



‘Why commencement of the Assisted Decision-Making (Capacity) Act Matters’

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Caoimhe Gleeson,
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Much of our focus and efforts over the past few months have been on preparing staff for commencement of the 2015 Act which we anticipated would be in June 2022. Further legislative drafting and amendments which must be considered by the Oireachtas has now delayed the commencement of the Act. At the time of writing we don't have a definite date of commencement save for an assurance from Government that it remains committed to commencing the Act as soon as possible.

Notwithstanding these delays there is much that can be done now to prepare for commencement of the 2015 Act. Our office has developed extensive information and learning resources for staff which can be accessed on HSEland and through www.assisteddecisionmaking.ie. We launched our e-learning modules on supported decision making in health and social care in April 2022 which are available on HSEland. The most recent webinar series on preparing for commencement is available through www.assisteddecisionmaking.ie. There are many other resources– video, audio and in written format available to access through our website. We regularly update the website to ensure that the most up to date information on what the Act will mean for front-line practitioners is available.

As we edge towards commencement we have focused our attention in this edition of the newsletter on why commencement of the 2015 Act matters to a diversity of people including individuals, healthcare workers, advocates and organisations for whom the Act will effect. We are delighted to have a contribution from the chief sponsor of the Act- the Minister for Disability, Equality, Children, Integration and Youth Affairs Mr. Roderic O’Gorman alongside a contribution from leading Dementia and Disability Advocate Helen Rochford Brennan who earlier this year gave a stellar interview on the Tommy Tiernan Show- https://www.youtube.com/watch?v=43igGmV_Qu8

The implications of commencement of the 2015 Act is not without its critics and there remains many outstanding issues not yet addressed as the amending Bill goes through the houses of the Oireachtas. This is particularly the case for the many carers in Ireland who are unsure of what the Act means for them and the persons they care for on a daily basis. John Dunne, CEO from Family Carers Ireland sets out some of these concerns while staff from the Dublin Midlands Hospital Group reflect on what these significant changes will mean for front line practice.

Evidence of compliance and assurance that the core principles are being adhered to are of critical concern to Mick Keating from the Health Information Quality Authority (HIQA) while Siobhán Young, Head of Quality, Safety and Service Improvement in CHO6 considers why ADM is integral to a quality and safety agenda.

Challenging times ahead remain as we await further debates on the amending legislation. However, as is clearly set out in the contributions here and by many Disabled Persons Organisations, it is critical that we remain on track with commencement to realise and protect many fundamental rights for people who have difficulties with decision making.



Update on the Assisted Decision-Making (Capacity) Act 2015

Jacqueline Grogan
Project Manager

The [Assisted Decision-Making \(Capacity\) \(Amendment\) Bill 2022](#) is currently progressing through the Dail. The proposed Bill will amend the Assisted Decision-Making (Capacity) Act 2015. The rationale provided for drafting an amending piece of legislation is to improve processes and safeguards for those who will make use of the new decision-making supports.



Pre-legislative scrutiny of the general scheme of the Bill took place in February 2022 at the Committee for Children, Equality, Disability, Integration and Youth. The Committee also issued a public call for submissions in December 2021/January 2022. The Committee published [a report](#) making 64 recommendations about how the Bill can be improved.

The Second Stage debate on the Bill took place in the Dail on 1st and 2nd June 2022 – transcripts of the debate are available on the [Oireachtas website](#). The Bill passed Committee Stage on 14th June and final stage amendments were debated in the Dail on 28th June 2022.

A statement has issued from the Department of Children, Equality, Disability, Integration and Youth confirming that progress on the Bill will resume in the Houses of the Oireachtas as early as possible following the beginning of the autumn session, and it remains the intention and firm commitment of Government to commence the 2015 Act in full as soon as possible.

In summary, the Bill provides for:

- Technical and procedural amendments to allow for the commencement of the 2015 Act in order to bring an end to wardship in Ireland and provide for a functional model of capacity assessment for relevant persons;
- Amended definitions of personal welfare and treatment decisions, to allow for participation by persons with capacity difficulties in health research and to clarify for medical professionals which person has authority to make decisions regarding actual medical treatment or clinical care where another person has capacity difficulties;
- Improved safeguarding provisions throughout the 2015 Act;

Amendment of the 2015 Act to streamline or to tighten existing provisions in order to improve safeguards, reduce bureaucracy for those using options under the Act and to enable the DSS to undertake its role more effectively. This includes streamlining the of processes to allow the DSS to draw up it's own forms and to give greater control over the DSS's own administrative procedures to the Director;

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- Additional powers have been given to the DSS Director to investigate issues and seek informal resolution of complaints. The property management role for the Director contained in the original Act has been removed. The Director will provide for the remuneration of panel member decision-making representatives where there are insufficient assets in the estate of the relevant person;
- A new system for enduring powers of attorney (EPAs) whereby the enduring power of attorney will be created by the relevant person and registered with the DSS while s/he has capacity, enabling any problems with the enduring power of attorney to be resolved with the person herself / himself. The enduring power of attorney will come into effect through a notification process by the attorney to the DSS when the relevant person has lost capacity;
- Strengthened protections for the rights of wards when their wardship is reviewed and they are discharged from wardship and / or migrated to the 2015 Act's structures; and
- The removal of provisions permitting the use of restraint in private settings.

An explanatory memorandum on the bill can be found at <https://data.oireachtas.ie/ie/oireachtas/bill/2022/59/eng/memo/b5922d-memo.pdf>

If you have any questions feel free to get in touch with us at adm@hse.ie.



‘Why commencement of the Assisted Decision-Making (Capacity) Act Matters’

Minister Roderic O’Gorman,
Minister for Children, Equality, Disability, Integration and Youth



The Assisted Decision-Making Act 2015 will bring an end to wardship in Ireland and it will provide for a functional assessment of a person’s capacity to make decisions affecting their own lives, which is a big change from status approach that currently exists.

I am strongly of the view that this is the right thing to do, as many people haven’t had a full say in the running of their own lives and it’s time this changed. This is also an important step for Ireland in meeting its commitments under the United Nations Convention on the Rights of Persons with Disabilities, which we ratified as a country back in 2018.

Ireland wants to be a country that empowers persons with disabilities to manage and affect their lives, as well as be to the fore of promoting equality of rights for all people in our country. The Assisted Decision-Making Act will bring about fundamental change in the way that we view capacity in the State, having much more regard for the will and preference of persons rather than simply doing what we think is best for them. The Act therefore matters to who we are as a people, as well as to persons who have a right to have a say in their own lives.



'Why commencement of the Assisted Decision-Making (Capacity)

Act Matters- to me'

Helen Rochford Brennan, Current Chairperson of the European Working Group of People with Dementia



So, how can the 2015 Act help a person like me - now several years on in my journey through dementia? And what are some of the conundrums I currently face in relation to this to this 2015 Act? Let's start with the positives

One great merit is that the enduring power of attorney component of the act now enables me to appoint a trusted person (like my son Martin) to not only make financial decisions for me, taking into account my will and preference, but also to make all sorts of other decisions such as those relating to my

welfare, property and other affairs.

Under the old system an enduring power of attorney was based on decisions being made in my best interest and not on my will and preference. This distinction between best interest and will and preference is important as it essentially delegates power and control back to me, the individual, to decide what I want to do with my life and what I believe is best for me, and not what others think is in my best interests.

The 2015 Act also enables me to make an advance health care directive, which for me is a further welcome aspect. This means that I now have the right to plan my future health care and, in particular, decide to refuse a particular treatment I do not want. A case at point here is the introduction of artificial hydration or nutrition where scientific evidence shows that for people with end stage dementia, these interventions will not prolong life expectancy and will do nothing to improve quality of life. Yet in the absence of making this directive, I might be subjected to such treatment. Another example is when I die, I want to die peacefully and do not want anyone to come along jumping up and down on my poor body trying to resuscitate me. The 2015 Act allows me to make provisions for this.

‘Why commencement of the Assisted Decision-Making (Capacity) Act matters’

Mick Keating, Regional Manager , Inspector of Social Services (Disability), Health Information and Quality Authority



The commencement of the Assisted Decision-Making (Capacity) Act 2015 will provide a key piece of legislation to protect the rights of adults who may be vulnerable. People who may need supports to make decisions include some people with an intellectual disability, mental illness or acquired brain injury, or some people with age-related conditions affecting capacity.

Of course this presents a challenge to service providers who have to support the will and preference of the individual, while taking into account the risks involved in supporting individuals to exercise their rights. As a regulator, the Health Information and Quality Authority (HIQA) gives consideration to how providers interpret decision-making which may be considered risky or ‘unwise’. As regulators, we are also conscious that positive risk taking is fundamental to an active and enjoyable lifestyle.

The current disability regulations support the concept of positive risk taking. For example regulation 13 (2) (b) requires the provider to provide opportunities for residents to participate in activities in accordance with their interests, capacities and developmental needs. In addition, regulation 9 (2) ensures each resident has the freedom to exercise choice and control in their daily lives, and participates in and consents, with supports where necessary, to decisions about their care and support.

On inspection and through our monitoring, inspectors consider whether providers have clear evidence to underpin these decisions, such as how the person was supported to make an informed decision and whether risk assessments were completed to support the resident and to mitigate any possible risk.

The commencement of the Assisted-Decision Making Act is a welcome development and should enhance the promotion and protection of the human rights of people who need support with making decisions.

HIQA has published other resources to assist with this human rights-based approach. Our *Guidance on a Human Rights-Based Approach in Health and Social Care Services*, developed in conjunction with Safeguarding Ireland, aims to assist health and social care staff to uphold human rights in their work. We also have an online learning course on *Applying a Human Right-based Approach in Health and Social Care*, which contains a module on positive risk taking. Furthermore, the associated Decision Making Flow Chart is a helpful tool for staff supporting decisions in relation to a person’s care. These are available at www.higa.ie.

‘Why commencement of the Assisted Decision-Making (Capacity) Act matters - Community Healthcare perspective’

Siobhan Young, Head of QSSI, Community Healthcare East.



I am one of nine heads of service in the CHOs for a relatively new function called Quality, Safety and Service Improvement (QSSI). QSSI was set up in 2021 to support services across CHOs to implement relevant policy and legislation related to quality and safety.

Key policies include the HSE’s *Incident Management Framework 2020* and *Safeguarding Vulnerable Adults at Risk of Abuse Policy 2014*. QSSI teams also support services to comply with legislative requirements such as the Children First Act 2015 and Part 9 of the Health Act (i.e. managing complaints). Our

teams will have a key role supporting services to implement the Assisted Decision Making Act.

ADM matters for all sorts of reasons and it is particularly relevant for quality, safety and service improvement. The Act obliges us to move from a paternalistic, best interests approach to a rights based approach.

A rights based approach is an approach that places service users at the centre of everything the service does. This is recognised as a key component of **quality** services. People that use our services have a right to live safely whether that is at home or in one of our residential centres. A key principle to ensuring people’s **safety** is to respect their human rights and support them to make decisions. Moving from a best interests approach to supporting people in this way is the kind of **service improvement** that will result in better outcomes for all concerned.



‘Why commencement of the Assisted Decision-Making (Capacity) Act matters - Hospital perspective’ – Part 1

Prof Catherine Wall, Clinical Director for Quality and Patient Safety, Consultant Nephrologist

Tallaght University Hospital



The Assisted Decision-Making (Capacity) Act 2015 is scheduled for commencement later this year. The Act establishes a modern legal framework to support and maximise decision-making capacity for people who currently have, or who may face challenges into the future with decisions relating to personal welfare and to property and affairs. The 2015 Act uses a human rights based approach with emphasis on privacy, autonomy and respect for a person’s will and preference. Key guiding principles under the act include the presumption of decision-making capacity, the requirement to support decision making, the right

of the person to make an unwise decision and any interventions should be made only when necessary, be least restrictive and give effect to a person’s will and preference.

The implementation of the 2015 Act is widely welcomed by Health and Social Care Providers including in the Acute Hospital setting as it puts the person at the centre of their healthcare treatment decisions. Additional benefits include an emphasis on the functional approach to capacity assessment, clarity as to who can legally give or decline consent for a person lacking capacity as well as providing a legal framework for Advance Healthcare Directives. Extensive educational and promotional resources have been made available to staff to raise awareness of the planned changes.

We have established an Assisted Decision Making Implementation Committee at Tallaght University Hospital along the lines of the HSE Implementation Framework. A key early step was the adoption of the HSE revised National Consent Policy 2022 with particular reference to presumed capacity, the requirement for healthcare workers to take all practicable steps to maximise capacity and the need for timely capacity assessment where decision-making capacity is in question. This policy outlines how and by whom capacity assessments should be performed as well as the expectations of the person undergoing a capacity assessment. It became clear that many staff were unversed in functional capacity assessment and how this should be documented and communicated and that additional learning resources were required in addition to HSE Land modules.

We have identified key work streams in order to operationalise the 2015 Act as follows;

- Communication with staff about the 2015 Act and their responsibilities in this regard

'Why commencement of the Assisted Decision-Making (Capacity) Act matters - Hospital perspective' – Part 1

Prof Catherine Wall, Tallaght University Hospital

- Education and training with emphasis on five levels of decision support, functional capacity of assessment and the relevant Codes of Practice (still in draft) for healthcare workers
- The need to align current practices that may be in conflict with the 2015 Act such as the custom and practice of 'next of kin' providing consent when capacity is in question
- Updating of PPPGs and current consent forms
- Quality and Risk considerations including audit of implementation

We have highlighted some risks associated with implementation of the 2015 Act including a very low level of awareness amongst clinical staff of most elements of the 2015 Act, short time frame to implementation with Codes of Practice still in draft form, need for additional staff to support decision-making capacity such as Occupational and Speech and Language Therapists as well as Medical Social Workers, impact on services as clinical consultations may take longer, increased need for legal support around complex cases / unwise decisions. Additionally clinical staff have expressed the view that all decision support arrangements should be registered with the Decision Support Service in order that they can be accessed in a clinically relevant time frame and in particular, Advanced Healthcare Directives.

In order to successfully implement this fully for people who access our services, we have emphasised a need for additional supports including senior social workers, OT, SALT, access to legal advice (in the early stages following implementation) and a resource to develop further learning materials including case studies that we would hope to share with other Hospitals and Organisations currently embarking on this important journey.



‘Why commencement of the Assisted Decision-Making (Capacity) Act matters - Hospital perspective’– Part 2

Gráinne Cunningham O’Brien, Principal Social Worker and Joan O’Toole,
Principal Medical Social Worker, Midlands Regional Hospital, Tullamore



In a nutshell, the Assisted Decision-Making Act validates in law a person’s right to be their own decision maker and to act according to his or her own values and interest. This person-centred ethos supports the individual’s human right to represent themselves, as they see fit in the absence of any form of oppression or coercion.

The commencement of the Act will challenge the historical notion of “best interest” for the patient where often the decisions were decided on interaction with family members, where capacity, age and stage of life were influencing factors.

This act places the individual at the centre of the decision making process with regard to proposed medical interventions and outcomes. Capacity or lack of capacity is no longer acceptable as a barrier to self-determination and self-representation in participating in the medical decision making process which will directly affect their lives. This person centred inclusive practice ensures that all decisions circle back to the patients’ right to autonomy.

The Act provides for:

- Improved decision support for people lacking capacity
- Broadens the scope of Enduring Power of Attorney to include health care decisions
- Introduces Advance Healthcare Directives in Irish Law
- Abolishes Wardship

In conclusion, **‘Commencement of the Assisted Decision-Making Act matters’** to demonstrate in law the importance of respecting each individual’s right to independently assert their own will and preference over the notion of best interest.

‘Why commencement of the Assisted Decision-Making (Capacity) Act matters – From the perspective of family carers.’

John Dunne – Chief Executive, Family Carers Ireland



The Assisted Decision-Making (Capacity) Act provides for the presumption of capacity of every adult and replaces ‘best interest’ with ‘will and preference’ as the guiding principle underpinning assisted decision-making. Its commencement will establish a tiered framework of decision-support arrangements to assist all who need help to live an autonomous and fulfilling life. All of this is extremely welcome to the carers of children and adults with intellectual disabilities who want nothing more than to see their loved one(s) live a fulfilling life that reflects their will and preference as much as possible. The Act will also be welcomed by a majority of family carers because it will give them the option of formalising their caring role and securing a statutory validation of that role.

But for a significant minority – those caring for adults with profound, life-long intellectual disability and therefore most likely to require a Decision-Making Representative order – the Act is problematic, creating confusion, uncertainty and, as a result, increased stress and carer burden. We find ourselves with little time to the target date with no sight of the final amended legislation or many associated codes, policies and procedures. As a result, it is impossible to provide clear answers to many questions family carers are asking about

- the nature of decisions covered by the Act;
- the circumstances in which an order under the Act is required;
- the capacity of the court system to deal with ‘emergency’ applications;
- the costs associated with individuals operating under the Act.

Progress is being made in this regard but a good deal remains to be done.

The loftier the building the deeper the foundations that must be laid. *Family Carers Ireland* acknowledges the very considerable efforts that are being made to prepare for the commencement of this ground-breaking legislation but feels more must be done to provide clarity to families on the issues raised by carers. None of us knows what the future holds, but we can be confident that building the right foundations now will create a better place in which we can grow old and live well in the future whereas failing to do so will result in long-term problems with the potential to compromise what should otherwise be a very positive development in the statutory context of care provision.

Further updates and resources

A number of organisations have a number of useful resources available on the Assisted Decision-Making (Capacity) Act 2015.

- [HSE Assisted Decision-Making website](#)
- [HSE Explainer video on the Act](#)
- [Decision Support Service](#)
- [Aine Flynn, Director of the Decision Support Service: Statement to the Joint Oireachtas Committee on Disability Matters May 2021](#)
- [NDA Annual Conference 2021 - Opportunities and Aspirations for the Assisted Decision-Making \(Capacity\) Act 2015](#)
- [Decision Support Service Explainer Video](#)
- [Sage Advocacy Decision-Making and Capacity](#)
- [Inclusion Ireland Assisted Decision-Making](#)
- [Inclusion Ireland Easy to Read Assisted Decision-Making \(Capacity\) Act 2015](#)
- [Decision Support Services guides and video presentations](#)



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