

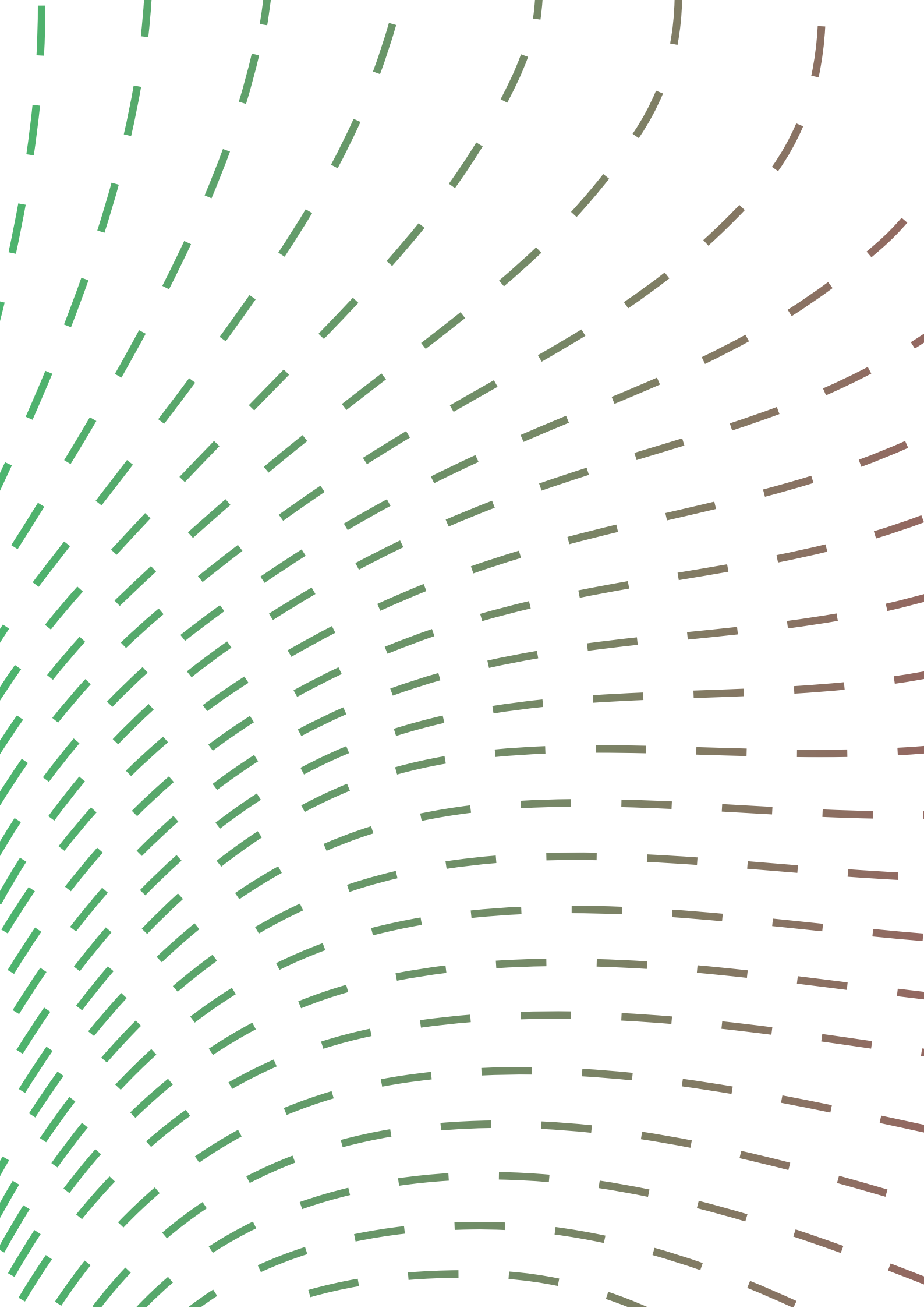


August 2023

Assisted Decision- Making (Capacity) Act 2015

**Information Booklet for
Parents and Families**





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Introduction

The Assisted Decision-Making (Capacity) Act (ADM) was signed into law in December 2015. The Act establishes a modern legal framework to support decision-making by adults 18 years and over, who may have difficulty making decisions. This may include, for example, people with an intellectual disability, acquired brain injury, mental health difficulties or dementia.

The Act introduces formal "Decision Support Arrangements". However, adults with intellectual disabilities and autism who already have decision-making supports in place based on their will and preference – through family, paid supporters, circles of support etc. can continue to make day to day decisions in the same way as previously.

There may come a time when a formal decision support arrangement under the ADM legislation is required, and this intervention may be chosen by the individual and could include a **Decision-making assistant** or **Co-decision maker**. Where it is deemed that a person does not have the capacity to make a particular decision(s) based on a functional assessment approach (see page 6), a **Decision-making representative** may be appointed by the Court. This is always seen as a last resort and all other less restrictive options should be explored first.

Accessing formal decision support arrangements could also come about when there is a very significant decision that needs to be made; and adults can then choose to put a Decision Support Arrangement in place to support them with that decision.

A guiding principle of the 2015 Act is to take the least restrictive action on adult's rights and freedoms. This means supporting the person to make their own decisions in line with their will and preference whenever possible.

There is a presumption of capacity i.e., that an adult is able to make the decision in question. Under the legislation a person does not need to prove their capacity to make a decision. The onus is on the individual who says that the person does not have capacity to show that this is the case. The decision could be, for example, about entering into a contract or a decision to give or refuse consent. This is a change from the Status approach whereby some people were previously assumed not to have capacity because they have a disability; or the Outcome approach where making an unwise decision implied that the person lacked capacity. A person no longer needs to prove their capacity to make a decision.

Introduction

Assessing capacity is not the first step. **The first step is to support a person as far as possible to make their own decision.** If capacity needs to be assessed, the assessment is based on their ability to make a **specific decision at a specific time.**

Note that this booklet has been developed as an information resource for the parents and families of people supported in Gheel. It is not legally binding. Please refer to the DSS website at <https://decisionsupportservice.ie> for further information.

What is the Assisted Decision-Making (Capacity) Act 2015?

The Act recognises that, as far as possible, all adults have the right to play an active role in decisions that affect them. These decisions can be about their personal welfare and property and affairs.

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

- Introduces new guiding principles about interacting with a person who has difficulties with their decision-making capacity
- Establishes a tiered system of decision support arrangements for people who need help with making decisions
- Abolishes the current wardship system and requires all wards of court to be discharged from wardship within three years of commencement of the Act
- Establishes the Decision Support Service

Types of decisions to which the Act applies

The categories of decisions to which the principles of the Act apply, include decisions around:

1. Property and Affairs including:

- Custody, control and management of property
- Sale, exchange, mortgage, gift etc. of property
- Acquisition of property
- Carrying on a business
- Share purchase agreements
- Discharging debts and liabilities
- Providing for other persons
- Conduct of Court proceedings
- Applying for benefits

2. Personal Care Decisions including:

- Accommodation
- Employment
- Education and Training
- Social activities
- Social services
- Healthcare
- Other matters relating to relevant person's wellbeing

The Guiding Principles

Section 8 of the Assisted Decision-Making (Capacity) Act 2015 sets out nine guiding principles for anyone interacting with a person who has difficulties with their decision-making capacity. These are:

- Presume every person has the capacity to make decisions about their life.
- Support people as much as possible to make their own decisions.
- Do not assume a person lacks capacity just because of an unwise decision.
- Only take action where it is really necessary.
- Any action should be the least restriction on a person's rights and freedoms.
- Give effect to the person's will and preferences.
- Consider the views of other people who know the person
- Think about how urgent the action is.
- Use information appropriately.

What does the Assisted Decision-Making (Capacity) Act 2015 mean when it refers to a "relevant person"?

When the 2015 Act refers to a "relevant person", it means a person whose capacity to make one or more decisions is, or may shortly be, in question. Under the new law, a person's capacity must be assessed based on their ability to make a specific decision at a specific time.

Capacity

What is a Capacity Assessment?

Article 12 of the United Nations Convention on Rights of Persons with Disabilities states that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. Section 3 of the Act encapsulates that ethos and provides that a person's capacity shall be assessed on the basis of his or her ability to understand at the time that a decision is to be made and the nature and consequences of the decision in the context of available choices.

The assessment used under the new law is called a "Functional Test" for capacity. This means the assessment is about a specific decision that needs to be made at a specific time. You may not make a blanket assessment that a person has no capacity.

A person will be deemed to lack the capacity to make a decision if he or she is unable to do one of the following:

- To understand the information relevant to the decision
- To retain that information long enough to make a voluntary choice
- To use or weigh that information as part of the process of making the decision or
- To communicate his or her decision (whether by talking, writing, using sign language, assistive technology, or any other means) or, if the implementation of the decision requires the act of a third party, to communicate with that third party

The ability to retain information relevant to a decision for only a short period shall not prevent a person from being regarded as having capacity. The fact that a person lacks capacity in respect of a decision on a particular matter or at a particular time will not prevent him or her from being regarded as having capacity to make decisions on other matters or on the same matter at a different time. Under the Act, the assessment of capacity will be functional and will be time and issue-specific. An unwise decision shall not be deemed to demonstrate incapacity.

Who can assess capacity?

Under the new law, everyone is presumed to have capacity at all times. The first step is to support people to make their own decisions. In some circumstances there may be a reason to question a person's capacity to make a certain decision. The person who requires the decision to be made will often be the best person to do the capacity assessment. This could be, for example, a lawyer, doctor, or a person providing financial services.

Under the new law, there are also limited circumstances where the capacity assessment has to be undertaken by healthcare professionals. This is during the process of registering a co-decision-making agreement or enduring power of attorney. Formal statements from healthcare professionals are required to register these arrangements.

What levels of decision support will be available?

There will be five different decision support arrangements available. These arrangements are based on the different levels of support that a person requires to make a specific decision at a specific time.

There are two types of decision support arrangement for people who wish to plan for a time in the future when they might lose capacity. These are:

- Attorney
- Designated Healthcare Representative

There are three tiers of decision support available for people who currently, or may shortly, face challenges when making certain decisions. These are:

- Decision-Making Assistant: The person makes their own decision with support from their decision-making assistant. Their decision-making assistant helps them to access and to understand information and to communicate their decision.
- Co-Decision-Maker: The person makes specified decisions jointly with a co-decision-maker.
- Decision-Making Representative: The Circuit court appoints a decision-making representative to make certain decisions on the person's behalf, when they have been found to lack capacity to make those decisions.



What is a decision supporter?

This is not a term in the 2015 Act. The Decision Support Service uses the term "decision-supporter" to refer to a person who has been appointed as a:

- Decision-making assistant (DMA) under a decision-making assistance agreement
- Co-decision-maker (CDM) under a co-decision-making agreement
- Decision-making representative (DMR) under a decision-making representation order
- Attorney under an enduring power of attorney (EPA)
- Designated healthcare representative (DHR) under an advance healthcare directive

The type of support they can provide depends on the decision support arrangement in place.

Ideally, a decision supporter will be a family member or trusted friend. At the upper tier of support, the person may not have someone who is available and suitable to act as a decision-making representative. The Decision Support Service will recruit and maintain a panel of people who are suitable to act as decision-making representatives. The court can ask the DSS to nominate two decision-making representatives from this panel and the court can choose to appoint one of them.

Advanced Healthcare Directive

If a person wishes to plan ahead, they can make an advance healthcare directive (AHD). This enables a person to set out their wishes regarding treatment decisions in case they are unable to make these decisions in the future. Importantly, it lets them write down any treatment they do NOT want. Under the new law, a person will be able to appoint someone whom they know and trust as their designated healthcare representative (DHR) to ensure their advance healthcare directive is followed.

Changing or ending an advance healthcare directive

A person can change or end their advance healthcare directive at any time, if they have capacity to do so. The advance healthcare directive only starts to apply if they lose capacity. It can be a good idea to review and update an advance healthcare directive on a regular basis to ensure that it reflects a person's wishes. It should also be reviewed and updated following any major medical treatment or diagnoses to ensure it reflects a person's medical situation.

The Act distinguishes between treatment refusals and treatment requests. In terms of treatment refusals, the Act provides that these shall be binding, provided the following conditions are met:

- At the time in question, the directive maker lacks capacity to consent to the treatment
- The treatment being refused is clearly identified in the directive
- The circumstances in which the refusal applies are clearly identified

In terms of treatment requests, however, the 2015 Act states that such requests are not legally binding, but they shall be taken into consideration during any decision-making relating to treatment, provided the specific treatment is relevant to the patient's condition.

Under the Act, once all of the legal requirements are met and an AHD is valid, a healthcare professional must comply with it, even if they do not agree with the patient's decision. Where there is any doubt as to the validity or applicability of an AHD, the healthcare professional must try to resolve this by consulting with the designated healthcare representative (if there is one) or, if there is none, with the patient's family.

Healthcare professionals who fail to comply with an AHD will not face civil or criminal liability provided that they:

- Were unaware of its existence
- Had reasonable grounds to believe it was invalid
- Required clarification by medical professionals which could not be obtained in the time frame necessary to take appropriate action

Role of the Designated Healthcare Representative (DHR)

A directive-maker may designate a specific person to be a designated healthcare representative (DHR) in his or her advance healthcare directive, and name other representatives if the original designated healthcare representative dies, or is unable, for whatever reason, to exercise the relevant powers, provided that the named individual is eligible.

A designated healthcare representative has one or both of the following powers:

- The power to advise and interpret what the directive-maker's will and preferences are regarding treatment as determined by the representative by reference to the relevant advance healthcare directive
- The power to consent to or refuse treatment, up to and including life-sustaining treatment, based on the known will and preferences of the directive-maker as determined by the representative by reference to the relevant advance healthcare directive

Advanced Healthcare Directive - Decisions and Eligibility

Nature of decisions: Health affairs

Medical evidence of capacity: Yes (medical and healthcare professional)

Who can be a designated healthcare representative?

- An adult (18 years and over), known and trusted by the person appointing them

People excluded:

- Anyone convicted of an offence in relation to the person or property of the directive-maker or the person or property of a child of the directive-maker
- Anyone who is the subject of a safety or barring order against the directive-maker or a child of the directive-maker
- An owner or a registered provider of a designated care or mental health facility where the person lives (unless they are a relative of the person or their primary carer)

Advanced Healthcare Directive - Monitoring and Supervision

- If or when the AHD comes into effect, the DHR must keep a record of the decisions made on behalf of the person. If the person regains the ability to make healthcare decisions, the DHR must provide a copy of this record to them. The DSS can also request a copy of the record.
- The DSS may send a general visitor or special visitor to talk to the person and/or DHR if a complaint has been received, who will report back to the DSS.

Enduring Power of Attorney

An Enduring Power of Attorney (EPA) is an arrangement whereby a donor (the person who may lack capacity in the future) gives a general power or specific power to an attorney (the person providing assistance) to act on their behalf.

A donor may, in an EPA, appoint more than one attorney and may specify that the attorneys shall act:

- (a) jointly
- (b) jointly and severally, or
- (c) jointly in respect of some matters and jointly and severally in respect of other matters

A donor may specify in an EPA who shall act as an attorney in respect of particular decisions if the first named attorney dies or is unable to act or is disqualified from acting as attorney. The Enduring Power of Attorney cannot contain any decision relating to the refusal of life-sustaining treatment, or any item already covered by a pre-existing Advance Healthcare Directive.

Under the 2015 Act, an Enduring Power of Attorney does not come into force until the person lacks capacity in relation to one or more of the decisions specified in the Enduring Power of Attorney and the instrument creating the Enduring Power of Attorney is registered with the Director of the Decision Support Service.

Changing or ending an EPA

An unregistered EPA can be changed or ended if the person has capacity – written request signed by 2 witnesses, documentation from attorney, medical and healthcare professional. An attorney can end an arrangement before it is registered by notifying the donor that they wish to do so. If it has been registered, the attorney can only end it with the consent of the court.

Enduring Power of Attorney - Decisions and Eligibility

Nature of decisions: Personal welfare (not medical), property and money matters, or both.

Medical evidence of capacity: Yes (medical and healthcare professional)

Who can be an attorney?

- An adult (18 years and over), known and trusted by the person appointing them. The attorney does not have to be a lawyer.

People excluded:

- Anyone convicted of an offence against the person, their child or property
- Anyone financially insolvent (unless the agreement is only about personal welfare decisions)
- An owner or a registered provider of a designated centre or mental health facility where the person lives (unless they are a relative of the person)
- Anyone convicted of an offence relating to making a false statement in or about an application to make a decision support arrangement
- Anyone convicted of an offence of forcing or pressurising a person to make a decision support arrangement
- Anyone who has been convicted of an offence of ill-treating or willfully neglecting a relevant person

Enduring Power of Attorney - Monitoring and Supervision

- The attorney must submit a written report to the DSS within 3 months of an EPA being registered; assets and liabilities and a projected statement of the donor's income and expenditure.
- The attorney must submit a written report to DSS minimum of every year; details of finances, payments and remuneration to self, any restraint procedures and rationale.
- The attorney must maintain financial accounts including costs and expenses paid to them and make the accounts available for regular inspection by the DSS.
- The DSS may send a general visitor or special visitor to talk to the donor and/or attorney if a complaint has been received. The general visitor or special visitor will report back to the DSS.

What will happen to a current Enduring Power of Attorney?

If a person has already made an Enduring Power of Attorney (under the Powers of Attorney Act 1996) then they can keep that arrangement and it will continue to be valid. The only change is that the Decision Support Service will be able to investigate complaints about an attorney under the 1996 Act. A complaints and investigation procedure will be established under the Amendment Act to deal with cases where there are complaints made over the way in which the attorney is handling the affairs of the donor. For example, this procedure would be used if it is believed the attorney is acting beyond the scope of the EPA, is unsuitable to act or is not giving due consideration to the will and preferences of the donor. The Director of the DSS can also investigate allegations that the attorney is acting in a fraudulent or coercive way or is exercising undue influence. The Director of the DSS can appoint a special visitor, gather evidence, summon witnesses and if required, refer the matter to court for civil adjudication or criminal investigation depending on the circumstances of the complaint made.

If a person wishes to make an enduring power of attorney following commencement of the 2015 Act, they will only be able to do so under the new law. All decisions regarding medical treatment will be removed from the scope of EPAs and will be confined to Advanced Healthcare Directives (AHD).

Decision-making assistant

What is the role of the decision-making assistant?

The Decision-making assistant (DMA) will:

- Advise the person by explaining relevant information and considerations relating to a relevant decision
- Ascertain the will and preferences of the person and assist the person to communicate them
- Assist the person to obtain any information or personal records
- Assist the person to make and express a relevant decision
- Endeavour to ensure that the person's relevant decisions are implemented. The DMA does NOT make the decision

Decision-making assistant - Decisions and Eligibility

Nature of decisions: Healthcare, financial, lifestyle etc.

Medical evidence of capacity: No

Who can be a decision-making assistant?

- An adult (18 years and over), known and trusted by the person appointing them

People excluded:

- Anyone convicted of an offence against the person appointing them
- Anyone who is the subject of a safety or barring order in relation to the person
- Anyone financially insolvent (unless the agreement is only about personal welfare decisions)
- An owner or a registered provider of a designated care or mental health facility where the person lives (unless they are a relative of the person)
- Anyone previously a decision-making assistant for the person but who was removed from that role

What is a decision-making assistance agreement?

- This is a written agreement that specifies the decisions with which the decision-making assistant will help. Signed by appointer, assistant and two witnesses. Sent to the DSS who return a certified copy for a fee.
- There can be more than one assistant but not more than one per decision to be made.
- The agreement can be for a certain period of time, or it can be ongoing.
- The appointer can decide to change the decision-making assistance agreement at any time. Any changes must come from the appointer and not the decision-making assistant. However, the decision-making assistant will need to agree to the changes.
- The appointer or decision-making assistant can end the decision-making assistance agreement at any time. It does not need to be replaced by another type of decision support arrangement.
- If someone else challenges the decision, the appointer can show them the agreement.

Decision-making assistance agreement - Monitoring and Supervision

Decision-making assistants will not be required to send reports to the DSS. The DSS may send a general visitor or special visitor to talk to the appointer if a complaint has been received. The general visitor or special visitor will report back to the DSS.

Co-decision-maker

What is the role of the co-decision-maker?

The co-decision-maker (CDM):

- Will make any decision (specified) together with the individual
- Will advise the individual
- Will ascertain the "will and preferences" of the person
- Will assist the person to communicate their decision
- Will access relevant personal information
- Cannot make any decision about the relevant person to which they object – however the relevant person needs the Co-decision-maker's agreement to make a decision
- Can only exercise veto power where: "it is reasonably foreseeable that such acquiescence or signature, as the case may be, will result in serious harm to the appointer or to another person."
- Will prepare an annual report for the DSS
- Can receive expenses paid from the appointer's estate

Co-decision-maker - Decisions and Eligibility

Nature of decisions: Healthcare, financial, lifestyle etc.

Medical evidence of capacity: Yes

Who can be a co-decision-maker?

- An adult (18 years and over), known and trusted by the person appointing them

People excluded:

- Anyone convicted of an offence against the person appointing them
- Anyone who is the subject of a safety or barring order in relation to the person
- Anyone financially insolvent (unless the agreement is only about personal welfare decisions)
- An owner or a registered provider of a designated care or mental health facility where the person lives (unless they are a relative of the person)
- Anyone previously a co-decision-maker for the person but who was removed from that role

What is a co-decision-making agreement

- This is a written agreement (DSS form) that specifies the decisions with which the co-decision-maker will help. Signed by appointer, co-decision-maker and two witnesses. Submitted within 5 weeks of date of signatures.

- There can be more than one co-decision-maker but not more than one per decision to be made. Therefore, if the person wishes to have different co-decision-makers for different types of decisions, they must appoint them under separate co-decision-making agreements.
- Evidence of capacity from doctor and another healthcare professional to confirm that the appointer is able to enter into the agreement.
- The agreement must be registered with the DSS. The appointer and co-decision-maker must inform certain people (e.g. cohabitant, spouse, adult children, any attorney for the appointer, any designated healthcare representative for the appointer, any co-decision-maker of the appointer under another co-decision-making agreement) about the agreement and provide them with copies of the agreement.

Changing or ending a co-decision-making agreement

- The appointer can change a co-decision-making agreement once it has been registered with DSS for more than six months.
- Minor changes – notify DSS. Major changes – register new agreement.
- The appointer or co-decision-maker can end all or part of the co-decision-making agreement at any time, either before or after it is registered with the DSS.
- The agreement must be ended in writing. If ended by the appointer, then it must also be signed by two witnesses. If the agreement is ended after it is registered, the person who is ending it must notify the DSS, and it will remove all or part of the agreement from the register.

Co-decision-making agreement - Monitoring and Supervision

- Co-decision-makers will have to submit a written report to DSS every year.
- The report must include details of big decisions made together as part of the agreement and will include details of the financial matters related to the agreement, including any costs or expenses. The report must be approved by the appointer.
- If the agreement relates to property and money matters, the report must contain information on all transactions relating to the agreement, for example, the purchase or sale of property.
- DSS may send a general visitor or special visitor to talk to the appointer and/or co-decision maker if a complaint has been received. The general visitor or special visitor will report back to DSS.

Decision-making representative

What is the role of the decision-making representative?

The decision-making representative (DMR):

- Will make certain decisions on behalf of the relevant person – can only make decisions that are listed in the decision-making representation order. They must follow any instructions given by the court
- When making a decision on behalf of the person, the DMR must act in line with will and preference – must make every effort to find out the person's past and present wishes about the decision. Help the person to be involved in the decision making as much as possible
- May have to work collaboratively with another DMR – court may appoint more than one and may require decisions to be made together
- Can receive expenses paid by the court from the estate of relevant person

Decision-making representative - Decisions and Eligibility

Nature of decisions: Healthcare, financial, lifestyle etc.

Process: Application to the Circuit Court by a person with bona fide interest in the relevant person (may be the person themselves). Applying for a DMR is considered to be a last resort and evidence will be sought that all attempts have been made to support the person to make the decision.

Medical evidence of capacity: Yes – assessed by Circuit Court

The Act introduces, as a safeguard, the requirement that the Court should review the capacity assessment every 12 months where there is a possibility that the person may recover capacity and a review every three years in situations where there is no prospect of the person recovering capacity.

Who can be a decision-making representative?

An adult (18 years and over), ideally, known and trusted by the person.

The court will consider several things, including:

- The known wishes of the relevant person
- The relationship and compatibility of the relevant person with a potential decision-making representative
- Ability of a potential decision-making representative to perform the role
- Conflicts of interest

If there is no one suitable to perform the role, the court will appoint a decision-making representative from a panel of experts maintained by the DSS.

People excluded:

- Anyone convicted of an offence against the person appointing them
- Anyone who is the subject of a safety or barring order in relation to the person
- Anyone financially insolvent (unless the agreement is only about personal welfare decisions)
- An owner or a registered provider of a designated care or mental health facility where the person lives (unless they are a relative of the person)

What is a decision-making representation order?

This is a written document which will specify the decisions, attachment of conditions, and the duration of the order. If the court appoints more than one decision-making representative in a decision-making representation order, it will say whether they:

- Must make the decisions in the order together
- Can make the decisions together or separately
- Must make some decisions together but can make other decisions together or separately

Changing or ending a decision-making representation order

The decision-making representation order can only be changed by the court following an application to the court by the relevant person, the decision-making representative or any other person with a genuine interest in the person's welfare.

The decision-making representation order can only be ended by the court if:

- Application by the relevant person, the decision-making representative or any other person with a genuine interest in the person's welfare
- Court decides that the relevant person has regained capacity
- Decision-making representative is unwilling or unable to continue in their role
- The period of time that the decision-making representation order covers has passed

Decision-making representation order - Monitoring and Supervision

- There is no limit on how many people the DMR may represent, nor how often they must meet with the relevant person.
- The DMR will have to submit a written report to the DSS every year. However, the court can stipulate more frequent reports to the DSS.
- Reports will include details of big decisions taken as part of the order including details of the financial matters, including any costs or expenses related to the arrangement.

- If the arrangement relates to property and money matters, the DMR must submit a list of the person's assets, debts, income and expenses within three months. The annual report will contain information on all transactions relating to the arrangement, for example, the purchase or sale of property.
- The Decision Support Service (DSS) may send a general visitor or special visitor to talk to the appointer and/or co-decision maker if a complaint has been received. The general visitor or special visitor will report back to the DSS.

The Decision Support Service

The Decision Support Service (DSS) is a new service for all adults who have difficulties with their decision-making capacity. The Decision Support Service is a public body established within the Mental Health Commission by the Assisted Decision-Making (Capacity) Act 2015. Their job is to register the new decision support arrangements and supervise the individuals who are providing a range of supports to people with capacity difficulties.

Codes of Practice

The DSS has published codes of practice for decision supporters, interveners and relevant professionals, providing guidance for their functions and responsibilities under the Assisted Decision-Making (Capacity) Act 2015. They are available on the DSS website.

Who needs the Decision Support Service?

Any adult who needs support to exercise their decision-making capacity could need the Decision Support Service. This may include, but is not limited to people with an intellectual disability, mental illness, dementia or acquired brain injury, as well as people with age-related conditions. People may require the Decision Support Service when a third party such as a bank, lawyer or hospital questions a person's capacity to make a decision or give consent.

Any person who wants to plan ahead for a time in the future when they may lose capacity could also need the Decision Support Service.

Can the Decision Support Service make decisions for a person?

The Decision Support Service will not make decisions for people. If a person needs help with certain decisions, they may appoint a "decision supporter" to help them. The type of help the decision supporter can provide will depend on the decision support arrangement that is in place. In some cases, the court may ask the DSS to provide a decision-making representative from their panel of trained experts to act as someone's decision supporter. A decision-making representative can only be assigned to a person by a court order.

How will a person access the Decision Support Service?

The Decision Support Service will provide a "digital-first" service. This means that a person will be able to access services through the DSS website. The DSS will provide information and guidance to help a person when using their online services. The DSS will also have an information services team who can help with any difficulties or questions. The DSS understands that using their online service may not work for everyone and will have paper options available for people who need them.

Will a person have to sign up with the decision support service to make an arrangement under the new Act?

A person and their decision supporter will need to set up an account with the Decision Support Service before they register a decision-support arrangement. When signing up, the DSS will require information such as MyGovID, some personal details and contact information. People can register a decision support arrangement with the DSS via the MyDSS portal.

Can someone look at the register of decision support arrangements?

People will be able to search the register if they can show that they have a legitimate interest. Approved persons and organisations, such as banks, lawyers and healthcare professionals will also be able to search the register.

What information will someone be able to access in the register of decision support arrangements?

The DSS will keep a searchable register for the following types of arrangements:

- Co-decision-making agreements
- Decision-making representation orders
- Enduring powers of attorney

If the DSS approve a request to search the register, they will decide whether the person can see some or all of the details in the arrangement. They will also decide whether the person can get a copy of the arrangement.

Approved professionals and organisations will be able to search the register to:

- Confirm that an arrangement exists and is active
- See the details of the arrangement
- Get a copy of the arrangement

Will the Decision Support Service work with adult safeguarding if there is a complaint or allegation about a decision supporter?

If the DSS receives a complaint or allegation of abuse as part of their supervisory and complaints functions, they will escalate this appropriately. It will also be important that organisations that become aware of a complaint of abuse involving a decision supporter, contact the DSS so that they can take appropriate action.

Any person who has a safeguarding concern about an adult at risk should contact the HSE Adult Safeguarding and Protection Team in their area. In an emergency, please contact the Garda Síochana or emergency services.

How to make a complaint

The DSS have the authority to investigate complaints about decision-making arrangements and decision supporters. You will find their complaints form on the forms section of the website, which you can then email or post to them. You can also contact the complaints team on 01 211 9750 or email complaints@decisionsupportservice.ie.

What sanctions will the DSS have if an organisation should fail to recognise or accept an appointed decision supporter, following commencement of the 2015 Act?

If the Director of the DSS receives a complaint that an organisation (such as a bank, utility or government department) has failed/refused to recognise an appointed decision supporter, the Complaints Team would contact the organisation to discuss the matter and, if necessary, explain the provisions of the 2015 Act. Under the 2015 Act, the Director is required to provide information and guidance to organisations and bodies in the State in relation to their interaction with relevant persons and the various tiers of decision supporters. The Director may also identify and make recommendations for change of practices in organisations and bodies in which the practices may prevent a relevant person from exercising his or her capacity under the Act – section 95(i).

The DSS has authority to supervise and regulate the decision support arrangements. There are no sanction or penalties, however, that the Director can directly impose on any external organisation or professional person who fails to recognise a valid decision supporter. However, depending on the response of the organisation, it would be open to the DSS or the complainant to notify the appropriate regulatory body, as this may amount to a breach of the standards and codes that apply to the particular organisation. In the usual way, the regulatory body would be required to examine the complaint and take appropriate action.

It is also worth noting the relevance of the DSS codes of practice in this context. As set out in section 103(14), where it appears to a court, tribunal or body conducting any proceedings that a DSS code/breach of a code is relevant, it shall take that into account in deciding the question before it.

Frequently Asked Questions

What if a person does not have anyone to be their decision supporter?

If a person does not have a person whom they know and trust who is able to be their decision supporter, at the upper tier of support only, the Decision Support Service may be able to nominate a decision-making representative from our panel. A decision-making representative can only be assigned to a person by a court order.

If a person needs someone to help them to access information and explain it to them, they may find it helpful to contact an advocacy organisation.

What will happen in a medical emergency?

If there is a medical emergency, and a person does not have a decision supporter or an advance statement (for example an advance healthcare directive or an enduring power of attorney), a healthcare professional may need to provide the person with necessary treatment without their consent. If the person does have a decision supporter or an advance statement - and the healthcare professional has access to it, they will have to consult the supporter or statement, unless the delay in doing so might cause the person serious harm.

It is important that if a person makes an advance healthcare directive or an enduring power of attorney, which includes their wishes about healthcare and treatment, that they let important people know, like family, friends and general practitioner. In this way, the person can help to make sure their medical wishes are respected even in an emergency.

What will happen to current Wards of Court?

When the new law comes into effect, people will no longer be able to be made a Ward of Court. Any ward of court or someone on their behalf can apply to the wardship court to have their case reviewed.

All current Wards of Court will be reviewed by the wardship court and discharged from wardship within three years after the new law comes into effect. The courts will decide whether a current Ward of Court needs formal support under the new Act.

Frequently Asked Questions

If an adult with an intellectual disability wants to marry, will they be able to?

Adults with an intellectual disability are presumed to have the capacity to make decisions, like everybody else. This includes the decision to get married. This is already the law.

As in every case, the registrar must be satisfied that both adults have the capacity to marry. If necessary, a person with a genuine interest in the adult's welfare will be able to make an application under Part 5 of the 2015 Act to ask the court to declare whether they have capacity to marry. The person who applies to the court could be the registrar.

A decision supporter will not have the authority to consent, or withhold consent, to marriage on a person's behalf. The 2015 Act also repeals a very old law which said that a person could not get married if they were a ward of court. This came into effect in February 2021. This means that a ward of court may now get married if they have capacity to do so.

Can I be on one of the panels??

In March 2022, the DSS conducted an extensive recruitment campaign for the decision-making representative, special visitor and general visitor panels. Recruitment for these panels is now closed, and the DSS is not currently recruiting for panel members. The panel of court friends has not been established at this time. Future recruitment campaigns will be advertised on the DSS website and social media.

How much will it cost to register an arrangement?

There will be fees to register a co-decision-making agreement and an enduring power of attorney. These fees have been set by regulation. You can view a full list of all fees in the resources section of the DSS website.

Some people may not have to pay a fee. This will depend on a person's household income and any dependents that they have. You can view information on the criteria for obtaining a fee waiver as well as the process for applying in the resources section of the DSS website.

There are also costs related to making an application to court to make a decision-making representation order. Some people may be able to get legal aid to help with this, this could include legal representation. For more information on this, contact the legal aid board.

Frequently Asked Questions

Will a person need a lawyer to make an arrangement?

A person will not need a lawyer to make a decision support arrangement. Detailed information on how to make a decision support arrangement will be available on the Decision Support Service website. However, if a person wishes to make an Enduring Power of Attorney under the new law, then they will need a statement from a lawyer that they understand the arrangement.

What rights do family have when it comes to making decisions for a person who faces challenges with their decision-making capacity?

At present, there is no legal basis for a family member or "next-of-kin" to take on an automatic decision-making role or to give or withhold consent on behalf of another adult. Every adult is presumed to have decision-making capacity and may choose whether a family member is involved when they are making decisions. They may also decide whether their information is shared with a family member. Once the 2015 Act has commenced, a person who faces challenges when making decisions may give someone they know and trust, such as a family member or carer, the legal authority to act as their decision supporter.

The person's need for a decision support arrangement will depend on their circumstances and the decisions that they need to make. At the upper tier, where the court appoints a decision-making representative to a person, it will appoint someone known and trusted by them where possible. The court must consider the wishes of the person when appointing a decision-making representative.

Can a family carer apply to be a decision supporter?

For the following types of decision support arrangement, the person who may require support must choose whether to make an arrangement:

- Decision-making assistance agreement
- Co-decision-making agreement
- Enduring power of attorney
- Advance healthcare directive

They must also choose who they wish to appoint as their decision supporter. A family carer cannot make a decision support arrangement for the person or on their behalf. The DSS will provide information for family members and carers who wish to help a person to make a decision support arrangement.

If you believe a person is unable to make certain decisions for themselves, you may ask the court to make a decision-making representation order. The court will decide whether to appoint a decision-making representative for the person and who will act in this role.

Frequently Asked Questions

Will there be someone in the DSS whom family members can talk to if they have any questions or concerns?

Part of the DSS' role is to promote public awareness of the 2015 Act and to provide information about their services. This includes providing information and guidance to people who may use the service and their families. There will be a dedicated information services team in the Decision Support Service to help with any queries and to provide relevant information. You can contact the team on 01 211 9750 or email queries@decisionsupportservice.ie.

Contact Information

Decision Support Service (DSS)

Address:

Waterloo Exchange
Waterloo Road
Dublin 4
D04 E5W7

Telephone:

+353 (01) 211 9750

E-mail:

queries@decisionsupportservice.ie

Website:

<http://www.decisionsupportservice.ie/>

Office of the Wards of Court

Address:

15-24 Phoenix Street North
Smithfield
Dublin 7

Telephone:

+353 (01) 888 6189

E-mail:

wards@courts.ie

Website:

<https://www.courts.ie/assisted-decision-making-capacity-act>

Resources

Starting points:

The Decision Support Service: <https://www.decisionsupportservice.ie/about-us/legislation>

The HSE National Office for Human Rights and Equality Policy:
<https://www.hse.ie/eng/about/who/national-office-human-rights-equality-policy/assisted-decision-making-capacity-act/assisted-decision-making-capacity-act-2015.html>

Information videos:

HSE, A short guide- Explainer video: <https://www.youtube.com/watch?v=xOd72CVcBCA>

HSE, Explainer video: <https://www.youtube.com/watch?v=4WOmSMlknkc>

Sage Advocacy, Introduction to the ADM: <https://vimeo.com/749937447>

Decision Support Service, Detailed Overview Presentation:
<https://vimeo.com/687042822>

Specific resources that might be helpful for families/supporters:

Webinars:

HSE, Webinar focusing on Respecting the rights of the person and the role of families under the 2015 Act: <https://youtu.be/jEuU2RvIPzs>

- Case Studies examined: <https://www.hse.ie/eng/about/who/national-office-human-rights-equality-policy/assisted-decision-making-capacity-act/webinars/case-scenario-for-web-5-respect-the-rights-of-the-person-and-the-role-of-fam-under-the-2015-act.pdf>
- Transcript of the Q&A session: <https://www.hse.ie/eng/about/who/national-office-human-rights-equality-policy/assisted-decision-making-capacity-act/webinars/qa-from-webinar-5.pdf>

Decision Support Service Resources:

- DSS, Online Resources: <https://www.decisionsupportservice.ie/resources>
- DSS, Family Resource Page: <https://decisionsupportservice.ie/news-events/families-and-assisted-decision-making-capacity-act>
- DSS, Information Leaflet:
<https://decisionsupportservice.ie/sites/default/files/2022-03/DSS-DL-leaflet-FINAL.pdf>

Specific resources that might be helpful for families/supporters:

FAQ documents:

- DSS FAQ page: <https://www.decisionsupportservice.ie/faq>
- HSE FAQ page: <https://www.hse.ie/eng/about/who/national-office-human-rights-equality-policy/assisted-decision-making-capacity-act/faqs/>

Wards of Court:

- DSS: <https://decisionsupportservice.ie/services/wards-court>
- Courts Service: <https://www.courts.ie/assisted-decision-making-capacity-act>
- Courts Service, Overview Flowchart Explaining the Discharge of a Ward of Court after Commencement of the ADM:
<https://www.courts.ie/acc/alfresco/41b73eee-2879-430e-8fe8-2068a612ecce/Flowchart%20for%20Wards%20of%20Court.docx/file#view=fitH>
- Courts Service, Detailed Flowchart Explaining the Discharge of a Ward of Court after the Commencement of the ADM:
<https://www.courts.ie/acc/alfresco/57d58031-61f3-4d8e-9505-6430c4a5f952/Flow%20Chart%20Committees%20V1.pdf/pdf#view=fitH>

Glossary of Key Terms

Acronyms and Abbreviations

ADMC	Assisted Decision-Making (Capacity) Act 2015
AHD	Advanced Healthcare Directive
CDM	Co-Decision-Maker
CDMA	Co-Decision-Making Agreement
Director	Director of the DSS
DMA	Decision-Making Assistant
DMAA	Decision-Making Assistance Agreement
DMO	Decision-Making Order
DMR	Decision-Making Representative
DMRO	Decision-Making Representation Order
DSS	The Decision Support Service
EPA	Enduring Power of Attorney
RP	Relevant Person
The Court	The Circuit Court, unless otherwise stated
WOC	Ward of Court

Glossary of Key Terms

Commonly used terms

Advanced Healthcare Directive	If a person wishes to plan ahead, they can make an advance healthcare directive. This lets them set out their wishes regarding treatment decisions in case they are unable to make these decisions in the future. Importantly, it lets them write down any treatment they do not want.
Applicant	An applicant is the person who is making the decision support application, for the benefit of the Relevant Person. The applicant could, in certain instances, be the Relevant Person themselves.
Assisted Decision-Making (Capacity) Act	The Assisted Decision-Making (Capacity) Act (often called "the 2015 Act") recognises that, as far as possible, all adults have the right to play an active role in decisions that affect them. The 2015 Act establishes a new legal framework for supported decision-making. These decisions can be about their personal welfare, including health and social care, and their property and affairs.
Attorney	A person who has the authority from an enduring power of attorney to make certain decisions on your behalf if you become unable to make them for yourself. A person does not have to be a lawyer to act as your attorney.
Capacity	Capacity is a person's ability to make decisions for themselves. This will be based on the person's ability to make a specific decision at a specific time. They must meet four criteria.
Capacity Application	An application to the Circuit Court for a declaration under section 37 of the Act as to the capacity of a Relevant Person.
Capacity Assessment	A capacity assessment looks at a person's ability to make a decision for themselves. The assessment used under the new law is called a "Functional Test" of capacity. This means the assessment is about a specific decision that needs to be made at a specific time.

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Commonly used terms

Capacity Declaration	If the court agrees that a Relevant Person is not able to make certain decisions for themselves, it can state that the person lacks capacity in relation to certain decisions and make an order for suitable arrangements to be made.
Co-decision-maker	A co-decision-maker can make certain decisions jointly with the Relevant Person. The co-decision maker can advise the Relevant Person by gathering and explaining information, helping the Relevant Person in communicating his/her will and preferences and making the decision together. They can also support the Relevant Person to let other people know about the decision.
Co-decision-making agreement	A legally recognised arrangement that a person can make if they are unable to make certain decisions for themselves and require support. It lets them set out the types of decisions they want help with and gives a person they know and trust the authority to make the decisions together with them.
Codes of Practice	The Decision Support Service has published Codes of Practice describing how decision supporters and healthcare workers should act in certain situations to meet their responsibilities under the Act.
Cohabitant	One of 2 adults (whether of the same or the opposite sex) who live together as a couple in an intimate and committed relationship, and who are not related to each other within the prohibited degrees of relationship or married to each other or civil partners of each other.
Court	The Circuit Court will have jurisdiction around most issues relating to the 2015 Act. The High Court will have jurisdiction about certain matters, for example, the withdrawal of life-sustaining treatment or donation of an organ from a living donor.

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Commonly used terms

Court friend	<p>A court friend is a trained person who can support a Relevant Person if there is an application to the Court about their ability to make certain decisions. The Court can appoint a court friend to them if they do not have anyone else to help them with this. The DSS will set up and maintain a panel of people who can perform this role.</p>
Decision-making assistant	<p>The Relevant Person will ask someone they know and trust to act as their decision-making assistant. In doing so this person will assist the Relevant Person in making one or more than one decision in relation to their personal welfare or property and affairs, or both.</p> <p>A decision-making assistant will help the Relevant Person to gather information and will explain it to them. A decision-making assistant can help the person to understand and weigh up their options. The decision-making assistant can also help to let other people know what the Relevant Person's decision is. Decision-making assistants do not have authority to make decisions on behalf of the Relevant Person, their role is simply to assist and aid the Relevant Person in making a decision. The decision-making assistance agreement can be for a certain period of time, or it can be ongoing. A Relevant Person can have more than one decision-making assistant in their agreement.</p>
Decision-making assistance agreement	<p>A legally recognised arrangement that a person can make if they need support to make certain decisions for themselves. It gives someone they know and trust the legal authority to help them, by gathering information and helping them to understand it.</p>
Decision-making order	<p>The Court can make a decision-making order to make a decision on behalf of the Relevant Person where it is satisfied that the matter is urgent or that it is otherwise expedient for it to do so.</p>

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Decision-making representation order	<p>If a Relevant Person is unable to make certain decisions on their own, even with support, the court may appoint someone to make decisions on their behalf. The court appoints this person in a decision-making representation order. The court will try to appoint someone the person knows and trusts. However, if that is not possible, the court can select someone suitable from the Decision Support Service's panel of trained experts.</p> <p>The decision-making representative can only make decisions that are written down in the order and must always consider the Relevant Person's wishes during the decision-making process. If the decision-making representative is from the DSS panel of trained experts, they will be paid for their work. This payment may be taken from the Relevant Person's estate.</p> <p>The Court can appoint more than one person to act as a decision-making representative. The Court decides whether the decision-making representatives must make decisions together or individually. The decisions included in a decision-making representation order and declaration as to capacity of the Relevant Person are kept under review by the Court.</p>
Decision-making representative	<p>A decision-making representative is a person appointed by the court in a decision-making representation order (court order) where the Relevant Person lacks capacity to make one or more specific decisions. The decision-making representative can only make decisions that are written down in the order and must always consider the Relevant Person's wishes. If possible, the court will appoint someone the person knows and trusts in this role. However, if there is no one suitable for the role, the court can select someone suitable from the Decision Support Service's panel of trained experts.</p>

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Decision support arrangement	<p>Decision support arrangement is an umbrella term for the five legally recognised support arrangements that are available under the Assisted Decision-Making (Capacity) Act 2015.</p> <p>Two of these are for the purpose of advanced planning:</p> <ul style="list-style-type: none">• advanced healthcare directive• enduring power of attorney <p>Three are based on the level of support that a person requires to make a specific decision at a specific time:</p> <ul style="list-style-type: none">• decision-making assistance agreement• co-decision-making agreement• decision-making representation order
Decision Support Service	<p>The Decision Support Service is a new service for all adults who have difficulties with their decision-making capacity. The Decision Support Service is a public body established within the Mental Health Commission by the Assisted Decision-Making (Capacity) Act 2015. Their job is to register the new decision support arrangements and supervise the individuals who are providing a range of supports to people with capacity difficulties.</p>
Decision supporter	<p>The Decision Support Service uses the term "decision-supporter" to refer to a person who has been appointed as a decision-making assistant, co-decision-maker, decision-making representative, attorney or designated healthcare representative. The type of support they can provide depends on the decision support arrangement in place. Ideally, a decision supporter will be a family member or trusted friend.</p>

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Designated healthcare representative	<p>If a person is planning ahead for healthcare decisions they may need to make in the future, they will be able to choose a designated healthcare representative. This is written down in an advanced healthcare directive.</p> <p>The designated healthcare representative's role is to make decisions on the person's behalf for the healthcare and treatment decisions written in the person's advance healthcare directive.</p> <p>The person can give their designated healthcare representative the power to interpret their wishes, and to agree or refuse treatment on their behalf, based on what is in the advance healthcare directive. A designated healthcare representative only acts on the person's behalf if they lose the ability to make certain healthcare decisions for themselves. Under the new law, people will be able to appoint someone they know and trust as their designated healthcare representative to ensure their advance healthcare directive is followed.</p>
Discharge Application	<p>An originating application to the Circuit Court for a declaration under section 55 of the Act in respect of a Circuit Court ward.</p>
Donor (in respect of Enduring Power of Attorney)	<p>The person who may lack capacity in the future and gives a general power to an Attorney to act on their behalf. This may be in respect of all or some of the person's property and affairs or to do specified things on the person's behalf.</p>

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Enduring power of attorney	<p>This arrangement gives authority to a person the donor knows and trusts, to act on their behalf should they lose the capacity to make certain decisions in the future. This person is called an “attorney” but does not need to be a lawyer. These decisions can be about personal welfare and property and money matters.</p> <p>A donor can say whether an attorney will have authority to act on their behalf regarding all or part of their property and affairs. They can also give the attorney the authority to do specific things regarding their personal welfare. A person can have more than one attorney and can specify if they have to make decisions together or separately.</p> <p>An enduring power of attorney only comes into force if a person loses capacity to make certain decisions. Under the Amendment Bill, enduring power of attorneys will be registered with the Decision Support Service at the execution of the enduring power of attorney, i.e., when the donor has capacity. The Decision Support Service is then notified when the donor lacks capacity. This is similar to the enduring power of attorney you can currently make under the Powers of Attorney Act 1996. The difference is under the new law, the Decision Support Service will supervise attorneys and make sure they are doing their job correctly.</p>
Expert panels	<p>A panel of trained experts that will be recruited and maintained by the Decision Support Service. The Decision Support Service will have panels of experts who can act as:</p> <ul style="list-style-type: none">• Decision-making representatives• General visitors• Special visitors• Court friends
Guiding Principles	<p>A set of nine key principles set out in the Assisted Decision-Making (Capacity) Act. These principles must be followed by people when interacting with a person who has or may have capacity challenges about a decision.</p>

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Hague Convention	The Hague Convention on the International Protection of Adults is an international agreement that aims to protect vulnerable adults in international situations, for example, where an adult is a citizen of one country but lives in another. Under the Assisted Decision-Making (Capacity) Act 2015, Ireland has appointed the Decision Support Service as its central authority.
Interim Order	Interim orders are temporary orders while the Court makes its decision. They are usually made when there is an urgent issue that needs action while the court process is going on.
Maker	Where any application to the Court under the Act concerns such agreement, power or directive or anything done or not done or purportedly done pursuant to such agreement, power or directive: (a) the decision-making assistant appointer in relation to a decision-making assistance agreement (b) the co-decision-maker appointer in relation to a co-decision-making agreement (c) the donor in relation to an enduring power of attorney or an enduring power under the Act of 1996 or (d) the directive-maker in relation to an advance healthcare directive
Presumption of capacity	A person is always presumed to have capacity. In a situation where a person's capacity is questioned, capacity will be assessed based on their ability to make a specific decision at a specific time.
Prohibition Order	The Director of the DSS can make an application for a temporary prohibition order against a decision-making supporter where there is an immediate risk of harm to the Relevant Person or the property of the Relevant Person.

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Register	<p>The DSS will keep the details of decision support arrangements in a searchable register. Each register will allow certain professionals, organisations and members of the public to confirm whether or not a decision support arrangement exists. In some circumstances, it will also let them access the content of the decisions in the arrangement. The DSS will keep a register of the following arrangements:</p> <ul style="list-style-type: none">• Co-decision-making agreements• Decision-making representation orders• Enduring powers of attorney
Relevant Person	<p>A Relevant Person is the person who the decision support application is being made for. The definition as per the Act is:</p> <p>(a) a person whose capacity is in question or may shortly be in question in respect of one or more than one matter</p> <p>(b) a person who lacks capacity in respect of one or more than one matter or</p> <p>(c) a person who falls within paragraphs (a) and (b) at the same time but in respect of different matters</p>
United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)	<p>An international agreement which aims to protect the human rights and fundamental freedoms of people with disabilities. Ireland has ratified the UNCRPD, which means that Ireland is part of the agreement.</p>

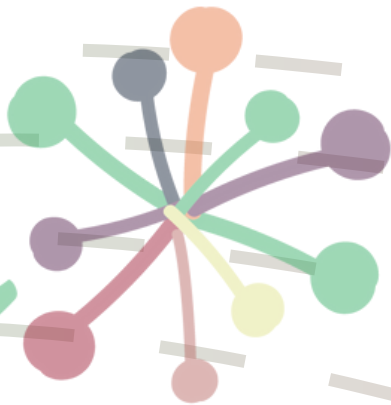
Glossary of Key Terms

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Ward of Court	<p>Previously, if a person was unable to make decisions about their property, money and other affairs, because of capacity difficulties, their only option was to be made a Ward of Court. This was a legal process set out under the Lunacy Regulation (Ireland) Act 1871.</p> <p>An application for a person to be made a Ward of Court was made to the High Court. The courts considered whether the person was of "unsound mind" and "incapable of managing their own affairs".</p> <p>When a person was made a Ward of Court, they were no longer legally allowed to make decisions about their lives. This included everyday decisions.</p> <p>People can no longer be made a Ward of Court. All current Wards of Court are currently undergoing review and will be discharged from wardship within three years. As part of this review, the courts must decide whether a current Ward of Court needs a decision supporter.</p>
Will and Preference	<p>If there is concern that someone lacks capacity to make a decision, it is essential that their past will and preferences are taken into consideration – therefore, what they would have wanted to happen before they lost capacity is of importance. The beliefs and values that that person held will have to influence any decision made.</p> <p>Will incorporates a person's values, personal beliefs, ultimate goals. "Will" carries a stronger sense of determination or planning than "preference".</p> <p>Preference means "a greater liking for one alternative over another".</p>



GHEEL



Information Booklet for Parents and Families of people supported in Gheel Autism Services
Produced by Gheel ADM(C) Committee
August 2023