

Update since Commencement



Caoimhe Gleeson,
General Manager,
HSE National Office for Human
Rights and Equality Policy

Since commencement of the Assisted Decision-Making (Capacity) Act 2015 on the 26th April 2023 we have been busy working to develop aids and tools that will support staff in implementing the Act in their practice. This edition of the newsletter focuses on what has been happening since commencement and some of the resources that have been developed to support staff to implement the Act in practice.

The Decision Support Service hosted two fabulous events to mark commencement of the Act. On 25th April, they held an event in the Lighthouse Cinema in celebration of the amazing champions that are involved in their public awareness campaign. On the 26th April, the Decision Support Service was formally launched by Taoiseach Leo Varadkar in Government Buildings.

Shauna Warren gives an overview of the recently launched Codes of Practice for Healthcare Professionals and the Code for Advance Healthcare Directives. Jacqueline Grogan gives information about the additional guides and videos that the Decision Support Service have developed to support staff and people who use our services to understand the provisions of the Act.

Shem Romanowski gives an update on the survey of learning needs that we undertook in April 2023. We have been looking at the feedback we have received to help inform further resources to be developed to support staff to implement the HSE National Consent Policy 2022 and the Assisted Decision-Making (Capacity) Act 2015.

The changes to the Nursing Home Support Scheme are highlighted in an article by Ultan Hynes and Ciara Palmer from CHO Dublin North City and County talks about the survey that they undertook to ascertain staff members understanding of the Act.

On the 14th June we hosted a webinar titled **Assisted Decision-Making (Capacity) Act 2015: Update since commencement. This webinar** was the first following commencement with over 1800 registered to attend. This webinar focused on providing an update on what has happened since commencement and updates were provided from the Decision Support Service, the Courts Service, the Nursing Home Support Scheme and the Office of the Wards of Court. If you were unable to attend on the day, you can view the recording of the webinar and see the presented slides on our [website](#).

For further information, updates and resources are available on our webpage www.assisteddecisionmaking.ie.

Caoimhe Gleeson
National Office for Human Rights and Equality Policy

Launch in Government Buildings on the 26th April 2023 Commencement of the Assisted Decision-Making (Capacity) Act 2015.

Caoimhe Gleeson,
General Manager

National Office for Human Rights and Equality Policy



Taoiseach Leo Varadkar officially launched the Decision Support Service and marked commencement of the Assisted Decision-Making (Capacity) Act 2015 at Government Buildings on 26th April 2023. Some of our team were invited to attend on the day and met with key Ministers including Minister Roderic O’Gorman, Minister for Children, Equality, Disability, Integration and Youth.

Photo above (L to R): Florin Nolan, Minister Roderic O’Gorman & Minister Ann Rabbitte.

Photo below left (L to R): Pat Shaler, Pádraig Schaler & Taoiseach Leo Varadkar.

Photo below right (L to R): Caoimhe Gleeson, Jacqueline Grogan, Minister Roderic O’Gorman and Helen Rochford Brennan



Pre-launch of the public awareness campaign in the Lighthouse Cinema Smithfield -Celebration of the Champions

Orlaith Branagan,
National Office for Human Rights and Equality Policy

On Tuesday 25th April we attended a pre-launch event organised by the Decision Support Service to celebrate the contribution of the champions to the public awareness campaign. This campaign was for the Decision Support Service and to support the commencement of the Assisted Decision-Making (Capacity) Act 2015.

The positive, feel-good atmosphere was palpable and filled the auditorium for the entire event. Mr. John Farrelly, CEO Mental Health Commission chaired the event and gave a an overview of the long journey taken by the Mental Health Commission up until the eve before commencement. Dr John Hillery, Chairperson of Board of the Mental Health Commission spoke about the passion and courage of the champions in telling their personal stories and how they resonated most with people. Dr. Hillery noted in his speech this campaign will go a long way towards guaranteeing the public understand the impact that this legislation and the Decision Support Service (DSS) will 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. Dr. Philip Crowley, National Director, Strategy & Research HSE greatly welcomed the commencement of the Assisted Decision-Making (Capacity) Act – a reforming piece of human rights legislation after the long lead in time. He noted the importance of the public awareness campaign in ensuring that as many people as possible are aware of the Act and the benefits it could bring to their lives. Ms. Aine Flynn, Director of the Decision Support Service thanked the champions again, thanked all those involved and presented each of the champions with a framed A3 poster of themselves. Each of the pieces of footage were played to the audience in Theatre 3 and were welcomed with a mixture of laughter, tears of joy, and empathy. The Decision Support Service could not have done this without the support of the attendees at the event and most especially the champions Helen Rochford-Brennan, Blessing Dada, Justyna Masklanka, Fionn Crombie Angus, Pádraig Schaler, Florin Nolan, Margaret Turley, Paul Alford and Lydia Fisher.



Above photo to the left: L to R: Margaret Turley, Florin Nolan and Lydia Fisher.



Above photo on the Right : L to R: John Farrelly Mental Health Commission Board, Aine Flynn, Decision Support Service & Dr. Philip Crowley, National Director, Strategy and Research HSE.

Pre-launch of the public awareness campaign in the Lighthouse Cinema Smithfield -Celebration of the Champions

Orlaith Branagan,
National Office for Human Rights and Equality Policy



Photo left (L to R):
Fionn Crombie Angus, Lydia Fisher, & Blessing Dada.



Photo below (L to R): Pádraig Schaler, Reinhard & Pat Schaler, Aine Flynn, Decision Support Service and Justyna Masklanka.



Photo to the left (L to R): Cormac Cahill, Alzheimer Society of Ireland, Helen Rochford-Brennan & Tadhg Daly, Nursing Homes Ireland.

Photo Right: Shauna Warren, Shem Romanowski and Orlaith Branagan from the HSE National Office for Human Rights and Equality Policy



The Assisted Decision-Making (Capacity) Act 2015:

Decision Support Service Codes of Practice for Healthcare Professionals

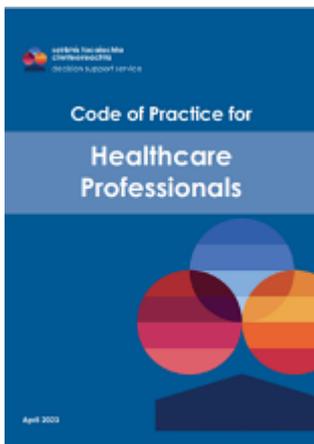
Shauna Warren

On commencement of the Assisted Decision-Making (Capacity) Act 2015, the Decision Support Service published 13 Codes of Practice for decision supporters, interveners and relevant professionals, providing guidance for their functions and responsibilities under the 2015 Act.

The 13 codes of practice can be found at <https://decisionsupportservice.ie/resources/codes-practice> along with a plain English [guide to the codes of practice](#).



Short videos to accompany each code of practice can also be found on the Decision Support Service website including a [video](#) on the code for healthcare professionals and a [video](#) on the code on advance healthcare directives for healthcare professionals.



In this article, we will have an in-depth look at two codes which are relevant to healthcare workers.

The [Code for Healthcare Professionals](#) covers four main topics:

Functions and duties of a healthcare professional

This section provides guidance on the issues to consider when capacity is in question, how to ascertain if a decision support arrangement applies, how to check the scope of the decision support arrangement, how to assess capacity for a specific decision, how to make a decision support arrangement and making court applications.

Your functions and duties in an emergency

This section outlines the steps to follow in an emergency including checking if a decision support arrangement is in place and if it applies, what to do where circumstances do not permit consideration of the decision support arrangement and record keeping following an emergency.

Interacting with decision supporters

Guidance is provided in this section on understanding the types of decision supporters, checking their authority to act as a decision supporter, providing information to a decision supporter and confidentiality considerations.

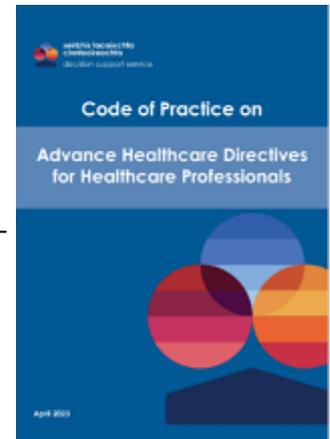
Interacting with the Decision Support Service

Healthcare professionals may need to interact with the Decision Support Service regarding making a complaint about a decision supporter, complying with an investigation or interacting with a general visitor, special visitor or court assistant.

The [Code on Advance Healthcare directives for Healthcare Professionals](#) covers five topics.

Your functions and duties as a healthcare professional

This section describes the steps a healthcare professional should take to ascertain if a person has an advance healthcare directive, how to read the directive and determine if the directive should come into effect, how to check the validity and applicability of the directive, and determine its applicability where the treatment decision is subject to other legislation such as the Mental Health Act. The code also contains guidance on the steps that should be taken to resolve ambiguity about a directive and how to respond to an advance healthcare directive including the records which must be kept.



Your functions and duties in an emergency

This section guides the healthcare worker through the steps that should be taken to ascertain if the person has an advance healthcare directive and check that the directive is valid and applicable in an emergency situation. There is also information regarding record keeping following an emergency which may include the circumstance in which the emergency situation occurred, steps taken to obtain and review the directive and the basis upon which treatment was provided or not provided.

Making, amending or revoking an advance healthcare directive

This section provides an overview of the steps involved in making, amending, or revoking an advance healthcare directive and the role of the healthcare professional in this.

Role of a designated healthcare representative

In making an advance healthcare directive, a directive-maker may appoint a designated healthcare representative. Their role is to act as the directive-maker's agent to ensure that the terms of the advance healthcare directive are complied with.

The code of practice outlines guidance to healthcare professionals on understanding the scope of authority of a designated healthcare representative, engaging with them as to the interpretation of the person's will and preferences and providing information to the designated healthcare representative on your response to a treatment decision. The code also provides guidance to healthcare professionals who have concerns about a designated healthcare representative who is not acting in accordance with their authority within the advance healthcare directive.

Liability issues

A valid and applicable advance healthcare directive setting out a specific refusal of treatment has the same legal status as a decision to refuse treatment made by a person with capacity at the time of treatment. This section sets out the liability considerations apply when acting contrary to or in accordance with an advance healthcare directive and when acting within the context of available information.

Additional resources from the Decision Support Service

Jacqueline Grogan
Project Manager



The Decision Support Service has published a range of additional resources to support people's understanding of the Assisted Decision-Making (Capacity) Act 2015.

These include:

[My Choices](#) – A short guide about who may need support to make decisions and an introduction to the decision support arrangements available.

An [easy read guide](#) to the Assisted Decision-Making (Capacity) Act 2015.

A list of [key terms](#) in the Act.

A [guide to making an objection](#) in relation to a decision support arrangement.

[Guidance about complaints](#).

A [story database](#) – a collection of stories developed to demonstrate how the codes of practice may be applied in real life situations.

They have also produced a range of resources, including videos, to support people when accessing the [MyDSS portal](#) including step-by-step guides on creating an account and guides on making a co-decision-making agreement and an enduring power of attorney.

The Decision Support Service will add to these resources over the coming months.

Update on the Assisted Decision-Making (Capacity) Act 2015 & the HSE National Consent Policy Learning Needs Survey

Shem Romanowski

In April 2023, the National Office for Human Rights and Equality Policy conducted a large scale survey aiming to better to understand the learning needs of HSE staff with regard to the Assisted Decision-Making (Capacity) Act 2015 as well as the HSE National Consent Policy 2022.

We received over 1890 responses from across of the organisation. The highest proportion of responses were submitted from Disability sector (33.4%), followed by Acute hospitals (15.3%), Older People (15.3%) and Primary Care (11.3%).

We also received over 270 case scenarios covering a wide range of challenging situations arising in practise and we are currently reviewing and analysing them. These case scenarios are very useful in terms of understanding the real issues arising in frontline services, thus informing training and education resources. We are grateful for your meaningful input.

In the coming months, we aim to produce further resources to help you to ensure your work complies with the HSE National Consent Policy 2022, and to understand and use the provisions of the Assisted Decision-Making (Capacity) Act.



‘What do the changes following commencement mean for the person?’

Ultan Hynes

Head of Service, Nursing Homes Support Scheme

Older People Operations



The Nursing Homes Support Scheme (Fair Deal) provides financial support to 22,400 clients in long term nursing home care. The Scheme receives 10,000 applications annually and has a budget of €1.1bn for 2023.

Key Changes to the Nursing Homes Support Scheme – Fair Deal

There have been changes to two key areas within the operation of NHSS.

The categories of people who can act as a **Specified Person** in relation to NHSS are reduced and their role and responsibility has been changed. A Specified Person may submit an NHSS application on behalf of an applicant when the applicant is unable to do so on their own behalf for certain defined reasons. Details of who can act as a Specified Person, and the principles with regard to specified persons are outlined within the NHSS Application Form, available at www.hse.ie.

A **Care Representative** will no longer be appointed by the Courts. An application to the Circuit Court for the appointment of a **Decision-Making Representative Order** will be required instead. Such an application is made in cases where the applicant was unable to apply on their own behalf for Ancillary State Support and/or the benefit of the 3-year cap on family farms and businesses. It will also be necessary where no one meets the requirement to act as a specified person to apply for state support.

[The NHSS Application Form](#) has been updated to reflect these changes to the NHSS Act and also to provide more information and support to applicants and their loved ones when completing the form.



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News round up from CHO Dublin North City & County (DNCC)

Ciara Palmer,

Quality Patient Safety Advisor & QPS ADM Lead

CHO Dublin North City & County

CHO DNCC started preparing for the commencement of the Assisted Decision-Making (Capacity) Act 2022 in February 2022 by conducting an internal scoping exercise. Following the scoping exercise, the CHO Steering Group for ADM was established in May 2022 with representation from all primary stakeholders within the CHO. A key output from the Group was an initial Impact Analysis and Implementation Plan. Both the Implementation Plan and Impact Analysis were recently revised post commencement of the Act.

There are approximately 6,000 directly employed HSE staff in CHO DNCC. In order to obtain a baseline of staffs understanding of the Act, a staff survey was conducted in December 2022/January 2023 and the results were incorporated into the revised Implementation Plan.

On 29 March 2023, Aoife Lenihan, Head of Quality, Service and Safety Improvement, supported by Ciara Palmer, QPS Advisor and QPS ADM Lead, held an Assisted Decision-Making (Capacity) Act Masterclass for the CHO. CHO DNCC were delighted to host Aine Flynn (Decision Support Service), Caoimhe Gleeson (HSE), Professor Amanda Phelan (Trinity) and Catherine Cooper (Service User) as speakers for this event.

QSSI continue to promote the Act by way of information sessions, development of ADM Option Grid, development of FAQs, development of a bank of legal Judgments and continued engagement with the National Office for Human Rights and Equality Policy and our staff.



(L to R) Helen Thompson (QPS Manager), Aoife Lenihan (Head of QSSI) and Orla Mahony (QPS Advisor).

The Fundamentals of Advocacy in health and social care

Cathy Duggan

Standards Development Lead

Health Information and Standards

HIQA has published new resources on The Fundamentals of Advocacy in Health and Social Care, to support implementation of national standards. These resources aim to enhance the understanding of advocacy among service providers and staff working in health and social care services, and to help them support people using services to have their human rights met.

HIQA's new resources include:

The Fundamentals of Advocacy in health and social care, an online learning course aimed at improving knowledge and understanding of advocacy among health and social care staff, available on [HSeLanD](#).

A [booklet on advocacy](#) in health and social care which complements the material in our online learning course.

An [educational video on advocacy](#), including interviews with nursing home staff, an advocacy expert and people who use services.

To date, over 3000 people completed the online learning course. Of these 96% said that, having completed the course they have a better understanding of their role in relation to advocacy and 90% said they will make changes to the way that they work. One respondent said:

"The course is very helpful with all the information provided to maximize a person's rights and ability"



The CORALE Study (Conscientious Objection after Repeal: Abortion, Law and Ethics)

Survey for Healthcare Workers

Funded by Irish Research Council

Dr Andrea Mulligan– School of Law; Prof Joan Lalor- Nursing and Midwifery are Co-PIs

Prof. Linda Hogan-School of Religion; Dr Des Ryan- School of Law



The CORALE Study (Conscientious Objection after Repeal: Abortion, Law and Ethics) is an interdisciplinary project based at Trinity College Dublin that examines conscientious objection in termination of pregnancy services in Ireland.

The study is funded via a €194,000 COALESCE Award from the Irish Research Council. Its Principal Investigators are Prof. Joan Lalor (TCD, Nursing and Midwifery) and Dr Andrea Mulligan (TCD, Law), with Prof. Linda Hogan (TCD, Chair of Ecumenics) and Prof. Desmond Ryan (TCD, Law) as co-investigators.

The Health (Regulation of Termination of Pregnancy) Act 2018 requires that the legislation shall be reviewed in the years following the rollout of the service provision. The CORALE team shared some preliminary observations with the chair of the review, barrister Marie O’Shea, and these preliminary observations were cited in the final report of Ms O’Shea, published in April 2023.

The research team is currently seeking input from healthcare workers on the operationalisation of the right to conscientious objection. All groups involved in the healthcare service provision in Ireland are being invited to participate in the anonymous [survey](#) e.g., doctors, nurses, midwives, pharmacists, hospital administrators and healthcare assistants and students.

The survey takes 10-25 minutes and can be done on any device. It can be accessed here:

https://nursingandmidwifery.fra1.qualtrics.com/jfe/form/SV_cl8fU0U73wT8Jx4

Further updates and resources

*For further updates, join our mailing list,
please email: adm@hse.ie*

Useful resources available on the Assisted Decision-Making (Capacity) Act 2015, please see below latest updates:

- [HSE Assisted Decision-Making website](#)
- [HSE Explainer video on the Act](#)
- [Webinar on Assisted Decision-Making \(Capacity\) Act 2015: Update since commencement from the 14th June 2023](#)
- Decision Support Service statutory [Codes of Practice](#) on the 2015 Act including codes relating to:
 - [Healthcare Professionals](#)
 - [Advance Healthcare Directives for Healthcare Professionals,](#)
 - [Supporting Decision-Making and Assessing Capacity.](#)
- **NHSS:** For updates to the fair deal scheme application process and changes following the Assisted Decision-Making (Capacity) 2015 Act - <https://www2.hse.ie/services/schemes-allowances/fair-deal-scheme/>
- [Webinar on Getting ready for commencement of the Assisted Decision-Making \(Capacity\) Act 2015](#)
- [Webinar on Getting ready for Advance Healthcare Directives under the Assisted Decision-Making \(Capacity\) Act 2015](#)
- [ELearning Programme on Assisted Decision-Making \(Capacity\) Act \(2015\) – Guidance for Healthcare workers on HSeLanD](#)
- [Assisted Decision-Making \(Capacity\) Act 2015](#)
- [Transition from Wardship to the Assisted Decision-Making \(Capacity\) Act 2015: Guidance for Staff webinar recording from the 1st December 2022 and other related documentation](#)
- [Launch of the Easy-to-read webinar on the HSE National Consent Policy on 5th December 2022](#)
- [Decision Support Service](#)
- [Courts Service - Office of Wards of Court](#)
- [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](#)