



Newsletter Spring 2024

HSE Strategy and Research



Caoimhe Gleeson
General Manager

It's been a busy start to 2024 for the HSE National Office for Human Rights and Equality Policy.

We were delighted to launch the revised HSE National Consent Policy in January this year with two online events. Elaine McCaughley will give an update on the events that we hosted to launch the revised policy. In addition, Professor Mary Donnelly and Professor Shaun O'Keeffe have detailed the main changes to the policy, post commencement of the Assisted Decision-Making (Capacity) Act 2015 and the new templates that have been included in the policy.

We hosted a wonderful event with Judge John O'Connor from the Dublin Circuit Court in February 2024. The evening was a great success, with great interaction and questions from attendees for the Judge and for the expert panel. We also hosted a webinar on Discharge from Wardship in February, with presentations from Alice White, Registrar of the Office of the Wards of Court and Marie Claire Butler, Office of the General Solicitor. Recordings and presentations from both of these events are available on www.assisteddecisionmaking.ie.

Áine Flynn's update in this edition of the newsletter looks at what the Decision Support Service have been doing in relation to Stakeholder Engagement and applications to court. Eleanor Leane provides an update on the work of the Legal Aid Board. Marie Claire Butler provides information on supporting people to leave wardship and the National Disability Authority share information on the research they are currently undertaking about the ending of adult wardship.

Donegal Disability Services held a great event in January on the Act, and they give a summary of it in this edition. Ber Grogan shares information about an animated video they have developed on the Act. Siobhan Donoghue shares her experience of her mentorship set in the HSE ADM Mentorship Programme. Andrew Rooney from Family Carers Ireland gives an update on their IHREC funded project CarerAid, a free legal advice clinic for family carers with queries related to the Assisted Decision-Making (Capacity) Act.

Dr John Lombard gives an update on the DNACPR scoping review. The National Advocacy Service has information on the launch of their easy to read leaflet *My Money, My Rights, My Options*. Lynn Swinbourne from HSE Screening Services shares information on a study they have carried out on the needs of people with disabilities accessing national screening programmes, and HSE Social Inclusion share information on a Roma health and accommodation pilot project they are undertaking.

It is hard to believe that we are nearing one year since commencement of the Assisted Decision-Making (Capacity) Act 2015. We are continuing to develop additional resources to support the implementation of the Act in practice.

We look forward to continued collaborations and partnerships throughout 2024 and beyond. I would like to thank you all for your support throughout 2023 and look forward to continuing to work with you all throughout 2024.

Caoimhe Gleeson



National Consent Policy News Elaine McCaughley, Programme Lead

Update to National Consent Policy

In January we launched an update to the HSE National Consent Policy. You can find the updated policy here [https://assets.hse.ie/media/documents/ncr/HSE_Consent_Policy_2022_v1.2 - Jan_2024.pdf](https://assets.hse.ie/media/documents/ncr/HSE_Consent_Policy_2022_v1.2_-_Jan_2024.pdf). We ran two webinar events to introduce the update and these are available to watch back on <https://www.hse.ie/nationalconsentpolicy/>. The second of these events was based on scenarios received from staff and features a very practical panel discussion which may be of particular interest.

Changes to the HSE National Consent Policy

The HSE National Consent Policy has been updated to take account of the Assisted Decision-Making (Capacity) Act 2015 (which was amended by the Assisted Decision-Making (Capacity) Act 2015 and Assisted Decision-Making (Capacity) (Amendment) Act 2022) and which we refer to here as the ADM Act. Both Acts came into force on 26 April 2023. Although the revised National Consent Policy, which came into effect in March 2022, had been drafted in light of the ADM Act, until the legislation came into force, it was not possible to provide detailed guidance on the application of the legislation in practice. This has now been addressed with these changes to the Policy.

In preparing this update, the HSE National Consent Policy Advisory Group consulted with key stakeholders including the HSE Office of Legal Affairs, Legal Counsel and the State Claims Agency. The Policy also incorporates relevant elements of the Decision-Support Service Codes of Practice, in particular the Code of Practice for Supporting Decision-Making and Assessing Capacity and the Code of Practice on Advance Healthcare Directives for Healthcare Professionals.

In summary, the key changes to the Policy (all of which relate to Part 1) are as follows:

- Part 1, section 1.4 is removed from the Policy
- There is a new section Part 1, section 4.2
- Part 1, section 5 is amended to incorporate the ADM Act
- Part 1, section 6 is expanded to include guidance on where a person's capacity is in question and the principles of the ADM Act
- Part 1, section 7 on Advance Directives is amended to incorporate the ADM Act
- Part 1 Section 8 has a change of title and some minor updates.

We can now look in a little more detail at some of these changes.





Part 1, section 4.2 provides greater clarity on how to make information more comprehensible where a person's capacity is in question. In doing this, section 4.2 addresses the requirement in the ADM Act that:

A person is not to be regarded as unable to understand the information relevant to a decision if he or she is able to understand an explanation of it given to him or her in a way that is appropriate to his or her circumstances (whether using clear language, visual aids or any other means).

Guidance provided in section 4.2 includes that information should be tailored to individual's needs, including using Plain English, diagrams, pictures and videos to facilitate the person's understanding that the person providing the information should concentrate on core information; that they should break down information, pausing to see that it is understood; and that they should avoid medical terminology and jargon.

Key updates to Part 1, section 5 concern capacity to consent to an intervention. These updates set out that the person should always be supported to make the decision **before** considered whether the person's capacity should be assessed. Section 5 also makes it clear that, in considering whether capacity assessment is necessary, it is important to consider what difference the assessment will make for the person. In doing this, it is important to ask whether the intervention proposed is in accordance with the person's will and preferences and for the person's benefit. If it is, it may not be necessary to assess the person's capacity prior to the intervention. Section 5 also makes it clear that capacity assessment has defined steps which must be followed and that these steps must be documented.

Updates to Part 1, section 6 set out the circumstances in which an intervention may be provided in a non-emergency situation where a person lacks capacity to decide about the intervention and does not have a decision support arrangement under the ADM Act. An especially important element of this guidance relates to circumstances in which an intervention in this kind of situation can proceed without the need for court approval.

The updated Consent Policy states that an intervention can proceed where the person lacks capacity and there is no decision-making arrangement/wardship in place where:

- 1 The intervention is in accordance with the person's will and preferences;
- 2 The intervention is in good faith and for the benefit of the person; and
- 3 Everyone who must be consulted under the ADM Act has agreed that the intervention should take place.

This section of the Policy also sets out how to address the situation if the person's will and preferences cannot be ascertained. In this situation, the intervention may proceed where the intervention is in good faith and for the benefit of the person and everyone who must be consulted under the ADM Act has agreed and those who close to the person all agree that the intervention should take place. Finally, this section of the Policy provides guidance as to when legal advice should be sought.

Part 1, section 7 incorporates the legal requirements for Advance Healthcare Directives (AHDs) in the ADM Act. It sets out the duties of Healthcare Provider in respect of AHDs as well as guidance on how to assess the validity and the applicability of an AHD and guidance on the role of a Designated Healthcare Representative appointed under an AHD.

Finally, Part 1, section 8 is re-titled as Deprivation of Liberty and includes a minor change, identifying that since the ADM Act came into force, applications for deprivation of liberty must be made to the High Court under the Court's inherent jurisdiction and not through wardship, which has been abolished for new entrants by the ADM Act.



New templates in Appendices 6-8 of National Consent Policy 2022 v1.2

The Assisted Decision-Making (Capacity) Act 2015 (ADM) has made some important changes relevant to health and social care and treatment decisions when a person’s capacity to make one or more decisions is in question or lacking. The HSE National Consent Policy 2022 has been updated to reflect these changes. In this article, I will discuss briefly the new decision support arrangements introduced by the Act and, in particular, the draft templates (Appendices 6-8 of the policy) that staff can adapt or use as a checklist or to record the basis on which treatment, such as a procedure, can proceed when a person’s capacity to decide is in question or lacking.

Who can consent?

The National Consent Policy 2022 states: “No other person such as a family member, “next of kin”, friend or carer and no organisation can give or refuse consent to a health or social care service on behalf of an adult person who lacks capacity to consent unless they have specific legal authority to do so”. This is not new, or something that has been introduced by ADM. It is simply a statement of what has always been the legal position. Prior to commencement of the Act, hardly anyone had such a ‘specific legal authority’ to consent on behalf of an adult. However, a false belief (perpetuated unfortunately by many HSE forms and policies) was common among staff and the public that ‘next of kin’ could provide consent if someone was unable to consent for themselves. Of course, considering the views of those close to the person, who will generally know him or her better than any healthcare worker, was and will remain important. However, they cannot provide a legally valid consent.

New decision support arrangements

The Act has introduced three new formal decision-making arrangements (or tiers of support) to replace the previous Wardship system. Also, advance healthcare directives (sometimes colloquially called ‘living wills’) now have a legal basis in Ireland. Since commencement of ADM, “supporters” appointed under the Act’s decision support arrangements may in some cases have legal authority to consent with or on behalf of someone who lacks capacity to decide about an intervention, and their authority must be respected if this is the case. (Not all support arrangements will include healthcare decisions, so healthcare workers will always need to be check the scope of any arrangement).

We appreciate that these new decision support arrangements will be unfamiliar to many staff. Appendix 8 provides a way that staff can record the different ways in which consent may be given since ADM commenced. This includes:

- consent by the person with the support of a Decision-Making Assistant (the lowest tier of support);
- joint consent by the person and a Co-Decision-Maker; and
- consent on behalf of the person by a Decision Making Representative (the highest tier of support, and appointed by the Circuit Court).

Consent may also be provided by a Designated Healthcare Representative appointed by the person under an advance healthcare directive. Attorneys appointed under an activated Enduring Power of Attorney are not able to make treatment decisions. The new decision support arrangements are tools that may be helpful in some circumstances. They are not mandatory. There are very few such arrangements in place at present. Even with time, many of those who have difficulty making decisions will never have a formal support arrangement. This means that there will be many situations there will be no one with the authority to provide consent on behalf of the person. On what basis can treatment, such as a procedure, be provided in these cases?

Guiding principles

ADM has introduced important guiding principles that must be considered when providing an intervention under the Act. The policy position taken by the HSE is that these guiding principles can provide the basis for proceeding with an intervention. In particular, it is necessary to consider the person’s own views (their “will and preferences” in the wording of ADM) and what would be for the overall benefit of the person. Staff must also consult, and consider the views of, anyone the person wants you to consult, any decision supporter and should also consult others who care about the person such as family members. It is important to be clear staff are consulting about what the person themselves would have wanted in this situation. In most situations, treatment can proceed unless there is significant disagreement or uncertainty. Appendix 7 provides a template for staff to summarise the basis for treatment in such circumstances.

Finally, Appendix 6 provides a sample checklist that may help staff to step through, and to help them record, all the relevant considerations if a person’s capacity to decide about an intervention is in question or lacking.



Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR)

We are pleased to be finalising the HSE research paper on DNACPR Policy and Practise and hope to have this ready in the coming weeks. I am very grateful to the research team in University of Limerick Dr John Lombard and Dr Hope Davidson and the project working group which consisted of Maureen Gilbert, Patient representative, Ciaran McCullough, National Ambulance Service, Dr Ashraf Butt, Emergency Medicine, Dr Michael Dockery, Anaesthesiology, Dr Marina Healy, Paediatrics, Mary Bedding, HSE Deteriorating Patient Improvement Programme and Avril Easton, Irish Hospice Foundation for all their work in producing this paper. I would also like to thank the service providers, advocacy organisations, members of the public and subject matter experts who participated in the consultation phases of this project. In April we will use this research to inform a standalone HSE DNACPR policy, thus removing Part 3 DNAR from the HSE National Consent Policy.



‘Do Not Attempt Cardiopulmonary Resuscitation decision-making process; scoping review’.
Dr John Lombard, School of Law, University of Limerick.

The National Office for Human Rights and Equality Policy are overseeing a piece of research examining DNACPR practice and policy with a view to producing a standalone HSE policy on DNACPR decisions. From this research Dr John Lombard, Dr Hope Davidson, and Dr Owen Doody of the University of Limerick have had an article published in the journal BMJ Supportive & Palliative Care. The article is titled, ‘Do Not Attempt Cardiopulmonary Resuscitation decision-making process; scoping review’ and is available here <https://spcare.bmj.com/content/early/2024/03/21/spcare-2023-004573>

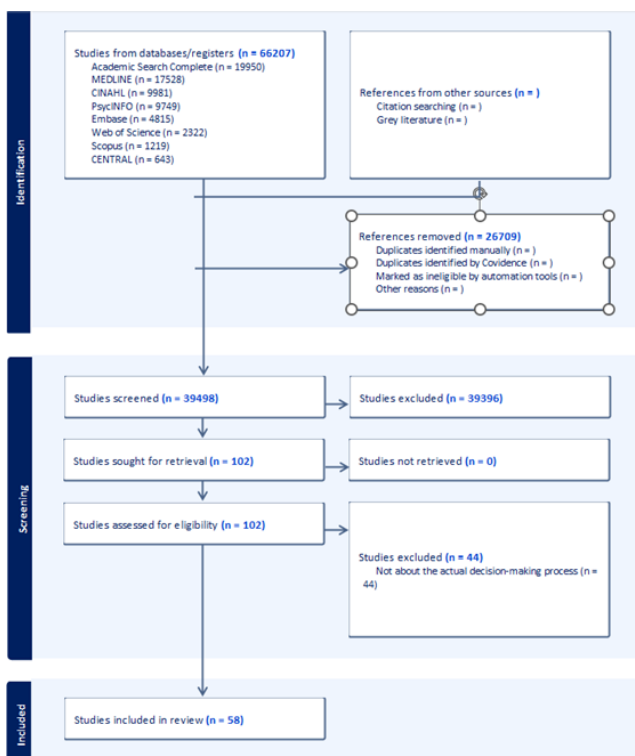
The article reports on a systematic search and review of articles from 1 January 2013 to 6 April 2023 within eight databases. A total of 66,207 search results were screened by the reviewers and 58 papers were included in the review. The data was

Dr. John Lombard, School of Law

mapped onto concepts to identify the timing of decision-making, evidence of involvement, evidence of discussion, evidence of documenting the decision, communication and adherence to a decision, and recommendations from the literature.

The article provides insights into the barriers and facilitators of DNACPR decision-making, process, and implementation. For instance, barriers arising in DNACPR decision-making related to timing, patient/family input, poor communication, conflicts, and ethical uncertainty. Facilitators included ongoing conversation, time for discussion, appropriate documentation, flexibility in recording the decision, good communication, and DNACPR policy.

The article highlighted how challenges in this area can persist over time and this requires changes to support and promote examples of good practice. Overall, the review underlined the complexity of DNACPR decision-making and how it is a process shaped by multiple factors including law and policy, resource investment, healthcare workers, those close to the person, and of central importance, the person themselves.





Upcoming Event

Webinar - HSE National Consent Policy – Considerations for Mental Health Services

When: Thursday May 9th 3-4.30.

Register: https://eu01web.zoom.us/webinar/register/WN_BgeFbS6kRwCDStjzbpGzBw

This webinar will consist of:

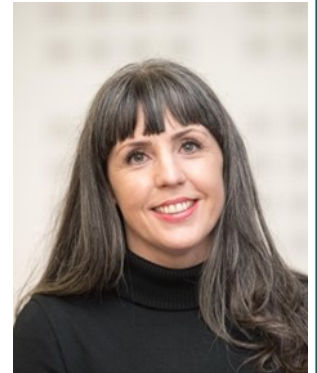
- an overview of the HSE National Consent Policy 2022 as it pertains to Mental Health Services; and
- a panel discussion of consent-related questions and scenarios received from staff in Mental Health Service.

Please send any questions or case scenarios for discussion to Aisling.Duffy3@hse.ie by close of business Friday 19th April.

The objectives of this webinar is are to:

- Raise awareness of the HSE National Consent Policy 2022 v1.2.
- Identify areas of uncertainty and learning needs of staff in mental health services in relation to the National Consent Policy.
- Provide practical guidance to Mental Health Services and practitioners.
- Stimulate discussion about practical implementation of the Policy in Mental Health Services.

Staff are encouraged to complete the National Consent Policy e-learning programme on HSeLand.ie in advance of the webinar. This event will be recorded and available to watch back on hse.ie/nationalconsentpolicy.



Elaine McCaughley
Programme Lead
Consent & DNACPR

Update from the Decision Support Service



Aine Flynn

Director of Decision Support Service



It has been a quick year and we now find ourselves fast approaching the first anniversary of commencement of the Assisted Decision-Making (Capacity) Act 2015.

Information, Communication and Stakeholder engagement

The demand for information about the 2015 Act and the functions of the DSS has continued and increased. By the beginning of March, the DSS Information Service had managed almost 18,000 queries by telephone and email and a further 3000 queries to a separate email about the creation of 'MyDSS' accounts.

Many of these are queries from potential service users and their families and carers, as they consider the opportunity to avail of the formal decision supports under the 2015 Act. Sometimes it is still necessary to counter misinformation and to provide reassurance that the Act provides the option of new measured supports to be drawn upon as needed and should not be seen as an imposition.

The DSS has continued its engagement with diverse stakeholders in health and social care, banking and financial services, disability services providers and the users of their services, regulators, carers' organisations, nursing homes' representative bodies, community groups, the Courts Service, the judiciary, and the legal profession. We have a full calendar of events in the coming months, with many organisations planning to mark the first anniversary of the Act and to reflect on the story so far.

Our public information campaign with the theme 'My Decisions; My Rights', had another outing that continued into this year across multiple platforms. As we bid farewell to our 9 amazing DSS champions who fronted the campaign, we are already planning for this year's media campaign on the theme of advance planning. As we always say, it is the opportunity to plan ahead by way of an enduring power of attorney and advance healthcare directive that makes the 2015 Act an Act for everyone.

Our direct engagement with the HSE ADM Leads and Mentors has continued and has provided a valuable opportunity to hear about the practical implementation of the Act (and to observe some impressive performance in ADM quizzes).

We are seeing steadily increasing direct engagement by the public with the DSS online portal for the creation and registration of decision support arrangements. By early March, over 2,400 active applications were in progress, by far the majority of which are for the registration of the new form of enduring power of attorney.

The DSS is continuing to engage directly with the HSE in relation to the development of direct digital access to the DSS register by members of bodies and classes of persons, which will include HSE staff. Pending direct online access, enquiries about the register of co-decision-making agreements, decision-making registration orders and EPAs should be sent to the DSS at registersearches@decisionsupportservice.ie.

Applications to court

The DSS is not a party to applications to the Circuit Court under Part 5 of the 2015 Act and is involved in the process only if there is a request for the nomination of a decision-making representative from the DSS panel. We have now received over 50 requests for panel DMRs from both the Circuit Court and wardship court.

The court sends its decision-making representation orders to the DSS for registration and supervision. We are aware that the rate of applications and orders is increasing. The DSS has been able to engage directly with the courts and the Courts Service to see how we can provide good information and supports to applicants, many of whom are lay litigants, with no legal representation.

Applications under Part 6 of the Act for review and discharge from wardship are also underway. Again, the DSS is not directly involved in these applications. We have collaborated with the Office of Wards of Court on an information session for the legal profession to ensure that the discharge process and the role of the DSS is well understood. Information on the discharge process is available from the Office of Wards of Court. It remains the case that the response to the Act has been overwhelmingly positive. This depends on good and reliable information. The DSS continues to be impressed by the work of the HSE National Office for Human Rights and Equality Policy to spread the word in healthcare and the DSS is committed to continuing its valuable engagement with this important sector.

Best wishes to all,

Áine Flynn, Director of the Decision Support Service

www.decisionsupportservice.ie



**An Bord Um
Chúnammh Dílthiúil**

Legal Aid Board

Providing access to justice since 1979

Eleanor Leane, Solicitor

Legal Aid Board



The Legal Aid Board, through the Law Centre network, provides legal representation to Relevant Persons in Capacity Applications under Part 5 of the 2015 Act and to Wards of Court in Discharge Applications under Part 6 of the 2015 Act. Legal representation is to be provided to the Relevant Person or Ward in the Capacity or Discharge Applications, irrespective of their financial position. The Relevant Person or Ward is not required to pay a contribution towards legal services although costs may be recoverable at the conclusion of proceedings in some instances, where the Relevant Person or Ward, would not have been eligible for legal aid under the normal rules. There is further information on the financial assessment process below. The Legal Aid Board may also represent other parties, such as a family member for example, in these two types of proceedings, subject to them satisfying the normal means test for legal aid. Looking specifically at Part 5 Capacity Applications, since the commencement of the Act over 11 months ago, the Legal Aid Board has received applications for legal services from social workers, hospital liaison officers and other staff members of the HSE, on behalf of Relevant Persons. Most of these applications for legal services have involved Capacity Applications seeking a Declaration of Capacity and the appointment of a Decision Making Representative so that an application can be made for Ancillary State Support on behalf of the Relevant Person under the Nursing Home Support Scheme. In most of these cases, the Capacity Application has already been instituted by the HSE and the application for legal services to the Legal Aid Board on behalf of the Relevant Person is to ensure that the Relevant Person has legal representation in those proceedings, to ensure that the rights of the Relevant Person are protected, to ensure that the ethos of the Act and the Guiding Principles set out in the Act are applied in the case and to facilitate the voice of the Relevant Person being heard by the Court. In most of these cases, the Court has directed that the HSE contact the Legal Aid Board to ensure that the Relevant Person is provided with legal representation, before making any Orders. Given the interaction between staff of the HSE and the Law Centres in the making and processing of such applications seeking legal services for a Relevant Person, it may be useful to set out the Legal Aid Board's requirements of the staff member of the HSE who is assisting or facilitating the legal aid application of the Relevant Person.

Application for Legal Services Form:

In order for the Legal Aid Board to provide representation to the Relevant Person in a Capacity Application, an application for legal services will be required in all cases. Application forms are available from any of the Legal Aid Board's Law Centres or from our Head Office, details of which can be found on <https://www.legalaidboard.ie/en/contact-us/find-a-law-centre/>. The application form can also be downloaded from www.legalaidboard.ie. An application for legal services can also be made online at <https://www.legalaidboard.ie/en/our-services/legal-aid-services/apply-for-legal-aid-online/>.

The Legal Aid Board has specified a number of Law Centres for the provision of legal services in Capacity Applications. The list of centres can be found under the Legal Aid and Legal Advice tab on <https://www.legalaidboard.ie/en/our-services/assisted-decision-making-and-discharge-from-wardship/>. These Law Centres may deal with the applications in-house or they may be referred to another Law Centre or to a solicitor on the Assisted Decision Making Solicitor's Panel, depending on the circumstances arising in the particular application. This is determined on a case by case basis.

Applications can be made in the Relevant Person's name, either by the Relevant Person themselves or by the third party assisting the Relevant Person, such as the social worker or liaison officer. If the Relevant Person cannot sign the application form, the party assisting the Relevant Person may sign the application form.

Contact Information:

It is important that the application form provide all relevant contact details. As a meeting with the Relevant Person will be necessary, it is important that the application form outlines the details of where the Relevant Person is currently residing whether that be in a hospital setting or nursing home or otherwise. The Law Centre will need contact information for the person with whom they can raise any queries on the application form, on the Capacity Application or queries in respect of the Relevant Person. This person should be the social worker or liaison officer or other person who is assisting with the making of the application. The person who assists with making the application will also be the person with whom the Law Centre will make initial contact with to arrange the visit with the Relevant Person so those contact details are necessary. If it is the case the Legal Aid Board is being requested to institute a Capacity Application on behalf of a Relevant Person, the Law Centre will require the details of a person with whom the Law Centre can interact to obtain all relevant information for the matter and this should be the person who is assisting with making the application for legal services. This person will need to be able to provide all of the necessary information to enable the Law Centre to institute the application.

If there are family members who are involved with the Relevant Person, details should also be provided of those family members in order that contact can be made with them where appropriate. In particular, if a family member is being proposed in the Capacity Application as the person who would act as Decision Making Representative where the Order is made by the Court, please provide that family members contact details. The details of the solicitors who are acting on behalf of the HSE in the Capacity Application should also be provided as contact between the legal teams may be required.



Court Date

As already mentioned, most of the applications received by the Legal Aid Board from a staff member of the HSE, on behalf of a Relevant Person, tend to be in circumstances where there are proceedings already instituted which are pending before the Circuit Court. It is important therefore that if there is a court date fixed, or if the case has been adjourned by the Court to another date with a direction that an application be made on behalf of the Relevant Person to the Legal Aid Board for legal services, that the application indicates clearly what that court date is. This is important so that the application can be identified for priority by the Law Centre.

Where such a request has been made by the Court, the application for legal services should be made immediately to allow sufficient time for the application to be processed, preliminary enquiries to be made and a visit organised with the Relevant Person in advance of the adjourned date, if possible.

Court Documents

It is absolutely necessary that a copy of all of the court papers in respect of the Capacity Application be provided with the application for Legal Services. This includes the following papers:

- The Capacity Application
- The Functional Capacity Assessment
- The Affidavit sworn in support of the Capacity Application
- The Statement of Particulars
- The Notice of Motion / Ex-parte Notice of Motion
- The Affidavit of Service of the Application on the Relevant Person
- The Form of Reply from the Relevant Person
- Any other documentation relied on by the applicant in the proceedings.

The role of the solicitor representing the Relevant Person is to meet the Relevant Person and discuss the nature of the Capacity Application with them and to obtain their views on the matter, where possible. The solicitor will also explain the findings of the functional capacity assessment to the Relevant Person and explain the tier of decision-making support that is being proposed by the assessor. The solicitor will record any response of the Relevant Person to these matters and seek to determine the will and preference of the Relevant Person in respect of the matter and report that to the Court. Legal representation may also involve making legal arguments, where appropriate, in relation to the Capacity Application, including whether decision support is necessary at all, in relation to the types of decisions that need to be supported, in relation to the tier of decision making support sought by the applicant or in relation to who should act as a decision supporter. Therefore, it is essential that the solicitor has a copy of all of the above documentation. There is often only a short adjournment of the court proceedings to facilitate the HSE making an application for legal services on behalf of the Relevant Person and for the Law Centre solicitor to meet with the Relevant Person by the adjourned date. If the court documents are not made available with the application this can lead to delays and to further adjournments of the matter so it would be best practice to ensure that those papers are provided with the application form.

Other Supporting Documentation

Where possible, please provide proof of income, proof of address and photo ID for the Relevant Person. If these are not available, it is certainly not a bar to the application being processed and dealt with and the Law Centre will advise if there are any further requirements on receipt of the application form where those documents are not available.

Financial Assessment

As has been noted above, the Relevant Person is entitled to legal services and legal aid regardless of their financial position in any case where they are the subject of a Capacity Application. The Law Centre does however need to carry out a financial assessment prior to closing the file in the matter in order to comply with the provisions on legal aid that are set out in the 2015 Act. The sole purpose of the financial assessment is to establish if the Relevant Person may be subject to some recovery of costs at the conclusion of the proceedings. This will be discussed with the Relevant Person, family member or the decision supporter who is appointed by the Court, as appropriate. Full information on the legal services that are provided by the Board under the 2015 Act, covering Capacity Applications, Discharge Applications and the other support arrangements and advance planning arrangements that are provided for under the Act, is available on the Legal Aid Board website at <https://www.legalaidboard.ie/en/our-services/assisted-decision-making-and-discharge-from-wardship/>. This includes information on the application process and on the financial assessment process. The Legal Aid Board has also engaged with the Wards of Court Office in relation to legal aid for Wards of Court in Discharge Applications and there is a recording available on same on <https://www.courts.ie/video-presentations-discharge-wardship>. General queries on the application process can be directed to the Law Centres outlined above or to the Head Office of the Legal Aid Board on info@legalaidboard.ie.



Jacqueline Grogan
Project Manager

Assisted Decision-Making (Capacity) Act 2015: An Evening with Judge John O'Connor

The HSE National Office for Human Rights and Equality Policy were delighted to host *Assisted Decision-Making (Capacity) Act 2015: An Evening with Judge John O'Connor* on 21st February 2024.

The event, with over 150 people in attendance, was chaired by Professor Mary Donnelly, School of Law, University College Cork. The purpose of the event was to explore with Judge O'Connor what has been happening in relation to decisions pertaining to Decision making Representatives and to reflect on how to ensure that the spirit of the 2015 Act remains at the centre of all decisions.

The evening started with a presentation from Judge O'Connor, followed by an interview with Judge O'Connor and Professor Donnelly. This was followed by an expert panel discussion, with inputs from Aine Flynn, Director, Decision Support Service, Professor Shaun O'Keefe, Consultant Geriatrician, University Hospital Galway, Suzy Byrne, Disability Advocate and Regional Manager, National Advocacy Service and Bibiana Savin, Deputy CEO, Sage Advocacy.

There was great interaction from the floor with the panel during the Q&A session. Feedback from the event has been very positive and we hope that this will be the first of many collaborations with the Judiciary.

The recording of the event can be found at www.assisteddecisionmaking.ie.



Judge John O'Connor, Professor Mary Donnelly, Aine Flynn, Professor Shaun O'Keefe, Bibiana Savin, Suzy Byrne



Dr. Philip Crowley, Professor Mary Donnelly, Judge John O'Connor, Caoimhe Gleeson, Professor Shaun O'Keefe



Judge John O'Connor, Professor Mary Donnelly

News Roundup



National Office for Human Rights and Equality Policy

Leaving Wardship

Marie-Claire Butler

The Assisted Decision-Making Capacity Act 2015 was commenced on the 26th April 2023. The commencement of the Act meant many things to many groups of people.

Specifically for people who are under the protection of the High Court in Wardship, it started the clock on a three-year period in which all Wards of Court (referred in this article as 'Relevant Person') are to be reviewed by the High Court and discharged from Wardship, with or without decision making support. This process is contained in Part 6 of the Act.

Some 11 months later, uptake has been relatively slow. Interestingly, in 2023, more than 200 Wards were declared. Despite the existence of a 'saver' provision in the Act (section 56) that allows for an option of appointing decision support under the Act in lieu of Wardship on declaration – it has not been availed of in a single case to date.

Discharge from Wardship process

The discharge from Wardship process under Part 6 of the 2015 Act is relatively straightforward. Legal Aid is widely available, and the Legal Aid Board have a dedicated panel for Part 6 applications. The application can be brought by the Relevant Person themselves, or by their Committee. With permission of the Court, any other person with a genuine interest in the welfare of the Relevant Person can bring the discharge application (in this case you need to apply to the Court first for the consent to do so).

The application is commenced by lodging a Notice of Motion with the Wards of Court office, which triggers the instruction from that office to a Court Medical Visitor to attend with the Relevant Person and undertake a Functional Capacity Assessment in line with the Act. This assessment captures three main areas – (i) healthcare, (ii) welfare (including ADL's) and (iii) property and financial affairs. This assessment is pre-arranged with the person and their caregivers/service provider.

A copy of the report when it is finalised is then sent to the Relevant Person for their consideration. It recommends what level of decision support, if any, they require on discharge from Wardship. There can be different decision support requirements for the different areas. The Relevant Person (or the Applicant if the Committee) can also request a second opinion themselves if they are not happy or do not agree with the recommendation of the Court's Medical Visitor.

Papers are then finalised by the applicant and service of the papers is arranged on the Relevant Person. The application will be explained clearly as well as the findings of the Medical Visitor. The Will and Preference of the Relevant person is extremely important and this is recorded in an Affidavit for the Court. Discussions around a possible decision supporter (Decision-Making Assistant, Co-Decision-Maker, Decision Making Representative) are important at this stage.

Once all the papers are in order, a date for court is fixed and the Relevant Person is advised of the date and is encouraged to attend the hearing. As the hearings are in a hybrid format, there is a choice to attend online (rather than in person) if this is preferred. The hearings are conducted by Judges sitting in the Four Courts, Dublin, who are experienced in dealing with vulnerable persons. The hearings are, as much as possible, informal and the Relevant Person is invited to speak to the Court on the day if they are comfortable in doing so.

Where there is no Decision-Making Representative is identified as willing or in a position to be appointed, the Court can request the Decision Support Service to nominate two suitable candidates from their panel. The Court will select one name in chambers. It should be noted that in the case of a person as having been assessed to have capacity with the assistance of a Co-Decision Maker, but there is no one available to act, then the Court will appoint a Decision-Making Representative from the Panel, but with an obligation to act jointly, where possible, with the Relevant Person.

What happens on discharge

On discharge, all assets held by the Court are returned to the Relevant Person or their Decision-Making Representative, as appropriate. In cases where there is a requirement to appoint a Co-Decision Maker, pursuant to the Act, discharge from Wardship is contingent on the registration of a Co-Decision-Making Agreement within a certain timeframe (usually three months) after the hearing. In cases appointing a Co-Decision-Maker or a Decision-Making Representative, reviews of the support arrangement and the capacity of the Relevant Person are directed by the High Court within a period of 1-3 years post discharge to take place in the Circuit Court in line with the Act

For more information,

- [Part 6 ADMCA 2015](#),
- [High Court Practice Direction 120](#)
- [Courts.ie](#)
- [Decisionsupportservice.ie](#)

Marie-Claire Butler

Deputy General Solicitor for Minors and Wards of Court

Leaving Wardship

1. Solicitor makes a discharge application on your behalf
2. Psychiatrist visits you to carry out a capacity assessment
3. You receive a copy of the capacity assessment
4. A court hearing date is set
5. Judge approves that you are discharged to look after your own affairs
OR
Judge approves the support arrangement that you need to register with the new service

Office of Wards of Court
15/24 Phoenix Street North
Sarnoff
Dublin 7
Tel: 01 8861140
Email: wards@courts.ie

An Irishish Chairwoman
Courts Service

Scan code to view our website
www.courts.ie/office-wards-court



Do you know someone who might like to participate in research about the ending of adult wardship?



One of the changes that will stem from the commencement of the Assisted Decision-Making (Capacity) Act 2015 is the end of adult wardship. The Irish system of wardship was established by legislation that dates back more than 150 years and reflects the values of the 19th century. Persons who were made Wards of Court were deemed to be 'of unsound mind' and to be unable to manage their affairs. The wardship system operated on the basis that people who were made wards of court lacked ALL decision-making capacity. The system lacked a graduated framework of supports that determines capacity in respect of a specific decision at a particular time and in a particular context, concerns remedied by the 2015 Act.

The end of adult wardship is therefore a welcome and potentially transformative change, designed to give effect to the UN Convention on the Rights of Persons with Disabilities. It is likely that many of those who were previously wards of court will require some form of decision-making supports and any new decision-making arrangements will be regulated and monitored by the Decision Support Service. Those that support people to make decisions or make decisions on their behalf will

be guided by their 'will and preference' rather than the principle of 'best interests', which shaped decisions made on behalf of persons who were wards of court.

The National Disability Authority is conducting research that is examining the process of ending wardship and the experiences of those leaving wardship. We are seeking to recruit adults who are wards of court or who were recently discharged from wardship. We are also seeking to recruit committees of persons who are wards of court. If you know of someone who is a ward of court or who acts as a Committee on behalf of a person who is a ward of court please tell them about our research. You can find more information about the research on our website (<https://nda.ie/justice-equality-and-safeguarding/wards-of-court-research>) or by contacting wardsresearch@nda.ie or calling 0876712376.



Dr. Caroline O'Nolan
Senior Research Officer



Mentalhealthreform.ie



Mental Health Reform (MHR) has launched a new animated video on the Assisted Decision-Making (Capacity) Act 2015 or ADM which was enacted into law last year. The video was co-created with a group of people with lived experience of mental health difficulties/psychosocial disabilities. It provides information in plain English to help people with mental health difficulties understand their rights under the legislation. It explains key terms including the Advanced Healthcare Directives (AHDs) and the Decision Support Service. The co-creation group also felt that it was important to ensure that front-line service providers, mental health professionals and clinicians are engaging with these changes in law and enabling people to access their human rights around supported decision-making.

<https://mentalhealthreform.ie/assisted-decision-making/>

**ASSISTED
DECISION
MAKING**

**Your Voice
Your Choice**



Cúram Sláinte
Phobail, Iarthar
ag freastal ar Ghailimh,
Maigheo agus Ros Comáin

Community
Healthcare West
serving Galway, Mayo
and Roscommon

SAOLTA/CHW Integrated ADMCA Mentorship Set **Siobhan Donoghue**

The Community Healthcare West (CHW) Assisted Decision-Making Mentorship Set have been meeting monthly since our inaugural meeting on the 13th October 2023. In December an opportunity arose for the CHW and SAOLTA mentees to come together and since then there has been an integrated Mentorship set. This integrated model of learning has afforded all an invaluable opportunity for looking at the ADMCA through the lens of the acute and community settings and the variation of case studies presented is a testament to same. This group is cross divisional in terms of composition and encompasses Occupational therapy, Social Work, Nursing, Social Care, and Administration across the hospital group, mental health, primary care and disability. The integrated model allows the practitioner to reflect on the challenges and opportunities in both the acute and community sector. Of note also has been how the organisations culture and resource issues interact with the guiding principles underpinning the Act.

This group is also the only Mentorship set where there is a co-mentorship model of facilitation.



Lynn Swinbourne Senior Health Promotion Officer, NSS

Breaking Down Barriers - an assessment of the needs of disabled people in accessing population-based screening services in Ireland

Lynn Swinbourne Senior Health Promotion Officer, NSS

This study sought to explore the needs of disabled people in accessing national population screening services, to capture their lived experience and to document their barriers and enablers to participation in screening.

The research was qualitative in nature, consisting of focus groups and interviews. Twenty disabled people participated in the study, representing those with Intellectual Disabilities, Autism, physical impairment, visual impairment, and the Deaf community. In addition, five healthcare professionals and five family carers were involved in the study.

What did we learn?

Before disabled people come to screening, they may receive inaccessible information from us as a service, they are reliant on others to support them to attend for screening and support for travel to screening is also a concern they raised.

During the screening appointment several good practices supporting the person to participate in screening were captured. Providing longer appointments, information provided in Braille and an empathetic and positive approach to the disabled person were all seen as enablers in this research. Following screening, some disabled people were unable to access their screening results and others wanted an online system to communicate their reasonable accommodations needed.

The literature review shows the potential reasons why disabled people may be under screened or never screened and their lived experience back up some of these findings. Understanding the reasonable accommodations that can make screening a person-centred service is vital.

The report is available in various accessible formats: a screen reader accessible version, an easy read summary, a plain English summary and an Irish Sign Language video summary. [Read the full report here.](#) [Read our blog](#) about the study.



Family Carers Ireland launches ADM legal advice clinics for family carers

Andrew Rooney, Family Carers Ireland

Family Carers Ireland is delighted to launch a new project CarerAid, a free legal advice clinic for family carers with queries related to the Assisted Decision-Making (Capacity) Act.

Funded by IHREC, CarerAid is delivered in collaboration with Community Law & Mediation and will provide help and guidance to family carers to better understand the Act and the decision-support arrangements for people who may need decision-making support. CarerAid has a particular focus on helping carers who want to make an application, where appropriate, for a Decision-Making Representative Order (DMRO). Since the Act's commencement, some carers have reported finding the DMRO process complicated and confusing. CarerAid will provide the legal expertise to help families navigate the DMRO process and provide easy-to-read guides that can be used by families who are beginning this process.

CarerAid is one of a range of supports we provide to help family carers understand and navigate the Act. We host online and in-person information sessions and have developed a [practical guide for family carers on the Act](#).

If you would like to discuss the project, please contact Andrew Rooney at arooney@familycarers.ie. For more information about Family Carers Ireland and the support we provide for family carers please visit www.familycarers.ie



Andrew Rooney, Family Carers Ireland



Coimisiún na hÉireann um Chearta an Duine agus Comhionannas
Irish Human Rights and Equality Commission

This project is supported under the Irish Human Rights and Equality Commission Grant Scheme



The National Advocacy Service (NAS) is delighted to announce the launch of ‘[My Money, My Rights, My Options](#)’, an easy-to-read leaflet which aims to build financial autonomy and enhance the capacity of people with disabilities to access and manage their own finances.

The leaflet provides people with explanations and definitions on key stakeholders and financial institutions, details on financial rights, support options, places to keep money and essential contact details. The availability of this vital tool highlights the fundamental impact our advocacy work has on the people NAS supports and showcases independent advocacy as solutions-based, which has a positive impact both for individuals and communities across Ireland.

This easy-to-read money guide follows on from the success of the Casebook, which spotlighted themed NAS case examples on access to finance issues. It will be followed by the launch of our Social Policy Paper on ‘Examining the Barriers to Equal Access to Finances for People with Disabilities’ in the coming weeks. In line with the principles of the UNCRPD and the Assisted Decision Making (Capacity) Act, the series of access to finance publications produced by NAS outline the key challenges people with disabilities face in managing their own finances.

This publication is a culmination of hard work and dedication from several NAS advocates who worked to produce the content and also to produce it in easy-to-read format.

Publication link: <https://advocacy.ie/app/uploads/2024/02/NAS-Easy-to-Read-Leaflet-My-Money-My-Rights-My-Options-Final-Web.pdf>
Full news story here: [My Money, My Rights, My Options: New Financial Resource for People with Disabilities – National Advocacy Service](#)



Community Healthcare West Assisted Decision-Making learning event Gabrielle Dunne, Social Work Team Leader for Disabilities



Donegal Disability Services attended their first Assisted Decision-Making (Capacity) Act 2015 in person learning event on the 31st January 2024, which was facilitated by Caoimhe Gleeson. Those in attendance included Multi-disciplinary members from Social Work, Psychology, Speech and Language Therapy, Occupational Therapy, Nursing, Health Care Assistants, Physical and Sensory Disability teams and Training Services. The event was a way for everyone to network and to continue working as multi-disciplinary members to support adults with a disability around decision-making.

The learning event looked at various case examples of scenarios that adults with a disability find themselves in and how professionals can best support them in collaboration with their families around their will and preference. The event also focused on the role of Professionals and how they adhere to the nine guiding principles of the Act by having a human rights based approach.

The feedback from the event was very positive and was a theoretical and practical way to learn about the Assisted Decision-Making Act, which included all MDT members from Disability Services.





National Office for Human Rights and Equality Policy

Tipperary Roma Health and Accommodation Pilot Project

Tipperary Roma Health and Accommodation Pilot Project aimed to improve the health outcomes of Roma living in insecure and/or unsuitable housing conditions in Tipperary. The Public Sector Equality & Human Rights Duty was used as a lever to address Roma health and accommodation needs as part of this project.

The final report on the Pilot Project as well as the findings of the Tipperary Roma Homeless & Housing, Health & Social Care Needs Assessment will be launched on Tuesday 21st May in Tipperary town.

This pilot project was funded by the HSE National Social Inclusion Office and was a partnership project between Youth Work Ireland Tipperary, HSE Social Inclusion Mid-West, HSE Social Inclusion South East and Tipperary County Council. This was a demonstration project, which aimed to identify good practices and apply them in Tipperary and then share learning, outputs and outcomes with other Community Healthcare Organisations and Local Authorities.

For further information please contact: Suzanne Nolan, HSE Regional Roma Health Lead (South East): Tel: 087 6468856; Email: suzannes.nolan@hse.ie

May 21st is also World Day for Cultural Diversity for Dialogue and Development as designated by the UN General Assembly.



The Radisson Blu Hotel Sligo hosted an event on Friday 8th March that brought together representatives from mental health services across CHO1. The Head of Service for Mental Health in CHO1, Leo Kinsella, and General Manager Pauline Ackermann joined mental health staff from social work,

nursing, occupational therapy, psychology, medical and administration teams to share knowledge on the interface between the ADM and mental health services.

Jacqueline Grogan from the National Office for Human Rights and Equality Policy brought together leading voices on the Act to open the day — Aine Flynn Director, DSS, Shaun O'Keefe, Consultant Geriatrician and HSE ADM lead and Professor Brendan Kelly, Consultant Psychiatrist, Tallaght University Hospital. They each gave presentations on the intricacies of the Act and how the Act can be used to improve how services are delivered and ensure the voice of the service user is central in the decision-making process. Ber Grogan, Mental Health Reform reiterated this message with a talk on the rights of individuals to have autonomy over decisions about them within mental health care.

The four speakers were joined by Tina Gardiner, Principal Social Worker for adult services in Donegal and ADM Mentor, for a panel discussion on case vignettes submitted by staff in mental health services across the region. These discussions gave delegates the opportunity to tease out with the panel the issues that are faced on a daily basis by front line mental health staff across CHO1. Many questions were answered but many more challenges remain and it will take time for the Assisted Decision-Making Act to embed itself fully into all services including mental health. With over 100 mental health staff attending the conference it is clear that the appetite is there from mental health services to engage meaningfully with all aspects of the Act. More localised events are planned across the region in 2024 to build on the success of the conference and help all disciplines ensure that the Assisted Decision Making Act is a core component on how we design and deliver mental health services in CHO1 now and in the future.

Paul Cartin, Principal Social Worker, Mental Health Services, Donegal/Sligo/Leitrim



Ber Grogan, Brendan Kelly, Jacqueline Grogan, Aine Flynn, Tina Gardiner

Further updates and resources

*For further updates, join our mailing list,
please email: adm@hse.ie*

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

- [HSE Assisted Decision-Making website](#)
- [HSE Explainer video on the Act](#)
- [Webinar on Assisted Decision-Making \(Capacity\) Act 2015: Update since commencement from the 14th June 2023](#)
- Decision Support Service statutory [Codes of Practice](#) on the 2015 Act including codes relating to:
 - [Healthcare Professionals](#)
 - [Advance Healthcare Directives for Healthcare Professionals](#),
 - [Supporting Decision-Making and Assessing Capacity](#).
- **NHSS:** For updates to the fair deal scheme application process and changes following the Assisted Decision-Making (Capacity) 2015 Act - <https://www2.hse.ie/services/schemes-allowances/fair-deal-scheme/>
- [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 \(Capacity\) Act 2015](#)
- [ELearning Programme on Assisted Decision-Making \(Capacity\) Act \(2015\) – Guidance for Healthcare workers on HSeLand](#)
- [Assisted Decision-Making \(Capacity\) Act 2015](#)
- [Transition from Wardship to the Assisted Decision-Making \(Capacity\) Act 2015: Guidance for Staff webinar 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](#)
- [Decision Support Service](#)
- [Courts Service - Office of Wards of Court](#)
- [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](#)