An Oifig Náisiúnta um Chearta
an Duine agus Beartas Comhionannaiser

National Office for
Human Rights and Equality Policy

Human Rights and Equality Matters

Spring 2025

Highlights in this edition:

NAS/PAS: Launches Casebook 2024

Advance Planning made easy: Insights from the DSS

Spotlight Series: Jacqui Browne

Functional Capacity of Assessment Training: Update

Opening the Umbrella of the Assisted Decision-Making (Capacity) Act 2015 to Include Litigation; A Summary of the decision In the matter of the Assisted Decision-Making (Capacity) Act 2015 and in the matter of JD

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National Office for Human Rights and Equality Policy

Welcome

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

As the days grow longer and the flowers begin to bloom, we welcome you to the spring edition of ***Human Rights and Equality Matters***. We continue to move forward in the spirit of the Assisted Decision-Making (Capacity) Act 2015 promoting equality and human rights for all.

As the Decision Support Service (DSS) approaches their second anniversary, Aine Flynn updates us on their progress. Aine reports that the demand on DSS services increases every day with a growing need for information and support.

Jim Lane shares his insights on the recent Future Planning Event led by the Decision Support Service (DSS) in Cork. He highlights the invaluable one-to-one sessions provided by the DSS staff, which focused on creating an Enduring Power of Attorney (EPA).

Our ***spotlight series*** continues in this edition, with an interview with Jacqui Browne Disability Advocate and campaigner. Jacqui's dedication to advocating for the rights and inclusion of people with disabilities continues to inspire and drive positive change.

Joanne Haffey provides an update on the HSE ***In-Person Training for Functional Assessment of Capacity.***

Joanne Condon, National Manager, National Advocacy Service for people with disabilities shares insights from the ***Casebook 2024***. This publication, created in collaboration with the Patient Advocacy Service, highlights key cases and developments in advocacy for people with disabilities.

Valerie Smith, Public Engagement Lead, Irish Hospice Foundation introduces us to the ***Think Ahead programme***, and shares information regarding webinars currently running for anyone considering Advance Care Planning. So far, two webinars have taken place, with two more to come.

Jacqueline Grogan highlights a recent training event for healthcare professionals on ***Assisted Decision-Making, Considerations for Mental Health Services*** which was held at the Trinity Centre for Health Sciences in Tallaght University Hospital.

Sandra Guidon provides a comprehensive overview of the ***Courts Service*** website, offering guidance for anyone seeking assistance with navigating the site, specifically in relation to the Assisted Decision-Making information. Sandra also shares information on the new ***European Accessibility Act (EAA)*** which comes into effect 28th June 2025

Elaine McCaughley shares an article based on research examining ***DNA-CPR practice and policy***. She also gives an update on the progress of the policy on Do Not Attempt Cardiopulmonary Resuscitation (DNA-CPR).

Norma O'Donnell provides an overview of the ***Decision Support Service (DSS) Register*** and steps out how to access the DSS register. Additionally, Norma gives an up on the ***Revision of National Guidelines on Accessible Health and Social Care Services.***

Welcome

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

We hear from PJ Herlihy who has recently exited the wardship legal regime. PJ shares his experience of becoming a ward of court and finally exiting wardship in 2025.

Patricia Rickard-Clarke, Chairperson, Safeguarding Ireland highlights the importance of making an ***Advanced Healthcare Directive.***

Caroline Howorth, Speech & Language Therapy Manager at St. Michael's House highlights best ***practice when undertaking a Functional Assessment of Capacity when supporting a person with a disability.***

Joe Nelis, Social Work Team Leader in Donegal, updates us on a series of ***ADM-focused workshop-based learning events***. These workshops aim to build confidence and knowledge among Social Workers, helping them integrate the Assisted Decision-Making Capacity Act 2015 into their daily practice.

Emer O'Shea, Community Engagement Manager at Inclusion Ireland provides an article on a recent self-advocacy event for the release of a training programme for people with intellectual disabilities titled ***Speak Up, Speak Out!*** Emer also shares information on ground breaking research published by Inclusion Ireland ***Exploring the need for a Representative Advocacy Service for Children with Intellectual Disabilities in Ireland.***

Dr. Nuala Kane, Consultant Psychiatrist and Dr. Jennifer Allen, Senior Social Worker guide us through the conference held at UCD which was funded by the HSE Spark Innovation Fund titled ***"Advance Healthcare Directives for Mental Health – from Law to Practice"***

Catriona Sneddon highlights a recent decision of the Circuit Court in her article, ***"Opening the umbrella of the Assisted Decision-Making (Capacity) Act 2015 to include litigation; A summary of the decision 'In the matter of the Assisted Decision-Making*** (Capacity) Act 2015 and in the matter of JD'." She provides a detailed summary of the case, highlighting its implications and the broader impact of the decision for people whose decision-making capacity is in question.

Dr. Clíona de Bhailís invites ***Individuals who communicate in unique ways, along with their supporters, to participate in a research project on Ireland's new Capacity Act.*** This project aims to explore how the Assisted Decision-Making (Capacity) Act 2015 can be utilized by those who use non-traditional forms of communication.

Winifred Ryan, HSE National Healthcare Communication program directs us to new training available for all HSE staff, available on the HSE website.

We hope you enjoy reading our newsletter. Thank you for being part of our community. Together, we can continue to make a difference in advancing human rights and equality for all.

Subscribe to our mailing list to stay up-to-date on all things Human Rights & Equality Matters

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Update from the Decision Support Service

Aine Flynn, Director of the Decision Support Service

Now approaching our second anniversary as an operating service, the DSS is busier every day across all our statutory functions under the Assisted Decision-Making (Capacity) Act 2015.

The demand for information continues. January and February have surpassed all other months in terms of calls answered- over 5,000 during these months- by the combined Information Services and dedicated enduring power of attorney (EPA) helpdesk.

EPAs continue to account for well over 50% of the decision support arrangements on the DSS register. At the end of February of 2,850 registrations, 1,840 were EPAs, with a further 1,952 submitted for review and registration. However, only a small number of these EPAs (45) have moved to the second stage of notification, so that the attorney as moved into the role of decision-maker.

Ideally the number of notifications should be low, as it means that in the relatively short time since registering their EPA with the DSS, the donor has already lost capacity in relation to decisions covered by the EPA. It is hoped that as people embrace advance planning and recognise that it is not something to postpone until late in life or until health issues arise, the gap between making an EPA and needing an EPA will become longer. Advance planning is the key theme of the DSS's public information campaign for this year.

Approximately 850 active decision-making representation orders made by the wardship court and Circuit Court are now on the register. We have 81 registered co-decision-making agreements and 75 decision-making assistance agreements with many more in progress.

Please note that our statistics are published on the DSS website. Click HERE to access DSS Arrangement Statistics

We are continuing to work with the HSE on the roll-out of automated access to our registers. 16 organisations are now set up to search the register in this way. In the meantime, enquiries relating to the register may still be sent to registersearches@decisionsupprtservcie.ie

The DSS has now closed out the second phase of recruitment to the panel of decision-making representatives and two training events are planned for April for new and existing members.

Our busy schedule of engagements with diverse stakeholders has continued. In recent weeks, the DSS has met and delivered presentations to banking and financial services professionals- including a standing meeting with the Vulnerable Customer Units of the main banks, health and social care colleagues, disability services providers and, very importantly our potential service users and their families and carers.

Update from the Decision Support Service

Aine Flynn, Director of the Decision Support Service

At the end of January, the DSS contributed to an in-person event for wards of court and their committees and families, organised by the Office of Wards of Court, to demystify applications for discharge from wardship under Part 6 of the 2015 Act.

In mid-February, the DSS attended the regular online check-in with the HSE ADM Leads team. These events are mutually beneficial, allowing the DSS a vital insight into the implementation of the 2015 Act in practice and an opportunity to answer questions and sometimes correct misunderstandings.

We ran a well-received two-day in-person event in Ballincollig in February in partnership with the HSE ADM service from the Cork-Kerry Community Healthcare Team, whose local support was invaluable.

The focus of the event was advance planning and the DSS team provided information and practical support with applications to members of the public and legal practitioners. A similar event will take place in Portlaoise on 8 and 9 April.

Booking is essential and information is available on our website by clicking on the link

Book Your Place

We are now looking forward to further collaborative events to mark our second anniversary at the end of April.

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

Aine Flynn
Director of the Decision Support Service

Click HERE to access DSS website.

Read below for further information on the Cork/Kerry event on Advance Planning

seirbhís tacaíochta
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decision support service™

Advance Planning Made Easy: Insights from the DSS Event

Jim Lane, Principal Social Worker
Quality, Safety & Service Improvement Quality and Safety Department

The Decision Support Service, supported by HSE SouthWest Assisted Decision-Making CKCH Team, hosted a Future Planning Event in Cork to help and support people to plan ahead. This event took place in the Oriel Hotel in Ballincollig over the 18th and 19th of February 2025 and was a huge success, with attendance exceeding expectations.

The event focused on the practical steps required to create an Enduring Power of Attorney (EPA), including one-to-one sessions with staff from the Decision Support Service (DSS).

The two day event commenced with a public information session, where the Director of the DSS, Ms Aine Flynn, addressed over 150 attendees.

Aine introduced the key reforms under the Assisted Decision-Making (Capacity) Act 2015, the guiding principles, the new support framework, the tools for advance planning, and the functions of the DSS.

The session particularly focused on Advance Planning and the promotion of Enduring powers of Attorney.

On the second day over 12 Decision Support Service staff facilitated a one-to-one ‘EPA Helpdesk Day’.

The team met professionals, including solicitors and members of the public and supported attendees in setting up a DSS account and start their own individual EPA application.

Yildiz Jennings, Aoife McMahon, Jim Lane

Appointments lasted 40 minutes approximately and spaces were allocated via pre-booking, with some places being made available on the day, or booked the night prior.

The professionalism and kindness shown by the DSS team were exemplary and helped ensure that approximately 50 new EPA’s were started on the day.

We look forward the Decision Support Service Team visiting Cork or perhaps Kerry during their next visit to the HSE SouthWest. Having seen the process first hand we encourage all HSE staff to complete and assist others with whom they work or know to commence this process.

We encourage everyone to educate themselves on the process and to seek clarity what is needed to start an application. If attending a future event, please read below for what to bring on the day.

Advance Planning Made Easy: Insights from the DSS Event

Jim Lane, Principal Social Worker
Quality, Safety & Service Improvement Quality and Safety Department

What you need to think about and bring with you to a DSS Future Planning Event

The DSS information services and registration teams will be on hand to show applicants how to register with the DSS online and to start your own individual EPA application.

Attendees must bring along their MyGovID login details or, if you do not have a verified MyGovID account, the DSS teams can verify your identity manually. Please bring the following required support documents:

- One photo ID (current and in date)
- Two proofs of address (dated within the last six months)

Should you require further information on which support documents to bring to verify your identity manually, the DSS Identity Verification form on their website lists accepted documents and the criteria these documents must meet.

In preparation for starting your own EPA application, you will also need to consider some important questions and have some information with you on the day. Please click on the DSS link Checklist to make you EPA ready.

You are welcome to bring your own laptop if you wish on the day and the DSS team will show you how to access the MyDSS portal on your own device.

The next DSS planning ahead event to take place is Portlaoise

Evening information session: Tuesday 8 April 2025

- Where: The Killeshin Hotel & Leisure Club, Portlaoise
- Time: 6-7pm
- Partners: The Lions Club, Portlaoise

EPA helpdesk day: Wednesday 9 April 2025

- Where: The Killeshin Hotel & Leisure Club
- Time: 12 noon to 6pm
- Partners: The Lions Club, Portlaoise

To book your place at these events, click on this link: Book your place

Alternatively, you can Freephone **(01) 211 9750** and ask for the EPA helpdesk; or email EPAhelpdesk@decisionsupportservice.ie and indicate your preferred location.

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CORK KERRY COMMUNITY HEALTHCARE

Spotlight Series - Championing Disability Rights

Norma O'Donnell, ADM Project Manager

Jacqui Browne - A Personal Journey

In this edition of our Spotlight series, I had the pleasure of speaking with a dedicated advocate for human rights and disability rights, that is Jacqui Browne. A lifelong champion for inclusion, Jacqui has worked tirelessly to challenge systemic discrimination and advance equality.

A Lifelong Passion for Human Rights

Born with a disability, Jacqui has experienced first-hand the challenges of accessibility and inclusion in Irish society. Growing up in the beautiful County Kerry as one of five children, she was fortunate to be raised in a supportive environment. However, it was through lived experiences and the influence of key disability rights leaders like Donal Toolan that her passion for advocating for systemic change truly took root.

> **My lived experience of disability, as a result of thalidomide, certainly informed my advocacy around disability as a human rights issue for the last 35 years**

Over the years, she has witnessed the gradual shift from the outdated medical model of disability, which viewed disability as a personal tragedy or deficit, to a social and human rights approach. Today, Jacqui's focus remains on ensuring that disability rights are recognised as fundamental human rights.

The Importance of the Assisted Decision-Making Act

A key milestone in disability rights, the Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act) has played a pivotal role in ensuring autonomy and dignity for individuals with disabilities. She highlights the repeal of outdated concepts like wardship as a crucial step in affording people the right to make their own decisions, with or without support.

Additionally, Jacqui emphasises the importance of enduring powers of attorney and advance healthcare directives as essential tools for personal autonomy.

The DPO Network

The DPO Network is an alliance of five national Disabled Persons' Organisations (DPOs) in Ireland.

> **We work together to help ensure that the UN CRPD in Ireland is fully implemented**

The five DPO member organisations outlined by Jacqui are:

- As I Am – Ireland's National Autism Advocacy Organisation
- Disabled Women Ireland (DWI)
- Independent Living Movement Ireland (ILMI)
- Irish Deaf Society (IDS)
- National Platform of Self Advocates

The DPO Network represents disabled people's lived experiences, expertise and analysis and is led and informed by the active input of disabled people. Their input provides a unique opportunity for an analysis of the issues faced by disabled people that truly covers all areas of society.

Spotlight Series - Championing Disability Rights

Norma O’Donnell, ADM Project Manager

Jacqui Browne - A Personal Journey

The DPO Network is committed to the human rights and social models of disability. This model says that the exclusion, inequality, and discrimination that disabled people experience is not because of a person’s disability but due to economic, cultural, social, and political barriers that continue in society.

Sailing the High Seas

Beyond Jacqui’s advocacy, she has also charted a remarkable course in the world of sailing. From single-handed dinghy sailing to tall ships and transatlantic crossings, she has logged countless nautical miles. A highlight of her maritime adventures includes participating in the Clipper Round the World Yacht Race in 2009/2010.

Progress Still Needed

While the 2015 Act is a significant legislative step forward, Jacqui acknowledges that much work remains. The transition away from wardship has been slow, with many individuals and their families struggling to navigate the change. She believes that more on-the-ground support is needed to build trust and understanding, particularly for older caregivers who may feel overwhelmed by the new system.

A Legacy of Achievements in Disability Rights

Throughout Jacqui’s career, she has been a key figure in Ireland’s disability rights movement. One of her proudest accomplishments was her role in the establishment and membership of the Commission on the Status of People with Disabilities, which ran from 1993 to 1996. The commission's 402 recommendations helped shift Ireland’s approach to disability from a medical perspective to one rooted in equality, rights and social inclusion. This work laid the foundation for vital legislative advancements, including employment equality laws and broader human rights protections.

Spotlight Series - Championing Disability Rights

Norma O'Donnell, ADM Project Manager

Jacqui Browne - A Personal Journey

How Others See Jacqui

When asked how Jacqui's friends and colleagues would describe her, she says her friend described her as "a person for strategic change, with an eye on the bigger picture but also acutely focused on detail." She is seen as warm, funny, and passionate about bringing people together to move things forward. She embraces leadership roles but is equally committed to ensuring that other disabled people are supported in stepping into key positions.

Jacqui's journey is a testament to the power of advocacy, resilience, and the belief that meaningful change is always possible.

> **A very important mantra for us as a disabled persons organisation is: Nothing about us, without us**

A New Beginning: My experience leaving Wardship

PJ Herlihy

PJ at the HSE Assisted Decision-Making Conference Cork

At a recent conference, in collaboration with University College Cork and the Decision Support Service, we discussed the dissolution of the wardship regime. During this event, we had the privilege of hearing from PJ Herlihy, who was in the process of exiting wardship, accompanied by his supporter, Michelle Angland from St. John of Gods Service in Kerry. Since the conference PJ has now been discharged from Wardship.

We are delighted that PJ shares his journey in his own words about his transition from wardship in this article. He tells the story of how he became a ward of court, the impact on his life, his campaign to leave wardship and what has now happened since his High Court hearing in January 2025. His story is one of optimism and resilience as he navigates the steps towards greater autonomy. PJ recounts his experience in his own words.

Hello, my name is PJ Herlihy. I am 63 years old and was born in Knocknagoshel, Co. Kerry. As an only child, I have no brothers or sisters. My educational journey took me to Cork, where I shared a dormitory with eight other people.

After spending many years in Cork, I moved back to Tralee in 2003 to join the Saint John of God service. I am proud to have my own apartment in Tralee town and to work at Garvey's supermarket, a job I truly enjoy because I love meeting people.

My life took a significant turn in 1997 when I was involved in a car accident and became a ward of court. Following the accident, I went to court and received compensation, which was managed by my solicitor in Dublin. Additionally, when my mother passed away in 1997, the money from our house and farm in Knocknagoshel was also sent to Dublin.

Now, all my money is managed in Dublin. If I need access to it, the staff must contact my solicitor who will send the money to me. I use this money for various needs, such as buying clothes, Christmas presents, going to a hotel in Killarney, or getting something nice for my girlfriend.

Understanding what it means to be discharged from wardship was challenging for me, so I had some easy-read material developed to help me understand the steps involved in the process. When the discharge process began, a social worker visited me to discuss my money, health, and apartment. After a few months, a doctor also visited to assess my situation. He spoke with me and the staff from Saint John of God about my health and finances, and asked about my future hopes and plans post-discharge.

Click to view some pictures of PJ's journey exiting wardship

> **I am proud to have my own apartment in Tralee town and work at Garvey's supermarket, a job i truly enjoy because i love meeting people**

A New Beginning: My experience leaving Wardship

PJ Herlihy

PJ & his girlfriend AnnMarie outside court the day of exiting Wardship

Once discharged, I will no longer need to deal with my solicitor in Dublin. I plan to find someone new to help manage my money, hoping it will be easier to access my funds. I met with a solicitor twice in Tralee, who explained the doctor's report to me and my support staff. Since I can't read, I need extra time with the staff from Saint John of God to understand what is happening.

> “I think it’s good that if I need help, I will have support from the staff, my friends and my new solicitor”

Click here to watch PJ’s Story from our Conference

I received a social story explaining the report, which indicated I needed someone new to help me with certain decisions. I had a video call with my committee, and it was nice to see her for the first time. She explained what would happen in court in Dublin.

My support staff informed me that the report recommended a co-decision maker to assist with my health, finances, and welfare. On January 28th, I traveled to Dublin with my girlfriend and a staff member from Saint John of Gods. At the High Court, I was officially discharged from wardship. The judge spoke to me and made me feel very welcome. I saw on a TV screen a new person who will now help me with my decisions. My support staff told me he is a solicitor based in Killarney and will be my Decision-Making Representative. Although I find this a bit confusing, I am looking forward to meeting him and seeing how things will work with my money.

To celebrate my discharge from wardship, we enjoyed a lovely dinner in Dublin. This week, I received a letter from the court detailing the court's decision. I think it's good that if I need help, I will have support from the staff, my friends, and my new solicitor.

PJ with Michelle Angland, St. John of Gods at HSE Assisted Decision-Making Conference Cork

> “Once discharged, i will no longer need to deal with my solicitor in Dublin.”

> “Understanding what it means to be discharged from wardship was challenging for me, so i had some easy-read material developed to help me understand the steps involved in the process”

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

Joanne Haffey, ADM Senior Project Manager

The HSE National Office for Human Rights and Equality Policy are delighted to announce commencement of the roll-out of the In-Person Training on Functional Assessment of Capacity. This training is for assessments required under the Assisted Decision-Making (Capacity) Act 2015 (herein the 2015 Act).

The provisions of the 2015 Act are applicable to all adults and it has particular relevance in disability, mental health and older person's services. Functional assessments of capacity are required to put in place all of the following decision support arrangements in the 2015 Act:

- **Part 4 Co-Decision Making Arrangement**
- **Part 5 Decision-Making Representation Order**
- **Part 7 Enduring Power of Attorney**

The Training Day:
The in-person training is an interactive day with a focus on practice and skill development relevant to functional assessments of capacity. It is a 'hands - on' experience using role plays throughout the day, presentation of video simulations of practice, group discussions and documentation.

The day covers the requirements and steps that assessors need to consider and take in all the following areas: preparation for undertaking an assessment including the types of decision/s to be made, consent, seeking information to be considered, how to prepare questions; the practice of undertaking the assessment with the relevant person, supports required, communication, information provided, range of questions depending on decision/s; and post assessment the completion of the required documentation - specifically the Part 5 template.

Who can attend this training?

The training applies to professionals from the prescribed classes as outlined in the 2015 Act:

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

In order to access the training professionals from the prescribed classes must work in the HSE or Section 38 and 39 organisations.

Pre- Requisite Training Requirements:

All staff from the prescribed classes must complete the Online ADM Functional Assessment of Capacity Modules.

The online training programme can be accessed here:

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

Joanne Haffey, ADM Senior Project Manager

Pilot Training Day:

On 28th February 2025 we held the first pilot of this training session in St Marys, Phoenix Park. Eighteen professionals from all the prescribed classes and registered medical doctors attended this training day. It was a successful day in that those who attended provided valuable feedback that has allowed us to strengthen and perfect the training even more.

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

Joanne Haffey, ADM Senior Project Manager

How can you access the training?

Each Regional Health Area (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	(Community) Ger Farren (Acute)	adm.dncc@hse.ie geraldinefarren@rcsihospitals.ie
Dublin South East	Sinéad Brennan	s.brennan@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	Dearbhla Ní Riordáin	dearbhla.niriordain@hse.ie
West North West	John McElhinney	John.McElhinney@hse.ie

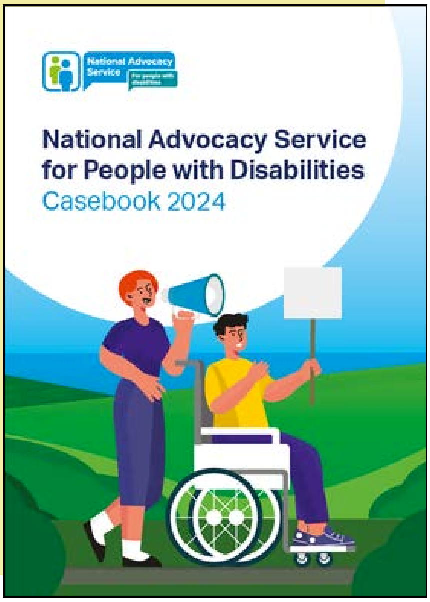
We look forward to seeing you in the training room soon!

Elevating Voices and Lived Experience of People with Disabilities: National Advocacy Service for People with Disabilities & Patient Advocacy Service - Casebook 2024

Joanne Condon, National Manager, National Advocacy Service

The National Advocacy Service (NAS) has released its third Casebook which is a compelling collection of advocacy case examples developed jointly by NAS and the Patient Advocacy Service (PAS). The Casebook has grown and developed in the last three years, giving voice to the lived experiences of those supported by NAS. This year's Casebook includes 17 case examples from NAS and 9 from the PAS. The publication details the complex case work carried out by Advocates in both services in 2024, highlighting the vital role independent, professional advocacy can play in supporting people to have their human rights protected and promoted.

Read NAS' Casebook here



National Advocacy Service for People with Disabilities
Casebook 2024

Jack's story

Voices of Lived Experience

Each Casebook offers a unique glimpse into the diverse range of complex issues that both NAS and the PAS have supported people with over the last 12 months. Each case example demonstrates how Advocates in both services help breach gaps in systems, ensure best practice across public services, promote positive systemic changes, and show how independent advocacy has a positive impact both for individuals and in communities across Ireland.

The Casebook covers a wide range of issues, including:

- **Access to justice**: Advocates help individuals navigate legal systems, ensuring fair treatment and access to legal resources.
- **Decision-making**: Support in making informed decisions, particularly for those with disabilities or those facing significant life changes.
- **Parenting with a disability**: Assistance for parents with disabilities to enable them to receive the support they need to care or their children
- **Housing:** Advocacy for fair and adequate housing, addressing issues of accessibility and discrimination.
- **Healthcare:** Support in resolving complaints, and ensuring patient safety in hospital and nursing homes.

Elevating Voices and Lived Experience of People with Disabilities: National Advocacy Service for People with Disabilities & Patient Advocacy Service - Casebook 2024

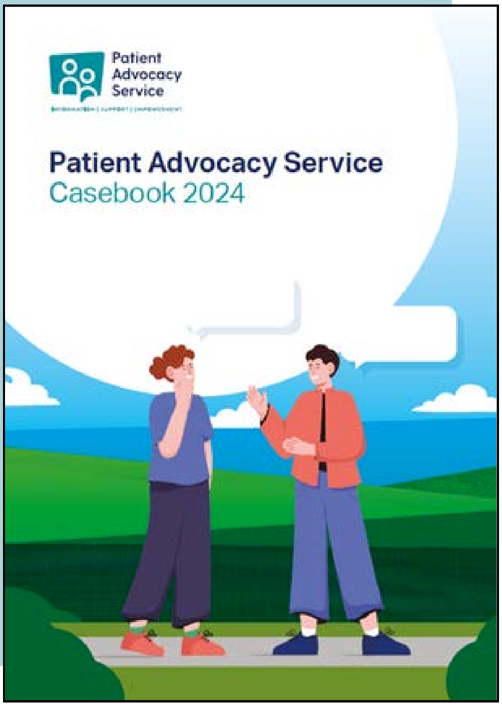
Joanne Condon, National Manager, National Advocacy Service

This year's Casebook is particularly significant as it includes a focus on assisted decision-making. The stories demonstrates how advocacy can drive systemic change. NAS has supported individuals to make their own decisions with the necessary supports. The examples demonstrate the practical application of the Act and it's potential to be transformative. Whilst the Assisted Decision-Making (Capacity) Act only came into force in 2023, already NAS is seeing that its Guiding Principles are often not being upheld, with many people rushing to seek the highest tier of support without exhausting more proportionate options. The Act emphasises the presumption that everyone has capacity until proven otherwise, which places an onus on all of society to treat people with disabilities equally as rights-holders.

NAS is dedicated to working with key stakeholders to promote progressive systemic changes across public services for people with disabilities.

This year's casebook is a testament to the value of collaboration and the critical role advocacy plays in enabling people to exercise their rights and access the supports they require.

Read PAS' Casebook here



Patient Advocacy Service

Patient Advocacy Service
Casebook 2024

Christopher and Noah's story

Patient Advocacy Service
INFORMATION | SUPPORT | EMPOWERMENT

On Your Mark, Get Set, Plan Ahead! – Webinars to Help You Plan for the Future

Valerie Smith, Public Engagement Lead, Irish Hospice Foundation

Think Ahead is a programme run by Valerie Smith, Public Engagement Lead at Irish Hospice Foundation. The programme helps you to make decisions about your care in the future, in case you can't make these decisions later because of illness, injury, or mental ill health. This is called Advance Care Planning. Sometimes people call it Future Care Planning, which I think is easier to understand, so that is what I will use here.

Lots of people think planning for the future is hard. Some people feel overwhelmed or confused by it. Other people think it is empowering, and it feels like a relief to make a plan. However you feel about planning ahead, we can help. We help you understand what your options are. We help you start conversations about your choices and decisions. We also make sure that what you decide is protected by the law.

To help you to prepare to plan ahead, we are hosting a series of webinars. Each webinar teaches you a little bit about what you need to do to plan for the future.

Your first step is to read about the webinars below. Then decide if you want to attend one, some, or all of them. Register for each one that you want to attend. After each webinar, you will be more prepared to make your very own future plan. You might also feel ready to help someone else make theirs!

Don't worry if you miss any of the webinars. We will record them and put them on our website (http://www.thinkahead.ie) and on our YouTube channel (@IrishHospice). Everyone who registers will also get an email before each webinar with helpful PDF worksheets and information. After the webinar, we will send a link to the recording.

Read about each webinar below and register for the ones you want to attend.

Visit the Irish Hospice website here

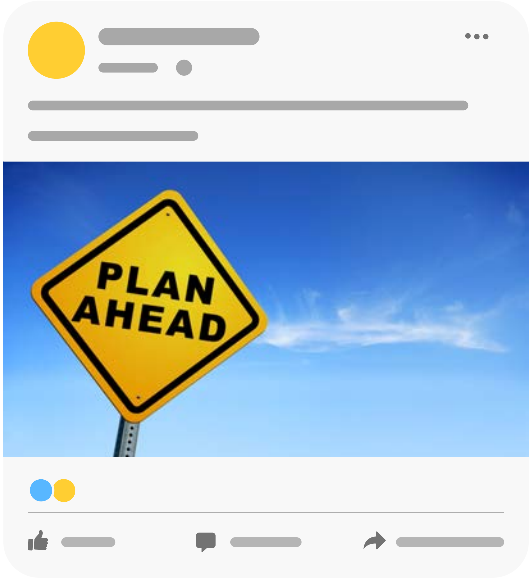
On Your Mark, Get Set, Plan Ahead! – Webinars to Help You Plan for the Future

Valerie Smith, Public Engagement Lead, Irish Hospice Foundation

Webinar 1: On Your Mark, Get Set, Plan Ahead: How to Plan for the Future.

In Webinar 1, we learned what Future Care Planning is. We learned the basics like, ‘What are my options?’ and ‘What do I need to start planning?’ We talked about Advance Healthcare Directives and Enduring Power of Attorney, among other options.

This webinar taught us how start conversations about our care for the future, even if others don’t want to listen! This webinar is a good starting point, so no, you don’t need to know anything or do anything before attending.



Click here to watch Webinar 1: On you Mark, Get Set, Plan Ahead: How to Plan for the Future

Webinar 2: Help Me to Help You: Supporting Others to Plan Ahead

Took place: Tuesday, 25th March. 10am-11am am on Zoom.
In Webinar 2, we learned the skills to help others plan ahead, like how to identify your most important values, how to discuss quality of life, and the basics of how people make healthy changes using the Stages of Change model.

This webinar was aimed at professionals, carers, and supporters. We recommend a basic understanding of Future Care Planning, so it is recommended to watch the recording of Webinar 1 beforehand.

Visit the Think Ahead website to watch Webinar 2: Help me to help you; supporting others to plan ahead

On Your Mark, Get Set, Plan Ahead! – Webinars to Help You Plan for the Future

Valerie Smith, Public Engagement Lead, Irish Hospice Foundation

Webinar 3: Future-Proof Your Health—Basic Treatment Options Explained

Tuesday 22nd April. 10am-11am on Zoom.
In Webinar 3, learn about common treatments you can include in your Advance Healthcare Directive including CPR, ventilation, IV feeding and hydration, and pain management. This webinar is aimed at the general public, as well as health and social care professionals who provide basic information to their patients and clients.

We recommend that you understand the basics of Advance Care Planning before attending this Webinar. You can attend the live session of Webinar 1 or watch the recording on our Think Ahead events page, www.thinkahead.ie. Be sure to tune in for more about choosing the right supporters in Webinar 4.

Register here for Webinar 3

Webinar 4: Build Your Dream Team: Choosing Supporters To Help You Thrive.

Tuesday 29th April, 10am-11am on Zoom. In Webinar 4, learn about what a Supporter is, and the different roles that a Supporter can have. We will explain important things to think about when you are choosing one or more Supporters. Learn about common mistakes, and ways to avoid them. We will also talk about how to protect yourself if you don't want or don't have Supporters.

Webinar 4 is open to to public, but we recommend that you understand the basics of Future Care Planning. If you missed Webinars 1 and 3, we recommend that you watch the recordings to be ready for Webinar 4.

Register here for Webinar 4

The last 15 minutes of each webinar will not be recorded, so that is your time to ask questions.

After you register, you can send us any questions about Advance Care Planning that you have. That way, we can make sure that we answer as many questions as possible during the Webinar. Send your questions to ThinkAhead@hospicefoundation.ie
We are excited to see you soon!

Navigating the Courts Service: A Simple Guide to access information on the Assisted Decision-Making (Capacity) Act 2015

Sandra Guidon, Project Support Officer, NOHREP

An tSeirbhís Chúirteanna
Courts Service

We understand that navigating the Courts Service can sometimes feel overwhelming, especially when you're looking for specific resources, such as the Assisted Decision-Making Act 2015. We have created this simple and comprehensive guide to help you find the information you need.

We will walk you through the key sections of the website in relation to the Assisted Decision-Making Act 2015, highlight some of the important resources, and provide tips on how to access them easily. Whether you're a first-time visitor or a regular user, our goal is to make you're experience as smooth and stress-free as possible.

Let's get started on making the Courts Service website work for you!

Who They Are

The Irish Courts Service is a statutory body established under the Courts Service Act 1998. It is responsible for managing the courts, providing support services for judges, and offering information on the courts system to the public.

Services Available on Their Website

The Irish Courts Service website offers a variety of online services, we are focusing on Assisted Decision-Making resources here:

- Explaining the ADMC process
- Capacity Applications and Decision-Making Representation Orders
- Procedural Information
- Legal Aid

Navigating the Irish Courts Service website can be straight forward with these tips:

Homepage: Start at the homepage, where you can find links to major sections like "Assisted Decision-Making."

Online Services: This section provides access to various online services such as Assisted Decision-Making related resources, there are forms for Capacity Applications and Decision-Making Representation Orders, Procedural Information and Legal Aid.

Search Function:

Use the search bar to quickly find specific information or services.

Help and Support:

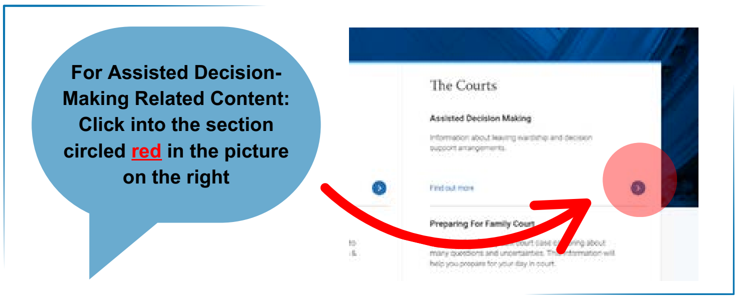
Look for help and support sections if you need assistance navigating the site

Navigating the process of Assisted Decision-Making can be complex and challenging. This section of our newsletter is dedicated to providing you with the essential information and resources you need to make informed decisions and complete Capacity applications under the Assisted Decision-Making (Capacity) Act.

The following pages will guide you through the the Courts service for all things related to the Assisted Decision-Making Capacity Act 2015 and will walk you through the key steps involved in making a Capacity application. Whether you are an applicant, a relevant person, or a supporter, you will find detailed instructions and helpful tips to assist you at every stage of the process.

Navigating the Courts Service: A Simple Guide to access information on the Assisted Decision-Making (Capacity) Act 2015

Sandra Guidon, Project Support Officer, NOHREP



For Assisted Decision-Making Related Content: Click into the section circled red in the picture on the right

The Courts

Assisted Decision Making

Information about leaving wardship and decision support arrangements.

Find out more

Preparing For Family Court

General Information about the Assisted Decision-Making (Capacity) Act

The Assisted Decision-Making (Capacity) Act 2015, (ADMC) is about supporting decision-making and making the most of a person's ability to make decisions.
At different points in your life, you may need to make important decisions about personal welfare, and property and affairs, for you or someone connected to you.

Find information below on a variety of ADMC-related topics and how they may apply to you. All information provided is for guidance only. Always check relevant legislation and court rules to ensure your understanding of the process is correct. You can find links below to information about legal advice and mediation, and other support services that may help you with your ADMC matters.

Explaining the ADMC process

What a capacity report is

A capacity report (sometimes known as a capacity assessment) is a report from a healthcare professional on the capacity of the Relevant Person. You will need one of these before you can proceed with an application.

Find out more about capacity reports.

Capacity applications and Decision-Making Representation Orders

A decision-making representation order is an arrangement to appoint a substitute decision-maker. There are many types of order. Find out which one suits your needs best.

Find out more about Decision-Making Representatives.

Getting consent of the court to make a Capacity Application

Only people with specific relationships to the Relevant Person can make Capacity Applications without court consent. Everyone else must get consent of the court first.

Find out more about consent.

What to do if you have been served with a capacity application

Learn what to do if you are the Relevant Party to a capacity application or if you are simply a notice party to the application.

Learn more about the steps you need to take.

Contact

Where you can go if you have procedural questions about the ADMC process.

Find out how to contact us.

Forms you need to complete to make a Capacity Application

There are three forms you need to complete to make a Capacity Application.

Access the forms you need here.

Procedural information

Background to the Act
What type of decision-making agreements can be put in place.

Learn about the background to the Act here.

Legal Aid

Certain parties are entitled to free legal aid as part of the ADMC process.

Learn more about the legal aid process.

Navigating the Courts Service: A Simple Guide to access information on the Assisted Decision-Making (Capacity) Act 2015

Sandra Guidon, Project Support Officer, NOHREP

After you have completed your Capacity Application forms

Who this guide is for

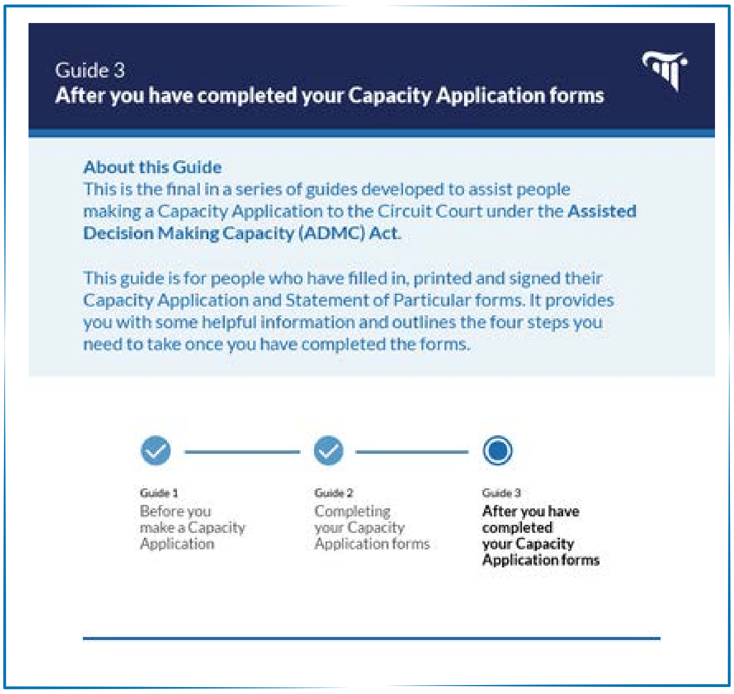
This guide is for people who have filled in, printed and signed their Capacity Application and Statement of Particular forms.

Access the guide

You can get the guide by clicking the link below.
[Guide 3: After you make a Capacity Application]

How it will help you

It provides you with some helpful information about what to do once you have completed your Capacity Application and Statement of Particular forms. This includes information to help you prepare for Court.



Guide 3
After you have completed your Capacity Application forms

About this Guide
This is the final in a series of guides developed to assist people making a Capacity Application to the Circuit Court under the Assisted Decision Making Capacity (ADMC) Act.

This guide is for people who have filled in, printed and signed their Capacity Application and Statement of Particular forms. It provides you with some helpful information and outlines the four steps you need to take once you have completed the forms.

Guide 1
Before you make a Capacity Application

Guide 2
Completing your Capacity Application forms

Guide 3
After you have completed your Capacity Application forms

What is included in this guide?

This guide provides you with some helpful information about what to do once you have completed your Capacity Application and Statement of Particular forms. This includes information to help you prepare for Court.

Information is included on the four steps outlined below, that you need to take once you have completed the forms.

Submit your Capacity application forms to the correct Court Office

- How to locate the correct Court Office
- What documents you need to submit
- What are the fees you will need to pay
- What happens when you submit your forms to the Court Office

Serve your application to the Relevant Person and Notice Parties

- Information on when and how to serve the relevant documents.
- Information on what a notice party is and who the notice parties are for a Capacity Application

After you serve your application

- Evidence of service of your application
- Response of the Relevant Person

Preparing for your Court Appearance

- Service documents you need to submit to the Court Office
- Requirements for attendance at your court hearing
- It also provides you with other sources of relevant information.

More guides on the Capacity Application process

[Before completing a Capacity Application]
[How to complete the Capacity Application forms]

Navigating the Courts Service: A Simple Guide to access information on the Assisted Decision-Making (Capacity) Act 2015

Sandra Guidon, Project Support Officer, NOHREP

Circuit Court ADMC forms

Access the most commonly-used Circuit Court form templates that can be used in Assisted Decision-Making (Capacity) Act, 2015.
It is recommended that you read the accompanying ADMC Information Guides that will help you complete the forms.

Circuit Court ADMC forms

Access the forms used in the ADMC process in the Circuit Court.

Circuit Court ADMC forms

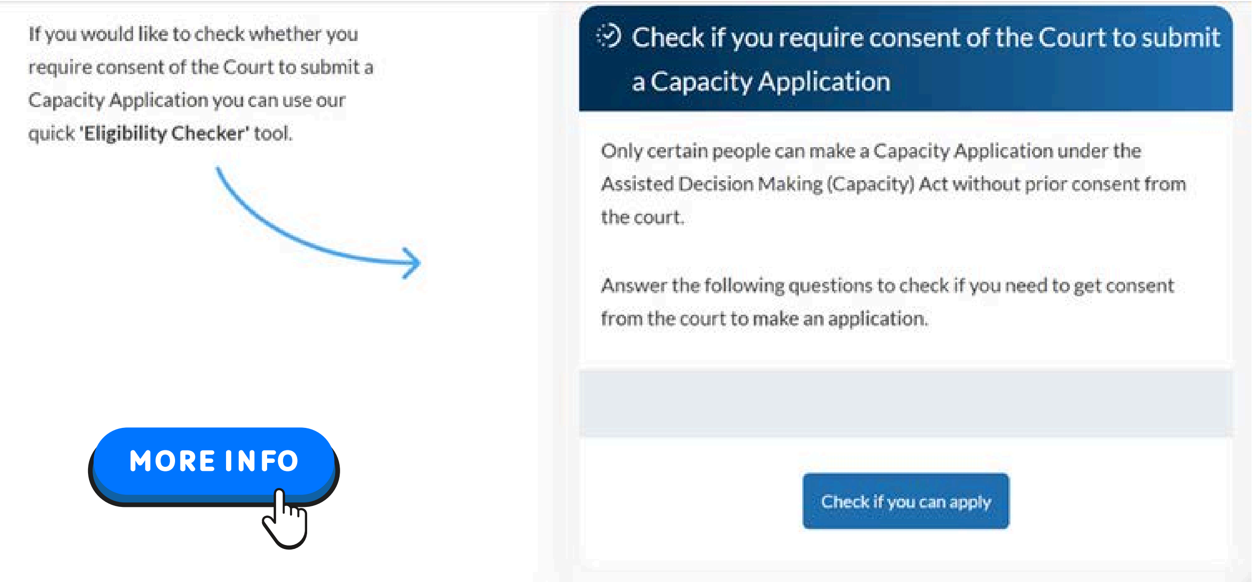
ADMC Eligibility Checker

Determine Your Need for Court Consent before Making a Capacity Application

Use the Eligibility Checker to find out if you need court consent before making a Capacity Application. Certain people with specific relationships to the Relevant Person (whose decision-making capacity is in question) do not need court consent. Everyone else must obtain it. Check below to see which process applies to you

ADMC Eligibility Checker

Check if you need to get consent from the court to make a capacity application



If you would like to check whether you require consent of the Court to submit a Capacity Application you can use our quick **'Eligibility Checker'** tool.

Check if you require consent of the Court to submit a Capacity Application

Only certain people can make a Capacity Application under the Assisted Decision Making (Capacity) Act without prior consent from the court.

Answer the following questions to check if you need to get consent from the court to make an application.

Legal Advice and Mediation

A link to information about legal advice and representation, and mediation to help you with your Civil Law matter.

Support Services

A link to supports and useful contacts that may be relevant and helpful to your Civil Law matter.

Navigating the Courts Service: A Simple Guide to access information on the Assisted Decision-Making (Capacity) Act 2015

Sandra Guidon, Project Support Officer, NOHREP

The Courts Service utilises the JAM Card to ensure inclusivity for individuals who need additional time and patience due to communication barriers. This initiative demonstrates their commitment to providing accessible and supportive services for everyone

What is a JAM Card?

A JAM Card allows people with a learning difficulty, autism or any communication barrier to tell others that they need 'Just a Minute' discreetly and easily. Those with a communication barrier are often reluctant, or unable, to tell others that they need more patience and space in a given situation. JAM Card allows this to happen in a simple, effective non-verbal manner.

Where can I get a JAM Card?

Smartphone users can download the JAM Card app which allows users to select different screen display options including ‘I have autism’, ‘I have a condition’ and ‘I have a brain injury’.
JAM cards are also available at Public Offices across the Court Service, at the Dublin Coroners Court and at two pilot locations (Midlands Prison and Castlerea Prison) across the Irish Prison Service into the future.

An tSeirbhís Chúirteanna
Courts Service

MORE INFO

Assisted Decision-Making, Considerations for Mental Health Services

Jacqueline Grogan , Project Manager

The Dublin and Midlands Regional Health Area facilitated a learning event on Assisted Decision-Making Capacity Act, Consent and Advanced Health Care Directives in Mental Health. The event took place on the 26th February 2025 in the Trinity Centre for Health Sciences in Tallaght University Hospital. We were fortunate to have 23 professionals present representing both acute and community Mental Health services.

Holly Canavan, Assisted Decision-Making Lead and Social Work Team Leader at Tallaght University Hospital opened the event with a presentation on maximising a person's ability to make their own decisions, the guiding principles of Assisted Decision-Making and updates to the HSE National Consent Policy 2022 v1.2. Holly discussed Appendices 6-8 of the Policy, which staff can use as a checklist or to record the basis for proceeding with treatment when a person's capacity to decide is in question or lacking. Additionally, she presented an update on the Discharge of Ward of Court, based on learnings from a recent webinar in collaboration with the National Office of Human Rights and Equality Policy.

Emma Mullins, Assisted Decision-Making Lead for Dublin and Midlands Regional Health Area, presented on the 3 tier Decision Support Arrangements and the Functional Assessment of capacity referencing the HSE Functional Assessment of Capacity template for guidance when documenting reports. She highlighted the importance of hearing the voice of the Relevant Person in judicial proceedings under the 2015 Act and discussed tools for Advanced Planning.

Assisted Decision-Making, Considerations for Mental Health Services

Jacqueline Grogan , Project Manager

Professor Brendan Kelly, Professor of Psychiatry, Trinity College Dublin discussed various scenarios pertaining to Advanced Health Care Directives in Mental Health, fostering an engaging discussion among attendees. He also raised the plan for new Liberty Safeguarding legislation (Protection of Liberty) highlighting that since the ADM Act came into force, applications for deprivation of liberty must be made to the High Court under the Court's Inherent Jurisdiction.

Attendees received useful resources during the presentation which were circulated after the event. A QR code for evaluation of the learning event was given to all attendees providing very valuable feedback.

It was evident from the response rate of the survey that attendees appreciated the format of the event, with 100% stating they would share their learnings with their colleagues. The survey included open-ended questions about what attendees would like to see more of at the learning event, with responses including:

> **more seminars and case discussions**

> **Focused seminars like this which allow staff to consider the details of some of these issues**

An ADM learning event was held in Naas General Hospital for Mental Health services in December 2024 for the Kildare West Wicklow area and a further ADM learning event took place with Dublin South Central (St. James's) Mental Health Services in March 2025.

Launch of Online Training on Functional Assessment of Capacity under the Assisted Decision-Making (Capacity) Act 2015

Jacqueline Grogan , Project Manager

The HSE National Office for Human Rights and Equality Policy and the Decision Support Service are pleased to announce that the online training on the Functional Assessment of Capacity for the purposes of the Assisted Decision-Making (Capacity) Act 2015 is now live on the Decision Support Service Moodle site.

This online learning programme has been developed for registered medical practitioners and healthcare professionals who will be completing statements of capacity under Part 4 (Co-decision-making), Part 5 (Decision-Making Representation Orders) and Part 7 (Enduring Powers of Attorney) of the Assisted Decision Making (Capacity) Act 2015 and will equip people with the background knowledge required to undertake a functional assessment of capacity and supply the relevant statement as required under the 2015 Act.

The training provides an overview of:

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

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

You can register for the training via this link.
You will need to complete all sections of the registration form, including completing the additional information section.

Since its launch in January 2025, over 1600 users have enrolled onto the training. Over 60% of those who have undertaken the programme work for the HSE, with 20% from HSE funded agencies. The main professions to have undertaken the training are social workers, followed by nurses and occupational therapists.

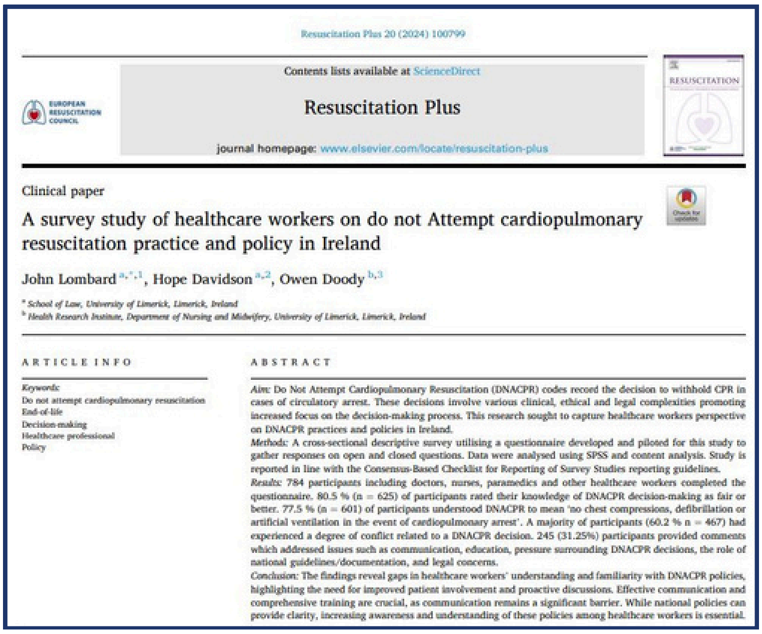
If you have any questions in relation to the online training, please contact us on adm@hse.ie or Jacqueline.grogan@hse.ie.

HSE DNACPR News

Elaine McCaughley, Programme Lead, HSE National Consent Policy

Dr John Lombard, Dr Hope Davidson, and Dr Owen Doody of the University of Limerick have had an article accepted for publication in the journal BMC Health Research Policy and Systems. The article is titled, 'Do Not Attempt Cardiopulmonary Resuscitation Practice and Policy in Ireland: A mixed- methods study'. This article is based on research conducted as part of the project examining DNACPR practice and policy.

The article reports on research which investigates service user and advocacy group perspectives on DNACPR practice and policy in Ireland. 148 participants completed the survey, and four interviews were completed with representatives of advocacy groups. 70.5% of participants selected the correct definition of a DNACPR decision.



Resuscitation Plus 20 (2024) 100799

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Resuscitation Plus

journal homepage: www.elsevier.com/locate/resuscitation-plus

RESUSCITATION

Clinical paper

A survey study of healthcare workers on do not Attempt cardiopulmonary resuscitation practice and policy in Ireland

John Lombard [a,*,1], Hope Davidson [a,2], Owen Doody [b,3]

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ARTICLE INFO

Keywords:
Do not attempt cardiopulmonary resuscitation
End-of-life
Decision-making
Healthcare professional
Policy

ABSTRACT

Aim: Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) codes record the decision to withhold CPR in cases of circulatory arrest. These decisions involve various clinical, ethical and legal complexities promoting increased focus on the decision-making process. This research sought to capture healthcare workers perspective on DNACPR practices and policies in Ireland.
Methods: A cross-sectional descriptive survey utilising a questionnaire developed and piloted for this study to gather responses on open and closed questions. Data were analysed using SPSS and content analysis. Study is reported in line with the Consensus-Based Checklist for Reporting of Survey Studies reporting guidelines.
Results: 784 participants including doctors, nurses, paramedics and other healthcare workers completed the questionnaire. 80.5 % (n = 625) of participants rated their knowledge of DNACPR decision-making as fair or better. 77.5 % (n = 601) of participants understood DNACPR to mean 'no chest compressions, defibrillation or artificial ventilation in the event of cardiopulmonary arrest'. A majority of participants (60.2 % n = 467) had experienced a degree of conflict related to a DNACPR decision. 245 (31.25%) participants provided comments which addressed issues such as communication, education, pressure surrounding DNACPR decisions, the role of national guidelines/documentation, and legal concerns.
Conclusion: The findings reveal gaps in healthcare workers' understanding and familiarity with DNACPR policies, highlighting the need for improved patient involvement and proactive discussions. Effective communication and comprehensive training are crucial, as communication remains a significant barrier. While national policies can provide clarity, increasing awareness and understanding of these policies among healthcare workers is essential.

A picture of the article "Do Not Attempt Cardiopulmonary Resuscitation Practice and Policy in Ireland: A mixed-methods study"

Many participants overestimated the rate of survival for both in-hospital and out-of-hospital cardiac arrest. There was a strong desire for involvement and support in the decision-making process. Participants drew attention to poor awareness of national policy, uncertainty as to the decision-making authority of family members, and difficulties in communication. Participants also highlighted the need for additional information concerning resuscitation status. The research study highlights points of weakness in the DNACPR decision-making framework for service users. While there is a desire to be involved in the DNACPR decision-making process this is challenged by deficiencies in the understanding of CPR and uncertainty surrounding decisional authority.

The National Office for Human Rights and Equality Policy continue to work with the HSE DNACPR Policy steering group and aim to publish this policy later this year. If you have any queries about this piece of work please contact Elaine.mccaughley@hse.ie.

You can read the full article HERE

New Legislation - European Accessibility Act

Sandra Guidon, Project Support Officer, NOHREP

On the 28th June 2025, the European Accessibility Act (EAA) will officially come into effect. Approved in 2019, this historic law seeks to standardise accessibility rules throughout the EU in order to build a more accessible and inclusive Europe.

A wide range of goods and services, such as consumer electronics, tickets and vending machines, websites, and mobile apps, are required by the EAA to adhere to accessibility criteria. This implies that devices such as gaming consoles, laptops, smartphones and TV's will be made accessible to all users, including those with disabilities.

European Accessibility Act (EAA) Easy Read

European Accessibility Act (EAA)

A law to make things more accessible.

Created by Enable Ireland's Virtual Service.

The EAA will facilitate the sale of compatible goods and services across the EU by standardising accessibility regulations, increasing consumer choice and stimulating innovation and market expansion.

According to the UN Convention on the Rights of Persons with Disabilities, this "design for all" strategy guarantees that goods and services be robust, perceivable, operable and comprehensible

Businesses and organisations operating in the EU may face fines and other penalties for noncompliance with the EAA. In order to guarantee compliance, it is important that all parties involved become familiar with the new standards and make required improvements.

Everyone is urged to be informed and take proactive measures to welcome these developments.

Thank you to our colleagues from Enable Ireland who produced an Easy Read Document to on the European Accessibility Act (EAA).

Click the picture to the left to access the Easy Read document

New Legislation - European Accessibility Act

Sandra Guidon, Project Support Officer, NOHREP

Accessibility Requirements:

The EAA mandates that various products and services, including health and social care services, comply with accessibility requirements for persons with disabilities. This includes ensuring that websites, mobile applications, and other digital interfaces used in health and social care are accessible.

Digital Accessibility:

The Act expands responsibility for accessible Information and Communications Technology (ICT) to many product types and service sectors, including health and social care. This means that digital tools and platforms used in these services must be designed to be accessible to all users, including those with disabilities.

Public Procurement:

The EAA also impacts public procurement rules, requiring that accessibility considerations are included when health and social care services procure goods and services. This ensures that accessibility is a priority in the selection and use of products and services within these sectors.

What does this act mean for Health and Social Care Services?

These changes aim to enhance the inclusivity and accessibility of health and social care services, making them more user-friendly for individuals with disabilities.

For more detailed guidelines and support materials, you can visit AccessibleEU's website HERE

Health and Social Care Services - Approved Organisations Accessing and Searching the Decision Support Service (DSS) Register

Norma O'Donnell, ADM Project Manager

The Decision Support Service (DSS) Register for Approved Persons and Organisations plays an essential role by offering a structured and accessible way to record decision-making arrangements for individuals who need assistance in managing personal welfare, healthcare, and financial decisions.

Established under the Assisted Decision-Making (Capacity) Act 2015, this register serves as a key resource, ensuring that care and support for individuals are consistent with their legal rights and choices.

Understanding how to access and navigate the DSS Register is crucial for healthcare professionals involved in delivering care and making decisions for patients who may not have full capacity to do so themselves.

Further information on the Decision Support Service can be accessed by clicking the logo below

seirbhís tacaíochta cinnteoireachta
decision support service™

What Is the Decision Support Service (DSS) Register for Approved Organisations?

The DSS Register is an official database that maintains records of individuals who have formal arrangements in place for decision-making support. The information included in the register helps identify who is legally authorised to make healthcare and welfare decisions on behalf of individuals who may lack the capacity to make such decisions independently.

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

What types of decision support arrangements are searchable by Approved Organisations?

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

- Co-Decision-Making Agreements
- Decision-Making Representation orders
- Enduring Power of Attorneys

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

Health and Social Care Services - Approved Organisations Accessing and Searching the Decision Support Service (DSS) Register

Norma O'Donnell, ADM Project Manager

Accessing the DSS Register.

Access to the DSS Register is essential for various health and social care services. Approved Organisation refers to a health and social care service that has been formally recognised and granted authorised access to the DSS Register. This may include a department within a hospital, a specific primary care service, a mental health service or a nursing home.

At this time, health and social care services can apply to the DSS for approval to access. The online DSS Register will be open to all other eligible organisations and professionals in Q4 2025.

A service can apply to the DSS to search the DSS Register as an 'Approved Organisation' through the online portal **myDSS.**

The person completing the application will need to set up a DSS Register account. 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

The National Office for Human Rights and Equality Policy have developed comprehensive HSE Guidelines for Approved Organisations accessing and searching the Decision Support Service (DSS) Register as a resource specifically for health and social care purposes. These guidelines will include 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
- For more information visit the Decision Support Service website here

seirbhís tacaíochta cinnteoireachta
decision support service™

Revision of National Guidelines on Accessible Health and Social Care Service

Norma O'Donnell, ADM Project Manager

Access to healthcare is a fundamental human right, yet many individuals face barriers that prevent them from receiving the care they need. To address this challenge, the development of the National Guidelines on Accessible Health and Social Care Services provide practical guidance to healthcare professionals, ensuring that services are inclusive and accessible to all individuals, particularly those with disabilities. By implementing these standards, healthcare providers can promote equality, dignity and effective care for all patients.

The Need for Updates and Consultation

A review of the National Guidelines.

The guidelines were shaped by a strong legislative and policy framework, including: A Future Health: A Strategic Framework for Reform of the Health Service 2012 – 2015, The Disability Act 2005, The Equal Status Acts 2000 – 2008, The National Healthcare Charter: 'You and Your Health Service' and various other health and social care policies and procedures. With evolving legislation, policies, and best practices, it is now essential to review these guidelines. Consultation work is commencing incorporating feedback from healthcare professionals, advocacy groups, and individuals with lived experience.

HSE National Guidelines on Accessible Health and Social Care Services - Corporate

A review of Access Officers.

Access Officers are designated staff members responsible for assisting individuals with disabilities in accessing healthcare services, addressing barriers and ensuring compliance with accessibility legislation and best practices. Additionally a review of Access Officers is commencing to assess their role and effectiveness in supporting individuals with disabilities in navigating health and social care services.

Conclusion

As part of this review of both the existing National Guidelines and the role of Access Officers across services, if you have any insights that you believe would be valuable to these reviews, we welcome your input. Please feel free to get in touch with us directly if you would like to contribute or discuss further at adm@hse.ie

For Further Information

- The Disability Act 2005 can be downloaded from oireachtas.ie. For further accessibility information, go to the website of the National Disability Authority
- For further information please contact the HSE National Office for Human Rights and Equality Policy at adm@hse.ie

National Guidelines on Accessible Health and Social Care Services

A guidance document for staff on the provision of accessible services for all

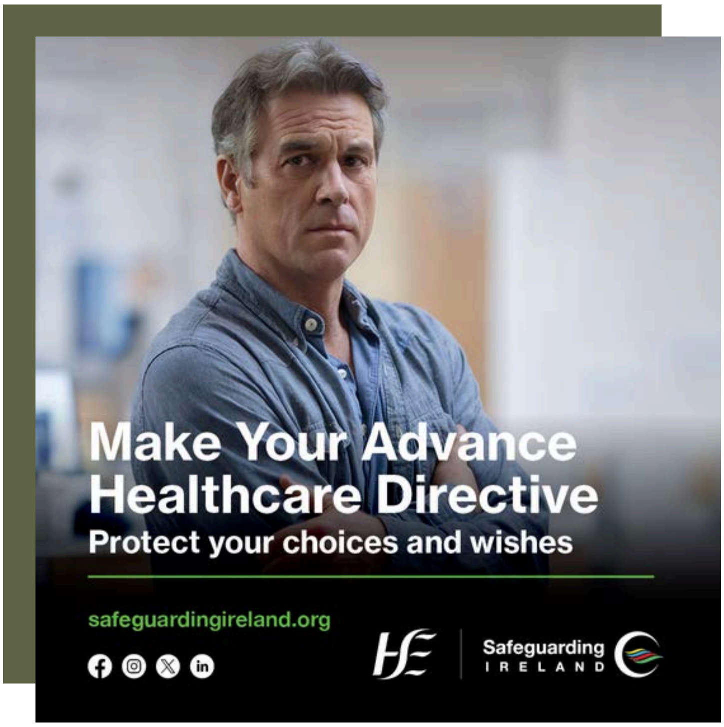
Supporting people to make an Advance Healthcare Directive with patients- the role of healthcare workers

Patricia Rickard-Clarke Chairperson, Safeguarding Ireland

Safeguarding Ireland has encouraged more adults to make a future healthcare plan – called an Advance Healthcare Directive – as just 4% of people in Ireland have one.

An Advance Healthcare Directive (AHD) is a document in which a person writes down their future healthcare decisions on refusals and consents regarding treatment, surgery, medicines and resuscitation.

Making an AHD is an important part of protecting rights and ensuring that people's wishes will be respected if in the future they lack decision-making capacity. It is also better for doctors, social workers and families to have clarity on a person's choices and wishes.



RED C research on a representative sample of 1,000 adults last year found that – just 23% understood what an Advance Healthcare Directive was, and just 4% said that a healthcare professional had ever asked them if they have one.

The uptake of Advance Healthcare Directives is very low in Ireland compared to other countries, and more take up is needed

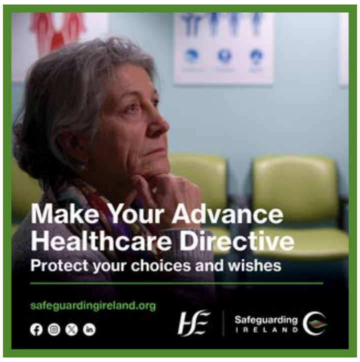
In response to this Safeguarding Ireland has encouraged more health and social care professionals who are working in the HSE to raise, as routine practice, healthcare planning with patients and clients, at a time when they are well and have decision-making capacity.

The plan only comes into effect if there comes a time in the future when a person lacks capacity to make, or communicate healthcare decisions. This could be due to the progression of a frailty, dementia, a serious illness, a physical or intellectual disability, or a sudden accident.

Making one is free of charge, is not difficult to do, but does need some time (this will vary but allow 20-30 mins and time for discussion). More information is available at www.safeguardingireland.org.

The recommended step to making one is to complete either of the Advance Healthcare Directive **templates** available at:

- Decision Support Service, www.decisionsupportservice.ie or call (01) 211 9750
- Irish Hospice Foundation Think Ahead portal, www.thinkahead.ie or call (01) 679 3188.



Supporting people to make an Advance Healthcare Directive with patients- the role of healthcare workers

Patricia Rickard-Clarke Chairperson, Safeguarding Ireland

The **details included** in an Advance Healthcare Directive are:

Refusals on life-sustaining treatments, artificial nutrition, surgery, medicines and resuscitation
Consents on medical and treatment options, including pain relief and where someone would like to be treated
Appointing someone a person chooses and trusts, called a Designated Healthcare Representative, to ensure the plan is correctly interpreted and complied with.

It is not required to appoint a **Designated Healthcare Representative**, however Safeguarding Ireland recommends doing so where possible.

Once made – healthcare professionals are bound to adhere to a person's refusals and to make every effort to provide the treatments they would like to receive. Also, there is clarity on who can act on a person's behalf.

Once a person has made their Advance Healthcare Directive copies need to be shared with relevant people such as; the person's Designated / Alternative Healthcare Representatives, Family Doctor (GP), healthcare professionals a person is dealing with, the Emergency Department if admitted to hospital, the person in charge if living in a healthcare or residential facility.

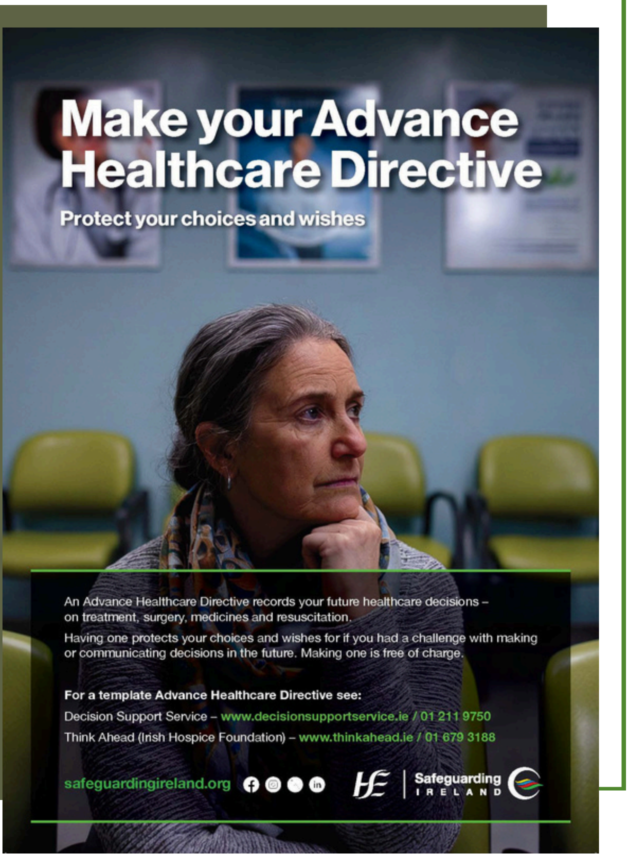
An Advance Healthcare Directive can be changed at any time while the patient or person has decision-making capacity. After changing it, the same steps need to be taken again to make it valid, including signatures and witnesses.

In practice many people complete their document in stages as relevant to them at the time, and make changes.

It is hoped that in the near future a centralised register of Advance Healthcare Directives will be established that health and social care professionals can access, and that it will be run by the Decision Support Service.

More information about Advance Healthcare Directives and making one is available at www.safeguardingireland.org.

Safeguarding Ireland promotes safeguarding of adults to protect them from all forms of abuse by persons, organisations and institutions and to deliver a national plan for promoting their welfare.



An Advance Healthcare Directive records your future healthcare decisions – on treatment, surgery, medicines and resuscitation.

Having one protects your choices and wishes for if you had a challenge with making or communicating decisions in the future. Making one is free of charge.

For a template Advance Healthcare Directive see:

Decision Support Service – www.decisionsupportservice.ie / 01 211 9750
Think Ahead (Irish Hospice Foundation) – www.thinkahead.ie / 01 679 3188

safeguardingireland.org

Completing an assessment of capacity when supporting a person with a disability

Caroline Howorth, Speech & Language Therapy Manager,
St. Michael's House

The Assisted Decision-Making (Capacity) Act 2015 provides a framework for supporting individuals with disabilities in making decisions about their personal welfare, property, and affairs. When completing an assessment of capacity, it is crucial to apply the functional test outlined in the Act, which evaluates a person's ability to understand, retain, use and communicate information relevant to a specific decision. This approach ensures that individuals are supported in a manner that respects their autonomy and promotes their participation in decision-making processes. By adhering to the principles of the Act, we can empower people with disabilities to make informed choices and enhance their quality of life.

<u>A. Core Principles</u>:

All assessments of capacity start with the goal of identifying the person's ability to make the decision. It is understood that if we are to initiate an assessment of capacity a valid 'trigger' for questioning the person's capacity should be identified in the first instance. But that does not make it inevitable that an outcome of 'lacks capacity' is where we end up.

I make this as a starting point because when we commence an assessment of capacity with a focus on abilities and strengths - at the very least we have set off on the right path.

But sometimes there can be a risk when supporting a person with a disability that seeing and believing strengths and ability is not where the assessment begins. And it can be hard to come back from that.

What other principles which inform valid assessments of capacity perhaps require an enhanced emphasis when supporting a person with a disability?

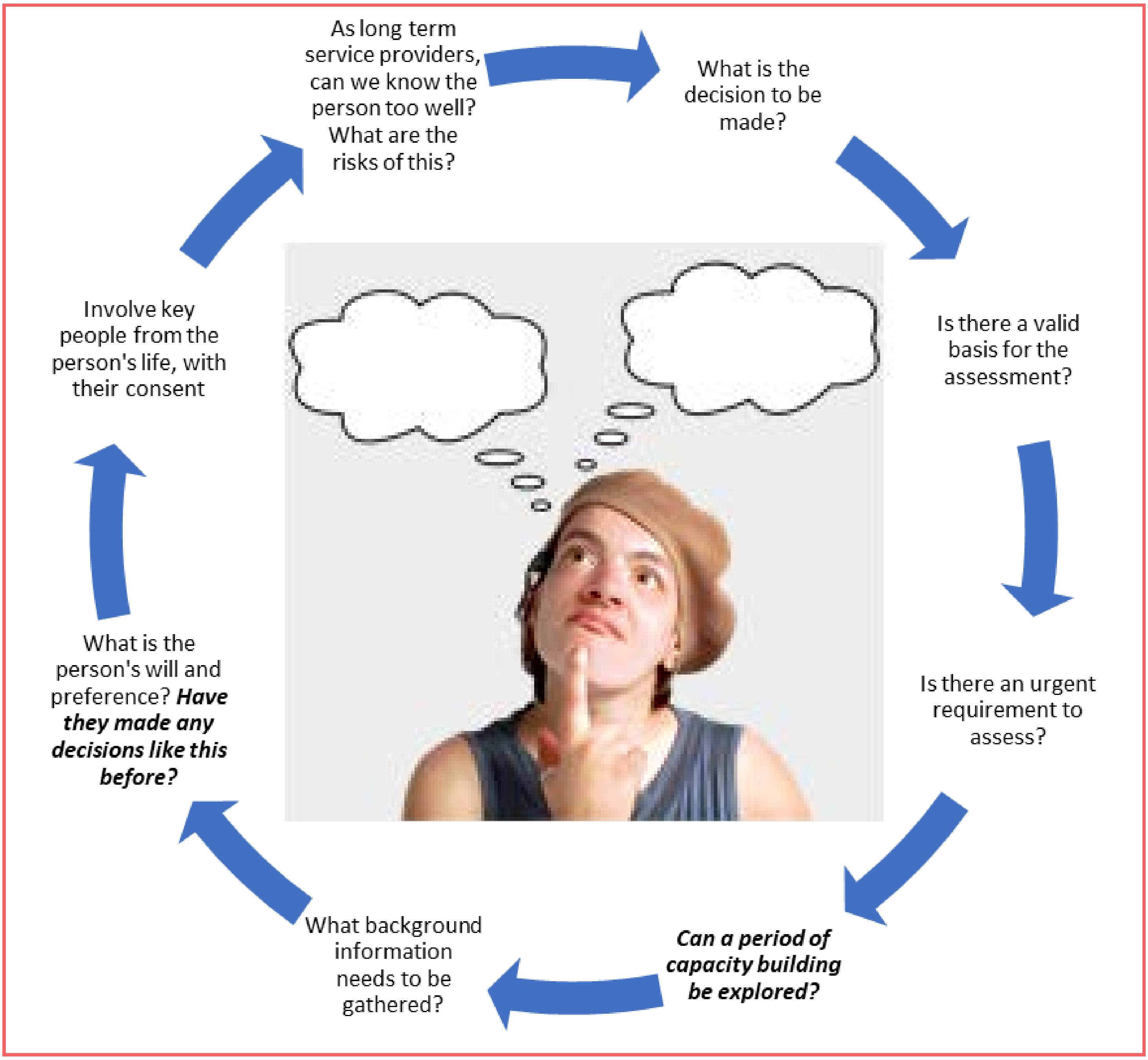
Assessments of capacity should be **<u>built and developed around the person</u>** – with their strengths, needs, will and preferences to the core. Intentionally, there is no standardised form or tool. This can be a challenge to the professional but is central to an individualised, person-centred assessment being completed. Assessments of capacity should be flexible and completed with the person at a **<u>time, location</u>** that works for them. This can be a challenge to the system but is essential when supporting a person with a disability where environment, routine and familiarity are often key.

Completing an assessment of capacity when supporting a person with a disability

Caroline Howorth, Speech & Language Therapy Manager, St. Micahel's House

Assessments of capacity are **not about us, the professionals involved**. Yes, we must upskill ourselves, do the background work and be equipped to assess the person's capacity appropriately. But we put any non-fact based 'opinions' aside. The assessment is not catching someone out. It is about providing the supports required (as necessary) to identify the person's competency.

B. Preparation;



What is the decision to be made?

Is there a valid basis for the assessment?

Is there an urgent requirement to assess?

Can a period of capacity building be explored?

What background information needs to be gathered?

What is the person's will and preference? ***Have they made any decisions like this before?***

Involve key people from the person's life, with their consent

As long term service providers, can we know the person too well? What are the risks of this?

Completing an assessment of capacity when supporting a person with a disability

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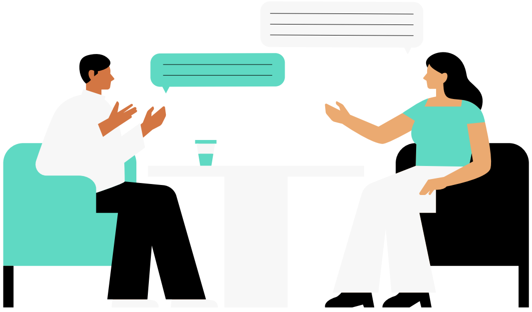
Building a person's capacity to make their own decision



- Apply practical, experiential learning. For example, if a hospital procedure is involved, see if a visit can be arranged.

- Provide information, relevant to the decision, in a way the person understands.

- Engage in supported conversations around the decision to be made, any risks/benefits and use the person' known preferred methods of giving and receiving information.

- Leave the information with the person for them to look at in their own time.

- Some people will benefit from having the topic revisited over a planned period of time; others may find this a source of anxiety or distress - consider what best suits the person you are supporting.

- It can be helpful, with the person's consent, to have familiar communication partners, use reliable information to discuss the decision with the indidividual.

- Ongoing review to see the period of capacity building is of help, if more time is needed or if it is time to move on (i.e. the person is ready to make their own decision or a functional assessment of capacity is indicated.

Completing an assessment of capacity when supporting a person with a disability

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St. Micahel's House

C. Completing the assessment:

Toolbox 1: Beliefs and values

I believe the person has capacity to make their own decisions unless/until the contrary is shown

I am able to observe the person's will and preference

I intend to really understand the specific decision that is to be made and to understand the implications of the outcome of the decision for the person

I understand whether this decision is important to the person or important for the person

I recognise the timeline for making the decision -and to advocate for more time if its's needed, wherever possible

Completing an assessment of capacity when supporting a person with a disability

**Caroline Howorth, Speech & Language Therapy Manager,
St. Micahel's House**

Toolbox 2: Understanding how communication influences a person's ability to participate in the capacity assessment.

Auditory memory - retaining information provided verbally.

Visual memory - retaining visually presented information

Symbolic understanding - understanding visual information; objects, colour photographs, black + white photos, line drawn symbols, printed words

Verbal comprehension - understanding the basic concepts of what is being considered; the load of information in each sentence used.

Verbal comprehension - complex grammar structures (if, because, probably, since, although); abstract choices being put before the person.

**Expressive communication – having access to the right communication system – do they use verbal language or other means?

Expressive communication - do they have access to the right vocabulary to express their opinions around this topic, is the person able to discuss options and ask questions?

How much **experience** does the person have in making decisions and in communicating their opinions? Are they comfortable expressing their thoughts? Have they the opportunity to do so?

Completing an assessment of capacity when supporting a person with a disability

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Toolbox 3: Understanding, retaining, weighing and communicating - being an assessor with inclusive communication skills

Modify your asessment to meet the person's everyday comprehension skills. What supports increase their understanding (e.g. objects, photographs, pictures, Lámh, sign language, written language)?

Update your assessment to accommodate the person's expressive communication. Do you anticipate verbal (single words, phrases, sentences) and/or non-verbal (vocalisations, body movements, body language, eye contact, gestures) responses?

Ensure your approach **faciliates alternative methods of communicating** - Lámh, visual supports, AAC devices.

Really **listen** to what the person is communicating to you – regardless of how they are communicating that information.

If necessary, with consent, talk to someone who knows the person well and ask them for information about the person’s communication – family, friend, support staff

Consider the **environment** - space, layout, background noise, time of day, the person's routine - all of these can be a factor.

Make listening easier - ensure you have the person's attention, reduce language levels by saying less and go slow.

Use a **total communication** approach, by combining gestures, visuals, Lámh, body language, facial expressions - or whichever modes of communication the person chooses.

Completing an assessment of capacity when supporting a person with a disability

Caroline Howorth, Speech & Language Therapy Manager, St. Micahel's House

D. Conclusion:

As I write, I am hugely conscious that I am purely providing a professional's perspective on how to complete an assessment of capacity when supporting a person with a disability. I strongly believe people with disabilities themselves are best placed to let us know what good healthcare, what good social care, what good assessments look like to them. As we all become more experienced with the ADM Act's implementation, I hope our engagement with people with disabilities will provide the opportunity for them to provide feedback and influence practice going forward.

In the meantime, I have aimed to give some suggestions for consideration.

Peer Learning Workshops- A model for culture change through capacity building

Joe Nelis, Social Work Team Leader, Donegal

Since March 2023, the HSE Social Work Service in Donegal have been co-ordinating and running a series of workshop based peer learning events for Social Workers focussing on the Assisted Decision Making (Capacity) Act 2015. The primary aims of using this model are to build capacity, confidence, and knowledge, and to integrate the Act into the daily practice of HSE Social Workers in Donegal. As a result, we are seeing the same benefits for our service users, their families, carers, and an overall growing awareness of this human rights based legislation across other disciplines and professionals.

In the first instance in early 2023, the support, advice and guidance of Caoimhe Gleeson, General Manager for the HSE National Office for Human Rights and Equality Policy and her colleagues was critical in starting these workshops. Caoimhe by virtue of her expertise, passion and remit over the implementation of the Act across the HSE provided us with a frame of reference. We started by focussing on the HSE National Consent Policy in March 2023, followed by a second event in April 2023 on the day the legislation was enacted looking at the functional assessment of capacity.

The success of the workshops has been down to the collaboration and partnerships between the HSE Social Work Teams in Donegal who alternate in leading out on certain themes, topics and aspects of the ADM legislation for each workshop. The key stakeholders include:

- HSE National Office for Human Rights & Equality Policy
- Older Persons Social Work
- Intellectual Disability Social Work
- Primary Care Social Work
- Children's Disability Social Work
- Medical Social Work
- Safeguarding & Protection Team Social Workers,
- Physical & Sensory Disability Social Work
- Mental Health Social Work
- Hospice Social Work

HSE Social Work Team, Donegal

Peer Learning Workshops- A model for culture change through capacity building

Joe Nelis, Social Work Team Leader, Donegal

When taking the lead on a workshop theme, the Social Workers/Teams work collaboratively in groups looking at issues and areas relevant to their area of practice, which fosters teamwork and a shared responsibility around learning content. The benefits of running the ADM workshops have seen the following:

- Promotes collaborative learning
- Enhances practical application
- Develops leadership skills amongst Social Workers
- Tailors content to specific professional needs for Social Workers
- Increases engagement & retention of knowledge
- Improves confidence in applying the ADM Act
- Fosters a culture of Continuous professional development
- Promotes consistency in practice
- Supports Mental Health & well-being of Social Workers

The ADM workshops for Social Workers are primarily hands on and interactive and we have used the following formats across the workshops to date:

- Anonymised Case Vignettes
- Group Discussions/Debates
- Role Play/Simulations/In-person/Pre-recorded
- Peer Teaching
- Presentations
- Jigsaw Model
- ADM Quizzes

HSE Social Work Team, Donegal

Peer Learning Workshops- A model for culture change through capacity building

Joe Nelis, Social Work Team Leader, Donegal

To date the HSE Social Workers in Donegal have run 8 ADM workshops with a further 4 planned workshops for 2025 with themes including ‘functional assessment of capacity,’ ‘balancing risk with duty of care/unwise decisions’ and ‘will and preference.’ If you require any further information on the ADM Workshops in Donegal email joe.nelis@hse.ie or Principal Social Worker tina.gardiner@hse.ie

HSE Social Work Team, Donegal

HSE Social Work Team, Donegal

HSE Social Work Team, Donegal

Speak Up, Speak Out!

Emer O’Shea, Community Engagement Manager, Inclusion Ireland

Inclusion Ireland are the national advocacy organisation for people with an intellectual disability. Participation is one significant strand of our work and we have worked for many years in supporting people to be heard, to be in spaces where decisions are made about their lives and to make sure that participation is never tokenistic. We feel very strongly that it is often people with intellectual disabilities who are left out of conversations, as the real barriers to participation - learning the confidence to speak up, understanding your rights, being given adequate time to prepare and to debrief, and importantly the use of accessible information, are not addressed.

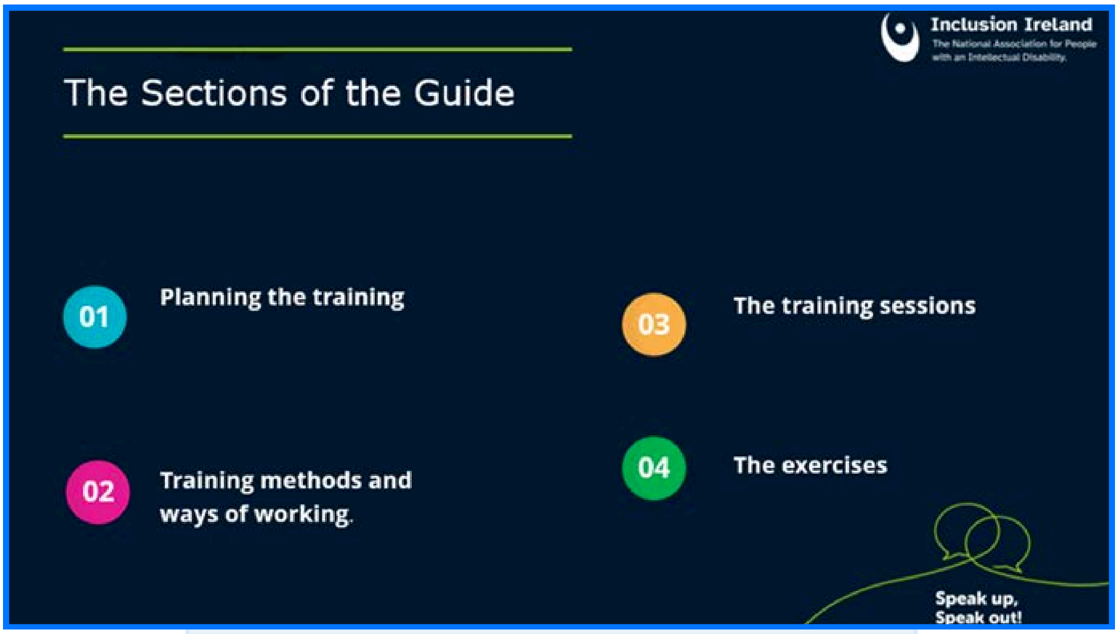
Inclusion Ireland with Sligo Advocacy Group at HSE conference.

Members of the Sligo Advocacy Group during recording of training activities.

We have a better understanding in society now about physical barriers to access, but we still do not fully understand that accessible information is often a more significant barrier. Our team have strived to remove these barriers for many years and we have created a resource to help others to do the same.

Speak Up, Speak Out!

Emer O'Shea, Community Engagement Manager, Inclusion Ireland



Inclusion Ireland
The National Association for People with an Intellectual Disability.

The Sections of the Guide

01 Planning the training

02 Training methods and ways of working

03 The training sessions

04 The exercises

Speak up, Speak out!

Image naming the four sections of the guide.

The Speak Up, Speak Out! training guide is a personal development and assertiveness training programme for people with intellectual disabilities. The digital Speak Up, Speak Out! training guide has been designed and developed by Inclusion Ireland to build essential skills for effective self-advocacy. The exercises and games described in the guide and illustrated in the accompanying videos, are accessible, enjoyable, and interactive.

This resource was developed with input from people with lived experience of an intellectual disability and staff working in the area of advocacy.

This resource is available on our website www.inclusionireland.ie and we are excited that over the next two years we will be supporting the HSE to implement the use of this resource and further develop advocacy in services.

Sligo advocacy group showcasing some of the activities at HSE conference in Ballybofey, Co Donegal.

Exploring the need for a Representative Advocacy Service for Children with Intellectual Disabilities in Ireland.

Emer O'Shea,Community Engagement Manager, Inclusion Ireland

Niall Muldoon (Ombudsman for Children), Emma Burns (CDLP NUI Galway), Lydia Fisher (Self-advocate), Derval McDonagh (CEO Inclusion Ireland)

Inclusion Ireland published a ground breaking piece of research on 27 March 2025 calling for the establishment of a representative advocacy service for disabled children in Ireland.

Inclusion Ireland
The National Association for People with an Intellectual Disability.

The research which was, conducted by the centre for Disability Law and Policy in the University of Galway, told the stories of children, families and their supporters who struggle on a daily basis to access what should be some fundamental human rights in Ireland; the right to a high quality education, the right to access therapeutic supports in a timely manner, the right to support as a child to be a part of your loving family.

Exploring the need for a Representative Advocacy Service for Children with Intellectual Disabilities in Ireland.

Emer O'Shea,Community Engagement Manager, Inclusion Ireland

Inclusion Ireland regularly hear stories of children and their families trying to access therapy services, access support of hospital services for medical conditions, access support of mental health professionals and applying to 30 schools only to be turned down. Right from the start of life children are being told blatantly, frequently and bluntly that they do not belong. We often hear of children labelled as "too complex", an age-old excuse for a system that needs to hold a mirror up and admit that it is our systems that are actually the complex one, designed to keep some children out rather than let all children in.

If you are spending your life as a parent applying to schools, pushing for support, your entire family life is consumed by this. This has a profound effect on siblings, on relationships, and on the financial wellbeing of the family. Most families we know, one parent has given up work, deepening the economic barriers that disabled children face. These disabled children grow up to be disabled adults. Their whole life caught in a whirlwind of a fight; no-one should grow up seeing photos of their parents sleeping out outside Leinster house protesting for their rights or lose their parents to stacks of paperwork gathered in their name, in the relentless pursuit of basic care from the state.

Family Members

The answer to all of this is fully functioning public services; where all teams and organisations across education, health, primary and acute care work together seamlessly with the child at the centre.

Exploring the need for a Representative Advocacy Service for Children with Intellectual Disabilities in Ireland.

Emer O'Shea,Community Engagement Manager, Inclusion Ireland

Joanne Condon (National Advocacy Service), Wayne Stanley (EPIC), Julie Ahern, (Children's Rights Alliance), Lucinda Murrihy (Inclusion Ireland/Parent)

This vision for integrated care seems a long way off at the moment, but we must relentlessly pursue it. In the meantime, whilst we work towards that ideal state Inclusion Ireland calls for a task force to establish an Advocacy Service for Children with Intellectual Disabilities. The National Advocacy Service advised us about the work that they do to shine a light where services are not working and to walk alongside a person as they speak up for themselves and access their rights.

If the state also establishes a service for those under 18, an advocate could help tip the balance of power in favour of the child.

Having representation from an advocate means that first and foremost you have someone to explain to you what your rights are. Most people are unaware that they have certain rights and take "no" as an answer. An advocate can also ensure that meetings, care planning, liaising between services all happens with the child at the centre.

He/she can take the administrative burden off the shoulders of the family and let them be what they need to be, loving daughters, sons, siblings and parents. Representative advocacy is not the answer to everything, but it is one way of getting us out of this endless fight cycle and towards a time where children are heard, believed, listened to and respected as rights holders in this state.

Inclusion Ireland
The National Association for People with an Intellectual Disability.

Exploring the need for a Representative Advocacy Service for Children with Intellectual Disabilities in Ireland.

Emer O'Shea,Community Engagement Manager, Inclusion Ireland

Speaking at our launch the Ombudsman for children said "I am delighted to launch this report into the importance of having an Advocacy Service for Children with Disabilities, because through the complaints we take for those children we can see the massive struggle many are going through, every day, just to have their rights upheld.

Dr. Niall Muldoon, Ombudsman for Children

Michael Feeney (ISL Interpreter)

The State should be set up in such a way that parents can be sure their children will have access to whatever services they need. Without that guarantee then an Advocacy Service becomes a necessary part of the infrastructure for those parents and their children."

You can find this research on our website **[Representative Advocacy for Children with Intellectual Disabilities]**

Advance Healthcare Directives for Mental Health – from Law to Practice

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

On 23rd January, 2025, we held a multi-perspective conference on ‘Advance Healthcare Directives for Mental Health – from Law to Practice’. The conference was held in the UCD University Club and funded by the HSE Spark Innovation Fund.

Advance healthcare directives (AHDs) are now a legal entity in Ireland under the Assisted Decision-making (Capacity) Act, 2015 (ADMCA) and, with exceptions, are applicable to mental health treatment. Evidence shows that advance care planning in mental health can reduce involuntary admissions, empower service users, and improve therapeutic relationships. However, as in other countries, there is still an ‘evidence to practice gap’ and mental health AHDs are rarely used in practice.

The conference covered expert clinical, legal, ethical, and lived experience perspectives on advance care planning in mental health, with speakers from Ireland, England, Germany, France and Northern Ireland. Experts by experience, advocates, human rights and equality leads, legal experts, nurses, occupational therapists, peer support workers, policy advisors, psychiatrists, psychologists, researchers and social workers attended.

Attendees at the AHD’s for Mental Health Conference, UCD

We aimed to create an atmosphere where people from different backgrounds felt comfortable to share their views and where all perspectives were equally valued. There were three sessions, ‘Law and Ethics’, ‘Irish Experience’ and ‘Implementation and Practice’, and each involved several short talks, followed by a question and answer session. The final session culminated in a panel discussion focusing on ‘How AHDs can be implemented in Irish mental health services’.

Law and Ethics:

Mary Donnelly, Professor of Law, University College Cork opened the conference setting out the legal and policy context of AHDs in Ireland, and chaired the morning session focusing on ‘Law and Ethics’. Dr Tania Gergel, Director of Research at Bipolar UK and Honorary Senior Research Fellow in the Division of Psychiatry at University College London, outlined three core principles, which should underpin progress toward implementation of mental health AHDs: expertise through experience; rethinking risk/harm and cost; and that AHDs can be simple and effective in practice.

Advance Healthcare Directives for Mental Health – from Law to Practice

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

Matthé Scholten, researcher and lecturer at the Institute for Medical Ethics and History of Medicine, Ruhr University, Bochum, Germany, presented research indicating that service users strongly endorse AHDs, and want support to create them, and barriers such as radical treatment refusals are not borne out in practice. Alex Ruck Keene SC (Hon), Professor of Practice at King's College London and Barrister spoke on legal aspects of advance care planning in mental health. He emphasised that an AHD should be regularly reviewed and treated as a living document.

Irish Experience:

The mid-morning session focusing on the 'Irish Experience' was chaired by Prof. Brian O'Donoghue, Department of Psychiatry, UCD. Dr Jennifer Allen, Senior Social Worker, Older Persons Mental Health, shared insights from her PhD research on multi-stakeholder (service user, family carer and healthcare professionals) perspectives of Advance Care Planning. Dr Maria Redahan, shared findings from survey research conducted in Tallaght University Hospital on 'Psychiatry Inpatients' Knowledge and Attitudes towards AHDs'.

A group photo of the Panel of experts at the Conference

Michael John Norton, early career researcher and author, presented on the use of WRAP (Wellness Recovery Action Plans) to facilitate AHDs. Prof. Gavin Davison, Praxis Chair of Social Care, Queen's University Belfast shared insights on the development of ACP policy & practice in Northern Ireland.

Implementation and Practice:

The afternoon session on 'Implementation & Practice', along with the panel discussion was chaired by Prof. Brendan Kelly, Department of Psychiatry, TCD. Dr Aster Harrison, Aix-Marseille University, shared insights from their research on the role of peer workers in facilitating AHDs in France.

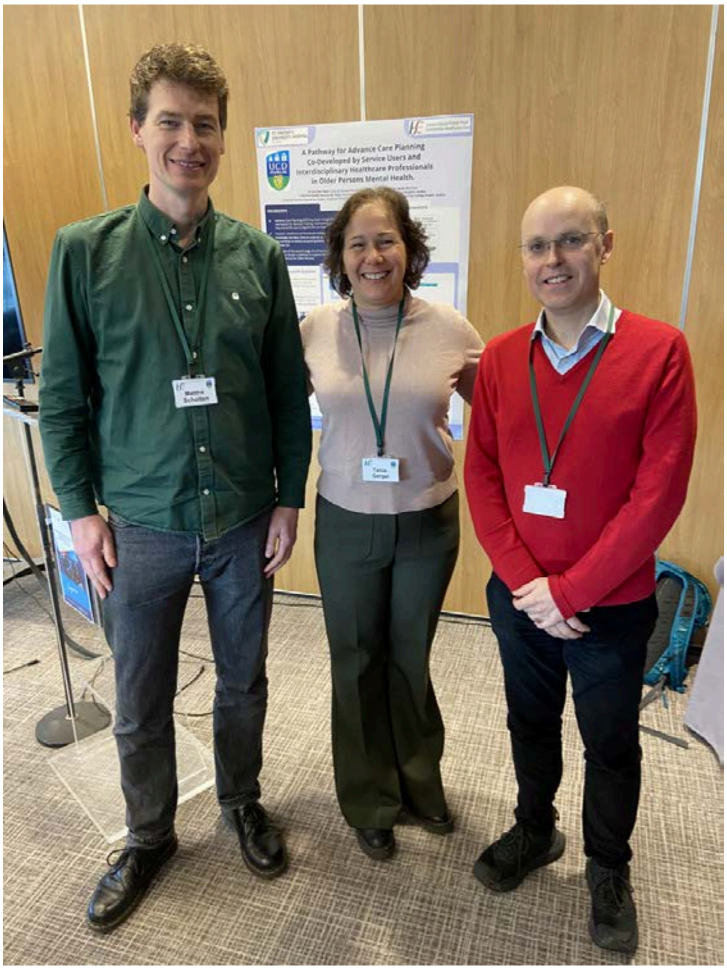
Dr Nuala Kane, Consultant Psychiatrist, St Vincent's University Hospital and Adjunct Clinical Lecturer at UCD, spoke on the role of psychiatrists and emphasised the importance of the therapeutic relationship as a key facilitator of AHDs, which resonated with attendees.

Themes:

Some of the main themes identified were: The importance of support and what it looks like; the value of lived experience; trust and the therapeutic relationship; the role of capacity assessments; and complexity in mental health.

Advance Healthcare Directives for Mental Health – from Law to Practice

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



Matthe Scholten, Tania Gergel, Alex Ruck Keene

Outcomes:

There were 65 delegates at the conference; of these 28 (43%) completed a feedback survey. Respondents rated sessions as “excellent” or “good” in 99% of cases. “Great range of speakers bringing together research, clinical & lived experience perspectives. It was valuable to hear from other international speakers when considering the Irish context. Enthusiasm from all speakers was evident. Very enjoyable and well organised event” (Psychiatrist). Delegates reported improved knowledge on mental health AHDs, and improved confidence in making or supporting someone to make an AHD. There was a significant interest in Wellness Recovery Action Plan (WRAP) as a tool for advance care planning. “Very interesting insight in to current level of interest and engagement in AHDs in Ireland, particularly the exploration of WRAP crisis planning and how it correlates to advanced healthcare planning in some very useful steps.” (Human Rights and Equality Lead). There was also a strong appetite for practical examples of AHDs in the feedback. “I'd love to look at practical examples of AHDs…. where we actually saw like 5 or 6 AHDs and how they were used in practice” (Advocate).

The Next Steps:

Following the conference, many delegates opted to join a network for those interested in events and developments related to mental health AHDs. We envisage this network as a ‘community of practice’, which will initially involve quarterly online seminars with guest speakers to share learning. Following on from conference feedback, the first seminar (date TBA) will have a practical focus on how to create mental health AHD documents. The network is open to all and interested parties can sign up by emailing nuala.kane@ucd.ie.

Opening the umbrella of the Assisted Decision-Making (Capacity) Act 2015 to include litigation; A summary of the decision *'In the matter of the Assisted Decision-Making (Capacity) Act 2015 and in the matter of JD'*

Catriona Sneddon, NUI Galway Human Rights Law Placement Student, National Office for Human Rights & Equality Policy

A recent decision by O'Connor J 'In the matter of the Assisted Decision-Making (Capacity) Act 2015 and in the matter of JD' addressed whether assessing a relevant person's capacity to litigate now comes under the scope of the Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act). The Court held that where concerns arise over the relevant person's capacity to conduct proceedings or instruct their legal counsel, the 2015 Act may now be applied.

The case involved the determination of whether a relevant person (RP) lacked the capacity to litigate regarding proceedings that his solicitors had commenced as per his previous instructions. These proceedings related to a claim under s.117 of the Succession Act 1965 in relation to proper provision. The Applicant, who is the solicitor of the RP and the individual bringing the capacity application, sought a declaration that the RP lacked the capacity to make decisions in relation to his property and affairs. The applicant sought the appointment of a decision-making representative (DMR). The Applicant raised concerns as to the RP's capacity to understand the consequences that might arise from failure to engage with his legal advisors in relation to his litigation, even if the support of a co-decision maker was made available to him.

The objective of appointing a DMR in these circumstances was to both respect and preserve the will and preference of the RP, as well as ensuring that his property and affairs would be dealt with for his benefit. The applicant believed that without the appointment of a DMR, the proceedings would carry on without the presence of the RP and would have a negative outcome, such as the possibility of dismissal or a potential compromise settlement being negatively affected. Therefore, counsel for the RP determined it essential that a DMR be appointed to protect the RP's interests.

The Court leaned on the leading case for the functional assessment of capacity is *Fitzpatrick v FK* and the six principles for capacity in regard to medical treatment:

1. There is a rebuttable presumption that an adult patient has the capacity to make a decision to refuse medical treatment,
2. In determining whether a patient is deprived of capacity to make a decision to refuse medical treatment, the test is 'whether the patient's cognitive ability has been impaired to the extent that he or she does not sufficiently understand the nature, purpose and effect of the proffered treatment and the consequences of accepting or rejecting it in the context of the available (including any alternative treatment at the time the decision is made',

3. The cognitive ability will have been impaired to the extent that he or she in incapable of making the decision to refuse by reason of the following factors:

- the patient has not comprehended and retained the treatment information and the consequences likely to ensue from their refusal,
- the patient has not believed the treatment information, in particular, that death may be the likely outcome,
- the patient has not weighed the treatment information, the alternative choices, and the likely outcomes, in the balance in arriving at the decision.

Opening the umbrella of the Assisted Decision-Making (Capacity) Act 2015 to include litigation; A summary of the decision *'In the matter of the Assisted Decision-Making (Capacity) Act 2015 and in the matter of JD'*

Catriona Sneddon, NUI Galway Human Rights Law Placement Student, National Office for Human Rights & Equality Policy

4. The clinician is under a duty to impart information as to the medically advised appropriate treatment, the risks and consequences and the choices available to the patient.

5. The clinician must recognise and note if misunderstanding and misperception of the treatment information is an issue as this may be evidence of a lack of capacity. An irrational decision or a decision made for irrational reasons is irrelevant to the assessment.

6. Regard must also be had to the gravity of the decision and the consequences that are likely to ensue.

The Court held that even though the capacity required for litigation is different the principles in Fitzpatrick *v FK* continue to apply when it comes to determining litigation capacity.

In determining litigation capacity as per Section 8 of the Guiding Principles of the Act, the burden of proof to establish that the RP lacks capacity falls to those declaring the incapacity of the RP. The standard of proof on which this assertion rests is on the balance of probabilities.

The Court confirmed that in making a declaration as to the capacity of an RP, expert evidence on the behalf of a doctor or some other professional, such as an occupational therapist or a registered nurse, is customarily required. The Court held that it is particularly useful to have reports from other professionals who are involved with the RP which include reports from social work, independent advocacy or an independent solicitor. This allows the court to see the full picture, as it provides the court with the most in-depth information possible in order to determine whether or not to appoint a DMR.

In the assessment of capacity for litigation, the Court held that tests solely based on memory, for example the Mini Mental State Exam, have no place in the assessment of a person's capacity. In accordance with the 2015 Act, a person can still possess capacity if their memory is impaired or if they make seemingly unwise decisions, such as refusing to accept their lawyers' instruction or denying their assistance to the court.

The Court held that the RP must, during the assessment of their capacity to litigate, be provided with all of the relevant information, given to them in a way that is both clear and concise, so that they can best understand their situation and its consequences.

The Court further stated that in keeping with the functional assessment of capacity, it is not necessary for the RP to fully comprehend the complexity of the litigation in order for them to exercise their capacity. However in order to instruct their legal council the RP must have an understanding of the consequences involved in whether or not they participate in their litigation.

The RP must also be able to use or weigh this information, regardless of the decision. Furthermore, the test to determine the capacity to litigate allows for the fluctuation of capacity, as an RP's levels of capacity can change and therefore their capacity must be reassessed if there is an indication of any such change, either positive or negative.

Opening the umbrella of the Assisted Decision-Making (Capacity) Act 2015 to include litigation;
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The decision provides a non-exhaustive list of factors that the court must take into consideration when assessing a RP’s capacity to litigate:

- their understanding of the particular proceedings,
- the role of the court, lawyers and the issues involved,
- their ability to formulate, evaluate, and articulate questions, replies as decisions, as well as their ability to communicate i.e. feelings, preferences, values and interest.

O’Connor J. emphasized measures to both enhance and enrich litigation capacity. These include:

- the manner (including tone of voice) of the experts and lawyers;
- the accompaniment of a support person, the time of day, length of session, a calm environment;
- the involvement of professional services such as an advocate, speech and language therapist, or a social worker.

This decision highlights the importance of Section 139 of the 2015 Act, namely the importance of the presence of the RP, except for in certain circumstances where their presence would prove to be an injustice on their behalf.

If the Court finds itself in a situation where the RP is unable to attend, the Court will take all reasonable steps to ensure that their voice is heard, either through an advocate or a solicitor with specialist knowledge of capacity interventions.

This decision, the third written decision from the Circuit Court since the commencement of the 2015 Act, is important as it concerns the application of the Assisted Decision-Making (Capacity) Act 2015 to issues of litigation. This legal area has not come under the consideration of the Court in relation to the 2015 Act to date. The decision provides clarity and assurance to practitioners and Relevant Persons alike.

Individuals who communicate in unique ways, along with their supporters, are invited to participate in a research project on Ireland's new Capacity Act.

Dr. Clíona de Bhailís,
Centre for Disability, Law and Policy, University of Galway

Age Range Extended! Now including people up to 35 years of age

What is this research about?
This research project wants to learn how young people who are non-speaking, sometimes speaking, or communicate differently can access and use the support agreements under Ireland's new capacity Act.

The Assisted Decision-Making (Capacity) Act 2015 was given full legal force in April 2023. The Act made a lot of changes to Irish law including offering people an opportunity to make formal agreements with their chosen supporters for the first time. It also changed how a person's decision-making ability is assessed to include being able to communicate a decision to others.

Who can take part?
The project is looking for young people who are non-speaking, sometimes speaking or communicate differently and their supporters to take part. To take part young people have to be between 16 and 35 years of age and living in the Republic of Ireland.

In this project different or alternative communication includes communicating using high or low tech alternative and augmentative communication (AAC) devices such as letters, symbols, pictures or speech generating devices and informal communication such as gestures, vocalisations, facial expressions and body language. Supporters could be a young person's parents, guardians, siblings or paid support staff.

EXTENDED

→ **LEARN MORE**

If you have questions or are interested in taking part, you should contact Clíona at cliona.debhailis@universityofgalway.ie or on 086-0081153 (call or text)

Individuals who communicate in unique ways, along with their supporters, are invited to participate in a research project on Ireland's new Capacity Act.

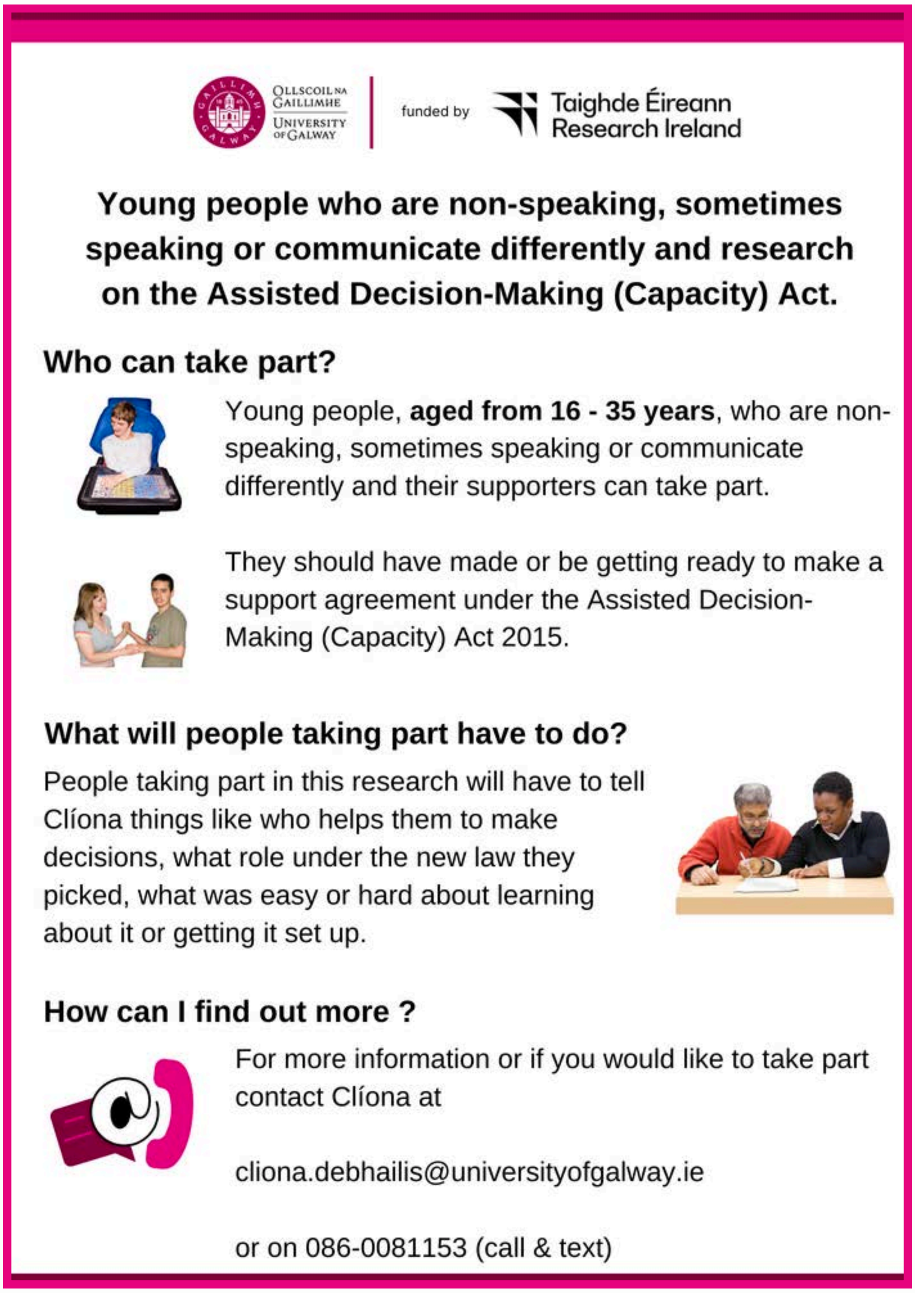
Dr. Clíona de Bhailís,
Centre for Disability, Law and Policy, University of Galway

What will people taking part have to do?

People taking part in this research will be asked to tell Clíona about how they are preparing to transition to a support agreement under Ireland's new capacity Act if they are under 18 or about their experience of making and registering a support agreement if they are over 18. They will be asked about how they communicate, who supports them to make decisions, what sorts of decisions they have made in the past. They will be asked questions about what the registration or transition process is like, and what barriers they faced. There will be lots of different ways for people to share their experiences including in writing, by drawing or taking pictures, using video recordings and/or interviews. People taking part will have to be happy for Clíona to use what they share in her research.

LEARN MORE

If you have questions or are interested in taking part, you should contact Clíona at cliona.debhailis@universityofgalway.ie or on 086-0081153 (call or text)



OLLSCOIL NA GAILLIMHE UNIVERSITY OF GALWAY | funded by Taighde Éireann Research Ireland

Young people who are non-speaking, sometimes speaking or communicate differently and research on the Assisted Decision-Making (Capacity) Act.

Who can take part?

Young people, **aged from 16 - 35 years**, who are non-speaking, sometimes speaking or communicate differently and their supporters can take part.

They should have made or be getting ready to make a support agreement under the Assisted Decision-Making (Capacity) Act 2015.

What will people taking part have to do?

People taking part in this research will have to tell Clíona things like who helps them to make decisions, what role under the new law they picked, what was easy or hard about learning about it or getting it set up.

How can I find out more ?

For more information or if you would like to take part contact Clíona at

cliona.debhailis@universityofgalway.ie

or on 086-0081153 (call & text)

Accessibility – making it easier to take part

It is important to Clíona that young people and their supporters who are interested in the research can be involved or simply have easy ways to contact her to find out more. Please let Clíona know what would help you to take part. You can contact her by phone, email or text and information about the project is available in multiple formats – plain language, EasyRead, large text etc. Please also let her know if you need sign language interpretation or other supports.

National Healthcare Communication Programme

Winifred Ryan, National Directorate: Public Involvement, Culture and Risk, Health Service Executive

Communication skills training aims to:

> …enhance what learners already do well, expand each learner's repertoire of skills and work with applying comfortable skills in more complex circumstances.
> (Kurtz & Cooke, 2017, p.66).

Such training not only focuses on behaviours and skills, but also frameworks to initiate, guide and complete difficult conversations, taking account of, and responding to, the person's needs.

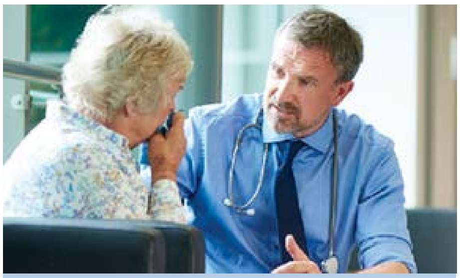
Delivering adult learning methodologies

The National Healthcare and Communication Programmed is designed for all HSE staff, is delivered via four core modules (and some associated deep dive modules) and is designed to use a range of adult learning methodologies including classroom-based discussion, role play, reflective practice, and group work. All Modules have web-based support materials (videos, case-studies, skills cards, etc.) on an easy-to-access section on the HSE website. This is used to store electronic links to articles and recommended readings for use as a resource by staff to enhance communication skills learning and development.

Modules include:

Module 1: Making Connections
https://bit.ly/3bxnjwH

Module 2: Core Consulation Skills
https://bit.ly/3eR02YD



Module 3: Challenging Consultations
https://bit.ly/47OYtUf

Module 4: Communicarting with Colleagues & Promoting Teamwork
https://bit.ly/3bu407F

Module 5: Demonstrating Empathy
https://bit.ly/3Bwxsr0

Module 6: Shared Decision Making
https://bit.ly/3qwxBnT

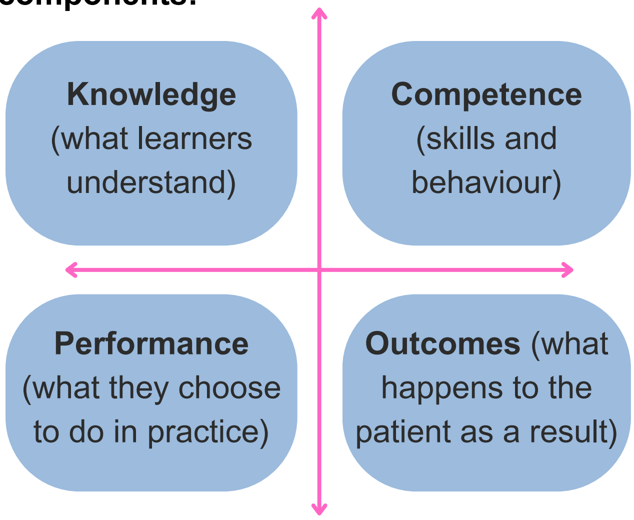
Click each ⬇ to download the modules

Communication skills training

Therapeutic communication is a complex interaction reliant on a willingness to engage and the skills to do so. A skill is a learned ability to do something well. Raising awareness or building knowledge is not sufficient. To improve communication, attention must be given to developing communication skills.

It is widely accepted that communicating in health and social care is different from how we communicate socially. This is not an innate talent, and effective skills and behaviours do not develop simply by being a 'caring' person or by observing others in the course of their work (Kurtz & Cooke, 2017)*. There is, however, an established and growing evidence base that communication skills can be taught and that they result in measurable improvements in performance (Kurtz & Cooke, 2017).

Improving professional communication competence relies on addressing 4 components:



Knowledge (what learners understand)

Competence (skills and behaviour)

Performance (what they choose to do in practice)

Outcomes (what happens to the patient as a result)

A culture of sharing information

The surgeon sat with me and explained all even drew pictures…

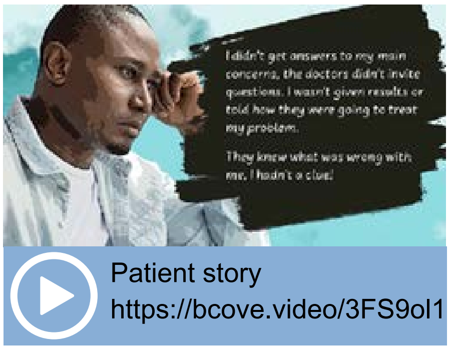
I sometimes struggled to understand medical language related to my illness...

For healthcare staff, sharing information with patients is a core communication skill, and a challenging one. Many surveys point to patients leaving consultations not well informed, which can lead to poorer healthcare outcomes. Staff often present information with a complexity or speed that may easily overwhelm the attention of patients who are ill and worried. Information is then lost on patients, and time is wasted. When staff pause to allow the patient time to think about the information given, patients will often respond with key disclosures and questions.

We envision a culture where sharing information is a dialogue, with the goal of shared understanding and where the person's perspective is explored throughout the conversation.

Skills video
https://bcove.video/3JqXUGn

Piece-to-camera
https://bcove.video/3WBKtIN



Patient story
https://bcove.video/3FS9ol1

Download our app

The National Healthcare Communication Programme's app is a practical tool to help you to consistently use core communication skills in each and every encounter with the people who use our services.

www.nhcprogramme.ie/download @NHCProgrammme

App Store Google Play

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* Kurtz, S. and Cooke, L. (2017) Learner-centred communication training in Kissane, D., Bultz, B., Butow, P., Bylund, C., Noble, S. and Wilkinson, S. (eds) Oxford Textbook of Communication in Oncology and Palliative Care. 2nd edn. Oxford: Oxford University Press, pp 61-70.