

HSE National Office for Human Rights and Equality Policy Newsletter



Issue 2

Winter 2020

Welcome

It has been a busy couple of months since our last newsletter. We completed our autumn / winter webinar series on Assisted Decision Making, Consent and tools for Practice. Over 3,000 people from across health and social care services, advocacy, other public services and from the legal profession attended the four webinars. The webinars were really well received and we are developing an FAQ resource to address the hundreds of questions which were submitted over the four sessions. We are currently putting the finishing touches to our spring / summer series in 2021—more information will be circulated on this early in 2021. If you missed any of the webinars in this series, you can watch them on www.assisteddecisionmaking.ie.



Work has commenced on the development of an e-learning programme on supporting decision-making, advance care planning and undertaking the functional assessment of capacity. Details will be circulated as it becomes available.

We also sought your views on consent through a staff survey. Over 2,000 people took the time to complete this which will provide us with invaluable information to support the implementation of the revised National Consent Policy which will be launched with the National Consent E-Learning Programme in early 2021. Sincere thanks to all of you who completed the survey. The results will be released early next year.

We are delighted with the announcement that Professor Gerard Quinn, former Director of the Centre for Law and Disability Policy at NUI Galway has been appointed as UN Special Rapporteur on the Rights of People with Disabilities. This comes at a critical time as the clock ticks slowly towards the commencement of the Assisted Decision Making (Capacity) Act 2015 (the 2015 Act). It is now 5 years since the 2015 Act was passed. In those intervening five years there are many people who fought and lobbied for the 2015 Act who have since passed away and did not benefit from the fruits of their labour. Professor Quinn was central to keeping the 2015 Act on the policy agenda over many years buoyed by the strength and vision of these people. In spite of delays in commencement, there is increasing evidence of the spirit of the UN Convention on the Rights of People with Disabilities (UNCPRD) and the 2015 Act filtering into the daily practice of Health Care Workers across a diversity of services. Through our work we strive to ensure that we are constantly building the capacity of staff to work with the spirit of national and international human rights law. The message is simple- keep the person at the centre. Always. Nothing about me without me. We look forward to 2021 being the year where real commitment to full commencement of the 2015 Act will be realised.

Thank you all for your continued support and for your commitment to the people who use your services.

I hope you all have a peaceful Christmas and wishing you all the best for 2021.

Caoimhe Gleeson, Programme Manager

National Office for Human Rights and Equality Policy—Plans for 2021

2021 is going to be a busy year for the Office. We are currently putting the finishing touches to our events plan, but we are looking forward to the following in early 2021:



- Spring / Summer webinar series
- Launch of the revised HSE National Consent Policy and e-learning programme
- Publication of *Towards a New Frontier for Human Rights: The Assisted Decision-Making (Capacity) Act 2015 Personal and Professional Reflections*
- Publication of our Consent Survey Report
- Publication of our report on the preparedness of CHO1 for commencement of the Act

Information will be posted on our website www.assisteddecisionmaking.ie.

Update from the Decision Support Service

The project to establish the Decision Support Service (DSS) is well underway. Commencement of the Assisted Decision-Making (Capacity) Act 2015 has been identified as a priority in the Programme for Government and the DSS has been allocated €5.8m in the 2021 Budget. This allocation is aligned to a planned July 2022 timeline for the DSS establishment project.

Responsibility for the Assisted Decision-Making (Capacity) Act 2015 has recently transferred to the new Department of Children, Equality, Disability, Integration and Youth (DCEDIY). The Inter-departmental Steering Group has reconvened, and work is progressing in relation to proposed amending legislation and finalised regulations.

Draft codes of practice on the Act were submitted by the National Disability Authority and the HSE Multidisciplinary Working Group appointed by the Department of Health. The DSS has undertaken an internal review of these codes which will provide information and advice for a range of stakeholders about how to apply the Act and how to access the new supports that will be available. These codes will go out for public consultation prior to the DSS becoming operational.

For further updates, please visit the website at www.decisionsupportservice.ie, sign up for the email newsletter or keep in touch through their Twitter @MHCIreland.



Caoimhe Gleeson,
Programme Lead, National
Office for Human Rights and
Equality Policy, HSE with
Aine Flynn, Director of the
Decision Support Service



Tools to support people making decisions

Supported decision-making happens when one person gives another person the support they require to participate in decision-making, e.g. to have a medical procedure, where they want to live, how to spend their money. The support required will depend on the context of the situation.

On the 5th November, we hosted a webinar on tools to support people to make decisions ([you can watch back here](#)). There are a number of tools that you can use to support people to make decisions, some of which are described below:

HIQA have developed a Guidance Document on [Supporting People's Autonomy](#). The purpose of this guidance document is to help services to demonstrate how they show respect for human dignity and how to value personal choice and decision-making. The document outlines a supporting autonomy framework, which outlines 6 steps in promoting autonomy. The framework is a practical tool to balance service provider responsibility and accountability with respect for autonomy and individual choice.

SAGE have developed the ALERT system and a guide to supporting decision making ([click here to access](#)). Their guide provides practical tips to help people prepare themselves and prepare with the person when supporting someone to make decisions.

St Michael's House have developed a number of toolboxes to support staff working with people who require assistance to make decisions. The toolboxes help staff to look at their own beliefs and values about the person, provides an ethical framework to support person-centered decision making, supports staff to understand how communication influences a persons ability to make decisions and provides tips and resources to facilitate inclusive communication. You can find out more about the toolbox [by clicking here](#).

IDS-TILDA have developed an accessible end of life planning tool ([click here to access](#)). These documents have been developed to help people with intellectual disabilities plan ahead so that their wishes can be respected at the end of their life. It is a tool for people with an intellectual disability, their families and their carers to use as they pause to think about the future. It supports ongoing conversations and building knowledge, attitudes and confidence for everyone involved so that wishes and desires are realised.

For more information on supporting people to make decisions, please contact adm@hse.ie.



COVID-19 Deaf and Hard of Hearing Resources

Communicating in a health setting such as a busy clinic or ward can be difficult.

The recent COVID-19 pandemic and the necessity for healthcare workers to wear face masks has made communication more difficult, especially for people who are deaf or hard of hearing who rely on lip-reading.

The Irish Deaf Society and Chime, in partnership with the HSE, have prepared a number of resources for use by healthcare workers and people who are deaf and hard of hearing.

Elaine Grehan, Advocacy Manager, Irish Deaf Society said "Covid-19 created a need for urgent co-operation between HSE and Deaf community organisations to address accessibility gaps in processes and communications. The Irish Deaf Society and Chime worked with the HSE to develop an accessible approach to address these gaps. This included guidelines, reviews of processes and translations of key public health documents. The resulting Irish Sign Language videos (or vlogs) were posted on the HSE partner resources pages and the Irish Deaf Society website. It is our hope that this positive work will continue and public bodies will champion a culture where accessibility is considered at the earliest stages of all projects in the future."

Brendan Lennon, Advocacy, Research and Public Affairs Director with Chime stated "The development of the COVID-19 supports for Deaf and hard of hearing people produced not only resources and guidelines for patients and health professionals in terms of COVID testing and tracing protocols, but also helped shine a light on the wider communication challenges many patients who are Deaf and hard of hearing face in healthcare settings."

He continued "We have heard of many instances where healthcare professionals adapted their practice to support communication, such as removing their mask temporarily while social distancing to ensure the patient got the necessary information."

You can access these resources by [clicking here](#).

Digital and Assistive Technology Use in Disability Services During COVID-19

Covid-19 has presented a considerable challenge to the effective provision of disability services in Ireland. The sector has responded in a variety of different ways and confronted an array of challenges in doing so. The use of technology has been a distinctive feature of their response. In the second quarter of 2020, the National Clinical Programme for People with Disabilities (NCPPD) undertook a survey of technology use to learn from the experience of service providers in the sector. They wanted to identify what difficulties services had encountered, highlight and share good practice and identify opportunities to strengthen the response across the sector.

[You can access the report here](#).



Update from the National Safeguarding Office



The HSE National Safeguarding Office recently published their Annual Report 2019 and launched an adult safeguarding explainer video.

The publication of the 2019 Annual Report is a timely reminder of the central position that adult safeguarding plays across all health and personal social care services. This is especially so at this time of uncertainty for adults who may be vulnerable and at risk of abuse with the impact of a worldwide pandemic. This Report highlights that interagency collaboration and associated public awareness are central in the protection of adults at risk of abuse in Irish society.

The 2019 Annual Report is available [here](#) and hard copies are available on request from the National Safeguarding Office.

The [Adult Safeguarding Explainer video](#) (which is Irish Sign Language interpreted) is an accompaniment to a HSE Safeguarding training programme and can be used by adults at risk of abuse, staff members and the wider public as a user friendly account of how to recognise and respond to adult abuse concerns.

The HSE is committed to implementing the revised Adult Safeguarding Policy during 2021 as a core part of the organisation's service improvement plans and in line with the commitments of the 2021 National Service Plan. The implementation of the revised Adult Safeguarding Policy will mean that there will be a singular and consistent adult safeguarding process for responding and managing safeguarding concerns. There will be updated communication with stakeholders when the implementation framework is finalised and circulated across services.



Ireland's first report to the UN under the UNCRPD

Ireland's first report to the UN under the Convention on the Rights of Persons of Disabilities was published for consultation on 3rd December 2020. The report describes recent advances in the rights of people with disabilities in Ireland.

This report, under Article 35 of the International Convention on the Rights of Persons with Disabilities, describes how each article of the Convention is being implemented in Ireland. It notes significant recent developments in public policy and legislation that contribute to the achievement of the objectives of the Convention.

Prior to the finalisation of the report for submission to the CRPD, the Department of Children, Equality, Disability, Youth and Integration are looking to hear your views on the draft report. [You can read the report and find out about the consultation here.](#)





Professor Mary McCarron, Principal Investigator, IDS-TILDA

IDS-TILDA COVID-19 Report Launch

Researchers from Trinity College launched a special report on COVID-19 and older people with an intellectual disability (ID) on 3rd December 2020. The report is part of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) study for Trinity and marks today's United Nations International Day of People with Disabilities. The report recorded a small number of COVID-19 infections amongst respondents and no deaths during the initial lockdown of 2020.

Principal Investigator Prof Mary McCarron said that it was '*particularly commendable that there were active plans and strategies for isolation and quarantining, with which most people with ID complied*'. She also acknowledged concerns arising from how people have been living with the social restrictions due to the pandemic:

'While we are very thankful that the numbers who tested positive for COVID-19 have been so small, with no reported deaths in this study, we must consider the effect that restrictions have had on people ageing with an intellectual disability. It is undoubtedly a good news story that many services and families reacted so rapidly to keep people safe. It is also very positive that over half did state that they found positive aspects to the change in circumstances. It is worrying, however, to hear of the stress and burden experienced by people ageing with an intellectual disability.'

You can access the report, the accessible report, infographics and watch the recording of the launch at

<https://idstilda.tcd.ie/wave4/launch.php>



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin



The Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing
(IDS-TILDA)

THE IMPACT OF COVID-19 on People Ageing with an Intellectual Disability in Ireland



Evidence from Wave 4 of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA)

Trinity Centre for Aging and Intellectual Disability Webinar Series

The Trinity Centre for Aging and Intellectual Disability ran a masterclass series in November 2020 for staff and family members caring for someone with an intellectual disability who was recently, or is likely to be, diagnosed with dementia.

The focus of the masterclass series was to reflect on, and to plan for, how to optimise high-quality person centered dementia care.

You can view the recordings of the masterclasses at <https://www.tcd.ie/tcaid/research/nidmsmasterclass.php>.



National Sharing Day

In lieu of their annual National Sharing Day, the Disability Operations, Quality Improvement Team hosted a series of three webinars in November and December of 2020. The National Sharing Day derived from the National Quality Forum which meets every quarter to discuss issues and sharing information with regards to quality improvement in disability services.

The Sharing Day Subgroup, which consisted of disabled people (50% of group), decided on the three themes for the webinars:

- Experiences of living during the COVID 19 lockdown
- Valuing the contributions of Disabled people
- Hearing and responding to the voices of Disabled people.

All topics were presented by Disabled people themselves who picked different media to portray their feelings and experiences, including using art, song, dance, and poetry. The webinars which took place over 3 different days were a huge success, with over 800 virtual attendees in total. COVID 19 brought great challenges but also new opportunities for us to reach a wider audience through online webinars, making information sharing much more accessible than ever. We have recorded each webinar and endeavour to upload them shortly.

If you are interested in being involved in the National Quality Forum or finding out more information about next year's National Sharing Day, please contact disabilitesQI@hse.ie or Nicole.Lam@hse.ie

DCU Intersex Study

Dr Tanya Ni Mhuirthile and Professor Anthony Staines from DCU are currently undertaking a study looking at what life is like for the intersex community in Ireland. The title of their study is *Mapping the Lived Experiences of Intersex / Variations of Sex Characteristics in Ireland: Contextualising Lay and Professional Knowledge to Enable Development of Appropriate Law and Policy*. They are looking for people who are intersex or who has an interest in intersex to participate in their research. You can find more information on their website www.dcu.ie/intersex or email intersex@dcu.ie.



Disability Legal Information Clinic—Now Online!

The Disability Legal Information Clinic, run by the Centre for Disability Law and Policy in NUI Galway, will be completely online for the 2020/2021 academic year.

The clinic provides free, accessible, confidential legal information on disability related legal issues and will now be available right across Ireland for disabled people, their families and supporters. The clinic is staffed by law student volunteers who are supervised by a member of the CDLP team and a qualified legal practitioner.

In the past the clinic has dealt with issues in relation to housing, education, employment, discrimination and access to supports or services. To find out more about the clinic's work visit www.nuigalway.ie/centre-disability-law-policy/dlic/. You can also email dlic@nuigalway.ie if you have any questions or would like to arrange an appointment.