Inclusion Ireland

The National Association for People with an Intellectual Disability.

The role of family and supporters in supporting decision-making

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Introduction

Decision-making is a natural part of life, and most of us rely on the people we trust when we need to talk something through, weigh up options, or feel more confident about the choices we make.

The Assisted Decision-Making (Capacity) Act 2015 recognises this reality. It does not seek to interfere with the ordinary ways that people with intellectual disabilities may wish to receive support from their families or trusted supporters. Instead, the law aims to protect a person's right to make their own decisions and, where they wish, to have the support of others to help them do so.

However, this can sometimes be an area where people are not fully informed. When there is a lack of understanding about how supported decision-making works, situations can arise where a person's rights are not fully respected — including their right to involve their family members and trusted supporters in decisions about their lives.

For families, supporters, and professionals alike, understanding these rights is essential to ensuring that the person remains at the centre of decision-making.

This guide aims to explain the role that families can play within supported decision-making. It is intended to help families, supporters, and practitioners better understand how the law supports a person's autonomy while recognising the important and valued role that families often have in supporting people to make their own decisions.

Please note this is a guide and not legal or clinical advice

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Introduction to the Assisted Decision-Making (Capacity) Act 2015

The **Assisted Decision-Making (Capacity) Act 2015 (ADMA)** in Ireland is a law that supports adults to make their own decisions as much as possible. It replaces an old system that often took decision-making power away from people with intellectual disabilities without giving the person any support.

The law says: every adult is assumed to be able to make their own decisions. This is referred to as their decision-making 'capacity'. If someone finds certain decisions hard, they must be given support to help them make the decision, rather than having decisions made for them automatically. Support can range from help understanding information, to having a trusted person assist with communicating choices, to formally appointing a decision-making supporter.

For adults with intellectual disabilities, this means more rights, more respect, and more control over their own lives — including decisions about healthcare, money and living arrangements. Their will and preferences must be listened to and taken seriously.

The Role of Families and People Providing Support Under the ADMA

Under the ADMA families continue to play a key supportive role. **The ADMA recognises this role and says that decisions may include the views of those closest to the person and must include the views of anyone the person has asked to be consulted.**

The ADMA can be seen as a tool to support a person to access their rights. Families and supporters often play a really important role in supporting a person to communicate their will and preferences and in turn, access their rights.

Many decisions are supported informally every day. This might look like:

- Talking a decision over with a sibling.
- Demonstrating that we want a parent or family member to attend an appointment with us for moral support.
- Indicating, through how we behave, that we want to have our family or friend included (if we communicate in ways other than using words).
- Supporting a person to communicate their preferences (which can be in a variety of ways).

It may be the person's will and preferences to have their families involved when they are making decisions. Leaving the family out of conversations can be detrimental when it is the person's preference to have them involved.

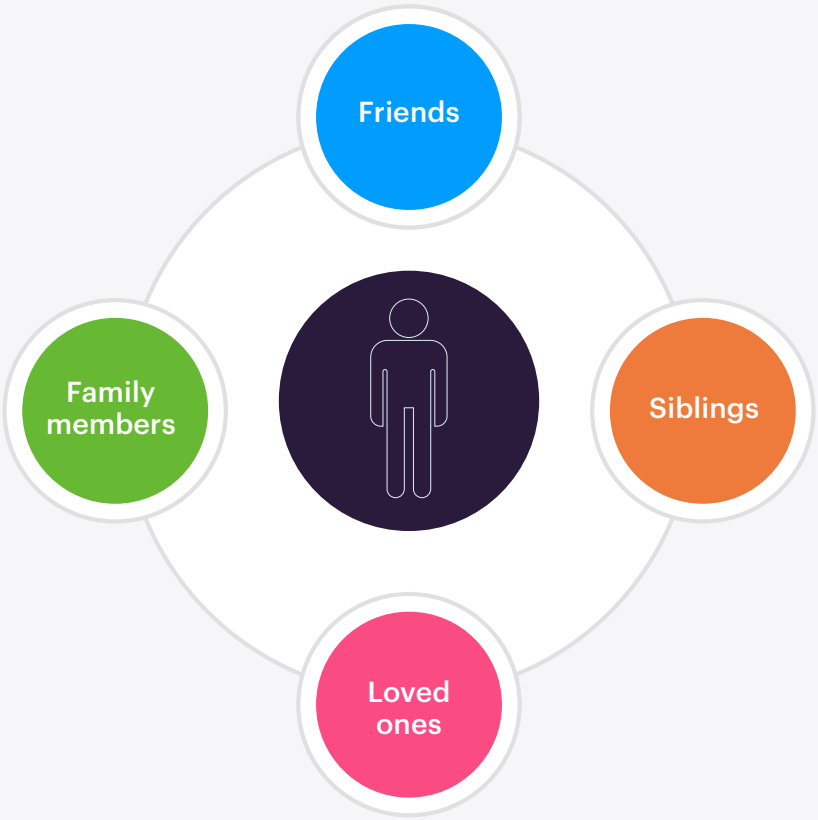
It should be noted that if there is a safeguarding concern or the person indicates verbally (or non-verbally) that they do not want their family or supporters involved, then that should be respected. Family support should be led by the person's will and preferences, including who the person wants involved and in which decisions. If a person wants family or supporter involvement in one decision it does not mean they want them involved for every decision.

Existing ways in which families may support decision making

There are already existing ways in which families may be involved in supporting decision making. Two examples are outlined below: Circle of Support and Health Passports.

Circle of Support

When supporting a person who has an intellectual disability we often refer to a "Circle of Support". The person chooses who is in their circle of support. The person is in the middle, their will and preferences, their wishes are at the centre. It is typical that we all rely on family and friends in our lives and sometimes they can support us in achieving our hopes and wishes. They are often considered part of the circle of support. The ADMA does not interfere with this natural way of working and living our lives – in fact, the ADMA explicitly supports it.



At times, support staff or other parties may be unclear about what their obligations are with the ADMA. Sometimes, the ADMA can be misinterpreted to mean that respecting the person's will and preferences means leaving their support circle out of conversations or that a formal arrangement is needed to include them. In many instances, this is not the case.

The ADMA specifically supports these informal, natural and important aspects of a person's life. **It is all of our responsibility to ensure that we respect the principles and intention of the ADMA.** This includes involving people's natural supports when it is their will and preference to do so.

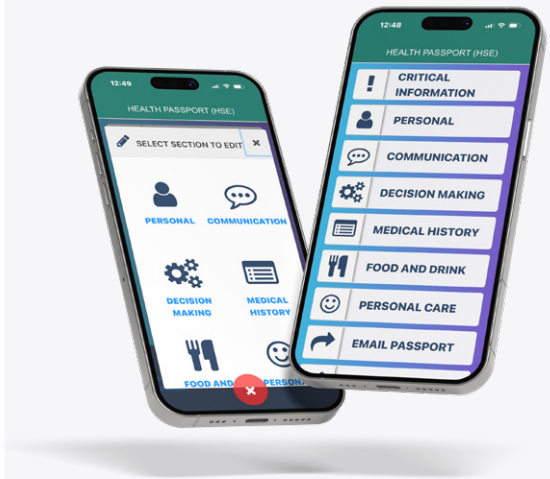
Supporting healthcare with health passports

People with intellectual disabilities and their families sometimes report issues or concerns when meeting health care professionals. It can be a challenge to have the person's voice heard in health care decisions. The HSE health passport is one way to overcome this. People with intellectual disabilities can complete it with the support of their families or supporters in advance of hospital or health care appointments.

It ensures that all the person's preferences about health care are documented. Health passports provide a structured way to record the person's voice and their will and preferences. Sections often include:

- How the person prefers to communicate
- What matters most to the person in care or treatment
- Who should be involved in decisions
- Things that cause distress or comfort

Because the passport is completed with the person and their supporters, it becomes a clear record of their wishes and preferences, which staff can refer to during care planning. People with intellectual disabilities often interact with multiple professionals and services (GPs, hospitals, disability services, nurses, carers). The health passport acts as a shared communication tool that provides essential information quickly to healthcare staff so they can make appropriate adjustments.



Online App version

Easy-to-read version

Click on the images above to go to the HSE Health Passport App download or Easy to Read version

Case Study 1: Jane - Supporting a Person Informally

Jane is a 40-year-old person with an intellectual disability. She is nonspeaking and communicates with facial expression and gestures. Jane is living at home with her parents. She attends a community hub four days a week.

Her family is an important part of her life. The staff in the community hub often notice that when her Dad picks her up, she smiles, laughs and reaches out her hands to him. She has a book she uses to communicate and often points to pictures of her family throughout the day.

Jane has a significant decision coming up. She may be supported to move out of her family home and into a house with three people she knows from the community hub. Jane meets these people every day.

Her family called the community hub to say that Jane really likes two of the individuals but does not seem comfortable with one of the others. The staff in the community hub agree to keep an eye on this as they haven't noticed this issue.

Through careful observation they begin to notice that Jane turns her body away when this individual comes into a room and becomes quieter. Sometimes she becomes a little agitated and makes sounds to indicate she wants to leave the room. This happens consistently over a number of weeks and the staff carefully document Jane's communication.

The staff decide to mention to management that it seems to be Jane's will and preferences that she does not live with this person in future.

This is an example of the person, staff and family working collaboratively to have Jane's rights respected. Even though where to live and who to live with are big decisions, it is clear from knowing Jane that she is expressing her will and preferences about this. No formal arrangement was needed to support Jane to express her feelings, but what was necessary was tuning into what Jane is expressing, respecting her opinion and working with her loved ones collaboratively.

Case Study 2: Chris - Informal Supports

Chris is a young person with an intellectual disability. He has a great sense of humour and loves being around people. He sometimes needs support to communicate but can use some words and has many friends. He is on a work placement programme with a retailer. He lives in a community home with four other people. Chris hates doctors and needles. He has a medical condition which requires frequent trips to the hospital and to his GP Chris had his sister attend the last couple of GP appointments with him. Chris's support staff noted that when she attended, Chris seemed happier and calmer.

The staff show Chris a picture of his circle of support, which includes his mum, his sister, his best friend James, and his key worker, Aisling. They ask him who he would like to support him at the GP appointment. Chris points to his sister, and the staff document this.

Chris's mum calls the centre to say that she will pick him up the following day for his appointment. The staff inform her that Chris has chosen his sister to accompany him. They also explain how they supported Chris to make that decision, how he usually finds GP visits difficult, and how things improved when his sister attended previously.

When Chris attends his appointment, his sister ensures that his will and preferences are respected. She explains that Chris prefers to sit in a certain position when having bloods taken.

The Role of Families in Formal Supports

Formal decision-making support is sometimes needed. Formal support means legally recognised support. Formal supports may become necessary when all informal supports have been carefully tried or there is a problem that needs to be addressed. If there is no problem to be addressed then informal supports continue as usual.

Formal decision-making supports may be necessary where a person's will and preferences cannot be determined and there is a decision the person needs to make.

Where formal support is required, the ADMA provides legally recognised decision support arrangements. These include:

Decision-Making Assistance Agreement

Co-Decision-Making Agreement

Decision-Making Representation Order

The ADMA also provides advance planning arrangements that allow a person to plan ahead for a time in the future where they may not have capacity.

Advance Healthcare Directive

Enduring Power of Attorney

Click on the images above to go to the websites

A family member may be involved in a formal support arrangement by being appointed by the person or by the court as a decision supporter. It is important to note that even if a family member is not appointed in a formal role, this does not mean they will be excluded from the decision-making process or being part of their Circle of Support.

The decision supporter may consider the views of family and friends and must consider the views of anyone the person specifically asks to be involved. Families can also continue to provide the informal supports described above, even where a formal arrangement is in place.

Case Study 3: Michael - Co-Decision-Making Agreement

Michael is a 35-year-old man with an intellectual disability who lives at home with his parents and attends a local day service five days a week. He manages small amounts of spending money independently and understands everyday purchases, such as paying for lunch or social activities.

Recently, Michael's aunt passed away and left him €40,000 in her will. Michael understands that the money belongs to him and that he can use it for things that are important to him, such as future holidays or possibly contributing towards supported independent living. However, he finds it difficult to understand investment options, long-term financial planning, and the potential risks involved in managing a larger sum of money.

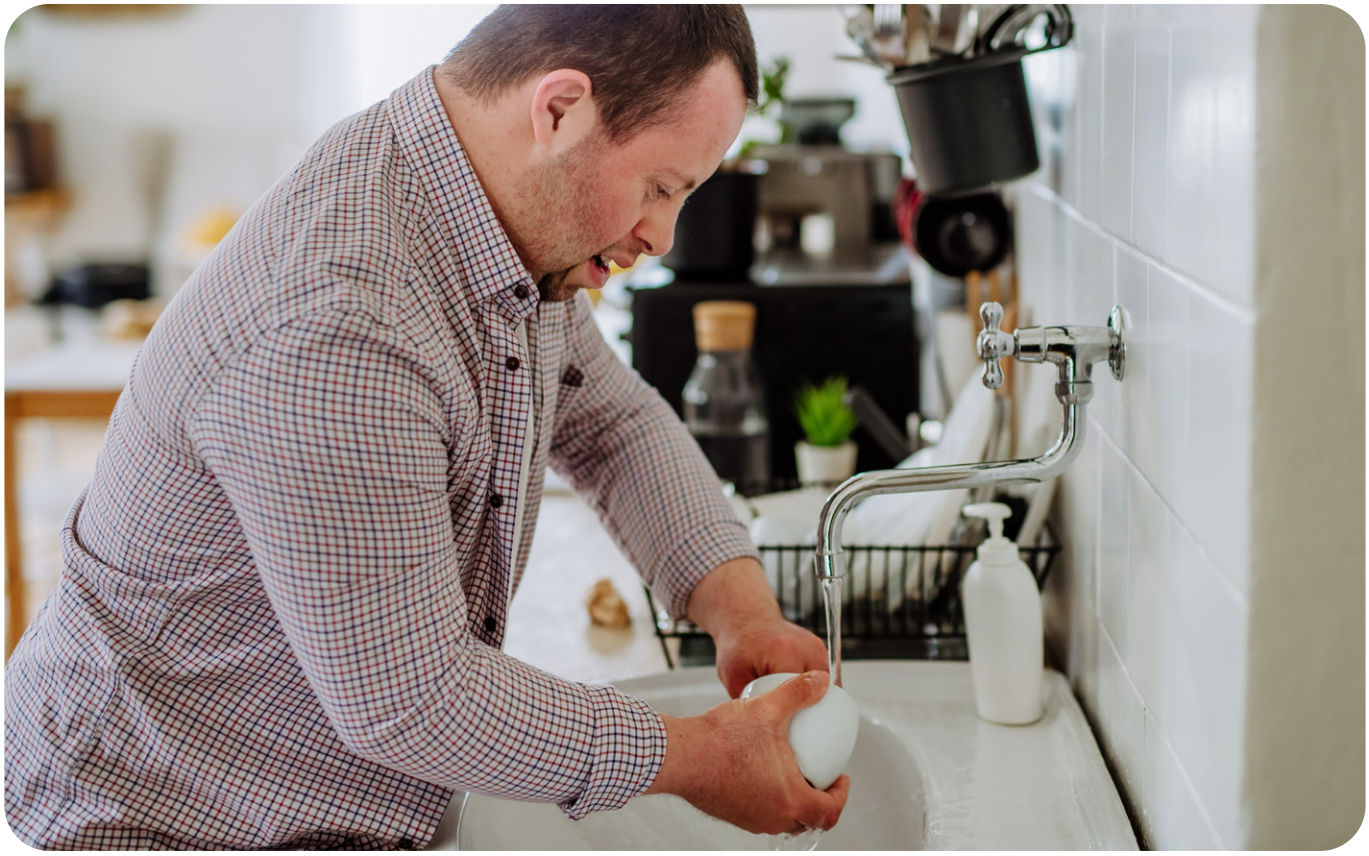
Under the ADMA, Michael and his older sister Maria, whom he trusts, talk about how to help him manage such a large sum of money. They get information about different options and after spending time teasing out the pros and cons they agree that a Co-Decision-Making Agreement would help Michael manage this large sum of money with the help of his sister Maria. They register a Co-Decision-Making Agreement with the Decision Support Service. Together, they review financial advice and make decisions jointly about placing the money in a savings and appropriate investment account.

This arrangement ensures Michael remains at the centre of the decision while receiving the structured support he needs to make an informed financial choice. This is the only decision Michael needs support with so the Co-Decision-Making Agreement only covers those decisions.

Case Study 4: David - Informal Supports Respecting Will and Preferences

David is a 30-year-old man with an intellectual disability who lives with his mother and younger brother. He receives home support and personal assistance. David cannot rely on speech to communicate, is nonspeaking and requires maximum support to express his preferences, using gestures, facial expressions, objects of reference and a communication device.

When discussions began about his long-term living arrangements, professionals considered whether a formal arrangement under the ADMA might be necessary. However, those who know David best – his family, personal assistants, and key worker – worked together over time to support him to explore different options.



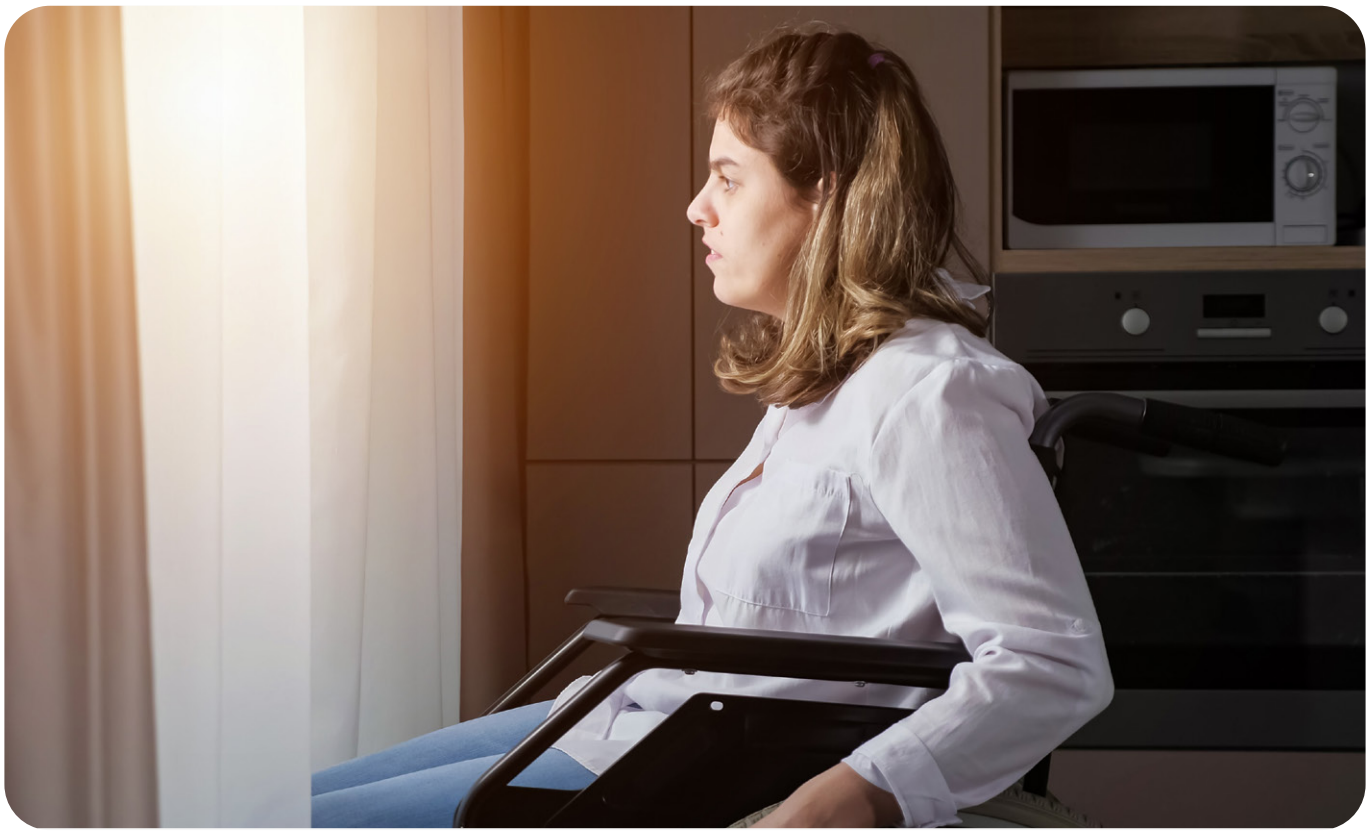
David visited a supported living house where two friends were planning to move. He consistently showed excitement during visits, used his device to select symbols for their names, and became animated when discussing having his “own place.” His positive and repeated responses were clear and consistent across settings.

Through coordinated informal supports, it was clear that David’s will and preferences were to move into his own home with friends. As his wishes could be reliably interpreted using established communication methods, no formal decision-making arrangement was required.

Case Study 5: Sarah - Decision-Making Representative Order

Sarah is a 40-year-old woman with an intellectual disability who lives with her ageing parents and attends a community hub during the week. As her parents' health has declined, the family began planning for Sarah's long-term housing needs.

Initially, every effort was made to support Sarah to express her will and preferences. Staff at her day service used visual aids, social stories, and visits to different supported living options. Family members and an independent advocate spent time discussing choices with her in familiar settings. A Decision-Making Assistance Agreement was considered, but despite sustained support, Sarah was unable to consistently understand or weigh up the information about housing options. Her responses varied significantly and it was not possible to clearly establish a stable preference. The people in Sarah's life did not want to wait until a crisis for the decision to be made about the future.



As no informal supports or less restrictive arrangements were sufficient, an application was made under the ADMA for a Decision-Making Representative (DMR).

The court made a declaration that Sarah lacks capacity to make decisions about her long-term accommodation and appointed her sister as her DMR, with specific authority to decide on Sarah's long-term accommodation, ensuring the decision reflected her known values, past wishes, and will and preferences.

How Services Can Involve Families in Decision-Making

Embedding a supported decision-making approach and including a person's circle of support in decision making, when the person wants their support, is considered good practice in disability services.

The following table shows how services give effect to the ADMA and how families can and should be involved if it is what the person wants.

Good Practice Checklist

Action	Steps
Identify the decision clearly and in good time.	What decision is being made? Is it urgent?
Support communication and understanding.	Use accessible information, plain language, visual supports, interpreters, assistive tools, and enough time.
Ask who the person wants involved. If a person communicates in ways other than words, observe what their will and preferences are and document this. Support and respect their wishes.	Don't assume. Confirm consent to involve family/supporters.
Check legal authority where relevant.	If someone is acting as a formal supporter, verify the arrangement and its scope[1].
Record will, preferences, supports used and outcome.	Notes should show how the person was supported and how the final decision was reached.
Review and escalate only when needed.	If there are concerns about undue pressure, conflict, or inability to proceed lawfully, seek specialist advice and follow safeguarding/ legal pathways.

[1]DSS searchable register includes co-decision-making agreements, decision-making representation orders, and enduring powers of attorney. It does not include decision-making assistance agreements or advance healthcare directives (these need hard-copy verification).

Case Study 6: Tom - Impact of Excluding a Family from the Person's Decision-Making

Tom is a 28-year-old man with an intellectual disability who lives in a residence funded by the HSE and attends a training programme during the week. His sister has always been closely involved in his life and understands his communication style, routines and anxieties.

When the service provider began reviewing Tom's day programme and future living arrangements, meetings were held with staff and external professionals, but his sister was not informed or invited to participate. Decisions were made to transition Tom to a new house and a different day service to "increase independence."

Shortly after the move, Tom became withdrawn and distressed. He stopped attending activities he previously enjoyed and began displaying behaviours associated with anxiety. Staff struggled to understand the triggers.

When his sister was finally spoken with, she explained that Tom finds change extremely difficult without gradual preparation and that he had strong attachments to specific peers and staff. With her input, a revised support plan was developed, reintroducing familiar routines and social connections.

The situation highlighted the importance of including those that know the individuals well, in this case it was Tom's family member. She had vital knowledge of Tom's will, preferences and communication – her exclusion led to poorer outcomes and avoidable distress.

Key Principles Under the ADMA

The following are some key principles under the ADMA that should be applied in both formal and informal support arrangements.

Start from rights and capacity:
Under the ADMA, adults are presumed to have capacity unless shown otherwise, and "unwise" choices do not by themselves prove lack of capacity.

Support first, then assess:
A person should not be treated as unable to decide until all practicable supports have been tried (e.g., plain language, visual aids, extra time, a trusted supporter like a family member or friend).

Capacity is decision-specific and time-specific:
Someone may need support for one type of decision but not another, or at one time but not another.

Use the least restrictive option:
Any intervention must be necessary, proportionate, and as limited as possible, while respecting dignity, autonomy and privacy.

Respecting a person's will and preferences:
Even when a formal support arrangement is in place, the supporter must respect and give effect to the person's will and preferences as far as practicable.

Case Study 7: Aisha - Managing an Emergency Without a Formal Arrangement

Aisha is a 33-year-old woman with an intellectual disability who lives at home with her father and attends a community employment programme. She does not have a formal decision-making arrangement in place, as she is usually able to make her own decisions with informal support from her family.

One evening, Aisha developed severe abdominal pain and was brought to the emergency department. She was distressed and found it difficult to process information due to pain and anxiety. Medical staff needed to carry out urgent tests to rule out appendicitis.

In the absence of a formal arrangement under the ADMA, the healthcare team followed the Act's guiding principles. They supported Aisha to understand what was happening using clear language and reassurance. Her father was consulted to help interpret her usual communication style and known preferences.

As the situation was urgent and Aisha was temporarily unable to engage fully in decision-making, clinicians acted in good faith, providing necessary treatment. Once her pain was managed, Aisha was better able to participate in decisions about her ongoing care with the support of her family.

Case Study 8: June - Right to Make Financial Decisions

June lives in her own apartment with the support of a personal assistant. She works locally and has a large circle of friends.

June has made her wishes clear that she wants to manage her money and finances herself and does not want the support of friends or family to do so.

At times June struggles with managing her budget. Sometimes her brother says that he should take over managing her account. This stresses June out and she gets worried about it.

Her supporters offer to help her learn how to manage things so that she isn't stressed about it. June takes a short course on household budgets and feels it has really helped her.

Case Study 9: Daniel - Using a health Passport

Daniel is a young man with an intellectual disability who attends a number of hospital and clinic appointments throughout the year. Because of his medical needs, he is very familiar with healthcare settings and the many different professionals involved in his care.

Daniel does not rely on speech to communicate. Instead, he uses an AAC device to express his views, make choices, and share how he is feeling. Hospital environments can sometimes make Daniel anxious, especially when appointments move quickly or when there are many unfamiliar people in the room.

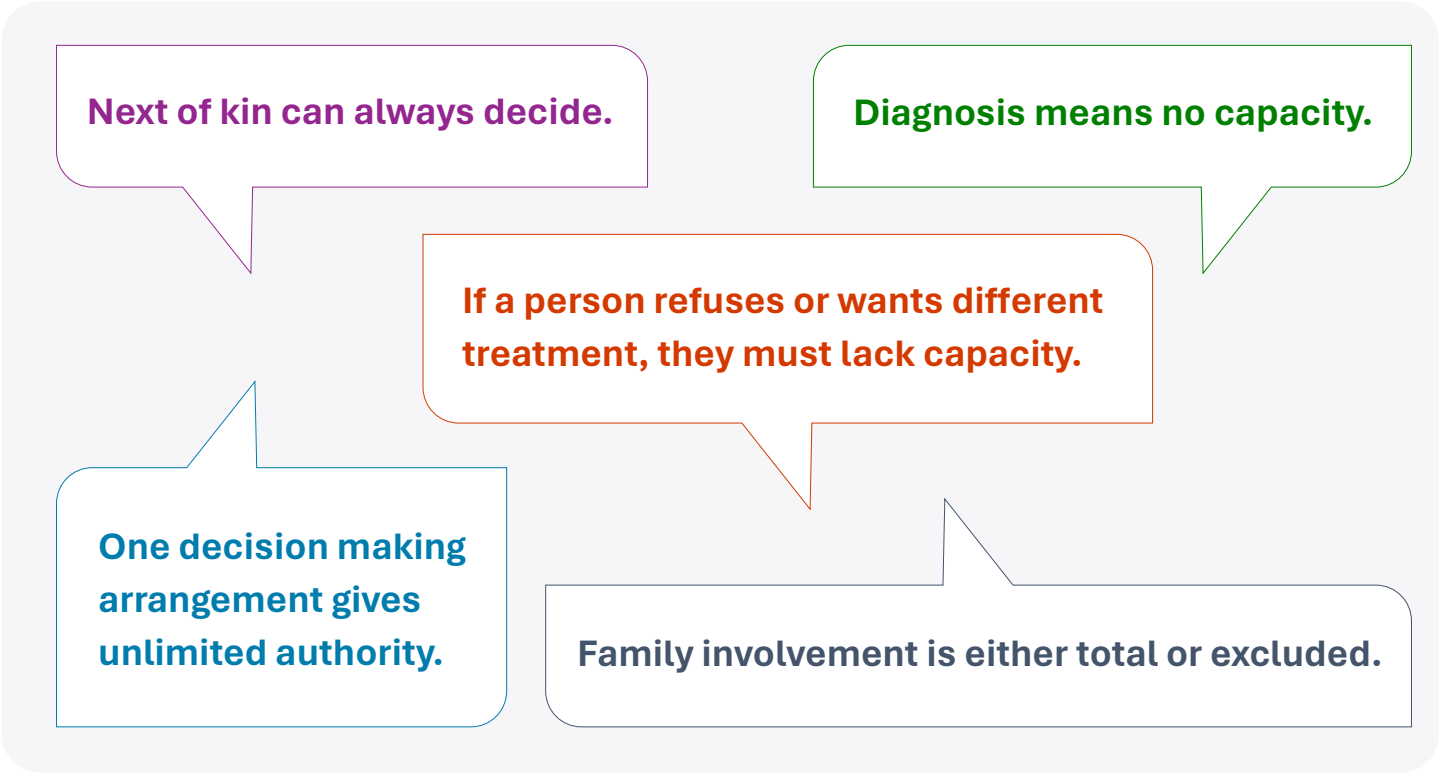
At those times, he prefers to use his health passport. The passport is a short document that explains how Daniel communicates, what helps him feel comfortable, and the ways he shows his likes, dislikes, and preferences. It also outlines how supporters can help him communicate effectively.

At one appointment, Daniel's doctor was unsure about speaking directly with Daniel's mother, as he wanted to make sure Daniel's own voice remained central to the discussion. Daniel's health passport helped guide the conversation.

It explained that Daniel chooses to have his mother support him during appointments and that she helps interpret his communication when he is feeling anxious. Using the passport, the doctor was able to ask Daniel questions, allow time for responses, and involve his mother in a way that focused on Daniel's will and preferences.

The passport helped ensure Daniel stayed at the centre of the decision about his care.

Common Myths to Avoid



Myth	Fact
“Next of kin can always decide.”	No automatic legal authority for adult decisions.
“Diagnosis means no capacity.”	Capacity is decision specific and time specific, with supports provided first. (Section 3 of the ADMA).
“If a person refuses or wants different treatment, they must lack capacity.”	A decision that others see as unwise is not, on its own, evidence that a person lacks capacity.
“Family involvement is either total or excluded.”	Involvement should be tailored to what the person wants, for specific decisions.
“One decision making arrangement gives unlimited authority.”	Authority is arrangement-specific and decision-specific; staff should always check scope.

Frequently Asked Questions

My family member has an intellectual disability; does this mean a formal decision-making arrangement is needed?

Most of the time, a formal arrangement is not necessary. Decision–making should continue to be seen as a natural part of life, involving our own choices and preferences and with the support of our loved ones.

What steps do I have to take now that ADMA is in place?

If the informal supports that are in place are working for the person, then nothing needs to change right now. If that changes or you are expecting changes, talk to a staff member if a person has the support of a service and the Decision Support Service about the options available.

Can a family member make decisions for an adult because they are next of kin?

No. A next of kin has no legal authority to make decisions. However, a person can nominate someone to be contacted in case of emergency or have a named nominated contact person. Formal legal authority is required under a recognised arrangement in some situations. Most of the time the person should and could be supported to make decisions for themselves. A formal arrangement is necessary where there is a significant issue which cannot be resolved informally and with support.

What is the difference between a decision-making assistant and a co-decision-maker?

A decision-making assistant supports the person by obtaining and explaining information, weighing up options and communicating their decision. Importantly the person is the one making their own decision. A co-decision-maker supports the person to obtain and consider information, but also makes specified decisions jointly with the person.

When does the court appoint someone to decide on behalf of a person?

Where all lesser supports are not appropriate an application can be made to court. Following a declaration that the person lacks capacity to make certain decisions, the court can appoint one or more persons to act as a decision-making representative. A decision-making representative makes certain decisions on the person's behalf in line with their will and preferences.

What should we do in an emergency?

In urgent situations, immediate care may be provided by a service where necessary to prevent serious harm to a person, while still respecting known will/preferences and any legal arrangement.

What if my family member is nonspeaking? How can I make sure their will and preferences are respected?

Being nonspeaking does not mean that a person lacks capacity. The person's preferred communication methods must be supported. You can ask service providers to use the person's preferred communication methods, involve trusted supporters whom the person chooses, and document consistent signs of preference so decisions reflect their will and preferences. If the person has a communication passport it is really helpful to make sure to have this with them to improve communication.

What if there is conflict between a service and the family?

Every effort should be made to resolve the conflict, if it is the person's will and preferences to have their family members in their life. Not including the family on the basis of conflict or disagreement may have a negative impact on the person. Sometimes challenging or complex issues may need to be referred to a manager or person in charge. There are times that the person may require an independent advocate.

Independent Advocacy

Independent advocacy can be very important for a person with an intellectual disability. An advocate is there to support a person to communicate their will and preferences and to ensure that their rights are upheld. If there is a concern with decision making or there is conflict between a person and their family or service provider, an independent advocate can ensure that the person's voice is cantered and that people are included in decision making based on the persons will and preferences.

Where to Go for Support

The Decision Support Service

The Decision Support Service is a statutory organisation that promotes the rights and interests of people who may need support with decision-making.

The Decision Support Service:

- promotes awareness and provides information about the Act;
- regulates and registers decision support arrangements;
- maintains a searchable register of decision support arrangements;
- supervises the actions of decision supporters;
- maintains a panel of suitable persons who act as decision-making representatives, special visitors and general visitors;
- investigates complaints.

seirbhís tacaíochta cinnteoireachta
decision support service

Decision Support Service
Click here for further information about the ADMA

- **Citizens Information:** practical public information on ADMA and decision support arrangements.
- **Legal advice:** for court applications, disputes, or complex legal questions.
- **Urgent safeguarding concerns:** follow safeguarding and statutory reporting pathways immediately.
- **Independent Advocacy:** an independent advocate can support the person to have their voice heard and make their will and preferences known. For information about independent advocacy and how to access an advocate, contact the National Advocacy Service (NAS).

Further Reading

Click on the images below to go to the websites

Citizens Information
Assisted Decision-Making (Capacity) Act 2015

Decision Support Service
Further information about the ADMA

Safeguarding Ireland
A Guide to Ireland's New Assisted Decision-Making Law

National Advocacy Service
For information about independent advocacy and how to access an advocate

Look up information on:

Click on the images below to go to the websites

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