



An Oifig Náisiúnta um Chearta
an Duine agus Beartas Comhionannais

National Office for
Human Rights and Equality Policy

Human Rights and Equality Matters

#NOHREP

Autumn 2024

Highlights in this edition:

- 15th International Disability Law Summer School
- Diagnostic Overshadowing
- Access to ISL and deaf interpreters
- Financial autonomy for people with disabilities
- Innovating for Inclusion- National Learning Day



National Office for Human
Rights and Equality Policy

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



Welcome

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

Welcome to our Autumn edition of *Human Rights and Equality Matters*. In this edition we celebrate the breadth of equality and human rights work currently underway around the country.

Aine Flynn helpfully provides an update of the work of the Decision Support Service as we enter into the 18th month since the commencement of the Assisted Decision Making (Capacity) Act 2015. Joanne Condon from the National Advocacy Service for People with Disabilities reflects on challenges and trends advocates are experiencing through the country in trying to uphold the rights of people with disabilities. Joanne Haffey provides a report on the launch of the social policy document 'Short-Changed' which identifies barriers to financial autonomy for people with disabilities. Micheál Walsh from the National Advocacy Service for People with Disabilities who led the work gives voice throughout the report to people who experience significant barriers to financial autonomy.

Ber Grogan from Mental Health Reform reflects on the long awaited Mental Health Bill 2024 and outlines some of the work Mental Health Reform are undertaking to ensure there is widespread public engagement as the Bill passes through the legislative process. Elaine McCaughley highlights a recent collaboration between the National Office for Human Rights and Equality Policy and a team of self-advocates in St. Michael's House on consent. Roisin O'Neill from St. Michael's House reflects on why it is essential to make national policy accessible for people with an intellectual disability. Elaine also provides an update on the revision of the DNA-CPR policy and highlights a new resource which has been developed for staff and trainers on the National Consent Policy.

Norma O'Donnell gives an overview of the excellent contributions at the 15th International Disability Law Summer School in NUI, Galway on 'Exploring Gender and Disability Justice'. Joanne Haffey distils the key lessons from a recent workshop on diagnostic overshadowing and how this is a fundamental barrier to the realisation of equitable health outcomes for people with disabilities. Sandra Guidon celebrates the successful National Sharing Day hosted by Marie Kehoe-O'Sullivan and her team in the HSE Quality Improvement Disability Team. The day was a celebration of work which has been undertaken across services trying to support the spirit and the letter of the Assisted Decision-Making (Capacity) Act 2015 in the lives of people with disabilities.

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Rights & Equality Matters





Welcome

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

In July we were very saddened to learn of the sudden loss of our friend and retired colleague Leigh Gath. We dedicate an article to her memory and her passionate advocacy for the realisation of rights of people with disabilities.

Barbara Brennan, Workplace Mental Health consultant, highlights the work of Mental Health Matters, a new NGO which has just launched a mental health campaign. Dr. Cliona de Bhailís from the Centre for Law and Disability Policy in NUI, Galway is seeking professionals to engage in a new chapter of her research on how young people who are non-speaking or who communicate differently can use the Assisted Decision-Making (Capacity) Act 2015. Elaine Grehan from the Irish Deaf Society provides guidance on the do's and don'ts of providing Irish Sign Language interpretation. She shares insights into how the skills of a deaf interpreter can provide additional supports to a deaf person in a health and social care context.

Teresa Mallon from St. John of Gods Community Services shares the success of the 'Butterfly lunch' which was a fundraising gathering of friends, advocates and supporters of the work of St. Joseph's Shankhill which provides a social model of person-centred dementia care. Martina Cooney is seeking to engage with people on a project which aims to uphold the rights of people whose capacity is in question. The NDA research on the experience of people exiting wardship continues. The NDA are seeking participants on a rolling basis as the numbers of people exiting wardship increases. Dr. Nicola Maxwell from the ID+ programme in UCC shares details of a forthcoming conference in UCC in December 2024 which addresses the rights of persons with Disabilities to access third level education. We are delighted to promote a forthcoming event in the Beckett Theatre in Dublin on November 4th 2024 by Encore Productions, a theatre company from Dundalk supported by Rehabcare who are on tour with their wonderful production 'The Beckett List'. This is a beautiful production and a must see. Finally check out our new look resources page - do send us on any feedback to make this more user friendly.

Thank you all for your continued engagement with our office as we build momentum on the importance of upholding people's human rights and right to equality.

Best wishes for an enjoyable mid-term break.

Caoimhe



18 Months On - The Decision Support Service

Áine Flynn, Director of the Decision Support Service

We are now approaching 18 months as an operating service and the DSS is busy with all our statutory functions under the Assisted Decision-Making (Capacity) Act 2015.

The demand for information is increasing all the time. The DSS Information Service team has now managed over 30,000 requests for information from members of the public and professionals.

Our busy schedule of presentations to diverse audiences at on-line and in-person events has resumed after the summer, including events with the Irish Wheelchair Association, the Irish Aftercare Network, service users of the Brothers of Charity, families of users of Cheeverstown Services and at the annual conference of Nursing Homes Ireland. We also provided an overview and update in relation to the functions of the DSS at the annual mental health service providers' engagement days in Limerick and Athlone, organised by our colleagues in the Mental Health Commission.

At the end of September, the DSS attended a periodic check-in with the HSE ADM Leads team. These meetings provide a valuable opportunity for the DSS to learn about the implementation of the 2015 Act on the ground in the healthcare sector and to try to answer some of the practical questions arising.

The DSS was pleased to be invited to the HSE Disability Quality Improvement National Sharing Day in Dublin Castle, which is always an inspirational event, and this year had assisted decision-making as its chosen theme. A key message from some of the impressive experts by experience who shared their stories was that persons with disabilities must be facilitated as far as possible to make their own decisions, drawing on their natural supports. As the DSS often has occasion to say, the formal decision support arrangements under the 2015 Act are there to be deployed as problem-solving tools and only as required.

This theme of minimal intervention and support for autonomy has also arisen in the DSS's engagement with the banking sector. The DSS has had very positive meetings with the heads of Vulnerable Customer Units in the main banks to help ensure that the 2015 Act is correctly applied to promote rather than impede access to financial services.

At the end of September, there were more than 1,400 registered decision support arrangements on the DSS register. More than half of these were enduring powers of attorney with over 1,100 further EPAs submitted for review and registration. The DSS has registered over 500 decision-making representation orders, made by the Circuit Court and by the wardship court.

Registrations of the lower-tier decision-making assistance agreements and co-decision-making agreements have been fewer but are increasing steadily with hundreds of applications now in progress.

We are working with the HSE to pilot automated access to our registers.

In the meantime, enquiries may be sent to registersearches@decisionsupportservice.ie Due to the level of demand from the courts, the DSS is currently running a campaign to recruit new members to its panel of decision-making representatives. Information about this and other news and updates, as well as resources in a variety of formats can be found on the DSS website.



Áine Flynn
Director of the Decision Support Service



seirbhís tacaíochta
cinnteoireachta

decision support service™

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



Independent Advocacy and the Assisted Decision-Making (Capacity) Act 2015



Joanne Condon, National Manager, National Advocacy Service

The Assisted Decision-Making (Capacity) Act, 2015 is built on a rights-based approach. It has transformed how we view decision-making in Ireland for people who may require support to make decisions independently.

The National Advocacy Service for people with disabilities (NAS) has worked on 249 ADM related advocacy cases (to July 2024) since the Act commenced and has seen a significant increase in demand for advocacy support relating to the Act. Demand for advocacy will likely continue to grow as the Act becomes more embedded. Much of NAS's work in the ADM space has concentrated on supporting adherence to the guiding principles of the Act.

Overall, NAS has observed an over emphasis on the top tier level of decision support - the Decision-Making Representative (DMR). A DMR is often the 'go to solution' people turn to. However, fundamental to the core principles of the Act is the concept that action should be the least restrictive on a person's rights and freedoms. Positively, NAS has observed instances where both professionals and the court have actively promoted this principle by identifying a less restrictive support mechanism for individuals appearing before the court, such as a co-decision-making arrangement rather than a DMR. But greater equilibrium is still needed to ensure full adherence to the principles of the Act over time.

“
At the heart of the Act is the recognition that all people have the right to make decisions about their own lives.
”

At the heart of the Act is the recognition that all people have the right to make decisions about their own lives. As advocates, we work as partners with the individuals we support, ensuring their voice is heard and respected in all decision-making processes. Through advocacy, we assist them in understanding their choices, options, and rights while ensuring that their preferences are central to the decisions being made on their behalf. We support people to access legal representation where required.



It is the role of the advocate to ensure that a person's human rights are respected throughout the legal process and that the Circuit Court hears their voice and can take their views and preferences into consideration. A key facet of NAS Advocacy is that it is person led and directed, rather than being directed by any third party or court system, hence its 'independence.' It is not the court that directs the Independent Advocate, but rather the 'relevant person' who is in the driving seat. The person determines the issues they wish to seek advocacy support with, and the person and their Advocate agree an Advocacy Plan together. Fundamental to ensuring that an Advocate represents the voice of the person with authenticity is the Advocate having sufficient time to meet with the person, build trust and ensure a thorough and accurate understanding of their unique will and preferences, free from the influence of all third parties.

A key facet of high-quality independent advocacy work is a keen focus on amplifying the voice of the person. Having voice and being able to assert views during interactions with legal authorities and justice systems is a key factor in individuals' assessments of whether authorities act fairly and are legitimate in legal processes (Baker et al., 2014; Cohen-Charash & Spector, 2001; Lind & Tyler, 1988). People with disabilities face multiple barriers in trying to exercise their rights and influence in the court system. The system can be complex, intimidating and very often difficult for people to navigate and understand without the rights supports. Hence the need for Advocacy support.

In our advocacy work to date, we have supported numerous individuals to understand information, to have their functional capacity recognised and supported, to put decision support arrangements in place, to engage meaningfully with their legal representatives, to attend court and to have their voices heard or represented to the court in accordance with their will and preferences. In almost all instances, the role of the advocate was well understood and robustly promoted by the Court. The Code of Practice for Independent Advocates produced by the Decision Support Service has been a useful resource for clarifying the Advocates role to all parties. The Act has reaffirmed the vital role that Independent Advocacy plays in ensuring that individuals can lead independent, self-directed lives. NAS looks forward to continuing to develop person-centred, high quality advocacy practice in line with the guiding principles of the Act as well as continuing to provide both informal and formal supports to enable people to exercise their decision-making capacity.

‘Short changed: Barriers to Financial Autonomy for People with Disabilities in Ireland’.



Joanne Haffey, ADM Senior Project Manager

On 10th October 2024 the National Advocacy Service launched their social policy paper ‘Short changed: Barriers to Financial Autonomy for People with Disabilities in Ireland’ to a packed room in the offices of the Irish Human Rights and Equality Commission.

The paper highlighted that despite significant advances in progressing the rights of people with disabilities, it has become increasingly evident that many people with disabilities face significant barriers in exercising financial independence and accessing financial products such as bank accounts. The types of barriers people with disabilities are facing include:

- difficulties in being able to open a bank account
- for those who have a bank account, difficulties in accessing the money in that account
- banks imposing daily withdrawal limits on bank accounts for people with disabilities
- banks insisting that people with disabilities would have co-signatories on their accounts

Caoimhe Gleeson from the National Office for Human Rights and Equality Policy moderated the panel discussion at the launch which included:

- Shelly Gaynor, Disability Activist
- Paul Alford, Disability Activist with Inclusion Ireland
- Derval McDonagh, Inclusion Ireland
- Linda Ayres, Irish Banking and Culture Board
- Clare O’Neill, National Advocacy Service for People with Disabilities

The panel discussion was lively and dynamic drawing on examples of persons with a disability accessing and using banking services. The discussion also examined positive developments that have been made in the financial services sector for people with disabilities as well as the challenges that remain.



Caoimhe Gleeson, Paul Alford, Rosemary Smith, Deputy Pauline Tully TD, Joanne Condon, Dearbla Crosse, Micheál Walsh



Amanda Casey, Joanne Haffey



Shelly Gaynor, Paul Alford, Derval McDonagh, Linda Ayres, Clare O’Neill, Caoimhe Gleeson



'Short changed: Barriers to Financial Autonomy for People with Disabilities in Ireland'



Joanne Haffey, ADM Senior Project Manager

Next Steps

The Social Policy Paper and the discussions which took place at the launch event identified a requirement for a multi-sectoral approach to ensure the rights of people with disabilities to exercise their financial autonomy are fully realised and supported. Some of the key next steps that were identified include:

- Education to all service providers and financial institutions on how decisions impact or limit a persons quality of life
- A legislative framework for responses to financial abuse and all forms of abuse in Ireland
- All steps which must be taken to support a person in managing their own finances and spending how they see fit
- Financial services must commit to consulting people with disabilities to ensure access to banking is fully accessible from the design to implementation stage



Click the picture above to read the full report



A time for change?

Reflections on the New Mental Health Bill 2024



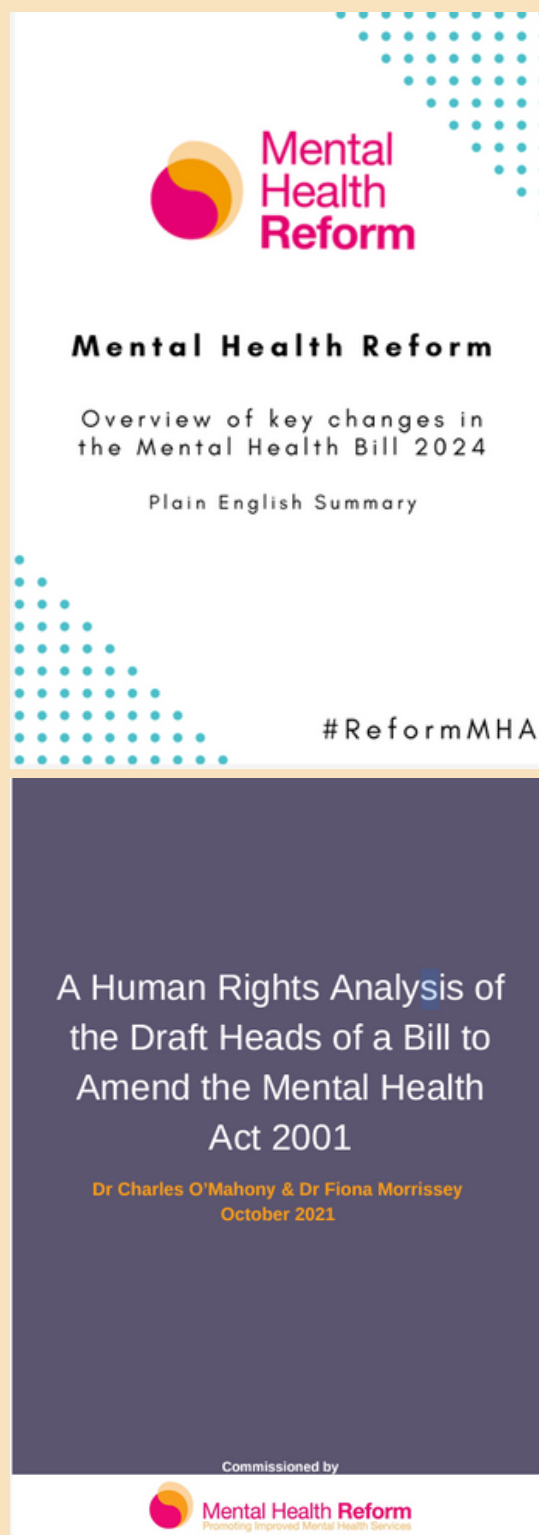
Ber Grogan,
Policy and Research Manager Mental Health Reform

Mental Health Reform (MHR) is Ireland's national coalition on mental health. MHR has been advocating for the reform of the Mental Health Act, 2001 for over a decade. They have been very involved in the Assisted Decision-Making (Capacity) Act 2015 and have in recent weeks welcomed the progress of the new Mental Health Bill 2024.

The Mental Health Act, 2001, though very progressive for its time, is now completely out of line with human rights, the UN Convention on the Rights of Persons with Disabilities (UNCPRD) and recovery-focused, person-centred care.

The Mental Health Bill will have a profound impact on people with mental health difficulties, their family members and carers. Every year, over 15,000 people in Ireland are admitted to in-patient mental health units. Last year, more than 2,500 people were involuntarily detained under the Mental Health Act. It is paramount that people who access mental health services receive care that respects their will and preferences and supports their recovery.

The second stage Dáil debate of the Mental Health Bill took place on the 18th and 19th of September. This reform bill has been long-awaited and already received significant consultation and discussion. The Draft Heads of the Bill were published in July 2021 and MHR published a Human Rights Analysis on the Heads of the Bill in October 2021. The Bill then went through the Pre-Legislative Scrutiny process and the Sub-Committee on Mental Health produced a PLS report with 19 recommendations.



A time for change?

Reflections on the New Mental Health Bill 2024

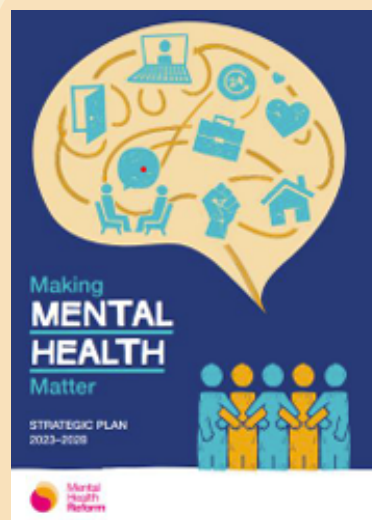


Ber Grogan,
Policy and Research Manager Mental Health Reform

Mental Health Reform published a [Plain English guide](#) to support people to understand the key changes in the Mental Health Bill. The guide aims to make the legislation more accessible to members of the public. It has been written to encourage optimum discussion about the new laws for everyone concerned with mental health.

[MHR's research](#) shows that many people using mental health services do not feel that they are being treated with dignity or respect. They say they do not have enough choice or control over their mental health treatment, such as the medications they are given. Without urgent reform, people with mental health difficulties will continue to be impacted by inappropriate and outdated practices. It is paramount that people who access mental health services receive care that respects their will and preferences and supports their recovery, and that new legislation aligns completely with the Assisted Decision-Making (Capacity) Act 2015.

You can follow MHR's campaign to [#ReformMHA here](#)




MENTAL HEALTH ACT 2001 TOOLKIT



Making Consent Clear: A collaboration with St. Michael's House



Elaine McCaughley, Programme Lead, National Consent Policy

In January 2024 we launched the updated HSE National Consent Policy 2022 v1.2. Since then the Easy to Read document of the Policy has been updated and is available on hse.ie/nationalconsentpolicy. 

To promote this resource we wanted to demonstrate the practical benefits of making information accessible, and bring the Easy to Read Consent Policy document to life. With this in mind I approached St Michael's House to try to find out what service users thought of the Easy to Read resource, whether it is useful to them, and to hear their thoughts on consent in health and social care.



Cora, Ciara & Fintan



Jodie & Daniel



Peer Leaders, Cora, Ciara, Fintan,
Holly & Brad



Brad

Making Consent Clear:

A collaboration with St. Michael's House



Roisin O'Neill, Quality & Risk Manager

For the individuals supported by St Michael's House and the staff the invitation to support the launch of the Easy to Read Consent policy was very welcome.

Supporting individuals with Intellectual disabilities to explore a topic such as consent, and decision-making can be a daunting task for many staff. All too often the lack of available resources or accessible material can impact on getting the conversation started.

Within St Michael's House we often find that we are constantly trying to adapt and develop information into a format that makes sense to the people we support.

Past experience has been that when policies are updated, despite having a real impact on the lives of those we support, there were no accessible format or resources available. As a service, we work to develop resources that will support individuals to understand the concepts and to begin discussions about what this might look like in their life.

Beyond the life of this project, we really wanted to support the conversation across the organisation, and for the individuals supported to be the ones to lead this conversation. And so began the idea of peer-to-peer workshop! While we held the workshop event on 31 July, preparations began back in May.

A group of five individuals supported by staff met weekly to consider the Easy to Read Consent Policy and explore ways that we could use the document to strengthen understanding about consent and decision-making. The highlight for us of being involved in such a project is the shared learning for all. When thinking about what consent is, and other words that can be useful to explain consent, one of the individuals Ciara explained it so well when she said 'Consent means asking somebody "Is it ok...?"'

During the peer-to-peer event that was held on 31 July, there was ample opportunity for us to demonstrate consent in action! Prior to the event, we needed to check if those who attended the event consented to having photos and videos taken on the day! The individuals developed an easy read consent form for the day. On the day of the workshop, there was an array of examples of how people are supported to understand information by staff who know the individuals well. They used everyday examples that were important to each individual service user, showing the many ways that they can give or refuse consent, and a variety of communication tools that individuals use to engage and be heard beyond the traditional spoken word.

Having a Policy in an easy read format is one piece of the puzzle, a useful one that we can refer to on a regular basis to start conversations and influence practice as we uphold the rights of those supported across this disability service.




New Resource Alert - HSE National Consent Policy Slide deck



Elaine McCaughley, Programme Lead, National Consent Policy

The National Office for Human Rights and Equality Policy have developed a slide deck on the HSE National Consent Policy in consultation with stakeholders across a range of services nationally.

The slide deck is intended to support local delivery of education sessions on the HSE National Consent Policy 2022 v1.2 The current Policy and supporting resources are available here hse.ie/nationalconsentpolicy.

If you would like to use the slide deck to deliver training on the Policy please contact national.consentpolicy@hse.ie to request access as part of this pilot. 

The slide deck will be available as part of a 6-month pilot. Trainers and learners will be asked to complete a feedback form on Smart Survey as part of this pilot.

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

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

Learners should complete the National Consent Policy e-learning programme on HSeLand in advance of attending training using the slide deck. Staff who have completed the e-learning programme receive a certificate of completion, and trainers may request this in advance of classroom session.



National Office for Human
Rights and Equality Policy

New Developments - HSE DNACPR Policy



Elaine McCaughley, Programme Lead, National Consent Policy

The HSE DNACPR Policy Steering Group has embarked on an important journey to craft a new DNACPR policy building on existing guidance. This policy will be guided by the recent HSE research on DNACPR Practice and Policy.

Dr John Lombard, the principal researcher of this new DNACPR research, recently attended the 9th Conference of the European Association of Health Law which took place from 18-20 September at the University of Warsaw.

The conference theme 'Health and Fundamental Rights' provided a perfect backdrop for Dr Lombard to present his paper titled, 'Do Not Attempt Cardiopulmonary Resuscitation Practice and Policy: Towards the Development of a new National Policy for Ireland'.

Dr. Lombard's presentation highlighted the comprehensive DNACPR project, which was funded and overseen by the HSE National Office for Human Rights and Equality Policy. Dr. Lombard's talk delved into the project's extensive scoping review, analysis of complaints, empirical research, and examination of both national and international policies which formed the report.

The conference was a fantastic opportunity for Dr. Lombard to engage with a diverse audience of academics, lawyers, healthcare professionals, policymakers and regulators from across Europe sparking insightful discussions and reflections on the future of DNACPR policies.

Please stay tuned to our future newsletters for updates on this significant initiative.

Exploring Gender and Disability Justice: Highlights from the 15th International Disability Law Summer School



Norma O'Donnell, Adm Project Manager

The Centre for Disability Law and Policy at University of Galway welcomed in-person and online attendees to the 15th International Disability Law Summer School on 17th – 21st June 2024. The National Office for Human Rights and Equality Policy team had the privilege to attend and chair at the event with a hybrid approach enabling speakers and delegates to participate.

The theme was “Gender and Disability Justice”. It was a pleasure to reconnect with familiar faces and meet new International experts at the Summer School. The exchange of ideas and experiences made it an enriching experience and will greatly inform our ongoing work at the National Office for Human Rights and Equality Policy.

Day one provided participants with a general introduction and background to gender and disability justice under the UN Convention on the Rights of Persons with Disabilities and other UN bodies, including Convention on the Elimination of all forms of Discrimination against Women.

On day two there was a focus on legal capacity, access to justice, and independent living. Panels explored gendered components of the application of the right to equal recognition before the law. Independent Living was chaired by Shelly Gaynor who is a well-recognised disabled activist in Ireland. Disability Activists and scholars shared insights into achieving the right to independent living, including intersections with often neglected aspects such as the right to family life.



“Several human rights bodies and treaties recognise forced sterilisation of persons with disabilities as a form of discrimination, and a form of violence degrading treatment”

Sara Rocha, Associacao Portuguesa Voz do Autista

Exploring Gender and Disability Justice: Highlights from the 15th International Disability Law Summer School



Norma O'Donnell, Adm Project Manager

The first session on Reproductive Justice on Day three was chaired by Caoimhe Gleeson, National Office for Human Rights and Equality Policy. The session included the following panellists: Mia Ives-Rublee, Center for American Progress, Hannah Gibson, University of Barcelona, Sara Roche, Associacao Portuguesa Voz do Autista and Majo Rivas, Nasc the Migrant and Refugee Rights Centre. The day focused on the right to health including reproductive justice and gender affirming care, the right to reproductive justice, disability and conflict and prevention/redress for gender-based violence.

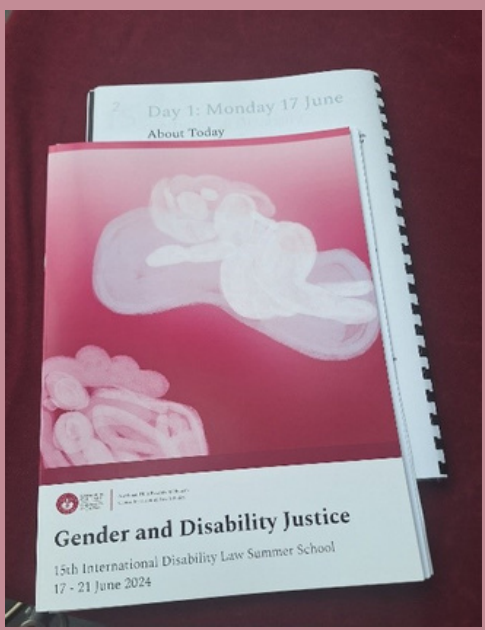
The focus on disabled people as they navigate justice movements, organise to build cross-movement solidarity and seek to exercise their right to participate in public and political life at all levels was achieved on Day four. The rights of women, LGBTQI+ people, gender minority people and people with multiple marginalised identities was discussed.

The week at the International Disability Law Summer School was wrapped up on Day five with an opportunity to apply the learning and discussion from the week to a moot court scenario based on Gender and Disability Justice. Well done to the organisers for a thoroughly engaging and thought provoking week.



“Your duty is to fight for the law, but the day that you find the law in conflict with justice, you fight for justice”

Majo Rivas, Nasc the Migrant and Refugee Rights Centre



Breaking Barriers: Tackling Diagnostic Overshadowing in Healthcare



Joanne Haffey, ADM Senior Project Manager

In July 2024 the National Office for Integrated Care held an in-person roundtable discussion on Diagnostic Overshadowing. The workshop was a blend of presentations and roundtable discussions. Members of the National Office for Human Rights and Equality Policy attended this event and facilitated the roundtable discussions.

Presentations were given by:

- Professor Mary McCarron, Director, Trinity Centre for Ageing and Intellectual Disability
- Professor Eilish Burke, Co-Director, Trinity Centre for Ageing and Intellectual Disability
- Professor Siobhan McHale, Liaison Psychiatry, Beaumont Hospital
- Dr Ciara Martin, National Clinical Advisor and Group Lead for Children and Young People
- Dr Shaun O'Keefe, Geriatrician and Clinical Lead, National Office Human Rights and Equality Policy

What is Diagnostic Overshadowing?

Diagnostic Overshadowing occurs when healthcare practitioners and providers attribute a patient's symptoms solely to their disability, mental illness or old age thus neglecting to investigate potential co-existing conditions.

Delayed or mis-diagnosis

Neglecting to investigate

Diagnostic overshadowing leads to delayed or missed diagnoses of treatable medical conditions. This compromises the health of individuals with disabilities, mental illness or old age, it can and has resulted in death.

Diagnostic Overshadowing is a broad term, it is not confined to one illness or condition and eliminating it relies on understanding a) the person and b) the disability, mental illness or condition that the person is already living with.

Presented Findings

Dr Ciara Martin presented findings from a Down Syndrome Ireland survey of their members about their experiences and concerns regarding access to healthcare. Many families reported feeling that health care professionals treated their family member with Down Syndrome differently with this negatively impacting on their care. One of the major findings of this survey related to health care professionals not always inviting or listening to family members concerns about their loved one. This is directly linked to delays in diagnosis and treatment which in many cases left people in ongoing pain and/or a progression of their illness.

Breaking Barriers: Tackling Diagnostic Overshadowing in Healthcare



Joanne Haffey, ADM Senior Project Manager

Listening to parents concerns in healthcare settings is crucial for accurate diagnosis and timely treatment. The experiences shared by families in this survey highlight the negative consequences of diagnostic overshadowing, where symptoms are dismissed or attributed solely to a pre-existing condition like Down syndrome. By actively listening to parents and taking their concerns seriously, healthcare professionals can avoid delayed or missed diagnoses, ensuring the best possible care for individuals with complex needs.

Professor Mary McCarron and Professor Eilish Burke presented findings from the 2023 first national-representative longitudinal study on ageing with an intellectual disability comparable to the general population (TILDA Study). These findings are stark and paint a bleak picture regarding the health care of people with intellectual disabilities. Here is a brief synopsis of the findings:

- Health issues in people with severe and profound Intellectual Disability are not being identified or sufficiently treated
- There are significantly more adverse health concerns for older adults with a severe intellectual disability
- People with intellectual disability experience increased multi-morbidity, increased joint disease, gastrointestinal disease, mental health issues, neurological disease
- Mortality is higher in women across age groups. Average age of death 19 years earlier than for the general population
- Oral health, individuals with intellectual disability are twice as likely to have difficulty eating and three times more likely to be on a softened/liquidised diet

Missed diagnosis of treatable Medical Conditions

Can and has resulted in death

Consequences of Diagnostic Overshadowing

The Down Syndrome Ireland survey and the TILDA – ID study both highlighted findings that are poignant but distressing. Where healthcare professionals attributed symptoms solely to the persons disability, this not only led to delayed, but at times missed diagnosis. This in turn has led to people dying without dignity and without adequate pain relief.

What next

The messages from all presenters and the round table discussion were clear about next steps in addressing the issue of Diagnostic Overshadowing:

Vision: We need to begin outlining what accessible and high quality healthcare looks like for people with a disability. This will facilitate the re-shaping of models of care and services.

Education: Healthcare providers require training to recognise and avoid diagnostic overshadowing. This includes raising awareness about the increased prevalence of certain medical conditions in relating to a person specific disability, mental illness or age.

Communication: Open communication with patients and their families is crucial. Healthcare providers should actively listen to people with disabilities and their families, and involve them in the diagnostic process.

Comprehensive Assessments: Develop standardised protocols for comprehensive assessments that consider alternative diagnoses beyond Down syndrome for any presenting symptoms.

Innovating for Inclusion - National Sharing Day 2024



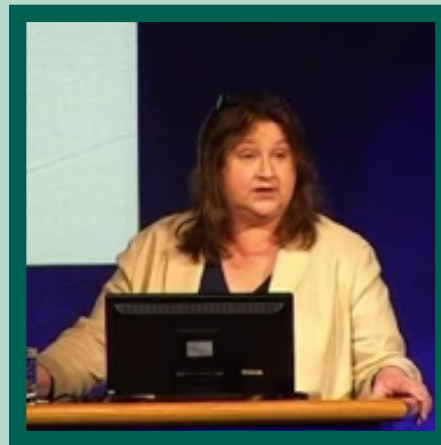
Sandra Guidon, National Office for Human Rights & Equality Policy

The recent HSE Disability Quality Improvement National Sharing Day was a resounding success, bringing together experts and advocates from across the country to share best practices and innovative approaches in disability care. This hybrid event, held both in-person and online, provided a unique platform for networking and exchanging experiences, all aimed at advancing the quality of care for individuals with disabilities.

The event focused on the theme of the Assisted Decision (Capacity) Act 2015, emphasising the importance of centering the experiences of disabled people in discussions about their care and decision-making processes. Attendees had the opportunity to hear from a range of speakers who shared their personal journeys and professional insights, highlighting the impact of the Act on their lives and work.

The day began with a captivating Uilleann Pipes performance by Amy Campbell. Bernard O'Regan then welcomed attendees, setting the stage for an inspiring opening address by Minister Anne Rabbitte.

Throughout the morning, speakers such as Leah Connolly, Bernie Finnegan, and Reece Carr shared their stories, covering topics from financial independence to personal empowerment and capacity building. A mid-morning break provided a chance to visit stalls from the Decision Support Service, Trinity IDS TILDA, HSE Human Rights and Equality National Office, and the National Disability Authority, as well as view poster displays.



Minister Anne Rabbitte

I love to travel, I have been to Lourdes, Spain, Portugal, Dubai, Italy, Greece, England, Turkey, Germany, Paris and at Christmas I'm hitting New Zealand. A lot of my travel has been through the Irish Wheelchair association and Erasmus and the rest is family holidays. I can't travel alone but then I don't think I would want too. Travelling is brilliant and helps you to grow and develop I hope to do lots more, the world is a big place.

Finally, I would like to find someone someday to share my life, but the whole marriage thing causes me great anxiety. However, I'm sure that if and when that time comes, I will be up for the challenge.

Thank you for listening to my story so far, the future is bright.

Shannon O'Farrell - The Future is bright



Enjoying the Poster Display

To watch a recording of this event
please click [here](#)



Innovating for Inclusion - National Sharing Day 2024



Sandra Guidon, National Office for Human Rights & Equality Policy

The second half of the event featured more insightful presentations, including Sarah Jane Levin's talk on independence, Padraic Hayes's discussion on decision-making, and Shannon O'Farrell Molloy's vision for a beautiful future. Kevin Foley's presentation, "My life, my choice," resonated deeply with the audience, emphasising the importance of autonomy and self determination to living independently.

Aine Flynn, Director of Decision Support Services, offered closing remarks, followed by a final address from Marie Kehoe O'Sullivan. The event concluded with a light lunch, providing further opportunities for networking and discussion.

Accessibility was a key consideration, with ISL interpreters available, a wheelchair-accessible venue, and a quiet room for those needing a break.

The event underscored the power of coming together to share knowledge, foster collaboration, and inspire innovation in disability care.



Amy Campbell,
Uilleann Pipes performance



Leah Connolly - Financial Independence



A poster on display

To watch a recording of this event
please click [here](#)



Leigh Gath

Champion for Disability Rights

The HSE National Office for Human Rights and Equality Policy was saddened to hear about the passing of Leigh Gath who died unexpectedly in July 2023.

Leigh, a disability advocate, was appointed the HSE's first confidential recipient in late 2014. Her job involved the examination of concerns and complaints relating to HSE-funded services for people with a disability and older people.

During her time in the post, she dealt with numerous allegations of abuse, negligence, mistreatment and poor care practices brought to her attention by staff or service users. She also challenged the HSE to develop much more robust structures and processes to protect people who experience vulnerabilities in their lives.

Leigh began her disability advocacy at a young age – first in Northern Ireland, then in Texas for many years and finally in Ireland. Leigh was passionate about people with disabilities having a voice, as well as the same rights as any other citizen

Leigh contributed a chapter to our book 'The Assisted Decision-Making (Capacity) Act 2015: Personal and professional reflections'. She wrote about the changes that the Act would bring for people who are in wardship.

Our thoughts and prayers are with Leigh's husband, Eugene; her son, Karl; her daughter, Aisling; and her sister, Phyllis.

May her memory shine on in our lives.



National Poster Campaign- Mental Health Matters Ireland



Barbara Louise Brennan, Workplace Mental Health Consultant and Founder of Mental Health Matters Ireland

On 24th September, Dublin's Smock Alley Theatre hosted the launch of a powerful new mental health campaign, spearheaded by prominent mental health advocate Barbara Brennan, who is a suicide survivor and has been campaigning for over a decade and a half to create positive change in this area. She has become a leading voice in Ireland's efforts to break the stigma surrounding mental health, and this campaign reflects her mission to inspire open conversations about mental well-being.

The centrepiece of the campaign was the unveiling of four winning poster designs, chosen from a national art competition partnered by the HSE National Office for Human Rights and Equality Policy, An Post, Mental Health Reform, The Mental Health Commission, Suicide or Survive, Spun Out, First Fortnight and Mental Health Matters and supported by The ESB, Irish Life and Salt Marketing. These posters are designed to encourage discussion and reduce the stigma that still surrounds mental health in Ireland. The designs were launched by the Lord Mayor of Dublin and will be distributed nationally, offering a powerful reminder of the importance of mental health awareness.

Barbara's personal experiences have shaped her commitment to this cause, and this campaign is another step in her journey to change how Ireland talks about mental health. The posters aim to create a dialogue that can save lives by fostering understanding and compassion for those who struggle with mental health issues, and most importantly helping people start conversations about their own mental health sooner. Her own story of survival has been a driving force in her advocacy, and she continues to push for change at both grassroots and national levels.

In addition to the posters, the event featured the premiere of a suite of mental health video resources, developed in collaboration with An Post. These videos are intended to be used in workplaces across Ireland, helping to facilitate conversations about mental well-being and providing practical support for both employers and employees. The videos, like the posters, aim to create a culture where mental health is openly discussed, and help is readily available. All resources are freely available to the public through www.mentalhealthmatters.ie and the partners' websites.

Barbara Brennan's leadership in this initiative highlights her ongoing commitment to breaking down the barriers that prevent people from seeking support. Her work with the HSE, along with the support of key partners, ensures that this campaign will have a lasting impact, encouraging a national conversation around mental health.



Workplace
Poster
Winner



Community
Poster
Winner



School
Poster
Winner



University
Poster
Winner

LEARN MORE

Research on the Assisted Decision - Making (Capacity) Act and communication- a survey of professionals



Dr. Cliona de Bhailis,
Centre for Disability, Law and Policy, University of Galway



What is the research about?

A research project which aims to explore how young people who are non-speaking or communicate differently can use the Assisted Decision-Making (Capacity) Act 2015 is being led by Dr. Cliona De Bhailis at NUI, Galway. The Assisted Decision-Making (Capacity) Act 2015 was given full legal force in April 2023. It made widespread changes in relation to decision making and access to support to make decisions in Ireland.

This survey which forms part of the research is seeking the views of professionals from a broad range of backgrounds including those working in the health, social care, financial, legal and community support sectors.

The survey aims to assess knowledge of the Assisted Decision-Making (Capacity) Act 2015 and different forms of communication among professionals in the Republic of Ireland. This includes understanding how much professionals are aware of the Act, their experiences of the Act and its impact on their professional practice and what the Act means young people who are non-speaking or communicate differently.

How long will the survey take to complete?

This survey should take around 10 - 15 minutes to complete.

What sort of questions will I have to answer?

It will ask you for some general demographic information, and some questions about the Assisted Decision-Making (Capacity) Act 2015 and different or alternative forms of communication. No identifiable information (e.g., your name, where you are from) will be collected as part of this survey.

Who can take part?

Professionals from a broad range of backgrounds working in the Republic of Ireland can take part. This includes those working in the health, social care, financial, legal and community support sectors.

Further Information & Contact Details

You can complete the survey or find out more [here](#)

If you have questions about the research or the survey you can contact Cliona by email at cliona.debhailis@universityofgalway.ie or by calling 086-0081153 (call and text).

Dr Cliona de Bhailis

Comhalta Rialtas na hÉireann an Comhairle um
Thaighde in Éirinn | Irish Research Council
Government of Ireland Fellow

[CLICK HERE TO TAKE
THE SURVEY](#)



Improving Health and wellbeing of the Roma community in Co. Tipperary.



Suzanne Nolan, Regional Roma Health Lead

In a collaborative effort the HSE, Tipperary County Council and Youth Work Ireland Tipperary have launched a comprehensive Needs Assessment. The initiative also includes a report detailing the progress of the Health and Accommodation pilot project since its establishment in 2022.

The project has identified over 300 members of the Roma community reside in Co. Tipperary with 200 individuals located in the South Tipperary area, while the estimated Roma population throughout the county is 700.

The report published provide detailed information on the Roma community locally, particularly regarding their housing conditions and other critical social determinants of health.

Key Findings: Access to adequate accommodation remains a pressing concern with issues such as insecurity of tenure, poor housing conditions, homelessness and overcrowding identified as the most significant issue. The reports also provide an evidence base from which to plan an effective response to improving the situation of the Roma community in Co. Tipperary.

The HSE's social inclusion services supported by funding from the HSE's National Social Inclusion Office initiated this pilot project to undertake a needs assessment to examine the housing situation of Roma families who were engaged with the HSE's Roma Health Project. This partnership approach involving Youth Work Ireland Tipperary, HSE Social Inclusion and Tipperary County Council also focused on the Public Sector Equality and Human Rights Duty to address the health and accommodation needs of the Roma community.

The findings underline the necessity for a concerted policy response to tackle inequalities faced by the Roma community. Additionally the findings highlight the importance of providing advocacy supports to help Roma community members, to understand their basic rights and entitlement to access and navigate essential services.

While the Needs Assessment indicated higher employment levels among the Roma compared to 2018 national data, unemployment remains a significant issue. Many households experience unemployment alongside a lack of Social Protection supports and complications in meeting Habitual Residence Conditions.



Marie Boyle, Suzanne Nolan and Sandra Broderick

Improving Health and wellbeing of the Roma community in Co. Tipperary.



Suzanne Nolan, Regional Roma HealthLead

Furthermore, some households reported difficulties in obtaining a Medical Card, due to the inability to provide evidence of paying rent – which in some cases meant being above an income threshold in eligibility.

Integrated pathways of care were developed to support Roma individuals experiencing homelessness and those living in insecure/unsuitable accommodation.

Speaking at the launch event in Ballykisteen Hotel Suzanne Nolan (HSE/South East Community Healthcare Regional Roma Health) highlighted the importance of partnerships in improving health service access for vulnerable groups in Co. Tipperary

Suzanne noted “We are beginning to see results of our engagement with members of the Roma community”. The initiative began during Covid 19 to identify the health needs of the Roma community. Organisations, such as those in the public sector, are responding sensitively and effectively to people who aren’t as socially included as others around them in Co. Tipperary.”

Congratulating everyone involved in contributing to the reports, Anna Marie Lanigan (Head of Service/Primary Care, HSE/South East Community Healthcare) highlighted : “The broadening of diversity resulting from the rich mix of cultures within Ireland in recent times has significantly enriched the fabric of social, economic and cultural life here.” Anna praised the manner in which partnerships across public service bodies, entities engaged in the community and the Roma community itself in Co. Tipperary have been effective in identifying needs, raising awareness of same and identifying ways in which improvements can come about are a template for facing up to such challenges elsewhere.”




The panel at the launch in Ballykisteen Hotel

Universal Access: Irish Sign Language Interpreters for Everyone



Elaine Grehan, Advocacy Manager, Irish Deaf Society

Elaine Grehan is a registered Deaf Interpreter, and the Advocacy Manager at the Irish Deaf Society. She is a member of CISLI, the professional body for interpreters which aims to advance the profession and provide support to its members.

International Week of Deaf People commenced on Monday 23rd September – see the Irish Deaf Society's [website](#) and social media for information on the themes and activities – it's a good time to consider standards in Irish Sign Language (ISL) interpreting services. 

You probably have seen ISL interpreters on the television in recent years, especially during covid, but you may not have come across any at work.

As we all know, clear communication is vital in healthcare settings.

And so, in accordance with the ISL Act 2017 and the Equal Status 2000-2005, the HSE provides interpretation free of charge to patients for all types of healthcare situations: outpatient appointments, in-patient stays (ie for rounds, in-hospital services such as physio, etc., and discharge advice), as well as appointments for services like ante-natal classes, OT, etc.

Interpreters can be arranged too when the patient is a hearing child with Deaf parents.

Before booking an interpreter, it's useful to consider the following:


Should the interpreter be there in person or is remote okay?

- As a general rule, even if there is an additional cost, it's better to have the interpreter in person.
- Online platforms, like Zoom, are very advanced now, and provide greater choice and availability of interpreters, but technical difficulties, for example computer and phone screens are 2D but ISL is 3D, can affect interpretation.
- If the interpreter is not on site, please talk to them about the kind of technology needed to complete the assignment successfully, eg a laptop or tablet and a wired connection (rather than WiFi). Don't expect the interpreter, Deaf person or their family to provide this equipment.
- For assignments with a Deaf and hearing interpreting team, at least one interpreter should present in person.

What is a Deaf Interpreter?

- A Deaf Interpreter is a highly skilled deaf language professional. Their specialist linguistic and cultural knowledge, experience and training can enhance understanding in both routine and sensitive situations.
- The role of DIs is especially important in situations involving vulnerable individuals. In healthcare settings, this could include - but is not limited to - mental health appointments, when the patient is Deafblind, uses a foreign sign language, or signs particular to a group, such as older Deaf people or children, or non-standard ISL because of mental illness, intellectual disability or language deprivation.

Demand for interpreters is very high at the moment. So please book the interpreter/s as soon as the appointment has been arranged.

RISLI, the [Register of ISL Interpreters](#), was established on foot of the ISL Act. Its role is to maintain a list of competent interpreters. Only interpreters on the list are eligible to work in the public sector. 


In 2014, the HSE produced [National Guidelines on Accessible Health and Social Care Services](#); much of that information is still relevant now. This guide will be revised in 2025.

In 2022, UCC, in conjunction with IHREC, produced [Guidance for Public Bodies on Providing Access for Deaf Irish Sign Language Users](#). This one page document has advice on ways to make public services more accessible to Deaf people.

If you're unsure how to book an interpreter, contact the HSE National Office for Human Rights and Equality Policy for advice.



Irish Deaf Society

Don't forget to click the link when you see this sign 

Butterfly Lunch: Empowering Dementia Care at St. Joseph's, Shankill



Teresa Mallon, Director Programme Quality and Safety and Callan Institute, Saint John of God Community Services clg



A very successful Butterfly Lunch took place on Friday the 21st of June at Elm Park Golf Club to support the award winning internationally renowned St John of God Dementia Care at St Joseph's Shankill, Co. Dublin who offer a social model of care based on an internationally established approach. The skilled team offer specialised person-centred dementia care focussing on not just people's physical and clinical needs but their emotional, psychological, social and spiritual needs too. There is an organisational wide commitment to the compassionate care of people living with dementia and their families in a real home environment where their feelings matter most.

While this was an important annual fundraising event, it also for the first time successfully facilitated networking opportunities to guests who have an interest in or expertise in supporting individuals with Intellectual disability who are ageing or living with dementia and the guests included colleagues from across Saint John of God Services, policy makers, and representatives from national umbrella bodies who advocate for older people with intellectual disability in our society to join other like-minded people.

Coming together for lunch and conversation can be a powerful catalyst for sharing information, collaboration, networking, innovation and creativity. It is often said that during these informal moments ideas can spark, connections can deepen, and new initiatives can take root.

Guests from national organisations included Patsy Fitzsimmons, Decision Support Service, Caoimhe Gleeson and Jacqueline Grogan, HSE Equality and Human Rights Office, Andy Heffernan, Alzheimer's Ireland; Patricia Richard Clarke, Safeguarding Ireland, Paula O Reilly, The Irish Hospice and John Condron and Gina Grant, Down Syndrome Ireland.



Caoimhe Gleeson,
Teresa Mallon
Jacqueline Grogan

Click [here](#) to see all the pictures of the event



Patricia Rickard Clarke,
Teresa Mallon



Enhancing Patient-Centered Care in Healthcare Transitions



Martina Cooney, Project Officer

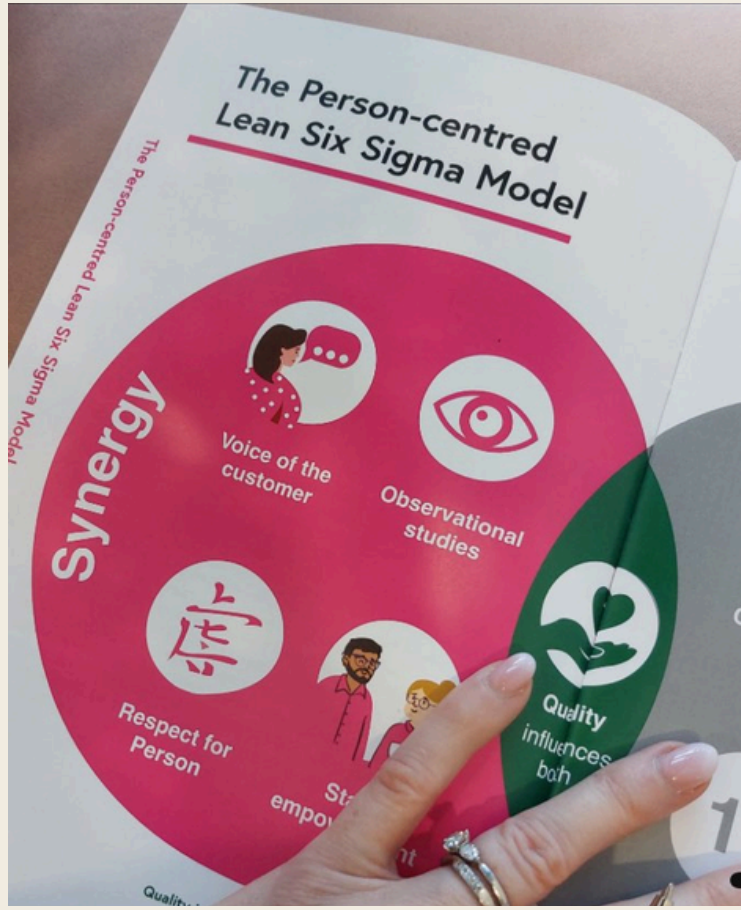
Improving the patient journey for patient's whose capacity is in question

Martina Cooney who is a project officer in the Project Management Office, Kilkenny is undertaking a Lean Black Belt with The Mater Lean Academy and UCD.

The project is focused on improving the delayed transfer of care from acute to community settings for patients whose capacity is in question and are in the process of applying for a Decision making representative (DMR). The project is sponsored by the Quality Safety Service Improvement (QSSI) Head of Service, Stephanie Lynch in CHO5.

The project aims to identify the optimal care placements for patients while placing person-centeredness, will & preference at its core.

Collaborating with other qualified Lean Academy black belts in the acute hospital system the goal of the project is to develop and implement a refined process that enhances this critical healthcare pathway, ensuring that dignity remains paramount throughout for individuals whose capacity is in question. It seeks to meet its obligations under Irish Human rights law and compliance with ADM legislation whilst improving on person-centered transfers from acute to community care .



Contact;
We will strive to make meaningful improvements in delivering human rights centered safe, cost effective and compassionate healthcare to those most in need. We would love to hear from you if have any suggestions for this project. Please contact Martina Cooney on 0871985057 or martinap.cooney@hse.ie

Inclusion in Action Conference

University College Cork

December 2024



Dr. Nicola Maxwell, id+ Project Academic Development Lead and Lecturer, School of Applied Social Studies, UCC

University College Cork will host an international conference in December 2024 on inclusive higher education. The conference is called '*Inclusion in Action: Creative and Critical Insights from Programmes for Students with Intellectual Disability in Higher Education*'.

Inclusive education is a right for people with intellectual disability (ID) under Article 24 of the United Nations Convention on the Rights of Persons with Disabilities. However, they have historically been excluded as participants in higher education programmes on university and college campuses. UCC offers two courses for adults with ID, under the umbrella of the id+ Project. Students with ID join degree students in existing modules of their choice, across a range of disciplines. This provides an exciting opportunity for "co-learning", where both groups learn with, from, and about each other.

This conference provides an opportunity to reflect on what is happening, both in Ireland and in other countries, in the field of inclusive education. There will be a particular focus on how inclusive education is experienced by students and educators, and translated into practice.

Together we will:

- Learn from students with ID what they need to feel included in higher education, what supports their inclusion, and what creates barriers to it.

- Share research and experiences from third-level programmes for people with ID.
- Showcase examples of good practice and shareable resources for promoting inclusion for people with ID in university and college life.

Participants from Ireland, Europe and the USA will share experiences and insights, with keynote addresses and workshops provided by:

- Students and Graduates with ID
- Professor Meg Grigal, Co-Director Think College & Senior Research Fellow, Institute for Community Inclusion, University of Massachusetts Boston
- Professor Melanie Nind, Professor of Education, University of Southampton
- Professor Jan Walmsley
- Professor Emerita Open University, Co-founder Social History of Learning Disability Research Group

The conference takes place over two days on December 4th and 5th, and all are welcome to attend.

More information and a link to registration can be found on the conference website [here](#)



The National Disability Authority carries out research about disability related issues.

We want to learn how the ending of the Wards of Court system is affecting people who are Wards of Court and people who act on their behalf.

This research is independent of the Wards of Court Office.

Are you an adult who is a Ward of Court or a Committee who acts on behalf of a person who is a Ward of Court?

If yes, we would like to hear from you!



**Get in touch with us at
wardsresearch@nda.ie
or on 087 671 2376**

nda

Údarás Náisiúnta Míchumais
National Disability Authority





An Táin Arts Centre's Community Company in Residence

Encore Productions presents



CLICK HERE

The Beckett List

Encore Productions
Presents: The Beckett
List – A Night of Samuel
Beckett at the Samuel
Beckett Theatre! Join us
on Monday, November
4th at 7 PM!



**Samuel Beckett Theatre
Trinity College Dublin**
Monday 4th November 7:00pm
Tickets €10


Chronicling Beckett's journey from quiet beginnings in turn of the century Dublin, to the publication of 'Waiting for Godot'.



BOOKING
beckett-theatre@tcd.ie



Useful Resources - please click on each logo to learn more on their services

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



**seirbhís tacaíochta
cinnteoireachta**

decision support service™

Decision Support Service statutory Codes of Practice on the 2015 Act including codes relating to:
Healthcare Professionals
Advance Healthcare Directives for Healthcare Professionals,
Supporting Decision-Making and Assessing Capacity.
Decision Support Services guides and video presentations
Decision Support Service
Decision Support Service Explainer Video



Inclusion Ireland

The National Association for People with an Intellectual Disability.




Údarás Náisiúnta Míchumais
National Disability Authority



An tSeirbhís Chúirteanna
Courts Service



For a list of our ADM Leads around the country please click [HERE](#) 



[NHSS: For updates to the fair deal scheme application process and changes following the Assisted Decision-Making \(Capacity\) 2015 Act](#)



HSeLand ELearning Programme on Assisted Decision-Making (Capacity) Act (2015) - Guidance for Healthcare workers

Useful past Webinar Links;

[Webinar on Assisted Decision-Making \(Capacity\) Act 2015: Update since commencement from the 14th June 2023](#)

[Webinar on Getting ready for commencement of the Assisted Decision-Making \(Capacity\) Act 2015](#)

[Webinar on Getting ready for Advance Healthcare Directives under the Assisted Decision-Making \(Capacity\) Act 2015](#)

[Transition from Wardship to the Assisted Decision-Making \(Capacity\) Act 2015: Guidance for Staff webinar recording from the 1st December 2022 and](#)

[Launch of the Easy-to-read webinar on the HSE National Consent Policy on 5th December 2022](#)



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

[HSE Assisted Decision-Making website](#)

[HSE Explainer video on the Act](#)



For further updates, join our mailing list, please click [here](#)



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

