the meaning of the 2015 Act.

36. Supportive engagement with individuals affected by the bill, carers, family members, and potential supporters should continue, and resources must be made available for these individuals and groups to discuss their concerns and become thoroughly informed about the Bill's implications.

37. The provision of legal aid should also be extended to as many parts of the Act as possible. Supports should be available as part of all alternative dispute resolution processes.

38. There should be no cost to create, amend or revoke a decision support arrangement under the Act. Costs and fees for other areas should be kept to an absolute minimum and the Decision Support Service should have the discretion to waive fees for relevant persons to access documents or records where necessary.

39. The DSS codes or guides will need to include comprehensive and different scenarios which take account of those experiencing mental health difficulties.

40. There must be careful alignment between the Assisted Decision-Making (Capacity) (Amendment) Bill 2021 and the Mental Health Acts which upholds the person's human rights, respects their will and preferences and ensures access to support in accordance with the UNCRPD including when involuntarily detained. The Committee recommends amending Sections 85(7) and 136 of the 2015 Act to extend provisions of the 2015 Act to people involuntarily detained under Part 4 of the Mental Health Act 2001 and the Criminal Law (Insanity) Act.

41. The Bill should include provisions for 16- and 17-year-olds to make decisions about their healthcare treatment, including mental health treatment, which align with those in development as part of the reform of the Mental Health Act.

42. Advance healthcare directives should be extended to people in all healthcare settings including those detained in hospital for mental health treatment and all pregnant people.

43. The provisions around legal representation, time frames and the right to appeal under part 10 of the Act need to be strengthened, including for wards.

44. Arrangements must be made for those in prison and other institutions to access the Bill's provisions.

45. Protection of liberty legislation which respects a person's right to liberty under Article 14 UNCRPD must be urgently progressed. A person's liberty must never be denied on the basis of an assessment of their capacity.

46. Explicit prohibition of chemical and mechanical restraint is necessary to meet our obligations under the UNCRPD and other human right's instruments.

47. The Bill should clarify that nothing in this act shall permit interveners to use either chemical or mechanical restraint. No one should be subject to the use of chemical or mechanical restraint on the basis of an assessment of their capacity.

48. No additional powers of restraint for use in order to ensure equal right to liberty.

49. Sufficient resources need to be made available so that this right can be meaningfully realised while ensuring the safety of the relevant person, their family and carer.

50. Family carers and others interacting with relevant persons should have access to appropriate training on avoiding the use of restraint and be properly resourced, supported and provided with alternatives to restraint.

51. There should be a provision in the Bill that gives responsibility and resources to maintain a register of AHDs to the DSS.

52. Health and medical treatment decisions should be retained in the scope of an Enduring Power of Attorney.

53. Removal of the two-step process for registering an EPA. Alternative approaches should be developed in conjunction with DPOs and other stakeholders, including those who made submissions to the Committee on this matter.

54. A repeal of section 85(6) is necessary to ensure that the rights of pregnant women/people are respected under this act.

55. Legal aid should be provided to those who create EPAs.

56. The safeguards in this Bill, especially concerning the relevant person's will and preference, including accountability, appeals and complaints mechanisms should be strengthened.

57. An alternative dispute resolution process, such as mediation, should be made available at no cost for the relevant person.

58. Independent advocacy and legal aid should be made available to those making complaints relating to a decision supporters' role or when a relevant person is applying to court to challenge the outcome of a complaint that the Director of the DSS dealt with.

59. The provisions IHREC outlined from the 2016 version of the Bill, which provided a broader basis for its independent monitoring mechanism role, should be restored.

60. The period provided for all wards to transition out of wardship should be shortened.

61. There must be early, accessible and ongoing communication with wards as they go through the process set out under the Bill and all efforts must be made to support them to build their decision-making capacity and explore options for support.

62. The provision of legal aid for wards must be addressed prior to commencement.

63. Alongside the existing sunset clause in the 2015 Act, a review of other legislation is required to ensure that all entry routes to wardship are removed.

64. The Bill should oblige the Irish Human Rights and Equality Commission to engage with disabled people and DPOs in its monitoring role of the UNCRPD, rather than with the NDA exclusively.

APPENDIX 1 - ORDERS OF REFERENCE

a. Functions of the Committee – derived from Standing Orders [DSO 95; SSO 71]

1) The Dáil may appoint a Departmental Select Committee to consider and, unless otherwise provided for in these Standing Orders or by order, to report to the Dáil on any matter relating to—

- (a) legislation, policy, governance, expenditure and administration of—
 - (i) a Government Department, and
 - (ii) State bodies within the responsibility of such Department, and
- (b) the performance of a non-State body in relation to an agreement for the provision of services that it has entered into with any such Government Department or State body.

(2) A Select Committee appointed pursuant to this Standing Order shall also consider such other matters which—

- (a) stand referred to the Committee by virtue of these Standing Orders or statute law, or
- (b) shall be referred to the Committee by order of the Dáil.

(3) The principal purpose of Committee consideration of matters of policy, governance, expenditure and administration under paragraph (1) shall be—

- (a) for the accountability of the relevant Minister or Minister of State, and
- (b) to assess the performance of the relevant Government Department or of a State body within the responsibility of the relevant Department, in delivering public services while achieving intended outcomes, including value for money.

(4) A Select Committee appointed pursuant to this Standing Order shall not consider any matter relating to accounts audited by, or reports of, the Comptroller and Auditor General unless the Committee of Public Accounts—

- (a) consents to such consideration, or
- (b) has reported on such accounts or reports.

(5) A Select Committee appointed pursuant to this Standing Order may be joined with a Select Committee appointed by Seanad Éireann to be and act as a Joint Committee for the purposes of paragraph (1) and such other purposes as may be specified in these Standing Orders or by order of the Dáil: provided that the Joint Committee shall not consider—

- (a) the Committee Stage of a Bill,
- (b) Estimates for Public Services, or
- (c) a proposal contained in a motion for the approval of an international agreement involving a charge upon public funds referred to the Committee by order of the Dáil.

(6) Any report that the Joint Committee proposes to make shall, on adoption by the Joint Committee, be made to both Houses of the Oireachtas.

(7) The Chairman of the Select Committee appointed pursuant to this Standing Order shall also be Chairman of the Joint Committee.

(8) Where a Select Committee proposes to consider—

- (a) EU draft legislative acts standing referred to the Select Committee under Standing Order 133, including the compliance of such acts with the principle of subsidiarity,
- (b) other proposals for EU legislation and related policy issues, including programmes and guidelines prepared by the European Commission as a basis of possible legislative action,
- (c) non-legislative documents published by any EU institution in relation to EU policy matters, or
- (d) matters listed for consideration on the agenda for meetings of the relevant Council (of Ministers) of the European Union and the outcome of such meetings,

the following may be notified accordingly and shall have the right to attend and take part in such consideration without having a right to move motions or amendments or the right to vote:

- (i) members of the European Parliament elected from constituencies in Ireland,
- (ii) members of the Irish delegation to the Parliamentary Assembly of the Council of Europe, and
- (iii) at the invitation of the Committee, other members of the European Parliament.

(9) A Select Committee appointed pursuant to this Standing Order may, in respect of any Ombudsman charged with oversight of public services within the policy remit of the relevant Department consider—

- (a) such motions relating to the appointment of an Ombudsman as may be referred to the Committee, and
- (b) such Ombudsman reports laid before either or both Houses of the Oireachtas as the Committee may select: Provided that the provisions of Standing Order 130 apply where the Select Committee has not considered the Ombudsman report, or a portion or portions thereof, within two months (excluding Christmas, Easter or summer recess periods) of the report being laid before either or both Houses of the Oireachtas.

b. Scope and Context of Activities of Committees (as derived from Standing Orders) [DSO 94; SSO 70]

(1) The Joint Committee may only consider such matters, engage in such activities, exercise such powers and discharge such functions as are specifically authorised under its orders of reference and under Standing Orders;

(2) such matters, activities, powers and functions shall be relevant to, and shall arise only in the context of, the preparation of a report to the Dáil/Seanad;

(3) it shall not consider any matter which is being considered, or of which notice has been given of a proposal to consider, by the Joint Committee on Public Petitions in the exercise of its functions under DSO 125(1) and SSO 108(1); and

(4) it shall refrain from inquiring into in public session or publishing confidential information regarding any matter if so requested, for stated reasons given in writing, by—

- (a) a member of the Government or a Minister of State, or
- (b) the principal office-holder of a State body within the responsibility of a Government Department or
- (c) the principal office-holder of a non-State body which is partly funded by the State,

Provided that the Committee may appeal any such request made to the Ceann Comhairle, whose decision shall be final.

(5) It shall be an instruction to all Select Committees to which Bills are referred that they shall ensure that not more than two Select Committees shall meet to consider a Bill on any given day, unless the Dáil, after due notice to the Business Committee by a Chairman of one of the Select Committees concerned, waives this instruction.

c. Powers of Committees (as derived from Standing Orders) [DSO 96; SSO 72]

Unless the Dáil/Seanad shall otherwise order, a Committee appointed pursuant to these Standing Orders shall have the following powers:

(1) power to invite and receive oral and written evidence and to print and publish from time to time—

- (a) minutes of such evidence as was heard in public, and
- (b) such evidence in writing as the Committee thinks fit;

(2) power to appoint sub-Committees and to refer to such sub-Committees any matter comprehended by its orders of reference and to delegate any of its powers to such sub-Committees, including power to report directly to the Dáil/Seanad;

(3) power to draft recommendations for legislative change and for new legislation;

(4) in relation to any statutory instrument, including those laid or laid in draft before either or both Houses of the Oireachtas, power to—

(a) require any Government Department or other instrument-making authority concerned to—

- (i) submit a memorandum to the Joint Committee explaining the statutory instrument, or
- (ii) attend a meeting of the Joint Committee to explain any such statutory instrument: Provided that the authority concerned may decline to attend for reasons given in writing to the Joint Committee, which may report thereon to the Dáil, and

(b) recommend, where it considers that such action is warranted, that the instrument should be annulled or amended;

(5) power to require that a member of the Government or Minister of State shall attend before the Joint Committee to discuss—

(a) policy, or

(b) proposed primary or secondary legislation (prior to such legislation being published),

for which he or she is officially responsible: Provided that a member of the Government or Minister of State may decline to attend for stated reasons given in writing to the Joint Committee, which may report thereon to the Dáil: and provided further that a member of the Government or Minister of State may request to attend a meeting of the Joint Committee to enable him or her to discuss such policy or proposed legislation;

(6) power to require that a member of the Government or Minister of State shall attend before the Joint Committee and provide, in private session if so requested by the attendee, oral briefings in advance of meetings of the relevant EC Council (of Ministers) of the European Union to enable the Joint Committee to make known its views: Provided that the Committee may also require such attendance following such meetings;

(7) power to require that the Chairperson designate of a body or agency under the aegis of a Department shall, prior to his or her appointment, attend before the Select Committee to discuss his or her strategic priorities for the role;

(8) power to require that a member of the Government or Minister of State who is officially responsible for the implementation of an Act shall attend before a Joint Committee in relation to the consideration of a report under DSO 197/SSO 168;

(9) subject to any constraints otherwise prescribed by law, power to require that principal office-holders of a—

(a) State body within the responsibility of a Government Department or

(b) non-State body which is partly funded by the State,

shall attend meetings of the Joint Committee, as appropriate, to discuss issues for which they are officially responsible: Provided that such an office-holder may decline to attend for stated reasons given in writing to the Joint Committee, which may report thereon to the Dáil/Seanad; and

(10) power to—

(a) engage the services of persons with specialist or technical knowledge, to assist it or any of its sub-Committees in considering particular matters; and

(b) undertake travel;

Provided that the powers under this paragraph are subject to such recommendations as may be made by the Working Group of Committee Chairmen under DSO 120(4)(a)/SSO 107(4)(a).

APPENDIX 2 – LINKS TO MEETING TRANSCRIPTS

[15th February 2022](#)

[16th February 2022](#)

APPENDIX 3 – LINKS TO SUBMISSIONS & OPENING STATEMENTS

OPENING STATEMENTS

Tuesday 15th February 2022

National Platform of Self Advocates

- [Mr Joe McGrath](#)

Independent Living Movement Ireland

- [Mr Peter Kearns](#)

National Federation of Voluntary Service Providers

- [Ms Alison Harnett](#)

Mental Health Reform

- [Ms Fiona Coyle](#)

Family Carers Ireland

- [Mr John Dunne](#)

Wednesday 16th February 2022

Centre for Disability, Law and Policy NUI Galway

- [Professor Eilíonóir Flynn](#)

The Department of Children, Equality, Disability, Integration and Youth

- [Ms Carol Baxter](#)

Decision Support Service

- [Mr John Farrelly](#)

Irish Human Rights and Equality Commission

- [Mr Adam Harris](#)

SUBMISSIONS

[AsIAM](#)

[The Bar of Ireland](#)

[Centre for Disability Law and Policy](#)

[Decision Support Service](#)

[Disabled Women Ireland](#)

[Dublin Solicitors' Bar Association](#)

[Disability Federation of Ireland](#)

[HSE](#)

[Inclusion Ireland](#)

[Inclusive Living Network](#)

[Independent Living Movement Ireland](#)

[Irish Banking Culture Board](#)

[Irish Penal Reform Trust](#)

[ISPCC](#)

[Law Society of Ireland](#)

[Mental Health Reform](#)

[Mark Ward T.D., Member of CEDiy Committee](#)

[National Advocacy Service for People with Disabilities](#)

[National Federation of Voluntary Service Providers](#)

[Parker Law](#)

[Safeguarding Ireland](#)

[Sage Advocacy](#)

[Vincent Prendergast](#)

[Brian Gallagher](#)

[Patrick Mangan](#)

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