



An Oifig Náisiúnta um Chearta  
an Duine agus Beartas Comhionannais

National Office for  
Human Rights and Equality Policy

# Human Rights and Equality

## Matters

#NOHREP

Winter 2025

### Highlights in this edition:

ADM Conference Cork

ADM Mentorship Programme

Highlights 2024

Launch of our new  
Spotlight Series



National Office for Human  
Rights and Equality Policy

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



# Welcome

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

Welcome to our winter edition of ***Human Rights and Equality Matters***. In this bumper issue, we celebrate the diverse and impactful human rights and equality initiatives which have taken place over the winter months of 2024. In this year's winter edition we are also delighted to share our highlights of 2024 with you.

Aine Flynn provides an in-depth update on the work of the Decision Support Service, as they close their first full year in operation. Joanne Haffey launches our new “**Spotlight Series**”, where we aim to highlight inspiring projects and individuals in their communities. The first in the series features Amanda Casey, the HSE's first Chief Social Worker. Joanne Haffey also provides an article on Dr. Emer Ahern's insights into “**Addressing the Healthcare needs of Older Adults**” which Dr. Ahern gave voice to at our Conference in Cork in December.

Elaine McCaughley brings our attention to the video “**Managing Risk: Getting Consent in Healthcare Right**” produced by our colleagues from the State Claims Agency. Elaine also shares the “**Interim Guidance on Data Sharing for Referrals under GDPR and the National Consent Policy**”, released in September by Dr. Siobhán Ní Bhriain, HSE National Clinical Director, Office of the Chief Clinical Officer.

Patricia Rickard-Clarke, Safeguarding Irelands Chairperson, gives an overview of the “**Adult Safeguarding Day 2024**”, held in November 2024 which focused on the theme of “**Financial Abuse**”.

Monika Kobylarska, Alcohol Related Brain Injury (ARBI) Resource Officer at Alcohol Forum Ireland shares insights from the first national conference on “**Bridging the Gap**” for ARBI in Ireland. The conference featured collaborations with Dr. Ken Wilson, Professor of Psychiatry and Professor Shaun O'Keeffe, Geriatrician and HSE Clinical Lead on Consent and Assisted Decision-Making Act (Capacity) 2015 among others.

We share episode #74 of the HSE Talking Health & Wellbeing podcast series, where Caoimhe Gleeson joined Suzy Byrne, Regional Manager of National Advocacy Services for People with Disabilities to discuss the importance of “**Planning Ahead for your Healthcare**”. Elaine McCaughley updates us on a National Survey conducted on Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) practices in Ireland.

Our colleague Professor Deirdre Daly, Director Trinity Centre for Maternity Care Research & Professor in Midwifery gives insights into research that commenced in January 2024. This research explores the experiences of deaf women with maternity services in Ireland, in collaboration with Reach Deaf Services.

Sandra Guidon shares highlights from our ADM Mentorship Programme Day which was held in the Mansion House in October 2024.

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date on all things Human  
Rights & Equality Matters





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

# Welcome

Brian Donohoe, the Secretary of the Inclusive Research Network (IRN) Steering Group, provides an update on the IRN's current research project, "**Support to Make Decisions.**"

Jacqueline Grogan updates us of the recent Willy Bermingham Memorial lecture titled "**Agesim, Human Rights and Growing Old with Dignity**" delivered by Associate Professor Sarah Donnelly, UCD School of Social Policy at the Irish Gerontological Society Conference. Jacqueline further updates us that the online training for the Functional Assessment of Capacity, in accordance with the Assisted Decision-Making (Capacity) Act 2015, will soon be available on the Decision Support Service Moodle site.

Derval McDonagh, Chief Executive of Inclusion Ireland, provides an overview of the recent launch of their accessible training materials titled "**Train the Trainer**" on the Assisted Decision-Making (Capacity) Act 2015. The materials were launched in December 2024 by Decision Support Service Director Aine Flynn, in collaboration with the Midlands Conversation Group and the Decision Support Service Champion's Lydia Fisher.

Marguerite Clancy from The HSE's National Safeguarding Office explains the workings of the **Adult Safeguarding Portal** which has been in use since September. Roisin McKeon from the Patient Advocacy Service celebrates the fifth birthday of the patient advocacy service and describes the nature of supports provided by the service.

We feature a number of contributions from the national conference 'Addressing Challenges in Maternity Care in Ireland' which was held in November 2024. Dr. Orla Sheil, Paula Power, Noelle Byrne, Georgina Cruise and Elaine McCaughley focus on issues including consent, human rights and advocacy in the provision of maternity care in Ireland.

Norma O'Donnell provides an in-depth and comprehensive overview of our two-day event "**The Assisted Decision-Making (Capacity) Act 2015 - Reflections, Challenges and Opportunities Conference Cork**". The event was a collaboration between the School of Law in UCC, the Decision Support Service and the HSE National Office for Human Rights and Equality Policy. The aim of the conference was to reflect on the implementation of the 2015 Act, to discuss the challenges encountered in implementation, and to explore the opportunities it presents for improving decision-making support and capacity assessment.

Another key focus of the event was to explore how the voice of the person is respected under the new regime. Elaine McCaughley highlights how the voice of the person was addressed throughout the two-day conference.

As we conclude this newsletter, we bring you some of our **highlights from 2024.**

Thank you all for your continued support of our office's work. As we move into 2025 let's maintain our focus and resolve in upholding human rights, equality and dignity for everyone.

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



# Latest Update - The Decision Support Service

Áine Flynn, Director of the Decision Support Service

At the close of our first full year as an operating service, the DSS is busier every day with delivery of our statutory functions under the Assisted Decision-Making (Capacity) Act 2015.

The demand for information is increasing and a vital addition has been the establishment of a dedicated helpdesk to manage queries in relation to enduring powers of attorney (EPAs). The helpdesk's function is to support members of the public and practitioners with the EPA process from account-opening through to registration. The helpdesk team handled over 1,300 EPA-related queries in November 2024 and more than 1,500 in the first three weeks of December 2024.

EPAs account for most of the decision support arrangements on the DSS register. The total number of active registrations has just passed 2,300. As of 20 December 2024, 1,400 EPAs were fully registered and a further 1,500 had been submitted for review and registration. Just over 30 registered EPAs have moved to the second stage where the donor has lost capacity, and the attorney is required to take over decision-making. Almost 700 active decision-making representation orders made by the courts are now on the register. Numbers of finalised co-decision-making agreements and decision-making assistance agreements are lower at 66 and 51 but increasing steadily.

We are working with the HSE to pilot automated access to our registers. In the meantime, enquiries relating to the register may still be sent to [registersearches@decisionsupportservice.ie](mailto:registersearches@decisionsupportservice.ie)



The DSS has now concluded its campaign to recruit new members to its panel of decision-making representatives. The expansion of the panel was necessary to meet the demands of the courts and there was a focus on ensuring good geographical cover and range of professional expertise. The level of interest and the calibre of applicants has been very encouraging.

Our busy schedule of presentations to diverse audiences has continued. The DSS has begun to work collaboratively with the Irish Hospice Foundation on their 'Getting Your House in Order' in-person regional events on advance planning. We have also begun a proposed series of DSS in-person events specifically in relation to EPAs. Our first event took place in Galway in November, where our team provided practical support to members of the public and legal practitioners who are progressing applications.

For more information please visit the DSS [website here](#)



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# Latest Update - The Decision Support Service

Áine Flynn, Director of the Decision Support Service

At the end of November 2024, the DSS attended together with Courts Service colleagues at the Four Jurisdictions Adult Capacity Conference in Edinburgh, hosted by the Scottish Office of Public Guardian. It is clear that Irish innovations are being watched with interest. This was followed by a very successful conference in Cork, jointly hosted by HSE colleagues, the UCC School of Law and the DSS. The title of the event was, 'The Assisted Decision-Making (Capacity) Act 2015': Reflections, Challenges and Opportunities' and included contributions by the judiciary, departmental colleagues, healthcare professionals, the Courts Service, advocates, and service providers. Most importantly the two-day conference was enhanced by the voices of experts by experience who shared their own stories to illustrate the impact of the 2015 Act in the lives of ordinary people. A key theme was that we deploy the 2015 Act when we give effect to its ethos and guiding principles to promote autonomous decision-making, and that the new formal support framework is there to be accessed as a problem-solving tool and only as required.

The DSS is now looking forward to an in-person event for wards of court and their committees and families, organised by the Office of Wards of Court to take place later this month. The purpose of the event is to provide information and guidance to help promote applications for discharge from wardship. Although the DSS has no direct role in these discharge applications, it is important that those leaving wardship are familiar with the functions of the DSS in potential future support arrangements.

In mid-February 2025, the DSS will attend a periodic check-in with the HSE ADM Leads team. These meetings allow the DSS to learn about the implementation of the 2015 Act in health and social care and to try to answer some of the practical questions arising.

As always, information about our activities, and other news and updates, as well as resources in a variety of formats can be found on the DSS website.

For more information please visit the DSS [website here](#)



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# Introducing Our New Spotlight Series!



Joanne Haffey, ADM Senior Project Manager

*We would like to introduce the launch of our new Spotlight Series in our newsletter! This series will shine a light on various inspiring individuals and projects who are seeking to make a significant impact in their communities and beyond. Our goal is to celebrate the achievements and contributions of these individuals and projects, providing our readers with insights, inspiration, and a deeper understanding of the inspiring work being done around us.*



**Amanda Casey, Chief Social Worker**

In this first edition of our spotlight series, we are delighted to feature Amanda Casey, the first Chief Social Worker in the HSE. Amanda shares her journey, experiences, and insights into the world of social work.

## Who is Amanda Casey?

Amanda is a native of Dublin and continues to live in the city with her family. She is married with two teenage children and has a beloved Labrador named Gus. When she's not working, Amanda enjoys walking her dog and has recently been dabbling in sea swims as part of her hobbies. Her strong family bonds and love for outdoor activities reflect her deep appreciation for both the personal and professional aspects of life.



## Amanda's Social Work Journey

Amanda's career in social work began in 1996. Her first position was with Connolly Hospital, Blanchardstown followed by work at the Cunamh adoption agency before she moved to the Mater Hospital in 2000. At the Mater, Amanda worked for several years in the infectious diseases clinic before joining the heart and lung transplant team, working on bereavement and organ retention. Amanda eventually took on the role of social work manager in the Mater hospital and she stayed in this post for ten years.



To contact Amanda Casey, Chief Social Worker,  
email; [csw@hse.ie](mailto:csw@hse.ie)



Joanne Haffey, ADM Senior Project Manager

# Introducing Our New Spotlight Series!

Throughout her career, Amanda has always maintained and practiced strong rights based values particularly in the area of people being able to make their own decisions. As a result, Amanda chaired the hospital's Assisted Decision Making (ADM) steering committee, building valuable connections throughout the HSE and the broader hospital group. Over time, Amanda moved away from the operational side of social work, focusing more on the strategic impact social work can have in a hospital setting.



## The Significance of the ADM Act

For Amanda, the most important element of the Assisted Decision Making (Capacity) Act 2015 (the 2015 Act) is the emphasis on human rights, specifically legally providing that the voice of the person is heard above all else. She believes the 2015 Act necessitates a focus on personal autonomy and individual rights, even when inconvenient and while this has always been pivotal in social work practice it is now enshrined in legislation.



## Why Social Work?

Amanda's passion for social work began with a deep interest in people and their stories. She wanted a career that allowed her to make a meaningful contribution to society by helping others. For her, social work is about more than just solving problems - it's about understanding the whole person and their environment, building on their strengths, and focusing on solutions.

## The Power of Social Work

What Amanda values most about being a social worker is the profession's ability to approach challenges from a solutions-focused perspective. Social workers often act as the voice of the person in multidisciplinary teams, representing those who often are not able to advocate for themselves. The profession's ability to navigate the intersection of policy and practice provides a unique and valuable perspective that ensures individuals are viewed holistically.





Joanne Haffey, ADM Senior Project Manager

# Introducing Our New Spotlight Series!

## Influences in Her Career

Amanda's greatest influence on her career is Bill, her first supervisor at the Mater, whose integrity and principled approach shaped her own social work practice. Bill's patience and understanding, particularly when working in the fast paced and transient environment of infectious diseases, left a lasting impact on Amanda. She admired his commitment to keeping promises and his willingness to take difficult stances, always advocating for the dignity and needs of those he was providing a service to.

Amanda also credits the Mater Hospital's culture, which was shaped by strong leadership and a commitment to professional development. For Amanda, the values instilled by leaders like Bill continue to guide her work.

## A Colleague's Perspective

If you asked Amanda's colleagues to describe her, they would likely mention her fairness, open-mindedness, and collaborative spirit. Amanda is known for her willingness to seek feedback and bring people along with her in the pursuit of improvement. She believes that for change to be sustainable, people must feel involved and empowered.



## Surprising Facts about Amanda

Outside of her professional life, Amanda has some great life experiences. She once played Sharon Curley's mother in the Mater Hospital's production of *The Snapper*. In addition, Amanda lived in Brussels for a few years, where she worked as an event planner before returning to social work.



Joanne Haffey, ADM Senior Project Manager

# Introducing Our New Spotlight Series!

## The Role of Chief Social Worker

As Chief Social Worker, Amanda's role is crucial in shaping the future of social work within the HSE. She believes that having a senior social work leader sends an important message about the value of safeguarding and the importance of human rights within health and social care services. It's essential, she believes, for the HSE to understand that social workers play a key role in improving the culture of care and ensuring the protection of people in vulnerable situations.

## Key Priorities

In the short term, Amanda is focused on the reform of adult safeguarding and the implementation of the McElroy report, a critical step in improving social work practice. She's also providing advice and guidance to the CEO on key issues. Long-term, Amanda aims to ensure that social work services continue to be high quality, and she is working towards establishing the office of Chief Social Worker to further promote the value of social work within the organisation.

Since her appointment in August 2024, Amanda has been working on raising the profile of social work, introducing her role, and building strong networks with key people within the HSE. She also highlights the overlap between adult safeguarding and assisted decision-making, stressing the importance of supporting individuals to make their own choices in order to reduce the risk of harm.

## In Closing

Amanda's journey in social work has been shaped by a passion for helping others, a deep commitment to human rights, and a belief in the transformative power of strong leadership. As Chief Social Worker, she remains dedicated to supporting individuals in making informed decisions and ensuring that social work services continue to evolve in a way that is both compassionate and effective.

We thank Amanda for sharing her story and look forward to the continued positive impact of her work in the future.

# Addressing the Healthcare Needs of Older Adults - Perspectives from Dr. Emer Ahern



Joanne Haffey, ADM Senior Project Manager

At the Assisted Decision-Making - Reflections, Challenges and Opportunities Conference in Cork in December 2024, Dr. Emer Ahern delivered a compelling presentation addressing the critical issues in healthcare for older adults. With a rapidly aging population, the urgency to rethink our approach to healthcare for this demographic has never been greater. Dr. Ahern's presentation underscored that modern healthcare systems must adapt to the evolving needs of older adults, who are not only the highest per capita users of healthcare but also face unique challenges that are often overlooked.



## Future Planning

Dr Ahern began her presentation by sharing a personal anecdote from her youth. She spoke of when she was 18, about to start college and fresh from a summer lifeguarding job in West Cork, using the money earned to travel to Greece with friends before heading off to university to study medicine. She mused that life could not get any better. Using this anecdote she drew on research indicating that while life satisfaction and quality of life generally decline with age, older adults often report levels of satisfaction comparable to the excitement of young adulthood. This suggests that people in their 70s and 80s can experience a similar sense of fulfilment as they did in their youth. Dr Ahern highlighted that research indicates, that as we age, life satisfaction and overall quality of life tend to decline. However, in contrast, studies also indicate that older adults often experience a level of life satisfaction that mirrors the youthful excitement of an 18-year-old heading off on an adventure. People in their 70s and 80s report levels of satisfaction comparable to those of young adults.



Dr. Ahern discussed the concept of “optimism bias”, where individuals believe negative events are more likely to happen to others rather than themselves. Dr Ahern noted that this bias is especially evident among older adults, particularly during major crises like the recent pandemic. Dr Ahern highlighted that this concept is important when we consider Advance Healthcare Directives (AHDs) and Enduring Power of Attorney (EPAs). She emphasised the importance of understanding these bias as a means to enabling proactive healthcare planning and interventions.

# Addressing the Healthcare Needs of Older Adults - Perspectives from. Emer Ahern



Joanne Haffey, ADM Senior Project Manager



Dr. Emer Ahern

Dr Ahern said that the spirit of the 2015 Act, particularly the presumption of capacity, often guides her work with older adults at Cork University Hospital. She noted that she regularly treats older adults facing injuries or trauma such as fractures or orthopaedic conditions that are often accompanied by mental health challenges like Post Traumatic Stress Disorder (PTSD) or delirium. These conditions further complicate a person's recovery which often affects their decision-making capacity. Older adults require time and space to recover physically and mentally regain their capacity. However, this is not always possible in a hospital setting and Dr Ahern pointed out that this makes it challenging to apply the spirit of the 2015 Act in real life settings.

## Case Study:

Dr Ahern presented a case study of an older woman who lived at home by herself, and after a serious fall and hip fracture, became very ill and delirious in hospital. Despite strong support from family and friends, numerous professionals assessed that she lacked the capacity to make decisions, leading to serious discussions about her ability to return home.

Dr Ahern observed that the woman was adamant about wanting to go home and had strong support from family and friends. Although she initially wasn't given the time she needed, her health eventually improved. With the involvement of an independent advocate, the woman was ultimately able to return home as she desired.

Dr Ahern used this study to emphasise that assessing an older adults capacity while they are hospitalised is often inappropriate due to functional and cognitive decline. Optimising recovery is crucial for enabling informed decision-making. Dr. Ahern highlighted there is a pervasive ageism in healthcare, noting older adults are often excluded from decision-making, health promotion and research leading to suboptimal care.

## Older Adults: Healthcare Utilisation

Older adults are the largest group of healthcare users in Ireland, with frequent GP visits and significant uses of emergency services. Furthermore, more than half of all National Ambulance Service emergency calls involve older adults and 90% of older adults attending the emergency department require immediate or urgent care. In Ireland this age group also accounts for 57% of acute hospital bed days and is the primary user of 22 million home support hours annually. In addition, over 30,000 older adults live in residential care facilities in Ireland. We must ask the question, how many of these older adults have been asked, how many have consented to living in a nursing home, how many are happy living there?

# Addressing the Healthcare Needs of Older Adults - Perspectives from. Emer Ahern



Joanne Haffey, ADM Senior Project Manager

Dr Ahern raised the question:

**At what age do we lose the human right to live in our own home?**

We do not lose this right and as a healthcare system we must move to a human rights approach. The volume of care required for older adults is significant, yet our healthcare system is not fully equipped to meet their complex needs.

## **A Call to Action**

Dr. Ahern's presentation at the Assisted Decision-Making Conference was a powerful reminder that the healthcare system must evolve to meet the needs of older adults. This population requires specialised care that takes into account the complexities of aging, from different health responses to the need for age-friendly environments and rehabilitation. It is crucial that healthcare systems, policies and staff adapt to the growing needs of older adults to reduce harm and improve outcomes.

The Assisted Decision-Making (Capacity) Act 2015 can support and empower individuals, but there is a gap in the healthcare system that needs to be bridged. Older adults deserve a system that recognises their unique needs, respects their dignity and supports their will and preference, and ensures their safety.



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



# Managing Risk: Getting Consent in Healthcare Right

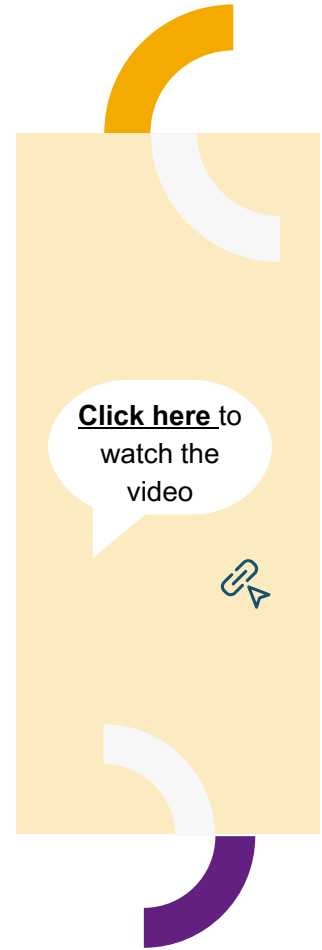
Elaine McCaughley, Programme Lead, National Consent Policy

Informed consent is not just a legal requirement but a fundamental human right that ensures patients have control over their own healthcare decisions.

This process involves providing patients with clear, comprehensive information about the potential risks, benefits, and alternatives of a proposed intervention. By doing so, healthcare providers respect patient autonomy and uphold the principles of equality and non-discrimination.

Effective informed consent practices help to protect vulnerable populations from coercion and ensure that all patients, regardless of their background, receive equitable treatment. Prioritising informed consent fosters trust, enhances patient outcomes, and aligns healthcare practices with human rights standards.

Click the link to watch a comprehensive video on Managing Risk; Getting Consent in Healthcare Right from our friends at the State Claims Agency [Managing Risk: Getting Consent in Healthcare Right](#)





# Interim Guidance on Data Sharing for Referrals

Elaine McCaughley, Programme Lead, National Consent Policy



## Interim Guidance on Data Sharing for Referrals under GDPR and the National Consent Policy September 2024

In September 2024 the Office of the Chief Clinical Officer issued interim guidance on data sharing referrals under GDPR and the HSE National Consent policy. This guidance is set out here in full. The guidance is also available [here](#)

The matter of whether a person's consent is needed for the purposes of referral from one clinician/service to another has been queried by healthcare workers, particularly as services move to delivering care across multiple settings. It has sometimes been the practice to formally seek such consent. With this in mind, we have worked with our colleagues in the HSE Data Protection Office, HSE National Access and Integration, members of the HSE National Consent Policy Steering Group and a range of senior clinicians to provide this guidance.

**The purpose of this interim guidance is to support HCWs in making referrals and outline the legal basis and requirements for the making of referrals only.**

**Key message: a patient's consent is not required to share necessary and appropriate data with other clinical services for the purposes of referrals. It is, however, good clinical practice to discuss with and inform patients that a referral is being made and that their clinical information will be shared for that purpose.**

### Context

The purpose of this memo is to provide guidance for healthcare workers when:

- Making and receiving a healthcare referral,
- Designing referral processes and forms.

**This guidance is provided in the context of requirements under:**

- The General Data Protection Regulations (GDPR, 2016),
- The Data Protection Act, 2018,
- The HSE National Consent Policy 2022 v1.2, and
- Good clinical practice.

[Click here to view the memo](#)

# Interim Guidance on Data Sharing for Referrals



Elaine McCaughley, Programme Lead, National Consent Policy



## Interim Guidance on Data Sharing for Referrals under GDPR and the National Consent Policy September 2024 - Version 2

### The National Consent Policy and GDPR

The National Consent Policy (in relation to clinical consent in its broad sense) states; *'Consent is the giving of permission or agreement for a treatment, investigation, receipt or use of a service or participation in research or teaching'*.

All data processing conducted by the HSE must have an appropriate lawful basis as required by the GDPR and Data Protection Act 2018. The HSE relies on the following lawful basis for the processing of clinical referrals within the healthcare system.

The following lawful bases underpin the issuing of clinical referrals within the healthcare system:

- Article 9(2)(h) GDPR: *The processing is necessary for the purposes of preventive or occupational medicine, for the assessment of the working capacity of the employee, medical diagnosis, the provision of health or social care or treatment or the management of health or social care systems and services on the basis of Union or Member State law or pursuant to contract with a health professional.*
- Article 6(1)(e): The processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller; for the HSE this official authority is vested in us through the Health Act 2004 (as amended).

Consent should not be relied on as a lawful basis for processing of patient data by the HSE for the purposes of referrals within the HSE, with Section 38 or Section 39 organisations or with other private healthcare providers. In particular Recital 43 of the GDPR states *'...consent should not provide a valid legal ground for the processing of personal data in a specific case where there is a clear imbalance between the data subject and the controller, in particular where the controller is a public authority'*.





# Interim Guidance on Data Sharing for Referrals



Elaine McCaughley, Programme Lead, National Consent Policy



## Interim Guidance on Data Sharing for Referrals under GDPR and the National Consent Policy September 2024 - Version 2

This means that clinical referrals can be made between healthcare practitioners in compliance with GDPR, without the need for consent. This includes referrals between all departments in the HSE and referrals to and from HSE services to Section 38 and 39 services and private healthcare providers. It is however good clinical practice to discuss with and inform patients that a referral is being made and that their medical information will be shared for that purpose.

**Note that explicit, informed and revocable consent is required for other purposes such as the use of patient identifiable data for research, for the investigation of a Your Service Your Say investigation etc.**

### Summary of Advice

- Healthcare staff should not seek to rely on consent as a lawful basis to issue a referral within the HSE or to a separate data controller organisation e.g. a S38 organisation, private healthcare provider etc. The HSE relies on Article 6.1 (E) and Article 9.2 (H) of the GDPR to process personal and special category data to issue medical referrals within the healthcare system.
- Data subjects should be informed of how their data is processed, but it is not appropriate to seek (or imply a need for) consent for data processing where it is not required. Data Subjects can be referred to the **HSE's Privacy Notice – Patients and Service Users** for more information on how the HSE processes personal information etc. It is reasonable for the service to which a referral has been made to ask if the person is aware of the referral.
- Referral forms which may currently be in operation which request consent for information sharing should be reviewed and where necessary redesigned to exclude the requirement for consent to data processing to ensure that they are compliant with GDPR. Further information and guidance can be provided by the **HSE DPO Office** or from your **local Deputy Data Protection Officer**. GPs and other non-statutory healthcare organisations should consult their own DPO for advice.

**Dr. Siobhán Ní Bhriain, MSc, FRCPI, MRCP, MRCPsych., MCRN: 15579.**

**HSE National Clinical Director, Integrated Care, Clinical Design and Innovation, Office of the CCO**

# Get informed and prevent Financial Abuse

Keep in charge of your money



8 Nov. 2024



Patricia Rickard-Clarke, Chairperson, Safeguarding Ireland

Adult Safeguarding Day 2024, coordinated by Safeguarding Ireland and supported by the HSE, took place in November 2024 and this year the theme was financial abuse.

The campaign encouraged professionals, family members, carers and people themselves to get informed and prevent financial abuse.

The following article sets out a broad understanding of financial abuse, gives top tips on what can be done to reduce and prevent it.

## Summary – tips to prevent Financial Abuse

- Keep in control of money, property and social welfare benefits as much as possible
- Avoid sharing a bank card and pin number, account number, or access to online banking
- If help is needed – first ask for advice from your bank, An Post or Credit Union
- If help is needed with day-to-day spending – choose only a really trusted person and limit their access
- Ask the person for receipts and get monthly account statements
- Plan for the future by making an Enduring Power of Attorney.



Safeguarding means putting measures in place to uphold rights, support health and wellbeing, reduce risk of harm – and empower people to protect themselves.

Adult abuse happens when a person's rights, independence, or dignity are not respected. This can be deliberate, or caused by a lack of knowledge, or omission of care. However, all circumstances of not respecting a person's rights are abuse and in some cases a serious crime.

There are many forms of abuse including – financial, emotional and psychological, physical, sexual, organisational, online, neglect, coercive control or discrimination. Approximately 14,000 cases of alleged abuse, and 1,500 cases of financial abuse, are reported to the HSE Safeguarding and Protection Teams each year, although the actual figures (what is not reported) are thought to be much higher.



# Get informed and prevent Financial Abuse



Keep in charge of your money

8 Nov. 2024



Safeguarding IRELAND



Patricia Rickard-Clarke, Chairperson, Safeguarding Ireland

Financial abuse is a serious and often overlooked form of abuse, particularly prevalent among older adults. While most people are trustworthy, international estimates suggest that one in ten individuals may misuse another person's money or property. Financial abuse is frequently perpetrated by those close to the victim. This can include family members, carers, neighbors, workers, or social welfare agents. Common forms of financial abuse include:

- Keeping change or taking cash found around the house
- Misusing a bank card or online banking
- Being dishonest about social welfare payments
- Using property or possessions without permission
- Threatening to withdraw care unless money or property demands are met
- Pressuring someone to change their Will, property deeds, or Enduring Power of Attorney

Often, the abuser may have their own financial difficulties, gambling problems, or addictions.



## Protecting Yourself from Financial Abuse

To safeguard against financial abuse, it is crucial to plan for future money management, especially if you anticipate facing challenges with capacity. While online financial fraud and scams are also significant risks, this campaign focuses on financial abuse by known individuals.

Stay informed and vigilant to protect yourself and your loved ones from financial abuse.

# Get informed and prevent Financial Abuse



Keep in charge of your money

8 Nov. 2024



Patricia Rickard-Clarke, Chairperson, Safeguarding Ireland

## Plan ahead – money and property

### An Enduring Power of Attorney (EPA)

This means making affairs and wishes known to a person (or more than one person) who is chosen, and appointing them with legal authority to make financial, property and personal welfare decisions if a person didn't have decision-making capacity at a time in the future.

An EPA is a legal document and required a statement from a Solicitor. Legal aid may be available.

### Decision Support Arrangement

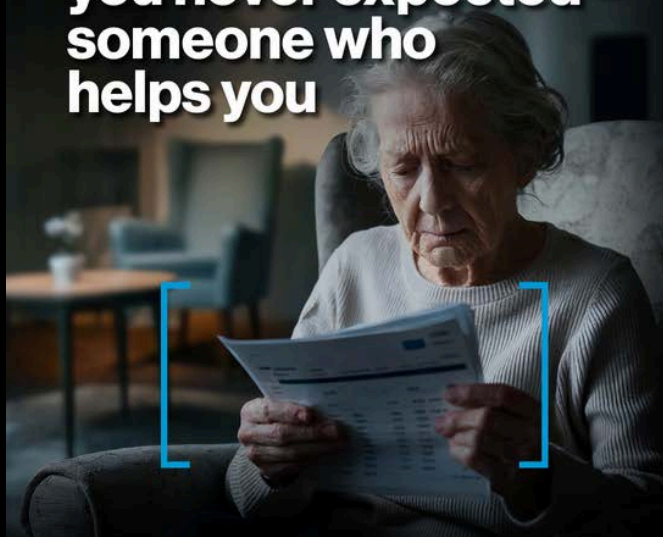
The Assisted Decision-making (Capacity) Act includes three levels of arrangement which have legal standing and can include support with decisions on money and property. The Decision Support Service (DSS) registers arrangements and records must be kept. Contact the Decision Support Service for more information.

- A Decision-making Assistant can be appointed by a person to gather and explain information and communicate a decision for them. However, the person still makes the decision personally
- A Co-decision Maker can be appointed by a person to make decisions jointly with them. This arrangement can be used where a person feels unable to make decisions on their own.

## Financial Abuse you never expected – someone who helps you

safeguardingday.ie

Prevent Financial Abuse -  
stay in charge of your money



Adult  
Safeguarding  
Day 8 Nov 2024



# Get informed and prevent Financial Abuse



Keep in charge of your money

8 Nov. 2024



Patricia Rickard-Clarke, Chairperson, Safeguarding Ireland



A Decision-making Representative can be appointed by the Court if a person is unable to make decisions even with help, and where there is no Enduring Power of Attorney in place.

If concerned about Financial Abuse – report it  
If suffering financial abuse, or concerned about someone, take action and report it.

- If there is a serious and immediate danger, call the Gardaí at 999 or 112
- If financial abuse is ongoing, report it urgently to the local Garda station (directory at [www.garda.ie](http://www.garda.ie)), or call the confidential line at 1800 666 111

If there are unexplained changes in spending – contact the bank, An Post, or local branch of the Credit Union.

For an ongoing financial safeguarding issue contact the regional HSE Safeguarding Team. Email [safeguarding.socialcare@hse.ie](mailto:safeguarding.socialcare@hse.ie), or see [www.hse.ie/safeguarding](http://www.hse.ie/safeguarding).

## Contact your Financial Provider

- AIB – 0818 227 056
- Bank of Ireland – 1800 946 146
- PTSB – 0818 818 721
- An Post – 01 705 8000
- Credit Unions – contact the local branch see [www.creditunion.ie/contactus/](http://www.creditunion.ie/contactus/)
- Dept. of Social Protection (social welfare payments) – 071 919 3259

## Get Independent Advice

- Money Advice and Budgeting Service – [www.mabs.ie](http://www.mabs.ie) / 0818 07 2000
- National Advocacy Service – [www.advocacy.ie](http://www.advocacy.ie) / 0818 07 3000
- Sage Advocacy – [www.sageadvocacy.ie](http://www.sageadvocacy.ie) / 01 536 7330

## Plan Ahead

- Make an Enduring Power of Attorney – talk with your trusted person and Solicitor
- Decision Support Service – [www.decisionsupportservice.ie](http://www.decisionsupportservice.ie) / or 01 211 9750.

# Bridging the Gap - Alcohol Related Brain Injury in Ireland



**Monika Kobylarska,  
Alcohol Related Brain Injury Resource Officer**



**Professor Shaun O’Keeffe, Caoimhe Gleeson, Paula Leonard, Siobhan Cullen and Dr. Ken Wilson**

The first national conference on ‘Bridging the Gap’ for ARBI in Ireland was held in Sligo on the 14th of November 2024. The event was organised by Alcohol Forum Ireland and HSE Social Inclusion in Donegal. It featured a diverse line-up of speakers and drew significant interest from various healthcare professionals.

Speaking before the event on Newstalk Breakfast CEO Paula Leonard of Alcohol Forum Ireland highlighted that ‘global estimates suggest one-in-eight people with Alcohol Use Disorder may develop an Alcohol Related Brain Injury or ARBI’. She said that ‘as many as 70% of people with severe ARBI will end up in a nursing home due to lack of specialised rehabilitative and assisted living services. She stated that 75,000 people in Ireland are at risk of developing ARBI’, underscoring the urgent need for service provision for people with this condition across Ireland.

ARBI is caused by the toxic effects of alcohol on the brain cells, often exacerbated by nutrition and vitamin deficiencies.



Monika Kobylarska,  
Alcohol Related Brain Injury Resource Officer

# Bridging the Gap - Alcohol Related Brain Injury in Ireland

Dr Ken Wilson a retired University of Liverpool Professor of Psychiatry and expert in ARBI highlighted the importance of thiamine or vitamin B1 in brain function. He stated that alcohol depletes the body of essential vitamins, particularly thiamine [Vitamin B1] which is crucial for brain function. Excessive drinking prevents absorption of thiamine which the brain needs in order to change sugars into energy, leading to brain damage that affects reasoning and memory.

Dr Wilson highlighted the severe consequences of inadequate treatment and rehabilitation for ARBI. Patients often face a cycle of ineffective care which in some cases can lead to premature death. With timely treatment and adequate rehabilitation, 75% of patients will improve, leading to an 85% reduction in hospital beds.

arbd network

steps of non-intervention





Monika Kobylarska,

Alcohol Related Brain Injury Resource Officer

# Bridging the Gap - Alcohol Related Brain Injury in Ireland

People with ARBI may be prone to impulsive decisions and may have difficulties with reasoning, problem solving, and assessing risk. All are potentially reversible if the brain has time to recover. Premature discharge from a hospital may lead to continued drinking and further damage. Therefore, decision-making ability is highly relevant in the context of ARBI.

Professor Shaun O’Keeffe, Consultant Geriatrician and HSE Clinical Lead on Consent and Assisted Decision Making discussed the Assisted Decision-Making (Capacity) Act 2015, highlighting it’s application and limitations. Professor O’Keeffe stressed to always start with the presumption of the person’s capacity and ensuring any intervention **must**:

- (1) Minimise restriction of person’s rights and freedom of action
- (2) Respects dignity and autonomy
- (3) Is proportionate to significance and urgency of the matter
- (4) Is limited in duration

Professor O’Keeffe clarified that if in the case of a person with ARBI, where executive functions of the brain may be impaired, any consideration in appointing a decision-making representative should be a last resort and only considered when all other options have been exhausted including the appointment of a co-decision-maker.

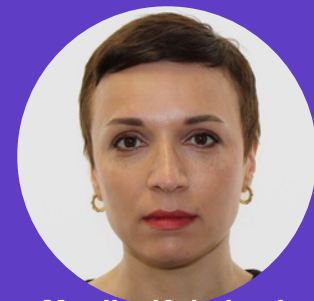


Nov. 14th 2024  
‘Bridging the Gap’  
Alcohol Related Brain  
Injury in Ireland





# Bridging the Gap - Alcohol Related Brain Injury in Ireland



Monika Kobylarska,  
Alcohol Related Brain Injury Resource Officer

Siobhan Cullen, Solicitor and Mental Health Tribunal Member presented a human rights framework on ARBI. Ms Cullen focused on the issue of a “dual diagnosis” (e.g. co-existing diagnosis of mental illness and addiction) and considered what happens when someone with ARBI has no diagnosis of mental illness? Ms Cullen identified ARBI as a gap in mental health legislation, as ARBI is not a diagnosed mental illness/disorder. She suggested that this gap may be addressed by the recent Optional Protocol to the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD); ratified by the Irish Government now effective since 30th November 2024.

Dr Paul Johnson, Clinical Neuropsychologist focused on the Challenges in assessment and treatment of ARBI. Dr Johnson highlighted research which indicates recovery from ARBI is possible, but is heavily dependent on the standard of rehabilitative services including access to trained support professionals, occupational therapists and physical therapists, appropriate housing and family supports.

Diane Watson, is the Clinical Lead for the only dedicated ARBI residential treatment and rehabilitation unit on the Island of Ireland which is based in Belfast. She highlighted the possibilities which can happen for recovery when a dedicated service is provided for people with ARBI.

The impact of alcohol on the nervous system was presented by the final speaker of the day, Dr Kevin Murphy, Consultant Neurologist from Sligo and Letterkenny University Hospitals. Dr Murphy highlighted the impact of alcohol on the nervous system which can lead to the development of over twelve neurological conditions.

Throughout the conference the lived experience of people with ARBI and people living with someone with ARBI was portrayed through a number of powerful short films.

The purpose of the conference was to identify the steps required to address the significant gap in services in the Republic of Ireland.



Dr. Ken Wilson, Monika Kobylarska



Tony Canavan, Regional Executive Officer, HSE West and North West

For further information on the outcome of the conference contact Monika at [monika@alcoholforum.org](mailto:monika@alcoholforum.org)



# Planning Ahead for Your Healthcare

Episode #74 HSE Talking Health & Wellbeing

with Caoimhe Gleeson and Suzy Byrne



General Manager of HSE National Office for Human Rights and Equality Policy, Caoimhe Gleeson and Regional Manager of National Advocacy Services for People with Disabilities, Suzy Byrne discussed the importance of Planning Ahead for Your Healthcare on the HSE Talking Health and Wellbeing Podcast Series.

In episode #74 of HSE Talking Health & Wellbeing podcast series, Caoimhe and Suzy delve into the HSE's initiative on Advance Planning, providing practical and easy-to-understand information on:

- Assisted Decision-Making (Capacity) Act 2015
- Understanding Capacity
- Open Communication
- Advance healthcare directives
- Supporting Individuals with disabilities.

This episode is a must-listen for anyone interested in proactive healthcare planning. Tune in to gain valuable insights and tips on how to ensure your healthcare wishes are understood and respected.

The podcast is available when you

[CLICK HERE](#)



**HSE** 

## Planning Ahead for Your Healthcare

Episode #74 HSE Talking Health & Wellbeing

- Advanced healthcare directives
- Assisted Decision-Making Act
- Understanding capacity
- Open communication
- Individuals with disabilities
- Practical steps
- Facilitating discussions

Listen to episode #74 HSE Talking Health & Wellbeing wherever you get your podcasts.





# DNACPR: Insights from a National Survey

Elaine McCaughley, Programme Lead, HSE National Consent Policy

## New Insights on DNACPR Practices in Ireland

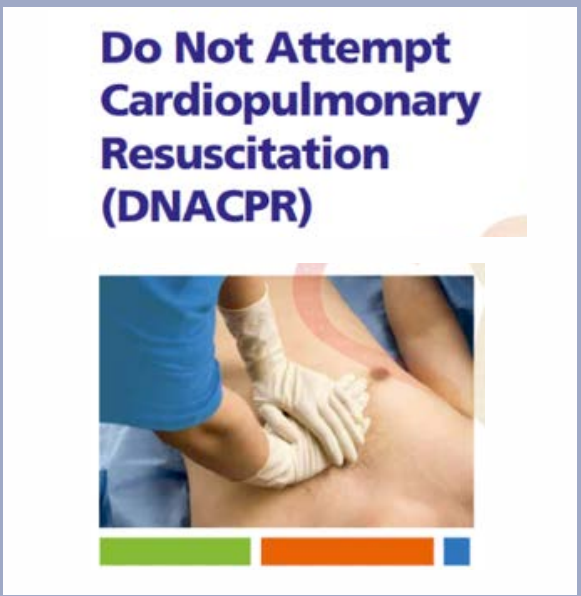
We are pleased to share the publication of a new article by Dr. John Lombard, titled "A Survey Study of Healthcare Workers on Do Not Attempt Cardiopulmonary Resuscitation Practice and Policy in Ireland" which was recently published in Resuscitation, the Official Journal of the European Resuscitation Council.

This comprehensive study highlights critical findings on the understanding and implementation of DNACPR policies among healthcare professionals in Ireland.

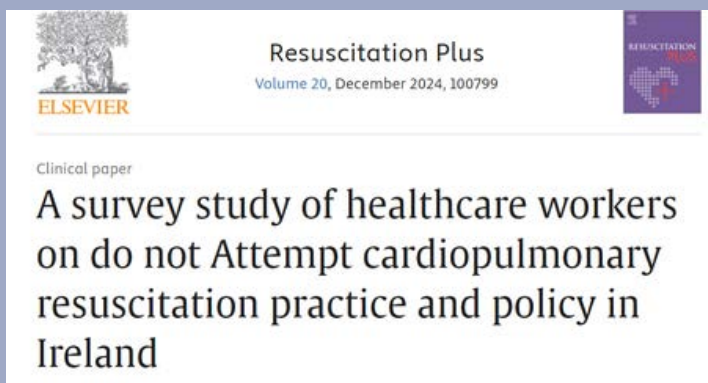
### Key Highlights:

- Knowledge Gaps:** Many healthcare workers lack a thorough understanding of DNACPR.
- Conflict in Decision-Making:** A significant number of participants have encountered conflicts related to DNACPR decisions.
- Communication Barriers:** Effective decision-making is often hindered by communication challenges.
- Policy Awareness:** There is a pressing need for greater awareness and understanding of national DNACPR policies.

Dr. Lombard's research underscores the importance of improved communication, comprehensive training, and proactive discussions to enhance DNACPR decision-making processes.



For more detailed insights, you can read the full article [here](#).



Stay informed and engaged with the latest developments in healthcare practices!



# SIGN – Deaf Women’s experiences of navigating maternity service in Ireland

Deirdre Daly, Director, Trinity Centre for Maternity Care Research (TCMCR)  
Professor in Midwifery

In January 2024 the Trinity Centre for Maternity Care Research at Trinity College Dublin with the support and in collaboration of Deaf Reach Services commenced research to explore deaf women’s experiences of maternity services in Ireland.

It is over 15 years since research on deaf women’s experiences of Irish maternity services has been conducted. Previous studies highlighted significant communication challenges with 61% of deaf women experiencing difficulties with both the method and quality of communication within the Irish maternity services. In one study, almost two-thirds of women (61%, n=80/135) rated access to care as poor/could be better.

There is no data on the number of deaf women birthing in Ireland annually. Estimates from one large maternity hospital suggest that 20 deaf women, and 30 women who are hard of hearing and use Irish Sign Language (ISL) give birth annually. Extrapolated to all maternity hospitals suggests that approximately 300 pregnant women use ISL to communicate. This highlights the need for better access to (i) knowledge on maternal health and wellbeing, and (ii) receiving culturally-appropriate maternity care.

Interpreter services are used by Ireland’s 19 maternity hospitals; however, none offer educational ISL resources. Despite the ISL Act being signed into law in Ireland in 2017, sign interpretation usage is still lacking in some maternity care services.



Check out [WHAM here:](#)

**Caoimhe Gleeson, Professor Eilish Burke, Dr. Teresa Lynch, Professor Deirdre Daly, Dr. Grainne Meehan, Ms. Mary Stringer (absent from photo Professor Lorraine Lesson)**

# SIGN – Deaf Women’s experiences of navigating maternity service in Ireland



Deirdre Daly, Director, Trinity Centre for Maternity Care Research (TCMCR)  
Professor in Midwifery

The research project aimed to address the research gap and explore deaf women’s experiences of the maternity services in Ireland.

Between January and March 2024, one-to-one interviews were conducted in ISL with 15 deaf women in Ireland. Findings were presented at an event in Trinity College Dublin on 11th December 2024. Videos and clips from deaf women who had experiences from across the continuum of pregnancy, birth and postnatal care were developed during the research were also shared at the event. These learning resources will be shared widely across all maternity services in Ireland, to the National Deaf Women Ireland (NDWI) and other services for deaf people.

The research found that:

- Some women experienced care without an interpreter present
- Some women were told they were responsible for booking their own interpreter
- The presence of just one interpreter during labour and birth raised challenges for women in situations when an emergency arose.
- Almost all women stated that interpreters were never present for postnatal care in hospital.
- Several women described themselves as being ‘well cared for’ throughout their childbirth experience – common to these women’s experiences was continuity of midwife (or doctor) carer and continuity of interpreter.



Professor Damien Brennan

In addition, to the videos developed as part of this project, the audio and video content of WHAM (women’s health after motherhood) has been translated into ISL.

These resources will help service providers implement processes that better respect the wishes and maternity care needs of deaf women. This initiative promises to significantly improve the maternity experiences of deaf women in Ireland, fostering a more inclusive and supportive environment.

For further information about this project please email Deirdre Daly: [dalyd8@tcd.ie](mailto:dalyd8@tcd.ie).

# Highlights from HSE ADM Mentorship Programme Event



Sandra Guidon, Administrative Officer, NOHREP



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

On October 9th, we 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 and the commencement of year two of the programme.

The event brought together a diverse group of participants including self-advocates, mentors and professionals, all dedicated to gaining knowledge, skills and competence in the implementation of the Assisted Decision-Making (Capacity) Act 2015.

The event featured a series of engaging workshops and interactive sessions designed to empower attendees with practical skills and knowledge.

Keynote speakers shared valuable insights on the principles of the Assisted Decision-Making Act (ADMA) and the importance of accessible information in upholding human rights.

Thank you for an informative day, looking forward to Year 2 of the mentorship programme.



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

[Take a look at the recording of the event here](#)



Aine Flynn, Director, Decision Support Service



# Highlights from HSE ADM Mentorship Programme Event

Sandra Guidon, Administrative Officer, NOHREP

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.

Overall, the event was a resounding success, leaving attendees inspired and better equipped to advocate for and support effective decision-making.



**Roisin O'Neill - Mentor, ADM Mentorship Programme**



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



**Mr. Roderic O'Gorman, TD, Minister for Children, Equality, Disability, Integration and Youth**

“ A fantastic & dynamic event celebrating the 1st Birthday of the ADM Mentorship program and launching the second year of this invaluable initiative. Well done to all involved in designing & running the day, a real pleasure to attend and participate in, thank you ”

[Take a look at the event here](#)

# Inclusive Research Network: Pioneering Change in Intellectual Disability Research



**Brian Donohoe, Secretary of the Inclusive Research Network**

The Inclusive Research Network (IRN) is a group of people with intellectual disability who do research on issues that are important to them.

In 2012 the IRN formed a Steering Committee made up of the IRN members which are voted for every four years by the members. The steering committee organise and run the meetings and decide the Agenda for its monthly meetings. The IRN is supported by the National Federation of Voluntary Service Providers, Trinity College Dublin & University College Cork.

IRN Members have given Submissions to various government departments including the Department of Justice and the Law Reform Commission. IRN members have also made presentations at conferences in both Ireland and abroad.

The IRN has completed various Research Projects since it was founded in 2008. The IRN Research Projects listed below can be read on the [IRN website](#).

- 'Where we Live' Report, 2009
- 'Relationships & Supports Study: People with Intellectual Disability in Ireland', 2010
- 'Our Homes' Report, 2015
- 'How we Work' Report, 2018
- Doctors & Us, 2019

## Support to Make Decisions

The IRN is currently doing a Research Project called 'Support to Make Decisions'. The Convention on the Rights of Persons with Disabilities (CRPD) promotes supported decision making where everyone can hold and exercise rights even when they need support making decisions.



**Malachy McManus and Mikey Fitzgerald, Steering Group Members**

The Assisted Decision-Making (Capacity) Act 2015 protects people's right to make decisions. Support to make decisions is very important in the law, however, there is little research about what support to make decisions works well for people with intellectual disabilities. The aim of this project is to find out what support people with lived experience of intellectual disabilities have to make decisions and if that support is appropriate or whether the support can be better.

We are using a new research method called Photovoice along with one-to-one interviews. This involves the interviewee taking a photo of a decision they have made and the interview will then involve the person talking about their decision using the photograph.



**Christina Burke, Steering Group Member**

For more information on the IRN please visit the website [here](#) if you would like to contact the IRN please email [info@fedvol.ie](mailto:info@fedvol.ie)



# Ageism, Human Rights and Growing old with Dignity - Associate Prof Sarah Donnelly



Jacqueline Grogan , Project Manager

## Willie Bermingham Memorial lecture

On 5th October 2024, Associate Professor Sarah Donnelly from the UCD School of Social Policy, Social Work and Social Justice, gave the Willie Bermingham Memorial Lecture on 'Ageism, Human Rights and Growing Old with Dignity' at this year's Irish Gerontological Society Conference.

She was also awarded the ALONE Willie Bermingham Medal in recognition of her work in this area.

The Willie Bermingham Lecture, which is sponsored by ALONE, is the keynote address at the Annual and Scientific Meeting of the Irish Gerontological Society. The theme of the lecture is reflective of the guest speaker's special interests and perspectives on ageing and older people.

You can view the recorded lecture at [HERE](#)

Learn more and see previous IGS Willie Bermingham Lectures at [www.irishgerontology.com/public-lectures](http://www.irishgerontology.com/public-lectures)



**Bibiana Savin, Sage Advocacy, Professor Sarah Donnelly, UCD School of Social Policy, Social Work and Social Justice, Dr. Emer Ahern, President of the Irish Gerontological Society.**



Jacqueline Grogan, Project Manager

# Functional Assessment of Capacity Online Training

The HSE National Office for Human Rights and Equality Policy and the Decision Support Service are pleased to announce that the online training on the Functional Assessment of Capacity for the purposes of the Assisted Decision-Making (Capacity) Act 2015 will be available on the Decision Support Service Moodle site from Friday 17th January 2025.

This online learning programme has been developed for healthcare professionals who will be completing statements of capacity under Part 4 (Co-decision-making), Part 5 (Decision-Making Representation Orders) and Part 7 (Enduring Powers of Attorney) of the Assisted Decision Making (Capacity) Act 2015. The training will be accessible to nurses, midwives, occupational therapists, social workers, speech and language therapists and registered medical professionals and will equip them to undertake a functional assessment of capacity and supply the relevant statement as required under the 2015 Act.

The training provides an overview of:

- The guiding principles of the 2015 Act.
- The circumstances in which a statement of capacity is required in relation to a co-decision-making agreement, an enduring power of attorney and a decision-making representation order.
- Conducting a functional assessment of capacity in relation to co-decision-making agreement, an enduring power of attorney and a decision-making representation order.
- Recording the results of a functional assessment of capacity undertaken in relation to a required statement for a co-decision-making agreement, an enduring power of attorney and a decision-making representation order.
- Making a statement to support and application to the Decision Support Service of capacity in relation to a co-decision-making agreement and enduring power of attorney.
- The role of the Court in relation to applications for decision-making representation orders.

The training includes recorded sessions from subject matter experts and gives examples of healthcare professionals undertaking a functional assessment of capacity. Additional resources are also signposted.

In-person training for HSE and HSE funded agencies on the functional assessment is currently under development and will be available in Q2 2025. Further information on this will be published in future newsletters.

Information on how to access the training will be circulated once the training is launched via the usual HSE channels.

**For further information on the training, please contact Jacqueline Grogan on [Jacqueline.grogan@hse.ie](mailto:Jacqueline.grogan@hse.ie).**





**Derval McDonagh,**  
Chief Executive, Inclusion Ireland

# Accessible materials on the Assisted Decision-Making (Capacity) Act 2015- Inclusion Ireland

Inclusion Ireland were delighted to launch our accessible training materials on the Assisted Decision-Making (Capacity) Act (2015) on the 10th December 2024. Over 650 people registered for the on-line event, and the materials were officially launched by Áine Flynn Director of the Decision Support Service. Speakers included Lydia Fisher, Decision Support Service Champion, Caoimhe Gleeson General Manager with the HSE National Office for Human Rights and Equality Policy, Stuart Mahony, Anthony Shoer and David King from the Midlands Conversation Group and Petria Malone from Inclusion Ireland.




**David King, Midlands Conversation Group,**  
**Petria Malone, Inclusion Ireland,**  
**Aine Flynn, DSS, Caoimhe Gleeson, National Office for Human Rights and Equality Policy**

What is of critical importance is that these training materials were co-designed with over 30 self-advocates over a number of months and are absolutely rooted in the guiding principles of the 2015 Act.

Inclusion Ireland is a human rights organisation and it is through this lens that the resources were created. Accessible information is often sadly still seen as a luxury “add on” and we frequently find ourselves challenging that kind of thinking. Accessible information is absolutely critical in human rights. How can we access our rights if we don’t understand them? It is our strong view that every human being has the capacity to make decisions with the right information and support. Every single person can communicate their will and preference in their own way and time, if they are surrounded by people who are willing to listen (not necessarily for words) but for all the other ways a person tells us what and who is important in their lives. None of us exist in a vacuum...we all need support. It’s really important we interpret the act and indeed the HSE consent policy properly by including our loved ones, family and friends who may all (if it’s the person’s will and preference) play a role as informal supports. In her opening remarks Derval McDonagh CEO of Inclusion Ireland challenged us to all to think about how we make decisions, good ones and bad ones, what we learned by doing that and who we had around us as sounding boards, supporters, listeners. She went on to say “It’s incredibly important that we do not pathologise decision making; it is a wonderful part of being human and how we all learn important and fundamental lessons in life.”

You can contact us for information on [info@inclusionireland.ie](mailto:info@inclusionireland.ie) , 01 8559891 .

You can join our movement for change and become a member of Inclusion Ireland as an ally/supporter on [Membership - Inclusion Ireland](#)

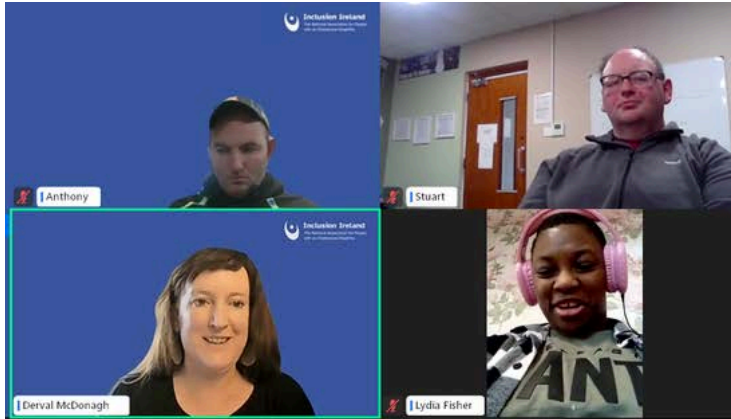
Click [here](#) to access the free materials 



# Accessible materials on the Assisted Decision-Making (Capacity) Act 2015- Inclusion Ireland



Derval McDonagh,  
Chief Executive, Inclusion Ireland



Anthony Shoer & Stuart Mahoney, Midlands Conversation Group, Derval McDonagh, Inclusion Ireland, Lydia Fisher, Decision Support Service Champion

The seed for the creation of the ADMA training materials came from the organisation leading numerous training sessions with advocates, family members and with disability service professionals.

In leading these sessions, our advocacy project worker Petria Malone, found that the same questions and concerns surfaced again and again. She also discovered a lack of accessible materials to support people to understand their rights and to help answer some of these questions.

This compelled her to begin working on the breakdown of elements of the ADM 2015 with an aim of making the act and people's rights accessible.

Through the process of working with advocates, Petria gathered feedback on the materials, shaping them into a practical set of resources for people. Creating visuals for interaction around decision making, around the decisions that people make and the decisions that people may make into the future, was important. The engagement through role play and through use of the "Decision Making Paddles" was enjoyable, too. As part of the process, Petria worked alongside 30 self-advocates, particularly those involved with the Midlands Conversation group. This group is an active forum for disabled people who come together to explore their rights and how to make their community more accessible. One of the members of the group shared his feedback by saying, "For me, decisions equal power and take courage. I can make decisions and I also need to be allowed to make wrong decisions so that I can learn to do better next time." Another advocate said that his favourite part of the training was thinking about the steps of decision making and use of the visual paddles in highlighting the steps involved. "I felt like I could follow along and that I could think about how I make a decision." Creating training material that people can engage with, enjoy, and appreciate the value of their own decision making is the aim of these resources.

Inclusion Ireland has made the materials free and on open access. We look forward to seeing them rolled out across the country and hearing the feedback about their use. Let's continue together as ambassadors for the true spirit of the Act and support people to do that most human of things; to make decisions big and small that are ours alone to make, to learn and grow, to feel powerful in our own lives.



# Accessible materials on the Assisted Decision-Making (Capacity) Act 2015- Inclusion Ireland



Derval McDonagh,  
Chief Executive, Inclusion Ireland



Click [HERE](#) to access the  
online tools



# Online System for Adult Safeguarding (OSAS)

Marguerite Clancy, HSE National Safeguarding Office

The Online System for Adult Safeguarding (OSAS) has been in use by safeguarding and protection teams since September 2nd 2024 across all 9 Safeguarding and Protection Teams. This is the first national case management solution for adult social work and its launch is a significant milestone for the HSE. OSAS provides a more efficient, secure, safer, standardised and client centred approach to social work practice. Furthermore, the inclusion of the Adult Safeguarding Portal, now live since the 11th November provides a standardised, safer communication between the Safeguarding and Protection Team and the wider referral network. The Project Board wishes to acknowledge the hard work and commitment of our super users both in the testing and go live phase of this project.

The Adult Safeguarding Portal enables the public, professionals or indeed HSE/HSE funded services (those currently submit preliminary screenings) to report an adult safeguarding concern online. Integral to the security of the information is the creation of individual user accounts with the requirement to use work emails when acting in a professional capacity. Further information on the creation of accounts and the submission process is available on the FAQ section of the portal.

## There are three pathways on the portal

### Public



### Professional



### HSE and HSE Funded Services



Professionals submitting a concern i.e. Gardai, HSCP, Legal, Financial

(Organisations Required to submit Preliminary Screening Form under the 2014 policy)

Access the FAQs [here](#)

Click here to access the Adult Safeguarding Delegation Portal



# Online System for Adult Safeguarding (OSAS)

Marguerite Clancy, Safeguarding Ireland

**Public** - for use by members of the public who want to make a report a community referral.

**Professional** - for use by health and social care professionals or a person acting in a professional capacity in the wider community for example An Garda Síochána, a member of a financial institution or working for another state body making a community referral.

**HSE and HSE Funded Services** - for use by staff who currently **submit preliminary screenings** in line with the **policy**. The oversight pathway of these cases will be managed via the Adult Safeguarding Delegation Portal. Note the same login credentials apply to both portals.



To date there are over 1,200 registered users on the portal with numbers increasing weekly.

Further information is available by accessing the user guides and the most recent demonstration webinars in November 2024.

Watch the Adult Safeguarding Information Webinar Submitting Community Referrals to HSE Safeguarding Teams here

For any further queries relating to the portal email: [Adult.SafeguardingPortal@hse.ie](mailto:Adult.SafeguardingPortal@hse.ie)



Watch the Adult Safeguarding Info Webinar–Submitting Preliminary Screenings & use of delegation portal 121124 here





# Celebrating Five Years of the Patient Advocacy Service

Roisin Mc Keon, Communications Officer, Patient Advocacy Service

The Patient Advocacy Service recently celebrated its five-year anniversary, an important milestone in its work, providing independent advocacy to patients of acute hospitals and residents of nursing homes, supporting them to either make a formal complaint about their care or supporting them following a patient safety incident. The Service has received over 6,500 enquiries since establishment in 2019.

People contacting the Patient Advocacy Service seeking independent advocacy support, has increased from 65 in 2019 to 2,012 in 2023 and contacts are on track to increase further in 2024. Our Advocates provided one to one empowerment advocacy in over 700 cases, empowering people to navigate the complex complaints and incident management processes.

Our Service has developed significantly in the last five years, extending our remit to include HSE Operated nursing homes in 2021 and in October 2022, following a recommendation by the Covid-19 Nursing Home Expert Panel Report, we further extended our remit to include private nursing homes. Amendments to the Regulations (Care and Welfare of Residents in Designated Centres for Older People), in March 2023 strengthened nursing home residents' rights to independent advocacy and facilitated the Patient Advocacy Service's expansion into all nursing homes.

**Celebrating Five Years of the Patient Advocacy Service.**  
**6,500 patients, nursing home residents and their families supported since 2019.**

**Access the Patient Advocacy Service website [here](#)**



**Patient Advocacy Service**  
 INFORMATION | SUPPORT | EMPOWERMENT





# Celebrating Five Years of the Patient Advocacy Service

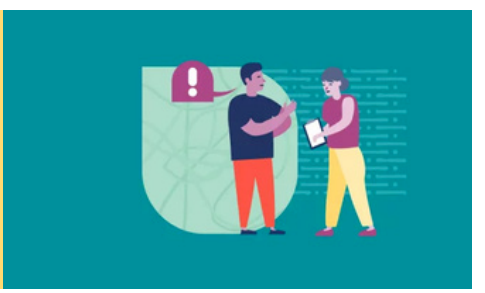
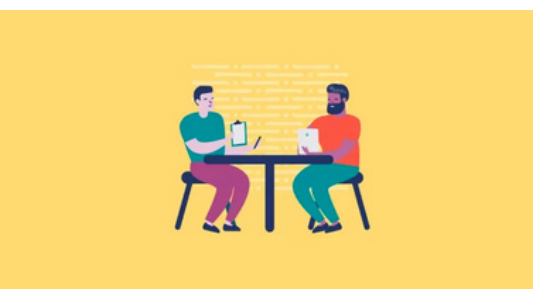
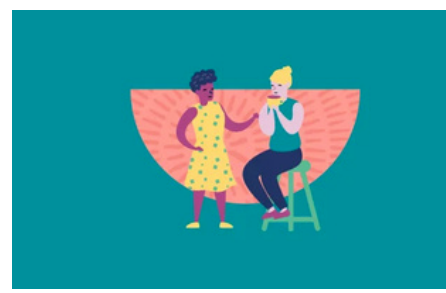
Roisin Mc Keon, Communications Officer, Patient Advocacy Service

Our Advocates help ensure adherence to policies and procedures e.g., HSE National Healthcare Charter, HSE National Consent Policy, National Open Disclosure Framework, Freedom of Information, GDPR, National Standards for Residential Care Settings for Older People and National Standards for Safer Better Care.

Recent legislative changes such as the Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) Regulations 2013, Patient Safety (Notifiable Incidents and Open Disclosure) Act 2023 and the Assisted Decision-Making (Capacity) Act (2015), have strengthened people's rights and underpin the independent advocacy work of our service.

Our Service fully supports the human rights-based approach in health and social care settings, ensuring people's voices, will and preferences are heard. Patients and nursing home residents should be respected, empowered and supported to be full participants in their own health care and treatment.

In our advocacy work we have seen how robust complaints and patient safety processes can not only provide a mechanism for patients and nursing home residents to have their voice heard, but also provide an opportunity for learning, improvement and safer services. By elevating the voice of the person and bringing the lived experience of patients and nursing home residents to service providers we have seen improved quality of care, quality of life and safety of people who use health and social care services. Alongside new and developing legislation we will continue to provide independent person-centred advocacy to foster a culture of a compassionate, empathic, open and transparent health and social care service.



Dr. Orla Sheil (MD FRCOG FRCPI)  
Consultant Obstetrician Gynaecologist and Director  
of QRPS, National Maternity Hospital, Dublin. Joint  
Director Women and Neonate's Health, HSE Dublin  
and South East.



Paula Power,  
Operations Manager, Women and Neonates Health  
Directorate, HSE Dublin and South East

# Addressing Challenges in Maternity Care in Ireland

The conference 'Addressing Challenges in Maternity Care in Ireland' took place on the 7th November 2024. It was facilitated by the HSE Dublin and South East and the National Women and Infants Health Programme (NWIHP).

The event aimed to bring together healthcare professionals to explore strategies for addressing some of the challenges in maternity care in Ireland, with a particular focus on improving the well-being of women and staff. Through knowledge sharing and practical case scenarios, the conference sought to inspire innovative thinking and demonstrate current effective practices.

The day was structured around three themes, each addressing key aspects of maternity care:

## **Morning Session: "Learning from Others"**

This session emphasized the value of shared experiences and learning from successful practices in other settings.

## **Mid-Morning Session: "Care Outside of Guidance"**

Expert speakers explored the complexities of providing care in unique situations, focusing on informed consent, risk management, and human rights considerations. Elaine McCaughley, Programme Lead, National Office for Human Rights and Equality Policy presented on the HSE National Consent Policy 2022 and its implications for Maternity Services. Noelle Byrne, Senior Clinical Risk Manager, SCA and Marie Hutton Solicitor/Clinical Risk Legal Advisor, SCA addressed issues relating to indemnity and consent in Maternity Settings. Sheila Cahill, Martina Cronin, and Michelle Grannell (Clinical Midwife Managers from SLGH, NMH and WGH) provided interactive case scenario presentations, demonstrating practical applications of care outside of guidance in clinical practice.

The conference was well-received, with attendees appreciating the diverse perspectives and practical insights offered by the speakers. Attendees noted their increased awareness of the importance of informed consent and legal considerations in maternity care.

The conference helped heighten recognition of the importance of respect and support in effectively implementing the National Consent Policy. It further enabled the recognition of the critical role of staff support in maintaining high-quality care during challenging circumstances.

## **Next Steps**

There are a number of actions which will be undertaken to build on the momentum of the event. This includes the establishment of follow-up workshops to delve deeper into the themes discussed, the fostering of partnerships with academic institutions, legal experts, and human rights organisations to support addressing systemic challenges and enhance care delivery.

The conference highlighted the importance of collaboration, innovation, and empathy in addressing some of the challenges facing maternity care in Ireland



National  
Women & Infants  
Health Programme

# Addressing Challenges in Maternity Care in Ireland- through the lens of consent



Elaine McCaughley, Programme Lead, HSE National Consent Policy

I was delighted to participate in this conference and discuss the National Consent Policy 2022 and explore the considerations for Maternity Services. This was the second such opportunity to explore the requirements of the Policy with staff working in maternity services and to hear their concerns and challenges.



National  
Women & Infants  
Health Programme

I participated in the session on 'Care Outside of Guidance'. This term references the increasing numbers of women choosing not to follow clinical recommendations in relation to maternity care. This situation is hard for everyone to navigate and highlights the importance of building trust, showing empathy, and listening.

It was very helpful to be joined by colleagues from the State Claims Agency who reinforced the importance of the HSE National Consent Policy, and to hear the case scenarios from maternity hospitals which illustrated some of the challenges staff experience in practice.

The HSE National Consent Policy provides comprehensive guidance on valid consent, including providing information, supporting a person to make a decision, support arrangements under the Assisted Decision-Making (Capacity) Act 2015, general principles if a person's capacity to decide about an intervention is in question or lacking, dealing with emergency situations, and documenting consent.

Seeking valid consent for every intervention, by providing clear information and supporting the woman to make her own decisions, is a legal requirement that offers many benefits. These include improved birth experiences, higher satisfaction with care, improved maternal mental health outcomes, reduced preterm birth, higher birth weights and safer care. Failing to involve women in decision-making can lead to their feeling out of control and powerless and is associated with negative and traumatic birth experiences, increased rates of postnatal depression, anxiety and PTSD (Hardman K, Davies A, Demetri A, et al.)



# Addressing Challenges in Maternity Care in Ireland- through the lens of consent



Elaine McCaughley, Programme Lead, HSE National Consent Policy



Key opportunities available to maternity services include ante-natal appointments and education sessions to support women's decision-making throughout pregnancy. Challenges to be addressed include staff resourcing, short consultation times, skills training for staff and continuity of information systems to ensure notes are always available.

Tools such as personal risk calculators and core information sets can help tailor information relevant to each woman, and create opportunities to discuss key decisions in advance of labour.

Key recommendations to improve consent practices in maternity services include:

- Listening to women,
- Exploring their birth preferences and values in advance
- Making the most of ante-natal education and consultations to explore common procedures, risks, and any personal risk factors/concerns
- Developing clear, objective, balanced information sets and visuals
- Improving transfer of information between ante-natal appointments and healthcare workers attending labour.
- Respecting the woman as a rights-holder and decision-maker.

## Suggested Reading

All Party Parliamentary Group on Birth Trauma. **Listen to mums: ending the postcode lottery on perinatal care.** National Birth Trauma Inquiry Report May 2024 [available here](#)

Hardman K, Davies A, Demetri A, et al. **Maternity healthcare professionals' experiences of supporting women in decision-making for labour and birth: a qualitative study.** BMJ Open 2024;14 : e080961. doi:10.1136/ bmjopen-2023-080961

Demetri A, Davies A, Bakhbakhi D, et al. **Vaginal birth core information set: study protocol for a Delphi study to achieve a consensus on a 'core information set' for vaginal birth.** BMJ Open 2023;13

on behalf of MBRRACE-UK. **Saving Lives, Improving Mothers' Care Core Report - Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2019-21.** Oxford: National Perinatal Epidemiology Unit, University of Oxford 2023

# Addressing challenges in Maternity Care in Ireland- perspectives from the State Claims Agency



Noelle Byrne - Senior Clinical Risk Advisor,  
State Claims Agency



It was a welcome opportunity to present the learning from our claims analysis and promote awareness around the importance of consent in maternity services, and to emphasise that consent is a continuous process of communication and information sharing to enable informed decision-making.

In particular, it was opportune to highlight the relevance and importance of documenting conversations around the benefits, risks and alternatives of a procedure or care decision, which facilitates continuity of care but also aids in the defence of a claim should issues relating to consent be alleged. Examples of inadequate consent in relation to vaginal birth after caesarean section (VBAC) was highlighted from our recent claims analysis[1].

The day was filled with informative and passionate speakers, and it was evident that there are many challenges facing staff in maternity services, including the amount of time and resources required to ensure women are fully informed and supported in preparation for labour, delivery and the postpartum period. This was especially evident in the case studies presented.

The event concluded with doctors and midwives sharing their own experiences of challenges faced, which was powerful in identifying what could be improved in order to support healthcare professionals, especially when there is a poor outcome.

My takeaway from the day is that all healthcare professionals working in maternity services are extremely dedicated to providing the best care for women and babies, but it is evident that appropriate resources are required to ensure women are fully informed and supported. Supports are also required for staff following an adverse event.

To read the Catastrophic claims relating to babies in maternity services article - click [here](#)



# Addressing challenges in Maternity Care in Ireland- perspectives from the Patients Advocacy Service



Georgina Cruise, National Manager

The Patients Advocacy Service recently had the opportunity at the 'Addressing challenges in Maternity Care in Ireland' Conference to share their experiences of supporting patients and their families within the maternity services. The Service has supported over 130 enquiries relating to maternity care, providing one-to-one advocacy support to 49 individuals.

The Patient Advocacy Service is an independent, free and confidential service dedicated to empowering individuals. The Service offers person-led and person-centred advocacy to people wishing to make formal complaints about their care in Public Acute Hospitals or Nursing Homes, or those affected by Patient Safety Incidents. Funded entirely by the Department of Health, the service operates independently of the HSE and other service providers.

The service supports families impacted by organ retention, unexpected stillbirth, bereavement supports, maternity care, antenatal and post-natal concerns, lactation issues, poor communication, informed consent, unaddressed complaints and a lack of awareness of reviews being undertaken. The service recognises that complaints and incidents in relation to maternity care can be complex and traumatic.

The Patient Advocacy Service offers impartial and independent support throughout the complaints and review process, ensuring procedures remain person centred. Their Trauma Informed Advocates offer empathetic, non-judgemental support. Listening to people's stories and provide a safe space for them to share, they empower individuals like Christine to elevate their lived experience.

The Patient Advocacy Service seeks to uphold the rights of patients, keeping the person at the centre of the process, amplifying the voice of the patient to improve learning and patient safety, fostering a culture of a compassionate, empathy, openness and transparency in health and social care services.



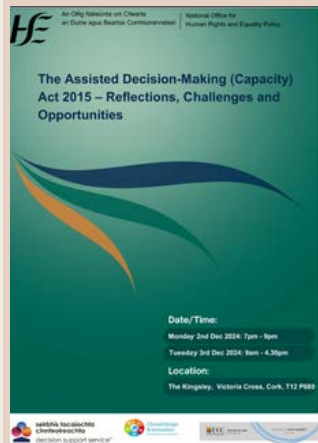
Click here to watch [Christine's Story](#)





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

Norma O'Donnell, ADM Project Manager



A thought provoking two-day event on the 2nd and 3rd of December at the Kingsley Hotel in Cork focused on the Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act). This highly engaging hybrid event was organised in collaboration with the HSE National Office for Human Rights and Equality Policy, the Decision Support Service (DSS) and University College Cork (UCC).

On the evening of Day One, Áine Flynn Director of Decision Support Service provided the opening address and welcome to all including the panel of speakers. The event brought together a wide range of stakeholders including policymakers, legal experts, healthcare professionals, academics and advocates for persons with disabilities to discuss progress, challenges and future opportunities in relation to the 2015 Act.

Áine began by introducing Florin Nolan, proud Cork man, creative artist and Decision Support Service champion. He presented one of his own works to the Decision Support Service. Florin shared that he was ***“so proud to be on the programme on the telly and able to get the word out there and able to express yourself and share to all with disabilities in Ireland”***.



John Farrelly, Florin Nolan, Aine Flynn

Mary Donnelly Professor of Law at University College Cork Ireland welcomed attendees to Cork on International Day of Person with Disabilities. She reflected on the first collaborative conference held in University College Cork in 2019 between UCC, the HSE and the DSS. At that time there was no line of sight of commencement of the 2015 Act. The goal of that conference was to make the strongest possible case for commencement of the Act. And she stated ***“happen it did”*** with the 2015 Act coming into force on 26th April 2023.

“ **One journey of our collaboration ended and another began** ”

If you would like to receive an email notification when the Conference Video becomes available please contact us [adm@hse.ie](mailto:adm@hse.ie)



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



Norma O'Donnell, ADM Project Manager

Aine Flynn took the opportunity to thank the Decision Support Service stakeholder forum who have helped in the development of their systems, process design, information and materials.

“  
“We couldn't do it without them”.  
”



Aine Flynn, Director of Decision Support Service



DSS Stakeholder Forum

Chief Executive of the Mental Health Commission, John Farrelly spoke about the importance of using the two day conference as a time for reflection to identify the challenges and opportunities arising from commencement. He urged delegates to remember the ethos of the 2015 Act in placing the person at the centre of all decisions.



The Honourable Mr Justice Mark Heslin of the High Court reflected on some of this insights on the transition of the wardship regime into the new legal parameters of the 2015 Act. He highlighted the importance of the foundational work which happens outside of court to enable a person exit wardship. He placed the person leaving wardship at the centre of his talk urging practitioners to at all times walk in the shoes of the relevant person, at every step of their legal journey.



His Honour Judge John O'Connor of the Dublin Circuit Court spoke about the centrality of the voice of the person. Presiding over one of the busiest courts in Ireland in relation to applications for Decision Making representation orders Judge John O'Connor has established a level of authority across Ireland and shared his experiences and insights gathered since commencement.





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



Norma O'Donnell, ADM Project Manager



Suzy Byrne, Disability Activist and Advocacy Manager, National Advocacy Service for People with Disabilities reflected on the commencement journey to date. Suzy reflected personally but also referred to article 12 of the United Nations Convention on the Rights of People with Disabilities. She cautioned that the gains disabled persons have made continue to be eroded and disabled persons are not afforded parity of equality, opportunity or outcome.

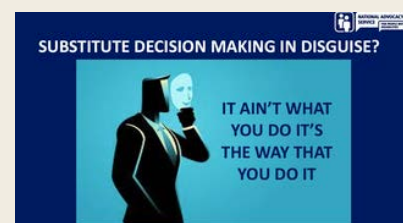
Dr Nicola Maxwell, University College Cork and head of the ID+ project shared William O'Donovan's story through a script and video as he was unable to attend the event. The video also involved other participants from the ID+ Project.

Niall Brunell, Principal Officer from the Disability Equality Policy Unit of the Department of Children, Equality, Disability, Integration and Youth reflected on the commencement journey to date. Niall has chaired the interdepartmental steering group which has done important collaborative work in getting the broader landscape ready for the Act and beyond.



## DAY 2

The first session of Day 2, chaired by Suzy Byrne, Disability Activist and Advocacy Manager, National Advocacy Service for People with Disabilities, critically analysed the application of the guiding principles of the 2015 Act in day-to-day practice since commencement. It examined what is working, where the gaps are and what more is required to ensure that the human rights underpinned by the 2015 Act are realised.



Joanne Condon, National Manager, National Advocacy Service for People with Disabilities specifically looked at the Act through the lens of an independent advocacy service. 23% of their advocacy work has related to assisted decision making with the majority of work in the area of expression of will and preference.

**“This chimes very much with the vision of the National Advocacy Service in recognising the capacity of people with disabilities to make their own decisions”**



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

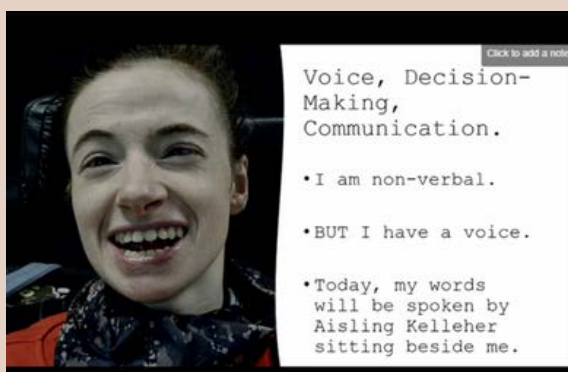


Norma O'Donnell, ADM Project Manager



Professor Shaun O'Keeffe, Consultant Geriatrician and HSE Clinical Lead for ADM and Consent reflected that “it ain't what you do, it's the way that you do it”. He stressed that the tools of the Act should only be used when necessary. Common sense should prevail over unnecessary and often unwieldy interventions.

Rosin O'Neill, Quality and Safety Manager with St Michael House, Dublin, acknowledged that this is a real opportunity to pause and reflect on this important piece of legislation while being a fitting way to celebrating International Day of Disabilities. She emphasised the importance of ensuring the voice of the person remains central to every aspect of ADM related work.



Click to add a note

Voice, Decision-Making, Communication.

- I am non-verbal.
- BUT I have a voice.
- Today, my words will be spoken by Aisling Kelleher sitting beside me.

Kayleigh Twomey delivered a powerful speech with the support of Aisling Kelleher. She spoke about the need to be heard and the importance of recognising that people who communicate differently have a voice, want to make decisions and have a right to be supported to make decisions.

***“Don't assume because I don't speak that I can't make decisions, I can communicate”***

Kayleigh Twomey, Bart Cronin and Brid Broderick, all participants of the ID+ Project in University College Cork, shared their insights and experiences in person and through video.

Special congratulations to Kayleigh on her successful completion of the Certificate in social citizenship (CSC) and the Certificate in Disability and inclusive practice.



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



ADM Project Manager

Bart stressed the importance as we try to make the assisted decision making Act 2015 inclusive to work for us all, with changes and awareness.



Jacqui Browne of the Disabled Persons Organisation Network in response to the first panel of speakers, commended the efforts by the courts to meaningfully establish the voice of the person. She cautioned that ableism, discriminatory treatment, ageism and intolerance remains endemic. She called for a rebalancing of rights over risk.

“—  
| **“meaningful engagement is critical”** |  
—”

Suzy Byrne concluded the opening session with a dynamic questions and answers session which enabled attendees online and in the room the opportunity to delve deeper into the topics discussed.



Dr. Siobhan Ni Bhriain, National Clinical Director for Integrated Care chaired the second session on planning ahead to preserve your will and preference. This session considered why people should plan ahead for a time when they lack capacity to make their own decisions. It examined the provisions to plan ahead in the 2015 Act. It considered the implications of not planning ahead on preservation of the will and preference of the person.

If you would like to receive an email notification when the Conference Video becomes available please contact us [adm@hse.ie](mailto:adm@hse.ie)



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



Norma O'Donnell, ADM Project Manager

Patricia Rickard-Clarke, Chairperson of Safeguarding Ireland addressed the recognition and implementation of rights including the right to autonomy, bodily integrity, privacy and control over financial affairs and property. Patricia concluded with that while there has been progress in Ireland in recent years in the recognition of rights, considerable challenges and shortcoming persist within and across the broad social, cultural, policy and legislative infrastructure.



Sarah Jane Lavin, supported by Dara Community Living, spoke about the importance of planning for a time when her parents are no longer able to support her. Through her extensive advocacy work as board member with Inclusion Ireland and Dara's Inclusive subcommittee and Advocacy group Sarah-Jane offered insights into why it is important for people with disabilities to think ahead and plan for their future selves.

Dr Fiona Morrissey who sadly passed away last year on 12th November 2023 in Galway was remembered at the conference. Fiona was a human rights advocate and activist whose research work focused specifically on mental health, advance healthcare directives and how they can protect and preserve a person's voice and dignity, particularly at times when they are acutely unwell. Fiona always pulled the discussions back to the voice of the person focusing on the centrality of the person.



An extract from a live presentation on planning ahead delivered by Fiona five years ago was shared with delegates.



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

Norma O'Donnell, ADM Project Manager



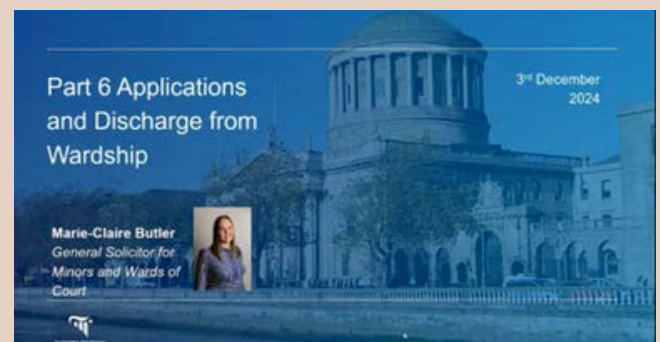
Session 3 chaired by Caoimhe Gleeson, General Manager, HSE National Office for Human Rights and Equality Policy, critically analysed the transition from the wardship regime into the provisions of the Assisted Decision-Making (Capacity) Act 2015. It explored the experiences and challenges in supporting people to transition from wardship to the supports in the Assisted Decision-Making (Capacity) Act 2015. It considered the gaps created by the Assisted Decision-Making (Capacity) Act 2015 and reflected on how these gaps are now being addressed through the inherent jurisdiction of the High Court.

Mary Donnelly explored the gaps created by the 2015 Act and why the High Court's Inherent Jurisdiction is now being used to address those gaps. She cautioned that while this provides an immediate remedy to a legislative gap, it should not be an alternative. She stressed the importance of having robust legislation to address these remaining gaps.

**“We definitely need to do something to develop our alternatives to the Inherent Jurisdiction”**



Marie-Claire Butler who is the General Solicitor for minors and wards of court provided an overview of Part six applications and discharges from wardship. Marie-Claire emphasised that a person has a right to be discharged from wardship and should be supported to do so. She encouraged services to support a person being discharged by making contact with the Office of the Wards of Court.



**“its really really important to recognise the right of a person to be discharged from wardship”**

**“It is good to talk”**

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



Norma O'Donnell, ADM Project Manager



Selina Doyle, Director of Strategic Development, Aurora Enriching Lives, Enriching Communities stepped out the processes involved in supporting a person being discharged from wardship. She explored particular cases and highlighted some of challenges in accessing legal aid and other supports for the person.

The session was enriched by the contribution of PJ Herlihy, supported by Michelle Angland from St John of Gods, Kerry who shared his experience of leaving wardship. PJ introduced his video where he explained to his journey in wardship to date and the challenges he has faced in his life. PJ shared his wishes for his life once he leaves wardship and the difference this will make to him.



Mary Donnelly chaired the final session which examined the operationalisation of decision-making representation orders since commencement of the 2015 Act in April 2023. It considered judicial, legal, advocacy, administrative, clinical and personal perspectives. It reflected on why the voice of the person matters in these legal proceedings and drew on practical experiences to date.

Darrin Maguire, supported Laura Dowling, Senior Advocate with the National Advocacy Services for People with Disabilities, provided a powerful personal written testimony of his experience of obtaining a DMRO. This account by Darrin was an important reminder of why the voice of the person always matter.



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

Norma O'Donnell, ADM Project Manager

Judge O'Connor reflected on the evolution of the DMR process since the commencement of the legislation. He outlined what he needs as a judge in order to ensure the relevant person is afforded the full protections of the Act. He explained the relevance and necessity of hearing the voice of the person either in court or remotely. The importance of an independent advocacy report to provide the wider context of the person and legal representation for the person to ensure matters such as property and financial affairs can be properly protected and safeguarded.

## “Voice of the Person”

## “Capacity Report”

## “Legal Representation”

Professor Shaun O’Keeffe, Consultant Geriatrician and Clinical Lead – ADM and Consent provided an input on the functional assessment of capacity and the importance of taking care in the preparation of the documentation needed for part five applications.

Mary steered a fireside chat with a panel of experts including Judge Dr. John O’Connor, Dublin Circuit Court, Professor Shaun O’Keeffe, Consultant Geriatrician, Bibiana Savin, Chief Executive Officer, Sage Advocacy, Dr. Joanna Ralston, Barrister at Law, Ultan Hynes, Head of Service, Nursing Home Support Scheme, HSE, Amanda Casey, Chief Social Worker, HSE and Áine Flynn, Director, Decision Support Service. Each panellist addressed questions in their particular area of expertise from participants online and in attendance.



The conference was closed by Caoimhe Gleeson who thanked all of the experts and contributors discussing some of our takeaways from the day which were profound, really important and they bring us back to the reason why we are here.

If you would like to receive an email notification when the Conference Video becomes available please contact us [adm@hse.ie](mailto:adm@hse.ie)



# Why the voice of the person matters- Highlights from the conference December 2024



Elaine McCaughley, Programme Lead, HSE National Consent Policy

The 'Voice of the Person' was a central theme of the conference as we examined how the Act, and the Guiding Principles have been operationalised. This theme was addressed by individual person testimony through experts-by-experience and by the contributions of speakers. The importance of the Court hearing the voice of the Relevant Person was clearly addressed by Judge John O'Connor and Judge Mark Heslin. Both Judges outlined the efforts being undertaken by the Courts to ensure that the person can be heard or can be represented in applications about them.

We had a number of contributions by experts-by-experience throughout the conference. These contributions helped reinforce the important message of supporting a person to remain at the centre of their decision making.

We are very appreciative of the time and effort all of our experts-by-experience and their supporters gave to our conference.

## Planning ahead to preserve your will and preferences.

Sarah Jane Lavin, a self-advocate living in Celbridge, spoke about her journey towards independent living, and why it is important to plan ahead.

Sarah Jane was prompted to plan for the future when she began to notice that her mother was getting older, and wondered what would happen to her when her mother was gone. Sarah Jane's first step was to ensure she was on the County Council housing list, and she encourages other adults with disabilities, who may be living in the family home with ageing parents, to consider doing the same. She emphasised the risk of 'crisis' decision-making if a person has not planned for the future. In such a situation a person may end up 'wherever they can find a place'.

Sarah Jane spoke about the importance of location, gaining her independence, healthy ageing and getting the right supports.



Joan Brady, Sarah-Jane Lavin

Sarah Jane is supported by Dara Community Living and produced this video with The Housing Agency. Click [here](#) to watch the video.



# Why the voice of the person matters- Highlights from the conference December 2024



Elaine McCaughley, Programme Lead, HSE National Consent Policy

## The Dissolution of the Wardship Regime – a critical analysis of the journey so far.



PJ Herlihy who is from Kerry, talked about his experiences of leaving wardship. He was supported at the conference by Michelle Angland, St John of God's Services. PJ became a Ward of Court in 1997 following a Road Traffic Accident. His Committee is a solicitor in Dublin. As a Ward of Court, PJ has had to contact the solicitor if he wants access to his money. He is looking forward to getting easier access to his money, so that he can buy clothes and Christmas presents and something nice for his girlfriend.

PJ described a visit from a medical visitor to complete a functional assessment of his capacity as part of the process of being discharged from Wardship. PJ would like to be present in Court for his hearing.

# Why the voice of the person matters- Highlights from the conference December 2024



Elaine McCaughley, Programme Lead, HSE National Consent Policy

## Decision Making Representation Orders – a critical analysis of the journey so far.

Darrin Maguire prepared a piece about his experience of obtaining a Decision-Making Representation Order (DMRO) which was shared by advocate Laura Dowling at the conference.



Following a hypoxic brain injury as a result of a drug overdose in 2022, Darrin was advised that an application to make him a Ward of Court had been lodged by the hospital. Darrin was supported by the National Advocacy Service for People with Disabilities (NAS) to express that he did not want to become a Ward of court, and instead pursued the option of appointing his sister as his Decision-Making Representative. Darrin's NAS advocate supported him to communicate with his solicitor through the DMRO process, to write to the Court and to attend at his DMRO hearing. Below are Darrin's direct words in relation to his experience of the DMR process:

“  
*‘I’ll be very honest with this. I could not believe the help I got and that I continue to get. Peadar (solicitor) has been nothing but positive and has supported me through this (DMR process) so well. It has been so rewarding to work with Peadar. He explained everything to me. I am so grateful. Not everyone gets the opportunity to get back your control, but I did and that was because of Peadar’s help. Peadar and my advocate made sure everything was about me, that I knew what was happening and that the outcome was what I wanted. Thank you. I can’t say enough how grateful I am to have had the support I have. I am a very lucky man in a lot of ways.’*  
”

Darrin wants to share his story with young people, to show where his drug taking led him, and to play a role in preventing young people taking drugs and facing similar situations.

**The HSE National Office for Human Rights and Equality Policy are very grateful to Sarah Jane, PJ and Darrin for sharing their stories with the conference. We would also like to thank Joan Brady and Dara Community Living; Michelle Angland and St John of God, Kerry; and Sara Dunne Rogers, Laura Dowling and the National Advocacy Service for People with Disabilities for all the support provided.**

# HIGHLIGHTS FROM 2024

An evening with Judge John O'Connor  
Royal College of Physicians  
February 2024



Judge John O'Connor

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



# HIGHLIGHTS FROM 2024

**An evening with Judge John O'Connor**



**Judge John O'Connor,  
Caoimhe Gleeson,  
Professor Brendan Kelly**

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



# HIGHLIGHTS FROM 2024

**An evening with Judge John O'Connor**



**Professor Mary Donnelly,  
Judge John O'Connor**



**Professor Shaun O'Keeffe,  
Bibiana Savin, Sage  
Advocacy**

# HIGHLIGHTS FROM 2024

An evening with Judge John O'Connor



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

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



# HIGHLIGHTS FROM 2024

## The National Consent Policy - Easy to Read Launch



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



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



**This is an Easy to Read version of the HSE National Consent Policy**



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

# HIGHLIGHTS FROM 2024

## The National Consent Policy - Easy to Read Launch June 2024



**Core Group Members,  
St. Michael's House**



# HIGHLIGHTS FROM 2024

**Episode #57 HSE Talking Health &  
Wellbeing Podcast Series - With  
Elaine McCaughley  
June 2024**



The image shows a podcast episode cover. On the left, there is a photograph of Elaine McCaughley speaking into a microphone. Above the photo are the logos for HSE and 'hi healthy Ireland'. The title 'Consent' is prominently displayed in white text on a dark green background, with the subtitle 'Episode #57 - Talking Health & Wellbeing' below it. On the right side of the cover, a light green diagonal banner contains a quote in white text: 'They might have had a successful surgery. But what lasts is how they were made feel.' followed by '- Elaine McCaughley'.

# HIGHLIGHTS FROM 2024

**Episode #74 HSE Talking Health &  
Wellbeing Podcast Series - With  
Caoimhe Gleeson & Suzy Byrne  
October 2024**



# HIGHLIGHTS FROM 2024



**Amanda Casey, Patricia Rickard-Clarke, Caoimhe Gleeson**

## Safeguarding Ireland - Financial Abuse Seminar, November 2024



**Patricia Rickard-Clarke, Safeguarding Ireland**



**Vivian Geiran, Caoimhe Gleeson, Amanda Casey, Geraldine Farren**

## Human Rights and Social Work responsibilities, Portlaoise, October 2024 - Irish Association of Social Workers



**Monica Hynds O'Flanagan, Caoimhe Gleeson, Denise Kirwan, Siobhán Nunn**

# HIGHLIGHTS FROM 2024

## The ADM Mentorship Programme - The Mansion House, Dublin October 2024



**Ber Grogan, Mental Health Reform**



**Lisa McGreevy**



**Mentors and mentees**



**Niamh Butler**

# HIGHLIGHTS FROM 2024

## The ADM Mentorship Programme - The Mansion House, Dublin October 2024



**Tina Gardiner**



**Bibiana Savin, Sage Advocacy**



**Janice Hanlon and Denise Ryan**



**Padraig Ruane**

# HIGHLIGHTS FROM 2024

## The ADM Mentorship Programme - The Mansion House, Dublin October 2024



**Siobhan Donoghue**



**Aine Flynn, Director of Decision Support Services**



**Bernard Gloster, CEO, HSE,  
Mentorship Programme delegates**

# HIGHLIGHTS FROM 2024



**Aine Flynn, Justice Mark Heslin, Catriona Sneddon**



**Elaine McCaughley, Joan Brady, Sarah Jane Lavin, Caoimhe Gleeson, Aine Flynn**



**Selina Doyle, Michelle Angland, PJ Herlihy, Professor Mary Donnelly, Caoimhe Gleeson**



**Aisling Kelleher, Kayleigh Twomey, Suzy Byrne, Professor Shaun O'Keeffe, Jacqui Browne, Joanne Condon, Roisin O'Neill**

# HIGHLIGHTS FROM 2024



**Joanna Ralston, Bibiana Savin, Judge John O'Connor**



**Ultan Hynes, Joanna Ralston, Bibiana Savin, Judge John O'Connor, Professor Shaun O'Keeffe, Aine Flynn, Professor Mary Donnelly**



**Gerry Rattigan, Liam Glendon, Sarah Carr, Laura Dowling, Joanne Condon and Suzy Byrne**



**Aoife McMahon, Kate Frowen, Joanna Macklin, Patsy Fitzsimons**



# HIGHLIGHTS FROM 2024



**Members of the Legal Aid Board**



**Aileen Colley, Joanne Haffey**



**Members of the Legal Aid Board**



**Aine Flynn**

# Useful Resources



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



**Inclusion Ireland**

The National Association for People with an Intellectual Disability.



**seirbhís tacaíochta cinnteoireachta**

decision support service™



**NATIONAL ADVOCACY SERVICE**

FOR PEOPLE WITH DISABILITIES

**NDA**

Údarás Náisiúnta Míchumais  
National Disability Authority



An tSeirbhís Chúirteanna  
Courts Service



If you would like any further information please contact us on [adm@hse.ie](mailto:adm@hse.ie)

**Sage**  
Advocacy

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