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### **Abbreviations**

ADM	Assisted Decision-Making
ADMA	Assisted Decision-Making Act
AHD	Advance Healthcare Directives
CSAR	Common Summary Assessment Report
DNACPR	Do Not attempt Cardiopulmonary Resuscitation
DPO	Disabled Persons Organisations
DSS	Decision Support Service
DTOC	Delayed Transfer of Care
HEI	Higher Education Institutes
HSE	Health Service Executive
ICGP	Irish College of General Practitioners
IEHG	Ireland East Hospital Group
KPI	Key Performance Indicator
LPF SOP	Local Placement Forum Standard Operating Procedure
NQPS	National Quality Patient Safety
RHA	Regional Health Authorities
UCC	University College Cork

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Overview

1

### 1.1 Statement from the General Manager

## 1.1 Statement from the General Manager

It is with great pride and gratitude that I present this year's Annual Report, reflecting the continued dedication, collaboration, and progress made by the National Office for Human Rights and Equality Policy.

Over the past year, we have taken significant steps forward in our mission to promote and protect human rights and equality in health and social care practice. Among our key achievements was the publication of the updated National Consent Policy 2022 v1.2, a vital document that reinforces the principles of autonomy, dignity, and respect in health and social care settings.

We also successfully concluded the first year of our Assisted Decision-Making Mentorship Programme and launched year two. This programme has made a meaningful impact by supporting professionals and individuals in navigating the evolving landscape of decision-making capacity.

One of the highlights of the year was our national conference in Cork, titled "The Assisted Decision-Making Capacity Act 2015 – Reflections, Challenges, and Opportunities."

This two-day hybrid event, held in collaboration with University College Cork, the Decision Support Service, and Clinical Design and Innovation, brought together a wide range of stakeholders, advocacy workers, and experts. It was a powerful demonstration of what can be achieved through shared knowledge, lived experience, and collective commitment.



The implementation of the Assisted Decision-Making (Capacity) Act 2015 continues to be a challenge in some settings. We provided ongoing advice and guidance to front-line practitioners navigating their way through complex and ever changing scenarios.

To our partners, stakeholders, advocates, and every individual who has contributed to our work, thank you. Your engagement, insight, and encouragement continue to inspire us and drive our mission forward.

As we look ahead, we remain committed to fostering a society where every person's rights are respected, voices are heard, and choices are supported.

Warm Regards

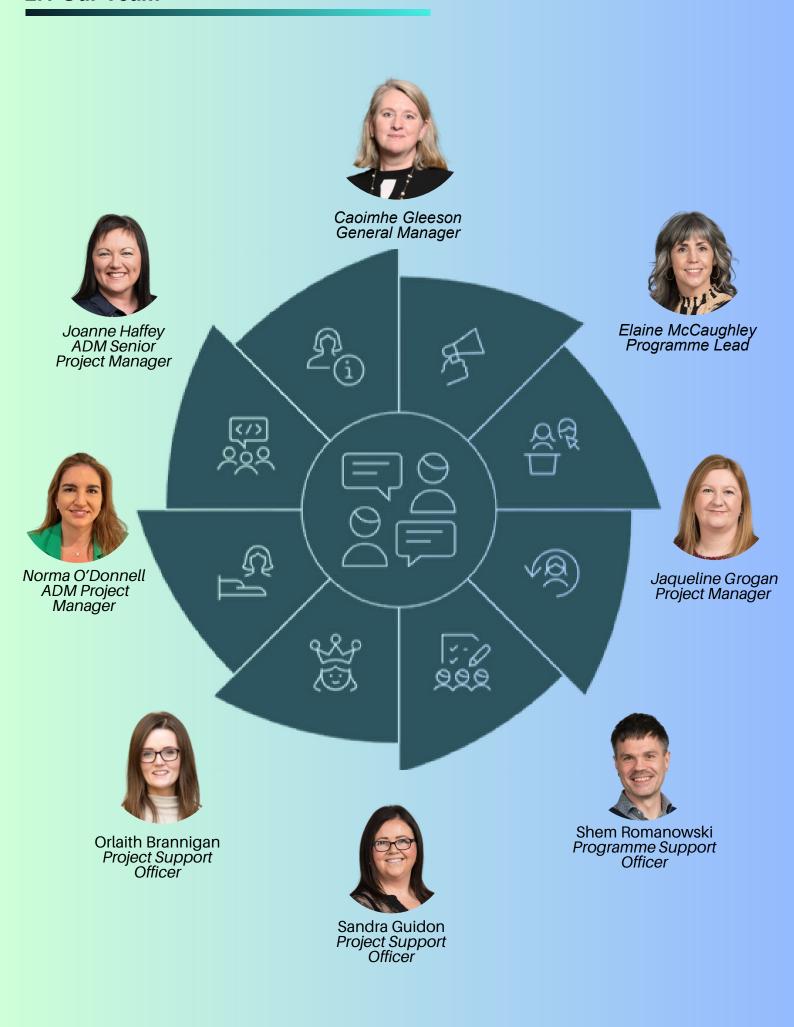
Caoimhe Gleeson General Manager.

Christe Gleer

#### **About Our Team**

2

- 2.1 Our Team
- 2.2 Overview of National Office for Human Rights and Equality Policy
- 2.3 Mission and Vision



#### 2.2 Overview of National Office for Human Rights and Equality Policy

The National Office for Human Rights and Equality Policy plays a central role in supporting the HSE to deliver healthcare services that respect the dignity, rights, and equality of every individual.

Our work ensures that human rights and equality principles are embedded across policies, practices, and service delivery, in line with national legislation and international best practice.

The National Office for Human Rights and Equality Policy comprises a team with expertise in various fields, including:

The team is led by a senior manager with extensive experience in human rights and equality. The team structure is designed to ensure a comprehensive and coordinated approach to promoting human rights and equality across the HSE.



#### **Human Rights Law and Policy**:

Specialising in human rights law, providing guidance on legal compliance and policy development.

**Front line Practice:** Professionals with frontline expertise in health and social care delivery.

**Equality and Diversity**: Professionals with expertise in equality and diversity, promoting inclusive practices.

**Training and Education**: Trainers and educators developing and delivering programs on human rights and equality issues and supports.

Research and Analysis: Conducting research and data analytics to inform policy development and identify areas for improvement.

Our vision is a health service where every person is treated with dignity and respect, and where equality is at the heart of care.

#### **Mission**

Our mission is to:

Build skills, knowledge and confidence of staff

Achieve HSE Compliance with Human Rights legislation

Develop and promote National Office for Human Rights and Equality Policy.

Influence legislative and organisational change to ensure that the human rights and dignity of each person using HSE services are respected.





#### Vision

Our vision is a health and social care service that respects the rights, autonomy and dignity of all the people who use services.

The National Office for Human Rights and Equality Policy is primarily responsible for the strategic oversight of the HSE National Consent Policy and to provide advice and guidance on the implementation of the Assisted Decision-Making (Capacity) Act (2015) in the HSE.

The National Office for Human Rights and Equality Policy also provides guidance and support on universal access and other human rights and equality issues including public sector duty and universal access for people with disabilities.

The National Office for Human Rights and Equality Policy works in collaboration with staff and people who use our services to ensure human rights and equality issues are addressed.

Strategy, Governance and Stakeholder Engagement

3

- 3.1 Strategic Priorities
- 3.2 Governance
- 3.3 Stakeholder Engagement
- 3.4 Activity in Numbers

#### 3.1 Strategic Priorities



During 2024, we continued the implementation of the Assisted Decision-Making (Capacity) Act 2015 by supporting awareness, training, communications, and cross-agency collaboration.

We strengthened the National Consent Policy and DNACPR policies through a review of compliance, raising staff awareness, and advancing inter-agency collaboration.

The National Office for Human Rights and Equality Policy continued to support the HSE's Regional Health Authorities (RHAs) and other HSE functions by providing up-to-date guidance on the implementation of the 2015 Act in HSE and HSE funded services.

RHAs, National Schemes and National Functions supported the operational implementation of the 2015 Act with clear leadership and governance across all HSE and HSE funded services

We enhanced communication through the National Office for Human Rights and Equality Policy function to ensure greater visibility and impact of this work.

## 3.2.1 Assisted Decision-Making (ADM) Transitional Oversight Group

The Assisted Decision-Making (Capacity) Act 2015, which came into effect on 26 April 2023, reforms how individuals needing support with decision-making are recognised and supported in health and social care. It promotes rights-based, person-centred care and requires a cultural shift for care providers.

To implement the Act, the National Office for Human Rights and Equality Policy established a Transitional Oversight Group, responsible for:

- Providing strategic and operational guidance.
- Identifying and escalating risks.
- Coordinating with key agencies and government departments.
- Overseeing the transition from wardship to new decision-making structures.
- Monitoring implementation progress through KPIs and plans.
- Ensuring stakeholder engagement and feedback.

The National Office for Human Rights and Equality Policy supports the group administratively and provides policy support. The group also consults with users, advocacy groups, and experts as needed.

The group has membership from across the HSE, HSE funded services, advocacy organisations, disabled persons organisations (DPOs), subject matter experts and experts by experience.

This collaborative approach has ensured that the voice of people who use our services and experts by experience is heard in the implementation of this reforming piece of legislation. This has led to a more personcentered approach to the implementation of the Act.

8



Number of meetings held for ADM Transitional Oversight Group

Through its engagement with key stakeholders, the HSE ADM Transitional Oversight Group has been able to understand the nuances of practice issues, ensuring that the voice of the person who uses our services can be heard throughout the implementation of the Act.

It has demonstrated that a collaborative approach in implementing a very complex piece of legislation can have numerous benefits.

Key activities in 2024 included:

- Commencement of review of local placement forum standard operating procedure (LPF SOP) and the common summary assessment tool (CSARs)
- Engagement with other key stakeholders in relation to practice issues raised at the group
- Ongoing work with the banking sector in relation to feedback received
- Development of a tracker for Type F DTOC cases that has been piloted in 2 sites
- Engagement with TUSLA in relation to young people aging out of care
- Development of online training for assessments of capacity under the Act

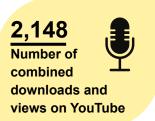
#### 3.2.2 National Consent Policy Steering Group

The overall purpose of the HSE National Consent Policy Steering Group is to develop, monitor and review implementation of the HSE National Consent Policy.

HSE National Consent Policy Steering Group:

- Develop, monitor and review an implementation plan for the National Consent Policy
- Inform the development of, and give guidance on measurement/audit tools for compliance with the policy.
- Identify and escalate any risks arising from non-compliance in services
- Support a campaign to increase awareness of the HSE National Consent policy
- Support and promote the education and training plan for staff in relation to the policy.
- Support a campaign to increase awareness and uptake of the supporting e-learning programme
- Support a campaign to promote key messages in relation to the National Consent Policy.

- Consent Policy Workshop at Irish Society for Disability and Oral Health Conference
- HSE Dublin and South East/ National Women and Infants Health Programme Conference "Addressing Challenges in Maternity Services in Ireland"



HSE Health and Wellbeing podcast on National Consent Policy

1557 Number of attendees to online events



Two online learning events to promote and explain the key updates to the Policy.

#### Key activities in 2024 include:

- Publication of HSE National Consent Policy 2022 v1.2 updated to take account of Assisted Decision-Making (Capacity) Act 2015.
- Update to Easy Read Consent Document -Peer-to-Peer launch event for Easy to Read Document, social media campaign co-designed with St. Michael's House.
- Consent in Practice in Maternity Settings Learning event with IEHG, NWIHP and State Claims Agency.

436
Number of attendees to webinar

National Consent Policy -Considerations for Mental Health Services Webinar



#### 3.2.3 DNACPR Policy Steering Group

The National Office for Human Rights and Equality Policy is revising existing HSE guidance on DNAR/DNACPR to produce a standalone HSE DNACPR Policy. This Policy will provide practical guidance to healthcare workers on the best course of action for an individual in the event of a cardiac arrest.

Current HSE guidance on DNAR/DNACPR consists of Part 3 and Appendix 10 (HSE Guidance Regarding Cardiopulmonary Resuscitation and DNAR Decision-Making during the COVID-19 Pandemic ) of the HSE National Consent Policy 2022.

The new standalone HSE DNACPR will build on this and incorporate key findings relevant to the Irish context as identified by research commissioned by the Office of National Office for Human Rights and Equality Policy Policy Policy.

#### **Research into DNACPR**

HSE research paper Do Not Attempt Cardiopulmonary (DNACPR) Decisions: Practice and Policy was published in 2024 and will be published with the HSE DNACPR Policy.





### A HSE DNACPR Policy Steering Group was convened in April 2024 to:

- 1. review existing guidance
- consider the findings of the DNACPR Research paper
- participate in DNACPR Policy Scoping process
- 4. review, develop and monitor the draft DNACPR policy
- 5. sign off a HSE DNACPR Policy for approval by EMT
- 6. develop an agreed governance model for the oversight of the policy across services with the HSE and HSE funded services
- Identify what supporting documentation may be required for the revised DNACPR Policy and identify implementation mechanisms of same.

This group is constituted by a representation of a broad field of stakeholders including;

- Pre-Hospital Emergency Care Council, National Ambulance service
- ICGP
- HSE Clinical Programmes
- · HSE Office for Legal Services
- National Advocacy Service for People with Disabilities
- SAGE Advocacy
- Irish Hospice Foundation
- Nursing Homes Ireland
- · ethicists and subject matter experts

This piece of work is ongoing in 2025.

#### 3.3 Stakeholder Engagement

The 2015 Act is a welcome and reforming piece of legislation that is having a positive, although sometimes complex, impact on those who benefit from the provisions of this legislation.

In order for the positive effects of the legislation to reach all of those who interact with the legislation, it is important that a robust stakeholder engagement strategy is developed and implemented at national, regional and service level.

In 2024, the National Office for Human Rights and Equality Policy placed stakeholder engagement at the centre of its work.

Ongoing dialogue with staff, people who use our services, their circles of support, advocacy groups, and partner organisations ensured that our policies and practices are informed by those most affected by them.



Front-line Staff

**Decision Support Service** 

**Department of Health** 

Advocacy Organisations

Department of Children, Disabilty and Equality

Higher Education Institutes (HEI)

**HSE Office of Legal** 

**Services** 

People who use our services and their

Regional Health
Authorities

National supporters

Safeguarding Office

**HSE Human Resources** 

**Legal Aid Board** 

**Courts Service** 

Disabled Persons
Health Service Trade Organisations

Health Service Trade
Unions

**Experts by experience** 

Health and Social Care Regulators

Professional Bodies and Colleges

HSE Funded organisations and agencies

Clinical Indemnity
Scheme

Safeguarding Ireland

National Disability
Authority

**Department of Justice** 

#### 3.4 Activity in Numbers 2024

In 2024, we undertook a wide range of activities across multiple programmes, including Assisted Decision-Making, the National Consent Policy, the Assisted Decision-Making Mentorship Programme, DNRCPR, and many others. Our key activity in numbers are the following:

5,428



Total Combined
Podcast Downloads
and Views on
YouTube



1,580



Wardship Webinar 2024 attendance

2,857



Consent Webinar 2024 attendance

6,103



Total completions HSE National
Consent Policy
E-Learning
Modules 1&2
2024

51,810



Website Page Views

September 2024



LinkedIn Page Launched

210



Queries Managed 26,279



Total Website
Users

9,706



Module 1
Total completions Assisted DecisionMaking E-Learning
2024

9,202



Module 2
Total completions Assisted DecisionMaking E-Learning
2024

6,017



Module 3
Total completions Assisted DecisionMaking E-Learning
2024

# Training and Awareness

4

- 4.1 E-Learning
- 4.2 Webinars

#### 4.1 E-Learning

The National Office for Human Rights and Equality Policy has delivered information sessions to staff across HSE services and HSE funded organisations, reflecting the importance of providing continuous learning support and development opportunities.

To date, three dedicated e-learning programmes comprising a total of eight modules are available on HSELanD to strengthen staff knowledge and practice in line with the Assisted Decision-Making (Capacity) Act 2015 and the HSE National Consent Policy.

- Assisted Decision-Making (Capacity) Act 2015 - Guidance for Healthcare Workers.
- HSE National Consent Policy e-learning Programme.
- Supporting Decision-Making in Health and Social Care programme



These resources were developed in collaboration with the Decision Support Service, advocacy groups, frontline staff, people using services, and subject matter experts equip staff working with adults (18+) in health and social care with the knowledge, skills, and confidence to implement the Act and uphold best practice in consent and supported decision-making.

## 4.1.1 Assisted Decision-Making (Capacity) Act 2015 Guidance for Healthcare Workers E-Learning

The Assisted Decision-Making (Capacity) Act 2015 Guidance for Healthcare Workers programme offers three modules covering guiding principles, the role of Decision Supporters, and Advance Healthcare Directives.

Assisted Decision-Making (Capacity) Act 2015 – Guidance for Healthcare Workers.

Module 1: **Guiding Principles** 

Module 2: Working with Decision Supporters appointed

under the 2015 Act

Module 3: Advance Healthcare Directives

Figure 1 - HseLanD Assisted Decision-Making (Capacity) Act 2015 - Guidance for Healthcare Workers Modules

9,706

**Module 1** 

Total completions -Assisted Decision-Making E-Learning 2024

#### **Module 1 - Guiding Principles**

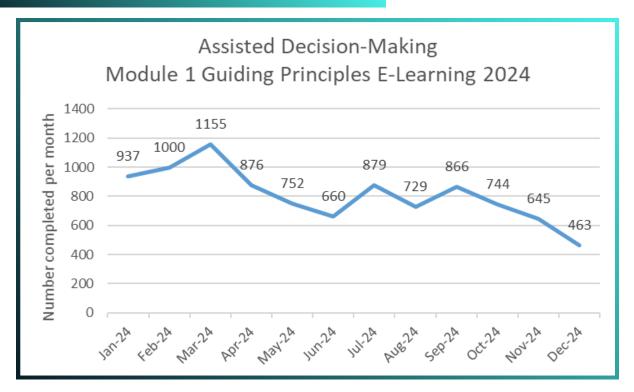


Figure 2: Total number of completions on Module 1 Guiding Principles of the Assisted Decision-Making E-Learning per month in 2024

## Module 2 - Working with Decision Supporters appointed under the 2015 Act

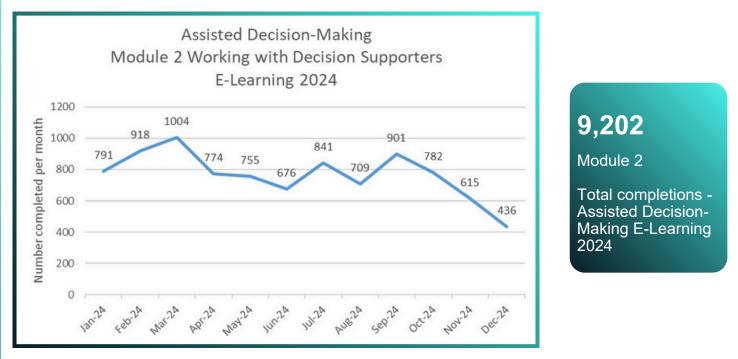


Figure 3: Total number of completions on Module 2 Working with Decision Supporters of the Assisted Decision-Making E-Learning per month in 2024

#### **Module 3 - Advance Healthcare Directives**



Figure 4: Total number of completions on Module 3 Advance Healthcare Directives E-Learning per month in 2024

#### 4.1.2 E-Learning - National Consent Policy

In addition, the National Consent Programme provides two modules focusing on general principles of consent and working with children and young people.

#### **HSE National Consent Programme e-learning.**

Module 1: General Principles

Module 2: Working with Children and Young People

Figure 5 - HSeLanD HSE National Consent Programme e-learning Modules

#### 6,103

Total number of people who have completed the HSE National Consent Programme elearning

Module 1 & Module 2 2024

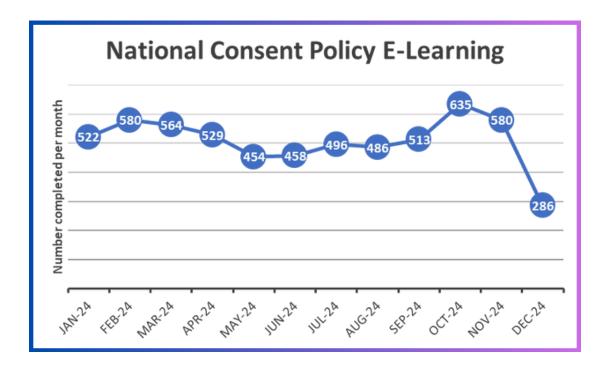


Figure 6 - Number of completions on the HSeLanD National Consent Policy Module 1 & Module 2 per month in 2024

#### 4.2.1 Consent Policy Learning Event Webinar 2024

In January we launched an update to the HSE National Consent Policy. You can find the updated policy here

We ran two webinar events to introduce the update and these are available to watch back <a href="here">here</a> and <a href="here">here</a>

The second of these events was based on scenarios received from staff and features a very practical panel discussion which may be of particular interest.

## **Changes to the HSE National Consent Policy**

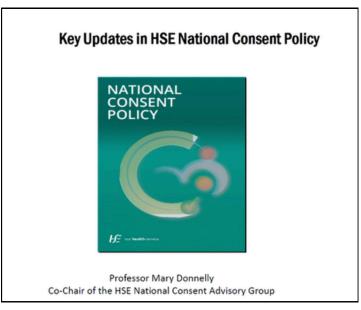
The HSE National Consent Policy has been updated to take account of the Assisted Decision-Making (Capacity) Act 2015 (which was amended by the Assisted Decision-Making (Capacity) Act 2015 and Assisted Decision-Making (Capacity) (Amendment) Act 2022) and which we refer to here as the ADM Act. Both Acts came into force on 26 April 2023. Although the revised National Consent Policy, which came into effect in March 2022, had been drafted in light of the ADM Act, until the legislation came into force, it was not possible to provide detailed guidance on the application of the legislation in practice. This has now been addressed with these changes to the Policy.

In preparing this update, the HSE National Consent Policy Advisory Group consulted with key stakeholders including the HSE Office of Legal Affairs, Legal Counsel and the State Claims Agency. The Policy also incorporates relevant elements of the Decision-Support Service Codes of Practice, in particular the Code of Practice for Supporting Decision-Making and Assessing Capacity and the Code of Practice on Advance Healthcare Directives for Healthcare Professionals.

In summary, the key changes to the Policy (all of which relate to Part 1) are as follows:

- Part 1, section 1.4 is removed from the Policy
- There is a new section Part 1, section 4.2
- Part 1, section 5 is amended to incorporate the ADM Act
- Part 1, section 6 is expanded to include guidance on where a person's capacity is in question and the principles of the ADM Act
- Part 1, section 7 on Advance Directives is amended to incorporate the ADM Act
- Part 1 Section 8 has a change of title and some minor updates. We can now look in a little more detail at some of these changes.

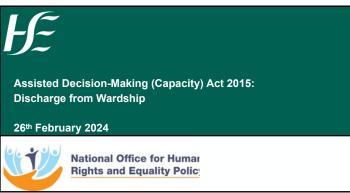






## 4.2.1 Assisted Decision-Making (Capacity) Act 2015 - Discharge from Warship Webinar

In February 2024, we hosted a webinar under the direction Professor Mary Donnelly (School of Law, UCC and Co-Chair of the HSE ADM Steering Group) which brought together key stakeholders to explore the implications of the Assisted Decision-Making (Capacity) Act 2015, with a focus on the discharge from wardship.





Click to watch the webinar



Assisted Decision-Making (Capacity)
Act 2015: Discharge from Wardship
HSE Webinar 26th February 2024

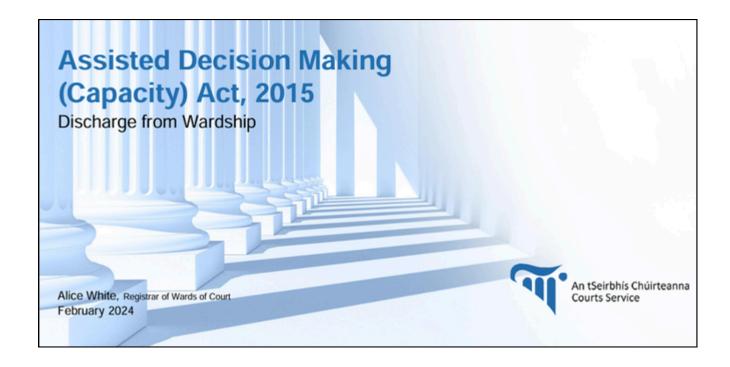
Marie-Claire Butler
Deputy General Solicitor
Office of the General Solicitor for Minors and
Wards of Court



## 4.2.1 Assisted Decision-Making (Capacity) Act 2015 - Discharge from Warship Webinar

The session featured expert insights from Alice White, Registrar of the Office of Wards of Court, and Marie-Claire Butler, Deputy General Solicitor, Office of the General Solicitor for Minors and Wards of Court.

The event fostered valuable discussion on legal, procedural, and practical aspects of transitioning from wardship under the new legislative framework.



### Assisted Decision Making (Capacity) Act

- Commencement
  - 26th April 2023
  - Applications accepted to 25th April 2023
  - All wards of court to be discharged by 26th April 2026
  - · Three tiers of decision support available
- Transitional Arrangements s.56A (amendment)
  - Option to withdraw & seek declaration under s.55 ADMCA
  - · This has not occurred
  - Court is still declaring adult wards of court

Office of Wards of Court

### Communications

5

- **5.1 National Office for Human Rights and Equality Policy Website**
- 5.2 Newsletter
- 5.3 Podcasts
- 5.4 LinkedIn

## **5.1 National Office for Human Rights and Equality Policy Website**

The National Office for Human Rights and Equality Policy website functioned as a central hub for information and guidance on a suite of human rights and equality issues.

#### It facilitated:

- Policy dissemination (e.g. revised Consent Policy, accessible versions).
- Stakeholder engagement through information on events, webinars, and conferences.
- Dissemination of information on in-person and online training events.
- Resource access including navigational aids and regulatory guidance.
- Ongoing communication through the dissemination of the quarterly newsletter.



In 2024, the National Office for Human Rights and Equality Policy significantly enhanced its reach and impact through its digital platforms chiefly by publishing policies, resources, and hosting events through its website and related domains.

You can view our website here

#### 5.2 Newsletters - Human Rights ar

In 2024, the National Office for Human Rights and Equality Policy produced a series of newsletters designed to highlight key developments, share good practice, and support staff across the health and social care system in embedding human rights and equality principles in their work.

The newsletters provided regular updates on national policy initiatives, legislative changes, and resources, as well as showcasing examples of innovative practice from services around the country.

Each edition focused on practical supports for staff, including guidance on the implementation of the Assisted Decision-Making (Capacity) Act, equality and diversity initiatives, and updates on consent, safeguarding, and access to services.

Feedback from staff indicated that the newsletters were a valuable source of information and learning, supporting greater awareness of rights-based approaches and providing accessible updates in a fast-changing policy environment.



#### 5.2 Newsletters - Human Rights and Equality Matters

Our newsletter is disseminated to a dedicated mailing list of over 6,500 subscribers and is also shared with our LinkedIn community of 2,000 followers, ensuring broad and targeted engagement with our audience and added to our office HSE website with activity of 26,279 views in 2024.

The newsletters also served as a platform for raising awareness of training opportunities, events, and new publications, helping to strengthen engagement and collaboration across the HSE and with partner agencies.



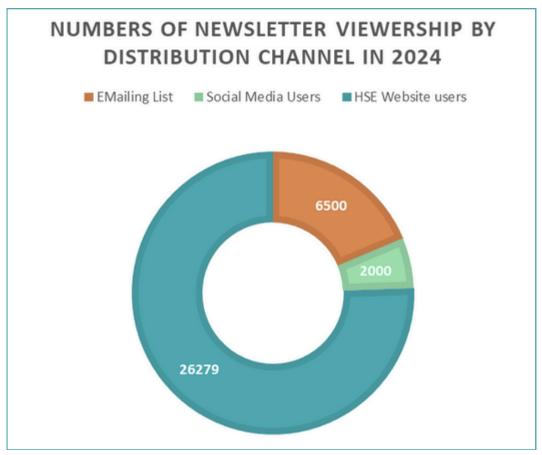


Figure 9 - Number of Newsletter viewership by distribution channel in 2024

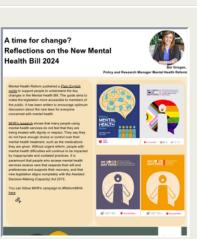


















News Roundup

National Office for Human Rights and Equality Policy







National Office for Human Rights and Equality Policy

Newsletter Spring 2024



Sage











## Promoting Consent and Autonomy on the HSE Talking Health and Wellbeing Podcast

The National Office for Human Rights and Equality Policy featured on the HSE Talking Health and Wellbeing Podcast, where there was a discussion of the updated HSE National Consent Policy with host Fergal Fox.

The conversation highlighted the policy's emphasis on informed, voluntary consent and the importance of supporting individuals to make their own decisions about their health and social care.

Challenges were addressed in mental health services and the role of families in contexts such as dementia, reinforcing a human rights-based approach to care.

The episode is available to listen and share across all major podcast platforms.

CLICK HERE >



1,088

number of views on YouTube for Episode #57

1,060

number of downloads on podcast channel for Episode #57



'They might have had a successful surgery.
But what lasts is how they were made feel.'

- Elaine McCaughley

## Advance Planning for Healthcare on the HSE Talking Health and Wellbeing Podcast

In episode #74 of the HSE Talking Health and Wellbeing Podcast, Caoimhe Gleeson, General Manager of the National Office for Human Rights and Equality Policy, and Suzy Byrne, Regional Manager of the National Advocacy Service for People with Disabilities, explored the importance of planning ahead for healthcare.

The discussion offered practical insights into the Assisted Decision-Making (Capacity) Act 2015, understanding capacity, open communication, advance healthcare directives, and supporting individuals with disabilities.

This informative episode encouraged proactive healthcare planning and promotes respect for individual autonomy and decision-making.

CLICK HERE D

1,340

number of downloads on podcast channel for Episode #74

540

number of views on YouTube for Episode #74



#### 5.4 LinkedIn

In September 2024, the National Office for Human Rights and Equality Policy launched its official LinkedIn page, marking a significant step forward in enhancing our visibility, outreach and engagement.

This platform was established to promote awareness of our work, share key updates and highlight initiatives that support the implementation of the Assisted Decision-Making (Capacity) Act 2015 and the HSE National Consent Policy.

The page provides a space to showcase best practices, celebrate milestones and connect with a wider audience including staff, partners and the general public.





Since its launch, the LinkedIn page has steadily grown in followers and engagement, reinforcing our role as a central hub for policy development.

We continue to use this platform to build connections and share knowledge.

Visit our LinkedIn page here



**In-Person Events** 

6

- 6.1 An Evening with Judge Dr. John O'Connor Royal College of Physicians February 2024
- 6.2 The Assisted Decision-Making (Capacity) Act 2015 Reflections, Challenges and Opportunities Conference Cork

## 6.1 An Evening with Judge Dr. John O'Connor - Royal College of Physicians February 2024

We were pleased to host an Evening with Judge Dr. John O'Connor on 21 February 2024, focusing on the Assisted Decision-Making (Capacity) Act 2015.

The event, attended by over 150 participants, was chaired by Professor Mary Donnelly of the School of Law, University College Cork.

Judge Dr. John O'Connor delivered a keynote presentation, followed by an engaging interview and a panel discussion featuring leading voices in law, healthcare, advocacy, and policy.

The evening provided valuable insights into the evolving role of Decision-Making Representatives and reinforced the importance of upholding the spirit of the 2015 Act in all decision-making processes.

Feedback was overwhelmingly positive, and the event marked a promising step toward future collaboration with the Judiciary.



Judge Dr. John O'Connor, Caoimhe Gleeson, Professor Brendan Kelly



Judge Dr. John O'Connor



Dr. Siobhán Ní Bhriain, Professor Mary Donnelly, Judge Dr. John O'Connor, Margaret Brennan, Caoimhe Gleeson Professor Shaun O'Keeffe

# 6.1 An Evening with Judge John O'Connor - Royal College of Physicians February 2024



Dr. Philip Crowley, Professor Mary Donnelly, Judge Dr. John O'Connor, Caoimhe Gleeson Professor Shaun O'Keeffe



Professor Mary Donnelly, Judge Dr. John O'Connor



Dr. Philip Crowley, National Director of wellbeing equality climate and global health, HSE



Professor Shaun O'Keeffe, Bibiana Savin, Sage Advocacy



Suzy Byrne, Regional Manager, National Advocacy Service for People with Disabilities

## 6.2 The Assisted Decision-Making (Capacity) Act 2015 - Reflections, Challenges and Opportunities Conference Cork

This highly engaging hybrid event was organised in collaboration with the National Office for Human Rights and Equality Policy, the Decision Support Service (DSS) and the School of Law, University College Cork (UCC).

A thought provoking two-day event on the 2nd and 3rd of December was held at the Kingsley Hotel in Cork focusing on the Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act).

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This event brought together healthcare professionals, legal experts, service users, advocates, and policymakers to reflect on the progress made since the Act's commencement, while also addressing the challenges and opportunities it presents for health and social care delivery.

The conference provided a valuable forum for dialogue on embedding a rights-based approach across services, with particular emphasis on supporting autonomy, dignity, and informed decision-making.

Keynote speakers highlighted the legislative and ethical frameworks underpinning the Act, while panel discussions and workshops explored practical implementation issues, case studies, and interagency collaboration.

Participants shared experiences from across the country, acknowledging the strides taken to enhance person centred practice, while also identifying areas requiring sustained focus, such as staff training, awareness raising, and ensuring equitable supports for diverse populations.

The event reinforced the HSE's commitment to advancing human rights and equality within healthcare, and to working collaboratively with service users and stakeholders in ensuring the principles of the Assisted Decision-Making (Capacity) Act are fully realised in everyday practice.





A recording of the second day of the event can be found at <a href="https://www.assisteddecisionmaking.ie">www.assisteddecisionmaking.ie</a>

# 6.2 The Assisted Decision-Making (Capacity) Act 2015 - Reflections, Challenges and Opportunities Conference Cork

HSE National Office for Human Rights and Equality Policy collaborated at a Conference with University College Cork, and Decision Support Service in Cork to discuss - The Assisted Decision-Making (Capacity) Act 2015 - Reflections, Challenges and Opportunities



John Farrelly, Caoimhe Gleeson, Prof Mary Donnelly, Prof Shaun O'Keeffe, Aine Flynn, Justice Mark Heslin



Suzy Byrne, John Farrelly, Dr. Nicola Maxwell, Niall Brunell, Caoimhe Gleeson, Prof Mary Donnelly, Aine Flynn, Justice Mark Heslin, His Honor Judge Dr. John O'Connor



Sarah Jane Lavin, Dr. Emer Ahern, Patricia Rickard-Clarke, Aoife McMahon, Aine Flynn



Our dear friend and colleague Jacqui Browne RIP

# 6.2 The Assisted Decision-Making (Capacity) Act 2015 - Reflections, Challenges and Opportunities Conference Cork



Caoimhe Gleeson, Aishling Kelleher, Kayleigh Twomey, Roisin O'Neill, Suzy Byrne, Professor Shaun O'Keeffe, Jacqui Browne, Joanne Condon, Aine Flynn



Michelle Angland, PJ Herlihy, Caoimhe Gleeson



Judge Dr. John O'Connor



Amanda Casey, Ultan Hynes, Dr. Joanna Ralston, Bibiana Savin, Judge John O'Connor

Mentorship Programme

7.1 Assisted Decision-Making (ADM) Mentorship Programme Year 1

- 7.2 End of Year 1 Event ADM Mentorship Programme
- 7.3 Mentorship Year 2

## Assisted Decision-Making Mentorship Programme Year 1

The mentorship programme built capacity of local Assisted Decision-Making mentees with hands-on support from mentors over a 12-month timeframe following commencement of the 2015 Act.

The programme took a group mentorship approach, also known as collaborative or collective mentorship. This mentoring approach supports a mentor to provide guidance and expertise to a group of mentees simultaneously. Instead of the traditional one-on-one mentormentee relationship, group mentorship allows multiple individuals to benefit from the mentor's knowledge and experience collectively.

"... a psychologically safe space for staff to support each other and validate their work with people who use the health services"

In group mentorship, the mentor facilitates a collaborative learning environment, encouraging mentees to interact, share experiences, and learn from each other's challenges and successes. The mentor guides discussions addresses common concerns, and provides advice and insights that are relevant to the group as a whole.

"The varied backgrounds of my peers add valuable perspectives that enrich our discussions"

This approach fosters a sense of community and peer support among mentees, creating opportunities for networking, skill development, and personal growth within the safe space of this group dynamic, providing a valuable platform for mentorship that leverages the collective wisdom and experience of both the mentor and the mentees, enhancing learning and development opportunities for everyone involved.

"The access to comprehensive case studies and ethical guidance has been incredibly beneficial. It's not just about theory; we get practical, actionable advice from experienced mentors that we can immediately apply in our work."

The mentorship programme built the capacity of mentees through hands-on support from mentors. The programme:

- built confidence and competence at a local level:
- provided targeted support and resources to healthcare workers;
- helped solve common issues arising in practice;
- developed a mechanism for escalation of issues which cannot be resolved at a local level:
- captured and recorded solutions and case studies:

The programme commenced with 46 mentors and over 510 mentees from across community and acute services, including Section 38 and Section 39 organisations. Each mentor and mentee participates in a monthly learning set where anonymised cases can be worked through to enhance and support knowledge and practice. The programme includes monthly mentor network session to support the mentors. There is a feedback and escalation loop which help identify any system or process issues which may need to be addressed at a national or policy level.

"The open, non-judgmental space is essential for us to discuss our difficulties and learn from each other."

"The real-life vignettes bring the ADM Act to life, allowing us to explore its application in concrete situations."

Right from the beginning the participants began to demonstrate progression and growth in their understanding of the Act. The mentorship programme has consistently been cited as a safe space to share experiences, ask for and receive constructive feedback, and reflect on practice. The demonstration of compassion and commitment participants have shown in applying the guiding principles of the Act in their practice has been remarkable.

"For me, the mentorship programme was an ADM Live event: real life examples of challenges faced by real people in the real world and how ADM principles can be applied in these situations."



Mentors and Mentees from the ADM mentorship programme



Padraig Ruane , Amanda Casey, Suzie Byrne, Caoimhe Gleeson, Ber Grogan, Dr. Philip Crowley



**Lisa McGreevy** 



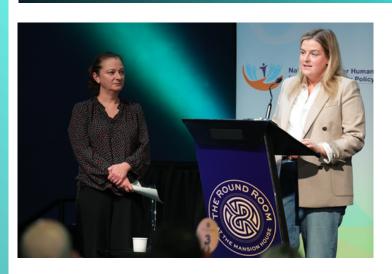
Mentors and Mentees from the ADM mentorship programme



Aine Flynn, Professor Shaun O'Keeffe, Aileen Colley, Cathy Cribben, Caoimhe Gleeson, Dr. Philip Crowley



**Tina Gardiner** 



Janice Hanlon, Denise Ryan



Mentors and Mentees from the ADM mentorship programme



Mentors and Mentees from the ADM mentorship programme



Mentors and Mentees from the ADM mentorship programme



Siobhan Donoghue



Mentors and Mentees from the ADM mentorship programme





every CHO
and Hospital
Group,
some HSE
funded
agencies and
NGO
organisations

44 LEARNING SETS



- 11 Monthly support meetings
  - 2 In-person seminars
- 12 Friday fortnightly ADM lead check-ins

#### 7.2 End of Year 1 Event - ADM Mentorship Programme

On October 9th 2024, the National Office for

Human Rights and Equality Policy hosted the Assisted Decision-Making (ADM) Mentorship Programme event at the Mansion House, Dublin.

The purpose of the event was to celebrate the conclusion of year one of the HSE ADM Mentorship Programme.

The event brought together a diverse group of participants including self-advocates, mentors and professionals, who had participated in Year 1 of the Mentorship Programme.

The event featured a series of engaging presentations to celebrate the success of the first year of the programme and to share learning and experiences.

Keynote speakers shared valuable insights on the principles of the Assisted Decision-Making Act (ADMA) and highlighted the importance of the mentorship programme in improving the knowledge and experience of staff in relation to the Act.

Participants had the opportunity to network, share experiences, and discuss best practices in providing decision-making support.



The collaborative atmosphere fostered a sense of community and mutual learning, reinforcing the belief that everyone has the capacity to make informed decisions with the right support.

#### 7.3 Mentorship Year Two

Year Two of the ADM Mentorship Program began in October 2024 with an event that brought together co-mentors and mentees at the Mansion House, Dublin.

With changes to the Regional Health Area structures and based on feedback from current participants, year two was designed to reflect the integrated nature of the new regions.

The groups were set up with a mix of Acute and Community participants with a further mix of people from Year one and new mentees. Groups were formed within their RHA and as close to geographical locations as possible. All participants will be formed into new groups with an emphasis on diversity and new learning opportunities.

Year 2 introduced a co-mentor structure, with 57 mentors and 430 mentees. The programme was supported with tailored information and webinar sessions for participants in addition to the monthly mentorship meetings.





**Consent Policy** 

8

- 8.1 Update of HSE National Consent Policy
- 8.2 Updates in detail of HSE National Consent Policy
- 8.3 Easy to Read version of the HSE National Consent Policy
- 8.4 HSE National Consent Policy Standard Slide deck

#### 8.1 Update of HSE National Consent Policy

## **Changes to the HSE National Consent Policy**

In January 2024 we published an updated HSE National Consent Policy 2022 v1.2 to reflect the Assisted Decision-Making (Capacity) Act (as amended) 2015 which commenced on April 26th 2023. The Act establishes a modern legal framework for adults who require, or may require, support in exercising their decision-making capacity, either now or in the future.

In preparing this update, the HSE National Consent Policy Steering Group consulted with key stakeholders including the HSE Office of Legal Services, Legal Counsel and the State Claims Agency.

The Policy introduces the Decision-Support Service (DSS) and signposts the relevant DSS Codes of Practice, in particular the Code of Practice for Supporting Decision-Making and Assessing Capacity and the Code of Practice on Advance Healthcare Directives for Healthcare Professionals.

The current version of the HSE National Consent Policy can be found at hse.ie/nationalconsentpolicy along with supporting resources. The e-learning programme on HSeLand was also updated to reflect the changes in v1.2 of the 2022 Policy.



#### 8.2 Updates in detail of HSE National Consent Policy 2022 v1.2

Part I, Section 4.2 provides greater clarity on how to make information more comprehensible where a person's capacity is in question. In doing this, section 4.2 addresses the requirement in the ADM Act that: A person is not to be regarded as unable to understand the information relevant to a decision if he or she is able to understand an explanation of it given to him or her in a way that is appropriate to his or her circumstances (whether using clear language, visual aids or any other means).

Part 1 Section 5 relates to capacity to decide about an intervention. This Section outlines a practical application of the Guiding Principles of the Assisted Decision-Making (Capacity) Act 2015. Section 5 provides useful prompts to consider whether a capacity assessment is necessary, and to consider what difference the assessment will make for the person. In doing this, it is important to ask whether the intervention proposed is in accordance with the person's will and preferences and for the person's benefit. If it is, it may not be necessary to assess the person's capacity prior to the intervention.

For cases where a capacity assessment is required Section 5 lays out the defined steps which must be followed when undertaking a capacity assessment and how these steps must be documented.

Part 1, Section 6 sets the general principles if a person's capacity to decide about an intervention is in question. This Section outlines circumstances in which an intervention may be provided in a non-emergency situation where a person lacks capacity to decide about the intervention and does not have a decision support arrangement under the ADM Act.

This guidance is particularly useful for healthcare workers as it details the circumstances in which an intervention may proceed without the need for court approval. New Appendices 6, 7, 8 support healthcare workers in stepping through and documenting this decision-making process.

Part 1, Section 7 incorporates the legal framework for Advance Healthcare Directives (AHDs) in the ADM Act. It sets out the duties of healthcare workers in respect of AHDs, and provides guidance relation to validity and applicability of an AHD and the role of a Designated Healthcare Representative appointed under an AHD.

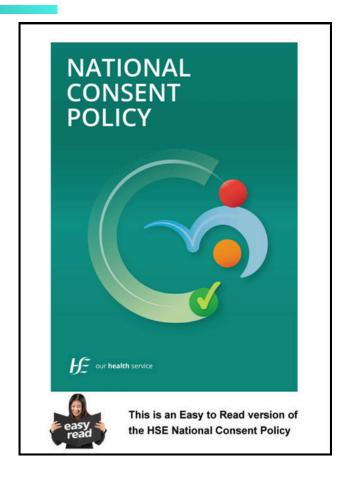
Finally, Part 1, Section 8 is re-titled as Deprivation of Liberty



#### 8.3 Easy to Read version of the HSE National Consent Policy

The Easy to Read Consent document was updated to reflect v1.2 of the Policy. To promote this resource we aimed to demonstrate the practical benefits of making information accessible, and bring the Easy to Read Consent Policy document to life.

With this in mind we approached St Michael's House to try to find out what service users thought of the Easy to Read resource, whether it is useful to them, and to hear their thoughts on consent in health and social care.



#### The National Consent Policy - Easy to Read Launch



Core Group Members, St. Michael's House

After we launched the updated HSE Nation Consent Policy 2022 v1.2, the Easy to Read document of the Policy was updated.

To promote this resource we wanted to demonstrate the practical benefits of making information accessible, and bring the Easy to Read Consent Policy document to life.

With this in mind we approached St Michael's House to try to find out what service users thought of the Easy to Read resource, whether it is useful to them, and to hear their thoughts on consent in health and social care.

### 8.4 The National Consent Policy - Easy to Read Launch



Daniel Akhilomen, Core Group Member, St. Michael's House



Brad Hickson - Core Group Member, St. Michael's House





Cora Sexton, Ciara Cummins & Fintan Whitehead - Core Group Members, St.
Michael's House

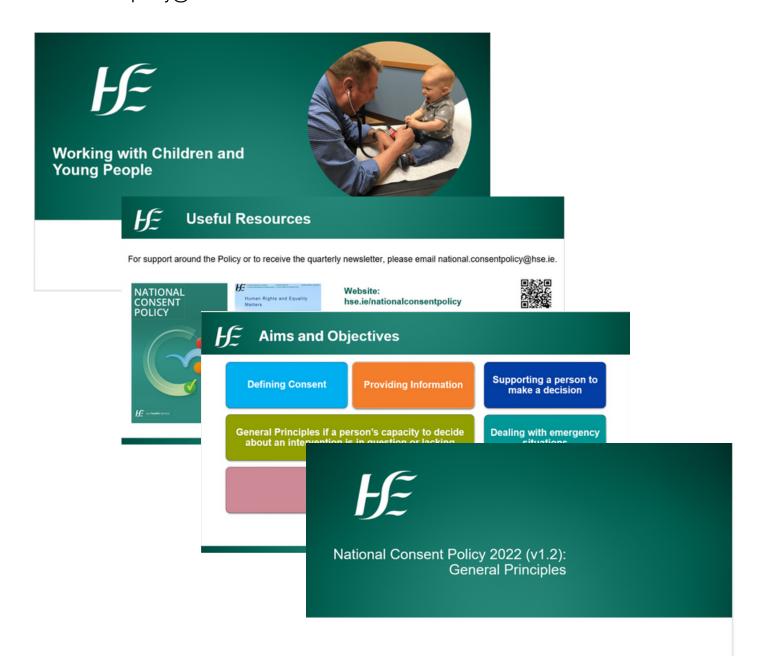
#### 8.5 HSE National Consent Policy Standard Slide deck

A working group was established to review and develop a standard slide deck on the HSE National Consent Policy. The slide deck is intended to support local delivery of education sessions on the HSE National Consent Policy 2022 v1.2 and is aimed at learners who have already completed the elearning programme.

The aims and objectives of the slide deck are to define valid consent and provide guidance on:

- · how to provide information when seeking consent
- how to support a person to make a decision
- · dealing with emergency situations,
- · documenting consent, and
- general principles if a person's capacity to decide about and intervention is in question or lacking.

This slide deck was piloted for 6-months and is now available on request from national.consentpolicy@hse.ie.



**DNACPR Research** 

9

9.1 'Do Not Attempt Cardiopulmonary Resuscitation Decisions: Practice and Policy

## 9.1 'Do Not Attempt Cardiopulmonary Resuscitation Decisions: Practice and Policy'

The National Office for Human Rights and Equality Policy contracted Dr John Lombard and his team in University of Limerick to

- (i) undertake research on Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Orders, and
- (ii) develop a stand-alone DNACPR policy and an implementation plan for the HSE with expert guidance from a HSE National DNACPR policy advisory group.

#### Research aims

- To identify best DNACPR practice, training, policy and response to inform the drafting of an updated DNACPR policy for the HSE.
- To produce a report which sets out key findings and recommendations to be considered in an Irish context.

The full research paper will be published with the HSE DNACPR Policy in Q4 2025.

The project was overseen by Elaine McCaughley Programme lead who convened a DNACPR research Project Working group of stakeholders including Irish Hospice foundation, HSE Deteriorating Patient Improvement Programme, HSE Clinical Programmes, National Ambulance Service, and Patient Partner representative.

Upon completion of the Research paper and draft Policy a HSE DNACPR Policy Steering Group was established to:

- review, develop and monitor the draft DNACPR policy;
- develop an agreed governance model for the oversight of the policy across services with the HSE and HSE funded services;
- Identify what supporting documentation may be required for the revised DNACPR Policy and identify implementation mechanisms of same.

This group includes the HSE DNACPR Research Project Working group and additional representatives from Pre-Hospital Emergency Care Council, HSE Office of Legal Services, ICGP, NQPS.

This work is ongoing.

## A number of journal articles have been published from this piece of research including:

Doody O, Davidson H, Lombard J. Do not attempt cardiopulmonary resuscitation decision-making process: scoping review. BMJ Support Pal-liat Care. 2024. Click here

and

Lombard, J., Davidson, H. & Doody, O. Do not attempt cardiopulmonary resuscitation practice and policy in Ireland:

a mixed-methods study of service user and advocacy group perspectives. Health Res Policy Sys 23, 43 (2025). Click here

**Universal Access** 

10

10.1 The HSE National Guidelines on Accessible Health and Social Care Services
10.2 Access Officers

## 10.1 The HSE National Guidelines on Accessible Health and Social Care Services

The HSE National Guidelines on Accessible Health and Social Care Services were developed to provide practical guidance for all health and social care staff on ensuring that services are accessible to everyone, including people with disabilities. While these guidelines reference specific disabilities, fostering a culture of accessibility benefits all service users and enhances the overall quality of care.

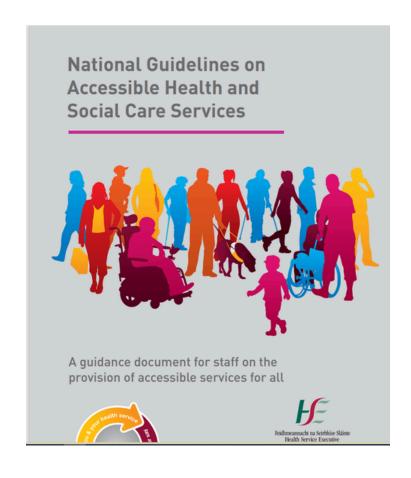
The guidelines also serve as a key resource for Access Officers, equipping them with the necessary tools and knowledge to support health and social care staff in addressing the access of needs of people with disabilities across all health and social care settings.

The guidelines were shaped by a strong legislative and policy framework, including:

- A Future Health: A Strategic Framework for Reform of the Health Service 2012 -2015
- The Disability Act 2005
- The Equal Status Acts 2000 2008
- The National Healthcare Charter: 'You and Your Health Service'
- Various other health and social care policies and procedures

Since their initial publication, legislation and policy have evolved significantly, necessitating a review and update of these guidelines to align with current legal and policy frameworks, as well as best practices in accessibility and inclusive service delivery.

A review of the guidelines commenced in 2024 and will continue into 2025 which will involve a wide range of stakeholders.



You can view the
National Guidelines on
Accessible Health and
Social Care Services
here:

The Disability Act 2005 is a positive action measure, which provides a statutory basis for making public services accessible. It gives effect to the underlying principle that mainstream public services provided to the general public must also serve people with disabilities as an integral part of the service they provide.

The health service is obliged to ensure that its buildings, its services, the information it provides, and how it communicates with people, are all accessible to people with disabilities.

The HSE has a network of designated access officers in order to comply with Section 26 of the Disability Act 2005. Designated access officers are located throughout the country.

Access to our services is everyone's responsibility and is about big and small things like access to buildings, how consent is obtained, how medication is explained, how appointments are managed and assigned and how bad news is broken, whether a person is blind, deaf, has autism or any other condition.

All HSE staff have a role, whether you are the person the patient meets at the reception desk, the hospital porter, the nurse, the catering staff, the cleaner, the junior doctor or the medical consultant - what you do and how you do it can not only influence a patient's experience positively but can ensure that their patient journey is safer. We also need to remember that in some instances it may not be the patient that has the disability, but their carer or family member.

Access officers will support staff to deal with these big and small things when additional support or guidance is needed.

There are gaps in the way that we provide some services, and it is fact that some of our facilities are not easily accessible to those with disabilities.

Access Officers will help us systematically work to address these gaps and ensure that future services and facilities comply with national guidelines, standards and legislation, and are fully accessible to everyone.

A review of the access Officers commenced in 2024 and will continue into 2025.

#### **Access Officers - HSE.ie**

**Disability Act 2005 - Access Officers: Contact Details** 

Hospital Groups: Access Officers
Community Health Organisations: Access Officers
National Ambulance Service: Access Officers
Primary Care Reimbursement Service (PCRS):
Access Officers

Queries

- 11.1 Queries
- 11.2 Query Monitoring

The National Office for Human Rights and Equality Policy provides ongoing advice and guidance on the implementation of the Assisted Decision-Making (Capacity) Act (2015) in the HSE. We began collecting data in 2022 prior to the commencement of the 2015 Act. Due to a significant rise in complex queries a Query Management System was established in 2024 to enable more efficient categorisation, allocation, tracking and resolution of queries.

The focus of the query management system is to ensure a better and more timely experience for the people issuing queries. The system supports data-driven decision making and compliance, recording keeping and reporting.

In 2024, 291 queries categorised under Assisted Decision Making and 90 Under HSE National Consent Policy were managed by the team.

Of the 291 Assisted Decision Making queries, 18 related to the delivery of training and information sessions nationally.

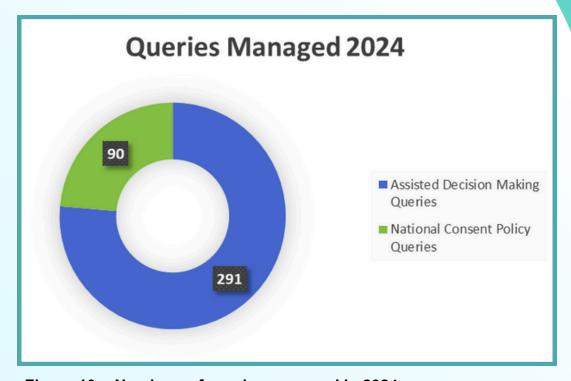


Figure 10 - Numbers of queries managed in 2024

#### 11.1 Queries

Throughout 2024, the National Office for Human Rights and Equality Policy received queries from a wide range of sources across the health and social care system. These included services in acute and community sectors, as well as queries from National HSE divisions, public representatives and other external stakeholders.

This diverse range of contacts reflects the nature of our work and the growing awareness and engagement across all levels. It also highlights the importance of continued collaboration and communication across sectors to support the implementation of policy and guide in practice.

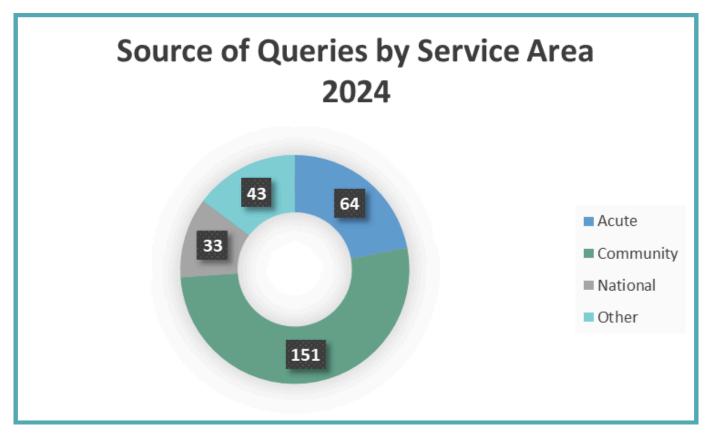


Figure 11 - The source of queries managed by service area in 2024

#### 11.2 Query Monitoring

In 2024, accurate and comprehensive data was collected from all queries received through the National office for Human Rights and Equality Policy.

We monitored the complexity of incoming queries using a 5-point scale (1 = low complexity, 5 = high). Over the course of the year 2024, we observed an increase in high-complexity queries (levels 4–5).

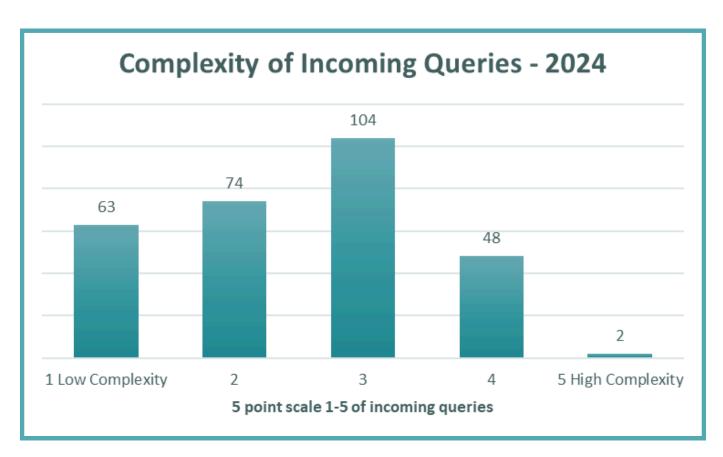


Figure 12 - The complexity of incoming queries managed in 2024 monitored using a 5 point scale





#### Health Service Executive

National Office for Human Rights and Equality Policy Wellbeing, Equality, Climate and Global Health, Bianconi Room, Stewarts Hospital, Mill Lane, Palmerstown, Dublin 20, D20 KH63



National Office for Human Rights and Equality
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National Office for Human Rights and Equality Policy