

## End of Year Round up-2022



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

2022 has been a very busy year for the National Office for Human Rights and Equality Policy as we prepare for the commencement of the Assisted Decision Making (Capacity) Act 2015. The year began with coordinating submissions on behalf of the HSE to the Decision Support Service’s Code of Practice consultation. There are 15 codes of practice, 13 of which have relevance to health care workers. We then coordinated submissions for the pre-legislative scrutiny of the amending Assisted Decision Making (Capacity) Bill in February 2022. We commenced our webinar series on preparing for commencement and implementation of the 2015 Act in February and concluded it in June. This series was developed using case studies from front line healthcare practitioners and panel members included healthcare workers, advocates, experts by experience and subject matter experts. The average number attendance was 1,500 which is a testament to the interest of front line staff in the 2015 Act. In March we launched the revised National Consent Policy 2022 which included significant updates since the 2013 was published. We also launched the National Consent Policy Elearning programme which includes two modules– one on the general principles of consent and one on consent involving children and young people. In April we launched the E-learning suite of training on supporting decision-making in health and social care. This suite includes three modules– supporting a person to make decisions, supporting a person to plan for the future and introducing the functional assessment of capacity. In April we undertook extensive consultations with CHO’s, Hospitals and HSE national services on the development of a HSE ADM National Implementation plan. This plan was disseminated in August 2022. In May we undertook consultations in relation to role of assessor of capacity for Co-decision making agreements and Enduring Powers of Attorney under the 2015 Act. A training programme is now under development by the Decision Support Service and the HSE to support these assessments. In June 2022 we commenced work on the E-learning suite of training on the 2015 Act. This suite will include three modules– the first will give an overview of the 2015, the second will focus on the interveners under the 2015 and the third will deal with advance healthcare directives.

Throughout the Summer and Autumn months we continued to co-ordinate a number of HSE submissions on the amending legislation. In November we collaborated with HSE Mental health operations to deliver a webinar which explored the inter-relationship between the Mental Health Act and the 2015 Act. In December we hosted a webinar on the transition from wardship to the provisions of the 2015 Act. Throughout the year we have also collaborated with a number of front line services in learning events including Limerick University Hospitals, St. John Of Gods Disability Services, CHO 6, CHO 9, Disability Federation of Ireland, CHO 7 and Co-Action West Cork.

At the time of writing the amending bill will conclude its legislative process in the Houses of the Oireachtas and we await an announcement by Roderic O’Gorman , Minister for Children, Equality, Disability, Integration and Youth as to a commencement date in early 2023. We look forward to the efforts from all of our work in 2022 coming into fruition in 2023. We also look forward to continued collaborations and partnerships with front line services, experts by experience, families and advocates to ensure that the rights of people who need decision-making supports are realised.

Thank you all sincerely for your support throughout 2022. Best wishes for a peaceful Christmas and a fulfilling 2023.

Caoimhe Gleeson

National Office for Human Rights and Equality Policy

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

Jacqueline Grogan  
Project Manager

## The Assisted Decision-Making (Capacity) (Amendment) Bill 2022

The Assisted Decision-Making (Capacity) (Amendment) Bill 2022 has nearly finished its passage through the Houses of the Oireachtas and will reach final stage in the Dail on Wednesday 14<sup>th</sup> December.



Once the Bill has been passed by the Dail, and the amendments have been accepted, the President will sign it into law. We expect that this will happen before the end of the year and that the Act will be commenced in early 2023.

A number of amendments have been included in the amending legislation, including:

- An extension of the applicability of an Advance Healthcare Directive to people who are involuntarily detained under the Mental Health Act 2001 where, in the opinion of the relevant clinicians, treatment is required to improve the condition or the condition will deteriorate without treatment. However, it will not apply to those persons who are being treated under Part 4 because there is an immediate and serious likelihood of that person harming him or herself or another person.
- An amendment to the Nursing Home Support Scheme Act 2009 meaning that applications for Care representatives will be accepted right up to the day before commencement of the Assisted Decision-Making (Capacity) Act 2015 and will be processed thereafter once the application has been correctly lodged with the County Registrar of the relevant Circuit Court.
- The provision for a register for Advance Healthcare Directives and alignment of the specifics of that register with the register of other agreements.
- To provide that a single capacity assessment is required for a co-decision-making agreement.
- Regulation for additional parties to make court application under Part 5 without first having to make Ex Parte application
- Capping of fees that can be paid to panel and non-panel decision-making representatives.
- Applications for wardship which are in train when the Act commences will continue to be processed to completion if no decision supporter of an appropriate tier is appointed. The process for subsequently exiting wardship will then apply.
- Consultation by the Director with disabled persons and their representative organisations when codes of practice are being developed.
- Inclusion of transitional arrangements for care representatives under the Nursing Home Support Scheme Act 2009.

You can access further information on the Assisted Decision-Making (Capacity) (Amendment) Bill 2022 at <https://www.oireachtas.ie/en/bills/bill/2022/59/?tab=bill-text>

# Webinar: Transition from Wardship to the Assisted Decision-Making (Capacity) Act 2015: Guidance for Staff – from the Decision Support Service

**Áine Flynn,**

**Director of the Decision Support Service**



After commencement of the Assisted Decision-Making (Capacity) Act 2015, which is now due to happen early in 2023, there will be no new applications for adults to be made wards of court. A recent amendment to the Act means that an application for wardship that has been initiated prior to commencement will not lapse and may continue to conclusion.



All adult wards, currently numbering approximately 2,200, will be reviewed by the wardship court (which is based in the High Court) and discharged from wardship within three years of the Act's commencement. Having reviewed the ward's capacity, adopting a functional assessment, the wardship court may find that a new support arrangement supervised by the Decision Support Service is appropriate.

A webinar on 1 December delivered by the HSE National Office for Human Rights and Equality Policy as part of a series in preparation for the 2015 Act looked at how the transition is to be managed and the implications of the new processes for healthcare. As Director of the Decision Support Service, I was invited to clarify the functions and responsibilities of our service, the elements of the support framework and what is expected in relation to the new Circuit Court procedures.

The webinar may be accessed [here](#) and further information is available on [decisionsupportservice.ie](https://decisionsupportservice.ie).

# Webinar: Transition from Wardship to the Assisted Decision-Making (Capacity) Act 2015: Guidance for Staff—An overview of the Webinar from the Office of the Wards of Court

**Alice White,  
Registrar of Wards of Court , Court Services**



The commencement of the Assisted Decision Making (Capacity) Act will trigger a review process for all wards of court (relevant person), leading to a Court application for their discharge from wardship.

The discharge application can be made by the relevant person, the committee or such other person who has a legitimate interest and person relation with the person.

The Wards of Court Office will arrange a functional capacity test by the Court's Medical Visitor, the report when received will be shared with the relevant person and the committee/applicant.

The views of the relevant person on the application and who, if applicable, is to be appointed to support their future decision making will be recorded as part of the application process and presented to the Court.

Each application is expected to take 2-3 months to be heard and for the person to be discharged from wardship. The Act provides for the return of property and assets to the relevant person, this will be done on presentation of proof of registration of the relevant agreement to the office. To facilitate this, the Wards of Court Office have been advising committees of the need to have a bank account opened in the name of the relevant person.

The office has been providing updates in relation to the discharge application process and the commencement of the Act to committees and legal practitioners. The office will recommence online Q&A sessions for committees after Christmas, dealing with queries on the discharge process and transition out of wardship.

More information on the discharge process can be found at <https://www.courts.ie/assisted-decision-making-capacity-act> or by emailing [wardsdischargeapplication@courts.ie](mailto:wardsdischargeapplication@courts.ie)

# The importance of transitioning from Wardship

**Prof. Mary Donnelly,**

**School of Law, University College Cork**

When the Assisted Decision-Making (Capacity) Act 2015 comes into force in early 2023, it will no longer be permitted to have an adult made a ward of court. Instead, all capacity-related matters must be dealt with within the structures provided under the 2015 Act.



There are currently about 2000 wards of court in Ireland and all wards will be transitioned out of wardship and into the new system under the 2015 Act. Transition will involve a High Court hearing which will decide if the ward should be discharged fully; should be discharged with one of the supporters under the 2015 Act (a Decision-Making Assistant or a Co-Decision-Maker); or should have a Decision-Making Representative appointed for some/all decisions.

Once the 2015 Act comes into force, the ward or the ward's relatives or friends may make an application to have the ward's situation reviewed by the High Court. The speed with which this review will happen will depend on the number of requests and the pressures on the court system. Even where a ward (or their relatives) does not make a specific request for review, their situation will be automatically reviewed by the High Court. These automatic reviews will likely begin once all the requested reviews have been completed. All wards must be transitioned from wardship within 3 years after the 2015 Act comes into force.

There are special review requirements where a ward is detained on the order of the wardship court. This detention order must be reviewed as soon as possible by the High Court which must decide whether the ward is suffering from a mental disorder (as defined under the Mental Health Act 2001).

New applications to wardship can continue until the 2015 Act comes into force. However, as we move toward the 2015 Act coming into force, it is necessary to think very carefully about whether a wardship application is necessary or whether the matter can wait and be dealt with under the 2015 Act.

The HSE has issued Guidance on wardship applications: <https://www.hse.ie/eng/about/who/national-office-human-rights-equality-policy/assisted-decision-making-capacity-act/wardship-applications-a-guide-for-health-care-workers-220222.pdf>) which sets out the factors to consider in thinking about wardship and how to ensure due process and fair procedures are followed throughout a wardship application process.

# The Transitioning from Wardship and what it means for a person

## Joanne Condon, Acting National Manager, National Advocacy Service.

Ireland is poised on the cusp of a major human rights transition, which will pave the way forward for people's rights, voice and choice to be respected in a much more meaningful way.

When the Assisted Decision-Making (Capacity) Act commences, it will no longer be possible for people to be made a Ward of Court. A new decision support framework will replace the current wardship system.

Wards of Court will be reviewed and discharged from wardship within a three-year period. Some people may transition to one of the new supports available under the 2015 Act and some of them may not.

The National Advocacy Services for People with Disabilities (NAS) continues to work with many people who are Wards of Court. There is a palpable sense of anticipation for many of these people as they await the prospects that the long awaited legislation promises to offer.

What exactly are these prospects? Here is a snapshot of just a few people that NAS supports who are currently Wards of Court, all of whom find themselves in this 'waiting room' for commencement of the Act. These real life stories demonstrate what the legislation will mean for each individual. (\*all examples below have been anonymised)



**Amy** lives within her own home in the community, which she inherited from her parents. Her committee have informed her they are exploring whether to move her to a residential home and sell her home, as they feel it would be in her 'best interests' to live in a safer environment. For Amy, the Act offers the prospect of living without the fear of removal from her home, against her will. The Act offers the hope that her will and preference will have to be central to decisions taken about her life, replacing a 'best interests' approach to decision making by others. The Act will ensure that Amy has the right to have her capacity assumed, to make day-to-day decisions that she is fully capable of making alone, whilst having support with bigger decisions where she may require it. It places Amy at the centre of decisions to be taken and ensures that her wishes about where to live are taken fully into account, maximising her autonomy to the greatest extent.

**Andrew** lives in a community based residential service with two others. His money is held by his committee and it is often difficult for Andrew to obtain access to his money to purchase what he would like to. His committee have strong views about how he should best use his money and believe that he should not waste it on certain items. This is an ongoing cause of upset to Andrew and he feels frustrated that he often cannot join his housemates for coffee and trips they go on. For Andrew, he hopes to gain access to and autonomy over his own finances, to be able to buy what he wants to and not have his choices scrutinised by others. Andrew has only recently for the first time been supported by his keyworker to build his capacity around money management. It is now evident that with support, he would be perfectly capable of managing his day-to-day finances. Andrew may, however, require support with bigger decisions. The Act will afford the ability for Andrew to have his autonomy respected; all the while ensuring he has support when it is required.

**Susan**, 43 has an acquired brain injury and lives in a nursing home in a very rural location. She is deeply unhappy, has a poor quality of life, minimal access to activities of interest to her and nobody her own age to interact with. The weekly cost of Susan's placement is high and paid for from her personal funds. She has never had the opportunity to have her will and preference heard or respected regarding where she lives or how she spends her money. She has never met her committee who decide where she lives. For Susan, the Act holds a real prospect for her will and preference to be central to informing a decision about where to live and how her money is spent.

While commencement of the Act holds great prospects for those who are Wards of Court, it is also understandably a little daunting for people to grapple with the seismic changes it signals. Independent Advocacy will continue to play a central role in supporting people to navigate the transition process that is so central to maximising people's autonomy and securing compliance with the UNCRPD.

\*For further information on NAS please click here <https://advocacy.ie/>

# Preparing for full commencement of the Assisted Decision-Making (Capacity) Act (2015) in CHO 8

**Niamh McGoldrick,**

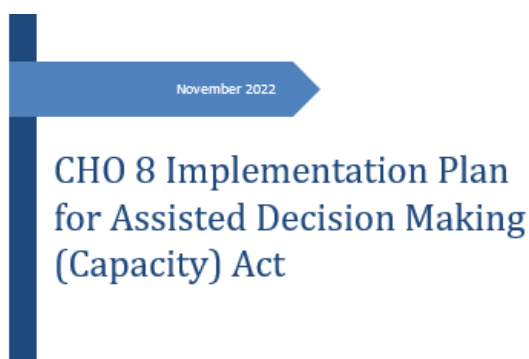
**Assisted Decision Making Project Manager, CHO 8.**

Midlands Louth Meath CHO has recognised the importance of the preparation of staff and services for the commencement of the Assisted Decision-Making (Capacity) Act. A number of priority areas have been identified. Initial emphasis has focused on getting in place support structures, governance structures, education and communication plans.

## **Actions have included**

- The Midlands Louth Meath CHO Implementation plan has been developed and agreed by the Senior Leadership Team- This plan provides a roadmap for the initial phase of implementation.
- An ADM Project Manager has been assigned and work is ongoing around developing an ADM team who will ensure that an emphasis has been placed on the need for staff support.
- A cross care group Multidisciplinary Working Group is in operation . This group has developed tools to support staff as well as raising awareness
- A survey tool to establish the current level of ADM awareness has been developed. The survey is currently live and will provide valuable information regarding the supports required to assist staff with implementation.
- Training programmes have been developed and training has commenced - The training schedule will be delivered through both Face to face and Virtual training.
- Database development is ongoing - We will be tracking and monitoring training statistics and collating information around the transition of Wards of Court to the new support structures. The utilisation of these and other systems will provide assurances to the Midlands Louth Meath CHO governance structures.

Cascading of information through the system is being facilitated by the ADM Project Manager through the circulation of all relevant material received from the National Office for Human Rights and Equality Policy.



# Launch of Easy-to-Read version of the HSE National Consent Policy



**Elaine McCaughley**



**Senior Project Manager,**

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

The HSE wrote the first National Consent Policy in 2013. In March of this year the National Office for Human Rights and Equality Policy published the revised National Consent Policy 2022. The 2022 policy reflects legislative changes since 2013, and emphasises the will and preferences of the person. There are two e-learning modules for staff on the National Consent Policy and these are available on HSEland.

On 5<sup>th</sup> December 2022 we launched an Easy-to-Read version of the 2022 National Consent policy. Easy-to-read information is important for people with intellectual disabilities and people with other conditions affecting how they process information, and useful for the staff who support them. We hope that the Easy-to-read version of the HSE National Consent policy will help each person to know their rights and to make their own choices. Every adult should be presumed to have capacity to consent on their own behalf and should be provided with relevant information in a way they can understand.

The National Consent Policy 2022, the Easy-to-Read version and a recording of the launch, and a range of other resources on consent are available at [hse.ie/nationalconsentpolicy](https://hse.ie/nationalconsentpolicy).

	<p>The Policy says that healthcare workers must start with the idea that each person is able to make their own decisions.</p>
	<p>Each person should be supported to make their own decisions wherever possible.</p>



# Launch of Easy-to-Read version of the HSE National Consent Policy

## Paul Crilly

### Expert by Experience and self-advocate

My name is Paul Crilly, and I am an advocate and expert by experience with Ace Communication. I have an interest in accessible communication and information.

I helped to put together the Easy to Read version of the HSE National Consent Policy.



As part of this work, I looked at how the information in the Easy to Read policy is presented. I checked the words and sentences in the policy to make sure they were easy for everyone to understand. I helped to choose pictures and symbols for the policy too.

Easy to Read information is very important for people with intellectual disabilities, and for people that cannot read or understand complicated information. I feel very strongly that we have a right to information in a way that we can understand.

The HSE National Consent Policy is an important policy. When I have information in the right way, I can understand and exercise my rights. I know what to expect of the staff that support me when it comes to consent. I know when, how and why I should be asked for consent.

I hope the Easy to Read version of the HSE National Consent Policy will support other people with disabilities to learn about consent, make their own decisions, and speak up for themselves.

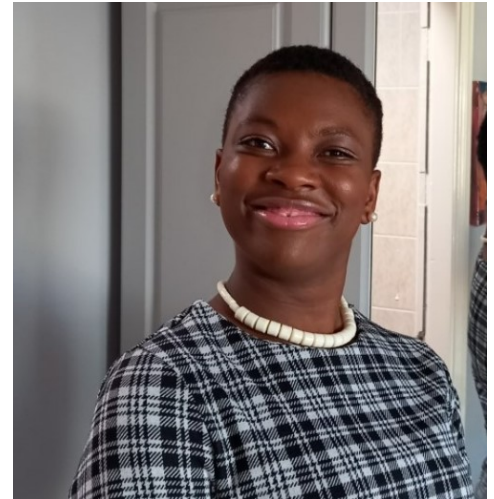
	<p>If you refuse consent, you say no. You do not agree to a test, treatment or service. You do not want to take part in research or teaching.</p>
	<p>The Policy sets out the rights of people that use health and social care services. It says how staff must respect these rights.</p>

# Launch of Easy-to-Read version of the HSE National Consent Policy

## Lydia Fisher

### Expert by Experience, supported by Cheshire

My name is Lydia Fisher, and I am going to take some time to talk to you about the word consent. Consent is just asking people the basic things every day like what they would like to wear for the day, or what they would like to eat. For myself I am going to take this opportunity to tell you how I felt when consent was taken away from me, and I am going to tell you how it felt to be involved in my own consent.



#### **How consent was taken away from me:**

As most people know, I am a Ward of Court. In the high court law this means that I cannot make my own decisions or I cannot give consent. My lawyer has to give consent for anything for me to do for example myself and best friend wanted to go to Belfast on holidays. I was very excited because I always wanted to go to Belfast. My carer and I did all the risk assessments and doing the risk assessment was not fun, but we had to do it because my lawyer needed to look at the risk assessment, and if my lawyer was not happy I could not have gone on the trip. But it was very good, we covered everything that we were meant to cover and we had a great time on holidays. So you see, by me going on any trip I have to ask the high court for consent.

#### **I am going to tell you how it felt to be involved in my own consent:**

I am going to talk to you about getting the contraceptive bar in my arm and how I got it in for the past few years. People have told me that would be good for me to get it in. I just said okay because I did not really understand that word consent, so I just got it in. For me this is very important because this year I got to take an active part in this consent by me going to the doctor by myself, and talking to her about getting the new bar in my arm for my health. She told me that it is a very good idea to put the bar back so I went to the chemist and I bought the bar and I went back to the doctor. I felt happy because I wanted this and decided for myself. I had to inform Cheshire just for them to put it in my file just in case I got sick in the few months for the staff to know what I have done in the few months prior.

So, you see how consent is especially important in the day-to-day life.

# Webinar- Preparations for the Commencement of the Assisted Decision-Making (Capacity) Act 2015- considerations for HSE Mental Health Services

**Kevin Brady,**  
**Head of Mental Health Services,**  
**Dublin South, Kildare & West Wicklow**



On the 9<sup>th</sup> of November, a webinar was hosted by the HSE to consider the implications of the Assisted Decision (Capacity) Act 2015. The planning for this webinar came about following the establishment of oversight group under the National Mental Health Operations, in collaboration with the HSE National Office for Human Rights and Equality Policy, Mental Health Reform, Clara Learning along with multi-disciplinary staff representation across the services.

The purpose of the webinar was to examine how the introduction of the Act, when commenced, will impact upon the day to day operations within mental health services.

The webinar heard from 5 speakers who have been working on the preparations for the introduction of the Act since 2015;

- Prof Brendan Kelly, Consultant Psychiatrist at Tallaght University Hospital and Professor of Psychiatry at Trinity College
- ◆ Professor Mary Donnelly from the School of Law in University College Cork
- ◆ Ms Aine Flynn, Director of the Decision Support Service
- ◆ Ms Ber Grogan, Policy & Research Manager, Mental Health Reform
- ◆ Ms Elaine McCaughley, Senior Project Manager , HSE National Office for Human Rights and Equality Policy.

All speakers provided a unique insight from their own particular areas of practise and expertise in order to raise awareness of the Act in mental health services and to provide practical guidance to staff on the implications for practice. The event culminated in a Questions & Answers session which provided participants the opportunity to explore further any questions they had in order to support their understanding in advance of its forthcoming commencement.

The Mental Health Operations Oversight Group look forward to the commencement of the Act and will continue to plan for any service implications as issues begin to emerge following its introduction with a view to supporting staff who will be working with service users under the new Act.

Please [click here](#) to access the recording of the webinar.

# Preparing for full commencement of the Assisted Decision-Making (Capacity) Act 2015

**Liz Maher,**

**Inspired, Brandon Court, Basin Road, Tralee, Kerry**



On Oct 20<sup>th</sup> Inspired invited Dr Maire Meagher to present the Assisted Decision Making (Capacity) Act 2015 to parents, staff and board members of the Inspired organisation. The presentation, sponsored by Kerry ETB, was held at Ballygarry Estate Hotel & Spa, and aimed to provide attendees with the knowledge and skills required to implement the Assisted Decision Making (Capacity) Act into everyday practice and in particular within the day service located in Tralee, Co. Kerry. The training evening played a key part in the continued development of the organisations communication strategy between family members, guardians, carers and healthcare practitioners at Inspired.

It also provided an opportunity for everyone to obtain a deeper understanding of the legislation and how it will be implemented not only into the operations of the service, but demonstrated how this legislation will transition into participants personal and social life. More importantly, it showcased how the Act could support participants attending the service and advance their progression towards leading a self-determined and independent life of their choosing.

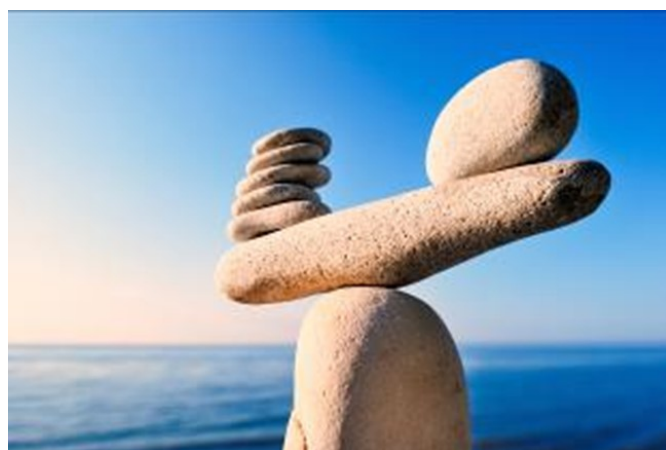
During the course of the presentation attendees were provided with insight into how people with intellectual disabilities must be afforded the dignity of choice and decision-making while placing the values and wishes of the person at the forefront. The presentation explored the UN Convention on the Rights of Persons with Disabilities, and the need to move towards a Human Rights Based model. In addition, case scenarios relevant to day-service participants and the assessment of capacity, including the concept of will and preference were examined. Needless to say, these topics led to a robust discussion post-presentation in relation to safeguarding vulnerable adults, particularly with regards to applying dignity of risk coupled with addressing the functional elements of capacity assessment while being compliant with the law.

Attendees agreed, that cross communication and enhanced circles of support would result in the best outcomes for participants attending the day service. Liz Maher, manager at Inspired addressed the need to comply with the law, but equally emphasised that as health practitioners we had a duty of care and were committed to safeguarding, this meant observing risks, while ensuring positive risks and the dignity of risk were extended to all participants attending the service. Liz committed to hosting individual meetings with each participant and their family members/guardians or carers over the coming months to discuss how they can work together and support each other. Inspired are now developing and planning the roll out of the participant training programme in advance of the November deadline.

# Further updates and resources

A number of organisations have a number of useful resources available on the Assisted Decision-Making (Capacity) Act 2015, please see below latest updates:

- [Administrative reprint of the Assisted Decision-Making \(Capacity\) \(Amendment\) Bill 2022](#)
- [Transition from Wardship to the Assisted Decision-Making \(Capacity\) Act 2015: Guidance for Staff webinar recording from 1st December 2022 from the 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](#)
- [Courts Service - Office of Wards of Court](#)
- [Aine Flynn, Director of the Decision Support Service: Statement to the Joint Oireachtas Committee on Disability Matters May 2021](#)
- [NDA Annual Conference 2021 - Opportunities and Aspirations for the Assisted Decision-Making \(Capacity\) Act 2015](#)
- [Decision Support Service Explainer Video](#)
- [Sage Advocacy Decision-Making and Capacity](#)
- [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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