



The Assisted Decision-Making (Capacity) Act 2015 and the Establishment of the Decision Support Service

In this statement I propose to set out the key reforms introduced by the Assisted Decision-Making (Capacity) Act 2015, to provide an update on the Decision Support Service (DSS) establishment project, including timelines and dependencies and throughout to comment on how the 2015 Act interfaces with the United Nations Convention on the Rights of Person with Disabilities (CRPD).

The Assisted Decision-Making (Capacity) Act 2015 is significant and long-awaited legislation. According to its long title, it is

“An Act to provide for the reform of the law relating to persons who require or may require assistance in exercising their decision-making capacity, whether immediately or in the future...”

The signing of the Act on 30 December 2015 followed a protracted legislative process and extensive consultation and it has been broadly welcomed as reforming, human rights-based legislation. On enactment, it was described by Inclusion Ireland as “a seismic cultural shift away from a paternalistic and ‘best interests’ approach to a rights-based approach of choice, control and consent”.

The Act applies only to adults and according to early estimates provided by the Department of Justice, as many as 220,000 adults could potentially benefit from the new statutory framework. This figure includes adults with decision-making capacity difficulties due to intellectual disability, acquired brain injury, enduring mental illness and age-related cognitive impairment.

It would be wrong, however, to presume that any one of those 220, 000 people will necessarily come within the ambit of the Act. That will depend on their individual circumstances. Equally, it would be a mistake to think that this legislation is targeted at or belongs to a particular cohort of people. Any of us could experience difficulties with our decision-making capacity in the future, due to illness or injury and the Act provides important tools for advance planning. Therefore, this really is an Act for everyone.

Although fully enacted, the 2015 Act is largely not yet commenced and intensive work to prepare for commencement is ongoing.

Commencement of the Act has been identified as a priority in the current programme for government and essential to compliance with CRPD. The 2015 Act is regarded by the State as the principal legislative reform required to give full effect to its obligations under Article 12 of the CRPD, 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.”

I am aware that other stakeholders who have appeared before this Committee have called for the Act to be operationalised as a matter of urgency and their impatience is understandable.

I will turn now to the key reforms contained in the 2015 Ac. These may be summarised as follows:

Abolition of wardship

The Act abolishes the wards of court system, which currently operates under the Lunacy Regulation (Ireland) Act 1871. When a person is taken into wardship, the court declares the person to be ‘of unsound mind and incapable of managing his or her person or property’. This has been described as a blunt instrument. In 2019, the Supreme Court acknowledged that an order for wardship,

".. can deprive a person of the power to make many of the choices which are fundamental and integral to day-to-day life. Orders can be over-broad in their effect and disproportionate in their scope".

Following commencement of the 2015 Act, there will be no further applications for wardship, and all current wards will have their cases reviewed by the wardship court within three years. These wards may have their assets and their autonomy fully restored or, where appropriate, will transition to the new supports available under the 2015 Act. The DSS understands that there are approximately 2,300 such adult wards at present.

The Act also repeals the Marriage of Lunatics Act of 1811 and this came into effect on 1 February, so that wards are no longer prohibited from marrying. Significantly, these antique acts from 1811 and 1871 are the only two pieces of legislation which the 2015 Act repeals. There is nothing else to repeal. The 2015 Act introduces structure and regulation to the area of decision-making and capacity, where currently we often operate based on custom and practice. There is a tenacious but unfounded proposition that the 'next of kin' enjoys some presumed status as a substitute decision-maker who can supply or withhold consent on behalf of another adult. There is no legal basis for such a proposition

Functional assessment of capacity

Under the Act, capacity is defined in a time-specific and issue-specific way.

Section 3 states:

A person's capacity is assessed on the basis of his or her ability to understand at the time that a decision is to be made, the nature and consequences of the decision to be made by him or her in the context of the available choices at the time.

Incapacity is not a status as in wardship and is not linked to a medical diagnosis. The intention of the 2015 Act was to adopt a disability-neutral approach, so that, a person lacks capacity in respect of particular decision if he or she is unable to:

- understand the information relevant to the decision
- retain that information long enough to make a voluntary choice
- use or weigh up the information

- communicate his or her decision, with assistance if necessary

This is already the applicable standard at common law, having been articulated by the High Court more than 12 years ago. The functional assessment has already been adopted in standards and policy, including the HSE National Consent Policy and the Irish Medical Council's Guide to Professional Conduct and Ethics.

Guiding principles

Section 8 of the Act sets out a number of important guiding principles to ensure the rights of the 'relevant person', who is defined as 'a person whose capacity is in question or may shortly be in question' in respect of one or more than one matter'.

As we see it, the 2015 Act's fundamental purpose is to ensure that the relevant person is supported to make his or her own decisions as far as possible

The guiding principles include:

- the presumption of capacity;
- a relevant person shall not be considered to lack capacity to make a decision, unless all practicable steps have been taken to help him or her to do so;
- a person is not considered to lack capacity on the basis of having made or being likely to make an unwise decision;
- minimal restriction of the relevant person's rights and freedom of action;
- respect for dignity, bodily integrity, privacy, autonomy and control over one's affairs;
- respect for a person's past and will and preferences
- to act in good faith and for the benefit of the relevant person

Respect for will and preferences has been held up by the UN Committee for CRPD as essential to Article 12. The Committee has emphatically rejected any approach based on a person's 'best interests. 'Best interests' as a standard is not mentioned anywhere in the 2015 Act. It is notable and encouraging that the recent statutory instrument to facilitate the COVID-19 vaccination programme contains a requirement to ascertain the will and preferences of a person who cannot supply consent. ' We

understand that this is the first reference to will and preferences in legislation other than in the 2015 Act itself.

At present, the guiding principles apply only to 'interveners' as defined. The DSS has called for an amendment to broaden the remit of the guiding principles so that they are of general application.

Three-tier framework of supports

'Decisions' under the Act are broadly defined and divided into two categories: property and affairs and personal welfare, including healthcare. All such decisions are capable of being supported within the new graduated framework.

At the lowest, least formal level on the framework, the relevant person may appoint a decision-making assistant to help to gather up and interpret information and communicate the relevant person's decision. The relevant person is still the decision-maker.

At the middle tier, a relevant person may register a co-decision-making agreement, under which specified decisions are made jointly with an appointed, trusted person.

At the upper level, there is provision for an application to the Circuit Court by any person who has a *bona fide* interest in the welfare of the relevant person. Foreseeably, the applicant will often be a family member or carer, or the HSE, as in the case in a significant number of wardship applications. The court may make a declaration in that the relevant person lacks capacity in respect of a specified decision or decisions. The court may either make the decision or may appoint a decision-making-representative, to make decisions on behalf of the person, under the supervision of the Decision Support Service.

In its General Comment 1, the Committee for the CRPD interpreted Article 12 as prohibiting substitute decision-making. At the time of ratification of the CRPD, the State, entered a declaration permitting the retention of substitute decision-making 'in appropriate circumstances and subject to appropriate and effective safeguards.'

Therefore, orders for substitute decision-making should be made as a last resort and only where lower-tier supports have been considered and discounted. The court must apply all of the guiding principles, having regard to the known will and preferences of the relevant person. Orders must be limited where possible in terms of time and scope, subject to periodic review and may be re-entered before the court by the relevant person.

In line with Article 13 CRPD guarantees of right of access to justice, the Act provides for the relevant person to be heard by the court and to have access to representation and to legal aid.

Advance Planning

The 2015 Act provides two tools for advance planning to allow a person to plan ahead in case he or she loses capacity in the future.

- Enduring Power of Attorney (EPA)

EPAs may already be created under the Powers of Attorney Act 1996. The scope of an EPA is extended under the 2015 Act so that an attorney may now be appointed to take decisions in healthcare matters. Attorneys under the 2015 Act will now be subject to a new form of supervision by the DSS.

- Advance Healthcare Directives (AHD)

AHDs are placed on a statutory basis under Part 8 of the Act, the part of the Act which is the responsibility of the Department of Health. The purpose of an AHD is to allow a person to be treated according to their will and preferences and to provide healthcare professionals with information about persons' treatment choices. A person may also appoint an agent, known as a designated healthcare representative in the AHD, to ensure that his or her AHD is complied with.

Part 8 states that the Minister for Health *may* make regulations to provide for the notification of a making of an advance healthcare directive to the Director of the Decision Support Service and for the Director to maintain a register of advance healthcare directives. It is the view of the DSS that these regulations would enhance the operation of Part 8 and would benefit the person and healthcare professionals alike. However, we are informed by the Department of Health that the absence of

unique health identifiers is an obstacle that must be overcome before these regulations can be written.

Certain other matters in Part 8 require attention by the Department of Health. The DSS and the Mental Health Commission has called for the amendment of a section which provides that an advance healthcare directive is not effective if the person is detained under the Mental Health Acts and purporting to refuse mental health treatments. It is our stated view that this is discriminatory. The section dealing with the applicability of advance healthcare directives in pregnancy also requires review following other legislative changes since the Act was passed.

Establishment of the Decision Support Service

The 2015 Act establishes the office of the Decision Support Service (DSS) within the Mental Health Commission (MHC). The MHC has proved to be a very good home for the DSS, as it has important experience of applying reforming human rights legislation to develop new structures. The support of MHC colleagues has been invaluable to the DSS establishment project.

The principal functions of the Director are:

- to promote public awareness in relation to the Act and related matters, including CRPD
- to provide information and guidance
- to set up a website
- to establish and maintain searchable registers of decision support arrangements
- to regulate and supervise the activities of 'decision supporters'
- to receive and investigate complaints
- to appoint four separate panels of suitable persons to assist with certain statutory functions
- to furnish reports to the Ministers and make recommendations on the operation of the Act
- to act as the Central Authority under the Hague Convention for the International Protection of Adults

Statement to Joint Oireachtas Committee on Disability Matters 20 May 2021

The Director may also publish a suite of codes of practice to provide guidance, including guidance for certain categories of professionals.

In general terms, the Act provides for significant regulation and oversight of the new support arrangements, and this in keeping with the requirement under Article 14 CRPD to ensure liberty and security of the person.

Update on the DSS Establishment Project and Dependencies

Responsibility for the 2015 Act and the DSS transferred from the Department of Justice to the new Department of Children, Equality, Disability, Integration and Youth (DCEDIY) in October 2020. The level of engagement with and the support of the new department and of the Minister of State for Disability have been very welcome.

An Inter-Departmental Steering Group for the implementation of the DSS has been in place since 2016. It is now chaired by DCEDIY with membership from the MHC/DSS, the Courts Service, the HSE National Office for Human Rights and Equality Policy, the Department of Health and the Department of Justice.

I was appointed to the post of Director in October of 2017 at a time when the only blueprint for the establishment of the DSS was the Act itself. The project is well underway and comprises six workstreams with 28 subprojects. Progress has continued without interruption while we have been working remotely during the last 14 months. The project is subject to detailed oversight and reporting requirements, internally and externally.

Our vision for the DSS is for a person-centred, accessible service with a digital first approach, while we must accommodate the challenges that some of our stakeholders may experience with digital literacy and connectivity.

Key milestones to date within the establishment project have included:

- the appointment of an experienced DSS senior management team;
- development of our organisation design and workforce planning strategy;

- mapping of approximately 60 detailed business processes;
- policy development;
- development of proposals around fees for our services, noting that costs must not be a barrier to those accessing our service;
- commencement of the ICT project with departmental approval; a provider has been procured and has been in place since July 2020;
- the review of codes of practice drafted by the National Disability Authority and the HSE Ministerial Working Group, in preparation for public consultation;
- launch of our website in August 2020;
- demand forecasting to support our planning activities;
- preparations for panel recruitment;
- extensive and diverse stakeholder engagement, including the procurement of Inclusion Ireland to facilitate focus groups of potential future service users
- development of our communications plan

At the request of the Department of Justice, a detailed 24-month, costed plan for the establishment of the DSS was presented to the Inter-Departmental Steering Group at the beginning of 2020.

This proposes that the DSS would commence operations in mid- 2022. This plan was approved by the Steering Group members. The requested uplift in budget allocation was achieved for 2021 and the DCEDIY had publicly committed to a date for full commencement of the Act of 20 June 2022.

Dependencies

As set out in our 24-month plan, the timeline for commencement of the DSS is subject to a number of external dependencies that affect the critical path of the project. These include:

- budget allocation;
- sanctioning of posts as per our workforce plan;
- finalised amending legislation;

- finalised regulations to provide for multiple procedural and documentary matters;
- decision on fees for services and terms and conditions for panel members

The Bill to amend the 2015 Act has been granted priority in the current legislative programme. The amendments will address certain matters, some of a technical nature and others more substantive and it is hoped that these will ensure the better functioning of the Act. In particular, it is proposed to improve the position of current wards of court in terms of access to the court, to representation and to ongoing periodic review.

It is important to say the readiness of the DSS is not the only precondition to commencement of the Act. The 2015 Act will have impacts on stakeholders to include the Courts Service, the Legal Aid Board, legal and financial service providers and their regulators, An Garda Síochána, disability services and generally across health and social care. There is much preparatory work to be done in these sectors. There must be support for training and education and the re-evaluation of policy and standards in line with the 2015 Act. Appropriate supports are required to ensure that costs are not a barrier, where, for example formal legal documents and capacity statements are required to support the registration of arrangements with the DSS.

The DSS welcomes the recent amendment of the Terms of Reference of the Inter-Departmental Steering Group so that its purpose is not just to prepare for the implementation of the DSS but for the commencement of the Act. It is our view that the appointment of a mandated single point of contact in the Department of Health to co-ordinate preparations for which it is responsible is now a matter of some urgency.

As part of our statutory functions, the DSS remains committed to working with all relevant stakeholders to provide information and to promote organisational change and we look forward to further engagement with this Committee.

Áine Flynn, Director of Decision Support Service.