

Human Rights and Equality Matters

Summer 2024



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Welcome

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



Welcome to our new look Human Rights and Equality Matters. In this edition we reflect on the impact of the Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act) in the time which has passed since commencement of the Act, we highlight on-going activity to promote the HSE National Consent Policy and we bring you special features on broader human rights and equality issues.

It is now 14 months since the 2015 Act has commenced. In this time many services across the HSE have recruited or assigned ADM leads in acute hospitals and community services to support staff to follow the spirit and intention of the legislation. Most hospitals and community services have an ADM committee or governance group in place where ADM issues can be raised and discussed. The most immediate change brought about by commencement was the dissolution of the Care Representative who could apply for Ancillary State Support under the Nursing Home Support Scheme. Families must now apply to the Judge in the relevant Circuit Court for Ancillary State Support. This change has been challenging for the relevant person, families and services. This has required lots of collaboration with HSE Services, the Decision Support Service, the Courts Service, Advocacy Organisations, the Legal Aid Board, Government Departments and Staff to find ways of making this new process less daunting for the relevant person and those trying to support them.

In this edition we highlight some of those collaborations. Aine Flynn, Director of the Decision Support Service shares ongoing efforts by her agency to support relevant persons and their supporters. As the DSS move towards going live with their digital first register of Decision Making arrangements the HSE is collaborating with the DSS and health and social care services to build capacity to access the new register when it is activated.

Jane Keogh, ADMC Registrar for the Courts Service steps out what is expected by the Court when an application for a Decision Making Representation Order is being made. She highlights the importance of hearing the voice of the person throughout the process- either in person, on-line or through the support of an advocate.

Bibiana Savin, CEO designate of Sage Advocacy shares the supports provided by Sage Advocacy to the relevant person and their supporters where a Decision Making Representation Order is being considered.

Rachel Glennane, Human Rights and Equality Lead with CH East reflects on the work which has been underway in CH East to support the implementation of the 2015 Act across community services.

Patricia Rickard Clarke, Chairperson of Safeguarding Ireland provides a spotlight on Advance Healthcare Directives and highlights a new campaign by Safeguarding Ireland encouraging the public to plan ahead to safeguard their future wishes.

Aileen Colley, Co-ordinator of the HSE ADM Mentorship Programme and Colm Harty, lead for Patient and Service User engagement in CH East and HSE Mentor provide an update on the ADM Mentorship programme which was set up to provide a forum for staff to work through cases and issues arising from the new legislation.

Fingal's Older Persons Council annual conference focused on the 2015 Act and its importance for the lives of older people. Cathrina Murphy, Age Friendly Programme Manager shares some of the highlights from the conference.

Elaine McCaughley who leads the HSE work on Consent has been collaborating with services across the country to highlight the revised HSE National Consent Policy and to provide a space for staff to consider what consent means in different health and social care contexts. Consent was a recent feature on the Talking Health and Wellbeing Podcast with host Fergal Fox. The Irish Society for Dentistry and Oral Health (ISDOH) had a special focus on consent in dental practice at their national conference in June 2024.

Siobhan Stapleton of the ISDOH provides highlights from the event. Earlier in May 2024 the Ireland East Hospital Group (IEHG) hosted a conference which address issues of consent in maternity practice. Paula Power, Operations Manager for the Women & Neonates Healthcare Directorate, IEHG reflects on the key learning from that event.

In May 2024 the Ombudsman for Children Niall Muldoon, launched “Uncertain Times”, the annual report for the Office of the Ombudsman for Children which set out key human rights and equality issues affecting children in Ireland today including discrimination, racism and homelessness. Niall shares how the report provides a telling reminder of the abject inequalities which prevail in Irish society and which disproportionately impact on children and young people.

Leanne Caulfield formerly of the Law Reform Commission provides a comprehensive overview of the proposed legislation to safeguard adults in Ireland. Underpinned by human rights and equality principles, these proposals will now be escalated to Government for further consideration.

By way of a parting glass, we are delighted to introduce our two new team members- Joanne Haffey and Norma O'Donnell. Joanne, a native of Co. Down, comes to the team with a social work and quality and patient safety background while Kerry native, Norma, brings a wealth of knowledge from her days in the National Ambulance Service as an Advanced Paramedic and latterly in quality and patient safety. Joanne and Norma are a huge asset to our team and bring a strong commitment to human rights, equality and ensuring the relevant person is at the centre of our work.

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

For more information you can view our website [here](#)
or contact our office below:
email - [ADM](#) or [National Consent Policy](#).



One year on - the Decision Support Service



Áine Flynn, Director of the Decision Support Service

With our one-year anniversary behind us, the DSS is busy with all our statutory functions under the Assisted Decision-Making (Capacity) Act 2015.

The demand for information about the 2015 Act and the DSS and its services is increasing all the time. From commencement in April 2023 until the beginning of June, the DSS Information Service team has managed over 25,000 queries by telephone and email, from members of the public and a diverse range of stakeholders, including health and social care professionals. Sometimes it is our job to counter misinformation and misunderstandings, providing reassurance to people who are wondering about what the 2015 Act might mean for them or people in their care.

We are seeing steadily increasing engagement by the public with the DSS online portal. By early June, over 3,300 active applications for enduring powers of attorney (EPAs), co-decision-making agreements (CDMAs) and decision-making assistance agreements (DMAAs) were in progress, the majority being for EPAs. We have added to the resources on our website with additional explainer videos to provide guidance on the opening of MyDSS accounts and the steps to create and register an EPA.

Every day, our team helps to steer people through the practicalities of the DSS application processes. These are important legal instruments and we want to ensure that people are able to put in place the support arrangements that they require. One applicant who wrote to us last month to express her thanks, commented on the 'wonderful help and attention to detail', adding "We are not very computer literate being in our late 70's so it was superb to be so kindly directed".

This is what the DSS is for, and we continuously seek to improve our delivery of this support.

We have maintained our direct engagement with stakeholders at online and in-person events with health and social care professionals, banking and financial services, academics, legal practitioners, peer advocates, disability service providers and people using their services, other residential services and a range of community groups, including several older persons' organisations. We have also reconvened our stakeholder forum of experts by experience who provide invaluable feedback on our resources and processes.

We have a busy calendar of events through to the end of the year. Any service that would like to hear from the DSS with a presentation is encouraged to contact us and we will try to facilitate. Also in our calendar is a training update for our panel of professional decision-making representatives. We have now received requests from the Circuit Court and wardship court for panel member nominations in over 90 cases.

We are working with the HSE to pilot automated access to our registers for those who are authorised to inspect them. In the meantime, enquiries about the register of CDMAs, EPAs and decision-making registration orders notified to the DSS by the courts can be sent to registersearches@decisionsupportservice.ie



We look forward to further meetings with the HSE ADM leads and mentors. The DSS benefits when services are conduits of good information, carrying the message forward and helping to build awareness and confidence.

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



**seirbhís tacaíochta
cainteoireachta**
decision support service™



Part 5 Obligations for the Circuit Court



Jane Keogh, ADMC Registrar
Courts Service

Part 5 Capacity Applications

In 2023, 299 Capacity Applications were issued in the Circuit Court pursuant to Part 5 of the Assisted Decision-Making (Capacity) Act 2015, as amended. In the first quarter of 2024, the number of applications has already surpassed any previous quarter, with 153 Capacity Applications issued to the end of March. In total, 259 decision-making representative orders (DMROs) have been made by the Circuit Court.

What is a Capacity Application?

A Capacity Application is an application to the Court under Part 5 of ADMC Act, seeking a declaration in respect of the Relevant Person's capacity to make specified decisions, and if the Court deems it appropriate to do so, the appointment of an individual or individuals as decision-making representative(s) (DMR(s)).

What is a Decision-Making Representation Order (DMRO)?

A DMRO is an Order of the Court comprising of a declaration that the Relevant Person lacks capacity to make specific decisions outlined in the Order and the appointment of one or more than one DMR(s) to make those specific decisions on behalf of the Relevant Person. In accordance with the Act, the declaration aspect of the Court Order is to be reviewed within a specified time period, as noted in the Order.

Part 5 Capacity Application:

- Originating Notice of Motion (Form 55A)
- Statement of Particulars (Form 55B)
- Affidavit in Support of Application (Form 55I) exhibiting a functional capacity report from a healthcare professional
- Affidavit of Service on the Relevant Person (Form 55D)
- Affidavit of Service on Notice Parties
- Independent Legal Representation for the Relevant Person
- Relevant Person's attendance pursuant to section 139 and/or Voice of the Relevant Person and/or Reply to Capacity Application (Form 55C)

Functional Capacity Statement from a Medical Practitioner or Healthcare Professional:

A functional capacity statement/report must be exhibited to the Affidavit (Form 55I) filed by the Applicant. In line with section 3 of the Act, the report must evidence a functional approach to the assessment of capacity. A useful template prepared by Professor Shaun O'Keeffe is in circulation, which is available at www.assisteddecisionmaking.ie. For clarification on which professions fall under the bracket of healthcare professional please see Assisted Decision-Making (Capacity) Act 2015 (Prescribed Classes of Healthcare Professionals) Regulations 2023.





An tSeirbhís Chúirteanna
Courts Service

Part 5 Obligations for the Circuit Court

Independent Legal Representation for the Relevant Person:

The Legal Aid Board provide legal representation to Relevant Persons the subject of Capacity Applications. Legal Representation is to be provided to the Relevant Person irrespective of their financial position. In order for the Legal Aid Board to provide representation to the Relevant Person, an application for legal services is required. This should be done in advance of the Court Date.

Voice of the Relevant Person in the Courtroom:

Section 139 of the Act states that applications under Part 5 shall be heard in the presence of the Relevant Person unless the Court dispenses with the requirement of the Relevant Person to attend. The Courts Service endeavours to support the Relevant Person's attendance at the hearing of the Application, whether it be by way of video link, or in person. If the Relevant Person requires any special accommodation, please consult with the relevant Court Office as facilities in courthouses vary from county to county.

If the Relevant Person is unable to attend the hearing, the Court requires the Voice of the Relevant Person to be communicated to the Court, independent to the Applicant. Common ways in which this is done is by way of a report from an independent advocate or independent social worker.

Review of Capacity Declarations:

When a DMRO is granted, the Order will specify a time period within which the Capacity Declaration is to be reviewed. Approximately 3 months in advance of the Review Hearing, the DMR will receive correspondence from the Court Office stating a date and location for the Review Hearing. The correspondence will also specify directions the Judge may have regarding documentation to be filed and served in advance, for example an updated capacity report from a healthcare professional. The Relevant Person will be notified by the Court Office of the Review Hearing.





Rachel Glennane, Human Rights and Equality Lead QSSI CH East

Implementation in practice – CH East

To commemorate the first anniversary of the Assisted Decision-Making (Capacity) Act 2015 on April 26, 2024, the Assisted Decision-Making (ADM) working group and ADM Mentors in CH East organized a networking event in Bray. The ADM working group for CH East, comprising representatives from various community services, including Older Persons, Mental Health, Primary Care, Disability, and Quality, Safety, and Service Improvement (QSSI), convened in January 2023 to facilitate the integration of ADM within services in CH East.

Throughout its inaugural year, the ADM working group spearheaded numerous initiatives, such as participating on the ADM Mentorship program, delivering workshops for disability service providers, delivering engagement sessions on ADM for multidisciplinary teams, and raising awareness about ADM during events like World Patient Safety Day and Safeguarding Day in CH East. Staff members were educated on the new Decision-Making Support Arrangements, including Decision-Making Assistant, Co-decision Maker, and Decision-Making Representative. Moreover, the group promoted future planning through the establishment of Enduring Power of Attorney arrangements and Advanced Healthcare Directives. They advocated for adherence to the Consent Policy 2022 v1.2 and the Code of Practice for health professionals in supporting decision-making and assessing capacity.

In CH East, feedback from ADM mentorship groups and workshops has been positive, with participants highlighting the efficacy of interactive case studies and discussions on legislation and decision-making structures. The ADM Mentorship groups have been convening monthly, with significant attendance at ADM Workshops by staff from HSE and 16 Disability Service Providers.

The momentum surrounding ADM initiatives in CH East is set to continue in 2024 with planned activities, including participating in a pilot project on healthcare professionals' access to the DSS register of decision support arrangements, facilitating access to training on the national programme on the functional approach to capacity assessment, delivering trainer sessions to expand the reach of ADM workshops, and supporting the national ADM mentorship program's second year. Additionally, the establishment of ADM communities of practice groups will address crucial areas such as financial control for individuals with disabilities in collaboration with the National Human Rights and Equality Policy Office.

For further information:

Human Rights Team QSSI CH East:
qssi.ch6East@hse.ie; rachel.glennane@hse.ie



National Advocacy Service and HSE Staff 26th April 2024 ADM Networking Event (L-R) Ann Roche (Complaints Manager CH East), Sean Greaves (National Advocacy Service), Fiona McCabe (National Advocacy Service), Rachel Glennane (Human Rights and Equality Lead QSSI CH East)



The Adm Working Group in CH East (L-R) Donal O'Mally, Gerard Chadwick, Siobhan Young, Rachel Glennane, Colm Harty, Sarah Traynor, Ernesta Jakaite, Lisa Dalton



ADM Mentors in CH East - ADM Networking Event 26th April 2024 Colm Harty, Rachel Glennane, Edel Kennedy, Damian Breen

Applying to the Court for a DMR

Sage Advocacy launches new online resource



Bibiana Savin, CEO Designate

The groundbreaking Assisted Decision-Making Act came fully into force on April 26, 2023 – putting an end to the system of wardship and enshrining the right in Irish law of all people to exercise control over their own decisions to the greatest extent possible. Soon afterwards, the Circuit Court began to hear applications for Decision-Making Representation orders – and this month marks one year since representatives of Sage Advocacy attended the first such hearing, with the aim of ensuring that the voice of the ‘relevant person’, independent of family, service providers or systems interests, should be heard and to the forefront in the court.

The Assisted Decision-Making Act 2015 puts in place graduated approaches to supporting people with their decision-making, aimed at providing a solution that honours their ‘will and preference’ at every stage of life and health. The least restrictive intervention provides for nominating a Decision-Making Assistant (when someone has difficulty making certain decisions unaided and they wish to appoint someone to advise and inform them in making their own choice). At a step beyond that, the Act allows for appointment of a Co-Decision-Maker (someone trusted and chosen by the person to be their partner in making the decision/s). And the tightest measure in the law – for when a person is not able to decide, even with support – is the appointment, via an order by the Circuit Court, of a suitable person to act as Decision-Making Representative (DMR) and to take due regard of the person’s wishes in making the decision on their behalf.

A Decision-Making Representative Order (DMRO) can be sought only after all other, less intrusive, options have been exhausted. If everything else has been tried, then a Capacity Application can be completed. There will be one or more hearings for the court to consider the application and to rule on it.

Since applications began coming to court, Sage Advocacy representatives have acted to ensure that the voice of the person is heard and considered at hearing – even if the person is unable to attend in person.

Sage advocates have been involved in over 350 cases to date linked with DMRO applications, providing advocacy services and support to the relevant person and preparing reports for the Circuit Courts around the country. Occasionally, when deemed necessary, our advocates have attended Court hearings and have also supported the person to attend the hearings either in-person or via video link.

Based on Information & Support queries to our office in the last year, and considering the matters arising from engagement with clients, family members and professionals as part of the casework, Sage Advocacy developed an information resource designed to help those interested to learn about the process of applying to the Court for a DMR.



For more information
please click [here](#)



Sage is a member of Safeguarding Ireland



Promoting the rights of vulnerable adults

safeguardingireland.org

Sage Supports



Speak for Yourself

thinkahead.ie



The online resource provides a walk-through of issues to consider before making an application. It sets out the requirement for the court to hear the point of view of the relevant person. It describes the role of an advocate in the process and how to make a referral to Sage Advocacy. It points up the need for a functional capacity assessment to be carried out in order to include Statement of Capacity with the application. It outlines types of decisions in respect of which an application can be made – and emphasises the need to be specific and descriptive. The resource reiterates that DMRO is the option of last resort – and gives a checklist of considerations to ensure that the person's privacy and wishes are centred. It explores the rules and duties attaching to a DMR; and sets out that the court will set a date to review the person's capacity, the work of the DMR, and the status of the Order that it put in place.

Find the resource [here](#); or for a printable PDF, email info@sageadvocacy.ie 

Further resources on the Assisted Decision-Making Act can be accessed [here](#). 

The Advocate Will Meet The Person Whose Life Decisions Are Under The Spotlight. Their Meeting Will Cover The Following Issues:



The advocate will explain to them, as fully as possible and in a way that they can understand, the reason for the visit.



The advocate is there to find out, insofar as possible, directly from the person, what their wishes are about the decision or decisions that need to be made.



As best as possible, the advocate will find out from the person what their beliefs and values are when it comes to decisions like this.



The advocate will ask them about their relationship with the proposed Decision-Making Representative. Is it a relationship of **trust**? Or is any power or **undue influence** being held over them? Could there be a **conflict of interest** between them?



The advocate will let the person know that he/she has the right to be supported to attend the court hearing. The advocate will then find out exactly what support he/she would need to attend; and will make sure that any necessary arrangements get made.



The advocate will note any particular support needs they may have that may not have been mentioned in the application.
The advocate writes up all the information into a report, which Sage Advocacy delivers directly to the relevant Circuit Court.



Patricia Rickard-Clarke
Chairperson, Safeguarding Ireland

National Campaign - Advance Healthcare Directives

General queries to
info@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. Safeguarding Ireland is commencing a public awareness campaign encouraging more people to make an Advance Healthcare Directive – as just 4% of people in Ireland have one according to new research from RED C.

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

It only comes into effect if in the future the person then lacks capacity to make, or communicate, those decisions. This could be due to the progression of a frailty, dementia, a serious illness, a physical or intellectual disability, or a sudden accident.

A poll carried out on a representative sample of 1,000 adults found that – just 23% understood what an Advance Healthcare Directive is – and just 4% said that a healthcare professional had ever asked them if they have one. The fact that just 4% of people said that they had never been asked by healthcare professional if they have an Advance Healthcare Directive is also very low.

Safeguarding Ireland encourages Doctors, Nurses and Social Workers, when they deem appropriate, to ask patients / clients if they have Advance Healthcare Directive.

Making one is free of charge and not difficult to do. It is also better for professionals and families themselves, giving clarity when supporting patients and loved ones.

It is important that those who need to know about it do and the following should all be given a copy: the person's Designated / Alternative Healthcare Representatives, Family Doctor (GP), current healthcare professionals a person is engaging with, the Emergency Department if admitted to hospital and the person in charge if living in a healthcare or residential facility.

The recommended steps to making one are to access and complete one of the two available Advance Healthcare Directive templates which are at:

- The Decision Support Service website – www.decisionsupportservice.ie
- The Think Ahead website – www.thinkahead.ie



More information is available at www.safeguardingireland.org.

Reflections one year on – the HSE ADM Mentorship Program



Aileen Colley, ADM Mentorship Programme Co-Ordinator



As we reflect on this time last year, the Assisted Decision-Making Act (2015) had just commenced in April, and our efforts were focused on recruiting mentors and mentees for an innovative mentorship program. Our primary goal was to build local capacity and confidence in navigating and implementing the Act, while also having a cascading effect, with ADM-related knowledge extending beyond the immediate participants to amplify impact across sectors.

Programme highlights:

The program was successfully launched in September with over 550 participants organised into 45 mentorship sets. Sets included staff from the HSE, Section 38 and 39 organisations, and spanned acute and community sectors and right from the beginning participants began to demonstrate progression and growth in their understanding of the Act.

Over the subsequent 10 months the mentorship programme has consistently been cited as a safe space to share experiences, ask for and receive constructive feedback, and reflect on practice. The demonstration of compassion and commitment participants have shown in applying the guiding principles of the Act in their practice has been remarkable.

Example of themes arising from mentee and mentor feedback:

Psychologically Safe Space: Participants emphasise that the mentorship group provides a unique environment where “professional hats” are set aside and where there is opportunity to engage in respectful dialogue, challenge the status quo, understand different perspectives and explore concerns openly.

Beneficial discussions and insights: The opportunity for participants to share de-identified case vignettes and receive valuable feedback has been very well received. Multidisciplinary perspectives and recommendations that emerge during the discussions have been helpful for mentees taking action as well as influencing their professional practice going forward.

Confidence and Practical Application: Mentees cite feeling more comfortable discussing the Act and are taking actions such as raising ADM as a standing agenda item in team meetings, sharing ideas for working with communication-impaired clients, and voicing commitment to implementing local awareness.

These are just a small sample of how the current group are experiencing the programme to date. And now we are excited to continue this journey in Year Two of the programme, fostering growth, collaboration and creating a positive impact!

Looking Ahead:

We're thrilled to announce that Year Two of the ADM Mentorship Program will begin in September 2024. With changes such as the Regional Health Area structures, along with feedback from current participants, the design for Year Two is based on integration - how people utilising the Act access care across continuums rather than individual sectors or episodes of care.

- **Integration:** There will be a mix of Acute and Community participants in each group; with a further mix of people from Year one and new mentees.
- **RHA aligned:** Groups will be formed within their RHA and as close to geographical locations as possible.
- **New Groups for All:** All participants will form into new groups with an emphasis on diversity and new learning opportunities.
- **Meeting modality:** Flexible to group needs – in person, online.
- **Co-mentor:** Two mentors per mentorship group
- **New Mentees: Bespoke recruitment** - shorter recruitment form & process available.
- **Practical application:** The programme will be supported by tailored themed training, resources and webinars with a focus on practical application.

If you would like to participate in Year 2 of the ADM Mentorship Programme please email: adm.mentorship@hse.ie to express your interest.



Finally, thank you to the current participants for making the ADM Mentorship Program a success. Together, we are shaping a future where it is presumed that every adult can make their own decisions, provided with all the help they need and all interactions are respectful of individuals' rights.



ADM Mentorship Programme - Reflections from a Mentor



Colm Harty, Patient & Service User Engagement, CH East

As a mentor on the ADM mentorship programme since September 2023, I have observed a significant shift in the awareness of the ADM Act in my community area. The programme is unlike any programme I have been involved in before, where the ask of each group is essentially to create a safe space to learn from each other. The group I facilitate are people from a variety of professional backgrounds and this gives a peer support dynamic that opens people to different ways of working across different areas of health and social care, always keeping the guiding principles of the Act at the forefront of any discussions.

Initially, as a mentor I observed that the group I facilitate were primarily discussing complex de-identified cases and supporting each other with suggestions based on these. As the knowledge base has grown, the sessions have become a mix of case discussion with an occasional guest speaker on an area of the Act.

I acknowledge facilitation for me has become less about being a central voice in our sessions and has become more about the pre-planning of sessions - this I feel is due to myself and the group becoming more comfortable with the Act and becoming more competent at supporting each other in the sessions. This increased knowledge base means many cases that may have appeared complex in nature six months ago are now being supported by their local service.

I would like to acknowledge the support we as mentors have received from Caoimhe, Jacqueline and Shem from the National Office for Human Rights and Equality Policy alongside their Mentorship training colleagues Cathy and Aileen who provide us with monthly mentor catch ups, giving us the opportunity to liaise with fellow mentors as well as providing us with very useful mentorship tips.





Fingal's Older People's Council Annual Conference 2024

Cathrina Murphy, Age Friendly Programme Manager,
Fingal County Council



One hundred and thirty representatives from groups across Fingal attended the Older People's Council Annual Conference on Tuesday 21st May 2024 in Kettles Country House Hotel.

The Conference, which was opened by the Mayor of Fingal, Cllr Adrian Henchy covered two themes: Housing in Fingal and Decisions Supports within the HSE. Housing presentations were provided by Aoife Lawler, Carmel Brennan and Danielle Monahan on Housing Options in Fingal, Age Friendly Design and Ageing in Place, respectively.

The presentations were informative and well received by delegates who were delighted to know that their needs were being considered in new housing developments in Fingal.

Presentations from the HSE's Ciara Palmer, Jacqueline Grogan and Geraldine Farren focused on the Assisted Decision-Making (Capacity) Act 2015 and the move to a human rights approach, supports available in acute settings and advance healthcare directive.

The presentations highlighted the guiding principles underlying this legislation with the presumption that every person has the capacity to make the decisions about their own lives. Delegates were reminded that we all make unwise decisions throughout our life, but this does not affect our capacity to make decisions.

Following a thought-provoking morning, the afternoon provided mental relief as delegates danced to the music of Joe Mann. It was obvious from the dancing that some delegates acted upon the information provided by speakers and made their own decision to forgo the walking sticks and join in the dancing. For them it was a wise decision and for one delegate it felt like "a weight had been lifted" from his shoulders – it was best time he had in years!

For more information
please click [here](#)



Consent

Episode #57 - Talking Health & Wellbeing



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

- Elaine McCaughley



Elaine McCaughley from the HSE National Office for Human Rights and Equality Policy, recently participated in an episode of the HSE Talking Health and Wellbeing Podcast. During the episode, she spoke with host Fergal Fox on the HSE National Consent Policy, emphasising the policy's focus on the person making their own decisions about their health and social care, ensuring informed and voluntary consent.

They also discuss challenges in mental health services and the role of family in cases like dementia, highlighting the human rights-based approach to care and the respect for individual autonomy and decision-making capacity.

Listen and share wherever you get your Podcasts or watch on the HSE Health and Wellbeing YouTube channel. Link also attached here



WEBINAR



HSE Mental Health Services

Recent Webinar : HSE National Consent Policy 2022 - Considerations for Mental Health Services

HSE Mental Health Services, in conjunction with the HSE National Office for Human Rights and Equality Policy, hosted a webinar in May titled - HSE National Consent Policy 2022 - Considerations for Mental Health Services. The webinar provided an overview of the HSE National Consent Policy 2022 as it pertains to mental health services and gave practical guidance to mental health services and practitioners about the implementation of the policy in services.

An expert panel, consisting of Prof Mary Donnelly, School of Law UCC, co-chair HSE National Consent Policy, Prof Shaun O'Keeffe, Consultant Geriatrician, UHG, co-chair HSE National Consent Policy, Prof Brendan Kelly, Prof of Psychiatry, Trinity College Dublin, Michael Ryan, Head of Mental Health Engagement and Recovery, HSE, Kerry Cuskelly, Principal Social Worker, CHO DNCC North Dublin Adult Mental Health Services, Trevor Phillips, Assistant Director of Nursing, Laois/Offaly Mental Health Services and Ber Grogan, Policy and Research Manager, Mental Health Reform, then discussed a number of consent related questions and scenarios that were received in advance from staff in mental health services.

You can view the webinar at HSE National Consent Policy 2022 - Considerations for Mental Health Services (youtube.com)



Consent and dental treatment



Dr Siobhan Stapleton, President, ISDH

The Irish Society for Disability and Oral Health (ISDH) invited the HSE National Office for Human Rights and Equality Policy to run a workshop at their Annual conference in the River Lee Hotel, Cork City on the 6th June 2024, focussing on the HSE National Consent Policy 2022 v1.2 (updated in January 2024 in respect of Assisted Decision-Making (Capacity) Act).

The workshop was excellently led by Ms Elaine McCaughley, Prof Mary Donnelly and Prof Shaun O'Keefe with input from dental experts in the area of Special Care Dentistry.

The workshop was attended by dental teams across the country who provide oral care for children and adults with disabilities in primary care services, hospital settings, and residential services.

After providing an overview of the policy and its update in relation to the Assisted Decision-Making (Capacity) Act 2015, the team discussed in detail scenarios specific to the provision of oral health care and how the new legislation would be applied. The emphasis was very much on quality clinical care and practical management of aspects of consent.

There was good discussion on the implications of the new legislation and the revised HSE National Consent Policy and its impact on clinical practice. The session was interactive and open to the floor.

Feedback from people who attended on the day complemented the team on a very practical approach, the great clarity the workshop brought to the clinical dental setting, how informative, engaging and enjoyable the session proved to be.

It was acknowledged by both the attendees and the presenters that collaboration in the form of workshops like this is absolutely paramount in providing the best oral healthcare outcomes for children and adults with disabilities. Dentistry often stands as an outlier, being provided in the primary care for patients with complex needs who unfortunately often require surgical intervention and valid consent for such interventions.

We in the ISDH look forward to working with the National Office for Human Rights and Equality Policy as this legislation and policy evolves in the clinical setting within the context of complex patient cohorts.



Prof Shaun O'Keefe



Participants of ISDH event



Prof Shaun O'Keefe,
Prof Mary Donnelly, Elaine McCaughley



Grúpa Ospidéal
Oirthear na hÉireann



Ireland East
HOSPITAL GROUP



Consent in Practice in Maternity Services



Paula Power, Operations Manager for the
Women & Neonates Healthcare Directorate, IEHG

The Ireland East Hospital Group (IEHG) facilitated a “Consent in Practice in Maternity Services” learning event on the 1st May 2024 in St. Luke’s Hospital Kilkenny.

We were fortunate to have 43 professionals present from across the 5 Maternity Services in IEHG, representatives from National Women and Infants Health Programme (NWHIP), the State Claims Agency, the Medical Council of Ireland, Nursing and Midwifery Board of Ireland (NMBI) and the National Office for Human Rights and Equality Policy.

Despite significant progress in the area of informed consent, including the publishing of the updated HSE National Consent Policy in January 2024, challenges persist in translating these principles into everyday practice within the complexity of maternity services. We heard presentations and case scenarios from a variety of professionals across our services who created an environment which fostered engaging conversations throughout the afternoon, including:

Elaine McCaughley, Programme Lead in the National Office for Human Rights and Equality Policy

Dr. Anne Twomey, Consultant Neonatologist and Clinical Lead for Quality, Risk and Patient Safety, National Maternity Hospital

Laura Harrington, Head Medical Social Worker, National Maternity Hospital

Amanda Casey, Principal Social Worker IEHG

Sheila Cahill, Midwifery Shift Leader in St. Luke’s Hospital Kilkenny

Martina Cronin, Clinical Midwife Manager 3, National Maternity Hospital

The aim of the event was to work towards creating environments where women can feel heard and respected, and staff can support each other to work through these sometimes complex and challenging situations. 25% of the attendees responded to a request for feedback, and scored their overall satisfaction as 4 or 5 out of 5.

Suggestions on how to improve further events included: “Possibly an action plan for the maternity units so that something happens to the feedback and it is not lost, agreed at the end of the session.”

What did people say?

“
Very informative session. It highlighted 2 different issues for me.:

1 – Communication antenatally, classes, visits etc. How are we doing this? Can we improve and involve women? Our language still comes across as very paternalistic even though we don’t mean to be.

2 – Unexpected situation where despite above, consent is withheld, importance of documentation. It would be good to see learnings from these workshops cascaded down to staff
”

“
Excellent presentations from all, really enjoyed the afternoon. Presentations were from HSE staff - having a patient there to share a lived experience could have provided a more balanced approach and perhaps hearing the ‘other side’ (not always positive feedback) could have enabled further reflection on how consent is perceived
”

‘Uncertain Times’ for children in Ireland

Niall Muldoon, Ombudsman for Children



In May, the Ombudsman for Children’s Office published our 2023 Annual Report, which we called *Uncertain Times*. Every year we try to give our Annual Report a title that reflects the current state of play for children, the changes that have taken place or the challenges they face.

This year I returned again and again to the themes of uncertainty and instability, as this is unfortunately what I see too many children facing every day. Children’s issues are fighting for Government’s attention at a time when there is a housing crisis, a cost-of-living crisis, an international protection crisis, and when all our public services are under increasing pressure.

As Ombudsman for Children I am also increasingly aware and concerned about issues raised by children in relation to discrimination and racism. In many ways Ireland is a wonderful place to be a child – we are one of the richest countries in the world, and most of our children live in happy, loving homes. However, world issues like war, migration, climate change, online safety, and AI have changed the reality of childhood for this generation.

2023 was another busy year for our Office with the number of complaints remaining steady at 1,790. We also noted more complex complaints, with one in five relating to more than one State agency, highlighting yet again the importance of interagency cooperation. The complexity of the cases we are seeing also means that by the time families come to us, they tend to be even more stressed and upset.

As we approach the end of the current Dáil term it is a natural time for reflection and to set targets for the coming years I hope, and we will continue to push, for children to be at the forefront of the minds of law and policy makers. Uncertainty is not good for any of us, but for children it can be extremely challenging. Let us hope that 2024 can bring an end to these *Uncertain Times* in the best interests of the children of Ireland.



Where can you find more information?

To find out more you can email:
oco@oco.ie or Call: 01 865 6800 or visit
www.oco.ie



ombudsman
do leanai
for children

Celebrating 20 years

Tomorrow starts with us
Tosaíonn an todhchaí linn



Regulating for Adult Safeguarding- a report from the Law Reform Commission



Leanne Caulifield
Law Reform Commission

The Law Reform Commission (“Commission”) published its Report on a Regulatory Framework for Adult Safeguarding on 17 April 2024. It launched the Report at an event featuring the Attorney General, Rossa Fanning SC, and representatives from regulators, government departments, advocacy bodies and others.

The Report addresses the need for an overarching safeguarding framework in Ireland, which would include duties and powers to prevent and respond to harm of adults who need support to protect themselves from harm (“at-risk adults”). It draws on research and analysis of domestic law and policy and a review of adult safeguarding legislative frameworks in other jurisdictions.

During its consultation process, the Commission engaged with regulators; statutory bodies; professional bodies; government departments; advocacy bodies; representative groups; professionals across various sectors; and the public, including people affected by adult safeguarding concerns.

The Commission recommends the introduction of adult safeguarding legislation, underpinned by a rights-based framework. The Commission published two draft Bills, the Adult Safeguarding Bill 2024 and the Criminal Law (Adult Safeguarding) Bill 2024.

The Adult Safeguarding Bill 2024 aims to provide a comprehensive, cross-sectoral statutory and regulatory framework that is rights-based and aimed at empowering at-risk adults. It is focused on preventing and safeguarding against all forms of abuse and neglect.

The Criminal Law (Adult Safeguarding) Bill 2024 contains proposed offences to promote the highest standards of safeguarding, and deter abusive, exploitative and neglectful behaviour. The offences would criminalise various behaviours, such as “cuckooing”, where a person befriends an at-risk adult and takes over their home to conduct illegal activities or engage in anti-social behaviour.

The Report, Executive Summary, and plain English and easy-to-read versions of the Executive Summary are available [here](#):



The Commission has prepared a video summarizing our recommendations, which is available [here](#):



Plain English and easy-to-read versions of the Report will be published soon.



For more information email
info@lawreform.ie





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

Research on the Assisted Decision-Making (Capacity) Act and Communication

Young people who are non-speaking, sometimes speaking or communicate differently and their supporters are invited to take part in a research project about using Ireland's new capacity Act.

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 19 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.

What will people taking part have to do?

People taking part in this research will be asked to tell Cliona 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 registering for 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 Cliona to use what they share in her research.

Accessibility – making it easier to take part

It is important to Cliona that young people who are interested in the research can be involved or simply have easy ways to contact her to find out more. Please let Cliona know what would help you to take part. You can contact her by phone, email, 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.

More information

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



For more information please [email](mailto:cliona.debhailis@universityofgalway.ie)



An tIonad DL & Beartais Michumais
Centre for Disability Law & Policy

funded by



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

Welcome to New Staff

We are delighted to welcome two new members to our team - Norma O'Donnell and Joanne Haffey who bring a wealth of health and social care experience to their new roles.

Norma O'Donnell

Norma O'Donnell is ADM Project Manager in the National Office for Human Rights and Equality Policy, Strategy and Research. She is responsible for programmes and projects in relation to the Assisted Decision-Making (Capacity) Act 2015, playing a key role in supporting the implementation of the HSE National Consent Policy across health and social care services.

With over 25 years of experience in the HSE, primarily in prehospital settings, Norma brings extensive clinical insights from her tenure as an Advanced Paramedic. She also possesses an educational background as a Tutor with the Pre Hospital Emergency Care Council. Her career has spanned roles in Education and Competency Assurance, Operational Management and Community Engagement with the National Ambulance Service (NAS).

Norma's adeptness at managing complex changes is evident from her tenure with the South Southwest Hospital Group, where she led patient safety projects in line with the Patient Safety Strategy.

Norma holds a PG Dip in Emergency Medical Science, MSc in Leadership in Healthcare, Grad Dip in Health Services Management and a Postgraduate in Quality Improvement. She has facilitated HSE improvements with the process improvement methodology of her Lean Six Sigma qualifications.

An Adjunct Clinical Lecturer and an After Action Review Facilitator, Norma is also a member of the Q Community—a network of professionals across the UK and Ireland committed to enhancing health and care quality and safety.

Norma is deeply committed to education and championing equality and fairness, advocating for the empowerment of individuals to make informed choices about their lives.



Joanne Haffey

Joanne Haffey joins the team as a Senior Project Manager. Joanne is responsible for work relating to assisted decision making, specifically the development of a HSE National Policy on Assisted Decision Making.

Joanne has 20 years' experience working in Irish health and social care settings. Joanne brings an array of experience as a professionally qualified social worker, having spent much of her career working in services for people with disabilities.

In 2018 Joanne began working for the HSE's National Independent Review Panel (NIRP) as the service manager, where she coordinated and managed comprehensive independent reviews into serious concerns within the HSE and HSE funded services. In 2022 Joanne joined the HSE's office of the National Clinical Director of Quality Patient Safety as the Senior Operations Manager, gaining significant experience in the operational management of a national HSE office.

Joanne holds a Bachelor of Social Studies (BSS), National Qualification in Social Work (NQSW), CORU registration, a Post Graduate Diploma in Public Management and Masters in Health Care Management.

At the centre of Joanne's practice and approach to work are the rights of people in receipt of health and social care services. Joanne is passionate about the voice of the person being at the centre of what we do.

