

National Office for Human Rights and Equality Policy

Spring Round up-2023

HSE Strategy and Research

SPRING 2023



Caoimhe Gleeson, General Manager, HSE National Office for Human Rights and Equality Policy It has been an eventful start to Spring 2023. We are delighted to inform you that the Assisted Decision-Making (Capacity) Act will commence on the 26th April 2023. Commencement will bring about a number of changes including the **abolition of wardship**, the **operationalisation of the Decision Support Service, and the introduction of a new system of tiered decision-making supports.** In this newsletter we focus on the wealth of information being produced by the HSE National Office for Human Rights and Equality Policy and the Decision Support Service to assist HSE staff prepare for implementation of the Assisted Decision-Making Capacity Act 2015.

Elaine McCaughley gives an overview of the recently launched e-learning programme on the Act - Assisted Decision-Making (Capacity) Act 2015 – Guidance for Healthcare Workers. The e-learning programme consists of three modules: General principles; Working with decision supporters appointed under the 2015 Act; and Advance Healthcare Directives. The e-learning programme aims to support staff to familiarise themselves with their new responsibilities under the Act and provides essential information on implementing the Act in practice. This e-learning programme can be accessed on <u>HSELand</u>.

We hosted two webinars in March in preparation for commencement. The first webinar, **'Getting ready for commencement of the Assisted Decision-Making (Capacity) Act 2015'** was held on 21st March with over 3,500 registrants. This webinar was recorded

and is available on our <u>website</u> along with presentations and questions from the event. The second webinar '**Getting** ready for Advance Healthcare Directives under the Assisted Decision-Making (Capacity) Act 2015' was held on 29th March. This webinar was aimed at all healthcare workers, in particular clinicians, and gave an overview of advance healthcare directives, focusing on some practical, legal, mental health service and advocacy considerations along with information about the Decision Support Service Codes of Practice relating to advance healthcare directives. The recording of this event is also available on our <u>website</u>.

We have developed a short **survey** to gain a better understanding of the learning needs of HSE staff to support the implementation of the 2015 Act and the HSE National Consent Policy 2022. **The closing date for this survey is extended to Monday 24th April 2023**. We welcome responses from a wide variety of staff and services. The survey link can be accessed <u>here</u>.

For further information, updates and resources are available on our webpage www.assisteddecisionmaking.ie

Caoimhe Gleeson

National Office for Human Rights and Equality Policy



Update on the Assisted Decision-Making (Capacity) Act 2015

Jacqueline Grogan Project Manager National Office for Human Rights and Equality Policy



Commencement of Assisted Decision-Making (Capacity) Act 2015

The Minister for Children, Equality, Disability, Integration and Youth, Roderic O'Gorman, and Minister of State for Disability, Anne Rabbitte, announced on 24th February 2023 that the Assisted Decision-Making (Capacity) Act 2015 will be commenced on **26th of April 2023**.

The announcement follows the enactment of the Assisted Decision-Making (Capacity) (Amendment) Act 2022, which was signed into law by the President on 17th December 2022.

A number of Statutory Instruments will be prepared over the weeks leading up to the 26th April in order to finalise preparations for the full operationalisation of the Decision Support Service.

The 2015 Act brings about important changes for people who require support to make decisions and for staff interacting with them.

The enactment of the 2015 Act will mean that from the 26th April 2023:

- wardship will be abolished
- people currently in wardship will have their circumstances reviewed by the wardship court
- all adult wards will exit wardship on a phased basis over the next three years
- the Decision Support Service will begin to process applications for new decision support arrangements
- the Circuit Court will begin to process applications for Decision-Making Representative Orders
- there will be statutory provision for the making and recognition of Advance Healthcare Directives
- there will be new regulations for the making and oversight of Enduring Powers of Attorney.

A range of resources have been developed for staff in preparation for commencement of the 2015 Act—information on these can be found on www.assisteddecisionmaking.ie and some are detailed further on in this newsletter.

The HSE National Office for Human Rights and Equality Policy will continue to develop national support and guidance for staff and services following commencement of the 2015 Act.

Transition from Wardship

For up to date information on the transition from wardship please go to the following: https://www.courts.ie/office-wards-court

Changes to the Nursing Home Support Scheme:

For up to date information on the changes to the Care Representative Application process under the Nursing Home Support Scheme please go to the following:

https://www2.hse.ie/services/schemes-allowances/fair-deal-scheme/application-process/

The Assisted Decision-Making (Capacity) Act 2015:

Information for families and carers & update on the Codes of Practice



seirbhís tacaíochta cinnteoireachta decision support service **Decision Support Service**

The Director of the Decision Support Service (DSS), Áine Flynn, has outlined in a short video message for families what the Assisted Decision-Making (Capacity) Act, 2015 might mean for them. The link to the video is available on the DSS website <u>here</u>.

In the video family carers are assured that the framework of supports available under the Act is not imposed on anyone. The DSS will be directly involved with individual families only in relation to formal arrangements that are made under the Act.

The level of formal support that is appropriate will depends on a person's circumstances and the decisions that they need to make. There is no obligation on a person to appoint a decision-making assistant or co-decision-maker. It is not expected that families will have to apply to court to become decision-making representatives to manage the practicalities of everyday decision-making.

Particular decisions may arise that require the formal support that can be provided under the Act. Such decisions could relate to a person's money, their property, or their personal welfare, including decision-making about healthcare.

To access further information, presentations and videos, or to request posters and guides please visit <u>www.decisionsupportservice.ie</u> or send a query to <u>queries@decisionsupportservice.ie</u> (phone: 01 2119750).

Update on the Codes of Practice

As part of the establishment of the Decision Support Service (DSS), 14 codes of practice have been prepared for the guidance of decision supporters and persons and professionals interacting with a relevant person under the 2015 Act.

This includes the code of practice for healthcare professionals and the code of practice on advanced healthcare directives for healthcare professionals. It also includes the code of practice on supporting decision-making and assessing capacity which also applies to healthcare professionals.

It is anticipated that these codes of practice will be published and accessible on the DSS website soon in advance of full commencement on 26th April 2023.

Additional resources and guidance documents are also being developed to support people and organisations using services, carrying out functions and interacting with a relevant person under the 2015 Act and will be available on the DSS website.



Feedback on the HSE National Consent Policy E-Learning Programme

Shem Romanowski

National Office for Human Rights and Equality Policy



The HSE National Office for Human Rights and Equality Policy gather data on how many learners complete the HSE National Consent Policy e-learning programme every month, and conducted a small-scale research project analysing the learners' experience. The source of data was a short, two-stage evaluation exercise conducted by the learners upon completing the programme. In the first part, the evaluation questionnaire contained ten structured statements covering topics from "*meeting learner's expectations*" to "*recommending the programme to others*". The second part comprised of two open-ended questions asking the learners to suggest any changes to the programme and provide additional comments. The data analysis in the current study covered the period between March and December 2022.



HSE National Consent Policy

★★★★★ 12 Reviews Skip to Session This programme will prepare staff to ensure that valid consent is sought for every intervention in line with the HSE National Consent policy. The programme inculdes 2 modules:

The programme received overwhelmingly positive feedback. Over 85% of those who completed the e-learning programme indicated they would not change anything about the programme, and supported that with their comments describing the course as "excellent, good, informative, useful, applicable, interesting, helpful, clear, flexible, wellpresented, and insightful".

On average 60%, and just over 22% of learners, respectively agreed and somewhat agreed with statements like "The e-learning content met my expectations", "The content of the programme was clear and easy to understand" or "Having completed this eLearning programme, I am more knowledgeable about the topics covered".

To date, the programme has been very well-received, and we encourage anyone who has not yet completed the programme, to do so. The HSE National Consent Policy e-learning programme can be found by typing *national consent policy* in the search bar on the main page of <u>www.hseland.ie</u>



The Assisted Decision-Making (Capacity) Act 2015 - Guidance for Healthcare workers E-Learning Programme.

Elaine McCaughley

Senior Project Manager, National Office for Human Rights and Equality Policy



We are delighted to have launched three new e-learning modules to support staff to understand the Assisted Decision-Making (Capacity) Act 2015 and their new responsibilities under it. This programme will introduce learners to the guiding principles of the 2015 Act, provide guidance on the roles and responsibilities of decision supporters appointed under the Act and how to work with them, and provide an overview of advance healthcare directives.

These modules are aimed at all staff working with adults (aged 18 and older) in health and social care. This programme was developed with support from the Decision Support Service, the National Advocacy Service, SAGE advocacy, frontline staff, people using services

and other subject matter experts. We are very grateful for the input of all reviewers on this substantial piece of work.

The modules are:

Module 1: The Guiding Principles:



This module gives a brief overview of the 2015 Act and outlines what it means for healthcare workers.



Healthcare workers have new responsibilities under the 2015 Act which specifies how they can best support a person to make their own decisions. This module helps to familiarise staff with these new responsibilities that are detailed in the guiding principles of the 2015 Act. This module will help staff to identify relevant situations and to incorporate the guiding principles into their work.

The Assisted Decision-Making (Capacity) Act 2015 - Guidance for Healthcare workers

E-Learning Programme.

Elaine McCaughley

Senior Project Manager, National Office for Human Rights and Equality Policy



Module 2: Working with Decision Supporters appointed under the 2015 Act



This module introduces the different types of decision supporters that can be appointed under the 2015 Act. Healthcare workers will need to know the roles and responsibilities of the decision supporter, how to interact with them and when it is appropriate to contact the Decision Support Service. By the end of the module staff should be able to work effectively with decision supporters to support a person and keep their will and preference at the centre of decision-making.



The Assisted Decision-Making (Capacity) Act 2015 - Guidance for Healthcare workers E-Learning programme.

Elaine McCaughley

Senior Project Manager, National Office for Human Rights and Equality Policy

Module 3: Advance Healthcare Directives.



This module provides an overview of advance healthcare directives and aims to provide guidance and confidence to staff about their responsibilities in relation to following an advance healthcare directive. The module will help staff to identify circumstances in which an advance healthcare directive is valid and applicable, to respond appropriately to an advance healthcare directive and to support a person who wishes to make an advance healthcare directive.



We refer learners on this programme to the Decision Support Service (<u>www.decisionsupportservice.ie</u>) for the relevant Codes of Practice which will be published shortly and for any practise updates.

Each module takes approximately 30 minutes to complete, and attracts the following points for CPD; RCPI 1 CPD Credits in the External CPD category, NMBI 3 Continuing Education Units (CEUs). A certificate for each module is generated when the learner completes the relevant assessment.

This programme relates to *the National Consent Policy* and *Supporting Decision-Making in Health and Social Care* elearning programmes on HSeLand.

Ombudsman for Children's Office (OCO) Youth Advisory Panel (YAP) involvement in the Children's Report to the UN Committee on the Rights of the Child

Christopher O'Sullivan, member of the Ombudsman for Children's office Youth Advisory Panel (YAP)

Christopher O'Sullivan writes below about the YAP's involvement in the children's report to the UN Committee on the Rights of the Child, <u>Pieces of Us</u>.

The Youth Advisory Panel (YAP) at the OCO was fundamental to the process of producing the children's report for the UNCRC. Our YAP members come from all corners of the country ensuring that every member can provide unique opinions and views as a child living in Ireland. We met regularly either online or in-person and worked on different aspects of the report. The YAP provided their youth perspective on the material put into the report and discussed issues directly affecting the children of Ireland.

The YAP travelled to Geneva in September 2022 to attend the Children's Meeting with the UN Committee. It was great to see the hard work of the YAP finally come to fruition. The members of the YAP spoke to the Committee on the relevant topics in the report, with one being the impact of health and services on young people in Ireland. The YAP spoke to the committee about the number of services that support children, including health services and family support services. However, mental health services were the biggest single issue across the board. It came up in every section of the report, particularly in education, equality and community. The YAP ensured that they conveyed the extent to which poor mental health affects every part of a child's life.

The YAP went on to further discuss the importance of the provision of Transgender health services for children and highlighted the knock on effects of its absence with the Committee. We made the Committee aware of the lack of support services for children with disabilities. We noted that, due to the lack of services, the child's life was impacted in school, family life and socialising. The YAP called for transparent ring fenced funding directly for children's mental health services, decreased waiting lists, increased beds for inpatient services and overall increased investment into rural mental health services. The YAP also called for increased support for children with disabilities, particularly investment in assessment of need and for clarification from the State on plans to develop Transgender services.

The YAP feel it is important to recognise that Ireland is such a positive place for children in so many respects and important progress is being made to improve children's rights - but it is equally important to recognise the areas in which children are being let down and that change is needed now more than ever. We are proud to say to all the children who took part in the research and consultation for the report, your voices were heard and amplified and enhanced the fight for their rights.



Members of the Youth Advisory Panel and the National Office for Human Rights and Equality Policy at the launch of 'Pieces of Us' in the Office of the Ombudsman



Bernard O'Regan, HSE Head of Operations Disability Services; Minister Roderic O'Gorman, Minister for Children, Equality, Disability, Integration and Youth; Elaine McCaughley and Caoimhe Gleeson, National Office for Human Rights & Equality Policy.

Do Not Attempt—Cardio Pulmonary Resuscitation (DNA-CPR) Research Project

Elaine McCaughley

Senior Project Manager, National Office for Human Rights and Equality Policy

Part 3 of HSE National Consent Policy 2022 provides a decision-making framework to facilitate the advance discussion of personal preferences regarding CPR and DNACPR orders and to ensure that decisions relating to CPR and DNACPRR orders are made consistently, transparently and in line with best international practice. A <u>supplementary</u> <u>guidance document</u>, *Guidance Regarding Cardiopulmonary Resuscitation and DNAR Decision-Making during the COVID-19 Pandemic* was developed in April 2020. A new standalone policy is going to be developed in line with best international practice and evidence.

The National Office for Human Rights and Equality Policy has contracted Dr John Lombard Lecturer in Law, and his team in University of Limerick to undertake research on DNACPR orders to identify best DNACPR practice, training, and policy to inform the drafting of the new standalone DNACPR policy for the HSE.

We look forward to working with John and his team on this important piece of work and have convened a project working group of internal and external stakeholders to provide guidance and feedback over the course of the research project. Further updates on this work is available from **<u>national.consentpolicy@hse.ie</u>** and https://www.hse.ie/eng/about/who/national-office-human-rights-equality-policy/consent/



Dr John Lombard, Lecturer, School of law, University of Limerick



Dr Hope Davidson, Lecturer in Health Law and Ethics , University of Limerick

Launch of the HSE National Policy for Consent in Health and Social Care Research.

Mary Clare O'Hara, Research and Consent

The <u>HSE National Policy for Consent in Health and Social Care Research</u> was launched on 9th February 2023. Dr Philip Crowley, HSE National Director for Strategy and Research, who launched the policy said,

"Health and social care research is a dynamic and interactive process. It has to be based on trust and on respect for the mutual aims of improving health, wellbeing and patient outcomes. The policy, a milestone for the HSE, aims to ensure that impactful research can be conducted safely, ethically, and in compliance with legal requirements, while maintaining the confidence of the participants and keeping them at the centre of the research process."

Dr Crowley was joined at the launch by a distinguished panel for a lively discussion. The policy builds on the publication of the <u>HSE National Consent Policy</u> in February 2022 by the National Office for Human Rights and Equality Policy.



For the purpose of this policy, the term 'consent' refers to the informed and explicit agreement of a prospective research participant to take part in a research study and, when relevant, to the use of their personal data for such research. The agreement for both must be ethically obtained, recorded, and retained; the proposed consent protocol must be approved by an appropriate Research Ethics Committee (REC) and,

Dr Ana Terrés, Research and Evidence Lead, HSE Strategy and Research, said

"International evidence has shown that health services where research is formally integrated as part of the organisational structure deliver better care. Research supports best practice and optimal healthcare outcomes. The new HSE National Policy for Consent in Health and Social Care Research will guide high-quality health research in the context of the <u>HSE National Framework for Governance, Management, and Support of Health Research</u>".

The policy aims to ensure that research is conducted safely, ethically and in compliance with legal regulations. It provides one overarching policy to guide healthcare services hosting research, particularly to those conducting research and to Research Ethics Committees approving research in the HSE and its funded organisations. This policy does not extend to clinical audits, standard service evaluations, or public health or advanced health analytics work carried out by the HSE for the purpose of fulfilling its legal obligations for the planning and delivery of health and social care services.

Watch this space!

HSE Research and Development are in the process of developing a short easy-to-read guide, specific training for REC members and training modules that will be available later in 2023 on HSELanD.

For more information, please see - https://hseresearch.ie/consent/

'ISL HEALTH' Project at UCC - exploring the provision of access for sign language users across public health services

Gill Harold, Principal Investigator, University College Cork







In its report entitled 'Information provision and access to public and social services for the Deaf Community', Citizens Information (2018) reported that a combined total of 73% of respondents to a survey indicated that their experience in accessing public health services in Ireland was either 'poor' or 'very poor'. This stark statistic corroborates the substantial international research evidence which tells us that the health needs of deaf populations remain persistently underserved. Deaf communities around the world have contributed generously to research in this area and it is important to now focus attention on healthcare providers, to assess their capacity to provide equitable access for deaf people, in an effort to effect meaningful change. In Ireland, this issue is linked closely to the HSE's public sector duty, as set out in the

Irish Sign Language Act 2017 (Section 6) and the Irish Human Rights and Equality Act 2014 (Section 42).

With a focus on access provision for Irish Sign Language users, the **ISL HEALTH project** aims to support the effective implementation of the Irish Sign Language Act 2017 in public healthcare settings. It will do so by acquiring the knowledge, views and experiences of HSE Access Officers and Irish Sign Language interpreters on the issue of access provision. The responses we receive will be used to identify best practice, opportunities for learning, as well as training and development needs.

As part of this project, a short survey (approximately 15-minute response time) will be circulated to HSE Access Officers during **April 2023**. The co-operation of this cohort is respectfully requested to enable us to gather data that is as representative as possible of the organisation's knowledge base.

The project is funded by the Irish Research Council and the research team is comprised of members from University College Cork in partnership with Cork Deaf Association, Kerry Deaf Resource Centre and the HSE's National Office for Equality and Human Rights. Ethical approval for this project has been obtained from the HSE's Reference Research Ethics Committee for Midlands and Corporate (Regional Health Area B) and UCC's Social Research Ethics Committee.

Full details of the research project can be found at the following link: https://www.ucc.ie/en/iss21/researchprojects/researchprojects/isl-health/

If you have a query about the *ISL HEALTH* project, please contact the principal investigator, Dr Gill Harold, by email: <u>g.harold@ucc.ie</u>

Team day on the National Consent Policy 2022 in Donegal

Joe Nelis, Social Work Team Leader Primary Care, Social Work Service Donegal

Primary Care Centre

In preparation for the commencement of the Assisted Decision-Making (Capacity) Act 2015, the HSE Social Work Service Donegal hosted a team day on 24th of March in St. Conal's Hospital Campus in Letterkenny. The event was focused on the HSE National Consent Policy 2022 where teams set out the relevant sections of the Policy with presentations, scenario role plays, and case discussions relating to applying the Policy and the new 2015 Act into Social Work practice.

The event was attended by staff from Older Person's Social Work, Intellectual Disability Social Work, Children's Disability Social Work, Primary Care Social Work, and Letterkenny University Hospital Social Work. The Social Work Service Donegal are currently planning a series of training events in the months ahead, and will be running further team training on 26th April to mark the commencement of the Assisted Decision Making (Capacity) Act 2015.



Nothing about me, without me.

Caroline O'Hehir

Assistant Director Of Nursing and Chairperson of the Human Rights Committee,

HSE Disability Services Sligo/Leitrim

The Sligo/Leitrim Disability Services Human Rights committee held an awareness day on March 3rd 2023 in the Sligo Park Hotel. "Nothing about me, without me!" was the theme of the event, which centred on Human Rights and Restrictive Practice awareness. The purpose of the Human Rights Awareness Day was to provide a forum for people with disabilities availing of residential services and staff from the range of disciplines supporting them to access information and to have the opportunity to have conversations regarding Human Rights and Restrictive Practices. The event also aimed to promote a sense of positivity and celebration regarding the launch of the Assisted Decision Making (Capacity) Act 2015.

An art competition was held and all entries were on display. Themes for the competition were My Rights/Human Rights, What The Assisted Decision Making Capacity Act Means To Me and the FREDA Principles of Fairness, Respect, Equality, Dignity, Autonomy.

The Sligo/Leitrim Disability Services Human Rights committee provides a forum to discuss, lead and support people with disabilities and staff regarding standards and responsibilities in embracing a Human Rights Based Approach across support services. Organiser of the event, Caroline O'Hehir stated "The awareness day served to enhance awareness of the committee and its role and also the rights and responsibilities of residents and staff in relation to Human Rights and Restrictive Practices, to ensure that a Human Rights Based Approach is embedded in staff and service users' minds."



Event: Real Productive Justice Final Conference, University of Galway

Caoimhe Gleeson and Jacqueline Grogan, HSE National Office for Human Rights and Equality Policy

Representatives from the HSE National Office for Human Rights and Equality Policy attended and participated in the Re(al) Productive Justice final conference on 27th January 2023 at the University of Galway.

The key goal of the Re(al) Productive Justice research project is to make visible the experiences of disabled people in Ireland seeking reproductive justice. The project took place from 2019-2023 and was funded by the Wellcome Trust.

This project explores the legal regulation and the real life experiences of disabled people in Ireland in making reproductive decisions. As part of this project, disabled people were invited to tell their stories of making, or being denied the opportunity to make, reproductive choices for themselves. The experiences shared in this project were used to develop toolkits and guides to support disabled people and health and social care practitioners. They are designed to encourage good practice in respecting the rights of disabled people to make reproductive decisions, and providing appropriate support so that they can make informed choices. Additionally, each toolkit contains a resource section with links to support organisations and other resources that were recommended to us by the disabled people and practitioners involved in the project.

Click the links below to view or download each toolkit. <u>Parenting toolkit</u> <u>Pregnancy and birth toolkit</u>

Abortion toolkit

Fertility and contraception toolkit



Event: Dementia Right Project, Leinster House

Jacqueline Grogan

Project Manager, National Office for Human Rights and Equality Policy

Representatives from the HSE National Office for Human Rights and Equality Policy attended a presentation on the Dementia Right project in Leinster House on 28th March 2023. It was hosted by Senator Fiona O'Loughlin, chair of the All-Party Oireachtas Group on Dementia.

St Joseph's Shankill, part of St John of Gods, are the Irish partner in the Dementia Right project, which is an Erasmus+ funded project. The aim of the project is to influence policy makers to ensure a better future for people living with dementia, where their rights

and wishes are respected and adhered to, and always taken into consideration. The outputs of the project include;

- A Charter of Rights for people living with dementia and their carers
- A European Human rights-based approach **practitioner's guide** to transformation and guidelines to access and monitor a human rights-based approach implementation.
- A **digital platform** for practitioners to access, including the online practitioner's guide and includes an innovative Training Materials.



Further updates and resources

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

- 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)
 <u>Act 2015</u>
- <u>ELearning Programme on Assisted Decision-Making (Capacity) Act (2015) Guidance for Healthcare workers</u> <u>on HSeLanD</u>
- <u>The Decision Support Service developed a webinar on Families and the Assisted Decision-Making (Capacity)</u>
 <u>Act 2015</u>
- Assisted Decision-Making (Capacity) Act 2015
- <u>Transition from Wardship to the Assisted Decision-Making (Capacity) Act 2015: Guidance for Staff webinar</u> recording from the 1st December 2022 and other related documentation
- Launch of the Easy-to-read webinar on the HSE National Consent Policy on 5th December 2022
- HSE Assisted Decision-Making website
- HSE Explainer video on the Act
- Decision Support Service
- <u>Courts Service Office of Wards of Court</u>
- <u>Aine Flynn, Director of the Decision Support Service: Statement to the Joint Oireachtas Committee on</u>
 <u>Disability Matters May 2021</u>
- Decision Support Service Explainer Video
- <u>Sage Advocacy Decision-Making and Capacity</u>
- Inclusion Ireland Assisted Decision-Making
- Inclusion Ireland Easy to Read Assisted Decision-Making (Capacity) Act 2015
- Decision Support Services guides and video presentations



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