



HSE Strategy and Research

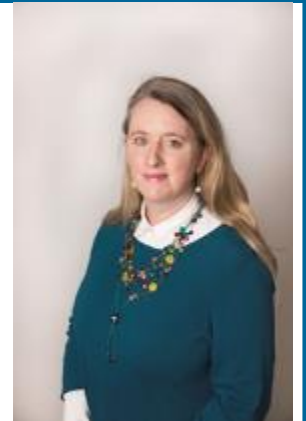
HSE National Office for Human Rights and Equality Policy Newsletter

'Towards Commencement'

Winter 2021



National Office for Human Rights and Equality Policy



Welcome

2021 has been a very busy year for the National Office for Human Rights and Equality Policy. We started the year with a series of webinars to support the consent process for the Covid-19 Vaccinations. These webinars helped to reinforce the message that the only person that can consent for another adult in Ireland is the person themselves or those who have legal authority to do so.

The National Consent Policy has just been revised and will be launched in a national webinar in early 2022. There will also be an E-Learning programme which will be available for those who have access to HSELand.

Concerted efforts are now underway to support commencement of the Assisted Decision Making (Capacity) Act 2015 in June 2022. The first set of the draft codes of practice from the Decision Support Service are now out for consultation with the closing date of January 7th 2022 for feedback. The second set of draft codes will be released on the 11th January 2022.

Our first set of E-learning programmes on supported decision making, planning for the future and undertaking the functional assessment of capacity will be released and available for those who have access to HSELand in March 2022.

We will be hosting monthly webinars on the practical implications of the 2015 Act for front line practitioners commencing at the end of January 2022. The purpose of these webinars is to support staff with particular questions and issues on the operation of the 2015 Act and implications of practice. These webinars will be recorded and will be available on www.assisteddecisionmaking.ie.

We launched a collection of essays on the 2015 Act in November 2022 and the publication is available for free on line on our website. In order to prepare for commencement we would suggest you keep up to date with news updates and education supports which will be available on-line in 2022. Our office will ensure that the most up to date information is available to staff and will provide learning spaces to build knowledge and skills.

Thank you for all of your support in 2021 and we look forward to another busy and important year in 2022.

I hope you all have a peaceful Christmas and wishing you all the best for 2022.

Caoimhe Gleeson, Programme Manager

National Office for Human Rights and Equality Policy Update

E-learning modules

We have been developing three new e-learning modules to show staff how they can assist people who may need support with decision-making. The topics are:

- **Module 1: Supporting a person to make decisions**—The aim of this module is to help staff support people who use our services to make decisions in health and social care, including day to day decisions and more complex decisions.
- **Module 2: Supporting a person to plan for the future**—The aim of this module is to help staff support a person to plan for their future care and treatment if they subsequently lack decision making capacity to make their wishes and preferences known.
- **Module 3: An Introduction to the functional assessment of capacity**—The aim of this module is to help staff recognise when a functional assessment of decision-making capacity is required and how to do one.



We have collaborated with a range of experts-by-experience, clinicians and subject-matter experts across a range of agencies to develop these modules. We are very grateful for their valuable contributions and feedback on the content of these modules.

In September we completed two busy days of filming for the character-based scenarios for these modules in St Michael's House Ballymun, and Stewart's Hospital, Palmerstown. We would like to give very special thanks to the experts-by-experience and healthcare workers who helped develop the scripts for these scenarios and showed their skills in front of the camera. These modules will be available to all health and social care staff on HSEland and will be launched in early 2022.

Webinar series 2022

As part of the ongoing preparation for commencement of the Assisted Decision-Making (Capacity) Act 2015 we are planning a new series of webinars in January 2022. Each webinar will be approximately one hour in length.

The purpose of these events will be to:

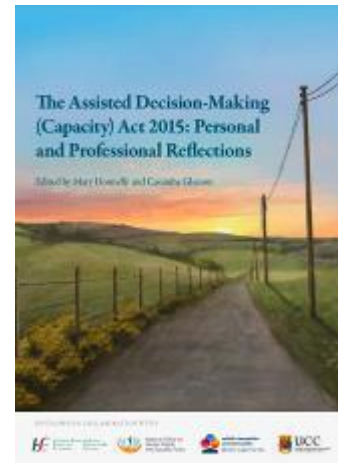
- Stimulate discussion about practical implementation of the 2015 Act
- Provide guidance to services and practitioners
- Identify areas of uncertainty and learning needs
- Explore case studies with the framework of the 2015 Act



We have just undertaken a survey with front line practitioners to find out what topics would be most useful to explore in these sessions. This will inform the content of the sessions to be delivered. If you would like to get in touch with us about this please email adm@hse.ie.

The Assisted Decision-Making (Capacity) Act: Personal and Professional Reflections

The National Office for Human Rights and Equality Policy in conjunction with the School of Law, UCC and the Decision Support Service, launched a collection of essays titled The Assisted Decision-Making (Capacity) Act 2015: Personal and Professional Reflections on Wednesday 3rd November 2021. This collection of essays, written from both personal and professional perspectives, highlights the importance of this ground-breaking piece of legislation. The powerful essays demonstrate the scale of impact that the Act may have on people's lives – from the ability to write a legally binding advance healthcare directive to being supported to make their own decisions if they have difficulties with decision-making capacity.



The event was chaired by Dr Philip Crowley, National Director, Strategy and Research, HSE with Paul Reid, CEO of the HSE delivered the Opening Address and Minister of State with Special Responsibility for Disabilities, Anne Rabbitte TD launching the book. There were also presentations from Aine Flynn, Director of the Decision Support Service, Professor Mary Donnelly, School of Law, UCC and Caoimhe Gleeson, Programme Manager, HSE National Office for Human Rights and Equality Policy. A powerful video with the perspectives of some of the essays authors was a highlight of the launch.

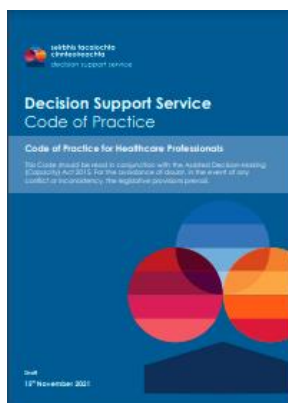
The recording of the launch, the video of the essay authors and an online version of the book are available at www.assisteddecisionmaking.ie.

Assisted Decision-Making (Capacity) Act 2015—Codes of Practice

The Decision Support Service commenced Phase 1 of their consultation on the Codes of Practice for the Assisted Decision-Making (Capacity) Act 2015 on 15th November 2021. The public consultation provides the opportunity to provide feedback to the Decision Support Service on the Codes of Practice.

There are six codes of practice currently out for consultation:

- 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
- Code of Practice on advance healthcare directives for healthcare professionals
- Code of Practice for healthcare professionals.



The closing date for feedback on the draft Codes is **7th January 2022**. The HSE ADM Implementation Steering Group will be submitting a formal response on behalf of the HSE. However, you can also submit your own views on the Codes of Practice directly to the DSS through the consultation webpage.

You can read the Codes of Practice and find out more information about the consultation at

<https://decisionsupportservice.ie/public-consultation/public-consultation-phase-1>.

Feature: Interview with Áine Flynn, Director of the Decision Support Service

Aine Flynn was appointed the inaugural director of the Decision Support Service in 2017. Prior to this role, she was a senior partner in Dublin law firm, KOD Lyons, specialising in public interest law. She was on the panel of legal representatives of the Mental Health Commission and the Mental Health (Criminal Law) Review Board from their inception in 2006 and represented wards of court instructed by the General Solicitor.



What made you decide to take on this role?

This is probably the only position for which I would have given up private practice at that point in my career. I feel strongly about the importance of the rights-based reforms that the Assisted Decision-Making (Capacity) Act 2015 introduces. It is exciting and challenging to be part of something entirely new that has the potential to bring about meaningful change.

What from your previous experience as working a solicitor are you bringing to the role?

It has been very useful to have experience in interpreting and applying legislation. My particular interest and experience of mental health and capacity casework has also provided an insight into what the 2015 Act will mean for real people. From running a practice for several years, I think I have learned valuable lessons about leadership and relationship-building. I have also spent a lot of time in the criminal courts and that definitely gives a person a healthy sense of perspective and builds resilience.

What are your plans to raise awareness of the Act to people who most need it and who may have the greatest difficulty in finding out about it?

We will be working with our communications team to deliver an awareness-raising campaign in the remaining months to commencement. Our targeted stakeholder engagement is already well underway. We have delivered presentations to thousands of people in a wide range of sectors including legal practice, banking and finance, disability services, housing, citizens' information, An Garda Síochána, regulatory bodies, civil society groups, family carers, advocates, the Courts Service and diverse colleagues right across health and social care. The 2015 Act is not disappplied in any setting. It is relatively straightforward to reach people who are professionally organised, but our priority must be to reach the ordinary person, who may benefit from the new support framework. The Decision Support Service has a role to spread the word but will also rely on all our stakeholders to promote understanding and access to the supports available under Act.

What can the Decision Support Service do to make an Enduring Power of Attorney easier and less costly to make?

It is very important for every adult to plan ahead and costs should not be a barrier. The cost of registering an Enduring Power of Attorney (EPA) with the Decision Support Service will not be significant and we have proposed that reductions and fee waivers should apply. Legal fees account for most of the cost of making an Enduring Power of Attorney (EPA) at present. An EPA is a very important legal document, and people will always want to be sure that it is carefully drafted so that it will be effective if required in the future. Under the 2015 Act, it will still be necessary to supply supporting statements from a legal practitioner and separate statements confirming capacity. The Decision Support Service intends to make available template EPAs which can be accessed through our public facing IT system and it is also hoped that a proposed amendment to the Act will somewhat streamline the process. These developments may help reduce legal costs. It is probably also true that, if there was a widespread adoption of EPAs, then legal fees would be lower.

Some people believe that the current wardship regime provides better safeguards for people who are vulnerable. What are your views on this?

It is true that there is occasional commentary that, for all its limitations, wardship at least ensures that a vulnerable person and their assets are protected by the court from abuse and exploitation. There is some apprehension that new 'decision supporters' might have improper motives and will be subject to inadequate supervision. However, significant protections are provided by the new Act. Eligibility and suitability criteria apply and there are opportunities to object to a person's appointment as a supporter. The Act provides for supervision by the Decision Support Service and, depending on the category of the arrangement, requires the filing of regular reports. There is an obligation to keep proper accounts and records and to make these available for inspection by the Decision Support Service. The Director may also investigate complaints and may apply to the court to remove a decision-making representative where a complaint is well-founded. An anticipated amendment to the 2015 Act will provide that the Director may apply to the court for the temporary suspension of a decision supporter where necessary to prevent further harm while an investigation is ongoing. In the worst cases, the Act creates offences of fraud coercion, abuse and neglect with penalties of up to five years' imprisonment.

Name one thing that health and social care staff can do to support the implementation of the Act when it commences

I think health and social care professionals are doing a lot already and I see lots of evidence that the ethos of the Act has already been adopted. If I could name one thing, it would be to end confusion about 'next of kin'. A person's next of kin has never had an automatic legal role as a decision-maker or as someone who can give or withhold consent and it would help if this was properly understood.

In five years' time what would you like to have achieved?

A widespread understanding of the Act, confidence in the new framework and an accessible Decision Support Service which is responsive to the needs and promotes the rights of its users.

The Decision Support Service Update

2021 has been a year of engagement as the DSS team has been actively listening to stakeholders, hearing from the people who will benefit from the new service and answering questions and concerns raised. These can be accessed via www.decisionsupportservice.ie/faq.



2021 has also been a year of planning, with a full programme of work, incorporating more than 20 sub-projects under way to prepare for operations in mid-summer 2022. Our intention is that ours will be a digital first service so that people will be able to log into a portal, create an account and be guided through the process creating an appropriate arrangement or managing an existing arrangement. It will also be possible to raise queries, access information and guidance, submit complaints and request searches of the registers of arrangements. An information team will be on hand to walk people through the process and the on-line system will be thoroughly tested by relevant focus groups.

In November, the DSS launched the first stage of a consultation on draft codes of practice. The consultation will run for ten weeks right through to early January 2022, so that stakeholders will get the opportunity to have their say. The second phase of the public consultation on the codes of practice will commence in January 2022. There are 13 codes in total, and you can access www.decisionsupportservice.ie for information on the consultation.

The Decision Support Service launched a demand forecasting report in November 2021—this report was undertaken to gain insights and understanding of the number and needs of potential users of the DSS. [Please click here to read the report.](#)

What can we do now ahead of the full commencement of the Assisted Decision Making (Capacity) Act?

Joanne Condon
Regional Manager
National Advocacy Service for People with Disabilities



Mahatma Gandhi said that, "The future depends on what you do today."

We are at a critical juncture in relation to Irish capacity law with the full commencement of the Assisted Decision-Making (Capacity) Act 2015 at last in sight for 2022. This Act will strengthen the rights of all individuals who may need support to make decisions. Any of us may need to use the provisions of the Act at one time or another in the course of our lives.

The Act moves away from an approach where others get to decide what is in a person's 'best interests' and moves to a rights-based approach that considers instead the will and preference (wishes and choices) of the person. A person is presumed to be able to make decisions for themselves, unless the opposite is shown. It signals a move away from a medical model of disability to a rights based approach under the social model that supports a person to maximise his or her ability (capacity) to make decisions. When the decision support service is up and running, there will be five different decision support arrangements for people may need support to make certain decisions. These arrangements are based on the different levels of support that a person requires to make a specific decision at a specific time.

There are three types of support arrangements for people who face challenges when making certain decisions:

1. Decision-making assistant agreement
2. Co-decision-making agreement
3. Decision-making representation order.

There are also two types of arrangements for people who wish to plan ahead for a time in the future when they might lose capacity. These are:

1. Advance healthcare directive and
2. Enduring power of attorney.

Among the many issues surrounding how people with disabilities have been discriminated against for years, none is more hotly contested than the debate over the right of persons with disabilities to make their own decisions. Stakeholders are therefore rightly impatient to see the game changing Act, that promises a much needed paradigm shift, finally deliver. But the reality is that the recognition of all persons as rights holders is not a new concept and the idea of person-centred, rights-based health and social care is already well established. It is possible right now to implement all of the guiding principles of the legislation to bring about an increased strengthening of people's rights, well in advance of full commencement of the Act, if we all step up and take responsibility for making it happen. So how is this possible in practice?

The Guiding Principles of the legislation are; to presume capacity, to support decision-making, the right to make an unwise decision, to intervene only where necessary, interventions that are least restrictive and respect the person's rights, interventions that give effect to the person's will and preference, the views of others are considered (to inform, not to decide), the likelihood of recovery and the urgency of the matter are considered and only information that is relevant and necessary to the issue at hand is obtained. Not implementing these principles, ultimately leads to individuals being denied respect and results in a failure to support individual autonomy.

The Act abolishes the Victorian wards of court system, which continues to operate at present under the Lunacy Regulation (Ireland) Act of 1871 and signals a clear departure from the paternalism of the past and furthers the incremental changes that have been taking place in the Irish health and social care services over the last decade. Whilst services have come a long way with the implementation of 'Time to Move On from Congregated Settings' and changes to Day Services, truly person centred health and social care services are not yet routinely embedded and legislation can only go so far. The establishment of a culture of supported decision making, rather than substitute decision making is down to every health and social care worker. Such a culture recognises the value of each person as an equal human being and supports them to make their own decisions, where they can. When they are not able to make a decision, they are supported to be involved to the greatest extent possible, with due regard afforded to their will and preferences.

What is the impact if such change does not happen? The harm associated with the experience of being denied recognition and respect and the loss of one's sense of self-determination and autonomy cannot be understated. To deny a person respect in this sense is to deny them dignity as a person. To be denied dignity, recognition and respect is to be denied status as an equal and infers that your existence is somehow beneath those of others. This reduces individuals to objects of decisions rather than active participants in their own lives. All substitute decision making practices masquerading as 'support' must therefore stop in order to put individual's preferences at the centre of decisions that shape their lives.

There are many existing policies, laws and human rights instruments that already exist to support the aforementioned principles. For example, The United Nations Convention on the Rights of Persons with Disabilities promotes, protects and ensures the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities to promote respect for their inherent dignity. The HSE National Consent Policy affirms a 'functional' definition of decision-making capacity that is time-specific and issue-specific and rejects a status model of incapacity. The same policy, as well as the Medical Council Guide to Professional Conduct and Ethics reinforces participatory decision-making and rejects any legitimate basis for substituted decision making by Next of Kin, where there is no specific legitimate legal authority for it (e.g. such as a committee for a person who is a ward of court). When family members are asked to sign consent forms to enable staff to proceed with treatments or interventions, without any attempt to obtain the consent of the individual, it is not in keeping with the policies in place and does not afford dignity and respect or uphold a person's autonomy.



Our personal rights are also well enshrined within the Irish Constitution. It sets out that all citizens shall, as human persons, be held equal before the law (Article 40.1) and guarantees in its laws to respect, defend and vindicate the personal rights of citizens (Article 40.3.1). The Equal Status Act, 2000 protects people from discrimination. The Disability Act 2005 requires reasonable accommodation for people with disabilities. Familiarising oneself with the contents of these policies, laws and instruments and undertaking to uphold these rights today in practice is not dependent on the full commencement of the Act, but rather down to individual choices and actions on all our part.

Empowering people begins with the little things, like addressing the person rather than those around them. Being open and honest. Providing information in accessible ways and communicating in a way that is best for each person. Assuming capacity. Exhausting all potential ways to support decision-making. Affording dignity and respect. It means we must avoid the temptation to have a one size fits all approach and very importantly hear each person's voice and choice. Independent Advocates can also play a vital role in representing a person's will and preference and speaking up when that is not occurring and people must be supported to access advocacy when they need to.

It is vital to recognise that to be human means that we sometimes change our mind, we sometimes take time to mull over decisions, we discuss them with those we trust. Sometimes we make really unwise decisions and have to live with the consequences. That's the stuff of life. Often what makes us feel most human and alive is making choices that others won't agree with. Common sense therefore tells us that the best approach we can adopt when interacting with people is simply to remember they are fellow human beings.

Charles Kettering said, "My interest is in the future because I am going to spend the rest of my life there." Remembering that this really is an Act for us all is a great motivator to invest in all of our futures by doing what we can now. After all, it's everybody's business to forge a new way forward; a way that recognises that despite requiring support to make decisions, people can continue to exercise choice, be valued, listened to and be fully included as active citizens and participants in society. Do you have the capacity today to make such change happen? Remember, "The future depends on what you do today."

<https://advocacy.ie/>

References:

United Nations (UN) (2006). Convention on the Rights of Persons with Disabilities.

New York: United Nations.

HSE National Consent Policy 2019 (V.1.3)

Medical Council Guide to Professional Conduct and Ethics (2019)

The Equal Status Act 2000

The Disability Act 2005



Useful 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 – www.assisteddecisionmaking.ie

HSE Explainer video on the Act - <https://www.hse.ie/eng/about/who/qid/other-quality-improvement-programmes/assisteddecisionmaking/assisted-decision-act-explainer-video.html>

Decision Support Service - <https://decisionsupportservice.ie/>

Aine Flynn, Director of the Decision Support Service: Statement to the Joint Oireachtas Committee on Disability Matters May 2021 - <https://decisionsupportservice.ie/sites/default/files/2021-05/Statement-to-Joint-Oireachtas-Committee-20.05.2021%20FINAL%20.pdf>

Decision Support Service Explainer Video - <https://decisionsupportservice.ie/news-events/decision-support-service-explainer-video>

Sage Advocacy Decision-Making and Capacity - <https://www.sageadvocacy.ie/resources/legal-rights/decision-making-capacity>

Inclusion Ireland Assisted Decision-Making - <https://inclusionireland.ie/assisted-decision-making/>

Inclusion Ireland Easy to Read Assisted Decision-Making (Capacity) Act 2015 - <https://inclusionireland.ie/wp-content/uploads/2020/11/ETR-ADM-Updated.pdf>

University of Limerick Interpretation and Application of the Assisted Decision-Making (Capacity) Act 2015 - <https://www.ul.ie/engage/node/2061>



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