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Enhancing supported decision-making skills amongst health and social
care staff in Ireland and the adult service-users with
disabilities they support

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Abstract

Introduction

Decision-making capacity legislation has changed fundamentally in Ireland since 2023 with the Assisted Decision-Making (Capacity) Act 2015 (ADM). Under ADM, all adults are presumed to have capacity, unless proven otherwise. Therefore, the onus is on health and social care organisations to respond quickly, by training health and social care professionals (HSCPs) to implement the required ADM changes and prepare service-users for supported decision-making.

Methods

This research aimed to explore (i) HSCPs' knowledge and understanding and barriers and facilitators, to ADM-implementation with adult service-users with intellectual disabilities; and (ii) service-user barriers and facilitators to engaging in supported decision-making. 118 HSCPs were surveyed about their knowledge, understanding and perceived barriers and facilitators to ADM-implementation. Data was analysed using content analysis and descriptive statistics. Service-users (N=16) participated in focus groups to explore their barriers and facilitators to engaging in supported decision-making. Data was analysed using Reflexive Thematic Analysis. Both studies were conducted in an Irish disability organisation.

Results

Survey results indicated the top three barriers to ADM-implementation were lack of family ADM-awareness, service user's not knowing what options were available and lack of service-user knowledge of how to make decisions. The top 3 facilitators to ADM-implementation were strong leadership, effective communication skills and being skilled in helping the service-user weigh up the information about the decision. Three identified themes in the focus group data were: *Intrinsic factors affecting independent decision-making*; *Social influences effecting decision-making* and *the which, who, how of supported decision-making*.

Conclusions

Gaps exist in the ADM-knowledge and understanding of HSCPs and service-users require training to engage in supported decision-making. Results of both studies inform the design of training interventions for HSCPs and service-users.

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I dedicate this thesis to my best friends in the world, Mark and Maya x

Declaration

I declare that, except where explicit reference is made to the contribution of others, this thesis embodies the results of my own research and was composed by me.

This thesis has not been submitted for any other degree at the University of Stirling or any other institution.

Signature:

A handwritten signature in blue ink, appearing to be 'SM Allen', on a light-colored background.

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Suzanne Martina Allen

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List of Abbreviations

Abbreviations	Meaning
ADM	Assisted Decision-Making (Capacity) Act 2015
AWI	Adults with Incapacity Act Scotland (2000)
HCPs	Healthcare professionals
HSCPs	Health and social care professionals
HSE	Health Services Executive
ID	Intellectual disability
MCA	Mental Capacity Act (England and Wales) (2005)
MCA-NI	Mental Capacity Act (Northern Ireland) (2016)
NRAC	National Representative Advocacy Committee
RTA	Reflexive Thematic Analysis (Braun and Clarke, 2006; 2019)
SDT	Self-Determination Theory (Deci and Ryan, 1985)
TDF	Theoretical Domains Framework (Cane et al., 2012)
UNCRPD	United Nations Convention on the Rights of People with Disabilities (2006)

Chapter 1: Introduction

1.1 Background

Decision-making is a cognitive process we engage in daily, from small decisions such as what to eat or wear to big, consequential decisions such as buying a house. Most people enjoy the right to tackle all these decisions on their own because they are deemed to have ‘decision-making capacity’, henceforth referred to as ‘capacity’. Capacity can be defined as “the ability to understand, at the time that a decision is to be made, the nature and consequences of the decision in the context of the available choices at that time” (Inclusion Ireland, n.d.).

A person’s capacity may be questioned due to intellectual disability (ID), degenerative conditions, or older age. As a result, a person may require additional support to make certain decisions, such as those related to their health. Historically, there have been changes in how the capacity and rights of adults with ID were viewed. Upon commencement of a new capacity law in Ireland in April 2023, the Assisted Decision-Making (Capacity) Act (2015) (ADM), adults with ID enjoy enhanced rights to the presumption of capacity and the right to be supported to make their own decisions. It is envisaged that ADM will force significant increases in the control that adults with ID have over their lives, which will require the health and social care professionals (HSCPs) who support them, to adapt their approach. This thesis explores what would help (facilitators) and hinder (barriers) adults with ID and HSCPs to implement the necessary changes that ADM requires. This section provides an overview of the former and current Irish capacity laws, how they evolved with the changing landscape of human rights conventions and implications for practice.

Ireland’s former capacity legislation: Lunacy Regulation (Ireland) Act 1871

Under the Lunacy Regulation Act (1871) an adult could be presumed to lack capacity for the reasons mentioned above and capacity was seen as static i.e. if someone was deemed to lack capacity for one decision, they were deemed to lack capacity for all decisions, for the rest of their lives. In these cases, an adult was deemed a ‘Ward of Court’ by the High Court, and all decisions were made for them by family and HSCPs in their ‘best interests’, up to and including depriving them of their liberty by placing them in residential care (Curtis et al., 2022). ‘Best interests’ is a legal and ethical standard that requires that any action or decision made on behalf of a person who lacks capacity must be in their ‘best interests’.

Use of the ‘best interests’ principle became increasingly challenged after the ratification of the United Nations Convention of the Rights of Persons with Disabilities (UNCRPD, 2006).

This convention enshrines a decision-making process based entirely on the person's 'will and preference', which considers their values, beliefs, goals and liking for one option over another, as opposed to what family or carers think is best (Donnelly, 2016). The Lunacy Regulation Act 1871 was repealed with the commencement of ADM in 2023.

Ireland's new capacity legislation: Assisted Decision-Making (Capacity) Act 2015

ADM was signed off by the President in 2015, and it commenced in April 2023. In the pre-commencement period 2015-2023 studies explored what impact ADM *would have* on practice and these are described below. Under ADM, all adults aged 18 and over, are presumed to have capacity to make their own decisions, with support, if necessary, unless proven otherwise. ADM represents a significant shift in practice away from 'best interests' towards 'will and preference', where the beliefs and values of the person are the *only* considerations in decision-making.

The purpose of 'will and preference' is to facilitate the individual to participate as much as possible in decision-making. Establishing a person's 'will and preference' involves consulting with them but also with anyone the individual suggests. Even if the individual, despite support, lacks capacity to provide or refuse consent, for any intervention, their will and preferences remain important, and HSCPs should, act in accordance with this when deciding whether to proceed or not with an intervention (ADM, 2015). ADM, therefore, aims to give individuals greater control over their lives and as such, Ireland is now compatible with the UNCRPD. See Table 1 for a comparison of these laws.

As Table 1 shows, the principles of 'best interests' and 'will and preference' have different implications for how HSCPs should approach their interactions with people whose capacity may be questioned. In practice this means, instead of HSCPs making decisions for adults with ID, they must support the adult to make their own decisions. They do this by presuming capacity and providing the individual with information about the decision in accessible and inclusive ways (like text, videos, conversation, pictures etc.) for as long as needed. HSCPs then check the person's understanding using the functional test of capacity which is a set of three questions stipulated under ADM. This functional test is used for healthcare decisions, financial decisions, or any other matter where capacity may be questioned and is now a statutory requirement under ADM, see Table 2.

Table 1

Comparison of the principles of Ireland's former and current capacity laws

Lunacy Regulation Act 1871	Assisted Decision-Making (Capacity) Act 2015
A person could be presumed to lack capacity by health and social care professionals (HSCP) or families, due to age, disability, a degenerative condition or communication needs.	Everyone has the right to the presumption of capacity, and the right to access decision-making support.
Capacity seen as static - if a person lacked capacity, it was permanent across all decisions.	Capacity is dynamic - applying to one decision, at one time.
Under the presumption of lack of capacity, the 'best interests' principle could be legally applied by family of HSCPs.	Where a person has difficulty reaching a decision, the principle of 'will and preference' must be applied by family and HSCPs. The right to make an unwise decision is upheld, i.e. a person cannot be presumed to lack capacity by means of making a decision, that some deem unwise, provided the person demonstrates understanding via a functional test of capacity.

Table 2*Assisted Decision-Making (Capacity) Act 2015 Functional Test of Capacity*

Step	Question
1.	Can the person understand the options they have, about the decision to be taken?
2.	Can the person weigh up the pros and cons of the options, retaining the information long enough to make a decision?
3.	Can the person communicate their decision (verbally or non-verbally)?

For example, if an adult with ID was deciding whether to attend a cervical smear, HSCPs must follow the steps in Table 3. This test focuses on one decision at one time, and a person can have capacity for one decision but not another, called ‘dynamic capacity’ (ADM, 2015). This reflects capacity in the general population, i.e. while there are many decisions we might easily make independently, there are others we seek support for, like housing. For example, the woman in the example below may face a future decision for which she fails the functional test. In that situation, HSCPs must consider the woman’s ‘will and preference’ and then make the decision that *the woman would make* for herself, if she could. This is how the principle of ‘will and preference’ is applied, see Table 3.

Comparison of Ireland’s current capacity law and those of nearby nations

Table 4 compares capacity legislation across the Republic of Ireland, Northern Ireland, Scotland, England and Wales. While Ireland abolished ‘best interests’, England and Wales retained it. However, all retained the presumption of capacity.

Table 3

Procedure HSCPs must follow when supporting a service-user to make a decision

Step	Action
1	Presume capacity and begin providing information about having a cervical smear, like the pros and cons.
2	This information should be presented in whatever person-centred ways are required like easy-reads, images, etc. and for as long as possible. There is no definition of this duration in ADM, but HSCPs must exhaust all possible means of decision-support.
3	The functional test of capacity is carried out by HSCPs to check if the person has decided whether to attend for the smear or not.
4	If the individual demonstrates understanding and communicates a decision for or against having a smear, via the functional test (see Table 2 above), their decision holds and HSCPs must respect it. This is true even if the individual decided against having a smear, a decision some may deem unwise. Under ADM everyone enjoys the same rights to make unwise decisions, provided they can demonstrate understanding as outlined.

Practitioner Context

In terms of positionality, the author works as a Chartered Health Psychologist in a nationwide health and social care organisation which provides day and residential services to adults with ID in Ireland. One of the largest such Irish organisations, RehabCare, is funded by the Health Service Executive (HSE) to provide lifespan disability services to people with ID, autism, physical and sensory disabilities.

The author's role is Principal Psychologist managing a psychology team that provides services to over 4,500 service-users across 210 locations. As part of this role, the author has directly observed from her own practice, but also received reports of the challenges that ADM presents to HSCPs and service-users.

Although all HSCPs employed in RehabCare have received theoretical training in ADM, there are anecdotal reports that, in practice, they do not have the skills to apply its principles. Therefore, HSCPs are calling for an applied training workshop to be provided. In addition, HSCPs report that service-users frequently delegate decisions and seem to lack the skills/knowledge/confidence to make decisions independently or with support and require education to engage with supported decision-making. The author is tasked with the responsibility to develop national training for both HSCPs and service-users. Therefore, the research questions of this thesis are: *what are the barriers and facilitators to HSCP's ADM-implementation with adults with ID? And what are the barriers and facilitators to service-users' engagement with supported decision-making under ADM?*

Table 4

*Comparison of the Principles of the Assisted Decision-Making (Capacity) Act 2015 with
Capacity Legislation in Scotland, England, Wales and Northern Ireland*

Principles of capacity legislation	Assisted Decision- Making (Capacity) Act Ireland 2015 (Commenced 2023)	Adults with Incapacity Act Scotland 2000 (Commenced 2003)	Mental Capacity Act (England and Wales) 2005 (Commenced 2007)	Mental Capacity Act (Northern Ireland) 2016 (Commenced 2019)
Presumption of capacity	√	√	√	√
Capacity is dynamic and decision-specific	√	√	√	√
‘Will and preference’ take precedence ('best interests' is rejected)	√	√	‘Will and preference’ are considered as part of an overall “best interests” assessment’	‘Will and preference’ have special - but not equal - standing with ‘best interests’
Right to make an unwise decision	√	√	√	√
Right to an informal functional test of capacity	√	√	Yes, but a ‘diagnostic assessment’ (which checks for impairment) is carried out first	√

1.2 Literature Review

This section outlines the findings from studies carried out on the barriers and facilitators to the implementation of capacity legislation in health and social care settings in Ireland and nearby socio-culturally similar nations. Studies that focused on implementation of the following laws were included, Mental Capacity Act 2005 (England and Wales), Mental Capacity Act (Northern Ireland) 2016, and the Adults with Incapacity (Scotland) Act 2000. Studies show that when these acts commenced, they had a significant impact on HCPs practice (Donnelly, 2016). Research is included from the HSCP and patient perspective.

All the Irish studies on ADM pre-date ADM commencement (2023), and so focused on *anticipated* barriers and facilitators of ADM. We now need to understand the *experienced* barriers and facilitators to inform the design of training interventions.

Literature search methods

Searches for relevant psychology, medicine and nursing studies were carried out via google scholar, the University of Stirling library information systems, PsycINFO and the HSE Health Library. The Decision Support Service (a state body providing ADM-services) was also consulted. Two search streams were carried out. In the first search stream, search terms included 'supported decision-making', 'assisted decision-making', 'decision-making', 'capacity', 'fluctuating capacity', 'capacity and 'everyday decision-making', 'capacity training'. These search terms were combined with (AND) 'adults with intellectual disabilities.'

In the second search stream, search terms included 'Mental Capacity Act', 'Mental Capacity Act Northern Ireland', 'Adults with Incapacity Act' and 'Assisted Decision-Making (Capacity) Act'. Each of these search terms were combined with (AND) 'implementation in health and social care settings'.

These searches resulted in 121 papers which were screened manually by the researcher by reading and summarising them into an excel spreadsheet according to whether they were ruled in or out and why. The following types of papers were excluded: papers that related to children, papers that focused on advance health care directives and palliative / end of life care, papers that investigated capacity and safeguarding, papers that focused on mental health capacity legislation, papers that explored deprivation of liberty safeguards, papers related to implementation of capacity legislation in other countries beyond Ireland and the UK. In addition, papers were ruled out that were authored by legal professionals that

examined intricate aspects of the legislative principles rather than implementation of the legislation in health and social care settings.

31 included papers had the following criteria: papers that examined the implementation of the four capacity laws listed above, in Ireland, Northern Ireland, Scotland, England and Wales, in health and social care settings with HSCPs, families or adults with disabilities. Sixteen included studies were from Ireland, see Table 5 and the remainder were from the UK, see Table 6.

Table 5*Characteristics of 16 Studies on ADM-implementation in Ireland*

Author (year)	Design	Method	Participants	Setting
Casey et al. (2025a)	Systematic review	PRISMA methodology (qual, quant & mixed)	HSCPs, family and adults with ID	Disability
Casey et al. (2025b)	Review	Environmental search for resources	Resources aimed at family, adults with ID, paid carer	Disability
Casey et al. (2024)	Qualitative	Interviews	Mothers of adults with ID	Disability
Casey (2025c)	Qualitative	Focus groups	Adults with ID, families & HSCPs	Disability
Casey et al. (2023)	Qualitative	Interviews	HSCPs and family of adults with ID	Disability
Cronin (2018)	Qualitative	Focus groups	HSCP (carers)	Disability
Curtis et al. (2022)	Quantitative	Survey	HCPs (doctors)	Hospital
Davies et al. (2019)	Rapid realist review	Rapid realist review	HCPs (nurses)	Hospital

Table 5 [continued]*Characteristics of 16 Studies on ADM-implementation in Ireland*

Author (year)	Design	Method	Participants	Setting
Donnelly et al. (2019a)	Mixed methods	Survey & Interviews	HCPs (social workers)	Hospital
Donnelly et al. (2019b)	Qualitative	Interviews	Patients (older)	Hospital
Ni She et al. (2020)	Qualitative	Interviews	HCPs & patients (older)	Hospital
O'Donnell et al. (2021)	Qualitative	Interviews	HCPs (nurses), family & patients (older)	Hospital
O'Donnell et al. (2022)	Qualitative	Interviews	HCPs (nurses), family & patients (older)	Hospital
O'Donnell et al. (2019)	Mixed methods	Rapid realist review, qualitative exploration, participatory learning and intervention trialling	HCPs (nurses)	Hospital
Rogers et al. (2020)	Qualitative	Interviews	HCPs (psychologists)	Disability
Ryan (2018)	Literature review	Literature review	Family of adults with ID	Disability

Seven of the Irish studies were carried out in hospitals gathering doctors and nurses' views on ADM-implementation with older inpatients, mostly with dementia (Davies et al., 2019; Donnelly et al., 2019a; Donnelly et al., 2019b; O'Donnell et al., 2019; O'Donnell et al., 2021; O'Donnell et al., 2023; Ní Shé et al., 2020). A more relevant hospital study, however, is Curtis et al. (2022) because they gathered views on ADM-implementation across a spectrum of wards such as emergency, general medicine and orthopaedic.

The remaining Irish studies (N=8) were from disability settings. Three were systematic or literature reviews (Casey et al., 2025a; Casey et al., 2025b; Ryan, 2018), one was specific to COVID-19-pandemic experiences of supported decision-making (Casey et al., 2023) another only gathered views of mothers of adults with ID (Casey et al., 2024) and another gathered psychologists' views only (Rogers et al., 2020). The remaining two studies offer closer insights.

The first of these is Casey (2025c) who, as part of a PhD dissertation, explored aspects of supported decision-making that adults with ID, families and HSCPs value most and Cronin (2018) who, as part of a master's degree dissertation, carried out focus groups with HSCPs enquiring about their perceived barriers and facilitators to ADM-implementation. Their informative findings are described in section 1.2.1 and 1.2.2.

Of the 15 studies sourced from other nations, 6 were from hospitals or the community (Ramsey, 2005; Alonzi et al., 2009; Todd et al., 2010; Walji et al., 2014). Of the 9 studies carried out in disability settings, 4 were literature reviews (Davidson et al., 2015; Lynch et al., 2022; Wilson, 2017; Stokes et al., 2025). The remaining 5 studies are particularly relevant to this thesis having explored capacity legislation implementation in disability settings (Badger and Parnell, 2009; Douglass, 2024; Davidson et al., 2018; Webb et al., 2020; Manthorpe et al., 2011) see section 1.2.3 and 1.2.4 for details and see Table 6 for a summary.

Table 6*Characteristics of 15 Studies on Capacity Legislation Implementation in Scotland, Northern Ireland, England and Wales*

Author (year)	Nation	Design	Method	Participants	Setting
Alonzi et al. (2009)	England & Wales	Quantitative	Survey	HCPs (nurses)	Hospital
Badger & Parnell (2009)	England & Wales	Qualitative	Interviews	HSCPs & adults with ID	Disability
Douglass (2024)	England & Wales	Qualitative	Interviews	HSCP, family and adults with ID	Disability
Davidson et al. (2015)	Northern Ireland	Literature review	Rapid evidence assessment	HSCPs, adults with ID & patients	Various
Davidson et al. (2018)	Northern Ireland	Qualitative	Interviews	Adults with ID & mental health issues	Disability & mental health
Hinsliff-Smith et al. (2017)	England & Wales	Systematic review	Mixed methods	HCPs, family and patients (frail older)	Various
Killeen et al. (2004)	Scotland	Quantitative	Survey	HCPs & patients	Hospital

Table 6 [continued]*Characteristics of 15 Studies on Capacity Legislation Implementation in Scotland, Northern Ireland, England and Wales*

Author (year)	Nation	Design	Method	Participants	Setting
Lynch et al. (2022)	Northern Ireland	Literature review	Integrative literature review	Adults with ID & families	Disability
Manthorpe et al. (2011)	England & Wales	Qualitative	Interviews	HSCPs	Disability
Ramsey (2005)	Scotland	Quantitative	Survey	HCPs (doctors & nurses)	Hospital
Stokes et al. (2025)	Scotland, England & Wales	Systematic review	Mixed methods	HSCPs (care homes for older adults with ID)	Disability
Todd et al. (2010)	Scotland	Quantitative	Survey	HCPs (doctors & nurses)	Hospital
Walji et al. (2014)	England & Wales	Qualitative	Interviews	HCPs (psychologists)	Hospital
Webb et al. (2020)	Northern Ireland	Quantitative	Qualitative	Adults with ID	Disability
Wilson (2017)	Scotland, England & Wales	Systematic review	Mixed methods	Carer & adults with ID	Disability

The Theoretical Domains Framework (TDF) (Cane et al., 2012)

As the current study aimed to support HSCPs behaviour change, it is necessary to understand the influences on, and context of, that behaviour. When designing research, it is important to use a theoretical framework because the resulting constructs are then underpinned by the theory that was used to design them. This is very useful when designing interventions, as results can be connected back to relevant theory, to inform intervention design. Therefore, the literature review is mapped onto the TDF's constructs. The TDF is a synthesis of 33 theories of behaviour and behaviour change, and 128 constructs clustered into 14 domains, see Table 7.

Table 7

The Theoretical Domains Framework (Cane et al., 2012)

Domain / Definition	Constructs
Knowledge: An awareness of the existence of something	Knowledge (including knowledge of condition); Procedural knowledge; Knowledge of task environment
Skills: An ability or proficiency acquired through practice	Skills development; Competence; Ability; Interpersonal skills; Skill assessment
Social/Professional Role and Identity: A coherent set of behaviours and displayed personal qualities of an individual in a social or work setting	Professional identity; Professional role; Social identity; Professional boundaries; Group identity; Organizational commitment
Beliefs about Capabilities: Acceptance of the truth, reality or validity about an ability, talent, or facility that a person can put to constructive use	Self-efficacy; Perceived competence; Self-confidence; Empowerment; Perceived behavioural control; Self-esteem
Optimism: The confidence that things will happen for the best or that desired goals will be attained	Optimism; Pessimism; Unrealistic optimism; Identity
Beliefs about Consequences: Acceptance of the truth, reality, or validity about outcomes of a behaviour in a given situation	Outcome expectancies; Characteristics of outcome expectancies; Anticipated regret; Consequences
Reinforcement: Increasing the probability of a response by arranging a dependent relationship, or contingency, between the response and a given stimulus	Rewards (proximal/distal, valued/not valued, probable/improbable); Incentives; Punishment; Reinforcement; Contingencies; Sanctions
Intentions: A conscious decision to perform a behaviour or a resolve to act in a certain way	Stability of intentions; Stages of change model and stages of change; Transtheoretical model
Goals: Mental representations of outcomes or end states that an individual wants to achieve	Goals (distal/proximal); Goal priority; Goal/target setting; Goals (autonomous/controlled); Action planning

Note. Source: www.medium.com/knowledgenudge

Table 7 [continued]

The Theoretical Domains Framework (Cane et al., 2012)

Domain / Definition	Constructs
Memory, Attention and Decision Processes: The ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives	Memory; Attention; Attention control; Decision making; Cognitive overload/tiredness
Environmental Context and Resources: Any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence, and adaptive behaviour	Resources (material/financial); Environmental stressors; Organizational culture/climate; Salient events/critical incidents; Person–environment interaction; Barriers and facilitators
Social Influences: Those interpersonal processes that can cause individuals to change their thoughts, feelings, or behaviours	Social pressure; Social norms; Group conformity; Social comparisons; Social support; Power; Intergroup conflict; Alienation
Emotion: A complex reaction pattern, involving experiential, behavioural, and physiological elements, by which the individual attempts to deal with a personally significant matter or event	Fear; Anxiety; Affect; Stress; Depression; Positive/negative affect; Burn-out
Behavioural Regulation: Anything aimed at managing or changing objectively observed or measured actions	Self-monitoring; Action planning; Breaking habit; Self-instruction

Note. Source: www.medium.com/knowledgenudge

Many studies, including a systematic review (Dyson and Cowdell, 2021) illustrate how the TDF has underpinned intervention design (Cane et al., 2015; Atkins et al., 2017). Its strengths include a wealth of evidence for each domain and construct, wide theoretical coverage and its usefulness in assessing problems. This is because if questions are designed using TDF constructs, the resulting data can be interpreted via the TDF lens (Dyson and Cowdell, 2021).

Limitations of the TDF include that it is a framework and not a theory; therefore, it will not generate testable hypotheses (Atkins et al., 2017). Instead, the results must then be linked to a theory, to form a testable hypothesis, leading to a longer process (Francis et al., 2012). However, the systematic review by Dyson and Cowdell (2021) concluded that although the review was limited (all studies were carried out in western countries in primary or secondary care), the TDF clearly demonstrated its usefulness for practitioners to understand the barriers to implementing best practices.

1.2.1 HSCP Studies

Previous studies have found evidence of poor implementation of capacity legislation in UK healthcare settings (Ramsey, 2005; Todd et al., 2010) and it is important to understand why. Starting with the barriers, studies exploring HSCP factors, often identify challenges at the *individual* and *organisational* level, see Table 8.

Knowledge and Skills Domains

At the *individual level*, a salient barrier to implementation of capacity legislation is lack of HSCPs awareness, knowledge and understanding (Davies et al., 2019; Donnelly et al. 2019; Alonzi et al. 2009). A systematic review by Hinsliff-Smith et al., (2017) found varying understanding while another study found the complexity of the knowledge to be a barrier (Walji et al., 2014). Gaps in knowledge and awareness were found amongst Irish nurses (Donnelly et al. 2019;) and low confidence among care home HSCPs in the UK (Douglass, 2024; Stokes et al., 2025). Evidence is mixed amongst hospital staff in Scotland, with some reporting low levels of knowledge and awareness (Todd et al., 2010) with one study reporting that 34% of staff were unfamiliar with capacity legislation (Ramsey, 2005); however, the same study found a significantly higher level of AWI awareness among acute ward staff (85%) compared with those from elective wards (54%) (Ramsey, 2005).

Another problem is that HCPs inconsistently apply the functional test, with some disclosing that physical illness (Ramsey, 2005) or patient non-compliance (Hinsliff-Smith et al., 2017) wrongly triggered the functional test or a presumption of lack of capacity. The same presumptions were found based on diagnosis in Irish studies (Donnelly et al., 2019). Misconceptions of older adults' capacity is still a barrier to implementation in UK care homes (Stokes et al., 2025).

Lack of training to support implementation of capacity legislation is an often-cited barrier (Davies et al., 2019; Killeen et al., 2004; Ramsey, 2005; and Walji et al., 2014; Todd et al., 2010; Douglass, 2024; Casey, 2025c; Stokes et al., 2025; Alonzi et al., 2009; O'Donnell et

al., 2019) with as few as 2% of Irish medical HCPs being ADM-trained and researchers calling for training to be urgently provided (Curtis et al., 2022).

According to Rogers et al., (2020), Irish psychologists, although welcoming the shift towards ADM, identify significant challenges, including a deeply ingrained culture of "incapacity," systemic resource shortages, and the need for better training. Community nurses reported a lack of confidence in implementation specifically with dementia patients as did paid carers (Hinsliff-Smith et al.; 2017 Manthorpe et al., 2011). Training, even when available, may be ineffective if it's theoretical rather than applied (Hinsliff-Smith et al., 2017) suggesting that training must go beyond imparting knowledge, to teaching participants how to apply the act in practice (Manthorpe et al., 2011; Davies et al., 2019; Donnelly et al., 2019; Killeen, 2004; Todd, 2018).

Poor HCP communication skills are detrimental to ADM-implementation (Davies et al., 2019; Donnelly et al. 2019) like failure to use aides like social stories and failure to adapt communication by breaking decisions down (Stokes et al., 2025). Other studies reported the need for HCP training around communicating with people with moderate and severe ID (Killeen et al., 2004).

Social Influences Domain

Limited understanding of ADM by families forms a barrier to HCPs implementation (Hinsliff-Smith et al., 2017) with potential conflict with families cited by HCPs as a barrier to even attempting to apply ADM (Cronin, 2018; Casey, 2025). Limited expectations of service-users has also been evidenced as a social barrier (Badger and Parnell, 2009) as well as lack of knowledge of how to make decisions by service-users, who sometimes delegate the decision to others before any ADM efforts can happen (Donnelly et al., 2019) and lack of awareness among hospital HCPs (Cronin, 2018).

Emotion Domain

Emotional barriers like stress (Stokes et al., 2025), moral distress and fear of letting go (Cronin, 2018), and of positive risk-taking (Donnelly et al., 2019; Casey, 2025) form barriers. Also, fear of personal liability (Curtis et al., 2022; Alonzi et al., 2009; Walji et al., 2014) which particularly impacts HCP's ability to support service-users making decisions they considered unwise (Casey, 2025), illustrating a tension between safety and independence (Badger and Parnell, 2009).

Social / Professional Role and Identity Domain

Evidence suggests that some HCPs perceive that ADM is not part of their role (Davies et al., 2019; Killeen et al., 2004; Curtis et al., 2022) and that personal or cultural beliefs (Stokes et al., 2025) and inadequate professional collaboration (Davies et al., 2019) can prevent ADM implementation.

Environmental Context and Resources Domain

Other barriers are lack of time and competing clinical work (Donnelly et al. 2019; Hinsliff-Smith et al, 2017; Davies et al., 2019; Douglass, 2024; Stokes et al., 2025) and lack of opportunities (Donnelly et al., 2019 and Hinsliff-Smith et al., 2019). Studies reporting *organisational barriers* to capacity legislation implementation under this domain, found evidence for lack of resources, like guidance documents (Cronin, 2018; Killeen et al., 2004; Douglass, 2024; Stokes et al., 2025); policies and processes to guide HSCPs (Casey, 2025c; Stokes et al., 2025) and accessible materials (Douglass, 2024) and balancing patient choice with organisational duty of care (Stokes et al., 2025). In addition, onerous paperwork (Cronin, 2018; Walji et al 2014; Casey, 2025c) dealing with fragmented care services (Davies et al., 2019) and a culture overly focused on safety (Cronin, 2018) that is risk averse (O'Donnell et al., 2021) especially towards those with cognitive impairment; are barriers (O'Donnell et al., 2023).

Furthermore, studies conducted in UK disability services found a multitude and complexity of care decisions that HSCPs deal with every day (Manthorpe et al., 2011; Alonzi et al., 2009; Hinsliff-Smith et al., 2017). This high frequency of opportunity for HSCPs to apply capacity legislation in care services, emphasises the urgency for implementation in disability settings.

Table 8

HSCP Barriers from the Literature Review Mapped onto the Theoretical Domains Framework (Cane et al., 2012)

Construct from the literature	Level	TDF Domain	TDF Construct
Limited expectations of service-users (Badger and Parnell, 2009)	Individual	Social Influences	Social / group norms
Liaising with families (Cronin, 2018)	Individual	Social Influences	Social pressure
Hospital healthcare colleagues (Cronin, 2018)	Individual	Social Influences	Intra/personal professional
Culture overly focused on safety (Cronin, 2018)	Organisational	Social Influences	Organisational climate / culture
Moral distress (Cronin, 2018)	Individual	Emotion	Negative affect
Fear of letting go (Cronin, 2018); Fear of blame (Curtis et al., 2022)	Individual	Emotion	Fear
Poor communication skills (Donnelly et al., 2019)	Individual	Skills	Interpersonal skills

Table 8 [continued]

HSCP Barriers from the Literature Review Mapped onto the Theoretical Domains Framework (Cane et al., 2012)

Construct from the literature	Level	TDF Domain	TDF Construct
Failure to use social stories (Cronin, 2018); Service-user delegates the decision before any supported decision-making efforts can be made (Donnelly et al., 2019); Lack of knowledge of how to make decisions by service-users (Donnelly et al., 2019)	Individual	Skills	Practice / skills development
Lack of time (Davies et al., 2019; Donnelly et al., 2019); No opportunity given (Donnelly et al., 2019)	Organisational	Environmental Context & Resources	Material resources
Heavy documentation (Cronin, 2018); Fragmented care services (Davies et al., 2019)	Organisational	Environmental Context & Resources	Environmental stressors

HSCP facilitators of implementation of capacity legislation – Skills Domain

According to HCPs, facilitators *at the individual level* include speaking directly to the patient, looking beyond their diagnosis and appreciating their life experiences and values (O'Donnell et al., 2021). Other effective communication strategies help such as collaborative problem-solving (Lynch et al., 2022), and reading patient's non-verbal cues (O'Donnell et al., 2021), all of which reduce potential for family conflict (O'Donnell et al., 2021). Furthermore, involving the patient and family early at MDT meetings was significant (O'Donnell et al., 2021; Donnelly et al., 2019), as well as having a sense of caring (Cronin, 2018). Evidence also shows that experiential training in how to apply the legislation, is a facilitator (O'Donnell et al., 2021; Lynch et al., 2022) especially in-person, using real examples to build a working knowledge (Stokes et al., 2025).

Environmental Context and Resources

Studies show that healthcare settings with a learning-focused culture (O'Donnell et al., 2021), inter-disciplinary support and professional forums, facilitates ADM-implementation (Davies et al., 2019; O'Donnell et al., 2021; Lynch et al., 2022). A culture of change and clear policy/procedures aid implementation as well as availability of assistive technology and more time to communicate (O'Donnell et al., 2021; Arstein-Kerslake et al., 2017; Davies et al., 2019; Donnelly et al., 2019; Stokes et al., 2025). Care homes that foster a culture of positive, trusting and reciprocal relationships among residents, families and staff (Lynch et al., 2022) and recognise resident's rights (Stokes et al., 2025) are facilitators. Also, organisations that provide opportunity (Lynch et al., 2022) and a private space for HCP-patient discussions (Davies et al., 2019; Donnelly et al., 2019) aid implementation. Availability of clinical guidelines, resources, protocols and quick record-keeping forms help (Cronin, 2018; Donnelly et al., 2019; Davies et al., 2019).

Social Influence Domain

Evidence shows that strong leadership (Cronin, 2018) and opportunities for mentorship act as social facilitators (Davies et al., 2019; see Table 9).

Table 9

HSCP Facilitators from the Literature Mapped onto the Theoretical Domains Framework (Cane et al., 2012)

Construct from the literature	Level	TDF Domain	TDF Construct
Strong leader support (Cronin, 2018; Davies et al., 2019)	Individual	Social Influences	Leadership
Investment in public awareness (Davies et al., 2019)	Organisational	Social Influences	Social norms
Use of social stories (Cronin, 2018)	Individual	Skills	Practice / skills development
Effective communication (Cronin, 2018)	Individual	Skills	Interpersonal skills
Mentoring as part of training and professional forums (Davies et al., 2019)	Individual	Social Influences	Social support
Organisational policy that supports ADM (Cronin, 2018; Davies et al., 2019)	Organisational	Environmental Context & Resources	Organisational commitment
Good ADM resources, templates and clinical guidelines, quick record keeping forms and a private space to meet (Davies et al., 2019)	Organisational	Environmental Context & Resources	Material resources

1.2.2 Patient studies

Skills Domain

Starting with the barriers (see Table 10), evidence shows that poor communication skills are challenges to engaging in ADM (Davies et al., 2019; O'Donnell et al., 2023; Killeen et al., 2004) as are lack of training and education for patients and families (Killeen et al., 2004; Cronin, 2018; Badger and Parnell, 2009). Studies found that the poorer the communication skills the patient had, the less choice they were given (Killeen et al., 2004). Having a negative perception of decisions formed a barrier too, such as beliefs that decisions are difficult (Webb et al., 2020).

A systematic review of everyday decision-making amongst adults with ID, their care partners and support workers reported patient barriers including under-estimating / not listening to the individual and not knowing their needs (Casey et al., 2025a). Adults with ID reported feeling underestimated and their preferences not taken seriously. Some papers that focused on supported decision-making found that the individual rarely had the final say despite being included and an overall lack of understanding amongst family carers prevails. However, as the review included papers from multiple jurisdictions, not all results are comparable as legislation varies. The review only included papers written in English and mostly from the UK, USA and Australia, however its' strengths lay in that it focused on studies that held the person with ID at the centre of the research (Casey et al., 2025a).

Knowledge Domain

According to patients, a lack of public understanding and awareness of capacity legislation is a barrier (Killeen et al., 2004; Wilson, 2017). A qualitative online survey with 8 professional carers and 8 family carers explored their views of the impact of the COVID19-pandemic on adults with ID's supported decision-making (Casey et al., 2023). While professional carers reported some positive outcomes, including greater chances for independence among service-users and new activities becoming available online, family carers however observed more isolation in their loved ones. Researchers concluded that the pandemic significantly restricted adults with ID's opportunities to make choices for themselves (Casey et al., 2023).

Social Domain

Despite growing interest in supported decision-making few studies have researched the role of family in this process (Casey et al., 2025a). HSCPs reported that adults with ID's decision-making was often impacted by family concerns about risk (Casey et al., 2023). In an Irish qualitative study, seven mothers were interviewed about providing supported decision-making to their adult son/daughter with ID (Casey et al., 2024). Results showed that the most often employed supported decision-making strategy by mothers was offering choices under supervision. However, mothers admitted that they have the final say if they felt their son or daughter was making an unsuitable choice. This was motivated by a desire to protect and was usually under 'best interests'. The more importance a mother placed upon a decision the less likely they were to permit their son/daughter to decide independently, often seeing their cognitive limitations as preventing them from doing so. The findings indicate that although mothers were supportive of the rights of their adult sons/daughters with ID to make their own decisions, and welcomed ADM, they were often hesitant to relinquish control. Researchers recommended that future longitudinal research is carried out to explore changes in how adults with ID make decisions over time and in different contexts (Casey et al., 2024). Another study found that, among family carers, lack of understanding is a barrier (Wilson, 2017) with carers often reliant on HCPs to make decisions (Hinsliff-Smith et al., 2017). Families act as barriers by excluding the patient from decision-making (Donnelly et al., 2019) and even when the patient is included, families' views can be considered more important (Badger and Parnell, 2009).

Environmental Context and Resources

A lack of information and resources aimed at the individual is a major barrier (Killeen et al., 2004; Wilson, 2017; Davidson et al., 2015). This is upheld by an Irish review that investigated what ADM-information is available online for adults with ID and their professional and family carers (Casey et al., 2025). Researchers found that resources were mostly targeted towards professional carers rather than the everyday decision-making of adults with ID. Authors concluded there is a gap in accessible ADM-information for people with ID and their decision-supporters.

Organisational barriers reported by Northern Irish patients with ID and mental health issues included influence from HSCPs, staff turnover, and insufficient time (Davidson et al., 2015). This is supported by evidence from Ireland with adults with ID reporting difficulty trusting staff due to high turnover, inconsistent communication and restrictive practices (Casey, 2025c).

Of relevance is an English study that explored what life was like for residents with ID in residential services before and after the Mental Capacity Act (MCA) (Badger and Parnell, 2009). Six residents were interviewed along with their carers and families about their experiences pre-MCA. Results showed that HSCPs and residents differed on what constituted decision-making opportunities, i.e. HSCPs perceived the resident's amount of choice to be higher than the residents did. Results also showed that residents had limited expectations of the choices available (Badger and Parnell, 2009). Researchers proceeded to carry out a 6-month follow-up to see the impact of MCA. Results showed that whether HSCPs deemed the resident to have or lack capacity had no bearing on the decision-making opportunities afforded, because all decisions were made for them by HSCPs. Also, results indicated that when residents made informed decisions that were deemed unwise, the opportunity to support these decisions was denied by risk assessments, showing that a culture focused on safety rather than rights, is a barrier. Organisational policies were also barriers, like not being permitted to decide on their own spending (Badger and Parnell, 2009). This is consistent with a recent systematic review that found that rigid policies are a barrier to ADM-implementation (Casey et al., 2025a).

Table 10

Patient Barriers from the Literature Mapped onto the Theoretical Domains Framework (Cane et al., 2012)

Construct from the literature	Level	TDF Domain	TDF Construct
Poor communication skills (Davies et al., 2019; O'Donnell et al., 2023; Killeen et al., 2004)	Individual	Skills	Interpersonal skills
A lack of public understanding and awareness (Killeen et al., 2004 and Wilson, 2017); Lack of patient education (Killeen et al., 2004; Cronin, 2018; Badger and Parnell, 2009)	Individual	Knowledge	Knowledge
Lack of information and resources aimed at the individual (Killeen et al., 2004; Wilson, 2017; Davidson et al., 2015; Casey et al., 2025); Influence from HSCPs, staff turnover, insufficient time (Davidson et al., 2015; Casey, 2025c)	Organisational	Environmental Context & resources	Resources
Family barriers (Donnelly et al., 2019; Casey et al., 2023; Casey et al., 2024)	Individual	Social Influences	Power
Rigid policies, risk assessment procedures, restrictive practices (Badger and Parnell, 2009; Casey et al., 2025a)	Organisational	Social Influences	Social norms

Patient Facilitators to engagement with ADM - Skills Domain

Individual facilitators that enhance patient engagement, include individualised communication strategies (Davies et al., 2019) and presenting information in accessible ways (Davidson et al., 2015). Opportunities to build confidence (Casey et al., 2024) and assertiveness were reported by participants with mental health issues and ID as being facilitators to their ability to express their decisions (Davidson et al., 2015). Attendance at advocacy meetings also facilitated feeling empowered to express individual preferences (Casey et al., 2025a).

Social Influences Domain

Having a good relationship with the decision-supporter (Davies et al., 2019; Fetherstonhaugh et al., 2016; Webb et al., 2020; O'Donnell et al., 2021). Decision-supporters who know the individual well (Casey et al., 2025a) and are kind, understanding, consistent, and good listeners, facilitates patient engagement (Davidson et al., 2015). This is supported by Irish evidence that being listened to, feeling trusted and respected, and having options clearly explained are the most valued aspects of supported decision-making according to adults with ID (Casey et al., 2024).

Environmental Context & Resources Domain

Having sufficient time and having a private space to meet (O'Donnell et al., 2021; Donnelly et al., 2019) facilitates supported decision-making discussions but the timing of supported decision-making can also help (Donnelly, et al., 2019) and having a policy focused on inclusivity, that emphasises the importance of supported decision-making (Casey et al., 2025a). Involving the patient early is helpful as it affords an opportunity for the patient to share their values and learn their rights (Davies et al., 2019; Davidson et al., 2015).

How decision-support is made available and sequenced was found to be a facilitator in a recent study in Northern Ireland who found that adults with ID don't usually think about decisions in abstract terms like the steps of the functional test (Webb et al., 2020). Authors argue that decision-support should be provided via the functional test steps, to familiarise adults with ID with the process and that this facilitates service-user engagement overall (Webb et al., 2020). This researcher argues that the quality of decision-support offered directly influences the person's ability to understand, reason, and communicate their decision and therefore *supporting* and *assessing* decision making are inseparable practices. Quality decision-support is therefore a vital requirement for a rights-based assessment. Their

approach encourages practitioners to transparently follow the steps involved in the functional test, arguing this repetition will increase decision-making skills amongst adults with ID (Webb et al., 2020).

Conversely, a dissertation study by Casey (2024), found evidence against such a rigid approach, from focus groups that were carried out with adults with ID, family and HSCPs stakeholders, where they agreed the features of supported decision-making each valued most. These features included flexibility for informal everyday decision-making, avoiding rigidity, with the adult with ID's voice being the starting point and central to all decision-processes. Decision-support should be tailored to the situation, roles should be clarified within supported decision-making, and conflict must be addressed between families and HSCPs. Stakeholders agreed that an ideal decision-support guide should be accessible (containing visuals, etc.), suitable for informal everyday decision-making, with most decisions happening outside of formal assessment and documentation, and user-friendly in the absence of HSCPs (Casey, 2025c; see Table 11).

Professional Role and Identity

Patients reported feeling more involved when MDTs saw themselves as having an advocacy role to play in ensuring a patient's 'will and preference' was heard (O'Donnell et al. 2021; Donnelly et al., 2019).

Table 11

Patient Facilitators from the Literature Mapped onto the Theoretical Domains Framework (Cane et al., 2012)

Construct from the literature: Facilitators	Level	TDF Domain	TDF Construct
MDT meetings that fully involve the patient and family (Donnelly et al., 2019)	Organisational	Environmental Context & Resources	Person-environment interaction
Use of assistive technology and communication aides and more time (Davies et al., 2019); A relaxed space to meet (Donnelly et al., 2019)	Organisational	Environmental Context & Resources	Material resources
Confidence and assertiveness building (Davidson et al., 2015)	Individual	Skills	Practice/skills development
Access to decision supported decision-making such as flexibility for everyday decisions (Casey, 2025c)	Organisational	Environmental Context & Resources	Material resources
Investment in public understanding and awareness (Davies et al., 2019)	Individual	Knowledge	Knowledge
Good relationship with the decision supporter, being listened to, involving the service-user early (Davies et al., 2019)	Individual	Social Influences	Social support
ADM policy focused on inclusivity (Casey et al., 2025a)	Organisational	Social / Professional role and identity	Leadership

1.2.3 Health decision-making

Beliefs about Capabilities Domain

Evidence suggests that opportunities to engage patients with ID in supported health decision-making are missed because they are excluded due to HCPs attributing capacity only to those who appear to have cognitive competency and communicate verbally (O'Donnell et al., 2023). Sometimes carers defer to HCPs to make health decisions on behalf of the individual (Hinsliff-Smith et al., 2017) also excluding them. Furthermore, Irish hospital research with dementia patients, found that often the *patient* delegates health decision-making to others before any supported decision-making is attempted (Donnelly et al., 2019) and evidence from Scotland concurs (Killeen et al., 2004).

Environmental Context and Resources Domain

In hospital settings, barriers include noise, lack of private space for discussion (O'Donnell et al., 2021), and the disorientating and disempowering nature of the environment (Ní Shé et al., 2020). In fact, older patients reported viewing the Irish healthcare system as being under significant pressure and describing HCPs as having no time to engage in supported decision-making resulting in patients feeling they must be very assertive to have their preferences heard (Ní Shé et al., 2020).

Knowledge Domain

Overall, lack of patient information (Killeen et al., 2004; Wilson, 2017; Casey, 2022) and health information being too complex (Douglass, 2024) are barriers to patient involvement in supported health decision-making. Lack of public understanding and awareness (Killeen et al., 2004; Wilson, 2017; Casey, 2022) is a key barrier to people's right to make their own health decisions. Douglass (2024) explored how adults with ID are supported to make health decisions, drawing on interviews and focus groups with adults with ID, family and HSCPs. Adults with ID reported that rushed appointments and not being listened to, were barriers to their engagement in supported health decision-making. Douglass concluded that good support for health decision-making happens only when these three factors are present (i) all supporters have a good understanding of the legislation; (ii) health literacy – the individual and decision-supporters must fully understand the relevant health information and (iii) valuing individuals - HSCPs must genuinely recognise adults with ID as decision-makers. See Table 12 for a summary of these studies mapped onto the TDF (Cane et al., 2012).

Table 12

Patient Barriers and Facilitators to Health Decision-Making Mapped onto the Theoretical Domains Framework (Cane et al., 2012)

Construct from the literature	Level	TDF Domain	TDF Construct
Decision-supporters having a good knowledge and understanding of the legislation (Douglass, 2024)	Individual (facilitator)	Knowledge	Procedural knowledge
Health literacy – the individual and the supporters must fully understand the specific health decision being made (Douglass, 2024)	Individual (facilitator)	Knowledge	Procedural knowledge
HSCPs recognising adults with ID as decision-makers (Douglass, 2024)	Individual (facilitator)	Beliefs about Capabilities	Beliefs
Perception of HSE being under pressure and HCPs lack time to talk (Ní Shé et al., 2020)	Organisational (barrier)	Environmental context & Resources	Environmental stressors

Table 12 [continued]

Patient Barriers and Facilitators to Health Decision-Making Mapped onto the Theoretical Domains Framework (Cane et al., 2012)

Construct from the literature	Level	TDF Domain	TDF Construct
Rushed appointments and a feeling of not being listened to (Douglass, 2024)	Individual (barrier)	Environmental context & Resources	Environmental stressors
Noise levels and the disorientating and disempowering nature of hospital environments (Ní Shé et al., 2020; O'Donnell et al., 2021)	Organisational (barrier)	Environmental context & Resources	Person / environment interaction
Health information being too complex (Douglass, 2024)	Individual (barrier)	Knowledge	Knowledge
HCPs wrongly attributing capacity to those who appear to have cognitive competency and can communicate verbally (O'Donnell et al., 2023); Tendency for carers to defer to HCPs to make decisions on behalf of the individual (Hinsliff-Smith et al., 2017); Patient delegates decision-making to others before any ADM efforts can be made (Donnelly et al., 2019; Killeen et al., 2004)	Individual (barrier)	Beliefs about Capabilities	Beliefs

1.2.4 Literature Review Conclusions and Limitations

Shifting from making ‘best interests’ decisions on behalf of the individual, to supporting them to make their own decisions according to their ‘will and preference’, is a significant challenge for HSCPs. There is a gap in knowledge about the barriers and facilitators that HSCPs in Irish disability services face, in ADM-implementation. As disability services support thousands of people for whom ADM is relevant, it is important to understand the specific issues these HSCPs face, so that appropriate interventions can be designed to address them. Therefore, this thesis proposes to fill this gap by gaining an understanding of the perceived barriers and facilitators to ADM-implementation by HSCPs, in an Irish disability setting.

Regarding patients, little is known about what helps and hinders them in engaging with ADM because adults with capacity-affecting conditions and communication needs remain under-represented in research investigating capacity legislation implementation (Jimoh et al., 2021). It is important that we provide adults with ID with opportunities to have their say on this important topic that could potentially impact their lives significantly and to involve them in co-producing interventions. This is another gap this thesis aims to fill.

Limitations

Although the above literature review informed the design of this thesis, aspects of these studies impact their relevance. Some of the systematic reviews were somewhat outdated (Hinsliff-Smith et al., 2017 and Wilson, 2017) and some only included studies that focused on capacity legislation implementation within specific populations, like older people (Hinsliff-Smith et al., 2017) rather than a cross-section of people the legislation applies to. Although one systematic review had more relevance as it was carried out in Ireland, the researchers disclosed that, to give policymakers quick results, their review was not exhaustive (Davies et al., 2019). The strength of the most recent systematic review (Casey et al., 2023) lay in its sole inclusion of papers that held the adult with ID at the centre of the research; however, it included papers from jurisdictions beyond the scope of this study (like Australia).

Although not a limitation, the fact that 13 studies focused on acute hospital settings and focused on doctors and/or nurses (Donnelly et al., 2019b; Curtis et al., 2022; O'Donnell et al., 2012; O'Donnell et al., 2023; O'Donnell et al., 2019; Ramsey et al., 2005; Todd et al., 2011; Alonzi et al., 2009 and Ní Shé et al., 2020) or social workers' views (Donnelly et al., 2019b) raises the question of whether their findings are relevant in disability services. Also,

some patient studies only included dementia patients (such as Donnelly et al., 2019a) or older patients (such as Donnelly et al., 2019b; O'Donnell et al., 2019; Ní Shé et al., 2020).

Although a few studies were sourced that focused on participants with disabilities, they were limited by being a master's thesis (Cronin, 2018); being specific to the COVID19 pandemic (Casey et al., 2023); only including HCPs that were psychologists (Rogers et al., 2020) and focusing on residential services that specialised in supporting adults with dementia (Manthorpe et al., 2011). While one study did investigate the views of adults with ID and their HSCPs, this was a piece of consultancy rather than research (Killeen et al., 2004).

1.3 Aims, Research Questions and Thesis Overview

Aims

As the literature review shows, with ADM being new, not enough is known about what helps HSCPs to implement its' principles and what helps adults with ID to engage in supported decision-making. Therefore, the aim of the thesis is to identify the barriers and facilitators to HSCPs and adults with ID engaging in supported decision-making to inform future training resources for both groups.

Research questions

The research questions are as follows. Study 1 (Chapter 2): What are the perceived barriers and facilitators to ADM-implementation by HSCPs in an adult ID setting in Ireland? Study 2 (Chapter 3): What are the perceived barriers and facilitators to actively engaging with supported decision-making, by adult service-users with ID in Ireland?

Dissertation overview

Chapter one introduced the research topic via a literature review. Chapter two describes a survey study with HSCPs in an Irish disability setting. Chapter three describes a focus group study with service-users. Chapter four concludes with a discussion of how the two studies intersect, offers plans for training interventions, reflections on the research process, and recommendations for future research and policy.

Chapter 2: A survey of barriers and facilitators to ADM-implementation among health and social care staff in adult disability services

2.0 Background

As described in chapter 1, capacity legislation has changed fundamentally in Ireland since the introduction of ADM, under which all adults are presumed to have capacity, unless proven otherwise. ADM represents a significant shift in practice away from 'best interests' decision-making towards 'will and preference', where the beliefs and values of the person are the only considerations in decision-making. This means that whilst historically HSCPs could have made decisions in the "best interests" of adults whose capacity was questioned, instead, HSCPs must now support service-users to make their own decisions following a process outlined by ADM. This is a significant change in practice for many HSCPs in Ireland which will require HSCPs to become skilled at supported decision-making and applying the functional test of capacity. Where the service-user has not reached a decision (i.e. has failed the functional test of capacity) HSCPs will need to be competent in establishing the service-users' 'will and preference' and then make the decision that the individual *would* make, if they could (see Chapter 1).

The problem is that evidence shows that HCPs in Ireland are not ready for these responsibilities (Curtis et al., 2022). The study by Curtis et al. (2022) was pivotal in the design of the current research because although the survey pre-dates ADM commencement, it is the only study that could be found that investigated ADM-implementation with HCPs that worked with a range of patients with conditions across ages rather than just older patients (e.g. O'Donnell et al., 2019). Curtis et al. (2022) issued a self-report questionnaire containing questions surrounding awareness and understanding of ADM to doctors in an Irish hospital. With a response rate of 44%, the 62 doctors who participated ranged in grade, from intern to consultant. Although 87% were aware of ADM, only one doctor (2%) had attended training. Only 5 doctors (8%) reported having full knowledge of ADM and 37 (60% of participants) wrongly believed that doctors would have the right to decide treatment for a patient who lacked capacity. This suggests that doctors remain uninformed about the decision-making process for patients lacking capacity, with only a third of doctors believing that patients in this situation were legally supported by ADM to decide for themselves.

71% of doctors did not know that 'will and preference' should replace 'best interests' showing clear evidence that 'best interests' decision-making remained current practice for some. 50% of doctors were unsure whether they had an obligation to perform the functional test and only 16% reported sufficient knowledge to perform it. Regarding unwise decisions, where a

patient had been assessed as having capacity and proceeded to make an unwise decision, 81% of doctors reported they would either *consider re-assessing* or would *definitely re-assess* capacity. A further 3% would automatically reverse an assessment in favour of incapacity. Further highlighting the ADM knowledge gap, only 39% of doctors were aware of their obligation to consult with others in establishing a patients' 'will and preference'. This shows that the tendency towards a paternalistic approach that ADM aims to abolish, still exists in the Irish health service.

It must be noted that Curtis et al. (2022) is limited by its response rate of 44% and the sole inclusion of hospital doctors as participants. Despite its limitations, this study is one of the most relevant to this thesis because of its key finding that there is insufficient knowledge and understanding of ADM amongst hospital doctors from which we can reasonably conclude that ADM-implementation will be problematic. It raises the question of whether HCPs in other Irish health settings similarly lack knowledge and understanding of ADM, a question that Curtis et al. (2022) recommended is addressed by future research. As such, the current study aims to fill this gap by surveying HSCPs in a disability service. Curtis et al. (2022)'s questionnaire has informed the design of the survey items (see methods, section 2.1) so that comparisons could be drawn across these health settings.

In conclusion, except for a study conducted during the COVID19 pandemic (Casey et al., 2023), a study conducted with psychologists (Rogers et al., 2020) and a dissertation study (Cronin, 2018), no other previous studies were conducted with HSCPs in an Irish disability service setting. This gap must be addressed because disability organisations provide services to thousands of people for whom ADM will be relevant, so it is crucial to learn the barriers and facilitators these HSCPs face in ADM-implementation. The secondary objective is to inform the design of appropriate interventions to address the barriers and enhance the facilitators.

2.1 Methods

Design

A survey was the chosen research method because it reaches large sample sizes and can provide anonymity, which may facilitate honesty (Goodfellow, 2023). Also, the widespread participant pool meant that other methods such as interviews would have been resource intensive for busy frontline HSCPs whereas a 10-minute survey was thought attractive to them. Disadvantages to be cognisant of with surveys include, unclear responses cannot be clarified, data can lack depth and respondents with biases might self-select (Andrade, 2020).

However, to attempt to compensate for lack of depth and potential clarity issues, several open-text questions were included to explore HSCPs views further.

Sample and sampling strategy

The participant pool was over 1,500 HSCPs from 210 locations across Ireland, identified using an email distribution list of day- and residential-service managers, who were asked to forward the survey link to frontline HSCPs. All HSCPs contacted met the eligibility criteria, which was, being employed by RehabCare in a frontline social care or social care manager role. Later the sampling strategy widened to include clinicians, regional and senior management also.

To allow for the possibility of comparison of perspectives around ADM across location and demographics, a power calculation indicated a minimum sample of 128 completed surveys was required based on a medium effect size of 0.5 which is the minimum size of the difference you would expect to get, between groups, that would be clinically or practically significant. To calculate this the power was set at 80%. The significance level is the probability of making a Type I error (a false positive, or concluding an effect exists when it doesn't). A significance level of .05 (5%) was chosen which implies that findings have less than a 5% chance of occurring by chance.

This aligned well with the aim to maximise the population reached and the diversity they represented in roles, geographic location etc. and to reach an anticipated 10% of the workforce response rate (N=150), with 10% being a generally accepted rule of thumb for recent exploratory survey sample sizes (McGuinness et al., 2025).

Survey development and stakeholder consultation

The six-section 44-item survey was developed by the researcher, informed by Curtis et al., (2022), and is described below. Three service-users were consulted by advocacy officers on the draft staff survey questions and were satisfied with no changes suggested. Following that, four staff - a manager, psychologist, behaviour therapist and senior manager - were consulted on the draft survey also. They suggested adding facilitator statements on specific supported decision-making tasks like *breaking down decisions into the relevant options* and *identifying the pros and cons of a decision* and these were added.

Participant recruitment

The MSForms survey link was emailed to HSCPs in November 2024 offering an option to voluntarily opt in. A participant information leaflet (PIL) and consent form were attached. The consent form explained that participation was entirely voluntary and anonymous. By clicking on the survey link, participants demonstrated their consent to participate and could opt out at any stage by closing the browser.

A deadline of 3 weeks was offered. However, after four weeks only 18 responses were received. It was anticipated that a participation barrier was that some HSCPs had no computer access, so a poster with a QR code was developed that provided access via mobile phones. This poster was circulated by email in December 2024 via the psychologists, behaviour therapists and regional managers, requesting the poster be printed for display in staff canteens. The rationale being, receiving it from a colleague may encourage uptake and the printed version allowed HSCPs to scan the QR code with their mobile phone and complete the survey during break-time. After one week, the response rate was 31 so it seemed the poster was improving access. After three months, the survey closed with 118 responses.

Survey

SECTION 1 DEMOGRAPHICS: contained five multiple choice questions enquiring about demographics (age, gender, role, type of service and profile of service-users supported).

SECTION 2 KNOWLEDGE AND UNDERSTANDING: explored participants' prior training on, and their knowledge and understanding of, ADM. These items were replicated from the Curtis et al. (2022) study; however, the 'Knowledge' section of Curtis et al.'s questionnaire was renamed 'Knowledge and Understanding' as this seemed more reflective of the questions. Out of ten multiple choice questions, one enquired about prior ADM-training and the remainder assessed ADM knowledge and understanding; For example, *do you think you have a legal duty to consult with others to establish a service-user's 'will and preference' about a decision?* Five items were assessed using multiple choice (no = 1, don't know = 2, yes = 3), one using free text and four using a five-point Likert scale from 1 to 5 (see Appendix D).

SECTION 3 BARRIERS: this section explored participant barriers to ADM-implementation and was informed by previous research. See chapter 1 section 1.2 for a detailed review of the literature on this topic and see Table 8a and 8b for the salient barriers mapped onto the Theoretical Domains Framework (TDF) (Cane et al., 2012). The TDF informed the design of the questions. Fourteen barriers were tested in the current survey, such as service users not knowing what options are available to them (Badger and Parnell, 2009) and lack of awareness of the ADM amongst families (Badger and Parnell, 2009; Walji, 2014; Cronin, 2018). Participants were asked to read the barrier statements and respond selecting the degree to which they viewed this a barrier from 0 = *not at all* to 5 = *very much*. This section concluded with an open-text question, enquiring about other barriers.

SECTION 4 FACILITATORS: replicated the format of section 3 but enquired about facilitators. Again, see chapter 1 section 1.2 and Table 9 for a detailed review of the literature on this topic and for the salient facilitators mapped onto the TDF (Cane et al., 2012) to inform the design of 8 facilitator statements. These included: having a mentor to help you implement assisted decision-making (Davies et al., 2019); availability of ready-to-use templates and checklists to guide you in providing decision-making support, for each type of decision e.g. health decisions (Cronin, 2018; Killeen et al., 2004; Davies et al., 2019) and simple, quick record keeping forms (Davies et al., 2019). Following stakeholder consultation four additional facilitator statements were added as follows: *Being skilled in breaking down decisions into the relevant options*; *Being skilled in identifying the pros and cons for each option related to the decision*; *Being skilled in helping the service-user to weigh up the information about the decision to be taken i.e. the pros and cons* and *Being skilled in demonstrating or role-playing aspects of the choice as part of decision-making support*. Again, participants were asked to read the statements and respond selecting the degree to which they viewed this a facilitator from 0 = *not at all* to 5 = *very much*.

At the end of section four, an open-text question enquired about any other facilitators and an additional open-text question was included to enquire specifically about health health-making support, as follows, “Do you think you would need anything different, to provide support to a service-user making a health decision? If so, please tell us more here”. The rationale for including a question specific to health decisions was because studies show that health decisions are more difficult due to the complex nature of the information to be considered and the consequences being potentially uncertain and long-term (Douglass, 2024).

SECTION 5 TRAINING: included five questions on participants’ views and preferences for training, as follows: two multiple choice questions asked about training modality (face-to-face

versus online) and structure (3-hour workshop or two 1.5-hour workshops). Two open-text questions enquired about what specific aspects they wanted included in a training workshop aimed at them; and another aimed at service-users. The survey closed with an opportunity to add other comments about ADM-implementation. (See full survey guide in Appendix D and sample survey items in Table 13 below).

Table 13

Sample Facilitator and Barrier Statements and the Corresponding Theoretical Domains Framework (Cane et al., 2012) Constructs (and Domains)

Survey statement	TDF Construct	TDF Domain
Service-user's not knowing what options are available (Badger and Parnell, 2009)	Knowledge	Knowledge
Fear of letting go of the service-user (Cronin, 2018)	Emotion	Fear
Being skilled in the development of social stories (Cronin, 2018)	Skills	Practice Development
Availability of ready-to-use practice guidelines / checklists (Davies et al., 2019)	Environmental Context and Resources	Material Resources

Note. Response options were: 1 (not at all) -----5 (very much)

Ethics

Ethical approval was granted from the University of Stirling (NICR 2024 19575 14712) and the RehabCare ethics committees. No potential risk to HSCPs was foreseen. To ensure anonymity, no personally identifying data was collected. HSCPs had the right to take part or decline, and participation was anonymous and confidential.

Analysis

Descriptive statistics using Jamovi™ (Version 2.6.44.0) were carried out on the demographics, knowledge and understanding and barriers and facilitators sections. Content analysis (Neuendorf, 2017) was performed on the five open-text questions. Content analysis is *“a scientific, objective, systematic, quantitative, and generalizable method for describing and making inferences about phenomena”* (Chapter 1, page 9, Neuendorf, 2017).

Neuendorf’s approach moves away from simply describing data (i.e. traditional content analysis) and instead endorses an integrative approach. To do this, analysis must be synthesised with multiple sources to verify meaning and establish relationships in the data. In this study, the literature review findings, offer an empirical background within which to understand the content analysis findings. In addition, the closed question survey results can be compared with the content analysis findings to make further connections in the results.

It was originally planned to carry out between-group analyses such as t-tests or chi squares, for example comparing various roles or regions, however the number of people in each group was not sufficient for meaningful analysis.

2.2 Results

Participant characteristics

There were 118 participants, most were female (65%) and most were aged 45 and under (58.6%) and held carer or social care manager roles. The majority worked in day- or residential-services with a good spread across the three regions within RehabCare. Most staff supported service-users with autism and one co-morbidity (mostly ID), see Table 14 below for details. Please note that where anonymous participant quotes are presented, these were selected due to either novelty or richness of detail.

Table 14*Survey Participant Characteristics*

Participant Characteristic	N	%
Gender		
Male	28	23.9%
Female	87	73.7%
Prefer Not to Say	1	0.8%
Missing	2	1.6
Age		
U24	4	3.4%
25-35	32	27.3%
36-45	37	31.3%
46-55	28	23.7%
56-65	16	13.5%
Missing	1	0.8%
Type of Service Supported		
Day Services	48	40.8%
Residential Services	37	31.3%
Day & Residential	15	12.7%
Regional	17	14.4%
Missing	1	0.8%
Summary of Profile of Service-user Need		
Autism + 1 or more disability (mostly ID)	92	78.1%
Physical & Sensory Disability (no ID)	14	11.8%
Neurological Conditions	7	5.9%
ID only	5	4.2%

Table 14 [continued]*Survey Participant Characteristics*

Participant Characteristic	N	%
Role		
Carer	78	66.1%
Social care Manager	13	11%
Clinician	14	12%
Regional/Senior Manager	9	7.6%
Advocacy officers	4	3.3%
Location by RehabCare operational region		
East (Dublin N=16; Wicklow N=1; Meath N=1)	18	15.25%
Midlands West Northwest (Westmeath N=1; Galway N=33; Leitrim N=2; Roscommon N=3)	39	33.05%
South (Clare N=13; Tipperary N=10 Cork N=7; Kerry N=5)	35	29.66%
Missing	26	22.04%

Knowledge and understanding relating to the General Provisions of ADM Act

98.3% of participants were aware of ADM and 93.1% had attended ADM training. Most (63.7%) had completed 3 or more training events (mixed providers), 15.2% had attended one training with a private training provider, 15.2% completed one training via the HSE, with the remainder not responding (5.9%). Although 98.3% were ADM-aware, only 52.3% reported having enough or excellent understanding of ADM-concepts, with 10.1% reporting a little understanding and 36% reporting some understanding with 1.6% missing. When participants were asked if ADM allows service-users to make health decisions if they lack capacity, 65.3% correctly said yes, 11.9% responded 'no' and 21.2% didn't know (1.6% missing). 53.6% of participants correctly identified that 'will and preference' takes precedence, showing excellent knowledge, which corresponds with the percentage of those who reported having *enough or excellent knowledge*, (53.6%), see Table 15.

Table 15

Responses to 'What emphasis do you think the Assisted Decision-Making (Capacity) Act 2015 places on 'best interests'?

Response	Percentage
1 = 'best interests' are paramount; 'will & preference' are not emphasised at all	2.4% (N=3)
2 = 'best interests' take precedence over 'will & preference'	5.2% (N=6)
3 = 'best interests' and service-user 'will & preference' have equal emphasis	25.6 % (N=32)
4 = 'best interests' are mentioned but service-user 'will & preference' take precedence	53.6% (N=67)
5 = 'best interests' are not emphasised at all in ADM	6.4% (N=8)
Missing data	1.6% (N=2)

Note. Mean = 3.61, Median = 4 and SD = 0.8

Of the respondents who answered the best interest question incorrectly, they had all attended training except one. Regarding 'will and preference', 30.5% of participants were unaware of their legal duty to establish the individual's 'will and preference'.

Knowledge and understanding relating to the assessment of a person's capacity to make decisions

When asked if they have a responsibility to perform the functional capacity test only 45% answered correctly (yes) and only 20.6% indicated confidence in their ability to do so (see Table 16). The median score of 3 on this question indicates that most respondents have some knowledge of capacity assessment but do not feel able to conduct an assessment.

Furthermore, only 42% could outline the test questions, (see Table 2, Chapter 1), showing a significant knowledge gap with 58% unsure how to perform this critical task. Participants were also asked whether the outcome of a functional test would be impacted by a service-user making an unwise decision. 46.1% reported that they would *consider re-assessing* or *definitely re-assess* capacity if they deemed a person to be making an unwise decision, showing very poor ADM-knowledge, see Table 17. A median score of 4 on this scale suggests that unwise decision-making by service users has a substantial impact on practitioners' judgements about their capacity. Most respondents reported that such decisions would prompt them to reassess capacity.

Table 16

Responses to 'Do you Know how to Carry out a Functional Test of Capacity'?

Response	Percentage
1 =No knowledge of how to assess capacity	21.4% (N=25)
2 = A little knowledge but wouldn't feel able to assess capacity	23.9% (N=28)
3 = Some knowledge but wouldn't feel able to assess capacity	33.3% (N=39)
4 = A good level of knowledge and feel able to assess capacity	19.8% (N=24)
5 = Excellent knowledge and feel totally confident in assessing capacity	0.8% (N=1)
Missing	0.8% (N=1)

Note. Mean = 2.56, Median = 3 and SD = 1.07

Table 17

Responses to 'If you conclude that a service-user has capacity, and they wish to make a decision that could prove harmful or risky to themselves what impact would this have on your conclusion about their capacity'?

Response	Percentage
1 = No impact at all, I am unconcerned about a service-user making an unwise decision	N=9 (7.6%)
2 = No impact at all, although I am uncomfortable with a service-user making an unwise decision	N=54 (45.8%)
3 = Some impact, I would consider whether I need to reassess their capacity	N=30 (25.4%)
4 = Significant impact, I would definitely reassess their capacity	N=24 (20.4%)
5 = Significant impact, I would reverse my conclusion without reassessment	N=0 (0%)

Note. Mean = 3.41, Median = 4 and SD = 0.902

Barriers

The most supported barriers were lack of family awareness (88.1%), lack of service-user knowledge of how to make decisions (76.3%), service-user's not knowing what options are available (76.2%), lack of awareness amongst HSCPs (75.4%) and lack of opportunity to offer decision-making support (69.5%). Less frequent barriers included a culture focused on safety (37.3%), lengthy records (37.3%) and fear of letting go (35.6%). See Table 18 for the barriers, means, percentages mapped onto TDF domains/constructs.

Table 18

Results to barrier questions 'to what extent do you think this acts, or would act, as a barrier to you implementing assisted decision-making in your work?' mapped onto the TDF (Cane et al., 2012)

Barrier	Mean	Standard deviation	Not at all	Slightly	Neutral	Somewhat	Very much	TDF Domain (Construct)
Lack of awareness of the ADM Act among families	4.34	0.972	3.4% (N=4)	3.4% (N=4)	5.1% (N=6)	32.2% (N=38)	55.9% (N=66)	Social Influences (Social Pressure)
Service-users not knowing what options are available to them	3.87	1.25	6.8% (N=8)	13.6% (N=16)	3.4% (N=4)	38.1% (N=45)	38.1% (N=45)	Knowledge (Knowledge)
Lack of service-user knowledge of how to make decisions	3.88	1.15	5.9% (N=7)	9.3% (N=11)	8.5% (N=10)	43.2% (N=51)	33.1% (N=39)	Knowledge (Procedural Knowledge)
Lack of awareness of the ADM Act among HCPs	3.82	1.17	6.8% (N8)	10.2% (N=12)	7.6% (N=9)	44.9% (N=53)	30.5% (N=36)	Knowledge (Procedural Knowledge)

Table 18 [continued]

Results to barrier questions 'to what extent do you think this acts, or would act, as a barrier to you implementing assisted decision-making in your work?' mapped onto the TDF (Cane et al., 2012)

Barrier	Mean	Standard deviation	Not at all	Slightly	Neutral	Somewhat	Very much	TDF Domain (Construct)
Lack of opportunity to offer supported decision-making to a service-user	3.69	1.31	10.2% (N=12)	11.9% (N=14)	8.5% (N=10)	37.3% (N=44)	32.2% (N=38)	Environmental Context & Resources (Organisational Climate / Culture)
Service-user delegates the decision before any support could be provided	3.57	1.27	10.2% (N=12)	10.2% (N=12)	19.5% (N=23)	33.1% (N=39)	27.1% (N=32)	Social Influences (Social / Group Norms)
Difficulty in communication with service-users	3.48	1.36	11% (N=13)	17.8% (N=21)	11% (N=13)	32.2% (N=38)	28% (N=33)	Skills (Interpersonal skills)
Moral dilemmas, (e.g. balancing duty of care with allowing service-users to make their own decisions, including unwise ones)	3.52	1.20	5.1% (N=6)	22% (N=26)	11% (N=13)	39.8% (N=47)	22% (N=26)	Emotion (Negative Affect)

Table 18 [continued]

Results to barrier questions ‘to what extent do you think this acts, or would act, as a barrier to you implementing assisted decision-making in your work?’ mapped onto the TDF (Cane et al., 2012)

Barrier	Mean	Standard deviation	Not at all	Slightly	Neutral	Somewhat	Very much	TDF Domain (Construct)
Fear of being blamed or litigation if any harm came to a service-user	3.40	1.39	11.9% (N=14)	19.5% (N=23)	14.4% (N=17)	25.4% (N=30)	28.8% (N=34)	Beliefs About Consequences (Outcome expectancies)
RehabCare’s culture as primarily focused on safety rather than positive risk taking	2.87	1.39	23.7% (N=28)	16.9% (N=20)	22% (N=26)	22.9% (N=27)	14.4% (N=17)	Social Influences (Organisational climate / culture)
Having to maintain lengthy records on ADM related work	2.78	1.39	29.7% (N=35)	10.2% (N=12)	22.9% (N=27)	27.1% (N=32)	10.2% (N=12)	Environmental Context & Resources (Environmental stressors)
Fear of letting go of the service-user (i.e. feeling a need to protect them)	2.68	1.47	32.2% (N=38)	17.8% (N=21)	14.4% (N=17)	21.2% (N=25)	14.4% (N=17)	Emotion (Fear)

Many participants (N = 94 / 79.6%) provided comments in the open text box when asked about other barriers. Most responses repeated barriers already mentioned in the survey, like lack of training (N=16) lack of knowledge (N=20), lack of awareness by families (N=18), the public (N=1) and HCPs (N=2).

“Families have been given all the documentation... [about ADM] however, this is not sufficient. Families do not know about it or are choosing to ignore the legislation, making it very difficult for staff. There needs to be workshops held for parents/guardians/family members also.” (Social Care Professional)

“There is a distinct air of mistrust amongst families when the topic of ADM is brought up. Families need to be better educated about the topic. However, this should not come from services, it should come an external source via the HSE.” (Advocacy Officer)

Fear of blame or litigation was raised by several participants (N=6).

“When I answered that I am reluctant around unwise decisions, my fear is around whether I can be confident that I have truly provided all the relevant information in an accessible way, and there are no outside influences on the decision. I am fearful of litigation finding that I didn't complete this process fully and accurately, rather than fearful around people making unwise decisions. I respect and value the right to make an unwise decision.” (Clinician)

Others mentioned perceived barriers posed by service-users, like being overly influenced by others (N=2) lack of awareness or expectation around supported decision-making (N=4) refusal to engage in supported decision-making (N=1) or seeing supported decision-making as pressure (N=1).

“I see that some service-users will automatically expect others to make choices for them. So, this culture is not only rooted in the staff and family members, it's in everyone, including the person in question.” (Programmes Facilitator / Social Care Supervisor)

“I would be concerned that the service-user may feel pressured into making a decision that would just gain approval of staff/management or may make a wrong

decision (thinking that they are a burden) if they are experiencing anxiety at that time.” (Programmes Supervisor / Social Care Supervisor)

Some offered new perspectives on barriers like HSCPs being unwilling to carry out the functional test (N=1) a perception of the value of best interest’s (N=3) and staff burnout (N=1).

“Direct support staff not understanding positive risk-taking and support staff feeling stress/burnout from working with service-users who consistently make poor decisions relating to their health. As a team leader I have to maintain the mental health of staff while also ensuring service-users are supported with their own decisions.” (Team Leader)

Finally, some participants detailed lack of time and resources (N=14) as a barrier highlighting the lack of accessible resources for non-verbal service-users (N=3) and hearing-impaired service-users, suggesting subtitled videos or having an Irish Sign Language interpreter at the service-user training (N=1).

Facilitators

All facilitators were highly supported, including leadership support (94.9%), effective communication skills (94%), practice guidelines (91.5%), being skilled in breaking down decisions into relevant options (90.6%) and identifying pros and cons (90.6%). Helping service-users weigh-up information (89.8%) developing social stories and easy-reads (86.4%) and creating role-plays (88.1%) were also significant facilitators, see Table 19.

Table 19

Results of facilitator question ‘to what extent do you think this acts, or would act, as a facilitator to you implementing assisted decision-making in your work?’ mapped onto the TDF (Cane et al., 2012)

Facilitator	Mean	Standard deviation	Not at all	Slightly	Neutral	Somewhat	Very much	TDF Domain (Construct)
Strong leadership support for assisted decision-making	4.68	0.597	0%	0.8% (N=1)	4.2% (N=5)	21.2% (N=25)	73.7% (N=87)	Social Influences (Leadership)
Effective communication skills	4.68	0.690	0%	3.4% (N=4)	2.5% (N=3)	16.9% (N=20)	77.1% (N=91)	Skills (Interpersonal skills)
Policy providing clear guidance on assisted decision-making	4.62	0.691	0%	1.7% (N=2)	6.8% (N=8)	19.5% (N=23)	72% (N=85)	Knowledge (Procedural knowledge)

Table 19 [continued]

Results of facilitator question 'to what extent do you think this acts, or would act, as a facilitator to you implementing assisted decision-making in your work?' mapped onto the TDF (Cane et al., 2012)

Facilitator	Mean	Standard deviation	Not at all	Slightly	Neutral	Somewhat	Very much	TDF Domain (Construct)
Availability of ready-to-use ADM practice guidelines / checklists	4.58	0.766	0%	4.2% (N=5)	4.2% (N=5)	20.3% (N=24)	71.2% (N=84)	Environmental Context & Resources (Material Resources)
Being skilled in breaking down decisions into relevant options	4.55	0.791	0.8% (N=1)	2.5% (N=3)	5.9% (N=7)	22% (N=26)	68.6% (N=81)	Skills (Practice / Skills Development)
Being skilled in identifying the pros and cons for each option related to the decision	4.62	0.727	0%	2.5% (N=3)	6.8% (N=8)	16.9% (N=20)	73.7% (N=87)	Skills (Practice / Skills Development)

Table 19 [continued]

Results of facilitator question ‘to what extent do you think this acts, or would act, as a facilitator to you implementing assisted decision-making in your work?’ mapped onto the TDF (Cane et al., 2012)

Facilitator	Mean	Standard deviation	Not at all	Slightly	Neutral	Somewhat	Very much	TDF Domain (Construct)
Being skilled in helping the service-user to weigh up the information about the decision to be taken	4.61	0.796	0.8% (N=1)	2.5% (N=3)	6.8% (N=8)	14.4% (N=17)	75.4% (N=89)	Skills (Practice / Skills Development)
Being skilled in demonstrating or role-playing aspects of the choice as part of decision-making support	4.53	0.781	0.8% (N=1)	0.8% (N=1)	10.2% (N=12)	21.2% (N=25)	66.9% (N=79)	Skills (Practice / Skills Development)
Having a mentor to help implement assisted decision-making	4.43	0.947	2.5% (N=3)	3.4% (N=4)	6.8% (N=8)	22.9% (N=27)	64.4% (N=76)	Social Influence (Social Support)

Table 19 [continued]

Results of facilitator question ‘to what extent do you think this acts, or would act, as a facilitator to you implementing assisted decision-making in your work?’ mapped onto the TDF (Cane et al., 2012)

Facilitator	Mean	Standard deviation	Not at all	Slightly	Neutral	Somewhat	Very much	TDF Domain (Construct)
Being skilled in the development of social stories and easy-read information	4.46	0.854	0%	5.1% (N=6)	8.5% (N=10)	22% (N=26)	64.4% (N=76)	Skills (Practice / Skills Development)
Simple, quick record keeping forms	4.50	0.814	0%	4.2% (N=5)	7.6% (N=9)	22% (N=26)	66.1% (N=78)	Memory, Attention and Decision Processes (Reducing cognitive overload / tiredness)
Having a relaxed, private space to meet the service-user	4.43	0.901	0.8% (N=1)	3.4% (N=4)	12.7% (N=15)	17.8% (N=21)	65.3% (N=77)	Environmental Context & Resources (Material Resources)

Applying content analysis to the responses when asked for other facilitators (N=56 / 47.4%), most repeated facilitators mentioned in the survey, like standardised resources / templates (N=4) and more training (N=16) particularly for families (N=5) as well as communication aides (N=3) and additional time (N=4). However, some new perspectives included having a good relationship with the service-user (N=3), a good team to work with (N=4) training in the difference between offering an opinion and offering information (N=2), more advocacy support including training in advocacy (N=6) and training that is focused on either high-support (non-verbal) or low-support service-users (N=1).

“Training where it focuses on either high support or low support residents. If there is a mix the focus is usually low support service-users who have a better understanding”. (Residential Service Manager)

Some respondents (N=4) suggested establishing a committee where ADM cases could be discussed and learning shared. The rationale offered was that this prevents isolated decision-making and if disseminated could facilitate shared learning about supporting specific decisions.

“Similar to the Restrictive Practice committee, it may be helpful for such a group to be established to support managers with service-user requests. It also removes isolated decision-making and could be documented and filed and so used as a tool for other [staff] to view how specific decisions were formulated.” (Residential Service Manager)

Some respondents suggested that support for families was important as this could assist families in becoming facilitators (N=4).

“Support for families - giving up their role as primary advocate for their (adult) child's decision [making] may be a very emotional process”. (Clinician)

Supporting health decision-making

When asked what HSCPs would need, to provide *health decision-making support*, applying content analysis to the responses (N=70), new insights included more time at health appointments for information processing, especially if a service-user has cognitive or communication difficulties (N=6), follow-up support to answer questions after the initial

consultation (N=2) and equipping HSCPs with a script with the correct wording of ADM for when they encounter HCPs who lack ADM awareness (N=3).

Family education on service-users' health decision-making rights was mentioned (N=6), as well as the importance of communication aides like braille with the suggestion that if health information was fully accessible some service-users could make health decisions without family involvement (N=2).

Many respondents suggested resources to support interactions between HCPs and service-users including guides for HCPs on how to break down decisions. Also, accessible resources were detailed like pre-populated easy-read checklists of factors to consider regarding service-user's 'will and preference' on the risks/benefits of common health decisions, specifically, eating, smoking, diabetes, oral hygiene (N=14).

Some suggested specific training for supporting health decision-making (N=8) especially on the threshold for the functional test (N=1) and how to gather relevant information related to health history (N=3) addressing HSCPs fear regarding duty of care when supporting health decisions (N=1) and the importance of engaging multi-disciplinary input including medical, psychological, health promotion and public health nursing (N=23). Again, the importance of designing these resources and trainings specifically for non-verbal service-users was highlighted (N=1).

HSCPs' training needs and preferences

When asked about training needs, out of the responses (N=85; 72%), many repeated concepts from the knowledge and understanding section. These were a clear summary of ADM (N=6), clarity on roles and responsibilities (N=10), performing the functional test (N=16), embedding ADM into practice (N=1), within time constraints (N=1), including supporting a change of mind (N=1). Others suggested ideas already questioned in the facilitators section, like resources that break down decisions into relevant options (N=7).

Some offered solutions to address specific barriers mentioned in the survey, like training on how to build service-users' confidence in decision-making (N=2) to prevent them delegating decisions before any supported decision-making happens. Regarding lack of family awareness, some requested training on how to engage families as advocates for ADM (N=5) and how to resolve family ADM-related conflict (N=3).

New perspectives included training on the organisation's policy stance on service-user's right to make unwise decisions (N=3) including what records to keep regarding this (N=1) and the disability service regulator's (Health Information and Quality Authority / HIQA) view on this (N=1). An example given was marrying this policy with situations that challenge it, like a service-user deciding not to wear their wheelchair seatbelt when in motion. Also, marrying the right to make unwise decisions, with HIQA's requirements to keep service-users safe.

Suggestions centred around training approaches included seeking feedback from service-users on their decision-making experiences (N=1), using case examples from service-users (N=17) with plenty of staff interaction (N=2) and mentoring (N=1) to offer separate training workshops for HSCPs supporting non-verbal service-users (N=4) with regular refresher training (N=1) and that train-the-trainer is provided for HSCPs to train service-users (N=6). Regarding training delivery, 74.5% preferred face-to-face and 83% preferred one longer workshop rather than two shorter ones.

HSCPs' perceptions of service-user's training needs

N=70 (59.3%) respondents commented to an open-text question offering their views of service-user training needs. Many (N=17) suggested a step-by-step training on how to make decisions, including addressing fear of decision-making.

“Decision-making, whether complex, including medical decisions or where service-users will live...should also be learned from the basics, like decision-making in simple and more commonplace situations, because I believe that these set the tone for how more important decisions will be made by service-users”. (Community Support Worker)

Others suggested an easy-read version of ADM (N=13) emphasising 'will and preference' (N=1) and the steps involved in the functional test (N=1) how it replaces the Ward of Court system (N=1) and ADM-policy including positive risk-taking (N=3). Some suggested education on their right to make their own (including unwise) decisions (N=3), differentiating their role versus their families' in decision-making (N=4), confidence building within the family setting (N=2), strategies for when rights are ignored within the family and when conflict arises (N=2) and conversely, how to engage families to support their decision-making (N=2).

“Reminding them of their rights and to know that help is available to them, so they can make the best decision for themselves. [That] nobody has the right to choose for them. They can choose a friend or family member or professional to help them decide”. (Community Support Worker)

Some suggested how to access supported decision-making from HSCPs (N=3) from the decision-support service (N=1) and from advocacy officers (N=1) and what to expect (N=2). Others suggested adapting training for non-verbal service-users (N=1) and providing easy-read handouts for service-users and HSCPs to refer to, to reinforce learning (N=2). Suggested approaches included service-users bringing their own real-life decisions to the training to increase relevance and interest (N=9), using videos to spark conversations about decision-making (N=1) and role plays (N=1).

“[Use] group activities where service-users practice making decisions in a safe and supportive setting. Role-playing exercises to build confidence in everyday decision-making. Practicing how to express your choices and preferences clearly. Strategies for dealing with pressure from family, staff, or friends. Understanding the steps of making a decision (gathering information, considering options, asking for advice, and making a choice)”. (Social Care Supervisor)

Responses to the open-text question (N=15 / 12.5%) where participants were asked for any other comments regarding ADM, most (N=8) repeated barrier statements from the survey, like lack of family awareness.

“With an older population, it is difficult to ensure that ADM is implemented outside of the service, in the family home”. (Social Care Supervisor)

“People are quite individual coming from different family...backgrounds into our service. Some people and their supporters can be unaccepting of this new way of thinking. Some service-users may not feel confident...to advocate for themselves in their own home” (social care supervisor).

Other comments (N=2) illustrated the range of attitudes towards ADM between HSCPs, like this team leader: *“it is going to be very big part of our career in the future”* versus this community support worker *“not sure how it applies to my role/work”*. Some comments offered further insights into training needs like what to do when a service-user does not consent to liaising with family regarding a decision (N=1) or changes their mind (N=1). The importance of support for staff was highlighted by this clinician (N=1) *“staff need to feel*

supported by the organisation to implement the ADM and not feel daunted by it. Clear roles and responsibilities are required for frontline staff, managers and clinical staff”.

Some comments offered new perspectives on facilitators like this quote from a service manager:

“I suppose a reminder to revisit the act as there may be instances where it is not used in service for a long period of time and you do not get to practice the skills needed in the implementation of the act”.

A final comment emphasised the importance of accessible resources as facilitators to ADM engagement: “Make available braille, easy-read, audio formats, and verbal explanations to ensure full understanding.” (Advocacy Officer)

2.3 Discussion

Although almost all respondents were ADM-aware and had attended training, there were some key gaps in understanding. There was also limited awareness of their responsibility to perform functional capacity tests and poor knowledge of the questions to ask. Lack of family ADM-awareness, service-users not knowing what options are available and lack of service-user knowledge how to make decisions, were the most endorsed barriers affecting HSCP’s ADM-implementation. Conversely, strong ADM leadership, effective communication skills and clear policy were the most endorsed facilitators. Barriers to ADM-implementation for health decisions included lack of HCP ADM-awareness, lack of time and accessible resources at health appointments. Facilitators to ADM-implementation for health decisions included pre-populated easy-read checklists of the risks/benefits of common health decisions, as well as a script for HSCPs who accompany service-users to health appointments and encounter HCPs who lack ADM awareness.

Many of these survey findings are consistent with previous research, like Curtis et al., (2022) and Davies et al., (2019) who also found gaps in understanding, limited awareness of HCP responsibility to perform functional capacity tests and Hinsliff-Smith et al., (2017) who reported that *applied* training is crucial to support HSCPs’ implementation. Other survey findings concurred with previous studies, like lack of family ADM-awareness (Walji et al., 2014; Cronin, 2018) and lack of HSCP ADM-awareness (Killeen et al., 2004).

Further support for previous research was found, in that some HSCPs barriers are posed by service-users such as not knowing what options are available (Badger and Parnell, 2009) and lack of service-user knowledge of how to make decisions (Killeen et al., 2004). Given that exercising control over one's life is a key element of self-determination and community integration according to Self-Determination Theory (Deci and Ryan, 1985) these barriers are critical to address.

Findings in relation to family acting as a significant barrier are consistent with previous studies like Walji et al., (2014). However, some comments by participants identified families as *potential* facilitators. The suggestion was that service-user training should aim to inform them on their rights within the family, build confidence and self-advocacy skills and identify the steps to take when their rights are ignored by their families. The findings suggest that if family involvement was activated by service-users from this rights-based approach, that families could play an important *facilitator* role in supported decision-making. Donnelly et al., (2019) also found that *how* families are involved is crucial to them being facilitators, including being involved early. Other facilitator results aligned with previous studies such as strong leadership support (Davies et al., 2019), effective communication (Donnelly et al., 2019), the availability of practice guidelines (Davies et al., 2019) and social stories (Cronin, 2018).

Respondents suggested that HSCPs who provide decision-support to adults with ID who are non-verbal/communicate differently will require training and resources, tailored specifically to this cohort's needs. These qualitative suggestions support previous research, like Killeen et al., (2004) who found a need for good practice guidance for HSCPs on how to communicate with adults with significant communication needs.

Some of the survey's barrier results are different to previous research with Cronin, (2018), Donnelly et al., (2019) and Alonzi et al., (2009) finding stronger evidence for emotional barriers like fear of letting go, than the survey did. Some new facilitators emerged in the findings related to the mechanisms of supported decision-making. Additional statements were added to the survey by HSCPs during the survey design stakeholder consultation. All added facilitator statements were highly supported, like *breaking down decisions into relevant options*. Although previous studies evidenced effective communication (Donnelly et al., 2019) and ADM resources (Davies et al., 2019) as facilitators to supported decision-making, no previous study could be sourced that broke down supported decision-making into its component skills and tested each one. Given earlier findings that there is still not one unified approach to effective supported decision-making (Davidson et al., 2015) the

individual components of supported decision-making tested in this survey, adds to existing research evidence.

Findings from health decision-making studies show that HCPs must have a good knowledge of capacity legislation if adults with ID are to be empowered to make their own health decisions (Douglass, 2024) and where HCPs lack ADM knowledge, they act as a barrier (Cronin, 2018; Curtis et al., 2022; Donnelly et al., 2019). The current survey added to this knowledge with the suggestion of a script as a solution. In practice, this means that if a HCP wrongly seeks parental consent to carry out a procedure on an adult with ID who has already decided to proceed, accompanying HSCPs could use the script to advocate for the adult with ID. Whereas currently, HSCPs report lacking confidence in how to have these conversations with HCPs resulting in health appointments being unfairly postponed to wait for parental consent.

Although ready-to-use resources were cited by earlier researchers as being facilitators (Davies et al., 2019), the survey added to this knowledge by describing the *type* of resources to address this need, like easy-read visuals to support health decisions.

Survey results on poor HCP communication skills as a barrier, supports earlier findings, like Donnelly et al., (2019). However, new findings from the survey include participant suggestions on how to address this, by training HSCPs on the difference between *offering an opinion* and *offering information*. This is a critical skill in supported decision-making i.e. providing unbiased information. However, Browning et al.'s (2021) model of supported decision-making sees decision-supporters as active, influential participants in the process and recognises that supporters may unintentionally slip into influence or control. ADM emphasises avoiding control and protecting autonomy, therefore this participant suggestion – training in offering impartial information – is more aligned with ADM than the Browning et al. (2021) model (see section 3.1 for details).

While survey results concurred with previous studies like Cronin (2018) on how a culture focused primarily on safety is a barrier to ADM-implementation, these survey results allow for targeted interventions to tackle real practice issues. The suggestions by respondents looked for clarity on marrying the right to make unwise decisions, with state regulatory requirements in residential services, showing the depth to which HSCPs considered ADM.

Strengths and Limitations

This study only included HSCPs who work in one disability setting however, being a nationwide organisation may buffer this limitation. The generalisability of the findings beyond HSCPs working in Irish disability services may be questioned, however the results broadly align with those of previous research in other services and nations, which suggests wider generalisability. Also, the data was self-reported meaning it may be subject to social desirability bias (where respondents want to show themselves in the best possible light) or selective memory (where respondents forget details). Also, since ADM is new, there was a scarcity of previous research to consult.

2.4 Chapter 2 Conclusions

Despite most findings concurring with previous studies, the significance lies in this being the first data of its kind from an Irish disability setting, post ADM-commencement, on HSCPs knowledge and understanding of ADM and their perceived barriers and facilitators to ADM-implementation. Given the critical gaps in HSCPs understanding of ADM, an applied training intervention is required to address the salient barriers, including how to overcome lack of family awareness, and harness the power of salient facilitators, like how to use the guidelines, checklists and resources that were requested. Further implications of these findings include amendments to and dissemination of organisational ADM policy to HSCPs and service-users and the development of applied training workshops for service-users aligned with the needs identified by HSCPs.

Recommendations

Recommendations for applying these results include developing and evaluating resources (like guidelines and checklists for HSCPs) and training interventions (including tailored to the needs of HSCPs who work with non-verbal service-users) making changes to policy and onboarding practices in disability services. See recommendations section in chapter 4 for details. However, we now need to understand the service-user perspective on ADM-engagement.

Chapter 3: A focus group study of adult service-users with disabilities exploring barriers and facilitators to engaging in supported decision-making with health and social care professionals

3.0 Background

Decision-making is a key element of self-determination and community integration (Deci and Ryan, 1985). With the changes ADM brings, adults with ID enjoy enhanced rights to make their own decisions, however we need to understand how best to support them in decision-making (Cronin, 2018).

3.1 Decision-making theory and frameworks

Decision theory explores how people make decisions or choices in situations where there is ambiguity and/or difficulty. Such theories are split between two schools of thought: normative and descriptive. Normative decision theory describes how decisions should ideally be made, like the Expected Utility Theory (EUT) which states that all decisions are made to maximise utility, defined as a subjective measure of satisfaction, happiness, or value derived from potential outcomes (Von Neumann and Morgenstern, 1947). The assumptions are that individuals are rational, can formulate decision consequences without error, and can consistently rank options following logical rules. This theory does not consider other factors that could affect decision-making like emotions.

However, descriptive theory focuses on how people make decisions in real life situations, taking into account their emotional states, the mental shortcuts (heuristics) they use, as well as any information processing limitations and any biases they may be operating from. Unlike normative theory, these models incorporate psychological factors, like social influences, that impact the decision-making process. One such theory is the Theory of Bounded Rationality (Simon, 1990) of which, cognitive limitation is a key aspect, which proposes that decision-makers have limited time, information, and cognitive abilities to make decisions. Simon proposes the notion of 'satisficing' meaning people settle for a satisfactory or "good enough" outcome, rather than seeking optimal solutions (as in EUT). This theory also suggested that people use simple rules, called heuristics, to make decisions efficiently.

Another descriptive theory is Dual Processing Theory (Kahneman, 2011) which states that decision-making is the product of two systems. System 1 is fast, automatic, and unconscious, relying on heuristics and emotions and although is more prone to biases, is

efficient for everyday decisions. System 2 is slow, deliberate, conscious, and effortful. It analyses situations and makes logical, reasoned judgments, especially for complex or unfamiliar decisions, like house purchases, which require consideration of multiple factors.

There is not one single, unifying decision-making theory developed for adults with ID. Instead, research relies on adapting existing rights-based theories to understand decision processes in this population. One such example is Self-Determination Theory (Deci and Ryan, 1985), a prominent psychological theory of motivation and personality development that promotes individual freedom of action. It posits that people with ID should be enabled to exercise control over their own lives and that decision-making is a key element of self-determination and community integration. It argues that people have an innate tendency toward psychological growth and wellbeing, and when the support systems surrounding adults with ID meet three needs - autonomy, competence and connection - they flourish.

Another relevant theory is Care Theory (Thaler and Sunstein, 2008), a philosophy that emphasizes the moral significance of interpersonal relationships, compassion, and the responsibility to meet the needs of vulnerable persons. In practice, it involves an empathetic approach that prioritizes nurturing relationships and responding to individual needs rather than adhering to rigid rules. Recently, Care Theory merged with a concept called Choice Architecture (Thaler and Sunstein, 2008) to form an approach to supported decision-making. Choice Architecture is defined as the deliberate practice of structuring the environment in which the person makes decisions, to simplify choices and make the individuals' goals easier to achieve.

Models of Supported Decision-Making

Moving onto models of supported decision-making, one by Browning et al. (2021) describes a dynamic interaction between the individual's will and preferences and these components: the experiences, attributes and beliefs of the individual and their decision-supporter; the quality of their relationship; the decision-making environment and the nature and consequences of the decision (Casey et al., 2024).

A literature review explored how family carers support people with profound and multiple disabilities in decision-making and explored two models of supported decision-making (Ryan, 2018). The first is a Canadian model by Bach & Kerzner (2010), Maximising Decision-Making Capability, which views supported decision-making as a process within which adults with ID move between three statuses, as their abilities and supports fluctuate. These statuses are 'legally independent', 'supported decision-maker' and 'facilitated

decision-maker'. This model however is misaligned with ADM which presumes everyone to have capacity ('legally independent') unless proven otherwise. The second is The Support Model (Flynn and Arstein-Kerslake, 2014) which emphasises universal legal capacity, rejects capacity assessments that remove rights, focuses on enabling environments (like accessible information) and suggests we interpret a person's imagined will and preferences.

A recent systematic review of experiences of everyday decision-making amongst adults with ID, their care partners and support workers carried out by Casey et al. (2025a) (see section 4.3) highlights the La Trobe supported decision-making framework. Core elements of La Trobe are noteworthy despite being rooted in the Australian jurisdiction. An evidence-based framework to guide supporters in helping people with ID, it is one of the most widely referenced supported decision-making approaches internationally, designed to uphold autonomy, rights, and person-centred practice. Built on two core principles that everyone has the right to participate in decision-making and people may need support to exercise that right, it's key components include three domains of support: knowing the person (understanding their communication style); providing decision-making support (offering options in accessible formats) and the decision context (ensuring the person is not pressured). Although a deeply respected model, as it is rooted in Australia's jurisdiction, it may not fully align with ADM.

Davidson et al. (2015) carried out a literature review of how supported decision-making is understood, implemented, and evaluated across different countries and found that there is no single definition or model. Approaches range from informal support from family or friends to legal supported decision-making agreements. They also found that supported decision-making is associated with greater self-determination, increased participation in decisions, improved confidence and wellbeing and stronger relationships. Although, supported decision-making is widely endorsed as an ethical and rights-based approach, authors caution against repeated questioning in supported decision-making, as this can unintentionally undermine autonomy. They conclude that supported decision-making implementation is inconsistent and evidence on what works is limited (Davidson et al., 2015).

In summary, current understanding of decision-making in adults with ID blends learning from cognitive psychology with an emphasis on rights-based frameworks with the crucial role of the social systems around the individual, in enabling autonomy, emphasised throughout. Challenges across these approaches include how to interpret the 'will and preference' of people who communicate differently, how to appoint the decision-supporter and how to avoid unintentionally applying substitute decision-making (Flynn and Arstein-Kerslake, 2014).

Relating the Assisted Decision-Making (Capacity) Act (2015) to decision theory and supported decision-making frameworks

On the surface it appears that ADM (see chapter 1 section 1.1 for description) operates from a normative approach, in asking decision-supporters to test capacity by asking three questions in a fixed sequence, under the assumption that people make decisions in this way. Yet we know from research that people with ID don't necessarily think about decision-making in these abstract terms or follow these steps (Webb et al., 2020).

Conversely, it could be argued that ADM appears to adopt a descriptive approach in that it makes provision for upholding a person's right to make unwise decisions. In this way, ADM aligns with the cognitive limitations concept that the Theory of Bounded Rationality (Simon, 1990) speaks to, i.e. that people won't always decide, based on optimal utility.

In addition, ADM could be criticised for forcing a 'system 2' approach (as in the Dual Processing Theory: Kahneman, 2011) to *all* decisions by persons whose capacity is questioned, as in the case with the fixed questions in the functional test, which checks a person's reasoning. This is counter to the Dual Processing Theory (Kahneman, 2011) which states that most everyday decisions are made by system 1 in an automatic, quick fashion rather than system 2 which relies on slower more considered approach that is more aligned with ADM's functional test. This is potentially holding adults with ID to a higher standard than the rest of the population in having to adopt a standardised approach to decision-making and not rely on heuristics.

Despite Care theories (Thaler and Sunstein, 2008) providing the ethical compass, ensuring that the Choice Architecture "nudges" and structured choices are rooted in a deep, understanding of the individual's preferences, this approach could be criticised for not fully upholding a person's rights under ADM. This is because Choice Architecture involves some 'interference' by HSCPs or family - and as such, possibly represents a return to the paternalistic best interest's approach.

Contrasting ADM's legal framework to Browning et al.'s (2021) practice model of supported decision-making, some components are opposing. ADM asks that decision-supporters assist the person without substituting their will, however Browning et al.'s (2021) model sees decision-supporters as influential participants in the process. The model recognises that supporters may unintentionally slip into control as context changes. While ADM focuses on protecting autonomy, Browning et al. (2021) show how difficult it is to avoid influence naturally emerging in practice.

ADM could be criticised for placing a lot of responsibility onto decision-supporters; however, this reliance on support systems is aligned with best practice according to Self-Determination Theory (SDT) (Deci and Ryan, 1985). Further commonalities between ADM and SDT are that both advocate for the rights of adults with ID to exercise control over their lives via decision-making, which SDT views as a key element of self-determination and community integration. Overall, ADM is a significant progression from the former act, in terms of upholding the right to autonomy for adults with ID.

Previous research into decision-making amongst adults with intellectual disabilities

One study aimed to examine decision-making capability regarding social situations in people with ID at different stages of the decision-making process (Funsinska-Korpik and Gacek, 2024). 80 vocational school students with mild ID were compared to 80 controls on their ability to make life decisions. This study also found that the most notable difference between the groups occurred during the evaluation of alternatives, where adults with ID struggled to identify the advantages and disadvantages of alternatives, which may relate to abstract reasoning difficulties. The second biggest difference between the groups was the students with ID struggled to identify the problem in the decision-making situation. This shows that the ID group started to struggle at an early stage of decision-making. The generation of alternatives was not as difficult for the ID group as evaluating alternatives was, which contradicts previous research by Suto et al. (2005) who found people with ID struggle with both generating and evaluating alternatives. However, Fusinska-Korpik and Gacek, (2024) only looked at one decision-type and only included adults with mild ID (no co-morbidities) from one school.

A recent systematic review on the views of adults with ID on autonomy and decision-making in everyday life, found that people with ID feel their autonomy is not prioritised and that decisions are often made for them (Sheerin et al., 2026). The findings suggest the need for the systems around the person to be mobilised to support the autonomy of people with ID. However, the research studies included, used a variety of different ways of collecting and analysing data, which resulted in variation across the findings of the systematic review. Researchers recommended that further studies investigate how adults with ID's level of independence are affected by the attitudes of the societies / communities in which they live (Sheerin et al., 2026).

Carey (2021) formed a grounded theory on choice and autonomy in decision-making practices among adults with ID. This theory states their primary concern was control specifically, how to navigate environments that were often controlling of them. Participants regularly encountered systems, routines, and interpersonal issues that limited their ability to make independent decisions. Carey also found that participants formed emotional responses to cope with constraints — including trust and the desire to avoid conflict - which influenced whether they complied with or opposed restrictions. Participants often altered their behaviour to comply with rules even when these reduced their autonomy. Although this was ‘compliance’, it was an active strategy to navigate everyday life and avoid conflict. Carey’s theory provides a conceptual account of how adults with ID manage the tension between independence and living in settings that prioritise safety, routine, or organisational needs over service-user’s choice. In conclusion, while there is some research into the decision-experiences of adults with ID, it is limited and more research is needed (Casey et al., 2023) particularly within the context of ADM-implementation.

Study aims and research question

There have been several barriers highlighted to service-users’ engagement with ADM, but few have been specific to ADM-engagement by adults with ID in Ireland (see section 1.2.5). The aim of this study is to gain insight to the barriers and facilitators to active ADM-engagement by adults with ID in Ireland. A secondary objective was to make recommendations for training interventions and comment on implications for policy. The research question was, what are the perceived barriers and facilitators to ADM-engagement, by adult service-users with ID in an Irish disability setting?

3.2 Methods

Design

Focus groups were conducted to explore service-users’ barriers and facilitators to ADM-engagement. Focus groups are commonly used in research with people with ID because the group provides a comfortable setting with natural peer support whereas interviews with a researcher may seem intimidating. Also focus groups have been found to be an effective method of carrying out exploratory research with adults with ID (Fraser and Fraser, 2011). Furthermore, participants don’t require literacy skills. Advocacy officers, who facilitate a

service-user representative forum, called the National and Regional Advocacy Committee (NRAC), advised that in their experience of carrying out service-user consultations, small sized (5-7), face-to-face focus groups yielded the best engagement.

However, focus groups carry risks like dominant participants influencing other's views and confidentiality concerns which the researcher must manage (Sim and Waterfield, 2019) but, in this instance, focus groups were preferable given that they facilitate a richness of detail in the data, which was important, as ADM is new. One-to-one interviewing was offered as an option to ensure the voices of those unsure/unwilling/unable to attend a focus group could be heard (as well as the option to answer the questions by email). However, all participants opted for focus groups.

Sample and sampling strategy

Participants were identified via advocacy officers who recommended recruiting from NRAC. A sample size of 15 was the aim because in similar qualitative studies 15 participants across 3-5 focus groups is sufficient to reasonably expect to gain a diversity of views towards data saturation, the point where additional participants no longer contribute new views (Bloor et al., 2001). However, Braun and Clarke (2006; 2019) are critical of data saturation, particularly in the context of reflexive thematic analysis (RTA), arguing that it is inconsistent with RTA's values. Their view is that data saturation is often used as an easy reason to cease data collection. Instead, they encourage researchers to embrace the unknown, bringing their own culture, values and experience to the data, believing that meaning is constructed from the data, rather than emerging. Due to further considerations like travel, time and small group size, a sample of 15 was decided.

Participant recruitment

Easy-read participant information leaflets (PILs) and consent forms were emailed to advocacy officers in locations in the east, southwest and west of Ireland (Wicklow, Limerick and Roscommon respectively) as a recruitment strategy, to get representation across Ireland and to obtain a gender balance as much as possible. The advocacy officers brought the PILs and consent forms to a face-to-face NRAC meeting and described the study to members. All interested members who met the eligibility criteria (English-speaking adult service-users)

were supported by the advocacy officers to complete the consent forms at the NRAC meeting.

The consent form explained the right to opt in, opt out and withdraw. Should participants have support needs during the focus group, they were reassured that the researcher or advocacy officer would provide support or contact their keyworker. Advocacy officers returned the signed consent forms to the researcher. It was then agreed that the focus groups would be held on the date of the subsequent NRAC meeting in each location (October/November 2024).

Topic guide

The focus group had three parts. First, an icebreaker to help participants settle in. Each participant was asked their name, age (or age-range if they preferred), county and country of origin, type of service they attend and favourite food. First name only was asked to preserve anonymity and yet, build rapport; favourite food because most service-users can discuss food easily and county because service-users often ask new staff this question as it is an important part of Irish identity.

In part two participants watched an ADM-video so that everyone could contribute to the discussion even if unfamiliar with ADM. The video (8 minutes 47 seconds) was from the Decision Support Service (DSS), which promotes ADM-awareness and provides balanced ADM-information. Entitled, '*Assisted Decision-Making Capacity Act 2015 A Short Guide - Explainer Video*' (<https://www.youtube.com/watch?v=xOd72CVcBCA>) this video was selected because it's led by people with disabilities, who summarise key ADM messages in plain English.

Part three included 8 questions (see Appendix G for the full topic guide) about ADM-awareness, decision-making skills and barriers and facilitators to ADM-engagement, like *do you think you know enough about how to make decisions?* Developed by the researcher, the topic guide was informed by previous studies that explored patient barriers and facilitators to ADM-engagement in healthcare settings (see Table 10 and 11, Chapter 1). It included a specific question about health decisions, given the evidence in the literature that health decisions can be particularly challenging, due to their consequences being vague and often long-term and the complexity of the information to be processed (Douglass, 2024).

Stakeholder consultation

Service-users were consulted on the draft focus group questions by the advocacy officers at an earlier NRAC meeting, and no changes were suggested. However, the advocacy officers recommended each question have a paraphrased alternative to aid comprehension.

Procedure

One focus group was held in each of the following provinces, Connaught, Munster and Leinster, facilitated by an advocacy officer (whom participants knew) and the researcher and was recorded using a digital voice recorder. Advocacy officers reminded participants how, at a previous NRAC meeting, they discussed the study, including that the focus group would be recorded, and showed participants their signed consent forms, as a reminder. All participants were given an option to change their mind, but everyone verbally verified consent.

After the icebreaker, participants were offered an opportunity for questions and then the video was played, after which, the voice recorder was activated, and questions began. The advocacy officer's role was to check comprehension and offer encouragement. The focus group closed with the researcher thanking them for participating and offering cakes for their tea-break provided (which they did not know in advance in case it swayed people to participate).

Ethics

Ethical approval was granted from the University of Stirling (reference number: NICR 2024 19575 14712) and RehabCare ethics committees.

Analysis

Focus group data were analysed using RTA, a method for identifying, analysing and interpreting patterns of meaning ('themes') across qualitative data (Braun and Clarke, 2006; 2019). RTA was selected because the aim was full data immersion and the flexibility for codes to evolve as data familiarisation occurred, rather than being limited by a codebook.

Also, as the researcher is an experienced practitioner psychologist, RTA facilitated their culture, values and experience to be applied to aid deep interpretation.

Role and Importance of Reflexivity in RTA (Braun and Clarke, 2006, 2019)

Reflexivity is the process of critical reflection in which the subjectivity of the researcher is central to the process, as in the researcher constructs the codes and themes *from* the data rather than ‘finding’ them *in* the data. In this way, subjectivity is viewed as a resource rather than a potential bias to be managed (Braun and Clarke, 2019) and can be applied from the data collection / focus group phase (such as listening with empathy and genuine interest) through to the analysis (such as using an interpretive approach, see below). This process allowed reflexivity to be operationalised and added validity to the interpretations.

In RTA, coding can be semantic - where it looks at surface meaning only - or latent, where the researchers look for more deeper, hidden assumptions and meaning underlying the data surface. Applying reflexivity, it was important to use a latent approach to coding, which was repeatedly discussed at supervision where the researcher was challenged to defend their choice of coding and later, positioning and boundary of the themes. This process involved defending the coding, which was sometimes successful, resulting in no coding changes and at other times, unsuccessful, resulting in re-consideration and adjustment of codes. For example, a code that was categorised as *‘decision-making rights not upheld’* was challenged at supervision and upon reflection, was separated out and changed to *‘not my decision’*.

It was important for the researcher not to let previous studies influence their coding, to facilitate a more data-driven, bottom-up or inductive approach (Braun and Clarke, 2013). This allowed the researcher to not only construct meaning from participants views but also to consider the wider context in which their experiences occur. However, at times the codes that were constructed by the researcher happened to link directly to previous studies and where this occurred, it was discussed and defended at supervision. For example, the sub-theme of *‘negative perceptions’* supported earlier findings by Webb et al. (2020) who found that people with ID face barriers to independent decision-making, by holding perceptions that decisions are difficult.

Furthermore, the coding process took both a descriptive and an interpretive approach - descriptive as in, each code described what the participant said and interpretive as in the researcher utilised their practitioner skills and their knowledge of the service-user’s needs and familiarity with the context of disability services, to consider a deeper meaning. This was important because given the nature of their IDs, at times participants could not articulate the

reason or link between the experiences they were describing and decision-making. For example, participants shared experiences of bullying and stigma but could not explain how this impacted their decision-making. The researcher interpreted this on the participants' behalf but also related it back to relevant previous literature.

In the write-up, which is a continuation of the analysis phase (Braun and Clarke, 2013), the researcher continued to notice further changes that were required in terms of the positioning of the codes within themes and further latent relationships between codes were made. Also in this phase, links are made to previous literature which facilitates a deeper interpretation of the themes which results in further latent patterns or relationships being formed. Performing this helps the researcher to not only further comprehend, but also to respectfully and adequately represent the important views, needs and stories of the participants (see Table 20 for the procedure).

Table 20

Reflexive Thematic Analysis (Braun and Clarke, 2006; 2019) steps

Phase	Tasks and key components
1. Familiarisation	Active listening to the audio files before transcription. No codes were created because the aim is to become familiar with the whole dataset and for codes to evolve as data familiarisation occurred. Audio files were then transcribed into Microsoft Word.
2. Initial coding	A reflective journal was commenced, to track code evolution. Each transcript was uploaded into NVivo™ (QSR International) and initial coding began. Each code (i.e. a word or phrase that captures meaning from a data segment) was then revised as part of an iterative process that was carried out until no new codes were identified. E.g. <i>'tension between desire to make own decisions and fear'</i> was re-coded <i>'tension between independence and risk'</i> . 18 initial codes were created from the first transcript, with two additional codes identified in the second transcript and none in the third, totalling 20 codes across the dataset.
3. Generating initial themes	Focus shifted from interpreting individual data items to interpreting meaning across the dataset. Themes were identified by gathering codes that related to similar concepts together in NVivo™ (QSR International) e.g., a theme called <i>'About Decisions'</i> was identified which contained these sub-themes: <i>'factors to consider in decision-making'</i> , <i>'decision outcomes'</i> and <i>'health decision-making'</i> . Three other themes were identified at this point: <i>'supported decision-making'</i> , <i>'Challenging Decisions'</i> and <i>'Awareness of Decision-Making Rights'</i> . Themes were handwritten in the researcher's reflective journal with their component codes listed but also on an A4 sheet which was hung on the wall. Both measures allowed for the researcher to see at a glance, each theme and its component parts, which facilitated checking if each theme continued to reflect its contents appropriately.

Table 20 [continued]

Reflexive Thematic Analysis (Braun and Clarke, 2006; 2019) steps

Phase	Tasks and key components
4. Developing and reviewing themes	Themes were then refined to ensure each represented its component items and had sufficient data to justify it. If not, themes were merged, e.g., theme <i>Awareness of Decision-Making Rights</i> was merged with sub-themes <i>Societal Challenges</i> and <i>Public Campaigns About ADM</i> to become <i>Social Influences</i> . This theme was re-defined as: the issues participants raised that reflect the societal context in which they make decisions. Other themes identified at this point were <i>Accompany Me! Practical Decision-Making Supports</i> , <i>All My Life Decisions Have Been Difficult (Perceptions)</i> and <i>It's Your Decision! (Decision-Making Strategies)</i> .
5. Refining, defining and naming themes	A deep analysis of each theme's underlying items was carried out, which involved examining each themes contents, resulting in thematic maps V2.0, V3.0 and 4.0. Following defending the themes at supervision, further refining occurred, resulting in thematic maps V5.0 and finally, V6.0 (created on 18.08.2025) containing three final themes. Naming of the final iteration of the themes was conducted in this phase also. The final themes are <i>intrinsic factors affecting decision-making</i> ; <i>Social influences on decision-making</i> and the <i>Which, Who, How of supported decision-making</i> . (In the Results section, see Figure 1 for the final thematic map V6.0 and Figure 2 for a screenshot of the final NVivo™ (QSR International) structure).
6. Write-up	This phase involved writing up the process of Reflexive Thematic Analysis (Braun and Clarke, 2006; 2019), which is a continuation of the analysis phase (Braun and Clarke, 2013). In this phase the researcher continued to notice further changes that were required in terms of the positioning and boundaries of codes within themes and further latent relationships between codes were made.

3.3 Results

Participant characteristics

12 male and 4 female (which is representative of the Irish male to female ratio of adults with ID: 57% male; 43% female; Health Research Board, 2018) participants aged 24-62 (mean 39.3) took part in one of three focus groups (see Table 21). All participant quotes are anonymised by using pseudonyms and were selected due to either novelty or richness of detail.

Themes

Three themes were developed from the focus group data. These were, theme 1: *intrinsic factors affecting independent decision-making*; theme 2: *social influences on decision-making* and theme 3: *the which, who, how of supported decision-making*. The three themes are detailed below.

Table 21*Focus Group Participant Characteristics (N = 16)*

Region	Gender (N)	Age Range (years)	Service Type (N)
Connaught	Male (4) Female (1)	35 - 62	Day Service (5)
Munster	Male (3) Female (1)	38 - 54	Day Service (3) Day & Residential (1)
Leinster	Male (5) Female (2)	24 - 62	Day Service (7)

Theme 1: Intrinsic factors affecting independent decision-making

Participants reported regularly making decisions independently. Understanding when and how they do this, would help in identifying when decision-support is and isn't required and what form it should take, to enhance the natural decision-making strategies that adults with ID already use. This theme captures the intrinsic factors that help and hinder adults with ID to make decisions independently.

Participants proudly described using mental shortcuts (heuristics) to make decisions independently. One participant, Alex, described a self-questioning strategy: *"Sometimes I try to do it without asking [for support]. Can I do this? Is this hard? Or is this challenging?"*. Another participant, Mark, described a black and white strategy *"the way I do is, try once...if you don't like it, don't do it again"*.

Other participants described perceiving they had made decisions independently despite receiving light-touch support, like Maya who decided independently to attend respite despite consulting her mother: *"I made it [the decision] myself. But I spoke to my mam about it. So, it was kind of like, myself"*.

Another participant, Ryan uses a strategy of asking himself what he valued most about the options, to decide independently, even after consulting with his parents:

I'm bowling [on]...Saturday...if they put me here [outreach] on Saturday...that clashes...in the end you have to try and work it out. I would have to make a decision what's important to me. I have to cancel outreach and tell [staff] it's more important to me. Because...I discussed with my parents. And then I have to work it out myself. What to do then? Do what's important.

An older participant, Chris, described using a strategy of determination (“put my mind on it”) to decide independently about an invasive health screening:

I had a decision last year. I lost my father from cancer. So, I said, you have to look after yourself. And I said I want to sit down and make an appointment for the check-up. So, down I went to...local doctor. I said, I want your checkup done. I want to, well, I was thinking about my dad and the cancer. Is there any chance you can check my whole body?... They put some stuff in you...like washing up liquid...to clean out your system. But I never looked back after that. [Staff] called me in the next day, well how did ye get on? Wasn't too bad [staff]. Clean out now, ye know. Ye wouldn't wish it on an animal. But was glad I done it. I wanted to do it; I put my mind on it and I done it.

These findings are evidence that not all adults with ID require support to make decisions all the time and that decision-support should not be assumed to be required unless the person asks for help. The results also inform us of the type of heuristics that adults with ID use, which could be shared with others who lack such strategies, in a peer group. They can also inform a co-produced guide on how to make decisions, for use with other service-users.

Despite participants making some decisions independently, they described factors that are barriers to making other decisions independently. These barriers included negative perceptions about decision-making and lack of awareness of their rights. Starting with negative perceptions, some participants shared cognitive barriers like Zac who said, “*All my life...decisions have been hard to make*” yet when this older male participant was questioned, he couldn't say why this was. The perception of deciding about something new got mixed reactions, with some reporting this as a neutral (it would make no difference) and others reporting it a barrier (it would make decisions harder). Another negative perception identified was that some decisions are ‘bigger’ than others, with bigger decisions requiring support, but participants couldn't explain why.

An important negative perception that participants shared was that some decisions are ‘*not theirs to make*’, such as Maya, who described a GP referral that she believed was her doctor’s decision:

I was in hospital this year, I had to get the camera... but that was my doctor's decision to make me go, it wasn't mine...the doctor first sent me for a scan on my tummy and then he sent me for the camera. So, it [the decision] wasn't really mine because he sent me for two things.

The perception that they do not have the right to make certain decisions was shared by Joey, who describes how, although a place in supported accommodation (on the site of the day service he attends) may become available, his mother wouldn’t allow it:

...my mother said if I was to get a place here, she wouldn't let me...because she knows what this place is like...she knows there's loads of junkies around...because that's what she said.

Conversely, other participants showed awareness of the right to make their own decisions including health decisions, like Ryan:

I have to go to the hospital ... I had to get ECG or EKG done...I'm not sure, but then mum said to me, it's your own decision, if you want to do it, get it done.

Theme 2: social influences on decision-making

This theme captures participants descriptions of the wider social context which positively and negatively influence their engagement in decision-making. One social influence, a facilitator, was ADM-awareness campaigning. All participants (except two) were ADM-aware, having heard about it via media advertisements or advocacy initiatives. Participants, such as Mark, spoke about the helpful impact of these advertisements, in informing their families of their rights:

I always have to talk to my mam about stuff and she wants me to be happy. She's still like... you know, you're in a wheelchair, blah, blah, blah. And...I showed her that [advertisement] on the telly, and she was like, 'OK, now I get it, we can't say anything to you now!'

This parent's interpretation of ADM was that she needed to give her adult son the freedom to make his own decisions and Mark described how this pleased him. This illustrates how ADM campaigns educate families on the importance of adopting a rights-based approach with their loved one. Mark spoke further about his mother's active encouragement:

...my mam is like...you can make the decision yourself, but you'll have to deal with the consequences. She would say it's your decision and she kept saying that. That's just what you do with decisions because if I asked my mam, like she would help me, but then she would be like, if you're old enough to get a job, you're old enough to make them decisions on your own.

However, some participants experienced family influence as a barrier, reporting their decision-making rights being ignored. Mila spoke about how, despite living in supported accommodation, when she visits her parents overnight, she is not treated as an adult *"They treat me like a child"*. For Mila, there was a stark contrast between the HSCP approach and that of her family. This was echoed by Finn who reported *"My family will not care about that [ADM]...no, they haven't heard about it, moving on"*.

Specific to decisions around progressing independence, another social factor which forms a barrier to ADM-engagement is bullying. Several participants spoke about being bullied in the community, like Dennis, who has a visible disability: *"It's hard, you get you called at"*. When she mentioned this, several others shared their own bullying experiences. This seemed to form a tension between the desire to live a fully independent life in the community and the risk this brings. This tension in turn, appears to be a factor that participants consider when making decisions to take part in their communities, because they fear what the consequences may be. For example, Mark describes the stigma he experienced following a decision to take up employment:

I was working down at the carnival and like...people's perceptions are like...ah you shouldn't be doing that, you're, you know, in a wheelchair. But I said I made that decision to do it. I'm paid to do it. That's funny the way they are 'oh, that's terrible, he's in a wheelchair'.

This is corroborated by Sammy, who experienced stigma following a decision to travel:

Yeah, so I was in San Francisco... cabin crew on the plane [saw my tablets and asked] do you suffer from epilepsy? I said I do. Said to me how many times you get seizures? I said a couple of times. He said to me, like, how does someone like you

cope with the epilepsy? I just think like there's a lot of stigma going around...I don't like it.

Although Sammy expressed irritation about the stigma he experienced, he did not let this deter him. However, it seems that people with disabilities are aware that if making a decision that results in them taking a visible part in their communities, it may result in experiencing stigma or bullying. Although this didn't deter the above two participants, it may deter others from making decisions to further their autonomy.

Within this theme, disability rights issues were also identified as barriers. Poor experience in services was one rights issue reported, for example, an older participant, Zac, who reported observing staff not upholding the decision-making rights of his peers. However, he noticed a positive shift however towards a rights-based approach: *"They all had their decisions made for them, but it's all fixed up now, they turned that place around"*.

Participants also reported feeling their rights were unrepresented in government policy and highlighted inequalities like paying for some healthcare services despite living on disability benefit and a lack of healthcare services to meet their needs. For example, Sammy, spoke about the benefit of speech and language therapy in helping him communicate effectively, a key aspect of decision-making, however it ceased:

Yeah, the government are not great for keeping up promises. I couldn't read or write properly...and my speech, I had to get therapy. But then when I was at school, it stopped...it's ridiculous. I don't trust this government. I don't trust the decision-makers. ...This government, they are so slow with people with disabilities, their speed is so slow.

Theme 3: The which, who, how, of Supported Decision-Making

This theme highlights the facilitators of supported decision-making by identifying *which* decisions participants require support with *who* they value as decision-supporters and *how* they wish to be supported. These facilitators apply not only in decision-making but also in decision-implementation. Knowing *which* decisions they require help with, seemed to facilitate participants in seeking support. Types of decisions participants sought help with were education, work and service-based (e.g. choosing a course); financial and legal (e.g. jury duty); lifestyle (e.g. attending a respite trip) and health (e.g. having an MRI).

Another facilitator to participants engaging in supported decision-making, is identifying *who* to approach for support, like advocacy officers, about moving into supported accommodation; GPs about jury duty and family about going to respite. Knowing who to approach was helpful to participants in accessing decision-making support.

Participants also described *how* they prefer to be supported to make decisions. Several reported having a family discussion was a helpful decision-support strategy, like Peter:

Yeah...as a family...sit together and discuss the decisions that maybe you might be making, that wouldn't be the right decisions. And I think that's the right way to do things. To talk about things.

Another strategy that participants reported helpful was having information relevant to the decision presented in accessible ways, like enlarged text, and information that is better laid out, with less text and more images. Highlighting the pros and cons was another approach participants valued, as well as identifying the consequences, as described by Mark, who was supported by a HSCP to decide about a literacy course:

I [said] I don't want to do that...I was kind of being like stubborn...She said, 'that's your decision, but just [here are] the ways it's going to help you'. I find like they have to support ye here...I'm learning [a] literacy course. And I wasn't going to do it. And then, I asked [staff] and she [said] look at all the positive things. And then I did it and I love it.

Participants also reported valuing when supporters help them to *implement* a decision, such as enrolment onto a course they had selected. Others reported accompaniment as helpful in decision-implementation, like Ryan, who described having an accompanying note-taker at dental appointments was important because he has accurate information to inform treatment decision discussions:

I have all my dates booked in with them [the dentist] and they give me a...card and I just say it to mum, I'm just going for a check-up...So, I clear it here with staff and [staff] takes my notes. And then I just gave them [notes] to her [mum]. And then I just do my own thing ye know.

Sammy described valuing his sister's support to co-sign financial documents, such as when opening a savings account or withdrawing large sums of money:

I remember when my mum passed away...my sister helped me so I can take it [money] out. They [my family] keep an eye on it, like just in case anything happens...so, I went to Bank of Ireland and now my sister co-signs.

For a summary of these themes, see Figure 1 below for Thematic Map V6.0, showing the themes and sub-themes and Figure 2 below for a screenshot of the thematic structure in NVivo™ (QSR International).

Figure 1 Thematic Map V6.0

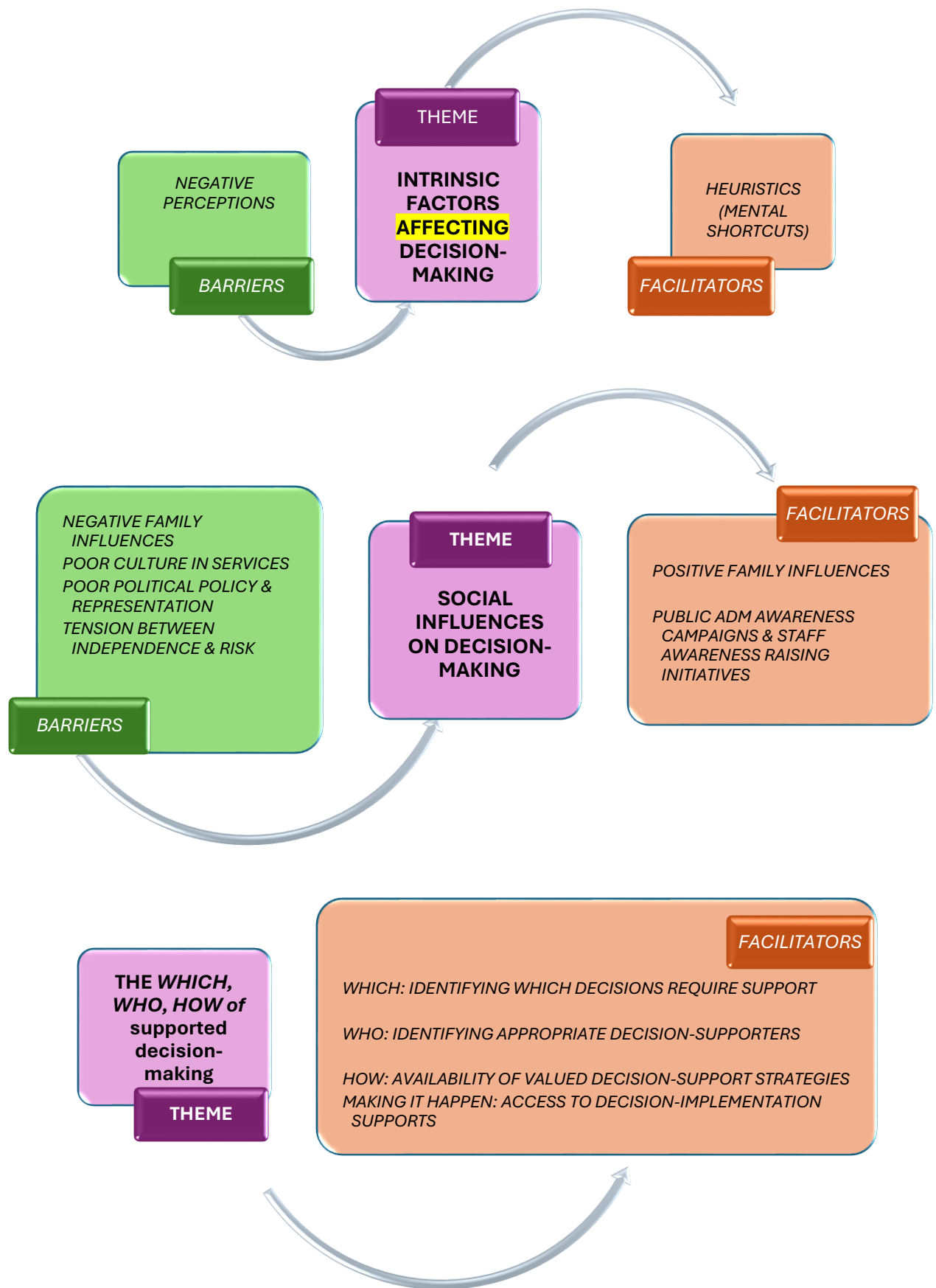


Figure 2

Final NVivo™ (QSR International) Thematic Structure

Name	Files	References	Created on	Created by	Modified on	Modified by
○ Intrinsic Factors Effecting Decision Making	0	0	14/03/2025 1	SA	26/01/2026 14:4	SA
○ Availability of heuristics (mental shortcuts)	2	16	16/04/2025 1	SA	09/02/2026 14:2	SA
○ Negative Perceptions	0	0	14/03/2025 1	SA	09/02/2026 14:2	SA
○ Social Influences on Decision-Making	0	0	16/04/2025 1	SA	26/01/2026 14:4	SA
○ Family Influences	3	11	13/03/2025 1	SA	25/08/2025 20:2	SA
○ Poor Culture in Services	1	9	25/03/2025 1	SA	16/04/2025 10:1	SA
○ Poor Political Policy & Representation	1	7	10/03/2025 1	SA	16/04/2025 11:0	SA
○ Public Campaigns & Staff Awareness Raising Initia	3	9	13/03/2025 1	SA	12/10/2025 16:0	SA
○ Tension Between Independence & Risk	1	4	16/04/2025 1	SA	29/08/2025 16:4	SA
○ Which, Who, How of Supported Decision-Making	0	0	16/04/2025 1	SA	12/10/2025 15:5	SA
○ How - Decision Implementation Strategies	3	10	07/04/2025 1	SA	09/02/2026 14:2	SA
○ How - Decision Support Strategies	3	7	07/04/2025 1	SA	12/10/2025 16:1	SA
○ Which - Decisions Require Support	0	0	10/03/2025 1	SA	12/10/2025 16:1	SA
○ Who (Identifying decision-supporters)	3	16	07/04/2025 1	SA	12/10/2025 15:5	SA

3.4 Discussion

Summary of key findings

Although almost all participants were ADM-aware, there were gaps in rights awareness and decision-making knowledge. Three themes were identified using RTA (Braun and Clarke, 2006; 2019): *Intrinsic factors affecting independent decision-making*, including facilitators like the availability of heuristics and barriers like negative perceptions of decisions; *Social influences on decision-making* including barriers like stigma and facilitators like family encouragement and *The which, who, how of supported decision-making* including facilitators like identifying *which* decisions require support, *who* to access for decision-support and *how* they wish to be supported to make decisions.

Theme 1, intrinsic factors affecting independent decision-making

Results of the current study concur with previous findings that adults with ID have negative perceptions towards decision-making, which seem to prevent them making some decisions independently. Therefore, training interventions and resources should, not only increase decision-making capacity but also address these perceptions (Webb et al., 2020). Davies et al., (2019) found that having a good relationship with the decision-supporter was a facilitator to patients engaging in supported decision-making. The current study illustrates the importance of decision-supporters providing reassurance within the context of this supportive relationship, to counteract these negative beliefs. Such beliefs must be addressed early in the process, because previous studies inform us that patients sometimes delegate decisions to others before any supported decision-making is offered (Donnelly et al., 2019). This is further evidence for previous findings that involving the patient early is important in facilitating their supported decision-making engagement (Davies et al., 2019).

Previous research highlighted that many adults with ID can and do make decisions independently and how important it is that research acknowledges this, to avoid forcing decision-making support on adults with ID from a paternalistic misconception that they all require it (Casey et al., 2023). It was clear in the current study that many participants use heuristics to make decisions independently, like the general population. Some participants shared their heuristics, like trying something once, which aligns with Simon's (1990) theory of bounded rationality. This proposes the notion of 'satisficing', the idea that people settle for a "good enough" outcome, rather than seeking the optimal solution. Participants' heuristics also align with what we know from dual process theory (Kahneman, 2011) about system 1 which involves making decisions quickly using heuristics. Although we all use heuristics, raising awareness of these mental short-cuts for everyday decision-making could be helpful for adults with ID e.g. the '*what's most important to me*' heuristic. However, for more consequential decisions, system 2 thinking could take over, alongside decision-support from HSCPs or family, where needed.

Theme 2, social influences on decision-making

Family's influence on decision-making got mixed reviews, acting as a barrier where ADM-awareness was lacking and a facilitator, where present. The mechanism by which participants valued family decision-making support was via family discussions. Interestingly, participants often reported making decisions independently, despite seeking family guidance.

This perception suggests that families provided impartial information rather than an opinion, leaving participants concluding that they made the decision independently. While these findings concur with previous studies that showed lack of public awareness is a barrier to families' implementation of capacity legislation (Killeen et al., 2004) there has been little evidence to date of families being facilitators. An exception to this is a recent Irish study which found that mothers' intimate knowledge and understanding of their adult son or daughter's preferences and capabilities is a valuable resource, and if harnessed through intervention, could enhance engagement of adults with ID in supported decision-making (Casey et al., 2023). This finding suggests that family training on providing impartial decision-making support could be very effective in improving adults with ID's engagement in supported decision-making.

In the current study adults with ID reported tension between the desire to live an independent life in the community and the risk this may bring. Previous studies evidenced lack of public awareness in the community, as a barrier to service-user's engagement in supported decision-making (Killeen et al., 2014). In self-determination theory (Deci and Ryan, 1985) decision-making is posited as a key element of self-determination and community integration. However, for adults with ID to be fully integrated in the community, their decision-supporters need to be cognisant of the possibility of experiencing stigma and to build service-user's coping skills around this. Contact is a way to reduce public stigma, so it's important that people with disabilities are encouraged and supported to continue to make connections in their communities. There is perhaps a societal move towards this with more representation of physical and ID on television, which is positive.

One participant with a visible disability reported the challenge of taking part in her community because she experiences name-calling. Many shared similar experiences. This is clearly a concern for families, with Irish research reporting evidence of family tension between protectiveness and promoting independence (Casey, 2025c). Any intervention to resolve this will need to be applied on multiple levels – the individual, family and societal levels. Without intervention, adults with ID may fear taking part in their communities which impacts their ability to be autonomous, a key principle of self-determination (Deci and Ryan, 1985). This is consistent with previous researchers who identified the need for future research to explore the impact of societal attitudes and beliefs on the autonomy of people with ID (Sheerin et al., 2026).

Theme 3, the which, who, how of supported decision-making

Whilst previous studies showed patients often delegate decisions to others before any supported decision-making happens (Donnelly et al., 2019) we did not know why. The current study fills some of this knowledge gap by detailing *which* decisions they require support to make, *who* they identify as decision-supporters and, *how* they wish to be supported with decision-making and decision-implementation.

The implication of being able to identify which decisions adults with ID require support with, makes planning early interventions easier. This is important because evidence shows that – for the decisions that adults with ID require support with - they start to have trouble early in the decision-making process (Suto et al., 2025).

Previous studies evidenced effective communication as a key element of supported decision-making for adults with ID, like open-ended questioning, simplifying information and listening carefully (Davidson et al., 2015). The current study found evidence for communication strategies like identifying the pros and cons of a decision. This concurs with a previous study which found that identifying advantages and disadvantages of alternatives is difficult for people with ID (Fusinska-Korpik and Gacek, 2024). Therefore, the development of structured tools for identifying the pros and cons or weighing up alternatives, may be effective.

Participants reported they require support to *implement* decisions as well as support to make them. These decision-implementation supports include practical assistance like form-filling/enrolment for their chosen course/activity. No previous evidence could be found for such decision-*implementation* supports for adults with ID. Knowing more about post-decision-making needs, helps inform the design of targeted interventions for service-users. For example, providing service-users with an easy-read menu of post-decision supports, may act as a facilitator by educating them on what's available.

Health decision-making

Although the findings related to health decision-making did not justify their own theme (and as such are reported in the results section according to the theme they fall within), there is merit in collating these findings and discussing them in relation to previous research. Despite the finding that most participants in the current study were aware of their decision-making

rights, some negative perceptions about health decision-making, were apparent. One participant reported that although she was aware of her decision-making rights, she had a belief that some health decisions were not hers to make. The implication of this finding is that knowing there is confusion among adults with ID about their rights to make their own health decisions, means it is critical that this key message is emphasised in training interventions.

Health decisions were identified by most participants as a type of decision they require support with. This is consistent with Douglass (2024) who found that many adults with ID want support to make their own health decisions. One participant however, described making a significant health decision independently, to attend an invasive health screening. He described using a determination strategy of '*putting his mind on it*' to decide. Despite making this health decision independently, this participant emphasised the importance for him, of a follow-up check-in with a HSCP afterwards, which seemed to act as a form of decision-implementation support.

Research shows that what makes health decisions more challenging (apart from consequences being potentially long-term and uncertain) is that health information can be complex (Douglass, 2024). The current study concurs, finding that adults with ID value when information is presented in accessible ways, especially in relation to health information like leaflets. Paradoxically, Douglass found that the more complex the decision, the less decision-support adults with ID receive (2024). This is supported by previous evidence that the more important a decision was perceived by family, the less likely the adult with ID was permitted to make it (Casey et al., 2024).

Whilst previous studies found that additional time and space for private discussions are facilitators to patient engagement in supported health decision-making, these are time-consuming (Davies et al., 2019). The current study provides insights into time-efficient strategies, like having a note-taker at health appointments. This is a solution to two barriers: not enough time at health appointments to process information (Davies et al., 2019) and health information being too complex (Douglass, 2024) because the notes can inform follow-on supported decision-making efforts by family or HSCPs, without time pressures.

3.5 Chapter 3 Conclusions

ADM has the potential to have a fundamental positive impact on the control that adults with ID have over their lives and there is evidence of multiple facilitators that can help including

family encouragement, knowing how to access decision-support and decision-implementation assistance. However, significant barriers to their engagement exist which must be resolved, including negative family influences and the tension between living an independent life and risk. The overall significance of these results is that they provide us with more knowledge and understanding of how adults with ID make decisions and how they wish to be supported when they find this challenging.

Limitations and strengths

The study only included participants from one service. However, given that focus groups were held across three of the four provinces on the island (Connaught, Munster and Leinster) in a nationwide service, a good spread was achieved. Although alternative methods like one-to-one interviews were offered to accommodate service-users with communication needs, none chose this option and therefore 100% of the participants were verbal communicators. To abide by the RehabCare ethics approval agreement, participants were recruited via NRAC and so this recruitment had to be carried out via the Advocacy Officers. As such, this resulted in the Advocacy Officers having potentially, a gatekeeping effect on recruitment. However, upon discussion at supervision, it was agreed that the presence of the Advocacy Officers at the focus groups (being familiar to participants) was hoped to encourage participation by making participants feel comfortable. It is hoped therefore that the Advocacy Officer's presence at the focus groups influenced the results such that improved engagement was achieved. It is unknown whether this influence had any negative impact on engagement and results.

Strengths of the focus group include having a mix of adults with varying levels of ID participate together, which may have resulted in opportunities for participants to learn from each other. Further strengths include the researcher can clarify meaning if needed and a richness of detail can be gathered. This was important given how few studies have been conducted on ADM so far, meaning that detailed data was essential to fully understand participant's views although the recency of ADM may mean that participants views were not fully formed but it was hoped the ADM video overcame this.

Recommendations

It is recommended that a guide to supported decision-making is co-produced with adults with ID, informed by theme 3, which could be used to educate peers about the decision-making supports available in the organisation and within their families and communities, and how to access it. This co-produced guide could include independent decision-making strategies (heuristics) that participants use in everyday decision-making. In this way, the service-user voice can act as peer-educator. Casey et al., (2025b) found that there are insufficient ADM-resources aimed at adults with ID in Ireland. Therefore, this is a gap that future researchers will need to consider.

Although also a facilitator, family was found to be a social barrier to adults with ID engaging with supported decision-making, it is important that future researchers develop and test interventions to educate families on a rights-based approach to supporting their family member with ID to make their own decisions.

Overall, it is important that a training intervention is designed to address the barriers and enhance the facilitators found in this study and to evaluate their effectiveness amongst adults with ID. It is crucial that any such interventions are aligned with psychological theories of decision-making and acknowledge human limitations while focusing on strategies that are feasible, but also effective, despite those constraints.

Chapter 4: Discussion

4.0 Chapter Overview

Frontline HSCPs in disability services have more day-to-day contact with service-users than any other group of HCPs, so their work plays a key role in implementing change and therefore, they are key stakeholders. In research, stakeholders can be divided into the people who will be implementing change (the 'effectors') and the people who may be subject to/effected by, the change (the 'effected') (Michie, 1998). In this thesis, the 'effectors' are the HSCPs and the 'effected' are the service-users and this chapter discusses how these stakeholders intersect across the two studies.

4.1 Interconnectedness between HSCPs and service-users

Interestingly, the highest endorsed barriers by HSCPs were posed by service user's families (such as lack of family awareness: 88.1%) and by service-users themselves (such as lack of decision-making knowledge: 76.3%). This means that to tackle these barriers we must intervene on multiple levels, i.e. the service-user, family, and HSCP level.

HSCP versus service-user perception of family as barrier or facilitator

Family was a significant factor in the results of both studies. For HSCPs, communicating with families was endorsed as a barrier because of families' lack of awareness of capacity legislation. This is consistent with past evidence that lack of awareness prevents families and carers engaging with capacity legislation (Killeen et al., 2004). Most HSCPs also perceived communication with family as a barrier for service-users, with suggestions that education should teach service-users self-confidence and self-advocacy techniques for when their rights are being ignored by families. So, it seems that, communicating with families is a barrier that HSCPs and service-users share.

However, a minority of HSCPs viewed families as potential facilitators. These HSCPs suggested training families on the difference between offering information and offering an opinion, a key element of supported decision-making. This HSCP view is aligned with most service-users' who spoke favourably about their families' role in supported decision-making and gave examples of making decisions 'independently' despite having family discussions. This interesting finding suggests that perhaps, in these cases, families were providing information and not opinion, because the service-users proudly described making these decisions by themselves. This impartiality is crucial to supported decision-making in giving a sense of control to service-users and the need to build these skills in families and HSCPs is therefore a key finding of this study.

HSCP and service-user perspectives on communication

Another crossover between the studies was the finding that communication skills significantly impact both HSCPs' implementation and service-users' engagement with ADM. Past studies found that poor HSCPs communication skills were detrimental to ADM (Davies et al., 2019; Killeen et al., 2004; Badger and Parnell, 2009) and the current survey supported this with HSCPs identifying communication skills as a training need. Service-user comments on communication centred around the importance of information about a decision being communicated to them in accessible ways, such as with less text, more images and better laid out. They also reported specific communication strategies they value in supported decision-making discussions, such as identifying the pros and cons of decision options.

Related to this, evidence from previous studies shows the poorer the communication skills, the less choice adults with ID had (Killeen et al., 2004). In the current HSCP study, participants were aware of this because they made an insightful recommendation - that training is adapted specifically for HSCPs working with service-users who are non-verbal and communicate differently. We know from the literature that adults with more severe ID were less likely to receive decisional support (Killeen et al., 2004), so it is important to address this barrier and make decision-support accessible to everyone.

Although HSCPs made this recommendation, they did not suggest what strategies may be effective for engaging non-verbal service-users in supported decision-making. While there are few previous studies carried out with non-verbal participants, one study found that the level of familiarity with the decision-supporter helps (Nicholson et al., 2021). Strategies used by HSCPs (who knew the service-user well) to infer 'will and preference' included

interpreting bodily cues, observing repeated interest in activities, food and people, and observing behaviours, all of which could be used to inform the HSCP training intervention.

Tension between independence and risk

An interesting link between the two studies is the concept of tension between independence and fear/risk which was apparent at the service-user, family, HSCP and organisational levels. HSCP participants spoke about a tension between their responsibility to uphold ADM and support (informed) unwise decisions and their duty of care towards service-users. This supports earlier studies that found HSCPs experience fear as a barrier to implementing capacity legislation, such as fear of letting go (Cronin et al., 2018). Fear of personal liability specifically, has been found in previous studies to have a significant impact on HSCP's tendency to support a service-users' right to make unwise decisions, illustrating the impact of this tension (Badger and Parnell, 2009). However, it was surprising to find that in the current HSCP study, fear of letting go was one of the weaker barriers (although still supported by over a third of participants, see section 2.2).

Previous studies have shown that an over-reliance on risk assessment in disability organisations, is a barrier to ADM-implementation (Cronin, 2018; Badger and Parnell, 2009). Risk assessment poses a particular barrier to the ADM principle of supporting unwise decisions, because studies show these decisions are often denied through risk assessment (Badger and Parnell, 2009). If this is not resolved, it may perpetuate the paternalistic approach that ADM aims to abolish. Some comments by HSCPs illustrated such complex risk-management issues that ADM-policy must consider. One example is how to marry the right to make unwise decisions, with state regulatory requirements around health and safety, in residential services. Another respondent sought guidance for when organisational health and safety policy is misaligned with ADM, for example a service-user making an (informed) unwise decision not to wear their wheelchair seatbelt when in motion. While previous studies identified a culture overly focused on safety as a barrier to ADM (Cronin, 2018) the specific issues in these results allow for targeted intervention to real practice issues. This shows the complexities of ADM-implementation in residential services. So, HSCPs will need to be supported by clear policy for them to alter their practice away from paternalism towards a positive risk-taking rights-based approach.

Service-user-participants clearly articulated the tension they feel between wanting to live an independent life and the risk that poses and outlined examples of their families experiencing

the same tension. This is supported by previous studies which found that mothers of adults with ID report a struggle between respecting the autonomy of their adult son or daughter and protecting them (Casey et al., 2023). Overall, this same tension – reported by families, service-users and HSCPs reflects a wider societal change from paternalistic “best interests” approach towards empowerment of the adult with ID, aligned with ADM. Future research is needed to explore the impact of societal attitudes and beliefs on the autonomy of people with ID (Sheerin et al., 2026).

HSCP and service-user perspectives on health decision-making-support

This tension that HSCPs report between a desire to empower the adult with ID to make their own decisions and a paternalism driven by risk management protocols, fear of criticism, and organisational culture is also evidenced to impact health decisions which adults with ID have reported noticing and resenting (Douglass, 2024). Supporting health decision-making spanned both studies with HSCPs being fearful of this, and some requesting legal advice before proceeding. Other HSCPs felt more confident but ill-equipped, seeking resources to guide them, specifically, a bank of easy-read visuals for common health decisions.

Service-users reported mixed experiences with health decision-making, with some taking the lead and requesting HSCPs to act as note-taker at health appointments showing a clear understanding of this right. The availability of a trusted note-taker complements previous evidence for facilitators of health decision-making being a good relationship with the decision-supporter and good understanding of the health information (Douglass, 2024). Having health notes taken by someone the service-user trusts, provides an opportunity for supported decision-making discussions to happen, after the appointment, offering the service-user more time to process the information and discuss options. However, research from Scotland found disadvantages of note-takers at health appointments in that the note-taker can compound the tendency for the service-user to be excluded from health decision-making by preventing their involvement during doctor visits (Douglass, 2024). So, this would require careful management.

Other service-user-participants reported a belief that some health decisions were not theirs to make. This supports earlier findings that adults with ID often identify 'others' as being responsible for making their health-related decisions even though they described making many everyday decisions themselves (Douglass, 2024). This could possibly be because, like the general population, adults with ID feel that HCPs are experts and should make these

decisions. Equally, it could represent low awareness of their role in health decision-making and so it remains an issue requiring input for service-users. However, it also emerged as an issue for HSCPs, who sought guidance for when they encounter HCPs who seem unaware of ADM, with some respondents suggesting a script. This is supported by previous studies who found that doctors can sometimes exclude the service-user and tend to attribute decision-making autonomy only to those who at first appear to have cognitive competency and can communicate verbally (O'Donnell et al., 2023).

HSCPs' versus service-users' perception of service-user training needs

Further commonalities across these two studies were the similar responses that HSCPs and service-users gave when asked about service-user training needs. HSCPs spoke about how helpful it would be for service-users to learn how to access decision-making support depending on the decision-supporter and a clear picture of what to expect. This strongly links with theme 3 from the service-user study – *the which, who, how of supported decision-making* - where service-users articulated the supported decision-making they value, for which decisions and from whom. As a result, one of the planned interventions informed by this study is to co-produce a menu of supported decision-making options with service-users, including how to access each option and provide training on how to use it (for HSCPs and service-users). This shows how aligned the HSCPs are with service-users' real-life needs. However, one aspect the service-users mentioned, which the HSCP omitted, was decision-implementation, i.e. supports they require to implement decisions they have already made, such as enrolling the service-user onto a course in the community. This is a new finding that hadn't been cited in the past – and one that came from service-users – which will also be addressed in the training.

The mechanics by which service-user-participants wish to be supported was noteworthy with participants reporting on the usefulness of cognitive decision-support strategies like identifying the consequences of decision options. This was a common result across the HSCP and service-user studies and so warrants intervention at the HSCP and service-user levels. Taking this further, this finding could be used to inform the development of service-user resources like easy-read checklists to help service-users attempt decisions independently, before support-seeking and equivalent checklists for HSCPs to follow.

Previous studies have evidenced that adults with ID are under-represented in research and non-verbal adults with ID are severely under-represented (O'Brien et al., 2013). This makes

designing interventions aimed at non-verbal adults more difficult. Although no non-verbal service-users opted to participate in the current research, in their absence, HSCPs who work closely with them have advocated through this study, to have training interventions tailored to their needs. It is recommended that a working group be set up of non-verbal service-users and the HSCPs who know them well, with the objective of co-producing a training intervention for HSCPs to address the specific needs of this cohort.

4.2 Intervention Design

The results from both studies were used to design interventions, which are beyond the scope of this thesis but will be carried out as part of the author's practitioner role soon and as such are described here. These interventions were developed using three theoretical frameworks, described below. Interventions are divided between those aimed at HSCPs and those aimed at service-users.

The first framework used was the TDF (Cane et al., 2012) which was used to design the survey and focus group questions. Doing so made the resulting data easier to interpret and the interventions arising from these results, easier to design. The TDF was selected because of its broad range of domains that influence behaviour and could be explored, making it easier for implementation researchers to use and for its proven applicability to HCP behaviour change (Dyson and Cowdell, 2021). Section 1.2 in Chapter 1 for a full description of the TDF.

The Behaviour Change Wheel (BCW), which was developed from 19 frameworks of behaviour change identified in a systematic literature review (Michie et al., 2023) is the second framework used and consists of three layers. The inner hub identifies the sources of behaviour that could prove useful targets for intervention, using the COM-B ('capability', 'opportunity', 'motivation' and 'behaviour') model. This model sees behaviour as part of an interacting system involving all these components. Surrounding the hub is a layer of nine intervention functions to choose from, such as persuasion, environmental restructuring etc. The outer layer of the wheel identifies seven policy categories that can support delivery of these intervention functions.

The Behaviour Change Techniques Taxonomy (BCTT) (Michie et al., 2013), a standardized system that categorises the components of interventions designed to change behaviour, is the final framework used. It consists of 93 distinct techniques, arranged into 16 groups, with each technique having a unique label, definition, and examples. The taxonomy is used to

describe interventions in specific terms which helps researchers and practitioners to replicate them correctly, and to understand what works. In this way the BCTT helps create a cumulative evidence base for effective BCTs.

HSCPs Interventions

Most HSCP intervention components were developed from the HSCP survey results however some were developed from the service-user focus group findings such as the availability of a note-taker at health appointments acting as a facilitator. All HSCP intervention components are grouped into the following selected TDF domains: Knowledge, Skills, Environmental Context & Resources and Social Influence.

Here is an example to illustrate how an HSCP intervention component was developed using these three theoretical frameworks. Survey results, when viewed via the TDF lens, and mapped onto the COM-B model, indicated that skills development interventions were required. Some of these results were barriers that require addressing, like *difficulty communicating with service-users* and others were facilitators that require enhancing like *identifying the pros and cons of a decision*. Consulting the BCTT, a mixture of BCTs were selected like demonstrating the behaviour, comparison of outcomes and instruction on how to perform the behaviour.

The HSCP training will include a second-tier intervention for each skill, via behavioural practice / rehearsal by asking HSCPs to suggest real-life examples and work through them in pairs. This approach aligns with earlier findings that training interventions for ADM-implementation must focus on real-life application (Stoke et al., 2025). See Appendices H to L for full details of all planned HSCP interventions and how they were each developed.

Service-User Interventions

Some of the service-user intervention components were informed by the HSCP survey results such as service-user lack of knowledge of how to make decisions is a barrier to HSCP implementation. Further HSCP results found that some additional barriers, although not posed by service-users, could be partially addressed via service-users, such as lack of family awareness and so, these results informed the development of other service-user interventions. Finally, the development of all remaining service-user intervention components was informed by the service-user focus group results.

All intervention components aimed at service-users fell within the following TDF domains: Knowledge, Beliefs About Capabilities, Skills, Social Influence and Environmental Context and Resources. Here is an example to illustrate the development of a service-user intervention informed by multiple findings such as from theme 1 *intrinsic factors affecting independent decision-making*: negative perceptions ('not my decision') and from the HSCP survey (lack of service-user awareness). These results, when mapped onto the TDF and COM-B model, lend themselves to intervention within the Knowledge Domain, and the Capability (Education) component of the COM-B. Mapped onto the BCTT the appropriate BCT is Shaping Knowledge (instruction how to perform the behaviour). From this an intervention will be developed to provide education on ADM using videos and easy reads and peer-led education on the heuristics suggested in the focus groups and other heuristics also. This approach aligns with previous evidence for the need for education and training on supported decision-making for adults with ID (Casey et al., 2025b).

The plan overall for the service-user training interventions, is to co-produce them with the service-users, with support from the advocacy team and where possible, to co-deliver the training alongside service-user representatives. Furthermore, HSCPs suggested that videos are used in the service-user training to spark conversations about decision-making that can then be repeated in the service. HSCPs also suggested that service-users bring real-life decisions to the training to increase relevance and interest. This interactive, co-produced workshop will be accompanied by a set of co-produced accessible resources, with a menu to guide them, as recommended by previous research (Casey, 2025b). The workshop will close with some fun affirmations around identity associated with changed behaviour, by asking service-users to describe themselves as 'decision-makers'. See Appendices M to Q for full details of all planned service-user interventions and how each was developed.

4.3 Chapter 4 Conclusions

The goal of Ireland's new capacity legislation is for people with disabilities to take control of their lives, make decisions independently (or with support) and take a more visible part in their communities, a key element of self-determination (Deci and Ryan, 1985). Supported decision-making has a vital role to play in adults with ID becoming fully engaged with their rights under ADM, however, it remains under-investigated, with evidence for its effective components still lacking specificity in the literature (Casey et al., 2024). However, this study

supported previous evidence of the multi-layered challenges that disability organisations face in ADM-implementation, with a combination of knowledge gaps, organisational barriers, and personal beliefs to be addressed (Stokes et al., 2025). Drawing on one of the key competencies of health psychologists – understanding processes influencing healthcare delivery (Michie, 1998) - this project has the potential for impacting not only HSCP behaviour change but also service-user empowerment.

Strengths and limitations

One of the limitations of the HSCP survey was that it wasn't possible to decipher between HSCPs who support low-support versus high-support service-users. This is because the question about profile of service-user supported, only asked about diagnosis (like autism etc.) but didn't enquire whether the service-users communicate verbally. However, this appears to be an important difference in training needs.

Related to this, all focus group participants were verbal communicators. Also, it wasn't possible to separate HSCPs who worked in day versus residential services because this question was presented as multiple choice and most people selected both options, either because they sometimes cover shifts across both services or they manage or offer clinical services to both service types. In addition, a question about length of service would have been interesting – to see what impact this had, if any, on ADM-implementation.

Also, both studies were carried out within one disability service, meaning the generalisability of the findings may be limited, although the organisation is a nationwide one which may mitigate this limitation somewhat. The overall strength of this thesis is that it addresses a critical gap. It is the first study of its kind post-ADM-commencement to explore the views of both adult service-users with ID and the HSCPs that support them, towards ADM engagement and implementation, in a disability setting in Ireland. The other overall strength of this thesis lies in its relevance to real-world application. All health and social care services in Ireland need to implement ADM and make the required changes to practice it necessitates. These two studies provide some key insights into what will help and hinder HSCPs and service-users to do so.

Recommendations

Overall, the results of these studies have important implications for how ADM-implementation is supported in Irish disability settings. Given the evidence from HSCPs that being skilled in the various components of supported decision-making is an important facilitator, these skills should be targeted during an applied training intervention and evaluated. With ADM being such a fundamental part of the role of HSCPs in disability services, ADM-training should be part of mandatory onboarding for all. In addition, refresher ADM-training should be mandatory as it is for training in the HSE National Safeguarding Policy, also underpinned by sectoral legislation.

HSCPs perception that families are a barrier was strong in this and previous studies (Killeen et al., 2004), however service-users' views of families influence on supported decision-making was mixed, with most reporting positive influences. Future research needs to explore the mechanisms by which impartial family involvement can be harnessed by HSCPs, to activate this highly valued resource by adults with ID, whilst maintaining a rights-based approach. Considering this, the ADM-implementation journey – to include family education – is long and shows the crucial role that community bodies like advocacy agencies, play in engaging the public around ADM.

Further potential applications for these results are to inform ADM-related policies to include a policy on positive risk-taking and the appointment of mentors to support implementation of complex ADM-related issues. In addition, relevant organisational policy in disability services will need to be reviewed to address the tension that HSCPs describe between ADM and the state regulators that residential services are governed by. In conclusion, an important application for these results, is, to make amendments to ADM policies to ensure service-users not only contribute to, but lead, ADM-implementation by taking their place on ADM-forums in disability services.

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6.0 Appendices

Appendix A

Participant Consent Form: Staff – Online Survey (August 2024, V3.0)

Enhancing supported decision-making skills amongst healthcare staff and the adult service users with disabilities they support.

Suzanne Allen

Principal Psychologist, RehabCare

I confirm that I have read and understood the information sheet explaining the research project and I have had the opportunity to ask questions about the project.	
I understand that my participation is voluntary and anonymous and that I am free to withdraw (up until I submit the online survey).	
I understand that once my online survey is submitted, it will not be possible to identify and remove my anonymised data from the study.	
I understand that my anonymised research data will be stored in a password-protected file on the Stirling one drive and will then be archived to the university's repository DATASTORRE for a minimum of 10 years and then destroyed. This data will be	

anonymous and not linked to me. I understand that consent forms will be deleted one year post publication.	
I understand that my responses will be anonymous, and that no personal data related to me will be collected.	
I give permission for members of the research team to have access to my anonymised responses.	
I give permission to be quoted in the research publication, anonymously.	
I understand that I can withdraw simply by closing the browser.	
I agree to take part in this study.	

If agreeing to take part, please Ctrl-Click here to commence the survey:

<https://forms.office.com/e/zr3MUqg445>

Researcher contact details: Suzanne.allen@rehabcare.ie

Sua4@stir.ac.uk

Appendix B

Staff Survey Poster (November 2024 V1.0)

Make sure to have your say!

Enhancing supported decision-making skills amongst healthcare staff and adult service users with disabilities.

We need just 10-15 minutes of your time for this survey please!

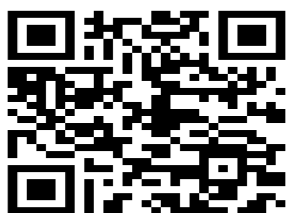


The questions in the survey include what helps and hinders you to support service users to make decisions.

The results will help us to create a workshop to support you and your colleagues to further implement ADM in your work.

Please use the link or scan the QR code below to take part soon:

<https://forms.office.com/e/zr3MUgg445>



This survey is part of a research project being conducted by Suzanne Allen, Principal Psychologist, RehabCare. Thank you!

(Suzanne.allen@rehabcare.ie and sua4@stir.ac.uk)

Appendix C

Participant Information Leaflet - Staff (September 2024, V5.0)

Enhancing supported decision-making skills amongst healthcare staff and the adult service users with disabilities they support.

Suzanne Allen

Principal Psychologist, RehabCare

1. Background

You are invited to participate in a research project which involves an online survey on implementing the Assisted Decision Making (Capacity) Act 2015 (ADM) in your work in RehabCare. You have been invited to participate because of your role supporting adults with disabilities. This survey is part of a research project being conducted by Suzanne Allen, Principal Psychologist, RehabCare. It should take approximately 10-15 minutes to complete. You will be given some questions to answer to explore what helps you (the facilitators) and what hinders you (the barriers) to implement ADM in your work.

I will use this information to design a pilot training programme which will be tested on a small scale. Please read through the terms below and if you choose to participate, please click on the survey link below to start. You have 3 weeks to decide if you would like to take part. The survey closes on Monday November 25th.

2. Aims of project

The aims of this study are to:

- Identify the barriers and facilitators to implementing ADM by staff in RehabCare.
- To design and test a pilot training programme for staff.
- (The study also aims to identify the perceived barriers and facilitators to actively engaging with supported decision-making, by adult service users in RehabCare, to inform the design of a training programme for service users also).

3. Do I have to take part?

No. Your participation in this survey is voluntary. You may refuse to take part in the research or exit the research at any time (prior to submitting the online survey) by closing your browser. You are free to decline to answer any question. However, if you decide to participate and then withdraw from the study after submitting your online survey, it won't be possible to identify or remove your anonymised data from the dataset.

4. Are there any potential risks in taking part?

There are no foreseeable risks involved in participating in this project.

5. Are there any benefits in taking part?

The benefits of taking part are that you will have an opportunity to inform the design of an applied training programme, specifically to your needs.

6. What happens to the data I provide?

Your answers will be completely anonymous, and we will use all reasonable endeavours to keep them confidential. You will not need to give your name. Your research data will be stored in a password-protected file on the University of Stirling one drive and will be stored safely and archived to the university's data repository DATASTORRE for a minimum of 10 years and then destroyed. This data will be anonymous and not linked to you. We will not have any personal data related to you as the survey is anonymous. Consent forms will be deleted one year post publication.

If you consent to take part, we may use direct quotes from you, but these will be anonymised. However, if you make a disclosure of past, current or potential future harm to a child or vulnerable adult, I have a responsibility to report this concern.

7. Will the research be published?

The research will be published in a peer reviewed psychology journal in Ireland and/or the UK. The research will also be presented at national and international conferences. The University of Stirling is committed to making the outputs of research publicly accessible and supports this commitment through our online open access repository DATASTORRE.

8. Who has reviewed this research project?

The ethics of this project have been approved via The University of Stirling and RehabCare's ethics committees.

9. Your rights

You have the right to withdraw from this project at any time (up until you submit the online survey) without giving reasons and without consequences to you, however, please note that once the data are being analysed and/or results published it will not be possible to identify and remove your anonymised data from the study.

10. Whom do I contact if I have concerns about this study or wish to complain?

If you would like to discuss the research with someone, you could contact the researcher, see contact details below. If you wish to complain you could contact Darragh O'Regan, Head of Multi-Disciplinary Teams, Clinical Services and Practice Development, at Darragh.OREgan@Rehab.ie. You may also contact Suzanne's supervisor at The University of Stirling, Dr. Purva Abhyankar at purva.abhyankar@stir.ac.uk or Professor Paul Dudchenko at the Faculty of Natural Sciences at paul.dudchenko@stir.ac.uk if you have an issue.

11. Begin Survey

By clicking on the survey link you are consenting to participate. If you wish to proceed, please Ctrl-Click here to begin <https://forms.office.com/e/zr3MUgg445>

Thank you so much for your participation.

Suzanne Allen, Principal Psychologist

Suzanne.allen@rehabcare.ie / sua4@stir.ac.uk

Appendix D

Staff Survey Questions (August 2024, V4.0)

Online Survey (via MSForms)

Enhancing supported decision-making skills amongst healthcare staff and
Adult service users with disabilities.

Introduction Thank you for agreeing to participate. This is an online survey on implementing the Assisted Decision Making (Capacity) Act 2015 in your work in RehabCare. You have been invited to participate because of your role, supporting adults with disabilities. This survey is part of a research project being conducted by Suzanne Allen, Principal Psychologist, RehabCare. It should take 10-15 minutes to complete.

You will be given some questions to answer to explore what helps you (the facilitators) and what hinders you (the barriers) to implement assisted decision-making in your work. The results of this survey will be used to design an applied training workshop, which will aim to enhance the facilitators and overcome the barriers, to support you to further implement assisted decision-making in your daily work.

Thank you again for your participation. By clicking the link to begin the survey you are demonstrating that you consent to take part. You may withdraw at any time by simply closing the browser. Please click [here](#) to begin the survey.

Section 1	
1. Gender	Male _____ Female _____ Other _____ Prefer not to say _____
2. Age	U24 25-35 36-45 46-55 56-65

	66+
3. What is your role in RehabCare?	Care Worker Programmes Facilitator Programmes Supervisor Team Leader Residential Services Manager Community Services Manager Social Care Manager Other (please specify) _____
4. Type of Service Model	Residential Supported Accommodation Independent Living Day Service / Resource Centre Physical and Sensory Respite Other (please specify) _____ (Tick as many as apply)
5. What are the primary needs of the people you support?	Intellectual Disability Autism Mental health Neurological (e.g. Acquired brain injury, Dementia, Parkinsons') Physical Disabilities

	Sensorial Disabilities (visual and hearing impairments) (Tick as many as apply)
Section 2	
6. Have you heard of the Assisted Decision-Making (Capacity) Act 2015?	Yes _____ No _____ Not sure _____
7. Have you completed any training on Assisted Decision-Making (ADM)?	Yes _____ No _____
8. If yes, please tick all the courses you have completed:	<i>Assisted Decision-Making (Capacity) Act 2015: Guiding Principles (hse land)</i> <i>Assisted Decision-Making (Capacity) Act 2015: Advance Healthcare Directives (hse land)</i> <i>Assisted Decision-Making (Capacity) Act 2015: Working with Decision Supporters (hse land)</i> <i>Supporting Decision-Making in Health and Social Care (hse land)</i> <i>Putting People at the Centre of Decision-making - Applying a Human Rights-based Approach in Health and Social Care: Putting national standards into practice. (hse land)</i> <i>'Guide to the Assisted Decision Making (Capacity) Act 2015 for all staff - Module 1: Introduction (Josephine McLoughlin, www.LegalCapacity.ie available on enIn)</i>

	<i>'Guide to the Assisted Decision Making (Capacity) Act 2015 for all staff Module 2: Building Decision-Making Capacity (Josephine McLoughlin, www.LegalCapacity.ie available on enIn)</i> <i>Assisted Decision Making (Capacity) Act 2015 – 15-hour training programme for select staff (Josephine McLoughlin, www.LegalCapacity.ie available on enIn)</i> <i>Other (please list here)</i>
9. How well do you understand the concepts of The Assisted Decision Making (Capacity) Act 2015? (Please circle whichever best represents your understanding)	1 (No understanding at all) 2 (A little understanding) 3 (Some understanding but not enough to undertake duties required by the Act) 4 (Enough understanding to undertake duties required by the Act but more learning needed) 5 (Excellent understanding with no further learning required)
10. Do you think the Assisted Decision-Making (Capacity) Act 2015 allows service users to make health decisions even if they lack capacity?	Yes_____ No_____ Don't know_____
11. What emphasis do you think the Assisted Decision-Making (Capacity) Act 2015 places on service user best interests? (Please circle whichever best represents your understanding)	1 ('best interests' are not emphasised at all in the Act) 2 ('best interests' are mentioned but service user will & preference take precedence) 3 ('best interests' and service user will & preference have equal emphasis) 4 ('best interests' take precedence over will & preference) 5 ('best interests' are paramount; will & preference are not emphasised at all)
12. Do you think you will have an individual responsibility to perform an informal capacity assessment of a service user?	Yes_____ No_____ Don't know_____

13. Do you know <i>how</i> to carry out an informal capacity assessment? (Please circle whichever best represents your understanding)	1 (No knowledge of how to assess capacity) 2 (A little knowledge but wouldn't feel able to assess capacity) 3 (Some knowledge but wouldn't feel able to assess capacity) 4 (A good level of knowledge and feel able to assess capacity) 5 (Excellent knowledge and feel totally confident in assessing capacity)
14. What 3 questions do you need to ask to assess a person's capacity?	1. 2. 3. 4. I don't know
15. If you conclude that a service user has capacity, and they wish to make a decision that could prove harmful or risky to themselves (e.g. a service user who has diabetes and continually eats sugary foods), what impact would this have on your conclusion about their capacity? (Please circle whichever best represents your opinion)	1 (No impact at all, I am unconcerned about a service user making an unwise decision) 2 (No impact at all, although I am uncomfortable with a service user making an unwise decision) 3 (Some impact, I would consider whether I need to reassess their capacity) 4 (Significant impact, I would definitely reassess their capacity) 5 (Significant impact, I would reverse my conclusion without reassessment)
16. Do you think you have a legal duty to consult with others to establish a service user's will & preference about a decision?	Yes_____ No_____ Don't know_____
Section 2: Barriers	Here are some factors which may act as barriers to staff implementing assisted decision-making in their work. Please read the statement and indicate, to what extent do you think this acts (or would act) as a barrier to you implementing assisted decision-making in your work?
17(i) Service users not knowing what options are available to them	1 (not at all)-----5 (very much)

17(lii) Lack of time to offer supported decision-making to a service user	1 (not at all)-----5 (very much)
17(iii) Lack of opportunity to offer supported decision-making to a service user	1 (not at all)-----5 (very much)
17(iv) Lack of awareness of the Assisted Decision-Making (Capacity) Act amongst families	1 (not at all)-----5 (very much)
17(v) Lack of awareness of assisted decision-making amongst other health professionals	1 (not at all)-----5 (very much)
17(vi) Service user delegates the decision before any supported decision-making efforts can be made	1 (not at all)-----5 (very much)
17(vii) Lack of knowledge of how to make decisions by service users	1 (not at all)-----5 (very much)
17(viii) RehabCare's culture being primarily focused on safety rather than positive risk taking	1 (not at all)-----5 (very much)
17(ix) Moral dilemmas, for instance balancing your duty of care to keep service users safe versus allowing them to make their own decisions (including unwise ones)	1 (not at all)-----5 (very much)
17(x) Difficulty in communication with service users (i.e. the service user requires communication aides or social stories etc.)	1 (not at all)-----5 (very much)
17(xi) Fear of letting go of the service user (i.e. you feel a need to protect the service user)	1 (not at all)-----5 (very much)

17 (xii) Fear of being blamed or litigation if any harm came to a service user	1 (not at all)-----5 (very much)
17 (xiii) Having to maintain lengthy records on your assisted decision-making related work	1 (not at all)-----5 (very much)
18 Is there anything else that you consider to be a barrier to you implementing assisted decision-making in your work?	If so, please tell us more_____
Section 3: Facilitators	Here are some factors which may act as facilitators (or aids) to staff implementing assisted decision-making in their work. Please read the statement and indicate, to what extent do you think this acts (or would act) as a facilitator to you implementing assisted decision-making in your work?
19 (i) Having a mentor to help you implement assisted decision-making	1 (not at all)-----5 (very much)
19 (ii) Effective communication skills, i.e. being able to explain complex concepts and ideas in simple, easy-to-understand ways	1 (not at all)-----5 (very much)
19 (iii) Being skilled in the development of social stories and easy-read information	1 (not at all)-----5 (very much)
19 (iv) Availability of ready-to-use templates and checklists to guide you in providing decision-making support, for each type of decision e.g. health decisions	1 (not at all)-----5 (very much)
19 (v) Simple, quick record keeping forms	1 (not at all)-----5 (very much)

19 (vi) Having a relaxed, private space to meet the service user	1 (not at all)-----5 (very much)
19 (vii) Strong leadership support for assisted decision-making (i.e. from service managers, regional managers, heads of functions etc.)	1 (not at all)-----5 (very much)
19 (viii) RehabCare policy providing clear guidance on assisted decision-making	1 (not at all)-----5 (very much)
19 (ix) Being skilled in breaking down decisions into the relevant options	1 (not at all)-----5 (very much)
19 (x) Being skilled in identifying the pros and cons for each option related to the decision	1 (not at all)-----5 (very much)
19 (xi) Being skilled in helping the service user to weigh up the information about the decision to be taken i.e. the pros and cons	1 (not at all)-----5 (very much)
19 (xii) Being skilled in demonstrating or role-playing aspects of the choice as part of decision-making support	1 (not at all)-----5 (very much)
20. Do you think you would need anything different, to provide support to a service user making a <u>health decision</u>?	If so, please tell us more here _____
21. any other facilitators?	If so, please tell us more here _____
Section 4: Additional information	

22. What would you like covered in a training programme aimed at helping you to implement assisted decision-making?	
23. Would you prefer online or face-to-face training?	Online _____ Face-to-face _____
24. Is it easier for you to attend a half day workshop? or two workshops of 1.5 hours each?	Half day workshop _____ Two 1.5-hour workshops _____
25. What do you think should be covered in a training workshop on assisted decision-making for service users?	_____
26. Please let me know if you have any other comments or concerns about implementing the Assisted Decision-Making (Capacity) Act 2015 in your work.	_____

Thank you for helping us design a training workshop on assisted decision-making, for you and your colleagues.

Principal Investigator contact details:

Suzanne Allen, Principal Psychologist, RehabCare
and University of Stirling

Suzanne.allen@rehabcare.ie / sua4@stir.ac.uk

Appendix E

Participant Consent Form - Service-User Easy Read (August 2024, V3.0)

Decision-Making Research Project – Consent Form

Have Your Say! Tell us about how decisions in your life are made!



My name is Suzanne Allen and I am a Psychologist in RehabCare. I am doing a research project about making decisions.



Please read each line (or we can read it to you)

and give us a thumbs up or



tick the box if you agree.

Please tick box	
I understand the information sheet and I had the chance to ask questions if I wanted to.	

I know that I can stop taking part in the project at any time, even during the focus group and I know who to tell.



I also know that if I decide to withdraw during the focus group, you won't be able to separate out what I said in the recording and delete it.

I give my permission for the words I say to be used in the report, but without my name beside it.



I know that the focus group will be recorded but just the sounds not video and this will be deleted after it is transcribed. The transcript will be kept for 10 years. The consent form with my first name on it will be deleted after one year.



I agree to take part in this study.



First Name: _____

Date: [Click here to enter a date](#)

Name of Researcher: Suzanne Allen

Suzanne.allen@rehabcare.ie

Sua4@stir.ac.uk



Appendix F

Participant Information Leaflet - Service-User Easy Read (September 2024, V5.0)

Decision-Making Research Project Information

Have Your Say! Tell us about how decisions in your life are made!

My name is Suzanne Allen and I am a Psychologist in RehabCare. I am doing a research project about making decisions.



This project is looking at how we can make decision-making easier for people with disabilities. RehabCare and University of Stirling are doing this project together. RehabCare are funding some of it and I am funding the rest. I am writing to ask if you would like to join our research group to help us make decision-making easier for people in RehabCare.



Before you decide to take part or not, we want to tell you what this project is about and why we are doing it. If you have any questions, please get in touch with me or a member of staff who can help you. You have 3 weeks to decide i.e. until _____.

What is a research study?



When a doctor or nurse or psychologist find something, they do not understand they have a choice. They can look things up in books or on the Internet, or they can try to work it out themselves, by asking people questions. This is called a

research study.

What is the study about?



Sometimes people don't know they have a right to make their own decisions or don't know how to make their own decisions. We want to learn more about this so that we can help.

What will happen if I take part?



You will be invited to join a focus group. A focus group is where a group of people meet and talk about something. There will be around 5 people in the group. Me (Suzanne) and one of the advocacy officers (Margaret, Sophie or Claire) will ask

everyone some questions. You will know the advocacy officer already.

We will record everything the group says but only the sounds, not video.

You would get the chance to tell us about how you make decisions, like,

what's easy? what's hard? What could staff do to help? We will use what

you tell us, to design a training workshop to help people that find decisions hard to make.



We want you to enjoy the focus group, so we hope to make it fun! You don't have to answer all the questions if you don't want to.

There will be paper and pens to draw or write with, and other creative things to help you form your ideas and thoughts.

What happens after?

After the research project is finished, we want to make sure that people continue to talk about decision making. We want the work that we do together to last, so we will be talking about how we make that happen.

What will happen to the results?

The recording from the focus group will be destroyed after they are typed up. Consent forms (with your first name on it) will be deleted from the University one drive one year later. Paper consent forms or notes from the focus group will be stored in a locked filing cabinet and shredded after one year. The recording will be kept until transcribed and then it will be



destroyed. The transcript will be stored at the university's one drive DATASTORE for a minimum of 10 years. The results from the focus groups will be published in a journal (small book) and I will present it at some large meetings (conferences). An easy read report will be written and sent to you as well.

Do I have to take part?



You can decide if you want to take part. You don't have to. It is your choice. If you decide to take part, you can stop whenever you like by emailing or phoning me at the email address or phone number below or if it's during the focus group by telling me or one of the advocacy officers. But if you decide to withdraw during the focus group, we won't be able to separate out what you said in the recording and remove it.

If you need some support to take part in the focus group, please contact me at the email address or phone number below and I can arrange a reader, or a scribe or any support you need. If you don't want to do the focus group, we can do a one-to-one phone call or email you some questions to answer instead.

Will I be named?



No. Your name will not be used. But we will know your first name from the focus group. Only the psychology and advocacy team who run the focus groups, will know what you said. What you say will be shared with staff at the University of Stirling, but they won't tell anyone at RehabCare what was said by each person. But if you tell

us that you or someone you know is being harmed, we will have to pass that on.

Will anything about the research upset me?



There are no right or wrong answers for this project, and you only talk if you want to. If you do get upset for any reason you can stop anytime and take a break from the focus group. If anything upsets you, you can talk to your keyworker afterwards or a helpline number will be provided.



Did anyone check this research is ok to do?

Before we are allowed to do a study it has to be checked by a group of people called an Ethics Committee. They check the study is fair. This study has been checked by an Ethics Committee at RehabCare and at the University of Stirling.

What do I do next?



If you like, talk to someone you trust and see if you would like to take part. You can talk to us if you have any questions by emailing Suzanne at Suzanne.allen@rehabcare.ie Or you can talk to

Joanne at joanne.nelligan@rehabcare.ie

Or if you wish to complain you could talk to Suzanne's manager. His name is Darragh and you can email him at Darragh.OREgan@Rehab.ie or ask staff to help you.

You may also contact Suzanne's supervisor at The University of Stirling, Dr. Purva Abhyankar at purva.abhyankar@stir.ac.uk or the Head of the Division of Psychology at the Faculty of Natural Sciences, Professor Paul Dudchenko at paul.dudchenko@stir.ac.uk



If you decide to take part, we will send you the details.

Thank you for reading this letter!

Suzanne

Suzanne.allen@rehabcare.ie

Sua4@stir.ac.uk

Appendix G

Service-User Focus Group Topic Guide (September 2024 V4.0)

Easy Read Project Title:

Have Your Say! Tell us about how decisions in your life are made!

Part One (Introductions and ice breaker)

To open the focus group: the facilitator introduces themselves and presents the information contained in the *Participant Information Sheet – Service Users* as a refresher. They then tell the participants that this is part of a project that is trying to help RehabCare service users learn how to make decisions easier. Housekeeping and boundaries will then be explained for example that what is said within the group is confidential and the boundaries of what we will discuss.

As consent is dynamic, the facilitator will then verbally check once more that everyone is consenting to participate and if so, hands out hard copies of the consent form to sign, for anyone who didn't bring theirs. Then the facilitator thanks everyone for agreeing to take part and then reminds everyone that if they change their mind during the focus group and want to leave, that is no problem, just tell us know. The facilitator asks everyone to respond not only on their own behalf but on behalf of their friends in RehabCare who aren't present as well.

Ice breaker: *"So now to get us warmed up, I'm going to tell you some things about myself. I am from County Meath, I'm 49, I'm married to Mark, have a 13-year-old daughter Maya and a dog called Mitzy. I love pizza and swimming in the sea."*

Now please tell me what county are you from? What age are you? What is your favourite food? What is your favourite thing to do in your spare time?" This will be written on a flip chart too, to aid comprehension.

Part Two Note: to support comprehension of verbal communication, an easy-read hard copy of the questions will be provided to each participant at the start of the focus group. This will be a copy of the same questions that were sent to participants by email in advance of the focus groups. Participants can refer to this throughout the focus group.

The facilitator then asks each participant verbally:

Question	Response
What county do you live in?	
<i>What is your gender</i>	<i>Male Female Other Prefer not to say</i>
What age (or age range) are you?	
What type of RehabCare service do you attend?	Day Service / Resource Centre
	Independent Living
	Supported Accommodation
	Residential Service
	Respite

Part Three

Then ask: “*Are you all ready to begin?*”? If they are, then play the video to familiarise the group with ADM. Then ask:

- 1. What do you think might be hard for you, or your friends in RehabCare, about making your own decisions (with support if needed)?**
- 2. What do you think might make it easier for you, or your friends in RehabCare, to make your own decisions (with support if needed)?**

(Note: regardless of their responses, proceed to ask questions 3 to 9, saying that “So now I’m going to tell you some things that other people have said make decisions easier or harder and you can tell me what you think, ok?”).

3. “I don’t know enough about my rights (under ADM)?

(Barrier: gaps in information aimed at the relevant person)

Re-phrasing: so, in other words, do you know about your rights under ADM?

Prompt: If not, what information or type of training would be helpful to you, or your friends in RehabCare?

4. “I don’t know enough about decision-making, to be able to make my own decisions or take part in supported decision-making”.

(Barrier: not enough knowledge)

Re-phrasing: so, in other words, do you think you know enough about how to make decisions? Or how to avail of decision-making support from staff, friends or family?

Prompt: If not, what part of decision-making would you, or your friends in RehabCare, like to know more about? What training would help do you think?

5. “If it was something new to me, I wouldn’t know what to expect, so that makes it hard to decide.”

(Barrier: limited service-user expectations)

Re-phrasing: in other words, if you had to make a decision about something new, would that be harder?

Prompt: What information would you, or your friends in RehabCare, need to help you to decide on something new?

6. “My family and friends are not aware of ADM”.

(Barrier: lack of public awareness of ADM, e.g. by families and carers)

Re-phrasing: in other words: do your family and friends know about ADM?

Prompt: have they heard of this act?

7. “My family don’t want me to make my own decisions”.

(Barrier: liaison with families)

Re-phrasing: in other words, do you think your family want you to make your own decisions?

Prompt: what would help you, or your friends in RehabCare, when speaking to your families about decisions you want to make?

8. Have you ever asked someone to make a decision for you? Yes/no

(Barrier: service user delegates the decision before any ADM efforts can be made)

Re-phrasing: in other words, have you ever asked friends or family to decide something for you?

Prompts: If yes, what was the decision?

And what would have helped you make it by yourself, with support?

9. Has a member of staff ever supported you to make a decision?

(My own suggested question - trying to learn about their perceived facilitators to decision-making)

Prompts: What was the decision?

What did they do that helped?

What else could they have done to help more?

What training do you think staff should get, to help them learn how to support your decision-making?

10. Would it make any difference if you were making a health decision?

(My own suggested question – trying to discover if health decision-making differs from other types of decisions)

Re-phrasing, in other words, if you were deciding something about your health for example whether to go to the doctor or not, would anything be different for you?

Prompts: if yes, what would be different? Would you need different type of support? Or a different amount of support?

11. Is there anything else you would like to tell me about decision-making?

Thank you for participating.

Conclude the focus group.

Researcher: Suzanne Allen

Suzanne.allen@rehabcare.ie sua4@stir.ac.uk

Appendix H

Table H1

HSCPs Interventions - Knowledge Domain

Variable	Identified via	TDF Domain (Construct)	COM-B Component	BCT- Taxonomy Group	Selected BCT
Lack of ADM knowledge and understanding	Knowledge and understanding questions	Knowledge (knowledge)	Capability – Education	Shaping Knowledge (Instruction on how to perform the behaviour)	Provide instruction on: general provisions of ADM; the organisations' policy on ADM especially in relation to supporting unwise decisions and practice guidance for when misaligned with HIQA requirements
Lack of clear policy/guidance on ADM especially related to supporting unwise decisions & when ADM policy is misaligned with HIQA requirements	And Barrier statements			And Comparison of behaviour (Demonstration of behaviour)	And Demonstrate how to support a change of mind
Supporting a change of mind					

Appendix I

Table I1

HSCP Interventions - Skills Domain

Finding	Identified via	TDF Domain (Construct)	COM-B Component	BCT- Taxonomy Group	Selected BCT
Communicating with service-users	Barrier statements Response to open-text question	Skills (inter-personal skills)	Capability - Training	Comparison of behaviour (Demonstration) and Behavioural practice (rehearsal)	Demonstrate how to:
Offering information versus opinion					explain decision-making concepts in easy-to-understand ways
Conflict with families					provide impartial decision-support
Setting up role-plays					de-escalate conflict & design role-plays
Lack of skill in the functional test of capacity					carry out a functional test of capacity & provide opportunity for practice
Skills deficits: breaking down decisions into relevant options; identifying pros and cons; weighing up the information; developing social stories and easy reads	Facilitator statements	Skills (skills development)	Capability – Training	Shaping Knowledge (Instruction how to perform the behaviour) Behavioural practice (rehearsal)	Provide instruction on: each supported decision-making skill & provide opportunity for practice

Appendix J

Table J1

HSCP Interventions: Memory, Attention and Decision Processes and Social Influence Domains

Finding	Identified via	TDF Domain (Construct)	COM-B Component	BCT- Taxonomy Group	Selected BCT
Simple, quick record keeping forms; Ready-to-use practice guidelines; checklists for providing decision-making support	Facilitator statements	Memory, Attention and Decision Processes (Reducing cognitive overload / tiredness)	Motivation – Enablement	Shaping Knowledge (Instruction on how to perform the behaviour)	Develop: simple, quick, record keeping forms practice guidelines a poster saying, “ <i>When you hear, ‘they don’t have capacity’ say STOP! have you provided decision-support?</i> ”
Lack of ADM-awareness amongst colleagues, HCPs and families.	Barrier statements	And Social Influence			a script to use with unaware families guidance on designating a private space in each service
Having a relaxed, private space to meet the service-user.		(intergroup conflict)			& provide instruction how to use them

Appendix K

Table K1

HSCP Interventions - Social Influence and Beliefs About Capabilities Domains

Finding	Identified via	TDF Domain (Construct)	COM-B Component	BCT- Taxonomy Group	Selected BCT
Strong leadership support for ADM	Facilitator & barrier statements	Social Influence (organisational commitment)	Opportunity – Social influences	Antecedents (re-structuring the social environment)	Advise senior management to:
Having a mentor to help implement ADM					provide regular communication to encourage HSCP's implementation of ADM &
Culture overly focused on safety					consider how policy supports HSCPs to balance ADM practice with the culture of safety/duty of care appoint ADM mentors to carry out monthly check in at team meetings
Moral dilemmas, fear of being blamed and fear of letting go	Barrier statement	Beliefs About Consequences (Outcome expectancies)	Motivation – Enablement	Natural Consequences (Information about consequences)	Advise local management that a space is created at team meetings for providing information about consequences of ADM supports

Appendix L

Table L1

HSCPs Interventions - Supporting Health Decision-Making

Finding	Identified via	TDF Domain (Construct)	COM-B Component	BCT- Taxonomy Group	Selected BCT
Lack of awareness amongst other HCPs	Barrier statements	Social influences - intergroup conflict	Opportunity – Social influences	Antecedents (re-structuring the social environment)	Advise to change the social environment by developing a script to use with unaware HCPs
Easy-reads on the risks & benefits of common health decisions & an accompanying note-taker* at health appointments for service-users to process information	Facilitator statement & Response to open-text question	Environmental Context & Resources - Resources	Opportunity – Social influences	Provide information about health consequences	Provide information about benefits and negative consequences of common health decisions & advise HSCPs to routinely request additional time & offer to act as note-taker, at service-user health appointments
Family training specific to health decision-making rights	Response to open-text question	Knowledge (knowledge)	Capability – Education	Shaping Knowledge (Instruction on how to perform the behaviour)	Provide education on everyone's right to make decisions including health decisions under ADM

Note. * indicates a focus group finding

Appendix M

Table M1

Service-User Interventions Informed by the HSCPs Survey (multiple TDF domains)

Finding	Identified via	TDF Domain (Construct)	COM-B Component	BCT- Taxonomy Group	Selected BCT
Service-user not knowing what options are available; delegates the decision before any support could be provided; lack of opportunity to provide decision-support; lack of knowledge of how to make decisions; lack of knowledge of how to access decision support from HSCPs and the DSS & what to expect; lack of knowledge how to engage families in supported decision-making and how to be a self-advocate	Barrier statements	Knowledge (knowledge)	Capability – Education	Shaping Knowledge (Instruction on how to perform the behaviour)	Provide education & training on: the importance of seeking support early step-by-step / 'how to' make decisions how to access decision support & what to expect Self-advocacy
Lack of awareness amongst service-users support circle	Barrier statements	Environmental context & resources – resources	Opportunity – Physical - Environmental context & resources	Antecedents (Add objects to the environment) & Shaping Knowledge	Develop a prompt card (& posters) saying ' <i>STOP, before you make that decision for me, I need you to take these steps</i> '

Appendix N

Table N1

Service-User Interventions – Knowledge Domain

Finding	Identified via	TDF Domain (Construct)	COM-B Component	BCT- Taxonomy Group	Selected BCT
Lack of ADM awareness amongst service-users	Theme 1: Intrinsic factors affecting decision-making	Knowledge (knowledge)	Capability – Education	Shaping Knowledge (Instruction on how to perform the behaviour)	Provide education on ADM using videos and easy reads & peer-led education on the heuristics suggested in the focus groups and other heuristics also
Share heuristics suggested by participants and provide input on others					
Knowing which decisions require support	Theme 3: the which, who, how of supported decision-making	Knowledge (knowledge)	Capability – Education	Comparison of behaviour (Social comparison)	Raise awareness of which decisions their peers do and don't require support with and discuss

Appendix O

Table O1

Service-User Interventions – Beliefs About Capabilities Domain

Finding	Identified via	TDF Domain (Construct)	COM-B Component	BCT- Taxonomy Group	Selected BCT
Negative perceptions about decision-making including some decisions are 'not mine to make'	Theme 1: Intrinsic factors affecting decision-making	Beliefs about capabilities – Empowerment	Capability – Education	Comparison of behaviour (Social comparison)	Address negative perceptions about decisions and emphasise their right to make ALL decisions, via a group discussion and provide reassurance
Lack of ADM awareness amongst families	Theme 2: Social influences on decision-making	Social role and identity – Identity	Capability – Education	Identity (Identity associated with changed behaviour)	Develop and support service-users to complete a supported decision-making workbook about 'being a decision-maker' to share their family

Appendix P

Table P1

Service-User Interventions - Skills Domain

Finding	Identified via	TDF Domain (Construct)	COM-B Component	BCT- Taxonomy Group	Selected BCT
Coping with bullying, stigma and poor experience of services	Theme 2: Social influences on decision-making	Skills – Skills development	Capability – Psychological capability	Goals and planning – Barrier identification and problem solving	Support the service-user to identify obstacles to using coping skills in these situations and develop strategies to overcome them
Feeling unrepresented at government policy level	Theme 2: Social influences on decision-making	Social Influences – social support	Opportunity – Social opportunity	Social support Practical	Arrange for practical assistance from advocacy officers to ensure their voice is heard about the issues that matter to them

Appendix Q

Table Q1

Service-User Interventions – Environmental Context & Resources Domain

Finding	Identified via	TDF Domain (Construct)	COM-B Component	BCT- Taxonomy Group	Selected BCT
Identifying appropriate decision-supporters (<i>who</i>)	Theme 3 – the which, who, how of supported decision-making	Environmental context & resources – resources	Opportunity –	Antecedents	Develop: a guide on identifying appropriate decision-supporters, depending on the decision &
Preferred decision-support strategies (<i>how</i>)			Physical –	(Add objects to the environment) &	a menu of decision-support options (e.g. identifying the pros and cons) &
Decision implementation supports (<i>how</i>) –			Environmental context & resources	Shaping Knowledge (Instruction on how to perform the behaviour)	a menu/checklist of options for decision implementation & provide instruction how to use them

Appendix R

Ethical Approval Letter from University of Stirling



University of Stirling
Cottrell 3B1
Stirling
FK9 4LA

09/09/2024

Dear Suzanne Allen

Ethics Application Form : Enhancing supported decision-making skills amongst healthcare staff and the adult service users with disabilities they support.

Ethics Reference Number: NICR_2024_19575_14712

Thank you for your submission of the above ethics application.

The ethical approaches of this project have been approved and you can now proceed with your project.

Please note that should any of your proposal change, a further change request submission will be necessary.

If you have any further queries, please do not hesitate to contact the Panel by email to ethics@stir.ac.uk

Yours sincerely,

NHS, Invasive or Clinical Research

Research Ethics in Practice training is available online:

[Staff & Postgraduate Research Students](#)

[Undergraduate & Postgraduate Taught Students](#)

Appendix S

Ethical Approval Letter from RehabCare



RehabGroup
Investing in People, Changing Perspectives

University of Stirling
Scotland
United Kingdom

25th June 2024

Dear Suzanne,

Thank you for submitting your application for ethical approval from the Rehab Group Research and Ethics Committee.

We are happy to support and approve your research project 'Enhancing supported decision-making skills amongst healthcare staff and the adult service users with disabilities they support' upon the receipt of ethics approval from the University of Stirling and look forward to reading your findings.

Please present this letter of approval to any centres you reach out to in order to conduct your research.

Kind regards,

Dr. Phil Smyth
Research and Ethics Committee Chair (Interim)