Assisted Decision-Making (Capacity) (Amendment) Bill 2022

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Abstract

The Assisted Decision-Making (Capacity) (Amendment) Bill 2022 seeks to amend the Assisted Decision-Making (Capacity) Act, 2015 (‘the 2015 Act’) by providing for the necessary amendments allowing for the commencement of the remaining parts of the 2015 Act. It will end the wardship system and introduce a modern statutory framework of supported decision-making for adults based on a functional assessment of capacity. It also gives further effect to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) including the State’s obligations under Article 12 of the UNCRPD.
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# Glossary and abbreviations

Table 1 Glossary and abbreviations.

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Background

The Assisted Decision-Making (Capacity) (Amendment) Bill 2022 (‘the Bill’) and the accompanying Explanatory Memorandum were published on Monday, 30th May 2022. The Bill will be taken for Second Stage in Dáil Éireann on Wednesday, 1st June 2022. Due to the timeframe between publication of the Bill and Second Stage debate, it is not possible for this Digest to consider all relevant issues in the Bill.

The Bill seeks to amend the Assisted Decision-Making (Capacity) Act, 2015 (‘the 2015 Act’), which aimed to provide a modern statutory framework supporting decision-making by adults and enabling them to retain the greatest amount of autonomy possible in situations where they lack or may shortly lack capacity. The 2015 Act was initiated in the Dáil in July 2015 and signed into law by the President in December 2015. The L&RS resources in respect of the 2015 Act can be found in the text box below.

L&RS Resources for the Assisted Decision-Making (Capacity) Act, 2015

- Bill Digest - Assisted Decision-Making (Capacity) Bill 2013, September 2013
- L&RS Note - Assisted Decision-Making (Capacity) Act 2015: how will it work?, May 2017

A number of sections of the 2015 Act have not yet been commenced, including:

- Part 3 Assisted Decision-Making
- Part 4 Co-Decision-Making
- Part 7 Enduring Power of Attorney
- Part 8 Advance Healthcare Directives
- Part 10 Detention Matters

Commencement of the 2015 Act is required to give full effect to the State’s obligations under Article 12 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD), which requires that: "States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life."

The UNCRPD is an international human rights treaty adopted by the United Nations General Assembly on 13th December 2006. It opened to signatures on 30th March 2007 and came into force on 3rd May 2008 following ratification by the 20th State Party.

In Ireland, the ratification process for the UNCRPD consisted of the following four steps:

1. Explanatory Memorandum, Assisted Decision-Making (Capacity) Bill 2013
4. Frequently Asked Questions regarding the Convention on the Rights of Persons with Disabilities, UN Department of Economic and Social Affairs (last accessed 29 May 2022)
• 30th January 2018: Cabinet decision to ratify the UNCRPD after a special Cabinet meeting on disability.
• 7th March 2018: The resolution to ratify the UNCRPD is passed in Dáil Éireann. The debate on the Motion can be accessed here.
• 20th March 2018: The instrument of ratification was deposited with the UN.
• 19th April 2018: The UNCRPD entered into force in Ireland.

The UNCRPD consists of 50 Articles, with its purpose set out in Article 1 as follows:

“The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.”

Source: UNCRPD

The parts of the 2015 Act that remain to be commenced involve several different areas including the wardship system which provides arrangements for those adults who are considered to lack capacity to make their own decisions. Until the 2015 Act is fully commenced, the wardship system remains in place. This means that a person who lacks decision-making capacity can be made a Ward of Court. As a Ward of Court, they are not allowed to make any decisions regarding their personal welfare or financial affairs, including the right to marry, enter into contracts or decide where to live. This is administered and managed by the Wards of Court Office in the Courts Service of Ireland. The Office provides an overview of how the system works as follows:

The purpose of wardship is to protect the person and the property of an individual when they lack the capacity to do so themselves.

When an adult is taken into wardship it means that the President of the High Court is satisfied on the basis of the medical evidence available that the person should be deemed to lack capacity and is incapable of managing his/her own affairs…

If there are concerns that an adult lacks capacity to manage their own affairs a Solicitor can be instructed to make an application to have the person made a Ward of Court. The concerned person, usually a family member or friend, can instruct a solicitor to make the application…

After the President of the High Court has made the Declaration Order bringing a person into wardship a Committee is appointed to act on behalf of the ward. Generally, the proceeds of accounts held in financial institutions are lodged in to Court. The Committee is requested to submit proposals in relation to a dwelling house or lands (if any).6

5 ‘A watershed moment': Resolution to ratify UN disabilities convention to go before the Dáil (thejournal.ie)/, (last accessed 29 May 2022)
6 Courts Service of Ireland, ‘Office of the Wards of Court’, Information on wardship for adults (last accessed 30 May 2022)
The Courts Service also provides information on preparing for the transition to the Decision Support Service. It advises that once the 2015 Act is fully commenced that “all wards of court will be discharged from wardship and where appropriate, the relevant person will then transition to one of the new supports available under the 2015 Act.” This will be outlined in further detail in the following section on the Decision Support Service (the DSS).

In December 2017, the National Safeguarding Committee published a review of current practice in the use of wardship for adults in Ireland. The review noted the delay in the commencement of the 2015 Act, and detailed the problems associated with wardship. The Committee also made recommendations in relation to ward of court procedures, that would ensure the human rights of the individuals concerned are respected. Several of their recommendations including a functional legal test, consideration of a relevant person’s will and preference as well as centralised guidelines are contained within the General Scheme of the Assisted Decision-Making (Capacity) (Amendment) Bill 2021.

According to a press release from the Department of Children, Equality, Disability, Integration and Youth announcing Cabinet approval of the General Scheme of the Assisted Decision-Making (Capacity) (Amendment) Bill:

> The proposed legislation will amend the Assisted Decision-Making (Capacity) Act 2015, improving processes and safeguards for those who will make use of the new decision-making supports. The full commencement of this Act will bring about an end to wardship in Ireland, changing the existing law on capacity from the status approach of the wardship system to a flexible functional approach, where capacity is assessed on an issue and time-specific basis.

> The proposed Bill also 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%.

The General Scheme of the Assisted Decision-Making (Capacity) (Amendment) Bill 2021 (the General Scheme) was published on 21 November 2021 and will replace the Wards of Court system with a graduated supported decision-making framework. Once enacted, it will repeal the Marriage of Lunatics Act, 1811 and the Lunacy Regulation (Ireland) Act, 1871, both of which are widely considered to be outdated and inappropriate for dealing with people whose ability to make decisions is affected. The General Scheme is divided into four parts and contains 88 Heads. Some of the provisions include:

7 See Courts Service of Ireland, ‘Office of the Wards of Court’, Wards of Court – The Decision Support Service (last accessed 30 May 2022)

8 The National Safeguarding Committee, 2017, Review of current practice in the use of wardship for adults in Ireland, December 2017

9 Cabinet approves General Scheme of the Assisted Decision-Making (Capacity) (Amendment) Bill (www.gov.ie)
1. to remove the provision allowing the court to confer, on the Director of the DSS, property of a relevant person for management or control (Head 26);
2. to delete provisions relating to the use of restraint in private settings by decision supporters (Head 27);
3. for the insertion of a new subsection (2)(c) in s.47 of the Act, to provide for a means of resolving complaints outside of the court system (Head 30);
4. that, following a declaration by the wardship court, as to the capacity of a ward, they will be discharged from wardship once the appropriate support arrangement has been put in place (Head 33);
5. for a review by the Circuit Court, where a declaration has been made in respect of a ward’s lack of capacity. This review would take place within 12 months, unless the wardship court is satisfied that the relevant person is unlikely to recover their capacity, in which case the review must take place no later than 3 years (Head 34);
6. for the Director of the DSS to be able to investigate complaints in relation to people other than (as is currently the case): decision-making assistants, co-decision-makers, decision-making representatives, and attorneys. The amendment also provides for investigations of complaints in relation to Designated Healthcare Representatives (DHRs) (Head 63);
7. for the Director of the DSS to seek a court order, temporarily prohibiting a decision supporter from acting in the role, until an investigation has been concluded, and that the relevant person’s assets be protected during an investigation (Head 64);
8. that a person with a mental illness or disability, receiving treatment or resident in an institution, would no longer be prohibited from serving on a jury. This prohibition would be replaced with a functional capacity test (Head 79);
9. to repeal the prohibition on a person of ‘unsound mind’ from standing for election to the Dáil. This Head would also remove the disqualifications for membership of the Seanad and for election to the European Parliament (Head 80);
10. for the National Disability Authority (NDA) to provide information and assistance to the Irish Human Rights and Equality Commission (IHREC), as part of the monitoring mechanism for the Convention on the Rights of Persons with Disabilities (CRPD). The Head also provides that staff of the Authority will become civil servants of the State (Head 81);
11. that unless there is good reason to the contrary, or otherwise prescribed, 4.5% of persons employed in a public body will be persons with disabilities up to end of 2023 and that 6% of persons employed in a public body will be persons with disabilities in 2024 (Head 84); and
12. for the Irish Human Rights and Equality Commission 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 (Head 85).

The Bill, as published, largely reflects the General Scheme and comprises 3 parts and 87 sections that provide for a range of measures to amend the 2015 Act, including:

- Technical and procedural amendments to enable the commencement of the 2015 Act, thereby ending wardship in Ireland and providing for a functional approach to capacity for relevant persons;
• Amended definitions of personal welfare and treatment decisions, thereby allowing people with capacity difficulties to participate in health research, and clarifying who has authority to make decisions in respect of medical treatment or clinical care where a person has capacity;
• Amendments to the 2015 Act in respect of safeguarding provisions, with a view to reducing bureaucracy for those utilising options under the Act and facilitating the DSS to operate more effectively (e.g. allowing the DSS to draft and prepare its own forms and divesting greater control over the DSS’s administrative procedures to the Director);
• Provision of additional powers to the Director of the DSS, including to investigate matters and seek informal resolution of complaints and to provide for the renumeration of panel member decision-making representatives in the event that there are insufficient assets in the estate of the relevant person;
• Progression of various provisions formerly included in the Disability (Miscellaneous Provisions) Bill 2016, which lapsed at the dissolution of the last Dáil, such as the doubling of the percentage of people with disabilities in the public services from 3% to 6% and repeal of certain provisions in respect of participation in public/civic life (e.g. repeal of the prohibition of a person of ‘unsound mind’ from standing for election to the Dáil, and consequently removing the disqualifications for membership of the Seanad and for election to the European Parliament)
• Establishment of a new system for enduring powers of attorney (EPAs), whereby the EPA will be created by the relevant person (with capacity) and registered with the DSS, thereby enabling any difficulties with the EPA to be resolved by the person themselves. In the event that the relevant person loses capacity, the EPA will come into effect via a notification process to the DSS by the attorney.
• Strengthened protections for wards when their wardships are reviewed and they are discharged from wardships and/or migrate to the decision-making support structures of the 2015 Act;
• Removal of provisions permitting the use of restraint in private settings\textsuperscript{10,11}

\textsuperscript{10} During PLS, Family Carers Ireland raised concerns around the removal of this provision as it considered that it would unintentionally create a situation whereby the only solution when somebody is at imminent risk of causing serious harm to themselves or somebody else would be to put them into institutional care because it is no longer possible, legally, to do it at home. See Mr John Dunne, Family Carers Ireland, General Scheme of the Assisted Decision-Making (Capacity) (Amendment) Bill 2021: Discussion (Resumed), Joint Committee on Children, Equality, Disability, Integration and Youth debate, 15 February 2022. It should be noted that safeguards that will apply where a person is deprived of his or her liberty in an institutional setting will be the subject of separate legislation which is currently being prepared by the Department of Health.

\textsuperscript{11} Explanatory Memorandum
Decision Support Service (DSS)

The Decision Support Service (DSS) is a new service established under the 2015 Act, which is one of four functions of the Mental Health Commission (MHC)\textsuperscript{12}. The DSS will operate the provisions of the 2015 Act to support the complex decision-making needs of people with capacity difficulties.\textsuperscript{13}

The DSS’s website provides the following update:

We exist to promote the rights and interests of people who may need support with decision-making. The DSS is not operational yet but our establishment project is well underway. We are working to a plan to commence the service in mid-2022. In the meantime, we will provide you with information about the new service and the things you can do to get ready.

\textit{Reproduced from DSS}\textsuperscript{14}

The MHC describes the DSS as below:

The DSS is an essential service for all adults who have difficulties with decision-making capacity. This may include people with an intellectual disability, mental illness or acquired brain injury, as well as people with age-related conditions who may need supports to make decisions. The DSS is provided for under the Assisted Decision Making (Capacity) Act 2015. The 2015 Act is a significant piece of reforming human rights legislation which provides a modern statutory framework for supported decision-making. The supports provided for, and monitored by the DSS, will help to ensure that people are afforded the fundamental human rights to make their own decisions as far as possible about their personal welfare, property and affairs and finances.

\textit{Reproduced from DSS}\textsuperscript{15}

The role of the DSS encompasses the following:

\begin{itemize}
  \item regulate and register decision support arrangements
  \item supervise the actions of decision supporters
  \item maintain a panel of experts who will act as decision-making representatives, special and general visitors, and court friends
  \item investigate complaints made under the 2015 Act
  \item promote awareness and provide information about the 2015 Act
\end{itemize}

\textit{Reproduced from DSS}\textsuperscript{16}

\textsuperscript{12} FAQ | Mental Health Commission (mhcirl.ie)
\textsuperscript{13} Cabinet approves General Scheme of the Assisted Decision-Making (Capacity) (Amendment) Bill (www.gov.ie)
\textsuperscript{14} Welcome to the Decision Support Service website | Decision Support Service
\textsuperscript{15} FAQ | Mental Health Commission (mhcirl.ie)
\textsuperscript{16} What we do | Decision Support Service
In addition, the DSS will act as the Central Authority in respect of the matters relating to the Hague Convention on the International Protection of Adults and, once operational, will also ensure that Ireland is compliant with the UNCRPD.¹⁷

A report on service demand forecasting¹⁸ for the DSS estimated that 1 in 20 of the population may require access to its services at some point in their lives.¹⁹ This estimate includes those who choose to advance plan, such as those who may wish to plan for a time when they might lose capacity, by way of an advance healthcare directive or an enduring power of attorney.²⁰

In terms of forecasting of service demand in the initial stages of the operationalisation of the DSS, the report calculated a "reasonable estimate" of 5,556 decision-support arrangements in its first six months of operations (July to December 2022), with an estimated 7,942 people accessing the service in 2026. In respect of the requirement for panel member decision-making representatives (DMR) for those who do not have a suitable person to act in this capacity, comparable service usage in a number of other jurisdictions and in the wards of court system in Ireland established an average public/private split of 33% for public (panel member) DMRs and 67% for private DMRs. Of the 1,695 estimated number of DMRs appointed for the first year of service, it was forecast that 1,136 would have a suitable person/family member to act on their behalf whilst 559 would require a public (i.e. panel member) DMR.²¹

Pre-commencement matters

Service planning, development and consultation

The DSS ran a two-phase consultation process concerning the development of codes of practice describing how decision supporters and relevant professionals should act in certain situations to meet their responsibilities under the 2015 Act.²²

Phase 1 of the DSS’s consultation on the Codes of Practice for the 2015 Act commenced on 15 November 2021, with closing date for feedback 7 January 2022. This purpose of this public consultation was to provide an opportunity to provide feedback on the codes. Six codes of practice formed part of the Phase 1 of this consultation process:

- Code of Practice on supporting decision-making and assessing capacity
- Code of Practice for legal practitioners
- Code of Practice for financial professionals and financial service providers
- Code of Practice for designated healthcare representatives

¹⁷ ibid

¹⁸ Phase 1 of this work sought to identify and establish a baseline population of adults within existing datasets (e.g. Census 2016, with supporting information derived from three nationally representative surveys) likely to benefit from supports and services provided by the DSS. [Source: Service Demand Forecasting, Report 2021 (decisionsupportservice.ie), p.6]

¹⁹ DSS could assist up to 5,500 people in its first six months of operation | Decision Support Service

²⁰ Service Demand Forecasting, Report 2021 (decisionsupportservice.ie), p.7

²¹ Service Demand Forecasting, Report 2021 (decisionsupportservice.ie), p.3,71

²² Codes of Practice | Decision Support Service
• Code of Practice on advance healthcare directives for healthcare professionals
• Code of Practice for healthcare professionals.\textsuperscript{23}

These draft codes are available to review at: Public Consultation Phase 1 | Decision Support Service.

Subsequently, the DSS launched Phase 2 of its public consultation on drafts codes of conduct, which ran from 10 January 2022 to 18 February 2022. The draft codes which formed part of Phase 2 encompassed the following:

• Code of Practice for decision-making assistants
• Code of Practice for co-decision-makers
• Code of Practice for decision-making representatives
• Code of Practice for attorneys
• Code of Practice for special visitors
• Code of Practice for general visitors
• Code of Practice for court friends
• Code of Practice for independent advocates

These draft codes are available to review at: Public Consultation Phase 2 | Decision Support Service.

In terms of the drafting of these codes of practice, the DSS indicates that the National Disability Authority was appointed by the Department of Justice to write non-healthcare codes, working with a number of expert groups (unspecified) to produce these drafts. Further, the DSS advise that, under Part 8 of the 2015 Act, the Minister for Health appointed a multi-disciplinary working group led by the HSE Human Rights and Equality Policy Office. Finally, the DSS report that they have reviewed these drafts and revised the codes to reflect anticipated amendments to the Act (as and where available). The DSS state that they intend to publish the final codes of practice (subject to Ministerial approval) in advance of the commencement of services.\textsuperscript{24}

The HSE National Office of Human Rights and Equality Policy\textsuperscript{25}, which has responsibility for the development and delivery of planning to ensure compliance with the 2015 Act\textsuperscript{26}, the Office ran a series of webinars beginning in February 2022. These webinars, the content of which was informed by feedback from a survey with front line practitioners/healthcare staff, sought to:

• Stimulate discussion about practical implementation of the 2015 Act
• Provide guidance to services and practitioners
• Identify areas of uncertainty and learning needs

\textsuperscript{24} Public Consultation Process | Decision Support Service
\textsuperscript{25} The Office has a webpage on the 2015 Act. which provides details and links to a range of materials, including latest news, explainer video, webinars, and FAQs.
\textsuperscript{26} HSE National Office for Human Rights and Equality Policy Newsletter ‘Towards Commencement’, Winter 2021, p.2
• Explore case studies with the framework of the 2015 Act\textsuperscript{27}

A total of 5 webinars were conducted, with details and video links (where available) in the text box below.

**Webinar 1** - Decision-making support arrangements under the 2015 Act - How do I support someone to make a decision?  
*February 2022*  
*YouTube link: Webinar 1 (includes ISL interpretation)*

**Webinar 2** - How and when to engage with the Decision Support Service  
*March 2022*  
*YouTube link: Webinar 2 (includes ISL interpretation)*

**Webinar 3** - Positive risk taking and 'unwise' decisions  
*April 2022*  
*YouTube link: Webinar 3 (includes ISL interpretation)*

**Webinar 4** - Functional Assessment of Capacity  
*May 2022*  
*YouTube link (not yet uploaded)*

**Webinar 5** - Respecting the rights of the person and the role of families under 2015 Act  
*June 2022 (forthcoming)*

**Budgetary matters**

In preparation of becoming fully operational, the DSS has received funding to put in place the necessary systems (including administrative and IT).\textsuperscript{28} For instance, the DSS received additional funding in Budget 2021, with a projected budget of €5.8 million in 2021, an increase in funding of €2.3 million over the previous year’s budget allocation.\textsuperscript{29} The DSS highlighted an uplift for the service in Budget 2022 (October 2021), with additional funding of €1.5 million announced by the Minister for Children, Equality, Disability, Integration and Youth, Roderic O’Gorman, and Minister for Disability, Anne Rabbitte. This uplift brought the total budget for the DSS in 2022 to €7.3 million.\textsuperscript{30} However, the budget for 2023 has yet to be agreed.\textsuperscript{31}

**Resources and guidance**

The DSS’s website has a [Resources](#) section related to the 2015 Act and the DSS, which includes subsections on [Guides & Tools](#), [Training Material](#), and [Codes of Practice](#). These are due to be populated with the commencement of the operationalisation of the DSS. For instance, the [Guides & Tools](#) sections indicates that a number of online resources (incl. how-to-guides, demonstration videos and toolkits) will be provided, whilst the [Training Material](#) section advises that information

\textsuperscript{27} [Webinar Series - Assisted Decision-Making Capacity Act 2015 - HSE.ie](#)  
\textsuperscript{28} [PQ - Assisted Decision-Making, 26 Apr 2022 – Houses of the Oireachtas](#)  
\textsuperscript{29} [Confirmation of budget allocation allows for launch of Decision Support Service in 2022 | Decision Support Service](#)  
\textsuperscript{30} [Countdown to launch of new service for people with disabilities begins in earnest | Decision Support Service](#)  
\textsuperscript{31} [PQ - Assisted Decision-Making, 10 May 2022 – Houses of the Oireachtas](#)
and training materials for decision supporters and for people undertaking capacity assessments will be provided, as will materials for professionals/organisations who will interact with people with decision support arrangements, their decision supporters, and the DSS. Further, the status of the Codes of Practice subsection of the website is outlined as follows:

We will publish codes of practice describing how decision supporters and relevant professionals should act in certain situations to meet their responsibilities under the 2015 Act.

Significant work has been carried out to draft these codes of practice. The National Disability Authority completed a large body of work with the input of relevant technical experts.

In addition, the Advance Healthcare Directives Multi-Disciplinary Working Group, commissioned by the Minister for Health, has submitted draft codes to the Director for review.

Our public consultation on the fourteen draft codes of practice has concluded and all responses received have been thoroughly considered.

The codes are currently being revised to take into account the feedback received. They are also undergoing a process of external legal review to ensure they are consistent with the 2015 Act and other relevant law.

We will publish the revised codes once Ministerial approval has been obtained to do so. We are working towards having the codes of practice available in mid-June.

In advance of updating its website with the final version of these codes/guides/information, however, the DSS has produced some material introducing the service and outlining its role, including a poster and leaflet. In addition, the DSS has published a number of videos containing information on the services offered. More recently, the DSS produced a video presentation aimed at financial professionals providing information on the guiding principles and the different tiers of support available for people, as well as focusing on advance planning (incl. an Enduring Power of Attorney and advance healthcare directives).33

Engaging with the DSS (once operational)

In terms of interacting with the service, the DSS has advised that it will be operating a ‘digital-first’ approach, whilst also indicating that they will not be ‘digital-only’ (i.e. accommodating all service users as necessary). It explains the rationale for this ‘digital-first’ policy as follows:

We have considered options for our service delivery and looked at the experience of other jurisdictions. We believe that there are many ways in which users will benefit from our service being digital-first. Firstly, digital-led systems are more efficient and more secure than paper-led ones. Paper-based systems are less adaptable and can become easily overwhelmed in times of high demand, leading to backlogs or delays. Physical documents are also hard to track and can easily get damaged or misplaced, which can pose a security

32 [Codes of Practice | Decision Support Service](#)
33 [Decision Support Service Video Presentation for Financial Professionals | Decision Support Service](#)
risk. Our service has been built from the ground up with efficiency, personal security, and privacy in mind.\textsuperscript{34}

Further, the DSS asserts that such an approach offers a range of benefits for its users, including:

With a digital-first system, you won’t need to search for physical copies of forms or applications. All your information will be accessible in your own individual account, and you’ll be able to easily view arrangements or check the status of applications using a computer, tablet, or your phone. You won’t need to bring cumbersome physical documentation to appointments, such as hospital, bank, or credit union visits. Instead, you can simply access your account on your phone and view all the relevant documents there. Being digital first makes the process faster and smoother for everybody involved.\textsuperscript{35}

The DSS outlines the process by which people will access its services, as well as the nature of the services offered, as below:

When we launch in mid-2022, people using our service will be able to log into a portal\textsuperscript{36}, create an account and be guided through the process of applying for an arrangement or managing an existing arrangement. It will also be possible to raise queries, access information and guidance, submit complaints and request searches of our registers of arrangements.\textsuperscript{37}

In terms of access for people with disabilities, the DSS asserts that:

We believe that our digital first approach can enhance accessibility. We are working to ensure that our electronic documentation can be easily understood and navigated by a wide range of users, including persons with disabilities.\textsuperscript{38}

However, whilst the DSS published a number of video guides to its service, including one described as an “Easy Read Presentation”, no Irish Sign Language version\textsuperscript{39} appears to have been provided\textsuperscript{40}.

\textsuperscript{34} Why we are taking a digital-first approach and what this means for users | Decision Support Service
\textsuperscript{35} ibid
\textsuperscript{36} The DSS advises that a MyGovID will be required in order to access services. [Source: Why we are taking a digital-first approach and what this means for users | Decision Support Service]. Of note is that Joint Committee recommended the removal of the requirement to have a MyGovID to register with and use DSS Recommendation No. 24).
\textsuperscript{37} Why we are taking a digital-first approach and what this means for users | Decision Support Service
\textsuperscript{38} ibid
\textsuperscript{39} Of note is that Joint Committee recommended that the DSS be sufficiently resourced to develop a wide range of resources for those seeking to understand the Bill. As well as recommending that this would include a selection of explainer videos, easy-to-read, and Plain English resources, and FAQ documents, the Joint Committee also explicitly recommended the provision of Irish Sign Language resources. (Recommendation No. 33).
\textsuperscript{40} DSS Launches Simple Guides and Video Presentations | Decision Support Service
Nature of decision support arrangements
The nature of applicable decision support arrangements - defined as “legally recognised arrangements for people who need support to make certain decisions”41 - include those as outlined by the DSS below. Further, please see Appendix 1 for examples of such arrangements and Appendix 2 for a list of key terms relevant to the work of the DSS.

Decision-making assistance agreement42
If you require support to make certain decisions on your own, you can make a decision-making assistance agreement. This agreement lets you appoint someone you know and trust as a decision-making assistant. Your decision-making assistant will help you to get information and explain it to you. They can help you to understand and weigh up your options. They can also help to let other people know what your decision is.

Co-decision-making agreement43
If you are unable to make certain decisions on your own, you can appoint a person you trust as your co-decision-maker under a co-decision-making agreement. This agreement lets you write down decisions you need help with and give someone the legal authority to make those decisions jointly with you. These decisions can be about your personal welfare or your property and money matters.

Decision-making representation order44
If you are unable to make certain decisions even with someone else's support, the court may appoint a decision-making representative to you. The decision-making representative is appointed by the court to make certain decisions on your behalf, taking into account your wishes.

If possible, the court will appoint someone you know and trust as your decision-making representative. However, if there is no-one willing or able to act on your behalf, the court may appoint someone from our panel of trained experts.

Advance healthcare directive45
If you are planning ahead, you can make an advance healthcare directive. This arrangement lets you to write down your wishes about healthcare and medical treatment decisions in case you are unable to make these decisions at some time in the future. You can appoint someone you know and trust as your designated healthcare representative to ensure your advance healthcare directive is followed.

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41 Decision Support Arrangements | Decision Support Service
42 For further information, please see: Decision-making assistance agreement | Decision Support Service
43 For further information, please see: Co-decision-making agreement | Decision Support Service
44 For further information, please see: Decision-making representation order | Decision Support Service
45 For further information, please see: Advance healthcare directive | Decision Support Service
Enduring power of attorney

If you do not currently have capacity issues, but would like to plan ahead, you can make an enduring power of attorney. This arrangement lets you appoint someone you trust as your attorney. The attorney’s role is to act on your behalf to make certain decisions if you are unable to in the future. An attorney does not need to be a lawyer.

PLS of the General Scheme of the Bill

The General Scheme was referred to the Joint Committee on Children, Disability, Equality and Integration (the Joint Committee) for pre-legislative scrutiny (PLS) in late 2021 and the Committee was asked to give the proposed legislation priority consideration so that the 2015 Act could be amended and, as the Department has stated, commenced by June 2022. The Joint Committee undertook a public call for submissions and held two public hearings with relevant stakeholders before publishing its report on 5 April 2022.

Overall, the Joint Committee identified eight key areas of concern in the proposed Bill and made 63 recommendations related to these. The Report also recommended that the Bill should oblige IHREC as part of its national monitoring mechanism (NMM) role under Article 33 UNCRPD to engage with disabled people and Disabled Persons Organisations (DPOs) not only the NDA. The eight areas are as follows:

1. presumption of capacity and protecting will and preference (recommendation 1-17);
2. consultation, language and accessibility (recommendation 18-27);
3. costs, capacity building and resources (recommendation 28-38);
4. mental health (recommendation 39-41);
5. people who are involuntarily detained, protection of liberty safeguards and restraint (recommendation 42-50);
6. advance healthcare directives and enduring power of attorney (recommendation 51-55);
7. accountability, appeals, complaints (recommendation 56-59);
8. wards (recommendation 60-63)

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46 For further information, please see: Enduring power of attorney | Decision Support Service
47 Decision Support Arrangements | Decision Support Service
48 Houses of the Oireachtas, ‘Children’s Committee to begin pre-legislative scrutiny of the Assisted Decision Making Bill’, Press Release, 14 February 2022
49 Houses of the Oireachtas, ‘Joint Committee on Children, Equality, Disability, Integration & Youth publishes report on the Assisted Decision-Making (Capacity) (Amendment) Bill’, Press Release, 8 April 2022
**L&RS traffic light analysis of PLS recommendations versus published Bill**

As part of the Bill Digest process, the L&RS compares the recommendations made in the PLS report with their inclusion, partial or otherwise, in the subsequent Bill. We do this through liaison with the Department, in this case, the Department of Children, Equality, Disability, Integration and Youth, by asking the Department to outline the extent to which, in their view, each of the recommendations of the Joint Committee influenced the drafting of the resulting Bill. The Department’s commentary in respect of this was not available at the time of this Digest’s publication.

The reach and breadth of some of the recommendations encompass wider policy implications and therefore it is difficult to ascertain the extent to which this is reflected in the Bill. Therefore, in relation to these recommendations there is insufficient information available to properly assess their implementation. It should be noted that some of the detail is left to regulations and codes of practice which will not be subject to parliamentary scrutiny.

As per Table 2 below, a traffic light system is used by the L&RS to indicate whether or not a key issue is accepted and reflected in the Bill, or whether a consistent or unclear approach is used in the Bill. This traffic light approach represents the L&RS’s own, independent analysis of the Bill (see Table 3 overleaf).

**Table 2 Key to traffic light dashboard comparing the Bill as published with Joint Committee PLS recommendations.**

<table>
<thead>
<tr>
<th>L&amp;RS categorisation of the Department’s response in the Bill to the Joint Committee’s key issues</th>
<th>Traffic light dashboard used to highlight impact of the Committee’s PLS conclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Key issue has clearly been accepted and is reflected in the Bill.</td>
<td>✔</td>
</tr>
<tr>
<td>The Bill may be described as adopting an approach consistent with the key issue.</td>
<td>–</td>
</tr>
<tr>
<td>Impact of key issue is not clear within the Bill or insufficient information available to assess.</td>
<td>!</td>
</tr>
<tr>
<td>Key issue has not been accepted or implemented in the Bill.</td>
<td>!</td>
</tr>
</tbody>
</table>
Table 3 Traffic light dashboard comparing the Bill as published with Committee PLS recommendations.

<table>
<thead>
<tr>
<th>Joint Committee’s recommendations</th>
<th>L&amp;RS traffic light assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Presumption of Capacity and Protecting Will and Preference</strong></td>
<td></td>
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</tbody>
</table>
| 1. The Committee recommends that 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. | ! |
<p>| 2. The Committee recommends that 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. The Committee recommends that 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. The Committee recommends that 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 Committee recommends that 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 Committee recommends that the definition of intervenor 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 Committee recommends that the Bill should explicitly reference the UNCRPD and specific articles therein, especially Article 12 and General Comment No. 1 of the UNCRPD. | ! |
| 8. The Committee recommends that 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 Committee recommends that the Bill should be based on a human rights-based approach and should adopt the social model of disability. | ! |</p>
<table>
<thead>
<tr>
<th>Joint Committee’s recommendations</th>
<th>L&amp;RS traffic light assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>10. The Committee recommends that 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.</td>
<td>![Important]</td>
</tr>
<tr>
<td>11. The Committee recommends that 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.</td>
<td>![Important]</td>
</tr>
<tr>
<td>12. The Committee recommends that 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.</td>
<td>![Important]</td>
</tr>
<tr>
<td>13. The Committee recommends that 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.</td>
<td>![Important]</td>
</tr>
<tr>
<td>14. The Committee recommends that the Bill should remove substitute decision-making.</td>
<td>![Important]</td>
</tr>
<tr>
<td>15. The Committee recommends removal of the Act’s reliance on the functional assessment of mental capacity.</td>
<td>![Important]</td>
</tr>
<tr>
<td>16. The Committee recommends that the 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.</td>
<td>![Important]</td>
</tr>
<tr>
<td>17. The Committee recommends that 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.</td>
<td>![Important]</td>
</tr>
</tbody>
</table>

**Consultation, Language and Accessibility**

| 18. 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). | ![Important] |
| 19. The Committee recommends the outstanding issues flagged in this section need to be addressed as a priority and well in advance of the June deadline for commencement. | ![Important] |
| 20. The Committee recommends that an accessible, multi-stakeholder revision of the draft Codes must occur before commencement. This process must be carried out in conjunction with DPOs. | ![Important] |
| 21. The Committee recommends that all Bills published should be accompanied by an easy-to-read, Irish Sign Language and Plain English summary. | ![Important] |
## Joint Committee’s recommendations

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>L&amp;RS traffic light assessment</th>
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<tbody>
<tr>
<td>22. The Committee recommends that 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.</td>
<td>![Lightning Bolt]</td>
</tr>
<tr>
<td>23. The Committee recommends that reliance on a decade old public consultation for this Bill or another piece of legislation is inappropriate.</td>
<td>![Lightning Bolt]</td>
</tr>
<tr>
<td>24. The Committee recommends that 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.</td>
<td>![Lightning Bolt]</td>
</tr>
<tr>
<td>25. The Committee recommends that 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.</td>
<td>![Green Check]</td>
</tr>
<tr>
<td>26. The Committee recommends that 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.</td>
<td>![Lightning Bolt]</td>
</tr>
<tr>
<td>27. The Committee recommends that 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.</td>
<td>![Green Check]</td>
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## Costs, Capacity Building and Resources

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<thead>
<tr>
<th>Recommendation</th>
<th>L&amp;RS traffic light assessment</th>
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<tr>
<td>28. The Committee recommends that an impact assessment on the resources required to fund and staff all aspects of the Bill should be carried out immediately.</td>
<td>![Red X]</td>
</tr>
<tr>
<td>29. The Committee recommends that 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.</td>
<td>![Red X]</td>
</tr>
<tr>
<td>30. The Committee recommends that 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.</td>
<td>![Red X]</td>
</tr>
<tr>
<td>Joint Committee’s recommendations</td>
<td>L&amp;RS traffic light assessment</td>
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<tr>
<td>31. The Committee recommends that supports for carers, family members, and potential supporters should be advertised in all publicity and awareness campaigns around the Bill.</td>
<td><img src="Image" alt="Green Light" /></td>
</tr>
<tr>
<td>32. The Committee recommends that 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.</td>
<td><img src="Image" alt="Yellow Light" /></td>
</tr>
<tr>
<td>33. The Committee recommends that 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.</td>
<td><img src="Image" alt="Yellow Light" /></td>
</tr>
<tr>
<td>34. The Committee recommends that 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.</td>
<td><img src="Image" alt="Red Light" /></td>
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<tr>
<td>35. The Committee recommends that 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.</td>
<td><img src="Image" alt="Red Light" /></td>
</tr>
<tr>
<td>36. The Committee recommends that 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.</td>
<td><img src="Image" alt="Yellow Light" /></td>
</tr>
<tr>
<td>37. The Committee recommends that 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.</td>
<td><img src="Image" alt="Red Light" /></td>
</tr>
<tr>
<td>38. The Committee recommends that 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.</td>
<td><img src="Image" alt="Green Light" /></td>
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<tr>
<td>Joint Committee’s recommendations</td>
<td>L&amp;RS traffic light assessment</td>
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</tr>
<tr>
<td><strong>Mental Health</strong></td>
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<tr>
<td>39. The Committee recommends that the DSS codes or guides will need to include comprehensive and different scenarios which take account of those experiencing mental health difficulties.</td>
<td>-</td>
</tr>
<tr>
<td>40. The Committee recommends that 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.</td>
<td>!</td>
</tr>
<tr>
<td>41. The Committee recommends that 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.</td>
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</tr>
<tr>
<td><strong>People who are Involuntarily Detained, Protection of Liberty Safeguards and Restraint</strong></td>
<td></td>
</tr>
<tr>
<td>42. The Committee recommends that the 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.</td>
<td>!</td>
</tr>
<tr>
<td>43. The Committee recommends that 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.</td>
<td>-</td>
</tr>
<tr>
<td>44. The Committee recommends that arrangements must be made for those in prison and other institutions to access the Bill’s provisions.</td>
<td>!</td>
</tr>
<tr>
<td>45. The Committee recommends that the 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.</td>
<td>!</td>
</tr>
<tr>
<td>46. The Committee recommends that explicit prohibition of chemical and mechanical restraint is necessary to meet our obligations under the UNCRPD and other human rights instruments.</td>
<td>!</td>
</tr>
<tr>
<td>47. The Committee recommends that 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.</td>
<td>!</td>
</tr>
<tr>
<td>48. The Committee recommends that no additional powers of restraint for use in order to ensure equal right to liberty.</td>
<td>✓</td>
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<tr>
<td>49. The Committee recommends that 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.</td>
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<tr>
<td>Joint Committee’s recommendations</td>
<td>L&amp;RS traffic light assessment</td>
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<tr>
<td>50. The Committee recommends that 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.</td>
<td>![ ]</td>
</tr>
<tr>
<td><strong>Advance Healthcare Directives and Enduring Power of Attorneys</strong></td>
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<tr>
<td>51. The Committee recommends that there should be a provision in the Bill that gives responsibility and resources to maintain a register of AHDs to the DSS.</td>
<td>![ ]</td>
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<tr>
<td>52. The Committee recommends that health and medical treatment decisions should be retained in the scope of an Enduring Power of Attorney.</td>
<td>![ ]</td>
</tr>
<tr>
<td>53. The Committee recommends the 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.</td>
<td>![ ]</td>
</tr>
<tr>
<td>54. The Committee recommends that repeal of section 85(6) is necessary to ensure that the rights of pregnant women/people are under this act.</td>
<td>![ ]</td>
</tr>
<tr>
<td>55. The Committee recommends that legal aid should be provided to those who create EPAs.</td>
<td>![ ]</td>
</tr>
<tr>
<td><strong>Accountability, Appeals, Complaints</strong></td>
<td></td>
</tr>
<tr>
<td>56. The Committee recommends that the safeguards in this Bill, especially concerning the relevant person's will and preference, including accountability, appeals and complaints mechanisms should be strengthened.</td>
<td>![ ]</td>
</tr>
<tr>
<td>57. The Committee recommends that an alternative dispute resolution process, such as mediation, should be made available at no cost for the relevant person.</td>
<td>![ ]</td>
</tr>
<tr>
<td>58. The Committee recommends that 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.</td>
<td>![ ]</td>
</tr>
<tr>
<td>59. The Committee recommends that 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.</td>
<td>![ ]</td>
</tr>
<tr>
<td><strong>Wards</strong></td>
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<tr>
<td>60. The Committee recommends the period provided for all wards to transition out of wardship should be shortened.</td>
<td>![ ]</td>
</tr>
<tr>
<td>61. The Committee recommends that 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.</td>
<td>![ ]</td>
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<tr>
<td>Joint Committee’s recommendations</td>
<td>L&amp;RS traffic light assessment</td>
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</tr>
<tr>
<td>62. The Committee recommends that the provision of legal aid for wards must be addressed prior to commencement.</td>
<td></td>
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<tr>
<td>63. The Committee recommends that 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.</td>
<td>![Warning Icon]</td>
</tr>
<tr>
<td>64. The Committee recommends 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.</td>
<td>![Warning Icon]</td>
</tr>
</tbody>
</table>
Selected issues of concern

The Assisted Decision-Making (Capacity) (Amendment) Bill (‘the Bill’) was published on 30 May 2022 and contains three Parts and 87 sections. It largely reflects the General Scheme published in November 2021, which contained three Parts and 88 sections. Due to the timeframe between publication of the Bill and Second Stage debate, it is not possible for this Digest to consider all relevant issues in the Bill. Instead, selected issues of concern have been examined to inform Members of some of the wider legal and policy issues.

A functional approach to capacity

The Joint Committee’s PLS report contains the following recommendations in respect of a functional approach to capacity:

Relevant recommendations from the Joint Committee’s PLS report:
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.

The functional capacity approach, as set down in Section 3 of the 2015 Act, has not been amended or removed in the proposed Bill.

Background

Professor Eilíonóir Flynn (Centre for Disability Law and Policy, NUI Galway) (2013) highlights that in “modern times”, mental capacity has frequently been conflated with or “used as a proxy for” legal capacity, resulting in the removal of the legal recognition of the validity of a person’s decision (and the use of substitute decision-making) in the event that they are deemed not to reach a certain standard of decision-making capacity. Highlighting this, the United Nations Committee on the Rights of Persons with Disabilities (‘the UN Committee’) observed that:

States parties must holistically examine all areas of law to ensure that the right of persons with disabilities to legal capacity is not restricted on an unequal basis with others.
Historically, persons with disabilities have been denied their right to legal capacity in many

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50 de Bhailís and Flynn (2017) highlight that mental capacity has been a mechanism to assess (and deny) legal capacity in many jurisdictions, with a common example of this being a test of mental capacity serving as a threshold for the conduct of legally binding decision. [Source: de Bhailís, C. & Flynn, E., 2017, “Recognising legal capacity: commentary and analysis of Article 12 CRPD” International Journal of Law in Context, Vol. 13 No. 1, p.10]

51 Flynn, E., 2013, “Mental (in)capacity or legal capacity? A human rights analysis of the proposed fusion of mental health and mental capacity law in Northern Ireland”, Northern Ireland Legal Quarterly, Vol. 64 No. 4 Pages 485-505, p.486

52 The UN Committee is a body of independent experts tasked with reviewing States’ implementation of the UNCRPD.
areas in a discriminatory manner under substitute decision-making regimes such as guardianship, conservatorship and mental health laws that permit forced treatment. These practices must be abolished in order to ensure that full legal capacity is restored to persons with disabilities on an equal basis with others.53

According to de Bhailís and Flynn (2017):

The right to equal recognition before the law is a key concept in international human rights law. It encompasses both the ability to be the holder of rights (including legal standing) and the ability to be an actor in law (legal agency).54

In line with this, Flynn (2013) assert that challenges, from a human rights perspective, to the removal of legal capacity began with the entry into force of the UNCRPD, with Article 12 establishing that all people, irrespective of their decision-making capacity:

.. should enjoy ‘legal capacity’ on an equal basis – that is, the right to be recognised as a person before the law, and the subsequent right to have one’s decisions legally recognised.55

The full text of Article 12 of the UNCRPD, including provisions related to legal capacity, is set out below.

**Article 12 – Equal recognition before the law**

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

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55 Flynn, E., 2013, “Mental (in)capacity or legal capacity? A human rights analysis of the proposed fusion of mental health and mental capacity law in Northern Ireland”, Northern Ireland Legal Quarterly, Vol. 64 No. 4 Pages 485-505, p.485
5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

Source: UNCRPD

For Schuthof (2021), Article 12 can be understood as representing a “paradigm shift” in the manner in which the legal capacity of people with disabilities is understood, with the UN Committee describing “incapacity as a social construct”, confirming the legal capacity of every person, and “denounce[ing] substitute decision-making in General Comment no. 1” 56. General Comment No. 1 (2014) was issued by the UN Committee to provide guidance in respect of the implementation of Article 12 at national level, including the following:

.. States parties should take the following steps to ensure the full implementation of article 12 of the Convention on the Rights of Persons with Disabilities:

(a) Recognize persons with disabilities as persons before the law, having legal personality and legal capacity in all aspects of life, on an equal basis with others. This requires the abolition of substitute decision-making regimes and mechanisms that deny legal capacity and which discriminate in purpose or effect against persons with disabilities. It is recommended that States parties create statutory language protecting the right to legal capacity on an equal basis for all;

(b) Establish, recognize and provide persons with disabilities with access to a broad range of support in the exercise of their legal capacity. Safeguards for such support must be premised on respect for the rights, will and preferences of persons with disabilities. The support should meet the criteria set out in paragraph 29 above on the obligations of States parties to comply with article 12, paragraph 3, of the Convention..

Source: General Comment No. 1 57

In respect of substitute decision-making, the UN Committee asserted that support in the exercise of legal capacity should respect the rights, will and preferences of people with disabilities. However, it further contended that such support “should never amount to substitute decision-making”. 58 The UN Committee specifically outlined States’ obligations as follows:

States parties’ obligation to replace substitute decision-making regimes by supported decision-making requires both the abolition of substitute decision-making regimes and the development of supported decision-making alternatives. The development of supported decision-making alternatives.

56 Schuthof, F., 2021, “Invisible before the law”, Family & Law, June 2021, p.6
58 ibid, p.4
decision-making systems in parallel with the maintenance of substitute decision-making regimes is not sufficient to comply with article 12 of the Convention.\textsuperscript{59}

de Bhailis and Flynn (2017) describe this General Comment as providing “interpretive guidance on the theory behind this highly contentious but equally important article”, as well as practical direction on how Article 12 should be implemented.\textsuperscript{60} However, noting that this General Comment “calls for an overhaul of all existing laws in the area of legal capacity”, they state that it has also been characterised as “impractical and radical”.\textsuperscript{61} Scholten and Gather (2018) observed that reactions to Article 12 have ranged from “unqualified enthusiasm to strong disapproval”, noting that:

While disability advocates and theorists tend to see the article as the key to the emancipation of persons with mental disabilities, psychiatrists have voiced the opinion that its provisions will make many persons with mental disabilities worse off. Others pass moderate criticism on the article or confine themselves to delineating how its provisions could be implemented within their local jurisdictions.\textsuperscript{62}

For instance, Dawson (2015) advocates for what he describes as “a realistic approach” to assessing the compliance of mental health laws with the UNCRPD. He asserts that the concept of capacity is often used to “define the line” between two “seemingly incompatible” obligations on States, that is individual autonomy on the one hand and the protection of the interests of vulnerable individuals on the other.\textsuperscript{63} According to Dawson (2015):

Intentionally, it seems, the Convention does not mention this central balancing concept in its text, despite the key role played by the concept of capacity in most jurisdictions’ healthcare law. This produces a quandary for the Convention’s interpretation. Is a person who would be judged to lack the capacity to make a certain decision still to be viewed as having the right to make it, as an aspect of their autonomy, or has their lack of capacity removed the ground upon which their autonomy stands? Are they no longer free to act in that domain, so their right to certain positive entitlements (to the best attainable standard of health, for instance) kicks in as the dominant aim? The spare text of the Convention does not indicate how to mediate conflicting rights of this kind.\textsuperscript{64}

\textsuperscript{59} ibid, p.6
\textsuperscript{61} ibid p.14
\textsuperscript{64} ibid.
In respect of decision-making processes relating to people with dementia, for instance, Alzheimer Europe advocated for the retention of substitute decision-making (within the context of a supported decision-making model) as necessary on the basis that:

.. it is not helpful or even ethical to focus solely on a concept (such as everyone having legal capacity, irrespective of their ability to make a decision) that does not work for all members of society. An effective and fair system is needed, which corresponds to everyone’s needs and seeks to provide all possible support needed to exercise legal capacity. We believe that such a system should also incorporate substitute decision making to the extent that this is necessary, proportionate and carried out in an ethical manner … It is not discriminatory as any potential loss of legal capacity is not based on belonging to a particular group but rather on the assessment of a person’s ability to make a specific decision about a specific issue at a specific moment in time, having been provided with all possible appropriate support. 65

More generally, Craigie et al. (2019) assert that interpretation and operationalisation of Article 12 of the UNCRPD remains contentious:

Uncertainty around the meaning of Article 12 is often said to have been settled by General Comment No. 1, for its interpretation is clear … The Committee explains that its position is based on the guiding principles of the CRPD … However, it is unclear how the step from these principles to the conclusions in General Comment No. 1, was made. Indeed, it seems plausible that the application of these principles might sometimes yield conflicting guidance that would need resolution. The requirements to respect the inherent dignity and value the independence of persons, for example, do not always point in the same direction. Much depends on the situation that is being considered, and how these principles are understood. 66

In terms of the operationalisation of the rights envisaged in Article 12 of the UNCRPD, Series and Nilsson (2018) assert that States’ interpretations have frequently been at variance with the standards established by the UN Committee:

The CRPD Committee interprets the CRPD to prohibit all forms of guardianship and substituted decision-making that involves overriding an individual’s expressed preference … Most, if not all, states parties take the opposite position and interpret the Convention to permit substituted decision-making under certain circumstances, including at the very least

65 Alzheimer Europe, 2020, Legal capacity and decision making. The ethical implications of lack of legal capacity on the lives of people with dementia: summary report, December 2020 p.4-5
in situations where decision-making ability is lacking and voluntary support is insufficient to prevent actions that entail serious negative consequences for the person concerned.\textsuperscript{67} Internationally, a number of jurisdictions have entered declarations\textsuperscript{68}/reservations\textsuperscript{69} in respect of Article 12 of the UNCRPD, including Canada, Estonia, the Netherlands and Norway\textsuperscript{70}. Of relevance here also is the annex to a position paper from Mental Health Europe that contains an analysis of EU Member States legislation (as of January 2017), including consideration of provisions in respect of substitute decision-making. Concerning reforming legislation in respect of Article 12 of the UNCRPD, Mental Health Europe asserted the following in its position paper:

The Fundamental Rights Agency of the European Union (FRA) stated in its overview of legal reforms in EU Member States that Article 12 'remains one of the areas with the largest number of reforms at the national level linked to CRPD ratification'\textsuperscript{72}. While some of these reforms have introduced supported decision-making, some of them conflate supported decision-making with substitute decision-making or continue to allow for the denial of legal capacity and substitute decision-making in certain circumstances. There is an acute risk that without the right training to legal professionals, including the judiciary, that where there is a choice between the two, substitute decision-making will prevail over supported decision-making due to outdated but pervasive misconceptions about persons with psychosocial disabilities and because it is easier and cheaper to apply as it does not require an individualised assessment. In addition, reform in relation to the particular forms of substitute decision-making in mental health laws allowing for forced placement and treatment are piecemeal and ensuring autonomy in relation to health is an area of the UNCRPD that States Parties find particularly difficult to implement.\textsuperscript{73}


\textsuperscript{68} According to the UN: “Sometimes states make "declarations" as to their understanding of some matter or as to the interpretation of a particular provision. Unlike reservations, declarations merely clarify the state’s position and do not purport to exclude or modify the legal effect of a treaty.” [Source: UN - Glossary of terms relating to Treaty actions]

\textsuperscript{69} According to the UN, a reservation is “a declaration made by a state by which it purports to exclude or alter the legal effect of certain provisions of the treaty in their application to that state. A reservation enables a state to accept a multilateral treaty as a whole by giving it the possibility not to apply certain provisions with which it does not want to comply … Reservations must not be incompatible with the object and purpose of the treaty. Furthermore, a treaty might prohibit reservations or only allow for certain reservations to be made.” [Source: UNTC -- Glossary of terms relating to Treaty actions]

\textsuperscript{70} For information, the then Mental Disability Advocacy Center (now called Validity) – an international human rights organisation – published a legal opinion which asserted Norway’s reservation to be incompatible with the “object and purpose” of the UNCRPD.

\textsuperscript{71} For further details, see: UN Treaty Collection, Convention on the Rights of Persons with Disabilities

\textsuperscript{72} For further details, see: FRA, 2015, Implementing the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (europa.eu)

\textsuperscript{73} Mental Health Europe, 2017, Autonomy, choice and the importance of supported-decision making for persons with psychosocial disabilities: MHE Position Paper on Article 12 UN CRPD on legal capacity
Further, a report from the European Network of National Human Rights Institutions and Mental Health Europe (2020) highlighted the retention of substitute decision-making in respect of the countries that they considered (including Ireland):

.. all countries in Europe still include some type of substitute decision-making schemes as a last resort. This means that, in many cases, where there is a choice between the two, substitute decision-making prevails over supported decision-making, which is problematic in view of compliance with the Convention. In addition, the UN CRPD Committee regularly reiterates that reforms that alter, but do not abolish, substitute decision-making continue to be in conflict with the Convention.

It is important to note as well that, while a legal framework can be positive in theory, very often it is not followed up by proper implementation and/or usage in practice.\textsuperscript{74}

A functional approach to capacity and the 2015 Act

According to Sage Advocacy\textsuperscript{76}, a functional approach to capacity can be understood as taking an approach whereby a person is supported either “to maximize their ability to make the decision themselves, or to maximize their participation in the decision-making process”.\textsuperscript{77} In this context, Sage Advocacy notes that, under a functional capacity approach, a person is deemed as lacking capacity to make a specific decision if they are unable to:

- to understand the relevant information;
- to retain this information for as long as needed;
- to use and weigh up this information as part of the decision-making process; or

\begin{quote}
A functional approach recognises that decision-making capacity can fluctuate and it is specific to the particular decision. Functional capacity is ‘issue specific and time specific’ … While a person may have difficulty or lack capacity to make some types of decisions it does not mean that the person lacks capacity to make other types of decisions. It also recognises that a person may lack decision-making capacity at one time, but not lack capacity if presented with the same decision at another time.
\end{quote}

\textit{Reproduced from Sage Advocacy}\textsuperscript{75}

\textsuperscript{74} European Network of National Human Rights Institutions and Mental Health Europe, 2020, \textit{Implementing supported decision-making: Developments across Europe and the role of National Human Rights Institutions}, 8 June 2020, p.11

\textsuperscript{75} \textit{Functional Approach to Capacity | Sage Advocacy}

\textsuperscript{76} Sage was established as a support and advocacy service for older people in June 2014 by the HSE and The Atlantic Philanthropies with the support of Third Age. With funding from The Atlantic Philanthropies ending in November 2017, Sage Advocacy subsequently assumed responsibility for the future development of the service. For further information, please see: \textit{About | Sage Advocacy}

\textsuperscript{77} Of note is that the concept of a functional approach to capacity was addressed by The Law Reform Commission in its report on \textit{Vulnerable Adults and The Law} (2006) and its consultation paper on \textit{Sexual Offences and Capacity to Consent} (2011),
• to communicate their decision by any means.\textsuperscript{78}

In the event that there are concerns in respect of a person’s capacity, Sage Advocacy notes that the 2015 Act establishes the basis for a range of “decision supporters” (or interveners) to support (in a tiered manner) the exercise of decision-making.\textsuperscript{79}

In the context of national legislation, Áine Flynn, Director of the Decision Support Service, acknowledged that the 2015 Act is considered by some as not fulfilling Ireland’s obligations under the UNCRPD:

The full commencement of the 2015 Act has been identified as essential to compliance with the United Nations Convention on the Rights of Persons with Disabilities, which Ireland ratified in 2018. It has been argued by some respected commentators that the 2015 Act fails to achieve full compliance with the Convention in that it retains as a last resort a form of substitute decision-making at the uppermost tier of the framework and applies a functional test of capacity to determine access to appropriate supports.\textsuperscript{80}

Further, Ireland has entered a declaration and reservation in respect of Article 12, which includes reserving the right to permit substitute decision-making arrangements:

\begin{shaded}
\textbf{Declaration and reservation: Article 12}

"Ireland recognises that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. Ireland declares its understanding that the Convention permits supported and substitute 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."

\textit{Reproduced from UN Treaty Collection}\textsuperscript{81}
\end{shaded}

Of note is that the specific feedback in respect of Article 12 in the summary document of submissions received by the Department of Children, Equality, Disability, Integration and Youth on the Draft Initial State Report under the UNCRPD included the contention that Ireland’s State Report “should outline plans to remove its reservation on Article 12” and outline how the State will “practically implement capacity legislation that is compliant with the Convention”.\textsuperscript{82} Ireland’s Initial

\textsuperscript{78} Functional Approach to Capacity | Sage Advocacy
\textsuperscript{79} ibid
\textsuperscript{81} UN Treaty Collection, Convention on the Rights of Persons with Disabilities
\textsuperscript{82} A Summary of the Submissions Received by the DCEDIY on the Draft Initial State Report UNCRPD, Short Version, August 2021, p.12
Report under the UNCRPD confirmed that it reserved the right to permit substitute decision-making arrangements, noting that:

The rationale for this declaration and reservation is to ensure that difficulties are not encountered in the operation of provisions in Part 5 of the Assisted Decision-Making (Capacity) Act 2015, which allow for the appointment of a decision-making representative to take specified decisions on behalf of a person and for the taking of certain decisions by a court on behalf of a person in limited circumstances.  

At national level, IHREC has focused on the issue of a functional approach to capacity in a number of submissions/commentaries, particularly in terms of its compliance with Article 12 of the UNCRPD. For instance, it highlighted concerns prior to the enactment of the 2015 Act in its commentary on Ireland’s implementation of the European Social Charter:

.. the Commission’s precursor body noted that the draft of the legislation was not compatible with the Convention on the Rights of Persons with a Disability in relation to legal capacity, mental capacity, and decision-making, but those concerns were not reflected in the amendments made to the Bill in its passage through the Irish parliament. The Act retains a functional assessment of mental capacity that can be used to restrict or deny legal capacity. The Commission is concerned that the Assisted Decision-Making (Capacity) Act 2015 fails to fully respect the rights of people to make decisions as provided for in the Convention on the Rights of Persons with a Disability.

Later, in a submission to the United Nations Human Rights Committee, IHREC asserted in respect of the 2015 Act that:

.. legislation now enacted retains a functional assessment of mental capacity that can be used to restrict or deny legal capacity, in contravention to the requirements of the Convention on the Rights of persons with a Disability (CRPD).

The Commission recommends the Committee asks the State to assess the compliance of the Assisted Decision Making (Capacity) Act 2015 with international human rights standards, including the CRPD.

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84 For instance, see IHRC (2014) IHRC Observations on the Assisted Decision-Making (Capacity) Bill 2013; see also IHREC (2018) Submission to the public consultation on Deprivation of Liberty: Safeguard Proposals
86 IHREC, 2020, Submission to the United Nations Human Rights Committee on the List of Issues for the Fifth Periodic Examination of Ireland, August 2020, p.35
In a recent contribution to a HSE publication on the 2015 Act, Professor Flynn acknowledged that a key achievement of a civil society coalition, which sought to “influence the development” of the 2015 Act, was the “the shift from ‘best interests’ to ‘will and preferences’ as a guiding principle of the legislation”. However, she also articulated concerns in respect of the capacity mechanisms within the 2015 Act:

The 2013 Bill used the functional test of mental capacity as a ground for depriving an individual of legal capacity through the appointment of a decision-making representative, and despite the best efforts of the coalition to change this, the 2015 Act retains this same approach. This represents, in my view, one of the most significant missed opportunities of the 2015 Act. We had come so far – we had convinced legislators of the need for supported decision-making to be the main focus of the Act. The drafters of the legislation had accepted that ‘best interests’ was no longer a valid principle to guide decision-making in respect of adults – a huge victory. However, with the retention of the functional test of mental capacity, we risked undoing all this progress.

Professor Flynn referenced the work of the coalition to introduce amendments to the Bill during its progress through the Houses which, ultimately, proved unsuccessful meaning that a functional assessment of mental capacity was retained as “the determining factor in whether a person can receive support, or whether she will have her legal capacity restricted or denied through the appointment of a decision-making representative”. Highlighting that additional international laws have been enacted that are compliant with General Comment No. 1, Professor Flynn contended that

Ireland can no longer argue that the shift away from functional tests of mental capacity towards respect for and, where necessary, a ‘best interpretation’ of will and preferences is impossible or without legal precedent. Together with others directly impacted by this law, I will continue to advocate for its reform, to bring Ireland fully into compliance with its obligations to respect the human rights of persons with disabilities.

Moreover, Professor Flynn problematises the processes involved in the assessment of functional capacity, noting that:

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87 This coalition, with which Professor Flynn worked, included organisations representing older people, people with disabilities and people with experience of the mental health services. It was co-chaired by the Centre for Disability Law and Policy (NUI Galway) and Amnesty Ireland.


89 ibid, p.110

90 ibid, p.111

91 ibid, p.111,112
.. studies suggest that the process of assessing an individual’s mental capacity, even on a functional basis, is inherently subjective and value-laden one. Therefore, the use of such assessments to restrict or deny legal capacity violates the requirement of objectivity demanded by human rights norms in order to avoid the categorization of disability-based discrimination.92

Such challenges associated with the subjective nature of functional assessment are reflective of General Comment No. 1, in which the UN Committee asserts that the use of a functional approach is “flawed for two key reasons”:

.. (a) it is discriminatorily applied to people with disabilities; and (b) it presumes to be able to accurately assess the inner-workings of the human mind and, when the person does not pass the assessment, it then denies him or her a core human right — the right to equal recognition before the law. In all of those approaches, a person’s disability and/or decision-making skills are taken as legitimate grounds for denying his or her legal capacity and lowering his or her status as a person before the law. Article 12 does not permit such discriminatory denial of legal capacity, but, rather, requires that support be provided in the exercise of legal capacity.93

Specifically, in respect of the 2015 Act, the Centre for Disability Law and Policy, NUI Galway, highlights a number of issues in respect of its compliance with the requirements of Article 12 of the UNCRPD, including:

- The requirement for a person to pass a function test of mental capacity in order to avail of the supports/assistance provided for under the Act. This is contrary to the requirements of Article 12 (and as expanded upon in the CRPD Committee’s General Comment No. 1 of 2014) which requires States to provide support the decision-making capacity of all individuals in order to give effect to their will and preferences.

- The potential for the appointment of a decision-making representative against the wishes of the individual (although such representatives will still be required to act with reference to the will and preferences of the individual).

- The inability of persons subject to involuntary treatment or who are subject to powers under the criminal law insanity provisions to enforce advance healthcare directives.

Reproduced from Centre for Disability Law and Policy, NUI Galway94

92 Flynn, E., 2019, “The rejection of capacity assessments in favor of respect for will and preferences: the radical promise of the UN Convention on the Rights of Persons with Disabilities”, World Psychiatry, Vol. 18 No. 1 Pages 50-51, p.50

93 UN Committee on the Rights of Persons with Disabilities (CRPD), 2014, General comment No. 1 (2014) - Article 12: Equal recognition before the law, 19 May 2014, CRPD/C/GC/1, p.4

94 Centre for Disability Law and Policy, 2017, A study on the Equal Recognition before the law: Contribution towards the Council of Europe Strategy on the Rights of Persons with Disabilities, NUI Galway, Centre for Disability Law and Policy, p.64
Wards of Court

The Lunacy Regulation (Ireland) Act, 1871 and Order 67 of the Rules of the Superior Courts 1986 govern the procedures involved in making an adult a Ward of Court. As previously outlined, an application can be made to the High Court to make a person a ward where they are deemed to lack capacity and are found, following a medical assessment, to be incapable of managing their affairs. The Court will make decisions based on the ‘best interests’ of the ward but there is no consultation with the ward.

According to Áine Flynn, the Director of the Decision Support Service:

“Almost 2,000 people have been made wards of courts since the Assisted Decision-Making (Capacity) Act 2015 was enacted. All adult wards will have their cases reviewed by the wardship court and must transition out of wardship within three years of commencement.”

In the Department’s opening statement to the Joint Committee during the PLS process, it set out an overview of the changes that the Bill will make to the wardship system:

Commencement of the 2015 Act will enable a fundamental change of the law on decision-making capacity to be brought into effect which will abolish wardship and provide persons with capacity difficulties – relevant persons – with access to new decision support options which are required to respect that person’s decision-making autonomy to the greatest extent possible. Once the Decision Support Service (DSS) becomes operational, people with capacity difficulties will have access to the agency mandated to enable them to avail of these new decision support options.

It also acknowledged the limitations of the General Scheme in fully reforming the law on capacity, specifically in relation to deprivation of liberty safeguards:

This is a complex area requiring careful deliberation. It is not possible for the General Scheme to address all of the issues which arise in such a fundamental reform of the law on capacity. The safeguards that will apply where a person is deprived of his or her liberty will be the subject of separate legislation which is currently being prepared by the Department of Health.

The Irish Human Rights and Equality Commission (IHREC) in its opening statement emphasised the vital need for such legislation while expressing concern as to the impact of the acceleration of the legislative process:

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95 DSS could assist up to 5,500 people in its first six months of operation | Decision Support Service
96 Department of Children, Equality, Disability, Integration and Youth, Statement to Joint Committee on Children, Equality, Disability, Integration and Youth, reproduced at Report on pre-legislative scrutiny of the General Scheme of the Assisted Decision-Making (Capacity) (Amendment) Bill 2021, April 2022, Appendix 3, p. 66
97 ibid
... for far too long we as a State have put up with a system of wardship, which is detached and divergent from any contemporary understanding of the concept of personal autonomy.

A strength of this new legislation lies in its greater assimilation of human rights standards as to privacy, expression, fair trial, liberty, association, stemming from our Constitution, the ECHR, the UNCRPD and the EU Charter of Fundamental Rights…

the Commission does hold concerns after years of delay, that such a significant piece of legislation is being moved at significant pace.98

A recent piece from Ms. Áine Hynes, Chair of the Law Society’s Task Force on Mental Health and Capacity Law, contended that there are “significant gaps” in the legislation “as it stands”, including the cessation of wardship applications in advance of the commencement of alternative provisions:

.. it is proposed that section 7(2) (which repeals the 1871 act) will take effect immediately on commencement of the 2015 act. Currently, applications in wardship take some three months to progress. Commencement of section 7(2) in tandem with the 2015 act means that the Office of the Wards of Court will not have sufficient time to progress applications that are received within a number of months of commencement of the 2015 act.99

Hence, she noted that the Law Society “strongly recommended” a phased implementation in order for the Office of Wards of Court to continue to progress and finish all applications received in advance of commencement of the 2015 Act and to ensure that there is no gap in provision:

It was noted that aspects of the proposed implementation plan could bring about unintended consequences that might cause undue hardship for families and carers, and deny access to justice for the most vulnerable in society.100

A notice101 was issued on 1 April 2022 by the Registrar of Wards of Court 2022 indicating that the Office of Wards of Court had been directed to stop accepting new wardship applications under section 15 of the Lunacy Regulation (Ireland) Act 1871 from 22 April 2022 in preparation for the commencement of the 2015 Act.102 However, on 12 May 2022, a Court notice indicated that the Office of Wards of Court would re-commence taking applications under section 15 of the Lunacy Regulation (Ireland) Act 1871 with immediate effect on the basis that transitional arrangements for “wardship applications in being” on commencement of the 2015 Act would be provided for in an amendment to that Act.103 Sections 39 to 43 of the Bill makes provision for such transitional arrangements.

98 Mr. Adam Harris, Irish Human Rights and Equality Commission, General Scheme of the Assisted Decision-Making (Capacity) (Amendment) Bill 2021: Discussion (Resumed), Joint Committee on Children, Equality, Disability, Integration and Youth debate 16 February 2022
99 Hynes, A., 2022, “Mind the gap”, Law Society Gazette, 6 May 2022
100 ibid
101 For further details, see: Notice In Relation to Applications for Wardship | The Courts Service of Ireland
102 Hynes, A., 2022, “Mind the gap”, Law Society Gazette, 6 May 2022
103 Wardship – Adults, Notice In Relation to Applications for Wardship | The Courts Service of Ireland
In addition to these procedural issues in respect of transitional arrangements for wardship applications, Ms. Hynes highlighted that whilst it was intended that 6 additional judges would be assigned to hear applications under the 2015 Act when it was first drafted, it is now not anticipated that additional Circuit Court judicial resources will be made available on commencement of the 2015 Act. Further, she asserted that:

.. there will be a considerable burden on Circuit Court office staff in familiarisation with, and processing of, the new form of applications under the act. Due to the processing time involved, it is unlikely that applications will be heard before the Circuit Court until October 2022.\(^\text{104}\)

A recent webinar hosted by the Courts Service of Ireland in conjunction with the Decision Support Service, outlined and explained the changes to wardship that will be brought about by the commencement of the remaining parts of the 2015 Act. It set out sample scenarios providing practical guidance on how to navigate the process and dealt with queries from attendees. It encouraged applications as soon as possible to ensure adequate time for transition within the three-year period accorded under the Bill. It also advised that the Office of the Wards of Court would be providing online Q&A sessions over the coming weeks.\(^\text{105}\)

At the time of writing, the outcome of a challenge is pending in relation to the constitutionality of the High Court’s wardship jurisdiction and the *Marriage of Lunatics Act, 1811*, and whether they are compatible with the *European Convention of Human Rights* and Ireland’s disability rights obligations. IHREC is acting as *amicus curiae* (friend of the court) in the proceedings where the person concerned has an intellectual disability and was prevented from marrying his fiancée following an application to have him made a ward of court.\(^\text{106}\) *Section 79* of the Bill amends *section 143* of the 2015 Act by deleting paragraphs (b) and (d) which provided for amendments to the *Civil Registration Act, 2004* concerning a lack of capacity to consent to marriage.

The Bill also provides for the assistance and support of a court friend or court assistant in the transition out of the wardship system. Section 41 of the Bill inserts a new section 54A into the 2015 Act setting out the assistance available to a ward during court proceedings where the capacity of the relevant person is being reviewed. Where the relevant person has no legal representation or a court friend or a court assistant as applicable, the court can direct the Director of the DSS to appoint a court friend for that person.


\(^\text{105}\) A Courts Service and Decision Support Service collaborative online information event - YouTube, 24 May 2022

The role of Disabled Persons Organisations (DPOs)

The Joint Committee’s PLS report referenced the role of DPOs across a number of its recommendations\(^\text{107}\), including those outlined below:

**Relevant recommendations from the Joint Committee’s PLS report:**

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.

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.

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.

The envisaged role of DPOs, as set out in the Joint Committee’s recommendations above, does not appear to be reflected in the Bill as published.

**Background**

In its opening statement to the Joint Committee as part of its PLS hearings, IHREC reiterated its appeal to ensure on-going meaningful involvement of stakeholders, particularly people with disabilities, in developing and implementing the Bill:

> We would restate our ask made first in respect of the original legislation in 2016 that, in line with CRPD obligations, every opportunity is afforded to a wide range of stakeholders, particularly people with disabilities, to meaningfully participate both in this pre-legislative scrutiny, and in a continued exchange with relevant stakeholders in the development of and implementation of this legislation.\(^\text{108}\)

In its PLS report, the Joint Committee observed that an almost unanimous theme from all contributors and submissions was that no meaningful or accessible consultation process was carried out during the development of the Bill. In particular, the call for submissions was made over the Christmas period and DPOs felt they were not given adequate time and opportunity to participate in the consultation process.\(^\text{109}\) In its introductory remarks, the Joint Committee made an initial general recommendation around the continued importance of stakeholder engagement:

\(^{107}\) Recommendations 59 and 64 relates specifically to the national monitoring mechanism role as per Article 33 of the UNCRPD.

\(^{108}\) Department of Children, Equality, Disability, Integration and Youth, Statement to Joint Committee on Children, Equality, Disability, Integration and Youth, reproduced at *Report on pre-legislative scrutiny of the General Scheme of the Assisted Decision-Making (Capacity) (Amendment) Bill 2021*, April 2022, Appendix 3, p. 67

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.\textsuperscript{110}

Distinct concerns were raised by several stakeholders during the hearings. These included issues around the accessibility and language of the legislation. Mr. Joe McGrath from the National Platform of Self Advocates shared his perspective on this:

This law is very important for us but we have not been given enough information about it. Since the law was passed seven years ago, no one from Government has told us what we need to do to get ready for it. Now the Government is planning to make more changes to this law before it will be up and running. The Government published a document with these changes that is almost 200 pages long. The language used in it is very complicated so we do not know what these changes will mean for us. This is not good enough. Everyone has the right to know what the law means for his or her life. There should be an easy-to-read version of the law so that we can understand it for ourselves.\textsuperscript{111}

Similarly, in its submission on the Bill, Independent Living Movement Ireland asserted that:

Given the importance of the Bill and the scale of the legislation to be reviewed (174 pages) and that the consultation period encompasses the year end, the timeframe places undue burden on Disabled Persons Organisations (DPOs) to organise participative spaces to fully review the legislation.\textsuperscript{112}

Further elaborating in his opening statement, Mr. Peter Kearns from Independent Living Movement Ireland stated that:

..the timeframe placed on responding by January this year placed undue burden on disabled persons organisations, DPOs, such as ILMI and others, to organise proper collective, participative spaces to fully review the legislation. It was a great chance to contribute to the discourse around the legislation but we were under undue pressure in terms of time.\textsuperscript{113}

\textsuperscript{110} ibid, p. 9.

\textsuperscript{111} Mr. Joe McGrath, National Platform of Self Advocates, General Scheme of the Assisted Decision-Making (Capacity) (Amendment) Bill 2021: Discussion (Resumed), Joint Committee on Children, Equality, Disability, Integration and Youth debate, 15 February 2022

\textsuperscript{112} Independent Living Movement Ireland submission on the Assisted Decision-Making (Capacity) (Amendment) Bill 2021, 21 January 2022

\textsuperscript{113} Mr. Peter Kearns, Independent Living Movement Ireland, General Scheme of the Assisted Decision-Making (Capacity) (Amendment) Bill 2021: Discussion (Resumed), Joint Committee on Children, Equality, Disability, Integration and Youth debate, 15 February 2022
This was reiterated by the National Federation of Voluntary Service Providers who also stressed the significant impact that the legislation will have on people’s lives and thus the need for prompt, clear and targeted information and training campaigns.\textsuperscript{114}

**The role of DPOs in respect of the assisted decision-making mechanism**

In [General Comment No. 1](#) (2014), the UN Committee specifically highlighted the importance of closely involving DPOs in the development and implementation of policy and legislative processes relating to Article 12:

.. States parties should take the following steps to ensure the full implementation of article 12 of the Convention on the Rights of Persons with Disabilities:

(a) Recognize persons with disabilities as persons before the law, having legal personality and legal capacity in all aspects of life, on an equal basis with others. This requires the abolition of substitute decision-making regimes and mechanisms that deny legal capacity and which discriminate in purpose or effect against persons with disabilities. It is recommended that States parties create statutory language protecting the right to legal capacity on an equal basis for all;

(b) Establish, recognize and provide persons with disabilities with access to a broad range of support in the exercise of their legal capacity. Safeguards for such support must be premised on respect for the rights, will and preferences of persons with disabilities. The support should meet the criteria set out in paragraph 29 above on the obligations of States parties to comply with article 12, paragraph 3, of the Convention..

*Source: [General Comment No. 1](#)\textsuperscript{115}*

Further, in [General Comment No. 7](#) (2018), the UN Committee again highlighted the centrality of role of DPOs\textsuperscript{116} in decision-making processes. For instance, Paragraph 13 (below) states that States parties should give particular importance to DPOs, including supporting the capacity and development of such organisations. In addition, the Committee asserts that priority should be given

\textsuperscript{114} Dr. Alison Hartnett, Chief Executive, National Federation of Voluntary Service Providers, [General Scheme of the Assisted Decision-Making (Capacity) (Amendment) Bill 2021: Discussion (Resumed), Joint Committee on Children, Equality, Disability, Integration and Youth debate, 15 February 2022](#)

\textsuperscript{115} UN Committee on the Rights of Persons with Disabilities (CRPD), 2014, [General comment No. 1 (2014) - Article 12: Equal recognition before the law](#), 19 May 2014, CRPD/C/GC/1, p.12-13

\textsuperscript{116} In its guidelines on the participation of disabled persons’ organisations and civil society, the UN Committee defined DPOs as follows: “The Committee understands disabled persons’ organizations as those comprising a majority of persons with disabilities – at least half their membership – and governed, led and directed by persons with disabilities”. [Source: UN Committee on the Rights of Persons with Disabilities, [Guidelines on the Participation of Disabled Persons Organizations (DPOs) and Civil Society Organizations in the work of the Committee](#), CRPD/C/11/2 (April 2014) paragraph 3, Annex II in: Report of the Committee on the Rights of Persons with Disabilities on its eleventh session (31 March–11 April 2014)]
to ascertaining the views of people with disabilities in the course of decision-making processes.

13. Organizations of persons with disabilities should be distinguished from organizations “for” persons with disabilities, which provide services and/or advocate on behalf of persons with disabilities, which, in practice, may result in a conflict of interests in which such organizations prioritize their purpose as private entities over the rights of persons with disabilities. States parties should give particular importance to the views of persons with disabilities, through their representative organizations, support the capacity and empowerment of such organizations and ensure that priority is given to ascertaining their views in decision-making processes.

Source: General Comment No. 7

In this context, a discussion paper from the Global Disability Summit (2022) highlights that participation within the UNCRPD “takes a new scope and purport, as both a process and an outcome”, with the full and effective participation of persons with disabilities in society on an equal basis with others recalled in the purpose of the Convention (Article 1), as a general principle (Article 3), as a general obligation (Article 4,3), and a cross-cutting issue under specific rights, such as the right to participate in political and public life. Further, this discussion paper notes that:

The nature of engagement is further qualified through numerous references of “full and effective” participation and mentions specifically “partnerships” in context of international cooperation. With these qualifiers, the CRPD adds another layer of obligation to States that participation is not just about a right but that certain parameters must be met to ensure that persons with disabilities and their representative organizations are meaningfully and actively engaged.

The “added value” of the DPOs includes promotion of ownership over actions, promotion of accountability (e.g. acting as a watchdog/monitoring compliance), contribution to better outcomes and promotion of agency and empowerment. However, in General Comment No. 7, the UN Committee establishes a number of obligations on States to “guarantee effective and meaningful participation of persons with disabilities” through DPOs, which the Global Disability Summit (2022) discussion paper observe can be characterised as “pre-conditions for meaningful participation”. These obligations of State Parties include:

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117 UN Committee on the Rights of Persons with Disabilities (CRPD), 2018, General comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention*, 9 November 2018, CRPD/C/GC/7, p.4
118 Global Disability Summit (GDS) Discussion Paper, 2022, p.9
119 ibid, p.10
120 ibid, p.12
121 ibid, p.13
• An obligation to ensure the transparency of consultation processes, the provision of appropriate and accessible information and early and continuous involvement. (Paragraph 43)
• An obligation to ensure accessibility for persons with disabilities to all facilities and procedures related to public decision-making and consultation. (Paragraph 45)
• An obligation to provide organisations of persons with sensory and intellectual impairments with meeting assistants and support persons, information in accessible formats (such as plain language, Easy Read, alternative and augmentative communication systems and pictograms), sign language interpretation, guide interpreters for deafblind persons and/or captioning during public debates. (Paragraph 46)\textsuperscript{122}

Specifically in respect of undertaking and conducting consultations with DPOs, General Comment No. 7 suggests that State Parties may undertake:

Consultations with organizations of persons with disabilities should be based on transparency, mutual respect, meaningful dialogue and a sincere aim to reach a collective agreement on procedures that respond to the diversity of persons with disabilities. Such processes should allow for \textit{reasonable and realistic timelines} taking into account the nature of the organizations of persons with disabilities, which often depend on the work of “volunteers”. States parties should undertake periodic evaluations of the functioning of their participation and consultation mechanisms, with the active involvement of organizations of persons with disabilities.\textsuperscript{123} [\textit{emphasis added}]

Further, General Comment No. 7 obliges State Parties to support capacity and resource building within DPOs with a view to facilitating participation in all stages of policy-development:

States parties should strengthen the capacity of organizations of persons with disabilities to participate in all phases of policymaking, by providing capacity-building and training on the human rights model of disability, including through independent funding. States parties should also support persons with disabilities and their representative organizations in the development of the competencies, knowledge and skills required to independently advocate for their full and effective participation in society, and in developing stronger democratic governance principles, such as respect for human rights, the rule of law, transparency, accountability, pluralism and participation. In addition, States parties should provide guidance on how to access funding and diversify their sources of support.\textsuperscript{124}

Finally, in respect of decision-making processes and the development of legislation, General Comment No. 7 asserts that:

\textsuperscript{122} UN Committee on the Rights of Persons with Disabilities (CRPD), 2018, \textit{General comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention*}, 9 November 2018, CRPD/C/GC/7, p.9
\textsuperscript{123} ibid p.9
\textsuperscript{124} ibid, p.11
To fulfil their obligations under article 4 (3), States parties should adopt legal and regulatory frameworks and procedures to ensure the full and equal involvement of persons with disabilities, through their representative organizations, in decision-making processes and the drafting of legislation and policies concerning issues related to persons with disabilities, including disability-related legislation, policies, strategies and action plans. States parties should adopt provisions granting organizations of persons with disabilities seats on, for example, standing committees and/or temporary task forces by giving them the right to nominate working members to these bodies.\textsuperscript{125}

**Monitoring the implementation of the UNCRPD**

**Article 33 – National implementation and monitoring**

1. States Parties, in accordance with their system of organization, shall designate one or more focal points within government for matters relating to the implementation of the present Convention, and shall give due consideration to the establishment or designation of a coordination mechanism within government to facilitate related action in different sectors and at different levels.

2. States Parties shall, in accordance with their legal and administrative systems, maintain, strengthen, designate or establish within the State Party, a framework, including one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation of the present Convention. When designating or establishing such a mechanism, States Parties shall take into account the principles relating to the status and functioning of national institutions for protection and promotion of human rights.

3. Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.

*Source: UNCRPD, Article 33*

Article 33 of the UNCRPD establishes that States must set up national focal points within governments to monitor implementation of the Convention. In addition, States must establish independent monitoring mechanisms – which usually takes the form of an independent national human rights institution.\textsuperscript{126} Further, the UN Department of Economic and Social Affairs advises that the full participation of civil society, in particular persons with disabilities and their representative organisations is essential in the national monitoring and implementation process.\textsuperscript{127}

\textsuperscript{125} ibid, p.10
\textsuperscript{126} Monitoring of the Implementation of the Convention, UN Department of Economic and Social Affairs (accessed 21 May 2021)
\textsuperscript{127} Monitoring of the Implementation of the Convention, UN Department of Economic and Social Affairs (accessed 21 May 2021).
Turning specifically to Article 33 (3), the Committee asserts that priority should be given to people with disabilities and DPOs. Further, a report from the Centre for Disability Law and Policy, NUIG and IHREC asserted that this Article should be read in conjunction with Article 4.3, which applies to the entirety of treaty (see overleaf). This report notes that this enshrines the principle of ‘nothing about us without us’, which is a common slogan of the disability rights movement.128

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

Source: UNCRPD

In its report on establishing a monitoring framework at national level for the UNCRPD, the Centre for Disability Law and Policy and IHREC set out three options for considerations:

- Option 1: Designation of the IHREC as a Single-Body Independent Mechanism;
- Option 2: Designation of a Multi-Body Mechanism without DPO Engagement;
- Option 3: Designation of a Multi-Body Framework with DPO Engagement.129

It asserted that Option 3 seemed “the most appropriate in the Irish context, given the current landscape of DPOs and civil society organisations that advocate on disability rights”130. Specifically, it concluded that:

In keeping with the spirit and purpose of the CRPD, and in acknowledgment of the current Irish civil society and DPO landscape, the research team’s recommendation would be for the Commission to be jointly designated as the monitoring framework with an advisory committee composed of a diverse group of people with lived experience of disability.131

Section 86 of the Assisted Decision-Making (Capacity) (Amendment) Bill 2022 creates a statutory basis for IHREC’s132 role in the monitoring framework in relation to the UNCRPD.133

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129 ibid, p.71-74
130 ibid, 2016, p.74
131 ibid, 2016, p.74
132 IHREC in its role as a National Human Rights Institution (NHRI) has acted as an independent monitoring mechanism for UNCRPD in Ireland, working with the National Disability Authority to carry out this task. Further, noting that Article 33 of the Convention states that people with disabilities must be part of the monitoring process, IHREC established a Disability Advisory Committee to ensure the direct participation of persons with disabilities and the organisations representing them in monitoring how the Convention is implemented in Ireland. [Source: The Convention on the Rights of Persons with Disabilities - IHREC - Irish Human Rights and Equality Commission (last accessed 31 May 2022)]
133 Explanatory Memorandum
to be more consistent with Option 1 (as opposed to the Option 3 which was recommended), which was assessed as follows:

This approach of designation has the advantage of simplicity and clarity – providing a single location for coordinating all monitoring activity under Article 33, and ensuring that the scope, functions and powers of the mechanism are clear to all stakeholders, as these will be based on the legislation already governing the Commission. However, … the CRPD Committee has been critical of the designation of single-body mechanisms if this occurs without providing the necessary resources to ensure the mechanism can fulfill its function. Further, without a dedicated process to build capacity in and engage with civil society, particularly DPOs, the validity of the mechanism is likely to be challenged by the CRPD Committee and by the representative organisations of people with disabilities in Ireland.

Further, Option 1 does not appear to involve DPOs in the manner consistent or envisaged by Article 33(3) of the UNCRPD:

While states are clearly obligated to include persons with disabilities and DPOs in the monitoring process, the exact form this participation shall take is left unclear. It should be noted, however, that Article 33.3 calls for ‘participation’, which is a stronger requirement than consultation. It should also be noted that the article requires that people with disabilities be allowed to participate separate from the participation of DPOs, if they so choose.\(^{134}\)

This is in keeping with IHREC’s observations on the General Scheme of the Equality / Disability (Miscellaneous Provisions) Bill, which stated that:

The Commission reiterates its recommendation that apart from the advisory committee proposed under Article 33.2 CRPD, appropriate formal mechanisms be put in place to ensure that all aspects of Ireland’s Article 33 infrastructure, including the focal point and coordination mechanism, are fully visible and accessible to persons with disabilities, in keeping with Articles 4.3 and 33.3 CRPD.\(^{135}\) (emphasis in original)

Concerning Ireland’s fulfilment of its obligations in respect of DPOs, of particular note is that a range of general issues/key concerns in respect of DPOs were raised in submissions to the consultation process on Ireland’s draft Initial State Report\(^{136}\), including that:


\(^{136}\) The Department of Children, Equality, Disability, Integration and Youth (DCEDIY) prepared this draft Initial State Report, which was published for consultation in December 2020 (open to submissions up to 9th April 2021). In addition, three half-day online stakeholder consultation events were hosted by the DCEDIY in March and April 2021. Following this consultation process, Ireland’s Initial State Report under the UNCRPD was finalised and submitted to the UN. For further information, see: Ireland’s first report to the
DPOs expressed the view that they are not yet adequately embedded in structures for monitoring disability strategies, and do not feel they are being duly recognised and prioritised in participation and consultation processes run by Government bodies, as required under Article 4.3 of the Convention and further to General Comment No. 7 of the Committee.

UN under the Convention on the Rights of Persons with Disabilities | Consultation draft published by Disabilities Minister Anne Rabbitte on International Day of People with Disabilities (www.gov.ie) and Minister Rabbitte announces Stakeholder Consultation on Ireland's first report to the UN under Convention on the Rights of Persons with Disabilities (www.gov.ie)

For instance, in respect of urgent actions required, the Disability Participation and Consultation Network stated that: “Persons with disabilities and Disabled Person’s Organisations (DPOs) are the heart of the Convention. This is not reflected in the State’s Draft Report. A differentiation must be made between DPOs and non-DPOs. DPOs must be recognised and prioritised. The State must commit to the adequate funding of DPOs to support the participation and representation of persons with disabilities. [Source: The Disability Participation and Consultation Network’s Response to the State’s Draft Report on the United Nations Convention on the Rights of Persons with Disabilities, April 2021]

Appendix 1 Examples of Decision Support Arrangements

A Guide to the Decision Support Service (DSS)

What is the Decision Support Service?
The DSS is a new service under the Assisted Decision-Making (Capacity) Act, 2015. Anne Flynn is the Director of the DSS. The DSS is not operational yet and work to establish the service is underway.

The role of the Decision Support Service will be:
- to regulate and register decision support arrangements, there will be a register of these arrangements that will be open to inspection
- to supervise the actions of the legally appointed decision support
- to maintain a panel of decision-making representatives, special and general visitors and court friends
- to investigate complaints made under the Act
- to promote awareness and provide information about the Act

Once commenced, the Act will help to ensure that Ireland is compliant with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)
The Wards of Court system for adults will be abolished. Adult wards will have their cases reviewed within three years after the commencement of the Act.

Examples of Decision Support Arrangements

Decision-Making Assistant Agreement (DMAA)
Breda, who is a widow, has some memory problems and sometimes struggles to understand certain information about her personal finances. Breda agrees that her daughter, Mary, will help her with decisions about her bank accounts, her pension and her bills. Mary will access relevant records and information on her mother and support her to understand and communicate the decisions she needs to make. Breda will continue to make her own decisions. Mary can only do as much as is agreed with her mother in the DMMA.

Co-Decision-Making Agreement (CDMA)
Francis, who has an intellectual disability, wins £5m in the Lotto. There are concerns about Francis’s ability to manage such a large sum of money, Francis is able to appoint his brother Keith as his co-decision-maker so that he and Keith can make decisions jointly about the money. Francis and Keith submit a CDMA to be registered with the DSS, which will supervise how the agreement works in practice.

Decision-Making Representation Order (DMRO)
Paul was involved in a motorcycle accident and has acquired a brain injury. He no longer has capacity issues and needs someone to make decisions on his behalf relating to his personal welfare and his property and affairs. His wife Blanche makes an application to the Circuit Court. The court makes a declaration of incapacity in relation to certain matters. The DSS registers the DMRO with Blanche named as her husband’s decision-making representative. The DSS will supervise how the DMRO works in practice and the court will keep the incapacity declaration under review.

Enduring Power of Attorney (EPA)
Sancha is married, has no capacity issues and has bought her first house. She creates an instrument for an EPA. She names her husband as her attorney so that he can make decisions if she loses capacity in future. Sancha acquires a brain injury as a result of a stroke and now has capacity issues. Her husband registers the EPA with the DSS, which will supervise how the EPA works in practice.

Advance Healthcare Directive (AHD)
Betty is in good health but wants to record her future will and preferences for medical treatment should she lose her capacity to make decisions. Betty makes an AHD, which is witnessed and registered with the DSS. She appoints her sister as her designated healthcare representative to act as her agent and to ensure that her family and healthcare team understand and interpret the terms of her AHD correctly.

Reproduced from DSS

Leafllet, DSS (decisionsupportservice.ie), November 2019
Appendix 2 Key terms in respect of the DSS

The DSS explains the key terms associated with the 2015 Act and the DSS and a selected number of these are set out in the box below.

Box 1 Key terms

**Advanced healthcare directive:** A legally recognised arrangement that lets you plan ahead for healthcare and treatment decisions. It lets you set out your wishes about these types of decisions in case you are unable to make these decisions sometime in the future.

**Capacity/Decision-making capacity:** A person’s ability to make decisions for themselves. Under the new law, this will be based on the person’s ability to make a specific decision at a specific time.

**Capacity assessment:** An assessment used to confirm if a person has the ability to make certain decisions for themselves. A person will have the capacity to make a decision if they can demonstrate all of the following:
- Understand the information relevant to the decision
- Recall that information long enough to make a choice
- Use or weigh up the information to make a decision
- Communicate their decision (or someone is able to communicate it on their behalf)

**Co-decision-maker:** A person who has the authority to make certain decisions together with you if you need support to make decisions. You can appoint someone you know and trust to be your co-decision-maker by making a legally recognised arrangement called a co-decision-making agreement.

**Co-decision-making agreement:** A legally recognised arrangement that you can make if you are unable to make certain decisions for yourself and require support. It lets you set out the types of decisions you want help with and give a person you know and trust the authority to make them together with you.

**Court friend:** A trained person who can support you if there is an application to the court about your ability to make certain decisions. The court can appoint a court friend to you if you do not have anyone else to help you with this. We will set up and maintain a panel of people who can perform this role.

**Decision-making assistance agreement:** A legally recognised arrangement that you can make if you need support to make certain decisions for yourself. It lets you give someone you know and trust the legal authority to help you, by gathering information and helping you to understand it.

**Decision-making assistant:** A person who has the authority to help you when you are making certain decisions for yourself. You can appoint someone you know and trust to be your decision-making assistant by making a legally recognised arrangement called a decision-making assistance agreement.
Decision-making representation order: A legal arrangement made by an order from the court. The court can appoint a person to make certain decisions on your behalf if you are unable to make them for yourself. This person is called a decision-making representative.

Decision-making representative: A person appointed by the court to make certain decisions on your behalf if you are unable to make them for yourself. Where possible, the court will appoint someone you know and trust in this role. If there is no one suitable who is able to do the role, the court can appoint a decision-making representative from a panel of trained experts maintained by us.

Decision support arrangements: An umbrella term for all of the legally recognised arrangements to support people who have challenges with their capacity to make certain decisions. There will be five different arrangements available. These arrangements are based on the type of support that a person needs to make a specific decision at a specific time. They include arrangements for people who would like to plan ahead.

Decision supporter: An umbrella term for any person who is given the legal authority to support someone with capacity challenges to make certain decisions. They must be appointed to their role in a legally recognised arrangement called a decision support arrangement. The type of support they can provide depends on the type of arrangement in place.

Enduring power of attorney: A legally recognised arrangement that lets you plan ahead for a time when you may be unable to make certain decisions for yourself. It lets you set out the types of decisions you may need help with and appoint someone you know and trust to make them on your behalf. This person is called an ‘attorney’ but does not have to be a lawyer.

Expert panels: A panel of trained experts that will be recruited and maintained by the Decision Support Service. They will help us perform a number of our functions. We will have panels of experts who can act as:

- Decision-making representatives
- General visitors
- Special visitors
- Court friends

General visitor: A trained expert who will help us to check that a decision support arrangement is working like it should. We will set up and maintain a panel of general visitors to help us with our work.

Personal welfare decisions: Decisions about a person’s interests, health and wellbeing. These types of decisions can include:

- Accommodation
- Employment
- Education and training
- Social activities
- Social services
- Healthcare
- Other matters about a person’s well-being
**Property and affairs decisions:** Decisions about property, business and money matters. These types of decision can include:

- Managing property, including purchasing good and services
- Selling, mortgaging or disposing of property
- Buying property
- Business decisions
- Ending a partnership
- Carrying out a contract
- Managing debts and taxes
- Exercising the powers of a tenant for life
- Providing for the needs of other people
- Court proceedings
- Applying for social services

**Register:** We will keep the details of decision support arrangements in a searchable register. Each register will allow certain professionals, organisations and members of the public to confirm whether or not a decision support arrangement exists. In some circumstances, it will also let them access the content of the decisions in the arrangement. We will keep a register of the following arrangements:

- Co-decision-making agreements
- Decision-making representation orders
- Enduring powers of attorney

**Special visitor:** A trained expert who can help us to check if a person has the capacity to make certain decisions. We will set up and maintain a panel of special visitors to help us with our work.

*Reproduced from DSS*¹⁴⁰

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¹⁴⁰ [Key Terms | Decision Support Service](#)