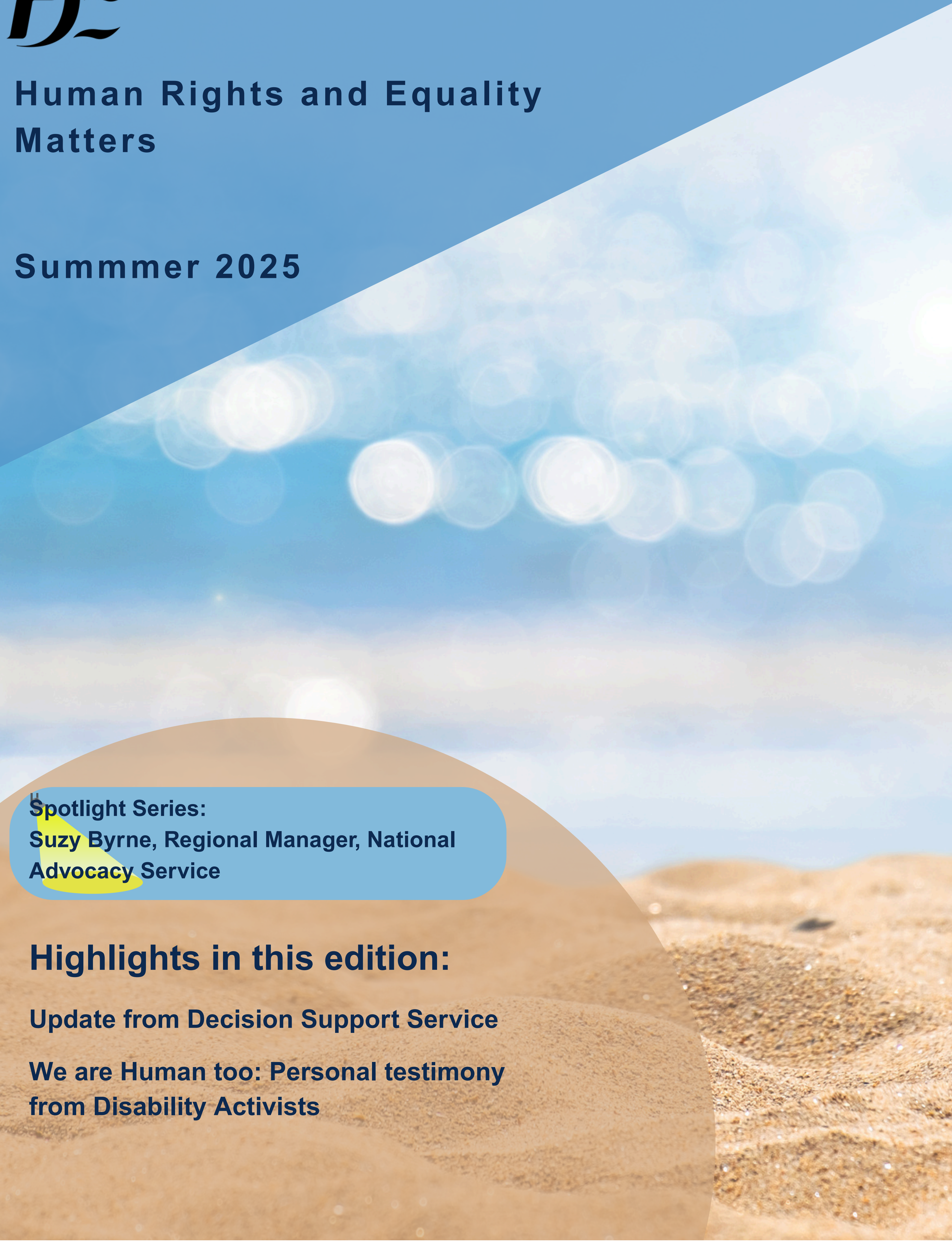
An Oifig Náisiúnta um Chearta
an Duine agus Beartas Comhionannaiser

National Office for
Human Rights and Equality Policy

Human Rights and Equality Matters

Summmer 2025



Spotlight Series:
Suzy Byrne, Regional Manager, National Advocacy Service

Highlights in this edition:

Update from Decision Support Service

We are Human too: Personal testimony from Disability Activists

CLICK HERE TO ACCESS OUR WEBSITE

Newsletter Team

Caoimhe Gleeson,
Editor

Sandra Guidon,
Co-Editor

Contributors:
Aine Flynn
Suzy Byrne
Norma O'Donnell
Joanne Haffey
Jacqueline Grogan
Ann Marie Flanagan
Nicola Lucey
Emily Moffatt
Emma Mullins
Michelle Angland
Bibiana Savin
Dr. Nuala Kane & Dr.
Jennifer Allen
Ultan Hynes
Alice White
Dr. Emer Rutlidge &
Michelle Darcy

Table of contents

The newsletter is an interactive PDF. When you click on a hyperlink, it will bring you directly to the website, webinar, registration link, podcast or other resource mentioned (where links are available) To access, just hover and click on the text with this symbol

National Office for Human Rights and Equality Policy

Welcome

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

As the warmth of summer surrounds us, I'm delighted to welcome you to this edition of ***Human Rights and Equality Matters***. This season offers us hope of sunshine and renewal, and also a chance to reflect on the progress we've made and the work that still lies ahead, in our shared journey toward a more inclusive and equitable society.

In this edition, we bring you inspiring stories of advocacy, highlight key developments in human rights and equality, and share practical tools and resources to empower our community. We hope you find insight, and encouragement in these pages.

As April marked the second anniversary of the commencement of the Assisted Decision-Making (Capacity) Act 2015 the ***Decision Support Service (DSS)*** continues to experience growing demand across all its statutory functions. Aine Flynn reports that by the end of April, the Information Services team—including the dedicated Enduring Power of Attorney (EPA) helpdesk—had already handled as many calls and queries as they had by the end of August 2024, highlighting the increasing public engagement and need for support.

In our ***Spotlight series*** we are delighted to feature Suzy Byrne, Regional Manager of the National Advocacy Service (NAS) whose career has been rooted in a steadfast dedication to human rights, equality and empowerment. Suzy has consistently championed inclusion and justice. Our Co-editor Sandra Guidon recently had the pleasure of speaking with her, where she shared reflections on her journey, her enduring passion for advocacy, and the personal experiences that continue to inspire her work.

Norma O'Donnell provides an update for health and social care services on how to access the ***Decision Support Service (DSS) Register.***

May was a particularly active month for our office as we officially launched the ***In-person training on the Functional Assessment of Capacity.*** Joanne Haffey provides an overview into how the training is being delivered and the feedback to date.

Jacqueline Grogan outlines the **WHO Quality Rights** global initiative. This initiative aims to improve the quality of care provided by mental health and social services and to promote the human rights of people with mental health conditions and psychosocial, intellectual or cognitive disabilities.

Ann Marie Flanagan, a disabled feminist and human rights advocate with over three decades of experience in public policy and community development shares work that she has co-authored. ***"We are human too"*** is a powerful chronicle of a century of disabled people's experiences in Ireland. Her work reflects a deep commitment to disability rights, systemic reform and trauma informed care.

Sandra Guidon shares a range of recent developments and resources that reflect ongoing efforts to promote inclusion, rights, and informed practice across the sector.

She begins by highlighting the launch of the first phase of the ***Irish Deaf Society's ground breaking English-Irish Sign Language (ISL) Digital Dictionary –*** an inspiring milestone in the journey toward greater inclusion and accessibility.

She provides highlights from a recent public lecture series from the Irish Gerontological Society (IGS) titled ***"Neurodivergence in Older Adults: Insights from Autistic Doctors".***

Dr. Paula Prendeville provides follow up information on the ***"Autistic SPACE framework"*** developed by Professor Mary Doherty and Autistic Doctors International (ADI).

Sandra shares a recent initiative from the ***Ombudsman for Children's Office (OCO)***, which has released a new series of briefing papers designed to help legislators, civil servants, and public sector professionals embed the principles of the UN Convention on the Rights of the Child (UNCRC) into their everyday work.

Sandra highlights a recent webinar hosted by the National Safeguarding Office in collaboration with the Disability Umbrella Groups Safeguarding Reference Group. The session focused on ***Financial Autonomy,*** for people with disabilities.

Welcome

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

For those who may have missed it, Sandra encourages readers to catch up on the Irish Hospice Foundation's recent webinar series, ***"On Your Mark, Get Set, Plan Ahead!"*** which is a valuable resource for anyone in planning for end-of-life care and decision-making. She also shares news from the ***Mental Health Commission (MHC)***, which has launched a public consultation on the use of surveillance technologies in mental health services.

Sandra introduces ***Little Journey,*** a digital support app designed to transform the hospital experience for children and their families. With a focus on empathy and empowerment, the app helps prepare and support young patients before, during, and after medical procedures—making healthcare more accessible and less intimidating.

Finally Sandra shares information on the very important ***"Hello, How are you campaign"*** which is a national campaign run by Mental Health Ireland promoting open dialogue around mental health and emotional well-being.

Barbara Brennan highlights the ***Mental Health Matters 2025 National Poster Competition,*** aimed to spark open conversations about mental health through the universal language of art.

Nicola Lucey, Community Worker HSE South West shares details of a recent ***Dementia Information day.*** The day provided a valuable opportunity for those with a dementia diagnosis and their carers to access information about available community supports.

Emily Moffatt, School of Nursing and Midwifery, TCD writes about a recent session held for Midwifery students, titled ***Understanding Consent in Maternity Care.*** HSE National Consent Policy Programme Lead, Elaine McCaughley explored the application of the HSE National Consent Policy within the field of maternity care.

Emma Mullins and Michelle Angland share their perspectives on the "***HSE's Assisted Decision-Making Mentorship Programme"***, highlighting the role of the programme in fostering a culture of learning and collaboration. Drawing from their own experiences, they reflect on the value of mentorship in building confidence, enhancing clinical practice, and strengthening peer support among healthcare professionals.

Sage Advocacy has recently published a report ***Voice Matters: The Experience and Perspectives of Sage Advocacy*** which reviews progress since the commencement of the Assisted Decision-Making (Capacity) Act 2015.

The report explores how the Act is functioning in practice, highlighting achievements, ongoing challenges, and opportunities for improvement.

The Community of Practice for Advance Care Planning in Mental Health, co-convened earlier this year by Dr Nuala Kane, Consultant Psychiatrist, and Dr Jennifer Allen, Senior Social Worker, held its inaugural online seminar on 7th May 2025. This event marked a significant step in fostering collaborative dialogue and shared learning in the field of mental health and advance care planning. The seminar featured Dr Lucy Stephenson, Consultant Psychiatrist at South London and Maudsley NHS Foundation Trust and Clinical Researcher at King's College London, as the guest speaker, offering valuable insights drawn from both clinical and academic perspectives.

Ultan Hynes, Head of Service, ***Nursing Homes Support Scheme (NHSS)*** commonly known as the ***Fair Deal Scheme*** provides guidance on the application process, eligibility criteria, and recent developments to the scheme in light of the Assisted Decision-Making (Capacity) Act 2015.

Welcome

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

Alice White, Registrar of ***Wards of Court,*** provides an update on the process for discharge from wardship. Since the commencement, her office has received 656 applications for discharge from wardship. As of 30th May, discharge orders have been granted in 136 cases. She outlines the plans being undertaken to transition the remaining 1,748 adults out of the wardship regime.

Dr. Emer Rutlidge, Consultant Psychiatrist and Michelle Darcy, Senior OT describe a model of care called ***"Open Dialogue"*** which has been introduced successfully in Meath Louth Mental Health Services**.**

We finish this edition with a special tribute to our friend and colleague Jacqui Browne who sadly passed away on the 23rd June 2025. Our thoughts are with her family and friends at this difficult time.

Thank you all for your continued support. I hope the summer days bring you rest and reconnection.

Caoimhe Gleeson
National Office for Human Rights and Equality Policy

Update from the Decision Support Service

Aine Flynn, Director of Decision Support Service

April marked the second anniversary of the commencement of the Assisted Decision-Making (Capacity) Act 2015 and the DSS is busier all the time across all our statutory functions.

By the end of April, the Information Services team which includes the dedicated enduring power of attorney (EPA) helpdesk had managed as many calls and queries as they had by the end of August in 2024.

Our updated statistics are published monthly and available on our website **HERE**

At the end of March, the DSS reported the registration of over 3,000 decision support arrangements. Before the end of May this number had risen to 4,000 registrations.

Registered EPAs continue to account for well over 50% (almost 2,700) of the decision support arrangements on the DSS register.

Only 74 of these EPAs have moved to the second stage of notification, with the attorney stepping up to the role of decision-maker.

As the DSS has previously commented, the number of EPA notifications, although increasing noticeably, should be low, as it means that the donor has already lost capacity to make relevant decisions in the relatively short time since registering their 2015 Act EPA with the DSS.

Healthcare professionals are reminded that an EPA cannot include decisions about treatment, which should instead be planned for in an advance healthcare directive.

A survey recently carried out by the DSS indicated that only 8% of Irish adults have an EPA in place, although almost 90% of respondents said that they would consider making one.

Advance planning is the key theme of the DSS's public information campaign for this year and was also the theme of our medal-winning 'Support Garden' at the Bloom Festival over the June Bank Holiday weekend. Our talented garden designer, Joe Eustace, superbly represented the importance of having conversations in a calm space to put in place trusted robust supports for the future.

Bloom gave DSS colleagues a valuable opportunity to showcase our service and engage with the public, and the many health and social care professionals who stopped by. The plants and furniture from the garden are now to be repurposed in a community-based disability service and Age Friendly Ireland project.

Our busy schedule of engagements with diverse stakeholders has continued. As we always say, the DSS seeks to prioritise engagement with our potential service users and their families and carers.

Information about our activities as well as resources in a variety of formats for professionals and the public can be found on the DSS website at decisonsupportservice.ie

Update from the Decision Support Service

Aine Flynn, Director of Decision Support Service

We ran a two-day in-person event in Portlaoise in April to promote advance planning and the DSS team were on hand to provide information and practical support with applications to members of the public and legal practitioners A similar event is planned for Dublin in September and information will be available on the DSS website.

In April, the DSS delivered two training events for new recruits and existing members of our panel of decision-making representatives, who are available to be appointed by the court in appropriate cases.

To date, the courts have appointed from the panel- whose membership includes experienced healthcare professionals- in approximately 20% of decision-making representation orders.

The role of the panel DMR and their relationship to the DSS was one of the themes covered at an online HSE ADM learning event on 30 May.

The DSS also provided information about its supervision and complaints functions and the DSS registers. From the DSS's perspective, these events provide valuable insight into the practical implementation of the 2015 Act and an opportunity to correct occasional misunderstandings and receive feedback from the front line.

The DSS's 2024 Annual Report containing a review of our first full calendar year as operating service will be published as part of the Mental Health Commission in late June.

Support Garden at the Bloom Festival

seirbhís tacaíochta cinnteoireachta
decision support service™

Spotlight Series - Suzy Byrne, Champion of Rights, Voice for Change

Sandra Guidon, Project Support Officer

In this edition, we shine a spotlight on **Suzy Byrne, Regional Manager of the National Advocacy Service (NAS)**, whose career has been defined by a deep commitment to human rights, equality, and empowering others.

From her student advocacy at Trinity College to a leader at NAS today, Suzy has championed inclusion and justice. I recently met Suzy and was inspired by her journey, passion, and the personal experiences that fuel her work.

> ***I love food and cooking - especially exploring foreign supermarkets when I travel. While most people are off seeing the sights, I'm mooching around the aisles picking up ingredients and delights.***

Suzy's Slice of Fun: From Supermarkets to Centre Court

Suzy finds joy in the unexpected – like exploring foreign supermarkets for culinary treasures while travelling.

A devoted sports fan, she's attended the Olympics, Ryder Cup, and is a regular at Bohemians matches. And this year, she finally fulfilled a dream; scoring tickets to Wimbledon.

A Lifelong Advocate: Suzy's Journey into Activism

Suzy Byrne's path into advocacy didn't begin with a job title—it began with a passion for justice and inclusion. During her time at Trinity College, Suzy was instrumental in initiating national discussions and influencing policy responses concerning the support needs of disabled lesbians and gay men. This work was carried out in collaboration with the National Disability Authority and the Equality Authority.

From 2007 onwards, She became involved in supporting survivors of the Magdalene Laundries and others who experienced institutional abuse.

This work began through advocacy pilot projects and later became a significant part of her role within NAS, focusing on helping individuals seek redress and recognition.

Suzy at the Sligo Pride 2007

Spotlight Series - Suzy Byrne, Champion of Rights, Voice for Change

Sandra Guidon, Project Support Officer

From Local Roots to Global Rights: Suzy's Advocacy Journey

Before joining the NAS, Suzy was deeply involved in community and rights work – from campaigning for LGBT equality in Ireland, to representing youth in European human rights forums. She helped shape Gardaí equality training, and served on the Irish Council for Civil Liberties (ICCL) board,

Though she's stepped back from volunteer board roles, Suzy continues to mentor and support civil society efforts. For Suzy, advocacy begins at the local level but reaches far beyond.

Suzy Byrne, Dublin Lesbian and Gay Pride March 1997

"We all have a role in ensuring rights are respected and democracy is upheld."

Suzy Byrne and Feargus McGarvey, Dublin Pride 1993

Why Human Rights Matter: Suzy's Driving Force

Suzy's human rights work is routed in personal experience. Having faced restrictions herself, shes driven to support others – especially young activists and groups like Disabled Women of Ireland.

"I've experienced, and continue to experience, restrictions on my rights,"

Shes open about the emotional toll of advocacy and stresses the importance of compassion, mutual support, and lifting each other up.

"It can be exhausting and emotionally draining. I've seen people burn out—and I've experienced it myself." That's why she believes in mutual support, compassion, and understanding. "Everyone is on their own journey. We need to lift each other up, not tear each other down."

Spotlight Series - Suzy Byrne, Champion of Rights, Voice for Change

Sandra Guidon, Project Support Officer

The Power of Peer Support and Inclusive Advocacy

For Suzy, peer support is vital for disabled people, especially youth who may feel isolated. She advocates for solidarity across all disabilities and ensures inclusion of those with intellectual and cognitive disabilities. Her work – like developing forums on transport access - highlights true inclusion means listening to every voice, not just building ramps.

Suzy highlights the National Transport Authority's travel assistance scheme as a key step in accessibility – helping young people gain confidence and independence through supported public transport use.

> **"We shouldn't immediately assume someone can't make a decision or rush to take over their choices,"**

> **"Instead, we need to ask: Where is the person at?**

Empowering Choice: The Heart of the Assisted Decision-Making Act

Suzy sees the Assisted Decision-Making (Capacity) Act as a vital shift toward respecting autonomy. It starts with the presumption of capacity and focuses on supporting individuals to make their own choices.

For her, it's not just about outcomes, but ensuring decisions are made through inclusive, transparent processes that honour each person's will and preferences."

Making Rights Real: What's Next for the ADM Act?

Suzy believes the next step for the ADM Act is public education. She stresses shifting the focus from procedures to empowering people and ensuring families and professionals understand the Act's human rights foundation.

A Career Built on Commitment

When asked about her biggest professional achievement, Suzy sees her career not as a single achievement, but as a journey of ongoing commitment to human rights and community development – something she never imagined in her 20s, but now deeply values.

A Day in the Life of a NAS Regional Manager

A typical day for Suzy as Regional Manager at the National Advocacy Service (NAS) blends internal coordination with external engagement.
Supporting advocates is central—offering guidance on cases, discussing developments, and identifying next steps, always with the individual's consent.
At its heart, the role is about empowerment: helping both disabled individuals and those who support them to understand and uphold their rights.

Adapting to Evolving Needs: How NAS Stays Person-Centred

NAS continues to evolve with a strong focus on person-centred advocacy - developing easy-read materials and supporting individuals to express their will under laws like the ADM Act. Advocates work alongside people to promote autonomy, always keeping the person at the centre.

Breaking Barriers to Advocacy Access

Access to advocacy remains limited due to low awareness, long waiting lists, and under resourcing, challenges that are growing as more people move into community living. Suzy stresses the need for accessible information and stronger support systems.

Spotlight Series - Suzy Byrne, Champion of Rights, Voice for Change

Sandra Guidon, Project Support Officer

Ensuring Voices Are Heard: NAS's Person-Centred Approach

NAS ensures advocacy is truly person-centred through personalised plans, flexible support and strong supervision – always focused on amplifying voices and respecting individual choices.

Staying Connected Through Informal Volunteering

While taking a break from formal committees, Suzy continues to offer informal support and mentorship, staying connected and contributing on her own terms.

Balancing Advocacy for Others—and for Yourself

When asked about balancing advocacy for others and herself Suzy admits self-advocacy remains a challenge. Even as a seasoned advocate, she's hesitant to seek support—including delaying an application for a disabled parking badge.

It's a reminder that speaking up for your own needs takes courage, and understanding that helsp us be more compassionate advocates.

What Keeps Suzy Advocating

Suzy's drive comes from lived experience and a deep sense of justice. She knows how hard it can be just to be heard – and believes it shouldn't be.

Her motivation isn't anger, but a clear-eyed commitment to standing with others and making rights real.

The People Who Shaped Suzy's Advocacy

When I asked Suzy who inspired her, she points to people -not books, She credits leaders like: Donal Toolan and especially Peter Moore, a pioneer of the Independant Living Movement in Ireland. Working alongside Peter for over a decade, Suzy learned lasting lessons about autonomy, dignity, and challenging assumptions – values that continue to shape her advocacy today.

Suzy on Strengthening Legal Support for Disabled People

Suzy advocates for a dedicated legal advice service for disabled people, noting gaps in Ireland's current system. Suzy also stresses the need for more disabled professionals in law and calls for disability-specific legal organisations to help tackle rights issues and discrimination effectively.

Suzy on Advocacy, Inclusion, and Everyday Joys

Suzy believes inclusion means removing social barriers-not isolating people.

> **“Disability isn't about the individual—it's about how society disables people”**

Outside of advocacy, Suzy finds joy in sports and flipping through cookbooks for relaxation.

Support Disabilties Rights

Spotlight Series - Suzy Byrne, Champion of Rights, Voice for Change

Sandra Guidon, Project Support Officer

Looking Ahead: The Heart of Advocacy

When asked how a friend or colleague might describe her, Suzy smiles and admits, “Probably a bit stubborn—but I’d hope they’d also say I’m someone who cares.” That blend of determination and compassion defines her decades of advocacy.

For Suzy, advocacy means walking alongside others, supporting their rights and dignity.

Her work continues to shape a more inclusive and rights-focused Ireland.

As Suzy herself puts it, **“Advocacy isn’t about fixing things for others—it’s about walking alongside them, supporting their journey, and ensuring they are seen as the rights holders they are.”**

We’re grateful for her leadership, her passion, and her unwavering commitment to making change happen.

NATIONAL ADVOCACY SERVICE
FOR PEOPLE WITH DISABILITIES

Update: Access to the Decision Support Service (DSS) Register for Approved Organisations

Norma O'Donnell, ADM Project Manager

The Decision Support Service (DSS) Register for Approved Organisations is now accessible to health and social care services across the HSE and other eligible providers. Access to the DSS Register is essential for a range of services, including hospital departments, primary care teams, mental health services, and nursing homes.

Established under the Assisted Decision-Making (Capacity) Act 2015, the DSS Register plays a vital role in supporting individuals who may need help making decisions about their personal welfare, healthcare, or finances. It ensures that such support is provided in a way that respects each person's rights, will, and preferences.

The online DSS Register offers a secure and structured platform to record and verify formal decision support arrangements. It provides legal clarity and consistency in care delivery by helping professionals identify who is legally authorised to act on behalf of a person who may lack capacity to make certain decisions independently.

Only certain types of decision support arrangements are searchable on the DSS Register. This includes:

Co-Decision-Making Agreements

Enduring Power of Attorneys

Decision-Making Representation orders

Enduring powers of attorney registered ***under the Powers of Attorney Act (1996)*** are NOT searchable on the Register but are kept on a register maintained by the Office of Wards of Court. You can find out more about enduring powers of attorney made under the 1996 Act on the Office of Wards of Court website here.

Update: Access to the Decision Support Service (DSS) Register for Approved Organisations

Norma O’Donnell, ADM Project Manager

Why would a health or social care service need to search the DSS Register?

Health or social care services may need to search the DSS Register to make sure that a decision support arrangement is in place or to confirm what authority a decision supporter has. For example, a service may need to confirm that a decision support arrangement is in place before sharing information or allowing a decision supporter to exercise their authority. It may be necessary to check the DSS Register if an arrangement is in place if a co-decision-maker seeks information about a relevant person to support them in making a decision. A guide to searching the register can be found here.

For more information visit the Decision Support Service website here

seirbhís tacaíochta cinnteoireachta
decision support service™

Current Status and Access

Health and social care services can apply for access as Approved Organisation’s through the online myDSS portal.

You can find out more about how to get ready to apply for approval for your organisation in the Resources section of the DSS website here.

Once an ‘Approved Organisation’ is registered to access the DSS Register, DSS Register account holders will have 24/7 access.

HSE Guidelines for Approved Organisations accessing and searching the DSS Register Now Available

HSE Guidelines for Approved Organisations accessing and searching the Decision Support Service (DSS) Register

The National Office for Human Rights and Equality Policy have developed comprehensive HSE Guidelines for Approved Organisations accessing and searching the DSS Register as a resource specifically for health and social care purposes. These guidelines include information on registering an account to access the DSS register as an Approved Organisation and making a search of the DSS register as a DSS Register account holder and nominated administrator.

For further information from the HSE Office for Human Rights and Equality Policy please contact adm@hse.ie

Assisted Decision Making (Capacity) Act 2015: Update on the In-Person Training on Functional Assessment of Capacity

Joanne Haffey, ADM Senior Project Manager

The HSE National Office for Human Rights and Equality Policy have been very busy in May 2025 as we began the official roll out of the In-Person Training on the Functional Assessment of Capacity.
Throughout the month of May we delivered at least one, sometimes two, training sessions in each Regional Health Authority.

We have trained two hundred and fifteen staff from the HSE including Section 38 and 39 agencies. All staff are from the list of staff prescribed by regulation as follows:

- **Registered Medical doctors**
- **Social workers**
- **Occupational Therapists**
- **Speech and Language Therapists**
- **Nurses**
- **Midwives**

The Training Day:

The in-person training is solely focussed on the functional assessment of capacity under part 5 of the Assisted Decision Making (Capacity) Act 2015.

Part 5 of the 2015 Act is concerned with the appointment of a Decision Making Representative. This is the most restrictive arrangement under the 2015 Act and can only be appointed by a court order.

The training day is a highly interactive day with participants getting the opportunity to practice conducting a functional assessment of capacity through role play.

Attention is also given to how to complete a part 5 functional assessment of capacity report on the HSEs template, which can be found here:

Collaborative energy fills the room as groups engage in the Functional Assessment of Capacity training

Assisted Decision Making (Capacity) Act 2015: Update on the in-Person Training on Functional Assessment of Capacity

Joanne Haffey, ADM Senior Project Manager

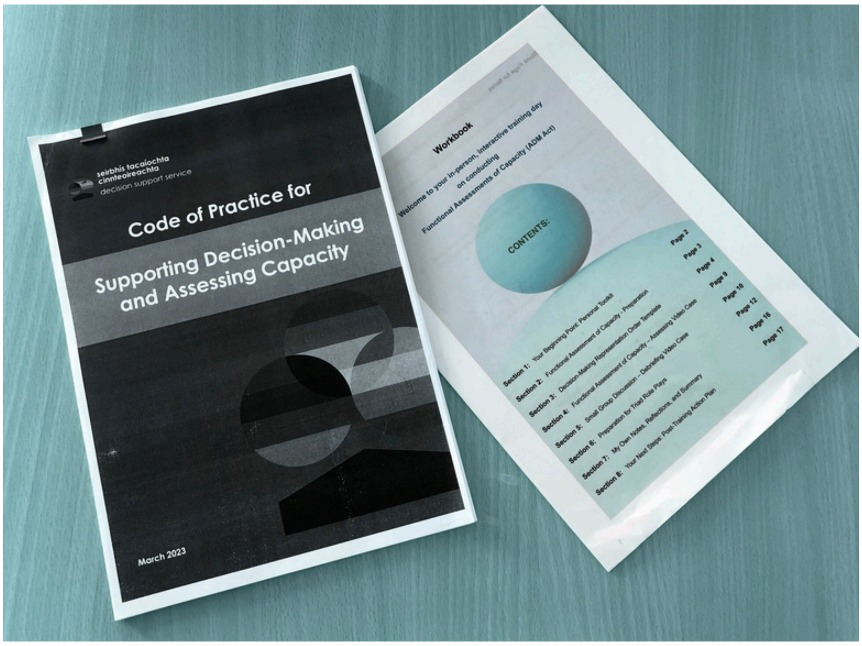
What are People Saying about the Training?

The training has received an overwhelmingly positive response to date, below are some of the quotes taken from the feedback we have received:

> **"It has helped de-mystify the assessment process. Great to hear from others in the room about their experiences doing assessments already"**

> **"The role play. As a team it helped to identify especially in the evaluation of it after what went well and what we could improve on"**

> **"I found every aspect of today's training very valuable. Particularly the role plays and getting to 'practice' being the assessor"**



seirbhís tacaíochta cinnteoireachta
decision support service

Code of Practice for
Supporting Decision-Making
and Assessing Capacity

March 2023

Workbook

Welcome to your in-person, interactive training day
on conducting
Functional Assessments of Capacity (ADM Act)

CONTENTS:

Section 1: Your Beginning Point: Personal Toolkit Page 2
Section 2: Functional Assessment of Capacity - Preparation Page 3
Section 3: Decision-Making Representation Order Template Page 4
Section 4: Functional Assessment of Capacity – Assessing Video Case Page 9
Section 5: Small Group Discussion – Debriefing Video Case Page 10
Section 6: Preparation for Triad Role Plays Page 12
Section 7: My Own Notes, Reflections, and Summary Page 16
Section 8: Your Next Steps: Post-Training Action Plan Page 17

> **"The knowledge and expertise of the facilitators - fantastic to hear their insights into ADM DMRO cases and to get real life information in relation to current patterns of practice evolving as a result of ongoing court cases"**

Assisted Decision Making (Capacity) Act 2015: Update on the In Person Training on Functional Assessment of Capacity

Joanne Haffey, ADM Senior Project Manager

What Next?

Throughout the second half of 2025 (June to December) the National Office for Human Rights and Equality Policy will continue to provide training in each Regional Health Area (RHA), each month (except August).

How can you access the training?

Each RHA has appointed designated leads who will coordinate and identify staff to attend the training sessions that will occur in their area. If you wish to attend a training session in the coming months please contact the designated lead in your RHA to express your interest.

Regional Health Area	**Designated Lead(s)**	**Contact Email:**
Dublin North East	Aoife Lenihan (Community) Ger Farren (Acute)	aoife.lenihan@hse.ie geraldinefarren@rcsihospitals.ie
Dublin South East	Sinead Brennan	sbrennan@iehg.ie
Dublin Midlands	Catherine Croke	catherine.croke@hse.ie
Mid West	Mary O’Dwyer (Community) Caroline O’Meara (Acutes)	mary.odwyer1@hse.ie Caroline.OMeara1@hse.ie
South West	Katie Lynch	katie.lynch@hse.ieie
West North West	John McIlhinney	John.McElhinney@hse.ie

WHO Quality Rights

Jacqueline Grogan, Project Manager

QualityRights is WHO's global initiative to improve the quality of care provided by mental health and social services and promote the human rights of people with mental health conditions and psychosocial, intellectual or cognitive disabilities.

WHO QualityRights
Act, unite and empower for mental health

Through QualityRights, WHO is supporting countries to put in place policies, strategies, laws and services that are in line with international human rights standards including the Convention on the Rights of Persons with Disabilities (CRPD).

The project has a number of objectives:

- Build capacity to combat stigma and discrimination and promote human rights and recovery
- Promote the participation of persons with lived experience and support civil society
- Create community-based services and supports that respect and promote human rights
- Reform national policies and legislation in line with the CRPD and other international human rights standards

As part of this work, the WHO has developed a range of training materials to build capacity on rights based, person centered care and support. These include the following:

- **Training materials on rights based, person centered care and support, guidance on peer support and tools for advocacy and civil society** -
- **E-learning programme on mental health, recovery and community inclusion**
- **Self-help tool for person-centered recovery planning**
- **Quality Rights assessment toolkit**

Dr Michelle Funk, of the WHO Policy, Law and Human Rights team in the Department of Mental Health and Substance Use, spoke about the WHO guidance on mental health policy & strategic action plan at the launch of the Implementation Plan 2025 - 2027 for Sharing the Vision: A Mental Health Policy for Everyone at the second National Mental Health Policy Conference in Dublin Castle on Wednesday 9 April 2025

You can watch her presentation here

You can find out more about this project here

World Health Organization

We are Human Too: About Us, By Us, For Everyone

Annmarie Flanagan, HSE Liaison Officer

Ann Marie Flanagan is a disabled feminist and human rights advocate with over 30 years' experience in public policy and community development. She currently serves as a Liaison Officer with the HSE's Personalised Budget Pilot and previously spent two decades with Shine.

Twice nominated to the Seanad by Independent Living Movement Ireland and the Irish Deaf Society, she co-authored We Are Human Too, chronicling a century of disabled people's experiences in Ireland. Ann Marie has led national efforts on personal assistance, accessible transport, advocacy, and inclusive childcare. A trauma-informed therapist, she also led the FRIENDS Family Recovery Initiative. She holds an MSc in Partnership Studies and Public Administration and is completing an LLM in Disability Equality Law. She is married and a proud mother, deeply committed to disability rights and systemic reform.

We Are Human Too

A landmark publication by the Clare Leader Forum, We Are Human Too is a powerful collection of stories by over 100 disabled people in Ireland. Co-written and edited by Ann Marie Flanagan, this book reclaims history, exposes ongoing injustices, and demands a more inclusive future. Honest, urgent, and deeply human, it speaks to activists, educators, policymakers, and anyone committed to equality and change.

A History That Cannot Be Ignored

We Are Human Too uncovers a hidden history of exclusion in Ireland—from institutionalisation and isolation to systemic barriers in education, work, and community life. Spanning from pre-independence to 2024, it reveals how the concept of "disability" was shaped by societal change and industrialisation, often at the expense of those who didn't fit the mold. But it's also a story of resistance—of disabled people in Clare and across Ireland rising up, organising, and demanding their rightful place in society.

Our Voices, Our Movement

We Are Human Too brings together over 100 voices—disabled people and allies—sharing powerful stories of exclusion, resilience, and activism. From being separated from families to fighting for rights, these lived experiences reveal both the harm of systemic discrimination and the strength of collective action.

The book traces the rise of Ireland's Disabled People's Movement, from the Clare Leader Forum to national advocacy, highlighting hard-won victories like Personal Assistance Services, independent advocacy, and the recognition of Irish Sign Language. It also explores ongoing struggles for legal equality and community inclusion.

Grounded in over 600 references but written in clear, accessible language, this is a book for anyone ready to listen, learn, and act. It champions the social model of disability, universal design, and the principle that lived experience must shape law and policy. We Are Human Too is a testament to a movement that is visionary, intersectional, and unstoppable.

We are Human Too: About us, By us, For Everyone.

Annmarie Flanagan, HSE Liaison Officer

The Law Must Work for Us, Not Against Us

We Are Human Too explores how Irish laws and policies have often been created without the voices of disabled people. It examines key legislation like the Disability Act 2005, the EPSEN Act, and the UN CRPD, highlighting both progress and persistent gaps.

A major focus is the Assisted Decision-Making (Capacity) Act 2015, which shifts from substituted decisions to supporting people's autonomy and rights. The book draws on lived experience and legal analysis to show how Ireland must move from controlling disabled people to empowering them as equal citizens.

It calls for legal recognition of essential supports—like personal assistance, housing, and transport—as rights, not privileges, and urges reform of outdated systems that still treat disabled people as passive recipients rather than active participants in society.

AVAILABLE NOW

Please contact Clare Leader Forum clareleaderforum@gmail.com for book details

Building a Society That Sees Us

We Are Human Too doesn't just tell hard truths—it offers a vision for change.

Using Maslow's hierarchy of needs, the book shows how true human rights are realised when the State moves beyond meeting basic needs to supporting belonging, purpose, and self-actualisation.

When disabled people have access to education, transport, housing, Irish Sign Language, personal assistance, and a living wage—and when laws enable everyone to thrive—then we can fully participate, contribute, and dream.

This isn't idealism—it's realism. But it requires a shift: from seeing disabled people as problems to be managed, to recognising us as people whose inclusion strengthens society for all.

The Role of Non-Disabled Professionals as Allies

If you work in disability or social services, this book is for you. It invites you to reflect on the power you hold and how you use it. Are you creating space for disabled voices to lead? Are your services shaped around people—not systems?

Many non-disabled professionals are committed to human rights.

We Are Human Too calls on you to walk with us, not ahead of us.

Respect lived experience as expertise. Involve disabled people in designing, delivering, and evaluating the services we use. Support and be guided by Disabled Persons' Organisations.

A Living Record of Truth and Hope

We Are Human Too is also a memorial—honouring those harmed or lost because society failed to see their humanity. Their vision of justice and equality lives on in these pages.

We are proud to include a foreword by Professor Eilionóir Flynn and a back cover endorsement by President Mary McAleese. Their support adds strength, but at its heart, this is our story—told by us, for everyone.

Get the Book – Join the Movement

We Are Human Too is available in hard copy at bookshops across Ireland, online at ennisbookshop.ie, and on Kindle. It's the only publication of its kind —written by disabled people, about disabled people, for everyone who believes in a fairer, more equal Ireland.

Read it. Share it. Reflect on your role in the story that's still unfolding. Disabled people are not problems to fix—we are leaders, changemakers, and visionaries. We are human too.

Release of First Ever English-ISL Dictionary

Sandra Guidon, Project Support Officer

We were delighted to celebrate the launch of the first phase of the Irish Deaf Society's first-ever English-Irish Sign Language (ISL) Dictionary, an inspiring milestone which was made possible through generous support and funding from Rethink Ireland. It is a groundbreaking project that focuses on employment-related terminology and represents a significant advancement in promoting inclusion, equity, and ISL access for the Deaf community in Ireland. The Irish Deaf Society are the first in Ireland to produce this type of dictionary. There are very few like it in the world, there are only three in other European countries.

The dictionary is currently available as an online resource. This digital format allows for easy updates and accessibility, ensuring that users can access the most current information and explanations.

As of now, there isn't a physical version of the dictionary, but the online platform is designed to be comprehensive and user-friendly. The Irish Deaf Society may consider expanding to a physical format in the future, depending on demand and resources.

For many Deaf individuals, whose first or preferred language is ISL, traditional English-based dictionaries can be difficult to navigate.

Unlike the general population, who can easily access resources like the Oxford English Dictionary, Deaf people often encounter significant barriers due to the heavy reliance on English literacy. These dictionaries typically lack ISL integration, making them less accessible and inclusive for the deaf community.

This project has several key objectives:

- Expand the vocabulary of Deaf people through ISL.
- Enhance their understanding and confidence in using employment-related English vocabulary.
- Empower Deaf professionals to be equal participants in a predominantly English-based society.

The English-ISL Dictionary aims to close this accessibility gap by offering over 200 employment-related terms, each paired with ISL definitions and examples, similar to how English-based dictionaries are structured, it provides deaf users with a familiar and user-friendly format tailored to their linguistic needs.

Release of First Ever English-ISL Dictionary

Sandra Guidon, Project Support Officer

This dictionary directly tackles barriers that contribute to underemployment and unemployment among Deaf individuals, particularly the lack of access to essential workplace vocabulary and confidence challenges that can hinder career progression. By providing clear ISL definitions for employment related terms, this resource has the potential to transform the professional experiences of deaf employees.

We encourage your organization to raise awareness of this valuable tool and explore how it can be integrated to support Deaf employees in your workplace. It also serves as a practical and valuable reference for employers, HR professionals, and colleagues committed to fostering a more inclusive work environment.

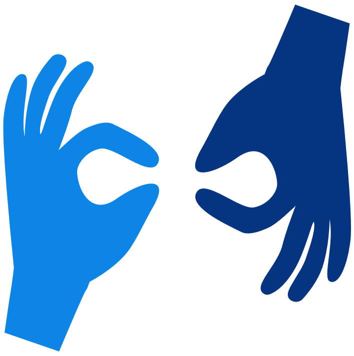
As part of their broader efforts under the Irish Sign Language Act 2017, the Irish Deaf Society offers an ISL Translation Service to support public bodies and organisations in producing ISL video content. This includes:

- Welcome videos for websites/homepages.
- ISL translations of reports, policies, publications, and public information.

These services not only help ensure compliance with the ISL Act but also demonstrate a genuine commitment to accessibility and inclusion.

Hearing people have access to dictionaries explaining words from a second language in their own preferred language, this has never existed for Deaf people before. This is the start of an exciting project that will support English language literacy and comprehension for the Irish Deaf community. Not only that, it will empower Deaf people to take part in the community on an equal basis.

We will expand and add to this dictionary in the coming years and work towards a complete dictionary and a brilliant resource for Deaf people in Ireland. Support this project, you are welcome to join us and make this dream a reality.



If you are interested in availing of this service, please contact ISL Media Production Coordinator, Sophie Kennedy, at sophie@irishdeafsociety.ie for quotes and further information.
Explore the English-ISL dictionary here: Irish Deaf Society Dictionary.

Irish Deaf Society

Neurodivergence in Older Adults: Insights from Autistic Healthcare Workers

Sandra Guidon, Project Support Officer

The Irish Gerontological Society (IGS) continued its impactful Public Lecture Series with a compelling session titled "Neurodivergence in Older Adults: Insights from Autistic Doctors."

The event featured a keynote presentation by Dr. Mary Doherty, Consultant Anaesthetist at Our Lady's Hospital, Navan, and Clinical Associate Professor at University College Dublin's School of Medicine, and a Q&A session by Panellists: Florence Horsman-Hogan, Quality & Patient Safety Manager, autistic Healthcare Professional Ruth Connolly, Lead Clinical Psychologist for Muriosa Foundation Una Sheehan, neurodivergent older adult

IGS Vice President Deirdre Lang opened the session by welcoming Dr. Doherty and highlighted her pioneering work as founder of Autistic Doctors International (ADI) – a global community of over 1200 autistic medical professionals, including members from as far afield as Antarctica.

Dr. Doherty began by sharing her personal journey into the world of autism, reflecting on how a late diagnosis reshaped her understanding of her career and identity.

Dr. Mary Doherty

> **If I'd known years ago that I was autistic, things would have been so different, but it's never too late**

Dr. Doherty's presentation covered a wide range of critical topics, including:

- The mission and growth of ***Autistic Doctors International***
- The ***healthcare needs of older autistic people***
- ***ADHD in later life***
- Recognising autistic individuals in our lives—whether as patients, colleagues, or loved ones
- The ***Autistic SPACE Framework***, a model for implementing reasonable accommodations in healthcare settings

She highlighted the importance of moving beyond mere autism awareness toward **autism competence** among healthcare providers.

Her vision is for a future where **all autistic children can grow up confidently autistic**, supported by systems that understand and affirm neurodivergent identities.

Dr. Doherty also shared insights from her ongoing PhD by publication, which draws on the lived experiences of autistic doctors to inform better healthcare practices for autistic patients. Her research spans topics such as:

- The experiences of autistic psychiatrists
- Reasonable accommodations for autistic clinicians
- The broader healthcare needs of autistic individuals across the lifespan

Neurodivergence in Older Adults: Insights from Autistic Healthcare Workers

Sandra Guidon, Project Support Officer

She introduced the Autistic SPACE framework—**Sensory, Predictability, Acceptance, Communication, and Empathy**—a practical, open-access model for inclusive environments. Originally published in the British Journal of Hospital Medicine and Practice: Social Work in Action, it's adaptable across healthcare, education, and social care. Versions for anaesthesia and geriatric medicine are in development via ADI.

She also shared personal reflections as a parent of two neurodivergent children. Her daughter's delayed recognition and mental health struggles illustrated the consequences of outdated, deficit-based models of autism—particularly for girls. Her message was clear: **early understanding and affirmation can change lives.**

Dr. Doherty shared findings from her recent qualitative study, "Autistic Psychiatrists' Experiences of Recognising Themselves and Others as Autistic," which involved eight participants. One had spent over 40 years working in psychiatry and only began to explore their own autism after retiring.

Another, a specialist in old age psychiatry, contributed rich case studies on recognising autism in older adults.

A key insight from the study was the importance of perspective:

Whether clinicians view the world through a **neurodivergent** or **neurotypical** lens. Many participants reflected that they had never seen themselves represented in their training. As Dr. Doherty explained, "If psychiatrists don't recognise themselves as autistic, how can they be expected to recognise autism in their patients?"
This theme emerged strongly, highlighting the need for more inclusive and reflective training in mental health professions.

Words matter: Reframing neurodivergence in science, medicine and society

May 3, 2024

By Zoë Mullan, Alison Bert, DMA

The Language of Neurodiversity

Autistic ✓

~~With autism~~

~~ASD~~

The Importance of Language

In a deep dive on language and identity, Dr. Doherty emphasised the importance of using respectful and accurate terminology when talking about autism.

She encouraged the use of identity-first language—"**autistic person**" rather than "**person with autism**" or **"ASD" (Autism Spectrum Disorder).**

"We're not disordered or diseased—we're different," she explained. "Yes, we may be disabled in certain contexts, but that doesn't mean we're broken."

This shift in language reflects a broader move toward a neurodiversity-affirmative approach, which recognises autism as a natural variation in human experience rather than something to be fixed or cured.

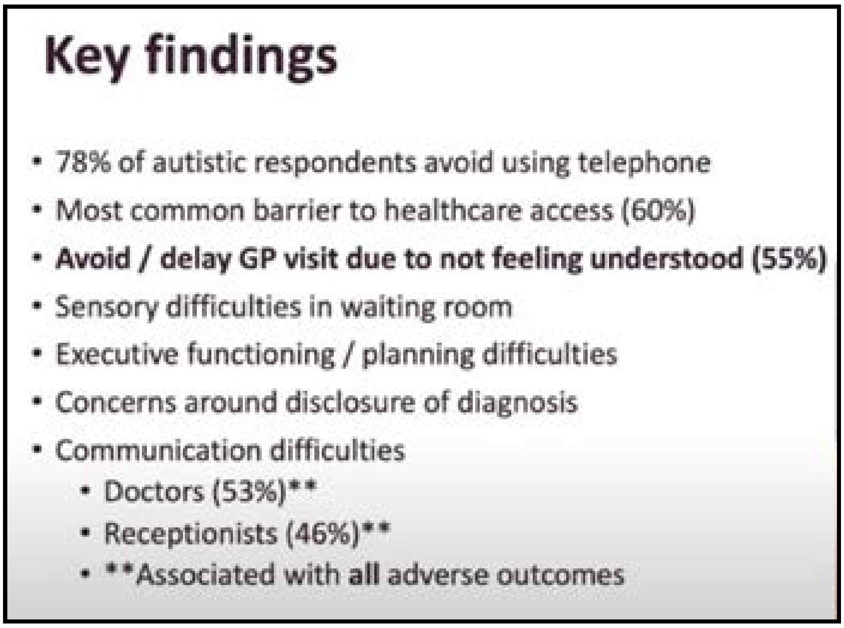
Neurodivergence in Older Adults: Insights from Autistic Healthcare Workers

Sandra Guidon, Project Support Officer

Barriers to Healthcare Access

Dr. Doherty shared that over half of autistic respondents in a recent study reported avoiding or delaying GP visits because they didn't feel understood. A major reason for this is the lack of autism-specific training among healthcare professionals.

She also spoke about her own challenges accessing healthcare, which she discussed in a recent interview with The Times, highlighting how even as a doctor, navigating the system can be difficult without proper understanding and support.



Key findings

- 78% of autistic respondents avoid using telephone
- Most common barrier to healthcare access (60%)
- **Avoid / delay GP visit due to not feeling understood (55%)**
- Sensory difficulties in waiting room
- Executive functioning / planning difficulties
- Concerns around disclosure of diagnosis
- Communication difficulties
  - Doctors (53%)**
  - Receptionists (46%)**
  - **Associated with **all** adverse outcomes

Recognising Autism in Institutional Settings

Ruth shared powerful insights from her work in deinstitutionalising care environments. She found that **around 90% of individuals referred for psychological or mental health support showed signs of autism**, yet had never been diagnosed. Instead, many had received **misdiagnoses** such as schizophrenia, bipolar disorder, or personality disorders, and were often labelled as "difficult."

These individuals—sometimes called the "lost generation"—are found across all sectors of society, not just in mental health or intellectual disability services. Common patterns in their histories include:

- **Trauma**
- **Overmedication (polypharmacy)**
- **Long-term institutionalisation**
- **Restrictive practices (e.g., seclusion, restraint)**
- **Lack of communication support, especially for the 30% who are non-speaking or minimally speaking**

On a hopeful note, Ruth emphasised that adapting environments—both socially and physically—can lead to transformative outcomes. She referenced autistic researcher Luke Beardon's model:
Autism + Environment = Outcome

With the right support, settings, and understanding, lives can be dramatically improved—and Ruth's team has seen this in action.

Neurodivergence in Older Adults: Insights from Autistic Healthcare Workers

Sandra Guidon, Project Support Officer

Florence's Story: Misdiagnosis Across Generations

Florence reflected on her mother's life and her own, both shaped by misdiagnosis. Her mother, diagnosed with chronic paranoid schizophrenia in the 1960s, was institutionalised and heavily medicated—yet Florence now believes she was likely misdiagnosed.

> "**She wasn't paranoid. She was kind, generous, and deeply connected to people's stories,**"

Florence said. Her mother's distress often surfaced as repetitive behaviours, not psychosis.

Florence herself was diagnosed with borderline personality disorder 22 years ago, despite meeting only part of the criteria.

After multiple suicide attempts and years of emotional struggle, she was re-diagnosed in 2023. Her psychiatrist apologised, and Florence is now tapering off medication to rediscover her true self.

She wonders if her mother might have been neurodivergent, not mentally ill. "**We just don't know enough yet,"** she said, highlighting the need for better understanding and diagnosis—especially for women and older generations.

Diagnosed at 70: Una's Journey to Self-Understanding

Una shared her powerful story of being diagnosed as autistic at age 70. Her journey began in 2016 after reading The Complete Guide to Autism Spectrum Disorders. The signs felt deeply familiar, and a follow-up online test confirmed her suspicions. Despite initial dismissal from her GP, Una persisted—attending a Trinity College autism conference where she connected with Dr. Mary Doherty and the Autistic Paddies community.

Within weeks, she participated in a research study on female autism. After a thorough assessment, she was told, "**There's no doubt. You really are.**" The diagnosis brought immense relief and clarity, reframing decades of misinterpretation, including a breakdown in her 20s and years of therapy.

Una reflected on family traits—intense focus, autonomy, and a nonverbal great-aunt who used sign language—as signs of undiagnosed autism across generations. Her story highlights how late diagnosis can bring healing and understanding, even after a lifetime of feeling "different."

Irish Gerontological Society

Neurodivergence in Older Adults: Insights from Autistic Healthcare Workers

Sandra Guidon, Project Support Officer

Reaching Undiagnosed Older Adults

A key question emerged: How do we reach neurodivergent older adults who don't yet know they're neurodivergent?

The answer lies in:
Building awareness through community and research.

Using robust screening tools like the Autism Quotient (AQ) and RAADS-R, which capture both masked adult traits and childhood signs.

Investing in data-driven projects, similar to Ireland's successful ADHD screening initiative, to secure funding and develop services.

Adopting a holistic view of neurodivergence—not separating ADHD and autism, but understanding them as part of a shared developmental pathway.

To watch the lecture in full please click here

WATCH NOW

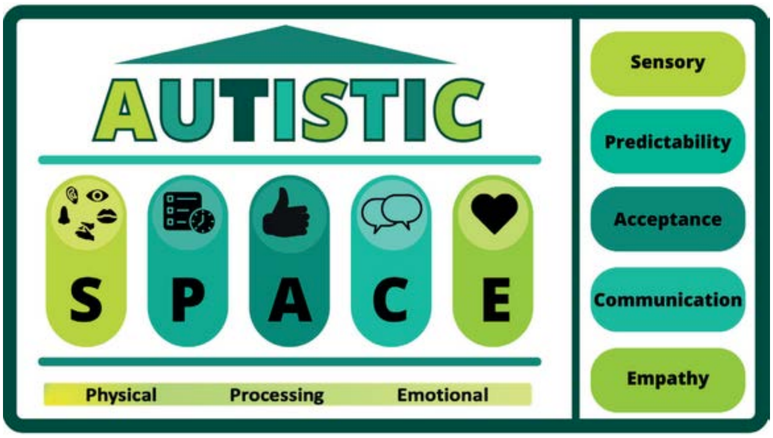
This lecture was a standout moment in the IGS series, offering both professional insight and deeply personal reflection.

It underscored the importance of inclusive, evidence-based approaches to aging and neurodiversity, and the transformative potential of listening to autistic voices from within the medical community.

‘Autistic SPACE’- Implementing a Rights-Based Neurodivergent Approach to Disability Services

Dr. Paula Prendeville, Senior Psychologist, Brothers of Charity Cork

The landmark Autistic SPACE framework, developed by Professor Mary Doherty and Autistic Doctors International (ADI), offers healthcare systems a valuable tool for promoting equitable access to clinical services for autistic individuals. It highlights five core needs—**Sensory, Predictability, Acceptance, Communication**, and **Empathy**—and emphasises the importance of supporting autistic people in relation to their physical, processing, and emotional spaces.



Developed from the lived experiences of autistic doctors, the SPACE framework offers a neuroaffirmative, rights-based approach to care. Adopted system-wide by the Brothers of Charity Services in Cork, it provides a shared language to support inclusive, person-centred healthcare for autistic and neurodivergent individuals across the lifespan.

The Autistic SPACE framework supports key principles of the UN Convention on the Rights of Persons with Disabilities, such as inclusion, accessibility, and rights-based policymaking. Its implementation also advances the UN Sustainable Development Goals.

The link to the article on Autistic SPACE is available here

SPACE is an accessible framework that fosters shared understanding and cohesive teamwork to meet the healthcare needs of autistic and neurodivergent individuals. Grounded in lived experience, it supports teams in taking collective responsibility for inclusive, person-centred care, while also improving the accessibility of planning documents and practices.

One key initiative is the development of a one-page accessible SPACE profile, designed using universal design principles with support from the HSE’s Innovation Sparks team. This tool helps identify individual needs across each SPACE domain, ensuring autistic and neurodivergent voices are central to healthcare planning. Openly available, the profile has been widely valued by teams and individuals alike for its impact on inclusive decision-making.

‘Autistic SPACE’- Implementing A Rights-Based Neurodivergent Approach to Disability Services

Dr. Paula Prendeville, Senior Psychologist, Brothers of Charity Cork

Person supported collaborating on their SPACE profile

Autistic Doctors International supported our proposal to use either Autistic SPACE or Neurodivergent SPACE, depending on individual needs and preferences, to promote inclusive application of the framework. It captures people’s voice, will, and preferences, and is adaptable across disability and healthcare contexts. Informed by Design Thinking, SPACE has been embedded into new processes that consistently centre the person’s voice, build autonomy, and support decision-making. The “My Voice and Supporting Me to Make Decisions” document illustrates how SPACE documents and respects individual preferences, while also helping teams create neuroaffirmative environments and ensure transparent, person-led decision-making.

SPACE is showing positive outcomes in Children’s Disability Network Teams (CDNTs), with children and young people reporting that the SPACE profile helps them express their neurodivergent needs in a clear and empowering way. It supports collaborative planning with clinicians to ensure safe, inclusive practices in educational settings.

By bridging health and education, SPACE promotes integrated care. Autistic youth also shared that using Neurodivergent SPACE helped reduce stigma and fostered a more affirming experience.

The SPACE framework is supporting seamless, collaborative transition planning between Brothers of Charity CDNTs in Cork and local Adult Disability Services. It enables a consistent, person-centred approach that captures voice, will, and preference. With its accessible, shared language, SPACE has the potential to support planning across the lifespan—including in employment and other settings.

you can download the document here

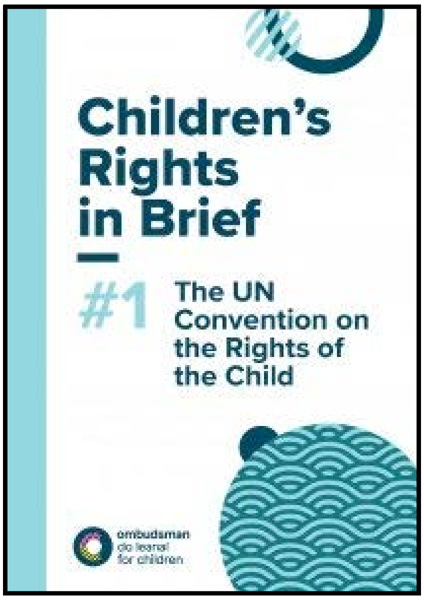
What’s Next for SPACE?

The implementation of the SPACE framework continues to gain momentum:

- It has been shortlisted for two national HSE Spark Awards: Best Patient Access and Best HSCP Led Award.
- A young adult from our service will co-present a keynote with Dr. Mary Doherty at the Autism European Congress in Dublin this September, sharing her experience with Autistic SPACE.
- In partnership with Innovation Sparks and Autistic Doctors International (ADI), the one-page SPACE profile is now openly available, along with guidance and sample profiles for wider adoption.
- ADI is exploring broader implementation of Autistic SPACE across healthcare to improve access and reduce barriers for autistic individuals.
- Two SPACE-related abstracts will be presented at the Autism European Congress in Dublin this September, in collaboration with ADI and Dr. Mary Doherty. These will highlight SPACE as a successful organisational change in disability services and its role in supporting adults with intellectual disabilities and high-risk needs.

Children’s Rights Briefing Papers for Legislators, Civil and Public Servants

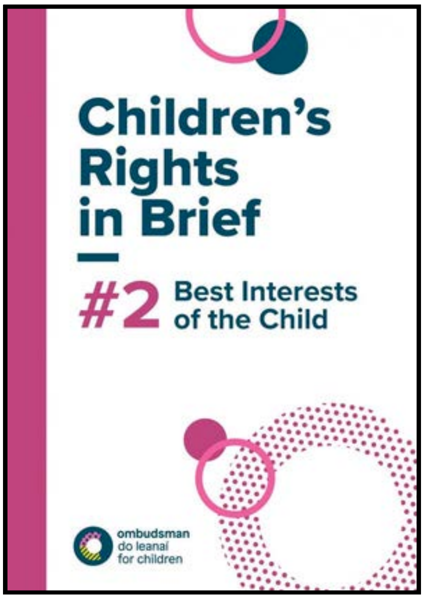
Sandra Guidon, Project Support Officer



Children’s Rights in Brief

#1 The UN Convention on the Rights of the Child

ombudsman do leanaí for children



Children’s Rights in Brief

#2 Best Interests of the Child

ombudsman do leanaí for children

Children’s Rights in Brief

#3 Respect for the views of the child

ombudsman do leanaí for children

The Ombudsman for Children’s Office (OCO) has taken a significant step toward strengthening the understanding and implementation of children’s rights in Ireland. Through a new series of briefing papers, the OCO aims to support legislators, civil and public servants in integrating the principles of the UN Convention on the Rights of the Child (UNCRC) into their daily work.

The UNCRC is the most widely ratified human rights treaty in the world, outlining the civil, political, economic, social, and cultural rights of children. While Ireland has made notable progress in this area, the OCO believes that more can be done to ensure that children’s rights are fully respected and upheld in all areas of public life.

These resources are designed for legislators, civil and public servants—anyone whose work affects children, directly or indirectly. By providing clear, accessible guidance, the OCO hopes to embed a child rights-based approach across all sectors of public service.

In addition to these educational efforts, the OCO is calling for the full and direct incorporation of children’s rights into Irish domestic law. This would ensure that children’s rights are not just aspirational but legally enforceable, offering stronger protections and accountability.

The OCO encourages all relevant departments and agencies to review and share these briefing papers widely. By doing so, we can collectively work toward a society where every child’s rights are understood, respected, and upheld.

These briefing papers can be found on the OCO website here

ombudsman do leanaí for children

Webinar’s worth a watch

Sandra Guidon, Project Support Officer

The National Safeguarding Office, in collaboration with the Disability Umbrella Groups Safeguarding Reference Group, recently hosted a thought-provoking webinar on Financial Autonomy—a topic of growing importance in the landscape of disability rights and safeguarding.

This joint initiative brought together experts, advocates, and community voices to explore how individuals with disabilities can be better supported in managing their own finances, making informed decisions, and exercising greater control over their economic lives.

Key Highlights:

Understanding Financial Autonomy: The webinar opened with a discussion on what financial autonomy means in practice, especially for people with disabilities. It emphasized the right to make financial decisions and the importance of accessible financial education.

Safeguarding vs. Empowerment: Speakers addressed the delicate balance between protecting individuals from financial abuse and empowering them to take control of their own financial affairs.

Click here to watch the webinar in full

WATCH NOW

Real-Life Experiences: Attendees heard powerful stories from individuals with lived experience, shedding light on both the challenges and successes in achieving financial independence.

Tools and Resources: The session also introduced practical tools and strategies for families, carers, and professionals to support financial autonomy in a respectful and person-centred way.

This webinar is part of an ongoing commitment by both organizations to promote dignity, choice, and control for people with disabilities. It was a collaborative effort, supported by the National Disability Services Association, DFI, and the National Federation of Voluntary Service Providers.

📣 **Just a Reminder!**

Irish Hospice Foundation

If you missed our colleages in the Irish Hospice Foundation recent **“On Your Mark, Get Set, Plan Ahead!”** webinar series, now’s the perfect time to catch up!

These sessions were designed to help individuals and families plan for the future with confidence, covering essential topics like decision-making, financial planning, and safeguarding supports.

✅ Practical advice
✅ Real-life stories
✅ Tools to help you take the next step

🎥 Watch the recordings anytime and start planning your future today!

You can watch the series HERE

WATCH NOW

National Federation of Voluntary Service Providers
Supporting people with intellectual disability (CLG)

dfi

National Disability Services Association
Equality through Quality

Little Journeys, Big Comforts: UHW Launches Child-Friendly Hospital App

Sandra Guidon, Project Support Officer

Navigating a hospital visit can be daunting—especially for children and their families. That's where Little Journey steps in, revolutionising the way young patients experience healthcare. Designed with empathy and innovation, Little Journey is a digital esupport app that prepares, supports, and empowers families before, during, and after medical procedures.

University Hospital Waterford (UHW) launched the new app designed to ease the hospital experience for children undergoing elective procedures or blood tests. Developed in collaboration with UK-based company Little Journey, the app offers a virtual tour of UHW's Paediatric and Theatre departments, helping children and their families become familiar with the hospital environment before their visit.

The initiative, led by nurse specialists from UHW's Paediatric and Theatre departments, aims to reduce anxiety and better prepare young patients for their hospital journey. The app also includes interactive games to distract children during procedures and provides useful information for parents.

To promote the launch, staff hosted an information stand in the hospital on Monday, May 26th

University Hospital Waterford staff at the launch

What Is Little Journey?

Little Journey is a customizable mobile app that offers:

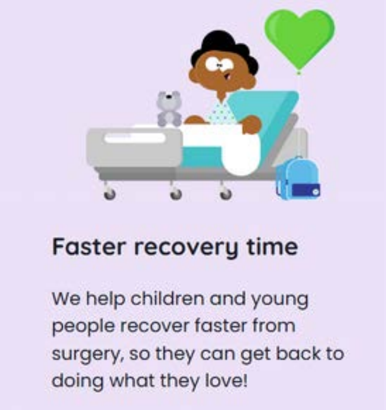
- Virtual hospital tours to familiarize children with the environment.
- Bite-sized educational content tailored by age, procedure, and hospital.
- Distraction and soothing activities to help manage anxiety.
- Accessibility-first design, including support for neurodiverse children.

All content is co-created with children, families, and healthcare professionals to ensure it's engaging, inclusive, and effective.

Tailored for Every Hospital Healthcare providers can easily configure the app's content through a web portal, ensuring it aligns with their unique patient pathways. Whether it's a routine procedure or a complex treatment, Little Journey adapts to meet the needs of every child.

Little Journeys, Big Comforts: UHW Launches Child-Friendly Hospital App

Sandra Guidon, Project Support Officer



Faster recovery time

We help children and young people recover faster from surgery, so they can get back to doing what they love!

Why It Matters

The impact of Little Journey is profound:

- 42% reduction in on-the-day cancellations.
- 30% less time spent in recovery.
- 22% reduction in the need for premedication.
- 97% satisfaction rate among families.

Studies demonstrate reduced anxiety in children. Fewer missed days of school/work.

These outcomes not only improve patient well-being but also enhance hospital efficiency and reduce costs.

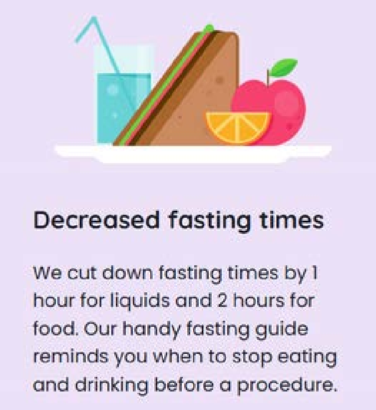
Reduced anxiety

We have reduced anxiety for children and their caregivers in multiple studies with our at-home learning and preparation support.

A Brighter Future for Pediatric Care

By reducing anxiety and improving communication, Little Journey helps children return to their daily lives faster and healthier. It's more than an app—it's a compassionate companion on every child's healthcare journey.

> **Thank you so much for developing such an amazing app!! I used it for my 4-year-old daughter's journey through surgery at Ipswich Hospital. She's so anxious usually and this app was like a magic wand! She knew exactly what to expect and completely got into the role of the patient! Absolute god send Thank you"**



Decreased fasting times

We cut down fasting times by 1 hour for liquids and 2 hours for food. Our handy fasting guide reminds you when to stop eating and drinking before a procedure.

> **We used the Little Journey app to help a 9 year old girl recently who was very anxious and has autism. Her previous procedures have been a real challenge due to this. After the patient downloaded and used the app, it was a much less stressful situation, simply due to the immersive distraction she experienced from playing with the app**

Download the app from Google Play or find it in your Appstore

Welcome to Little Journey

Supporting all children to better health through personalised care.

We believe that by providing engaging, interactive and age-appropriate content designed to psychologically prepare and support families throughout healthcare interactions, we can improve healthcare experiences and health outcomes for all.

Hello, How are you?

Sandra Guidon, Project Support Officer

Our colleagues in Mental Health Ireland held a heartwarming morning event on 21st May 2025 in the Recovery Village, Kalladreen, Co. Wicklow.

The event focused on a tea, coffee, and meaningful conversations approach as they brought people together to celebrate “Hello, How Are You?” Day — a national campaign encouraging open conversations about mental health and emotional well-being.

[Click here to find out about the national campaign](#)

Mental Health Ireland

H: Hello E: Engage L: Listen L: Learn O: Options

Attendees of the event in The Recovery Village

This event was a chance to pause, connect, and check in with one another in a welcoming and supportive environment.

Whether you were a local resident, a visitor, or part of the Recovery Village community, your presence mattered.

Check out the website to see all other Hello, How are You? events.

Mental Health Commission Launches Public Consultation on Surveillance in Mental Health Services

Sandra Guidon, Project Support Officer

The Mental Health Commission (MHC) has officially launched a public consultation to gather views on the use of surveillance technologies in mental health services across Ireland.

This initiative, open until July 16 2025, aims to inform the development of a new Code of Practice that will guide the ethical and effective use of surveillance tools in inpatient mental health settings.

Why This Matters

Surveillance in mental health services—such as the use of CCTV, body-worn cameras, infrared sensors, alarms, and GPS trackers—is a sensitive and complex issue.

While these technologies can enhance safety and support care delivery, they also raise critical concerns about privacy, dignity, and human rights.

Currently, the use of surveillance is governed by Regulation 25 of the Mental Health Act 2001 (Approved Centres) Regulations 2006, which primarily addresses CCTV use.

However, with rapid technological advancements and evolving care environments, the MHC believes it is time to revisit and expand these guidelines.

The Code of Practice is for those working in services and to promote, encourage and foster high standards and good practices in this area.

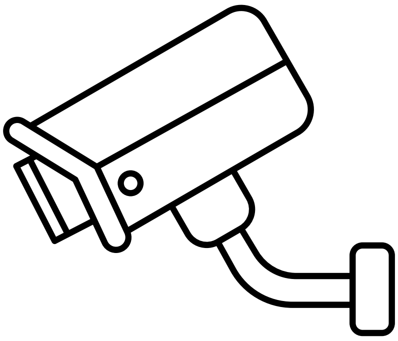
The Mental Health Commission want to hear from you, particularly if you are;

- A service user of mental health services
- A family member, loved one, friend of a service user
- Working in inpatient or community mental health care settings
- Working with a relevant organisation
- A member of the public

The public consultation will close at 5pm on 16 July 2025.

What's Next?

The Code of Practice will initially apply to inpatient mental health services, with the potential to expand to community mental health services and residences as the MHC's regulatory remit grows.



To be part of this consulation, please visit this link: HERE

Mental Health Matters: A Creative Call for Equality and Inclusion on World Mental Health Day 2025

Barbara Brennan, Mental Health Matters

The **Mental Health Matters 2025 National Poster Competition** invites individuals, community groups, and organisations from across Ireland to use creativity as a tool for inclusion, awareness, and advocacy — with entries now open until Sunday, July 13th.

This national campaign, proudly supported by An Post, the HSE National Office of Human Rights and Equality Policy, Mental Health Reform, The Samaritans, Suicide or Survive, and sponsored by Nua Healthcare Services, is part of Ireland's official programme for **World Mental Health Day 2025**. It aims to spark open conversations about mental health through the universal language of art — and ensure those conversations reflect the richness and diversity of the communities we live and work in.

Centring Equality, Accessibility, and Diverse Voices

At the heart of this initiative is a commitment to equality, accessibility, and the representation of all people — including those often left out of national campaigns. Entrants are encouraged to explore mental health through their own lived experience and cultural lens, with space for stories and perspectives from across society: older people, young people, ethnic minorities, LGBTQ+ individuals, people with disabilities, carers, mental health service users, and anyone passionate about mental health. By engaging people in creative reflection — from schools to community groups, health and social care settings to advocacy networks — the campaign seeks to inspire not just beautiful artwork, but also meaningful connection and change.

A National Celebration of Creativity and Inclusion

The winning posters will be unveiled at a high-profile celebration in Dublin on **September 25th**, ahead of World Mental Health Day on October 10th. The launch will showcase the selected designs, which will then be distributed nationwide by An Post and other partners, helping communities across Ireland to engage in powerful conversations about mental health.

Free Resources and Support for Entrants

The competition is **free to enter,** and a full suite of accessible campaign information is available on the official campaign website.

This is not just a contest — it's a national invitation to ensure that **everyone's voice can be seen and heard** in our mental health narrative.

Enter Now – Deadline Extended

To allow more time for schools and community groups to get involved, the deadline has been extended to **Sunday, July 13th.** Whether you're creating as an individual, representing a community, or supporting someone to share their vision — this is your opportunity to be part of something bigger.

EXTENDED

Visit the campaign website today to take part in a movement for mental health, equality, and inclusion.

MHM
MENTAL HEALTH MATTERS

Dementia Information Day

Nicola Lucey, Community Worker, HSE South West

The Cork North and East Community Work Department, HSE Southwest working in partnership with The Alzheimer Society of Ireland and The North Cork Dementia Alliance organised a Free Community Dementia Information Day on Thursday the 10th of April at the Firgrove Hotel, Mitchelstown.

The information day consisted of presentations from both professionals and persons living with dementia. The day provided an opportunity for people living with a dementia diagnosis and their carers to access key information on the community-based supports and advocacy services available to them. Presenters included:

- Charlie Drake - Living with a diagnosis of Dementia
- Ann Cunningham - Family Carer
- Dr Emma Jennings - Consultant Geriatrician
- Yildiz Jennings- Team Leader, HSE Southwest- Assisted Decision Making
- Amy Murphy - Dementia Advisor Alzheimer Society of Ireland
- Sheena Cadoo - Occupational Therapist- North Cork Dementia Alliance
- Fermoy Singing for the Brain Performance
- Exercise for the Brain- North Cork Dementia Alliance

The event featured a variety of Information stands and advocacy support several organisations Including:

- Singing for the Brain Ireland
- The North Cork Dementia Alliance
- TASK Community Care
- Cork County Council -Older persons council
- HSE Safeguarding- ADM
- Cork County Library Services
- SAGE Advocacy
- The Alzheimer Society of Ireland
- Walker Hearing
- Mitchelstown Social Hub
- Ballyhoura Rural Services
- Age Action
- Cork County Library Services
- Mitchelstown ETB
- Culture Companions
- An Garda Siochana- Community Policing

Sorcha Ni Chrualaoich, Principal Community Work, HSE Southwest, expressed here enthusiasm: “We were delighted to be able to bring this Dementia information Day to North Cork, building on the success of previous events held in Cork City and County. These events are made possible through collaboration between the HSE and our community and voluntary partners. We hope that they will be beneficial to local families living with a diagnosis of dementia”.

Attendees of the Dementia Information Day

Dementia Information Day

Nicola Lucey, Community Worker, HSE South West

Ann Cunningham, who cares for her husband Tom, highlighted the significance of attending the event: “We hope that the various topics discussed will provide knowledge and comfort to both carers and people with dementia.”

An event attendee shared their experience:

> **It was a very well organised and interesting event. My mother has recently been diagnosed with Dementia and the information I received today has been invaluable**

The Dementia Information Days are open to anyone living with a diagnosis of Dementia, family carers, home helps (Health Care Support Assistants), professionals or those with an interest in learning more about Dementia.

For further information and support in North Cork contact the Dementia Advisor, Alzheimer Society Ireland or the North Cork Dementia Alliance.

Some of the informative and interactive displays at the event

Attendees at the Dementia Information day

For further details please phone 086 4668484 or email Nicola.Lucey2@hse.ie

Fermoy Community Health Project

Cork College of FET
Cork's Further Education & Training Service

Empowering Future Midwives: Building Confidence in Consent Practice Through Education

Emily Moffatt, Teaching Fellow, School of Nursing and Midwifery, TCD

The School of Nursing and Midwifery at Trinity College Dublin was pleased to welcome Elaine McCaughley, Programme Lead for the National Consent Policy, for a dedicated session with Higher Diploma Midwifery students. These students, already qualified nurses, are on track to register as midwives this September

Understanding Consent in Maternity Care

Elaine's session focused on how midwives can apply the HSE National Consent Policy in their practice, particularly within the unique context of maternity care. Students explored the complexities of obtaining valid consent while upholding women's autonomy and supporting informed decision-making during pregnancy, labour, and birth. The session concluded with a discussion of real-life scenarios that midwives may encounter, emphasizing the importance of clear, compassionate communication and respect for women's choices.

In maternity care, where decisions often affect both the woman and her unborn baby—and may need to be made urgently—these principles are especially critical.

Building Knowledge and Confidence

This was the students' first dedicated session on the HSE Consent Policy and its practical application. Prior to the session, knowledge levels varied. While most students had a general understanding of consent principles from their nursing training, only 10% felt confident applying the HSE Consent Policy in practice. One-third were unaware of the policy altogether.

After the session, all students reported increased confidence in navigating consent in clinical settings. They particularly valued the scenario-based discussions and appreciated receiving guidance from a professional outside the midwifery field.

Student Voices

"I think it gave me a bigger perspective on this matter and helped me understand more."

"Think more about everyone's situation, and have in mind things I wouldn't have considered."

"Feel more comfortable to deal with complicated situations."

Supporting Women's Rights and Choices

A strong understanding of consent empowers midwives to advocate for women's choices—even when those choices diverge from standard guidelines. The session reinforced that valid consent is more than a signature; it involves ensuring women have the information, time, and freedom to make informed decisions without pressure or judgment.

The overwhelmingly positive response from students underscores the value of targeted education on consent. This foundational knowledge will support them throughout their careers and enhance the care they provide to women and families.

Click here to contact Emily Moffatt, Teaching Fellow, School of Nursing and Midwifery, Trinity College Dublin

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Assisted Decision-Making Mentorship programme

Emma Mullins - ADM Mentor

Mentor experience - Emma Mullins

Year 2 of the ADM Mentorship programme commenced in November 2024 and together with my Co-mentor, I started out my journey as a Mentor for this programme. The ADM Mentorship programme was a new journey for me. The National Office of Human Rights and Equality and our Mentorship training colleagues Aileen and Cathy provided support and guidance. Monthly mentor catch ups provided us with various tools in coaching, mentoring, emotional intelligence including the skill of “reading the room” and the “art of active listening.

This year the programme incorporated an integrated approach to include membership of the Acute and Community Healthcare area and this has been instrumental in providing an opportunity to network, share experiences and explore best practices in supporting decision making. This collaboration provides a safe space for mutual learning for the group to form a circle of support for each other. The diverse group of professionals fosters a culture of empowerment and peer support as we acknowledge a combined desire to enhance our knowledge, skills and competence in Assisted Decision Making.

To date my experience as a Mentor is rewarding and motivating as my confidence in mentoring has grown and as the group dynamics have evolved. There is a shared view that we are better equipped to advocate and support our Patient’s and Service Users to enhance their decision-making.

Assisted Decision-Making Mentorship programme

Michelle Angland, ADM Co-ordinator

Mentor experience

The HSE mentorship programme has provided guidance for the people I support and resources that support the service I work in. The meetings are always focused on applying the guiding principles. Look at how we can enable, encourage and support the people we all work with to build their capacity, increase knowledge and be supported in decision making .

In year 2, I am now a mentor on the programme, and I'm so delighted my co mentor is the mentor I had in year 1. I learned so much from her on the role of a mentor in year 1 by observing how everyone in the group was included and how everyone's opinion was valued. The change to have co mentors on the programme has been so supportive. I really value the planning we do together and the support and guidance it provides me. Our year 2 group is for Kerry only, so we meet in person. This affords the opportunity to network, and the group are working in such a variety of various settings in both community services and acute services. The learning is rich, and I have learned so much this year from the expertise in the room and have a fresh perspective of the ADM Act.

Contact Us
adm.mentorship@hse.ie

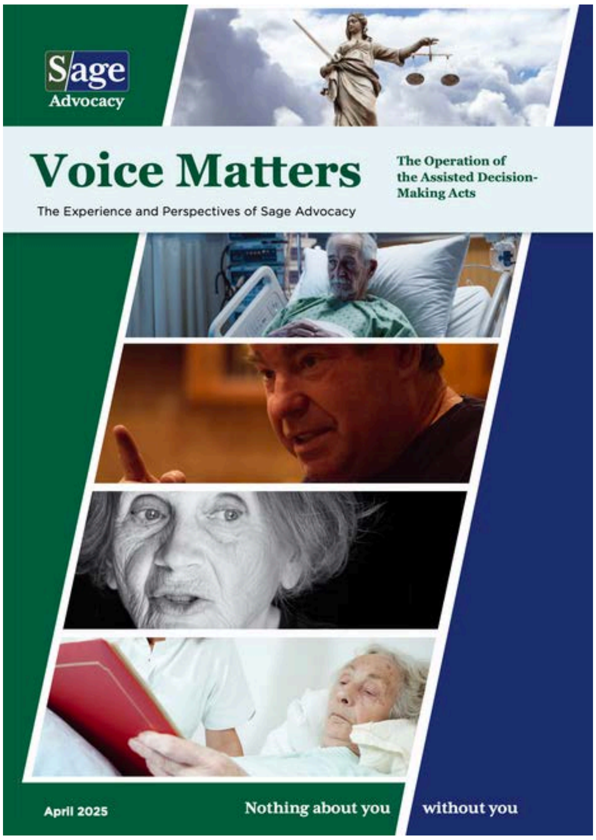
Voice Matters: A Report on the Assisted Decision-Making Act in Practice

Bibiana Savin, CEO, Sage Advocacy

Sage Advocacy has published a two-year review of the Assisted Decision-Making (Capacity) Act 2015, titled **Voice Matters**: The Experience and Perspectives of Sage Advocacy. The report examines how the Act is working in practice, highlighting successes, challenges, and areas for improvement to ensure a truly rights-based, person-centred approach.

Rooted in the motto "**Nothing About You, Without You**," the report shows how independent advocacy plays a vital role—especially in Part 5 DMRO applications—by ensuring the person's voice is heard, even if they cannot attend court.

By March 2025, Sage Advocacy had received 993 DMRO-related referrals and submitted 581 reports to the courts. These reports aim to convey the relevant person's voice and their wishes and preferences on specific decisions, while also identifying relevant values, beliefs, and the people they would trust to support them. This helps courts uphold the Act's Guiding Principles by placing the person at the heart of proceedings.



Sage Advocacy

Voice Matters

The Experience and Perspectives of Sage Advocacy

The Operation of the Assisted Decision-Making Acts

April 2025

Nothing about you without you

Bibiana Savin, CEO, Sage Advocacy

Key Themes

While significant progress has been made, Voice Matters stresses the need to further strengthen the voice of the relevant person through accessible structures and meaningful supports that empower individuals to make and express their own decisions — including independent advocacy where needed.

Voice Matters: A Report on the Assisted Decision-Making Act in Practice

Bibiana Savin, CEO, Sage Advocacy

Despite the Assisted Decision-Making (Capacity) Act's promise, Sage advocates report that the shift from a paternalistic "best interests" model to one based on individual rights has been slow. Two years in, significant cultural and systemic change is still needed.

Launched on May 7th in Dublin with Chief Justice Donal O'Donnell, **Voice Matters** highlights that many professionals have yet to fully embrace the Act's requirement to support people in making and participating in their own decisions.
The report shares real-world challenges, good practices, and illustrative case scenarios from Sage's advocacy work.

Issues identified:

- **Knowledge gaps:** Varying levels of understanding among legal, health, and social care professionals about ADMC principles.
- **Premature Applications:** DMROs, intended as a last resort, are sometimes initiated before less restrictive options are exhausted.
- **Overreach:** Many applications seek overly broad powers, akin to Wardship, contradicting the Act's functional approach to capacity and demonstrating a widespread misunderstanding of the guiding principles.
- **Bottlenecks:** Inequities in capacity assessment availability — particularly for private nursing home residents. Delays in DMRO processing that jeopardize continuity of care funding in addition to the worryingly slow pace of discharge from Wardship.
- **Unclear responsibilities:** Confusion persists around who should initiate DMR applications and support the relevant person to attend court particularly for individuals in the community or private nursing homes.
- **Inconsistent Court Practices:** Variations across regions, especially in areas with infrequent court sittings.
- **Inadequate Legal Representation:** Some Solicitors appointed for a Relevant Person fail to challenge inappropriate or overly broad applications. Failure to scrutinise the merits of the application, alignment with the guiding principles or conflicts of interest on the basis that the relevant person is "unable to instruct" them, undermines the relevant person's right to equal recognition before the law and effective legal support, contradicting Article 12 of the UNCRPD.

Mark Mellett, Chair of the Board of Sage Advocacy, Chief Justice Donal O'Donnell, President of the Supreme Court, Bibiana Savin, CEO Sage Advocacy

Voice Matters: A Report on the Assisted Decision-Making Act in Practice"

Bibiana Savin, CEO, Sage Advocacy

Proposals for Action

Drawing from significant frontline experience, Voice Matters outlines some key recommendations including:

- **Legislative Recognition of Independent Advocacy:** Independent advocacy should be formally recognised in legislation and sustainably funded by the State
- **Improved Professional Training:** Ongoing education for legal, health, and social care professionals is needed to embed the Act's functional, time-specific, and issue-specific approach in everyday practice.
- **Clarification of Roles & Responsibilities:** Define who is responsible for initiating DMROs and ensuring relevant persons can attend court.
- **Safeguarding Focus:** Adult safeguarding principles should be integrated into all ADMC-related interventions.
- **Discharge from Wardship:** The Wards of Court Office should ensure that all Wards are given the necessary supports they require to enable them to avail of the review process including independent advocacy and independent legal representation.
- **National Stakeholders' Forum:** Establish an independently chaired forum for ongoing collaboration among key agencies to tackle issues stemming from fragmented, 'siloed' systems across services.
- **Formal Review:** Sage calls for an urgent Government review of the Act, as promised in the Programme for Government.

A copy of Voice Matters can be viewed here

Working together: Collaboration is Key

Voice Matters highlights the strong benefits of collaborative working. Joint visits involving professionals—legal, financial, health, or social care—alongside an independent advocate help ensure the person understands their options and that their communication needs are met.
When professionals share insights and align with the person's will and preferences, outcomes are more respectful, creative, and person-centred. Sage Advocacy sees this joined-up approach as a powerful example of the Act's principles in action.

Sage Advocacy is Ireland's National Advocacy Service for Older People. It also supports vulnerable adults and healthcare patients when no other service can help. Sage offers free, confidential, and independent advocacy, ensuring individuals' voices are heard and their wishes respected in decisions affecting them.

Since late 2023, with support from the Department of Education, Sage has extended its services to support survivors of institutional abuse.

Guided by national quality standards, Sage operates under the motto: "**Nothing About You / Without You.**"

Sage Advocacy can be contacted at 01 536 7330, or email info@sageadvocacy.ie.

Community of Practice- Advance Care Planning in Mental Health

Dr. Jennifer Allen, PhD Senior Social Worker, & Dr. Nuala Kane, Consultant Psychiatrist

A Community of Practice for Advance Care Planning in Mental Health co-convened by Dr Nuala Kane, Consultant Psychiatrist and Dr Jennifer Allen, Senior Social Worker earlier this year, held its first online seminar on 7th May 2025.

Dr Lucy Stephenson, Consultant Psychiatrist at South London and Maudsley NHS Foundation Trust and Clinical Researcher at King's College London, was the guest speaker.

Lucy's presentation focused on the findings of a qualitative study she undertook in London on the experience of individuals with bipolar of using the PACT (Preferences and Advance Decisions for Crisis and Treatment) template. Interviews were held pre-and-post engagement, and contact with also made with the treating teams.

Lucy also outlined further research studies building on this work including the AdStAC study which focuses particularly on advance care planning for Black service users.

In the PACT study, a trauma informed approach was engaged with and participants each had experience of a previous compulsory admission. A focus upon the advance care planning process rather than outcome and building alliances with healthcare professionals was underscored.

'Risking hope' that things could be different and that engagement could positively influence future treatment was a theme. Interestingly participants were offered the option of having decision-making capacity confirmed, and all chose the capacity assessment.

Lucy's presentation and the subsequent discussion posed interesting considerations for policy and practice in the Irish context, in particular around how a person's AHD might be accessed and honoured, including through the digital landscape.

Feedback from the seminar indicated that the seminar 'enhanced knowledge of using AHDs in practice', with mixed responses on enhancing 'confidence of using AHDs in practice'.

Suggestions for future seminar topics included 'Further exploration of the use of peer support as facilitators of AHDs' and 'More effective assessment of capacity in difficult situations'.

This feedback along with feedback from the initial conference will inform the focus of the next seminar planned for the Autumn (date TBC).

The Community of Practice is open to individuals with lived experience, mental health care professionals, policy makers, and others, and interested parties can sign up by emailing nuala.kane@ucd.ie.

Understanding the Fair Deal Scheme: Support for Long-Term Residential Care in Ireland

Ultan Hynes, Head of Service, Nursing Homes Support Scheme, National Services & Schemes

The service most significantly affected by the commencement of the Assisted Decision-Making (Capacity) Act 2015 is the Nursing Home Support Scheme (NHSS), more commonly known as the Fair Deal scheme.

This article highlights the key changes introduced by the Act and their implications for applicants and healthcare professionals involved in the scheme.

When The Act, came into effect on 26 April 2023, it introduced a new legal framework for supporting adults who may lack decision-making capacity.

One of the most notable impacts has been on the administration of the NHSS, particularly in relation to applications for Ancillary State Support

Key Changes to the Scheme

Under the Act, if a person lacks the capacity to apply for Ancillary State Support, they must now have a Decision-Making Representative (DMR) appointed by the Circuit Court.

This replaces the previous system where a Care Representative could be appointed by the courts.

As a result, there has been a significant increase in DMR applications directly linked to the Fair Deal scheme

Other important changes include:

- The role of a “Specified Person”—who can act on behalf of an applicant for State Support—has been narrowed to include only close family members and certain professionals (e.g., registered medical practitioners, nurses, or social workers).
- Applications should be made using the current NHSS - application form, which reflects these legislative changes.

What is Fair Deal?

- Fair Deal is a financial support scheme for individuals requiring long-term residential care.
- Governed by the Nursing Homes Support Scheme Act 2009.
- Co-funded by the HSE and the client, with contributions paid directly to the nursing home.
- Applicants choose their nursing home, and funding follows the resident.

Who Can Apply?

- The applicant themselves (if they have capacity).
- A Specified Person (e.g., spouse, adult child, medical/social professionals).
- A Legally Appointed Representative (e.g., under Enduring Power of Attorney or Decision-Making Representative).

When Should You Apply for Fair Deal?

Apply as soon as long-term nursing home care is being considered.

- Early application helps avoid delays in funding.
- You can apply even while waiting for legal documents (for example DMRO).
- Submit your completed application form to your local Nursing Home Support Office

Application Process

There are four parts in the application process:

- Care Needs Assessment
- State Support Application
- Ancillary State Support (optional nursing home loan)
- 3-Year Cap on Family Farms/Businesses (optional)

Applications are submitted to your local Nursing Home Support Office.

Understanding the Fair Deal Scheme: Support for Long-Term Residential Care in Ireland

Ultan Hynes, Head of Service, Nursing Homes Support Scheme, National Services & Schemes

Financial Assessment

The weekly client contribution is calculated as follows:

Contributions based on income and assets:

- Single person: 80% income, 7.5% assets
- Couple: 40% joint income, 3.75% joint assets

Asset disregards and allowable deductions may apply.

HSE pays the remainder of the nursing home cost.

Ancillary State Support (Nursing Home Loan)

- Optional loan for those who wish to postpone paying the weekly contribution based on their land or property assets.
- Based on property value at time of application (e.g., family home).
- Loan repaid after a Relevant Event (e.g., death of client, sale of property).
- The loan is repaid to Revenue Commissioners.
- Reason for most DMRO applications to date.

For more details, visit www.hse.ie/nhss or contact HSELive at 1800 700 700.

Further Deferral of Loan Repayment

- Available for Principal Private Residence loans only.
- The applicants spouse or a connected person, must apply for a further deferral within 3 months of the applicant's death.
- Repayment must be made 6 months from date of sale of PPR or 12 months from date of death of deferral grantee.

3-Year Cap on Farms/Businesses

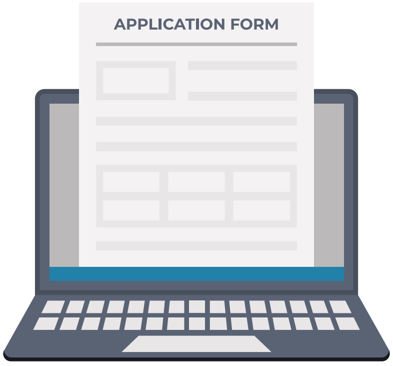
- An application can be made to extend the 3-year cap benefit to family farms and businesses.
- Requires appointment of a Family Successor and meeting eligibility criteria.

Entitlements & Obligations

- NHSS provides financial support only.
- Contract of Care must be signed with the nursing home.
- Applicants have the right to appeal decisions and request financial reassessment.

You can get an Application Form from: Your local Community Care Office or NHSO Online at the [hse.ie](hse.ie)

The website – also has information to help you through the process



Please see key steps flyer below from the NHSS

Fair Deal Key Information for Applicants

What is Fair Deal?

Fair Deal (Nursing Homes Support Scheme – NHSS) provides financial support to people who require long term residential care. The person contributes towards the cost of their care and the HSE pays the balance.

Who should be informed about Fair Deal?

Anyone who may need long term residential care should be informed about Fair Deal.

Who can apply?

People who require long term residential care can apply. A designated person e.g. spouse or partner, legal rep, relative over 18 and certain healthcare professionals can assist someone who is unable to apply themselves; ***full details of designated persons are on the application form and at: www.hse.ie/nhss***

KEY STEPS

A person must apply for Fair Deal using the NHSS Application form. This is available on www.hse.ie/nhss, from a local Nursing Homes Support Scheme Office or from HSE Live.

CARE NEEDS ASSESSMENT:

A person must be assessed as requiring long term residential care. This assessment will be arranged by HSE staff once a Fair Deal application is submitted.

FINANCIAL ASSESSMENT:

A person's income, cash assets and property will be assessed to calculate their weekly contribution towards the cost of their care. Use the check list on the application form to make sure that you have included all required supporting documents.

SINGLE PERSON:

For a single person this is normally **80% of income and 7.5% of cash and fixed assets, less a €36,000 disregard.**

MEMBER OF A COUPLE:

This is normally **40% of income and 3.75% of cash and fixed assets, less a €72,000 disregard.**

This is a basic overview of the financial assessment. Each person will be individually assessed to allow for other allowable expenses or charges.

ANCILLARY STATE SUPPORT

(also called Nursing Home Loan):

If someone e.g. a home owner needs assistance paying the part of the weekly charge generated by their property, they can apply for a loan.

This loan is generally paid back from the person's sestate after death.

Answers to key questions

- The applicant (or their representative) chooses their preferred nursing home (HSE, private or voluntary).
- Fair Deal is available to everyone who requires long term residential care, including people under 65 or people who do not own a property.
- A person's home is only included in the financial assessment for a period of 3 years. This cap can extend to a farm or business in certain circumstances.
- If a person's financial contribution is calculated at €200 per week, this is what they will pay, regardless of whether the nursing home charge is, for e.g. €770 per week or €1,050 per week. The HSE pays the balance.
- Applicants/families should visit the nursing home prior to the person moving in and review the contract of care agreement.
- The nursing home loan can be paid back at any time and is normally collected from a person's estate after their death. If their partner or certain other family members are still living in the home, they can apply for a deferral and the loan can be collected from their estate after their death.

Further information from

1. **www.hse.ie/nhss**
2. **Your local Nursing Homes Support Scheme Office** *(details on www.hse.ie/nhss)*
3. **HSELive Freephone: 1800 700 700, Monday to Friday: 8am to 8pm Saturday and Sunday: 9am to 5pm**

This information provides a quick summary of Fair Deal. This can be a difficult time for applicants and their families. There is a lot of helpful information on the website, in the information booklet, and staff in the Nursing Home Support Offices who can support people with the application process. All details on www.hse.ie/nhss

Discharge from Wardship & Assisted Decision-Making (Capacity) Act 2015

Alice White, Registrar of Wards of Court

Minister O'Gorman signed the commencement order for Assisted Decision-Making (Capacity) (Amendment) Act 2015 (ADMCA) on Wednesday 26th April 2023.

The Decision Support Service became operational on 26th April 2023 and the Wards of Court Office ceased accepting new wardship applications on 25th April 2023.

The Wards of Court Office has now received 656 discharge from wardship applications. Discharge orders have been made in 136 cases (as of 30th May) and the current number of declared adult wards of court is 1,748.

In January and February 2024, the Registrar of Wards of Court and the General Solicitor ran a series of information sessions on discharge from wardship for legal practitioners to assist with the discharge application process.

In addition to various online awareness raising events, the Wards of Court Office organised a series of multi-agency in-person events for 2025. These included two in Dublin and one in Tullamore, Cork and Galway. Representatives from the Wards of Court Office, Decision Support Service, National Advocacy Service, Legal Aid Board and National Disability Authority attended each of the in-person events for wards of court and committees. These were very successful in terms of reaching those who did not participate in online awareness raising events.

The office also continues to recruit medical practitioners as a Court medical visitors to complete functional capacity assessments. Any medical practitioners (not limited to psychiatrists) can apply to become a medical visitor for the President of the High Court through wocmedicalvisitors@courts.ie

While applications for discharge remain below the levels expected and indicated through survey results, the Wards of Court Office continues to work towards its statutory requirement to have all adult wards of court discharged by April 2026.

To assist with the discharge process, the office has submitted applications for Legal Aid on behalf of all wards of court who have yet to submit a discharge application. The office is writing to all wards of court and committees to inform them of this and provide a choice of taking up the legal aid certificate and selecting their own solicitor or the office will list the matter before the court for directions.

Multi-Agency In-person event

Ciaran Finlay-National Disability Authority, Eleanor Leane-Legal Aid Board, Suzie Yorke-Wards of Court Office, Kate Frowein & Joanna Macklen-Decision Support Service

Open Dialogue to support better outcomes in mental health

Dr Emer Rutledge, Consultant Psychiatrist, Open Dialogue Clinical Lead & Michelle Darcy, Senior OT, Project Manager Louth Mental Health Services

Over the last seven years in Meath Louth Mental Health Services, we have successfully introduced a new model of care called Open Dialogue.

This transformational change first began in the Navan team in 2018. Since then, the practice has extended to three other community mental health teams in Drogheda, Dundalk and Ashbourne. We now have 24 mental health professionals, across all disciplines (including three consultant psychiatrists), trained and working in this way.

Open dialogue is both a therapeutic intervention and a way of organising services. It is a form of therapeutic engagement with patients and families which was developed during the 1980s in Finland's Western Lapland region (Alanen et al. 1991).

It is currently the subject of a large randomised controlled trial in the NHS. The results of which are to be expected later this year.

It is an integrated approach incorporating principles of systemic family therapy and psychodynamic principles. In essence, open dialogue promotes a network perspective, bringing together both social and professional networks to provide continuity of psychological care across the boundaries of traditional services.

It encourages the patient and family to meet immediately and frequently after referral to openly explore acute mental health crises. The network, comprised of the person of concern, a family member or members and two mental health practitioners, trained in open dialogue, become the decision makers together. We have found through our experience of working this way, that patients and families truly value the network meetings as a response to their crisis situation.

We encourage polyphony within the network meetings, allowing the voices of all participants in the meeting to be heard and to have equal standing.

We do not seek consensus or agreement, simply a shared understanding of the problem by the network. We work as an inter-disciplinary team.

In keeping with the transparency of the model, all professional discussions take place within the network, in the presence of the person of concern, not at team meetings or elsewhere.

This includes discussions about risk or treatment plans. This ensures that the person of concern can be an active part of the decision making process, at all times.

Open dialogue gives the patient the space to consider what they really want and the role of the clinicians is to respond to that; that is to be directed by the views and wishes of the person using the service. Thus, the whole intervention aims to promote respect for the decisions, values and priorities of the person involved.

Open Dialogue attempts to promote the patient's potential for self-exploration, self-explanation and self-determination.

To find out more about Open Dialogue contact: Emer.Rutledge@hse.ie

or michelle.darcy@hse.ie

Open Dialogue to support better outcomes in mental health

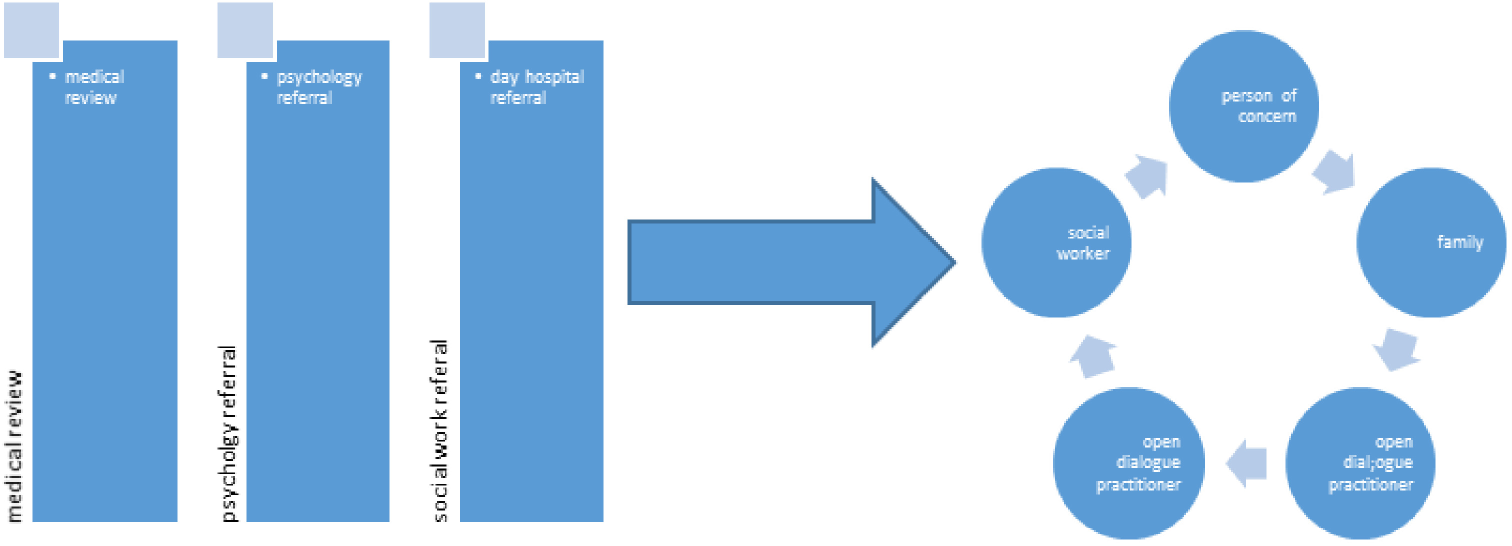
Dr Emer Rutledge, Consultant Psychiatrist, Open Dialogue Clinical Lead & Michelle Darcy, Senior OT, Project Manager Louth Mental Health Services

The seven principles of open dialogue as outlined in box 1 illustrate the priorities of the service in adhering to this model of care.

Open Dialogue is an organisational intervention as much as it is a treatment built on building social networks, dialogue and relationships. It is inherently a psychotherapeutic approach thus facilitating the delivery of psychotherapy to the person of concern from the very first point of contact. This is unlike the traditional model of care which tends to be a transactional exchange of knowledge and often the patient is referred on to another discipline, for example, psychology or a day hospital to avail of a psychotherapeutic intervention. This way of working is a significant change in treatment approach for the mental health professional, one that requires training, ongoing supervision and a reflective practice.

System	Language (Skills)
Immediate help	Tolerance of uncertainty
Social network perspective	Dialogue
Flexibility & Mobility	
Responsibility	
Psychological Continuity	

The pathway of the person of concern and their family through the system is both simplified and more effective. In moving from the traditional individualised discipline orientated approach to an integrative network approach, (see diagram a), the delivery of care is more cohesive for the patient and their family. Sometimes it is the system we work within, which hampers our ability to treat our patients optimally.



From individual assessments & treatment

To a network approach Diagram a

Recent Events

UNCRPD- from rights to realisation

Caoimhe Gleeson, General Manager, National Office for Human Rights and Equality Policy participated in a panel discussion on 'Exploring the UNCRPD- from rights to realisation' which followed the AGM of the Disability Federation of Ireland (DFI) in June 2025.

The session was brilliantly chaired by Emer Begley, Director of Advocacy with DFI. Panel members included Dr. Mary Keogh, International Disability Advisor, Advocate and Mediator and Colm O'Conaill, Assistant Secretary, Department of Children, Disability and Equality.

Elaine Teague, Caoimhe Gleeson, Mary Keogh, Colm O'Conaill

Caoimhe Gleeson, Monika Kobylarska , Paula Leonard

Alcohol Forum Ireland- Awareness raising on Alcohol Related Brain Injury (ARBI)

Alcohol Forum Ireland recently held an early coffee morning in Letterkenny, Co. Donegal to raise awareness of the abject lack of services and pathways of care and support for people with an Alcohol related brain injury in Ireland.

Alcohol Forum Ireland are still accepting donations as they work to lobby for bespoke and tailored services for people with alcohol related brain injury, their families and their circles of support.

Click here to donate

Recent Events

Aine Flynn, DSS and Caoimhe Gleeson, National Office for Human Rights and Equality Policy

Civil Service Excellence and Innovation Awards

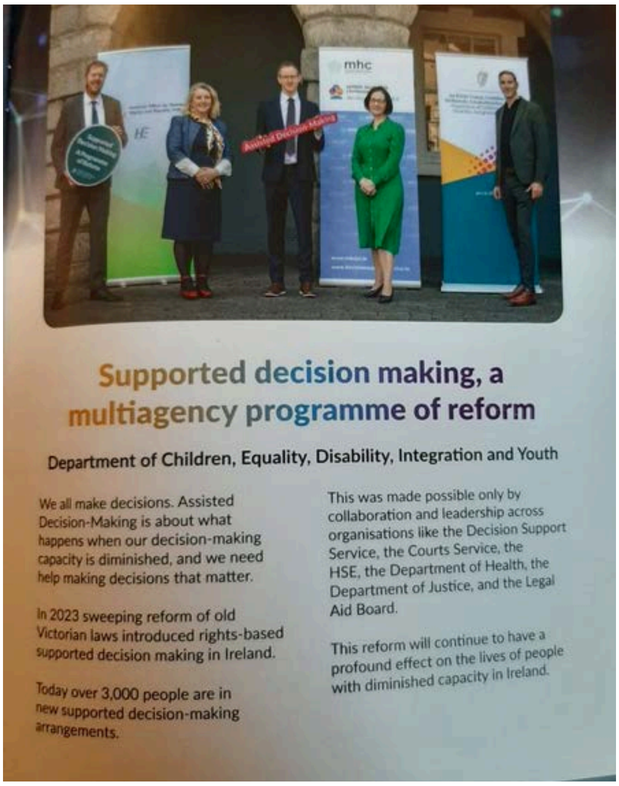
It was a great privilege to be shortlisted by the Department of Children, Disability and Equality and to be further shortlisted for the Civil Service Excellence and Innovation Awards in Dublin Castle in May 2025.

The project 'Supported Decision-Making- a multi agency project of reform' brings together the Departments of Health, Justice, Disability, Equality and Children, the Mental Health Commission, the Decision Support Service, the Courts Service, the Office of the Wards of Court and the Legal Aid Board to collaboratively work through changes brought by the commencement of the Assisted Decision-Making (Capacity) Act 2015.

To watch a video on the project click here

WATCH NOW

John Gilbane, Niall Brunell, Caoimhe Gleeson, Aine Flynn, James Kelly



Supported decision making, a multiagency programme of reform

Department of Children, Equality, Disability, Integration and Youth

We all make decisions. Assisted Decision-Making is about what happens when our decision-making capacity is diminished, and we need help making decisions that matter.

In 2023 sweeping reform of old Victorian laws introduced rights-based supported decision making in Ireland.

Today over 3,000 people are in new supported decision-making arrangements.

This was made possible only by collaboration and leadership across organisations like the Decision Support Service, the Courts Service, the HSE, the Department of Health, the Department of Justice, and the Legal Aid Board.

This reform will continue to have a profound effect on the lives of people with diminished capacity in Ireland.

Jacqui Browne, Disability Activist- A Tribute

It is with great sadness that we remember our friend and colleague Jacqui Browne who sadly passed away on June 23rd 2025.

Jacqui represented the Disabled Person's Organisation on the HSE ADM Oversight Group and was an active contributor to our webinars and conferences.

As an experienced disability advocate and activist she provided advice and guidance to many groups and organisations at both a national and local level for decades. She played a pivotal role during the Covid-19 Pandemic in challenging the exclusion of the voices of disabled people in the public health responses to the pandemic. She reminded us to always ensure disabled people are central to discussions about their own lives and to always check our ableist assumptions.

In March this year Norma O'Donnell interviewed Jacqui as part of our 'Spotlight' series where she shared her thoughts on what mattered to her. Little did we know then that we would be remembering her legacy in this edition. We have included a link below to the spring edition for those who wish to read Jacqui's own words.

We will greatly miss her energy, friendship, sharp wit and love of the Atlantic ocean. Our thoughts and prayers are with her family and friends at this difficult time.

Ar dheis Dé go raibh a hanam.

See our Spotlight Series Interview with Jacqui HERE