Young people who are non-speaking, sometimes speaking or communicate differently and the Assisted Decision-Making (Capacity) Act

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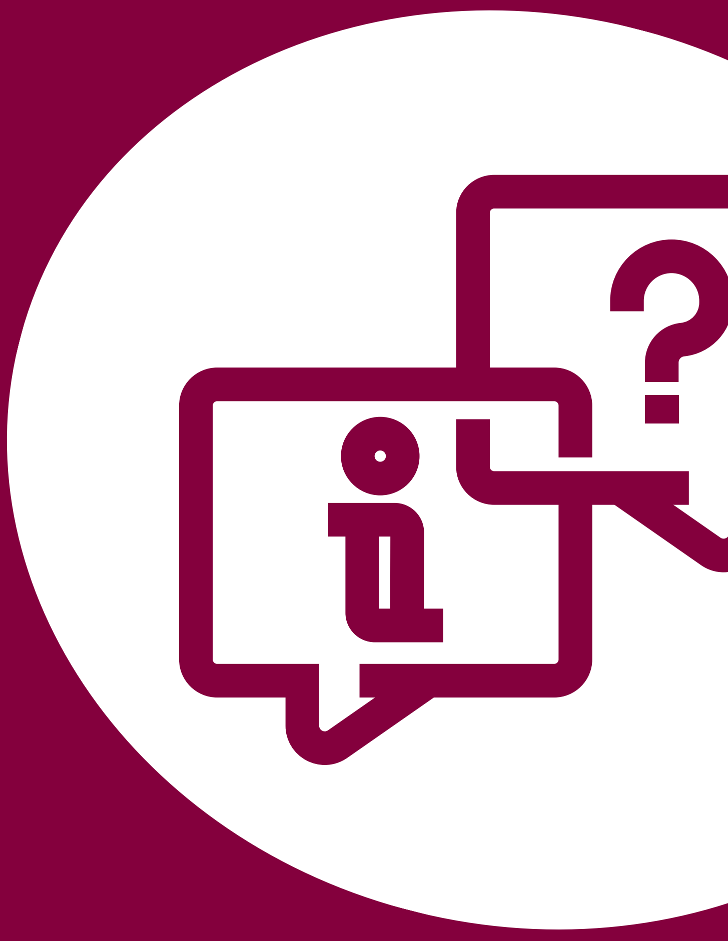
Dr Clíona de Bhailís



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1. Introduction

Disabled people are often denied their right to legal capacity or their right to make decisions with legal consequences. Some groups of disabled people, such as those with cognitive impairments and those who are non-speaking, sometimes speaking or communicate differently[1] may be particularly at risk of having their capacity questioned or denied. The Assisted Decision-Making (Capacity) Act 2015, as amended, made considerable changes to the law regarding the recognition of and denial of legal capacity in Ireland. It introduced formal supported decision-making arrangements into Irish law and placed a functional assessment of capacity, with a requirement to communicate a decision, on a statutory footing. The majority of the provisions under the Act were commenced on the 26th of April 2023.

This research aimed to understand how the Act was applied to young people who were non-speaking, sometimes speaking or communicated differently and document professionals understanding of the Act and its application to this cohort in the first phases of its implementation. This research was completed by Dr Clíona de Bhailís at the Centre for Disability Law and Policy, University of Galway between September 2023 and December 2025. This report provides an overview of the key findings of the empirical research conducted with young people who are non-speaking, sometimes speaking or communicated differently, their supporters and professionals implementing the Act in their practice.

Report Structure

This report has four main sections. The first section outlines the background and context to this research including providing an overview of the key aspects of the UN Convention on the Rights of Persons with Disabilities and the Assisted Decision – Making (Capacity) Act 2015, as amended. It then goes on to outline the approach taken in this research and the methodologies employed to collect data from young people, their supporters and professionals working in the area. Section 3 presents an overview of the key findings from the empirical research completed with young people who are non-speaking, sometimes speaking or communicated differently, their supporters and professionals. Finally, section 4 presents some conclusions and recommendations that can be drawn from this research.

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[1] In this research young people who are non-speaking, sometimes speaking or communicate differently include those who communicate using high or low tech alternative and augmentative communication (AAC) devices such as letters, symbols, pictures or speech generating devices and informal communication such as gestures, vocalisations, facial expressions and body language.

Funding

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2. Background and Context

The UN Convention on the Rights of Persons with Disabilities

The UN Convention on the Rights of Persons with Disabilities(UNCRPD) was adopted in December 2006. The Convention adopts a broad conceptualisation of disability to include those with 'long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others'.[2] Across 50 articles the UNCRPD sets out a range of human rights that disabled people must be afforded on an equal basis with others and was heralded as marking a shift from viewing disabled people as objects of charity or in need of medical treatment and care to subjects with rights and active participants in society.[3] Article 12 of the Convention on equal recognition before the law is viewed by many as central to this shift.

Article 12 UNCRPD sets out that persons with disabilities have a right to legal capacity on an equal basis with others. Paragraph 3 of Article 12 further outlines that States must ensure that persons with disabilities have access to support to exercise this right if they require it. The UN Committee on the Rights of Persons with Disabilities have clarified States Parties obligations under Article 12 in General Comment No. 1.[4] The General Comment clearly sets out that in order to fulfil their obligations under Article 12 States must to abolish all denials of legal capacity that are discriminatory in purpose or affect, including perceived or actual deficits in mental capacity.[5] States must also move from substituted decision-making regimes to supported decision making. The Committee defines substituted decision-making as where a person's legal capacity is removed even if only for a single decision, where a third party can be appointed to make decisions on a person's behalf against their will or decisions are made by a third party based on a person's 'best interests'.[6]

On the other hand while the Committee does not provide a strict definition of supported decision making, they have noted that such systems will be based on the rights, will and preferences of the person, will never amount to substituted decision-making and may

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[2] UN Convention on the Rights of Persons with Disabilities, Article 1.

[3] 'Statement by Louise Arbour UN High Commissioner for Human Rights on the Ad Hoc Committee's Adoption of the International Convention on the Rights of Persons with Disabilities' (*Office of the High Commissioner for Human Rights*, 5 December 2006) <https://www.ohchr.org/en/statements/2009/10/statement-louise-arbour-un-high-commissioner-human-rights-ad-hoc-committees> accessed 16 October 2015.

[4] Committee on the Rights of Persons with Disabilities, 'General Comment No.1 (2014) Article 12: Equal Recognition Before the Law' (2014) UN Doc. No. CRPD/C/GC/1.

[5] ibid 25.

[6] ibid 27.

include both formal and informal support arrangements.[7] Within the broad conceptualisation of support outlined by the Committee they noted that it can include providing assistance for communication including the development and recognition of alternative methods of communication for those who are non-speaking or 'who use non-verbal forms of communication to express their will and preferences'.[8] Neither methods of communication nor the requirement of a high level of support may be a barrier to accessing support under Article 12 and all forms of support, including more intensive or complex support, must be in line with a person's will and preferences.[9] In line with the spirit of Article 12 States are obliged to provide training for individuals who are being supported in decision making to ensure they can decide on the type of support they prefer and when or if they may require less or no support. [10]

Ireland signed the UNCRPD in March 2007 and ratified the treaty in March 2018.[11] In doing so it entered a reservation or declaration in relation to Article 12 which outlines that Ireland understands that both substituted decision making are permitted under the UNCRPD where necessary and subject to appropriate and effective safeguards.[12]

Assisted Decision-Making (Capacity) Act

The Assisted Decision -Making (Capacity) Act 2015 was enacted to bring Ireland in closer compliance with the UNCRPD.[13] The Act was amended by the Assisted Decision-Making (Capacity) (Amendment) Act 2022 and the majority of its provisions did not have legal force until the 26th April 2023.[14] The Act makes significant changes to the law relating to legal and mental capacity in Ireland. This includes the abolition of the Ward of Court system, placing a functional assessment of capacity on a statutory footing and the recognition of formal decision-making arrangements.

The Ward of Court system can be traced back to the Lunacy Regulation (Ireland) Act 1871. A form of plenary guardianship, once an individual was declared a Ward of Court their legal capacity was denied and a Committee of Ward was appointed to make all

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[7] ibid 17.

[8] ibid.

[9] ibid 29.

[10] ibid 24.

[11] United Nations, 'Depository: Status of Treaties - Convention on the Rights of Persons with Disabilities' (*United Nations Treaty Collection*) <https://treaties.un.org/pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4#top> accessed 6 April 2020.

[12] 'United Nations Treaty Collection - Depositary' <https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&clang=_en#EndDec> accessed 8 December 2025.

[13] Department of Justice and Equality, Roadmap to Ratification of the UN Convention on the Rights of Persons with Disabilities (October 2015).

[14] Assisted Decision-Making (Capacity) Act 2015 (Commencement) (No. 2) Order 2023, S.I. No. 193/2023.

decisions on their behalf.[15] Following the commencement of the Assisted Decision-Making (Capacity) Act in April 2023 no new applications for Wardship could be accepted. Existing Wards of Court must have their cases reviewed and will be discharged from Wardship and declared to have legal capacity or placed into one of the new formal decision making arrangements under the 2015 Act.[16]

Under the Assisted Decision-Making (Capacity) Act an individual whose capacity is or may soon be in question may choose to register one of a number of formal supported decision-making arrangements including a decision making assistance agreement or a co-decision-making agreement. The Act also introduces legal recognition for Advance Healthcare Directives[17] and provided new mechanisms for registering an Enduring Power of Attorney.[18] It is envisaged that a family member or trusted friend will undertake each of the roles and places a specific prohibition on those employed by a residential service or centre where a person lives undertaking a formal role.[19] An individual can appoint a decision-making assistant or a co-decision-maker to support them in making decisions regarding personal welfare or property and affairs.[20] While the assistant is limited to supporting the individual in their decision making, as required, the co-decision-maker is tasked with making decisions jointly with the individual.[21] In order to enter into a formal decision making arrangement an individual must meet a number of requirements including be aged 18 years of age or older, agree to and understand the agreement and be in a position to perform their duties under the agreement. In order to register a co-decision-making agreement, the appointer must provide statements from a registered practitioner and another healthcare professional that they have capacity to enter into the agreement.[22]

The Act retains a provision whereby an individual can be declared to lack capacity and in this instance the Court may appoint a decision-making representative to make decisions on their behalf or the Court may make decisions where it is time sensitive.[23] A primary function of a decision-making representative is to, in so far as is practicable, ascertain the individuals will and preferences regarding all decisions that must be made and assist them in communicating their will and preferences.[24] Under the Act capacity is considered decision and time specific therefore, a decision making representative may only be appointed to make decisions in relation to specific topics and orders must

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[15] Anne-Marie O'Neill, *Wards of Court in Ireland* (First Law Ltd 2004).

[16] Assisted Decision-Making (Capacity) Act 2015, s55.

[17] Assisted Decision-Making (Capacity) Act 2015, s84.

[18] Assisted Decision-Making (Capacity) Act 2015, s59.

[19] Assisted Decision-Making (Capacity) Act 2015, s11, 18 and 39.

[20] Assisted Decision-Making (Capacity) Act 2015, s10.

[21] Assisted Decision-Making (Capacity) Act 2015, s17.

[22] Assisted Decision-Making (Capacity) Act 2015, s21(4).

[23] Assisted Decision-Making (Capacity) Act 2015, s38.

[24] Assisted Decision-Making (Capacity) Act 2015, s41.

be subject to review. In line with the Assisted Decision-Making (Capacity) Act, a person will lack capacity if they are unable to understand the information relevant to the decision, unable to retain the information long enough to make the decision, unable to use or weigh the information or communicate their decision to a third party.[25] Communication in this instance is construed very broadly and includes communication by 'talking, writing, using sign language, assistive technology, or any other means'.[26]

Section 8 outlines a number of guiding principles which apply to these and all other interventions undertaken under the Act.[27] These include that an individual is entitled to a presumption of capacity unless the contrary is shown and that an individual cannot be considered unable to make a decision unless 'all practicable steps' have been taken to enable them to do so. In line with the guiding principles an intervenor must 'permit, encourage and facilitate, in so far as is practicable' an individual to participate in a decision and, in so far as they are ascertainable, give effect to the past and present will and preferences of the person.[28] The principles also include the requirement to respect a person's rights to 'dignity, bodily integrity, privacy, autonomy and control over his or her financial affairs and property'.[29]

The Act also provided for the appointment of the Director of the Decision Support Service as part of the Mental Health Commission.[30] The Director of the Decision Support Service is charged with promoting awareness of the Act, providing information to individuals about their options, supervising formally registered agreements and maintaining registers.[31] They also have the authority to investigate complaints in relation to formally registered agreements and may give advice to the Court when called upon.

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[25] Assisted Decision-Making (Capacity) Act 2015, s3

[26] ibid.

[27] Assisted Decision-Making (Capacity) Act 2015, s8.

[28] Assisted Decision-Making (Capacity) Act 2015, s8(7).

[29] Assisted Decision-Making (Capacity) Act 2015, s8(6).

[30] Assisted Decision-Making (Capacity) Act 2015, s94.

[31] Assisted Decision-Making (Capacity) Act 2015, s95.

3. Research Methodology and Approach

This research aimed to explore how the Assisted Decision-Making (Capacity) Act 2015 is applied to young people who are non-speaking, sometimes speaking or communicate differently in Ireland. In doing so it sought to collect data from two groups. Using a multiple case study approach the research aimed to document the experiences of young people who are non-speaking, sometimes speaking or communicate differently and their supporters who were in the process of, or had completed registering, a formal agreement under the Act. Data was also collected from professionals who may implement the Act in their practice including assessing individuals' decision making capacity were using an online survey. The research sought to understand experiences of young people and their supporters in accessing the new formal arrangements under the Act and professionals understanding of the new legislation, its impact on their practice and how it applied to a group that is often excluded or marginalised.

In this research young people who are non-speaking, sometimes speaking or communicate differently include those who communicate using high or low tech alternative and augmentative communication (AAC) devices such as letters, symbols, pictures or speech generating devices and informal communication such as gestures, vocalisations, facial expressions and body language. Before completing the data collection for this research ethical approval was obtained from the University of Galway Research Ethics Committee and a Data Protection Impact Assessment for the project was reviewed by the University of Galway's Data Protection Officer.

Advisory Group

In line with a human rights based research methodology the research had an advisory group which included people who are non-speaking, sometimes speaking or communicate differently, parents of young people who are non-speaking, sometimes speaking or communicate differently, and key stakeholders in the field including a speech and language therapist and representatives of the National Advocacy Service and the Decision Support Service. The advisory group provided feedback on all aspects of the project from the design of the materials and data collection tools to the analysis of the findings. The group met online and, for access reasons, meetings were limited to one hour in duration.

The group, and particularly the advisory group members who were non-speaking, sometimes speaking or communicated differently, provided invaluable feedback on the terminology used in the project in particular. At one of the first advisory group meetings the use of the phrase 'non-traditional communication' in the project's funding application and some of the draft materials was highlighted as potentially value-laden.

Other terms commonly used in the sector such as augmentative and alternative communication (AAC) users were considered. However, the group felt that some may, mistakenly, believe that AAC users only refer to those who use high-tech AAC devices such as iPads, tablets or other speech generating devices and that it was vital that a broad range of communicate styles was represented. The need to ensure part-time AAC users or those who are sometimes speaking were represented in the research was also highlighted by the advisory group. Therefore, the group selected 'non-speaking, sometimes speaking or communicates differently' as a more inclusive and broadly understood descriptor for the cohort of individuals that would be recruited to participate in this research and this terminology was used across all project materials and in this research report.

Recruitment and Data Collection

This research undertook a multiple case study approach to collect data from young people and their supporters. [32] While data was predominately gathered via semi-structured interviews, a 'toolkit approach' was employed which offered the young people and their supporters a range of participation options that would meet their communication and access needs.[33] This included participation via self-reporting (writing or recording their experiences) or interviews supported by photo elicitation, the use of symbols or systems such as Talking Mats. This broad range of options and commitment to accessibility was outlined to the young people and their supporters when the participant information sheets were provided. The researcher then worked with the participants to adapt the interview process to make every aspect of participation as accessible as possible.

Originally, the study set out to complete three case studies and collect data from young people, between 16 and 19 years of age, and their supporters. The first call for participants was shared via the Centre for Disability Law and Policy's national mailing list and across all its social media platforms. The information was also shared with groups representing disabled people, their families, or supporters with a request to share it among their networks. Unfortunately, only one participant agreed to take part in the study at this initial stage and this may be because, as noted earlier in this report, it has since come to light that very few young people (aged 30 years or younger) have formally registered agreements under the Act. To address this issue, the age range for participants was increased to between 16 and 24 years of age and later between 16 and 35 years of age in order to ensure that three case studies could be completed. The

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[32] Joanne Watson, 'The Right to Supported Decision-Making for People Rarely Heard' (PhD Thesis, Deakin University 2016).

[33] Gail Teachman and Barbara E Gibson, 'Children and Youth With Disabilities: Innovative Methods for Single Qualitative Interviews' (2013) 23 Qualitative Health Research 264.

project also initially set out to meet with participants on multiple occasions to document their experiences and any reflections on the process as they progressed.

Ultimately, each of the three case studies was completed following one meeting with the participants. Follow up meetings and the opportunity to provide updates via alternative methods of participation was offered to all participants. However, as they were all at an early stage of the process and often felt they were making very slow progress, none of the participants availed of this option. The small sample size and narrow scope of the engagement for the case studies is acknowledged as a limitation of the research and further research is required. However the findings from this portion of the research are included in this report as they provide key insights into the experiences of an often overlooked or excluded group.

Professionals, working in the Republic of Ireland, from a broad range of backgrounds were surveyed online via Microsoft Forms. The survey, designed in consultation with the Advisory Group, had 30 questions in total spread across four main sections. The first and second sections obtained participant's consent and collected demographic data including age, gender, and professional background. The third section explored professional's knowledge of the UN Convention on the Rights of Persons with Disabilities, the Assisted Decision-Making (Capacity) Act and how the Act was affecting their practice in a general sense. While the fourth and final section explored professional's views and understanding of the Act's application to young people who were non-speaking, sometimes speaking or communicated differently and how they could support this cohort.

Participants for the survey were recruited through sharing a call for participants on the Centre for Disability Law and Policy mailing list, social media and through targeted email to professional bodies, networks of professionals and companies providing professional indemnity insurance. In recognition of the need to share the survey link widely while ensuring the responses collected were genuine and representative, a number of strategies were utilised to deter and identify responses generated by automated software applications or bots including open text box questions and repeated questions. The survey was conducted from September 2024 to January 2025.

4. Findings

Introduction

This research has documented some critical insights into the experiences of individual's receiving or providing support and professionals understanding of and experience implementing the Assisted Decision-Making (Capacity) Act in its first two years of implementation. These relate to the content of the law, the broader cultural or systemic change required to truly implement the Act and the practical challenges encountered when supporting decision making or registering a formal agreement. Each of these themes and findings will be explored in more detail below.

Case Study Participant Profiles

Three young people, aged between 16 and 24 years old, and their supporters participated in the case study research. Profiles of each of the participants can be read below. The names provided are pseudonyms chosen by the researcher and inspired by a fictional characters the young person was interested in.

Thomas

Age: 19

Family: Mum (Emily), Dad (Henry) and 2 brothers - Edward and Gordon.

Communication style: Thomas uses a text to speech app, typing answers to questions or what he wants into his phone or his mother's phone. He doesn't always write full sentences or refer to things in a way that other people, who don't know him well, would understand. He also writes things by hand and uses gestures, noises and body language to communicate.

Interests, Likes and Dislikes: He enjoys watching Thomas the Tank Engine, Tractor Tom and videos on YouTube. He has toy or model trains, and he enjoys organising them into neat rows. He likes taking things apart and helping his Dad on the farm.

Supporters: His family, particularly his Mum and Dad, are Thomas' main support. Mum (Emily) participated in the supporter interview.

School/College/Services: Day Service and an individual support worker for a few hours on Saturday morning.

ADM application: Very early stages of applying for Decision-Making Representative application. Thomas is not involved in the process himself.

Holly

Age: 17

Family: Mum (Lucy), Dad (Derek), 1 sister (Daisy) and a cat (Snowy).

Communication style: Holly uses a Tobii eye gaze computer to communicate. When a supporter holds a finger on either side of her head – each finger representing a different option - she will also turn her head towards the option she would like to choose. She also uses vocalisations and body language.

Interests, Likes and Dislikes: Her favourite TV shows are Peppa Pig and Ben and Holly. She enjoys cooking and baking at school and really enjoys eating good food. She also likes going for walks, being outside and looking at animals. She particularly enjoys watching the wind and on very windy or wild days she loves watching the trees

Supporters: Family are Holly's main support. Mum and Dad are the main supporters. Mum (Lucy) participated in the supporter interview. Poppy, a student, lives with the family and provides a few hours of support daily.

School/College/Services: School

ADM/Transition planning: No plans in place and no resources shared about ADM. From a brief overview of the Act shared by the researcher, Lucy, (Holly's Mum) felt a decision-making representative could be the best option.

Andrew

Age: 24

Family: Mam (Mary) and Dad are separated. Andrew has 1 younger (half-) sister (Amy).

Communication style: Andrew uses some words to communicate. He responds to certain questions and follow-up questions that are phrased in an way that is accessible for him. Those closest to him know the best way to do this. He also communicates using his behaviour, facial expression and body language.

Interests, Likes and Dislikes: Andrew loves lots of different types of music including Bruce Springsteen, Pink Floyd, traditional Irish music, classical and instrumental music. His favourite movie is Finding Nemo. He likes to travel and all kinds of movement. He likes to chill out by swinging on his hammock swing. He loves food, especially chocolate, and enjoys trying new foods. He doesn't like being in crowded places, around a lot of people where he feels he is not being included and being pushed into things he doesn't want to do.

Supporters: His Mam (Mary) is Andrew's main supporter. He also has personal assistants (PAs) that work with him throughout the week. Other family friends or former PAs will also spend time with him and support him from time to time.

School/College/Services: Direct payments that are used to cover the cost of his PAs throughout the week.

ADM application: Very early stages of finding out about or applying for a Decision-Making Representative. Andrew is not involved in the process himself.

Survey Overview and Demographic Information

Of the 268 responses collected via Microsoft Forms for the professionals survey, 259 met the eligibility and consent requirements. 62% of respondents to the survey identified as women and 37% as men. Only 2% selected non-binary or prefer not to say in response to gender identity. The majority of participants (144 responses) were aged between 36 and 55 and were employed in the public sector (156 responses).

A broad range of professional backgrounds are represented in the responses to the survey, a breakdown of which can be seen in the chart below. An open text box, as distinct from multiple choice, was used to collect responses to the question, ‘What is your role/professional background?’. This was used to identify responses from bots or automated software applications and ensure that no professional backgrounds were excluded from the process. As a result the descriptions of roles or backgrounds varied across responses and some respondents noted more than one role. The list below provides an overview of the professions which participated in the survey and responses have been categorised by the researcher for ease of reference. Overall, the survey was completed by professionals in 24 counties across the Republic of Ireland.

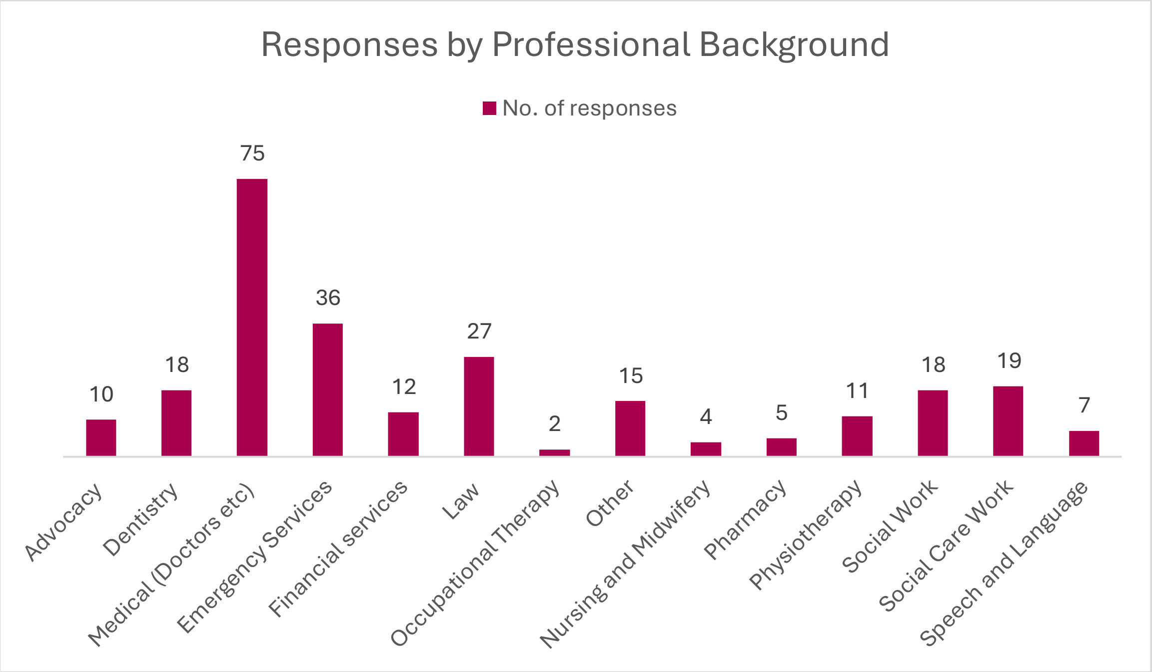

Figure 4.1 Number of responses by professional background

Changes and Challenges Relating to content of the Law

Specific provisions of the Assisted Decision-Making Act and the amendments the Act made to existing Irish law were among the key changes referenced by professionals in response to the survey.

The abolition of the Ward of Court system

Professionals were particularly aware of the abolition of the Ward of Court system and its impact on decision-making in a practical sense. This was referenced in both a positive and negative way by respondents. Some respondents highlighted that young people would no longer be transitioned into the restrictive Wardship system upon reaching the age of majority and others noted its replacement with a tiered system of support.

> *"Young people who would have in the past been Ward of Court turning 18 will not have this overall restriction, we will begin from the belief that the young person has capacity to make decisions on various aspects of their lives but may need some level of support to do so." [SR73 – Aftercare Worker]*

On the other hand many were concerned that, in the absence of Wardship, disabled people would not be adequately protected or that alternative mechanisms without a similar oversight, such as the inherent jurisdiction of the High Court, would be used to address gaps.

> *"Lack of protection without wardship for the most vulnerable service users ie mild id who do not meet the criteria for residential care under the HSE" [SR80 – Social Care Worker]*

> *"Wardship was abolished so coercive orders are made under inherent jurisdiction, nursing home loan is made under 2015 Act, there are proceedings in high court and circuit court for same person" - [SR86 – Barrister]*

> *"End of the ward of court system has meant having to support service users in trying to access appropriate levels of support through the DSS and where necessary inherent jurisdiction" - [SR164 – Psychiatry Registrar]*

Assessing Capacity

The requirement to assess an individual's capacity to make decisions and the guiding principles under the Act which relate to this were also frequently referred to by respondents to the professionals' survey. The requirement for an individual to have a certain level of decision making capacity in order to make a legally binding decision has been a feature of Irish law for many years. The functional assessment of capacity, specifically, has also been a feature of Irish law, particularly in relation to consent to medical treatment, since 2008.[34] However, the findings of this research would suggest that the Assisted Decision-Making (Capacity) Act has placed an increased focus on this requirement. A number of responses to the professionals' survey referred to the challenges that the increased demand for capacity assessments had caused including delays, increased workload, a lack of clarity about when to complete assessments and inadequate training and resources.

"Increased work completing capacity assessments as part of MDT" – [SR26 – Speech and Language Therapist]

"Capacity assessments are over requested. Delays discharge hugely if DMR required.

Too much time spent discussing cases with hospital solicitors" – [SR232 – Doctor]

While professionals understood or referred to the presumption of capacity under the Act, there is some ongoing confusion regarding individuals with certain kinds of impairments or conditions and those who communicate differently.

"Everyone is presumed to have capacity and a diagnosis of dementia or mental health is not a lack of capacity"- [SR3 – Social Worker]

"It created some confusion with those who have cognitive impairments effecting reasoning or judgement on their level of need" – [SR111 – Physiotherapist]

For example, in response to a question on how they would support someone who was non-speaking, sometimes speaking, or communicated differently in their professional practice professionals referred to starting with a capacity assessment.

"Seeking relevant GP/consultant led opinion in capacity" – [SR110 – Solicitor]

"identify their capacity and ask the help of a capacity officer at the work place" – [SR221 – Medical Consultant]

"I would seek professional assessment re capacity and third party appropriate translator. After that I would explore legal route for DMR." – [SR 235 – Gynaecologist]

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[34] Fitzpatrick v F.K. [2008] IEHC 104

Similarly some professionals understood that capacity under the Act was considered decision and time specific. However, no one referred directly to the requirement to take ‘all practicable steps’ to support an individual to participate in a decision before they were considered unable to do so, or before even undertaking a capacity assessment.[35] Some did note taking a human rights based approach to decision making on foot of the Act’s implementation, taking time to communicate with the individual or to the guiding principles in a general sense.

> *“Treating all decisions as separate in terms of supports required and where a trigger is identified for capacity (ie a person may not have capacity to make a decision (supported or otherwise) in relation to finances but they may need no support making a decision in relation to their living situation).” –[SR22 Speech and Language Therapist]*
>
> *“I have incorporated the 9 guiding principles into my practice, I cases where a patient cannot consent to a service/ treatment I am formulating a letter outlining the basis of the treatment in accordance of HSE consent policy.” – [SR 2 – Medical Social Worker]*
>
> *“4 principles. No need to intervene unnecessarily. Least restrictive option*
>
> *Assume capacity.” – [SR96 – Occupational Therapist]*
>
> *“To ensure adequate time is taken to explain Give an opportunity to communicate when there are difficulties Ensure constant communication throughout any intervention” – [SR48 – Civil Servant]*

In the case study research a request for evidence of capacity or the need to complete a capacity assessment was the starting point for two of the three participants’ exploration of the Act. In both cases it would seem that an assessment of capacity overtook the requirement to take all practicable steps to support participation in decision making. In the first case study, Thomas was subject to a capacity assessment to determine if he could make a decision regarding the use of a seatbelt lock while travelling with his service provider. His Mum, Emily, had used a similar device in her own car and noted that Thomas often looked for the lock when he got into the car. This was in her view his acceptance of or consent to the use of the lock. However, as Thomas was over 18 the service noted she could not consent to the use of the lock on his behalf and arranged a meeting to assess his capacity. Emily wasn’t aware of any attempts by the service to support Thomas to participate in the decision before the capacity assessment was scheduled. The capacity assessment meeting was attended by a psychologist, occupational therapist and a speech and language therapist. They had a number of different tools or methods of communication that Thomas could use. However, despite

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[35] Assisted Decision-Making (Capacity) Act 2015, s8(3).

the communication tools available the overall approach and method of questioning was not accessible for Thomas and he was very distressed. Ultimately the team decided that he lacked the capacity to make this particular decision.

“So anyway, get back to my lock..... so the psychologist, occupational therapist and speech service came in. They had their vision board. They had pictures of the [service provider] girls. They had pictures of the lock. I brought the locks in. They had a whiteboard and marker. And Thomas had.. I brought Thomas' phone. So we had loads of methods of communication.” - Emily

“They asked him about, what do you put on the seatbelt? And I think he typed lock. They asked him, showing the lock, and he showed it. And then they asked him about, how does he go to school? I think he typed mammy, you know. So you sometimes you get the right answers. Wasn't wrong either. And stuff about the car, they'd pictures of the car and but they never even got to the stage of asking him, was he happy to use the lock. And at this stage, if Thomas gets into my car, he's there with his hand up for the lock.” – Emily

“So anyway, they asked him a million questions, and they drove him insane. They asked him way too many questions. He ended up hitting his head, crying, screaming, and I hadn't seen that in a long time. I did tell them that ye caused that that that day like but. Anyway, I wanted to say more, but I didn't.” – Emily

Holly’s Mum, Lucy, shared their experience of setting up a bank account for Holly when she turned sixteen so she could receive Disability Allowance. The bank requested proof of Holly’s capacity in order to set up the account and indicated that Holly and Lucy may need to employ a solicitor to create a formal decision making arrangement in order to proceed with the process.

“So I got the doctor to say, you know, I make her decisions, and I would be able to do her bank. She would[n’t] be able to do it herself. And then, then they told me, I needed a solicitor involved. And thankfully, before actually going down that route, I contacted the guys on [independent support service], and they were like, No, you shouldn't have to do that. This was going to cost 1500 or 2000 to do it.” – Lucy

The Assisted Decision-Making (Capacity) Act does not apply to those aged under 18 and therefore, Holly and Lucy could not have created any of supported decision-making arrangements under the Act or applied to the Courts for a decision-making representative order. Despite this the bank’s initial response was to seek a formal declaration of some kind and, similarly to Thomas’ story, they did not seek to understand how they could support Holly to participate in the decision before this request.

The Need for Cultural or Systemic Change

Another recurring issue across the research was cultural change. Both where the Act has positively impacted the broader culture, beliefs and attitudes towards decision-making and where participants highlighted areas where further cultural or systemic change was required to allow for the Act's effective implementation. While the Act has had a positive impact some aspects of an individual's involvement in decision making, participants in both the case study research and the professional's survey spoke of an overall lack of systematic approach in relation to the Act's implementation and the disjointed nature of accessing information in order to get clarity or support.

"Where a person has advised that a family member who holds an account with us has very obvious capacity issues, we have directed these individuals to the Decision Support Service , which is what we were told to do during all initial training sessions with the DSS. These people have all been directed back to us, having been advised that we should have internal policies for handling such circumstances. On the back of this we now risk assess all such members and put our own financial safety measures in place. The support of the DSS for our members has not been what was expected." – [SR150 – Compliance Officer in a Credit Union]

The number of survey respondents which stated that there had been no change to their practice since the Act's implementation or that it was not directly relevant to their work was also noteworthy. This is despite the survey being completed by a majority of professionals who are charged with the Act's implementation. 58 responses to the question, 'List 3 major changes the Assisted Decision – Making (Capacity) Act 2015 had on your professional practice?' indicated there had been no changes to their professional practice, it wasn't applicable or they had not encountered anyone with a formally registered agreement and therefore did not have to apply the Act. It was unclear from many of the responses why this was the case however, some clearly stated a broader reluctance towards the Act's implementation or

"None to date, just having an awareness of it being enacted." – [SR118 – Physiotherapist]

"n/a" – [SR132 – Pharmacist]

"None. No one allows this in my practice." – [SR109 – Social Care Worker]

"Not applicable as I've not read it unfortunately" – [SR155 – Dentist]

"none in mine as I don't have any dealing with anyone who is not permanently unable to make decisions for themselves" – [SR227 – General Practitioner]

Respect for views, will and preferences

Responses to the professionals' survey clearly show that the Act has placed a focus on the voice of the person and at times supported people to develop a new view of disability or disabled people's right to make decisions. This was expressed by professionals in a number of different ways when asked about the major changes the Act made to their professional practice including by referencing the Act's focus on a person's will and preferences in line with the UNCRPD and using rights based language.

> *"1) Respect will and preference, ensuring the persons voice is central. 2) Be mindful of other peoples agendas. 3) Ensure the person is a part of the process." –[SR13 – Advocate]*

> *"The right to be consulted. The right to be heard. The right to me make decisions" – [SR56 – EMT]*

Beyond the concept of will and preferences the Act has also made professionals more aware of their responsibilities in the area or fostered a new outlook on or view of disability and communication. Disability advocates and other professionals, such as speech and language therapists, noted that they were consulted more to support people to participate in decision making.

> *"Other professions are more aware of their responsibilities and are calling on me more and more to assist people record their will and preference, consent and decision making especially people who communicate differently. Increased enquires regarding financial decision making and difficulties that people who communicate differently are experiencing with financial institutions. Increased time spend on researching issues around the act, seeking clarification and explaining the act to other services, ie when and when not the act applies." – [R74 – Disability Advocate]*

Other professionals, particularly those that did not work in 'disability specific' sectors, noted a new outlook or engaging further with disabled people because of their awareness of the Act.

> *"Gave me a new outlook. Acknowledged different forms of communication. Engaged more with the person." – [SR55 – Paramedic Supervisor]*

> *"1 An awareness about individual's rights on decision making.*

2 Awareness this is in law.

3. Makes me reflect more on this area" – [SR104 – Midwife/Lactation Consultant]

Beyond a change to the overall awareness of individual's decision-making rights there was also, to a lesser extent, a shift in thinking regarding how individuals can be involved in a decision from an increased awareness of different forms of communication to providing Easy Read or other accessible forms of information. A handful of professionals also expressed how the Act had altered their understanding of the need for individuals to be in a position to refuse treatment or to make an 'unwise decision'.

"In terms of my work specifically, much more interest from professionals in relation to how they can support a person's understanding and decision making in terms of augmentive communication etc. therefore I am doing significant training in this area." – [SR22 – Speech and Language Therapist]

"Sending information prior to visit including easy read documents if they are helpful." – [SR105 – Senior Physiotherapist in Intellectual Disabilities and Elderly Care]

Training and knowledge of the Act among professionals

Unfortunately, far more responses to the survey noted limited knowledge or awareness of the Act and its implications among professionals, disabled people and family members. 44% of respondents to the professionals' survey said that they had not completed any training sessions on the Act or how it applied to their professional practice. Many of those that had completed some form of training referred to programmes such as HSEland modules or the HSE ADM mentorship programme which are only available to certain health and social care professionals. While others noted having heard about the Act in college or university. Beyond this access to information or training seemed disjointed and varied from independent programmes, internal or bespoke training within organisations to attending webinars hosted by the DSS and the Courts Service. Some participants listed attending one webinar or conference presentation on the topic as their overall training on the Act.

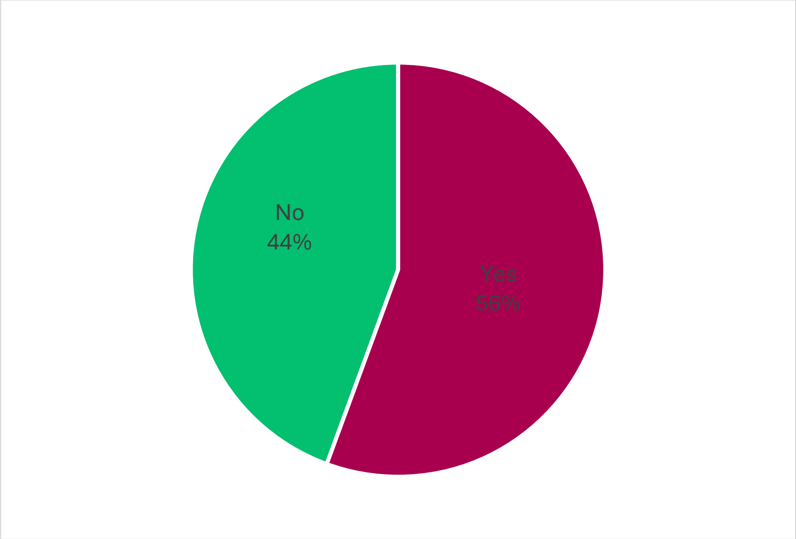

Figure 4.2 Responses to 'Have you attended any training sessions on the Act and how it applies to your professional practice?'

When asked about the challenges they faced in implementing the Act some responses indicating a lack of awareness or engagement with the Act were quite stark. While others cited the lack of knowledge as their main challenge and called for better training on the topic that was practical and broke down legal terminology.

"Not familiar with Act in any capacity" – [SR199- Assistant GP]

"Unwillingness of other disciplines to adhere / apply the act. Disinterest in the act and confusion (myself included) around the act and its implications" – [SR2 – Medical Social Worker]

"Doctors really don't know how the new system works, and the legalistic language is very difficult to understand. Practical examples of how the system should work are needed." – [SR184 – Consultant]

"Not knowing enough about it - definitely need more education!" – [SR7 – General Practitioner]

"Accessing adequate training. Communicating about the act as it's a sensitive topic." – [SR103 – Physiotherapist]

According to professionals the lack of knowledge or awareness of the Act cause tensions, and disagreements mean that outdated approaches continue to be applied.

"Colleague difference of opinion. staff not up to date with current legislation.

Risk adverse amongst staff. Treating adults like children or minors" – [SR 96 – Occupational Therapist]

"Differing viewpoints or traditional/ outdated practice being applied. Poor risk management. Other people's lack of knowledge of the act and it's implications" – [SR65 – Social Care Worker]

"Poor practice by key decision makers (services, family, professionals) with regard to people who are being identified as requiring support under the Act - example not assuming capacity, opting for DMR when co decision or decision making asst would suffice." – [SR12 – Advocacy Regional Manager]

"2. The lack of understanding of the act by other professionals and family members or the lack of the want to invoke the principles of the act

3. Using the ACT to go straight to DMRO applications rather than invoke the principles and test lower levels of decision support options" – [SR 14 – Advocate]

"1. In many ways (as mentioned above) the ADM has made it harder for people living semi-independently to have access to their own funds and belongings as non-healthcare bodies now see it as their duty to challenge peoples' ability to access their own money etc. This means, as a psychiatrist, having to support people through the frustrations of this and having to explain to families that it is not as simple as my writing a letter to say that this person has capacity to undertake a specific action." – [SR164 – Psychiatry Registrar]

Knowledge and awareness among disabled people and their families

The lack of awareness or need for a broader cultural shift was not limited to professionals. Many responses noted the need for increased awareness amongst family members and disabled people. For family members this was often in relation to the traditional decision-making status afforded to them as next of kin. However, the next of kin status did not have legal standing and the Act has increased awareness of the need for the appropriate legal authority to make decisions on another person's behalf. To a lesser extent, responses showed concern that disabled people, particularly people with intellectual disabilities, did not view themselves as having decision making rights and that there were insufficient resources or supports available to help them to develop their awareness.

"no-one support arrangement in place. family still believing they have power to decide treatment" – [SR141 – Dentist]

"Peoples knowledge particularly families, supporting person to make unwise decision, NOK [Next of Kin] feeling they have say over their sibling or child" – [SR5 – Social Worker]

“Families struggle/argue when there choice or decision differs from the PWS. Families struggles when PWS chose to keep decisions they make about their service private.

PWS need a lot of encouragement and reassurance that they have the right and control over their life. I often hear "I dono what my mother would say about it but...."” – [SR39 – Social Care Leader]

“Guiding service users and families. There is a proliferation of information but a simple how-to to my knowledge does not exist. The DSS website is quite good and by in large user friendly but is still quite fragmented. The DSS phoneline is very responsive.” – [SR116 – Senior Social Worker]

Neither of the case study participants had accessed any training or supports in relation to the Act or their role as decision makers and supporters. They observed that it was possible that there were events they had missed due to the large volume of correspondence received and the numerous administrative requirements associated with accessing services and supports. However, they felt that any sessions that were provided whether by schools, organisations or by local Children’s Disability Network Teams would be ad hoc or limited in nature and that there was no transition planning supports or targeted awareness raising aimed at young people and their families who may wish to avail of support options under the Act. This was also reflected in a small number of responses to the professional’s survey.

“You know, there's emails, so many of them. Now I tend, but you know, some of them coming from Holly's school, some of them are relevant, and some of them aren't, and actually they're probably all relevant, you know what I mean, but you can only cope with some many. It'd be great if there was a case worker. Do you know what I mean? That that's really what needs to happen” – Lucy

“It's very strange. It's all very …….. It's like….your child reaches 18 and just everything. that you struggled with past 18 years to try and put in place just falls apart” – Lucy

“2 - it can be difficult to forward plan for young people prior to 18th birthday for a process that can only begin when the young person turns 18, leaving them vulnerable during time of engaging with ADM process 3 - Trying to explain the ADM process to carers/family members of young people - will need to guide them towards the DSS a lot in advance of young person turning 18” – [SR73 – Aftercare Worker]

The supporters that participated in the case study research felt that systems were primarily reactive in nature – considering the Act when someone’s capacity was questioned or a major decision needed to be made – rather than proactively supporting people to create formal decision making arrangements or learn about supported decision making as a practice. Mary also emphasised that young people who were non-speaking, sometimes speaking or communicated differently continue to be overlooked as decision-makers or as potential users of supported decision making.

> *"No, I mean I think for for Andrew. with his high support, I think that that we're very much still in this situation where it's assumed he doesn't make decisions. It's assumed that he's a passive participant in life. It's assumed that whatever, whoever is pushing his wheelchair or whoever is driving his car is the go to person. And Andrew just gets a little tap on the head. And isn't he grand. Really, that's where we are and it's assumed I think by everybody, everybody in society, in the shops, in the surgeries, in.....everywhere, the banks, everywhere that he's just a passive person in a wheelchair, that really is being minded. And I I correct people all the time that when they refer to John or Denis as his carer, I said no, no, they're his personal assistant. There his PAs like. Because they he's still very much seen as somebody that has to be cared for rather than somebody that's an individual in his own right. Oh yeah, not not for Andrew anyway, I can't speak for other people who would have high support needs, but no, Andrew is still very much seen as somebody that's passively existing." – Mary*

The supporters own engagement with, or recognition of their son or daughter's decision-making rights also varied. While many of the supporters spoke about making decisions in line with their son or daughters likes or dislikes or using their likes, dislikes and communication to decide aspects of everyday life this was not always framed as supported decision making or recognised as the use of will and preferences. Some of the young people that took part in the research had lots of choice and control in their everyday lives. However, those supporting an adult believed that their son could not be part of bigger or more complex decision making and that as the parent they would need to continue to undertake this role in their lives. The reasoning for this was different for each individual with some expressing that their son could not make more complex decisions and they needed to protect them. Others framed it in terms of the young person's engagement and interest in the decision with more immediate or day to day issues being more relevant or interesting to the young person they supported. The level of change in the young person's involvement in decision making also varied with some having increased choice or involvement and others staying the same as it was when they were younger.

> *"Like, realistically, Thomas' decisions are so simple. It's like a toddler really. It's about food. It's about places to go. It's about what are you going mommy or daddy? You know, they're very simple, but, like, that's a lot of us too. You probably keep it very simple, but kind of have to. Can't, can't let him make dangerous like, if I gave him decision, are you going to jump in that water or stay on the edge? You probably jump in the water and drown like, do you know? So we have to make the decisions." – Emily*

"So you know, if you said to Andrew. You know, Andrew, you know your car is broken. We need a new car. [Is that] you OK? He'll go. Yeah. What car would you like? He doesn't care. It's just, you know. So yeah, so the bigger decisions, the more that they go outside of his immediate day and his immediate routine, he doesn't have any interest in." - Mary

Practical Considerations and Supporting Decision-Making

The practicalities of supporting an individual's decision-making or the challenges that frequently arose engaging with the processes under the Act was the final theme that emerged in this research. There was a view, both among both the professionals and family members or supporters that participated in this research, that the Act had introduced more complex processes, increased bureaucracy and workload. The difficulties in creating an Enduring Power of Attorney under the Act were commonly referenced in this regard, with the increased need to apply to the courts and engage with legal processes for Decision-Making Representative Orders also specifically referenced by many. These are also the formal arrangements with the highest registration figures according to figures published by the Decision Support Service.

"3. The bureaucracy with decision making assistance which many families/friends had been doing seamlessly before the Act." – [SR16 – Social Worker]

"Slow. Stressful and a lot of work for family.

Some families find it complex" – [SR201 – Medical Consultant]

"Not possible to make an EPA any longer. Parents of children with complex needs feel disempowered without their children being empowered, the system is too procedural" – [SR250 – Solicitor]

Professionals also noted the lack of assistance available to support young people to complete a formal decision making arrangement and that existing information seemed to be focused on older adults which may refer to the focus on Enduring Powers of Attorney. Beyond this there is a view that professionals are spending more time filling in paperwork in order to ensure people have their basic rights respected and that the cumbersome processes were leading to applications for a wide range of orders to avoid the need for further applications at a later stage.

"We do not place applications directly, however we do work with individuals going through the process. It is too complicated for a lot of clients to fully grasp and the different strands are not clearly illustrated. The DSS itself is very geared towards older

> *people and very muddy guidance there relating to younger citizens such as care leavers with ID or complex needs and safeguarding vulnerabilities." – [SR53 – Independent Advocate]*

> *"3. Changes made to how other services interact with service users with ID (particularly e.g. Banks) has meant I spend more time filling out paperwork to try and support people to get access to their own property instead of i.e. actually treating illness." – [SR164 – Psychiatry Registrar]*

> *"There is still paternalism among judges and they are not adhering to guiding principles. They make very broad orders which are not issue specific. They create barriers to RPs exercising rights. Inherent jurisdiction for detention and treatment orders operates parallel to ADMCA 2015. The process is cumbersome and costly so families want to get wide orders "just in case" to avoid coming back to court a second time." – [SR86 – Barrister]*

Emily, Thomas' mother, was at the early stages of applying for a Decision-Making Representative Order and also believed that a broad range of powers would be necessary to avoid future engagement with the process or further capacity assessments for Thomas.

> *"So, I had a read down through them. And I said look, to be honest, it was like either assisting him making a decision. But like, really, if I'm assisting him, I'm going to be telling him. And is that going to be an issue for somebody, you know, if they were watching the decision? Does he? Would he have to go in on his own and tell'em, rather than me, hinting at him, what to say? Yeah. So I just said, Henry, I think we're better off go for the higher level one. I know it's courts and costs and all the rest, but if we have it, you're sorted for when this shit hits the fan. You may never need it, but if we do need it, we need it immediately. So that's really where we I just read them all online. I rang the Decision Support Service just really to back it up. And she did agree that we should go with the higher one, and she didn't really give me any help on where to go, or you know what to do around it, like." - Emily*

Other barriers to supporting people to create formal arrangements under the Act included the Decision Support Service's digital first approach or preference for online applications, the costs associated with applications and the limited availability of legal aid.

> *"Time, cost, use of on line system for epoa" – [SR183 – Consultant Psychiatrist in Old Age Psychiatry]*

"The cost and time associated with implementing a decision making representation order can be prohibitive for customers - especially if they only have smally amount of funds / money in their accounts . Need something more user friendly / flexible for low risk, low wealth situations." – [SR146 – Financial Services]

"A Solicitor led portal should be available. My client base is elderly, do not have access to email or internet. Therefore due to GDPR constraints I am unable to assist them on the digital first approach. Clients also have difficulty attending with relevant social welfare office to have PPN card and id verified l. Clients reside in remotes rural locations." – [SR110 – Solicitor]

Supporting Decision Making in Practice

The survey also sought to capture professional's understanding of how they could support decision making and what barriers they encounter in doing so in their professional practice. The responses to this varied greatly with some professionals showing a detailed knowledge or understanding of support, including how to support people who were non-speaking, sometimes speaking or communicated differently.

"Speak to people who know them best: family, friends, support staff, get to know them, check how others say they communicate on a day to day basis, have they a communications support plan, do they use thumbs up, do they use facial things like smiles, do they use pictures to communicate, get to know as much as possible about the person" – [SR9 – Advocate]

However others had a very limited understanding of how to support an individual or the kinds of communication access needs they may have. They stated that they would seek further information when or if the need arose and at times conflated the access needs of people who were non-speaking, sometimes speaking or communicated differently with individuals who spoke a language other than English including Deaf people who would communicate via a sign language interpreter.

"seek assistance from somebody who is equipped to deal with the situation" – [SR28 – Healthcare]

"Have a registered interpreter who will assist with communication" – [SR197 – Dentist]

"I would seek professional assessment re capacity and third party appropriate translator. After that I would explore legal route for DMR." – [SR235 – Gynaecologist]

The survey highlighted an overall lack of training in this area and a dearth of resources. However, many respondents were open to learning about augmentative or alternative communication methods, with some suggesting that this should be further embedded in professional practice education.

"Be open to interpreting non verbal cues and other forms of communication. I feel it would be helpful if staff had more training in this area and if perhaps we could be taught alternative communication such as irish sign language and/or lámh. We also need to be mindful of our office environment and how it might feel to other people." –[SR242 – Solicitor]

"I could learn some sign language skills to help when a person who has hearing challenges attends the surgery. I can train and improve methods of helping a person who may have anxiety, sensory issues which can lead to lack of communication. It could be included in all health care professional courses and education so we all play a role in improving our way of communication. Teach sign language to all health carers and professionals from the top down. We all play a role in providing care and listening is a huge part of this. Teach everyone how we can all work together in improving our skills to help anyone who has any form of communication challenges. If we all learn together, it should improve care provided, reduce risks of errors and provide better service to all as a result." – [SR206 – Dental Hygienist]

Overall, establishing communication with a person and determining an individual's will and preferences was the most common barrier stated by professionals to supporting people who were non-speaking, sometimes speaking or communicated differently in their professional practice. To overcome this professionals discussed needing to rely on family, friends and supporters in order to communicate with an individual or on previously completed documentation such as a communication passport. However, the limited availability of communication records or support plans was also raised as a barrier by professionals.

"Ask the individual what is the preferred method. Review what is used across the person's daily life such as in day service, respite, home support, with family & friends, review SLT plan in place and link any other people/services who engage with individual. Spent time developing a relationship and using the preferred communicate aid with the individual." – [SR18 – Social Worker]

*"Lack of paperwork.. Unable to reach people who may be the patients nominated person *a hospital passport type form that is always with the person explaining their*

situation and communicating methods would be beneficial" – [SR54 – Advanced Paramedic]*

There were also concerns about family members interpreting communication and this accurately reflecting a person's will and preferences. As a result many professionals felt they would need to have the individual's communication verified by a third party. This was reflected in responses to multiple questions across the survey including a specific question outlining an encounter with someone who was non-speaking or communicated differently, that the professional was not familiar with, and their decision making assistant. The majority of responses to this question stated that they would need to have a third party verify the individual's communication before any decisions could be made despite the individual having a formal decision making arrangement with the supporter that is accompanying them.

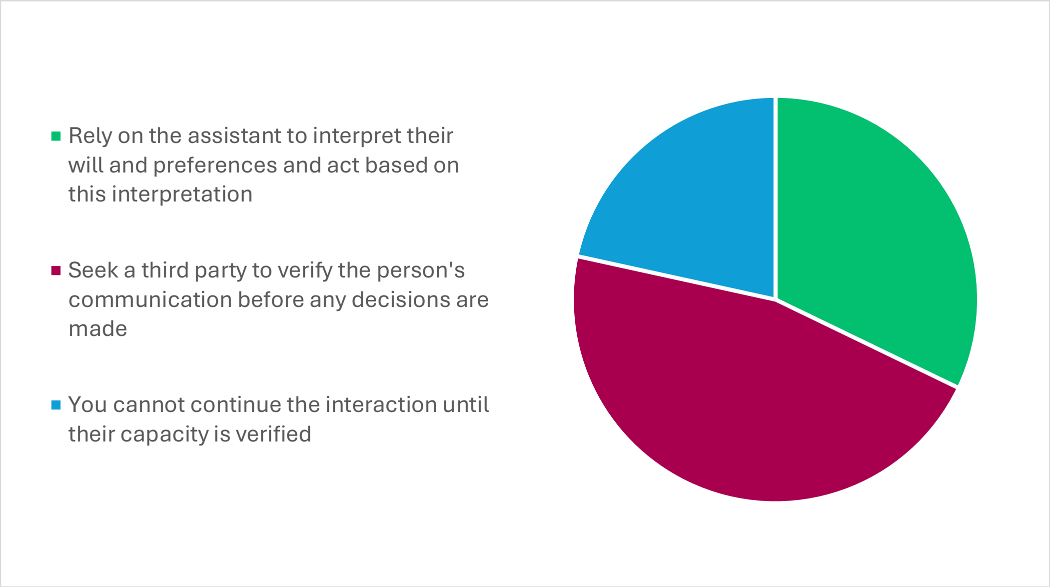

Figure 4.3 Responses to Question 26 on an encounter with a non-speaking person and their Decision Making Assistant

"The biggest barrier is determining what their will and preference is when I have to rely on those close to them to assist them in expressing this/interpreting this. Not all of those (families for example) understand the boundary between what they want for their family member and what their family member really wants." – [SR62 – Social Care Worker]

"find out what method of communication they are more comfortable with and see if there are at least 2 people eg primary carer, doctor, healthcare professional, teacher who can help with the communication." – [SR252 – Solicitor]

The participants in the case study research for this project, and indeed many individuals who are non-speaking, sometimes speaking or communicate differently, would have only a few trusted or close supporters that could interpret their communication well. Therefore, the need for a third party to verify all communication could be a considerable barrier to their engagement in decision making. One survey respondent clearly articulated how professionals felt the need to balance the individual’s right to access support with the need to protect them from

“It is more likely to come from a family member or person supporting who presents as an advocate. If there is no formal arrangement in place, we have to make sure that there is no duress being exerted on the person, while at the same time, making sure that they are being able to avail of the support they want/need. It is a balancing act, which can frustrate the family member/other advocate. Unfortunately, we cannot assume all supports come with good intentions or even wanted. Making sure that they directly have understood the process in full and any consequences.” – [SR150 – Compliance Officer in a Credit Union]

Outside of limited knowledge, training and information time and resources were the other most significant barriers to supporting individuals in practice. Professionals noted having limited time to engage with individuals and support their communication but also the length of time it took to access other supports and how this was a significant barrier in interactions. This was particularly noted by professionals working in healthcare settings who also noted that other support services such as speech and language therapy may not be available in the evenings or at weekends.

“Speech and language therapy can be vital in enabling communication and the shortages and subsequent waiting lists for their services can be a huge barrier.” – [SR32 – Occupational Therapist]

“Healthcare system is under huge strain which results in time and resource constraints. Often such people need a lot of time to facilitate other (often time consuming) communication methods and staff can lack this. Also, a shortage of appropriate and experienced MDT staff to help medical staff in navigating these situations” – [SR234 – Doctor]

“Time. Even knowing they are there, waiting for a prescription as different communication may not be noticed.” – [SR139 – Pharmacist]

“It can take time to build rapport.

Health decisions may need to be made quickly.

Support services often work 9-5.” – [SR210 – Doctor]

Lack of services, limited choices

Finally, professionals discussed the barriers they face supporting an individual in decision making where the limited availability of services or options mean that individuals have limited choices or it is not possible to implement their decision in practice. They also documented how challenging they found it to support an individual with unwise decisions or to ensure that people who were non-speaking, sometimes speaking or communicated differently understood the risks associated with the decision.

"Lack of choice e.g. where to live with support" – [SR113 – Nursing]

"Balancing preference and risk Explaining to care staff the need to respect a person's decision, even if we don't feel it is the right one" – [SR20 – Speech and Language Therapist]

5. Conclusion and Recommendations

Overall, this research has found that, for people who are non-speaking, sometimes speaking or who communicate differently in particular, there remains an emphasis on substituted decision-making options and a considerable lack of knowledge and resources available to support in decision-making in practice. Each of the three case studies in this research centred around the decision-making representative option with supporters stating they felt it was the best or in some cases the only viable option. A continued focus on substituted decision is also evidenced in the registration numbers published by the Decision Support Service which show that of the 6,521 arrangements registered since the Act's commencement in 2023, 1,769 were Decision-Making Representative Orders.[36] This is second only to Enduring Powers of Attorney of which there were 4417 registrations.[37] 12% of the Decision-Making Representatives registered in 2024 were orders from the Wardship Court.[38]

While the exact reasons for this emphasis on substituted decision-making are not clear from the findings of this research, it may be attributed in part to the lack of awareness of the Act and its ethos among professionals, family members and supporters, and an overall lack of training and resources for supporting decision-making in practice. While there are positive changes to the culture in relation to supporting decision making, the research highlighted that these are not sufficiently widespread. International research suggests that when supported decision-making options are introduced in law, there are misconceptions that the most empowering forms of support are only available to people with the lowest support needs.[39] Research also suggests that where countries maintain substituted decision-making options, these remain in focus[40] and are used as a problem solving method especially in situations where people have high support needs.[41] Current understandings of the legislation may be placing an increased focus on the need to assess an individual's capacity before ensuring that all practicable steps have been taken to support an individual. Further, professionals responding to the

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[36] Decision Support Service, Decision Support Arrangement Statistics <https://www.decisionsupportservice.ie/decision-support-arrangement-statistics>, accessed 8 December 2025.

[37] ibid.

[38] Mental Health Commission, Mental Health Commission Annual Report 2024 including the report of the Inspector of Mental Health Services and the report of the Director of the Decision Support Service <https://decisionsupportservice.ie/sites/default/files/2025-06/MHC%202024%20Annual%20Report%20FINAL_0.pdf>, accessed 8 December 2025.

[39] Michael Bach, 'Inclusive Citizenship: Refusing the Construction of "Cognitive Foreigners" in Neo-Liberal Times' (2017) 4 Research and Practice in Intellectual and Developmental Disabilities 4.

[40] Pablo Marshall and others, 'Are We Closing the Gap? Reforms to Legal Capacity in Latin America in Light of the Convention on the Rights of Persons with Disabilities' (2023) 56 Vand. J. Transnat'l L. 119.

[41] Michelle Jennett Browning, 'Developing an Understanding of Supported Decision-Making Practice in Canada: The Experiences of People with Intellectual Disabilities and Their Supporters' (La Trobe University 2018).

survey referred to completing a capacity assessment as a key part of supporting someone who communicated differently and expressed concerns about understanding and verifying their will and preferences. This highlights a need for further education, awareness and resources to support professionals from a broad range of backgrounds to understand how the Act applies to people who are non-speaking, sometimes speaking or communicate differently and how they can support them in their professional practice.

Family members and supporters must have access to information on how to support decision making in practice for people with a range of different support and communication needs. Neither of the family members or supporters who participated in the case study dimension of this research had ever accessed any training about the Act or how to support decision-making in practice. Watson's research highlights the critical role supporters assumptions play in ensuring that people with high support needs can have their rights realised under Article 12 CRPD.[42] Bigby et al. have also shown the importance of building the capacity of decision supporters.[43] This must be undertaken alongside awareness raising and capacity building the decision-makers or disabled people they support and is most effective when supported by broader systemic change.[44] Therefore, it is vital that family members and supporters are provided with the appropriate training and assistance in order to build their confidence to undertake formal supported decision making roles beyond that of a Decision-Making Representative and that disabled people are supported to view themselves as decision makers.

It is also vital that these supports are put in place at an early stage in order to support young people and their families to easily transition to supported decision making. This research highlighted that there is no structured transition support for young people in relation to the Assisted Decision-Making (Capacity) Act. Participants highlighted that many existing resources on the Act seemed to target older people and that the system seemed to be reactive rather than proactive in its approach. Appropriate transition planning would support individuals and their families to document their will and preferences, how preferences can be built into decisions and explore a range of options under the Act beyond a Decision-Making Representative.

Finally, while this research has documented key insights into the Act's implementation in its first two years, further research is required to truly understand the experiences of

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[42] Joanne Watson, 'Assumptions of Decision-Making Capacity: The Role Supporter Attitudes Play in the Realisation of Article 12 for People with Severe or Profound Intellectual Disability' (2016) 5 Laws 6.

[43] Christine Bigby and others, '"I Used to Call Him a Non-Decision-Maker - I Never Do That Anymore": Parental Reflections about Training to Support Decision-Making of Their Adult Offspring with Intellectual Disabilities' (2021) 0 Disability and Rehabilitation 1.

[44] ibid.

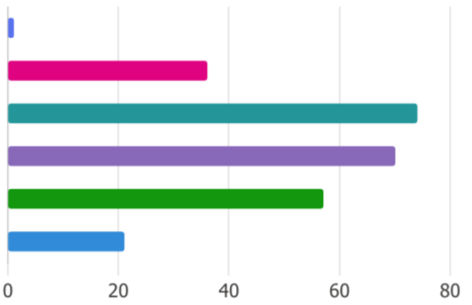
people who are non-speaking, sometimes speaking or communicate differently registering a formal arrangement under the Act and the cultural and systemic change required to ensure it is implemented in a way that maximises and promotes their human rights.

Appendices

Demographic Information

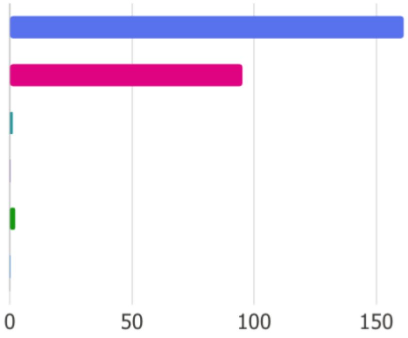
3. **What age are you?**

● 18 – 24	1
● 25 – 35	36
● 36 – 45	74
● 46 – 55	70
● 56 – 65	57
● Over 65	21



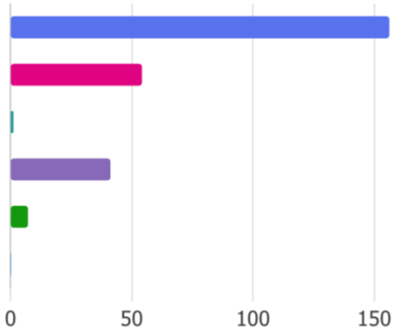
4. **What gender do you identify with?**

● Woman	161
● Man	95
● Non-binary	1
● Genderqueer	0
● Prefer not to say	2
● Other	0



7. **What is your employment status?**

● Employed in the public sector	156
● Employed in the private sector	54
● Student	1
● Self-employed	41
● Retired	7
● Unemployed	0



Profession/Professional Background	**No. of responses**
Advocacy (including Advocate, Disability Advocate, Advocacy Manager)	10
Dentistry (including Dentist, Dental Hygienist, Dental Associate, Dental Nurse and Orthodontist)	18
Doctor (including GP, Medical Practitioner, Medical SHO, NCHD, Registrar, Consultant, Psychiatrist)	75
Emergency Services (including EMT, Paramedic, Advanced Paramedic, Fire Service)	36
Financial services (including Banking, Credit Union and Post Office)	12
Law (Solicitor and Barrister)	27
Occupational Therapy	2
Other	15
Nursing and Midwifery	4
Pharmacy	5
Physiotherapy	11
Social Work	18
Social Care Work	19
Speech and Language	7

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