

HSE National Office for Human Rights and Equality Policy Newsletter



Interview Spotlight



Mervyn Taylor

Former CEO of Sage Advocacy talks to us about his time with Sage Advocacy and some of the human rights challenges of COVID-19 for older people and people with disabilities.

[Please click here to listen to the interview.](#)

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Issue 1

Autumn 2020

Welcome

We are pleased to share with you the first issue of our new quarterly newsletter, keeping you up to date with all of the latest news from the HSE National Office for Human Rights and Equality Policy (formerly the HSE National Office for Assisted Decision-Making and Consent). You are receiving this newsletter because you have attended one of our events or information sessions in the past, or have requested to be added to our mailing list.

COVID-19 has changed our ways of working, with all of our work moving from face-to-face delivery now to on-line training and support. Since June 2020 we have been able to connect with over 4,000 people virtually through our webinar series. We are mid-way through delivering our second webinar series—you can find out more about these on page 2 (Update on the Office) and page 4 (Upcoming events).

If there is anything you would like to see covered in our future newsletters, please contact Jacqueline.grogan@hse.ie.

Caoimhe Gleeson, Programme Manager



Assisted Decision-Making (Capacity) Act 2015 Update

The Government has confirmed that the [Assisted Decision Making \(Capacity\) Act 2015](#) will be commenced in early 2022. Work is underway across Departments to establish plans and programmes to enable full commencement of the Act. You can find more information on www.decisionsupportservice.ie. Additional amendments are currently being made to the Act and a draft Heads of Bill with these amendments will be published in the Autumn session 2020. Further updates will be available on www.assisteddecisionmaking.ie. If you would like more information on the Act, please email Jacqueline.grogan@hse.ie or contact the Decision Support Service at dss@mhcir.ie.



seirbhís tacaíochta cinnteoireachta
decision support service

Update on the office



Photo: The Team from the HSE National Office for Human Rights and Equality policy

The HSE National Office for Human Rights and Equality Policy (formerly the HSE National ADM and Consent Office) was established to build the capacity and capability of staff to achieve compliance with human rights policy and legislation. The office is responsible for the revision of the HSE National Consent Policy and for the development and delivery of a plan to ensure compliance with the Assisted Decision Making (Capacity) Act 2015. Recent guidance produced during COVID-19 has included [Guidance on Advance Care Planning and Do Not Attempt Resuscitation \(DNAR\)](#) which was developed to support staff to address the added complexity of PPE and CPR, advance care planning and DNAR. A series of webinars to support key issues and messages of the guidance is available here [click here to access the webinars](#). The office worked in collaboration with HSE Disabilities Services on a rights based approach to testing for COVID-19 which can be accessed [here](#).

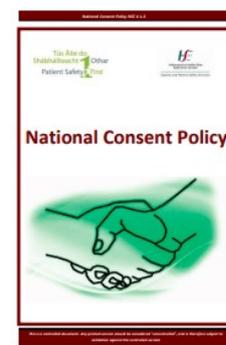
We will continue to collaborate and partner with staff and people who use our services to ensure human rights and equality issues are addressed. To find out more about the team [click here](#).

For further details contact: orlaith.branagan@hse.ie

“Well done, the video is a great resource to have to support understanding of the Act. Loved the powerful ending!”

Update on the National Consent Policy

The HSE National Consent Policy is currently being revised and will be completed by early 2021. If you would like to make suggestions on how to improve consent practices in the HSE please email Marie.Tighe1@hse.ie



Assisted Decision-Making (Capacity) Act 2015 Explainer Video

We had a very successful online launch of our explainer video on the ADM (Capacity) Act 2015 on 24th September 2020. The video was developed by this office in collaboration with people who use our services, staff, advocates and NGO's. You can view the video on www.assisteddecisionmaking.ie.

Excellent presentations - hopefully we can rise to the challenges being set for us - to ensure that everyone's rights are recognised regardless of presentation

very thought provoking. this video needs to be shown to all doctors, nurses and health care staff. still a lot of presumptions made in health care settings, similar to a presumption of nursing home care

Excellent video – a brilliant resource

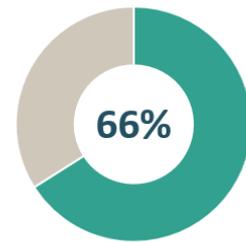
I just wanted to congratulate you on the launch today – it was so moving and inspiring- and the explainer video is a great resource which will, no doubt, be well watched!

Consent—What the Public Think

In November 2019 we commissioned Red C to conduct a nationally representative survey of 1016 adults over 18 years who had used the health service for themselves, or for their child, in the preceding 3 months.

- This survey showed that while 66% of adults were aware that their consent should be sought for any health or social care intervention, only half reported that this consent was always or frequently sought.
- For consent to be valid the person must be given sufficient information, in a format they can understand. Most people felt they were given enough information (68%), in a way they could understand (75%) and that they could ask a professional questions about their treatment (80%). However, 1 in 5 respondents reported that it can be difficult to understand the information they are given because of medical terminology and jargon.
- The survey identified some areas for improvement. Only 6 in 10 respondents reported they were told what the purpose of the treatment was and what it would involve. Only 3 in 10 said they were told about side effects, benefits, risks and the likelihood of success. A significant percentage of respondents felt they did not receive sufficient information about the cost of their treatment and how this should be paid (30%), alternative treatment options (25%), or that they had been given enough time to make a decision (18%).

[Click here for further information from the Red C poll](#)



% of adults living in Ireland aged 18+ that are aware of the requirement for consent



“Planning ahead is better for our loved ones and families as they can support us, guided by clarity

on our preferences”

*Patricia Rickard-Clarke,
Safeguarding Ireland*

Planning Ahead

In June 2020, Safeguarding Ireland published research highlighting that the vast majority of adults had not taken steps to record their future care wishes. The research also demonstrated that almost a quarter of the people surveyed had been prompted to think about doing so because of COVID-19.

The research found that just 4% of adults surveyed had completed an Advance Healthcare Directive and 4% the [Think Ahead form](#). Just 5% of adults had completed either document.

[Click here for more information](#)



Towards a New Frontier for Human Rights: The Assisted Decision-Making (Capacity) Act 2015- Personal and Professional Reflections

The National Office of Human Rights and Equality Policy, the School of Law in UCC and the Decision Support Service are currently collaborating on a collection of essays from individuals, families, academics, health care workers, advocates and Non-Governmental Organisations (NGO's) on the potential of the Assisted Decision Making (Capacity) Act 2015 as a conduit for change. The publication will be virtually launched in early 2021. Electronic copies of the book will be available free to download following the launch. For further details contact Caoimhe.gleeson@hse.ie

About the National Office of Human Rights and Equality Policy

The Office of Human Rights and Equality Policy is responsible for a number of areas including:

- Supporting health and social care services to prepare for the commencement of the Assisted Decision-Making (Capacity) Act 2015;
- Revision, implementation and oversight of the HSE National Consent Policy;
- Improving universal access to mainstream health and social care services for people with disabilities;
- Co-ordinating the development of guidelines on Wardship for services;
- Partnering with TENI on a Transgender and intersex policy and guidance for Health Care Workers
- Policy oversight of Guidance on Do Not Attempt Resuscitation.
- Developing an organisational response to the Public Sector Duty.

For more information go to www.assisteddecisionmaking.ie.

Upcoming events

The Autumn 2020 webinar series focusing on **Consent and Assisted Decision Making** is now well underway. We examined what is valid and informed consent and explored the role of advocacy in decision-making. Remaining webinars will provide detailed guidance on supported decision making and will explore why consent matters in pregnancy and maternity care.

Dates and details as follows:

- Thursday 22nd October 2020, 11am - 1230pm: Consent and its application in pregnancy and maternity care
- Thursday 5th November 2020, 11am - 1230pm: Tools to support decision making

For further details contact: orlaith.branagan@hse.ie or go to www.assisteddecisionmaking.ie.

You can watch the previous webinars in the series [by clicking here](#).

