Supported Decision-Making with Adults with Intellectual Disabilities, their Family Carers and Professional Carers

By

Hannah Casey, BSc

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Supervised by Dr Laura Coffey and Professor Deirdre Desmond

Head of Department: Professor Deirdre Desmond

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Supported Decision-Making with Adults with Intellectual Disabilities, Their Family and Professional Carers

Summary

Supported decision-making (SDM) – where people use trusted friends, family members, and professionals to help them understand the situations and choices they face, so they may make their own decisions – is a means for increasing autonomy. This research aimed to explore the views and experiences of adults with intellectual disabilities in Ireland and their decision-making supporters (family and professional carers) regarding SDM in order to inform the development of recommendations for guidelines to facilitate SDM for this cohort in anticipation of the commencement of Assisted Decision Making (Capacity) Act. A mixed methods systematic review identified a gap in current understanding of how adults with intellectual disabilities and their supporters use SDM to make everyday decisions. A qualitative survey exploring family and professional carers' experiences of providing decision-making support during the COVID-19 pandemic indicated that carers struggled to facilitate decisional support for adults with intellectual disabilities while restrictions were in place. An environmental scan of online Irish resources on SDM for adults with intellectual disabilities and their supporters identified a paucity of resources relating to the application of SDM in everyday decision-making. Focus groups conducted separately with four stakeholder groups (adults with intellectual disabilities, family carers, professional frontline staff and professional supervisory staff) explored aspects of SDM each group valued most. Two World Cafe-style multi-stakeholder workshops were held to show focus group participants the preliminary focus group conclusions and obtain further thoughts and perspectives on SDM. All findings across this project were synthesised into five key recommendations for the construction of a guide to SDM. This thesis contributes to the literature by providing a multi-stakeholder perspective on the most valued aspects of SDM for adults with intellectual disabilities and their decision-making supporters in an

Irish context and offering evidence-based recommendations for the construction of a resource to be designed for their benefit.

Publications Arising from this Research

Casey, H., Desmond, D., & Coffey, L. (2023). Professional and family carers' perspectives on the COVID-19 pandemic and its impact on supported decision-making with adults with intellectual disabilities: A qualitative online survey. *Disabilities*, *3*(2), 206-216. https://doi.org/10.3390/disabilities3020014

Casey, H., Trayer, Á., Desmond, D., & Coffey, L. (2023). Experiences and perceptions of everyday decision-making in the lives of adults with intellectual disabilities, their care partners and direct care support workers. *Journal of Intellectual Disabilities*, online first publication. https://doi.org/10.1177/17446295231189020

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Glossary of Terms

Assisted Decision-Making (Capacity) Act (ADMA), 2015: Irish legislation signed into law in 2015, and commenced in 2023 following amendment, replacing the Lunacy Regulations (Ireland) Act, 1871 which previously governed the decision-making rights of persons with intellectual disabilities.

Care Partner: A person acting in the capacity of a carer for a person with intellectual disability, who is not doing so on a professional basis, who may or may not be a relative of the person, i.e., a close friend (see Chapter 3).

Client: A person with an intellectual disability who attends a disability service to access its support facilities and staff.

Day Service: A branch of disability services typically open Monday to Friday on a 9-5 basis, that clients may attend. The service facilitates classes, activities, and outings with members of frontline care staff acting in a support capacity.

Direct Care Support Worker (DCSW): A person acting in a professional capacity as a carer to a person with intellectual disability who directly and regularly supports the person in making decisions (see Chapter 3).

Family Carer: A person acting in the capacity of a carer for a person with intellectual disability, who is not doing so on a professional basis, and is a relative of the person.

Frontline Care Staff: Professional carers who work directly with clients to support them in decision-making within residential, day, or outreach services.

Outreach Services: A branch of disability services in which clients have less regular contact with frontline care staff, who will often call to the client’s home for a set number of hours in a week to offer support. Many outreach clients live independently in the community.

Professional Carer: A person acting in a professional capacity as a carer to a person with intellectual disability, who has a role in supporting that person to make decisions, but may or may not be their regular, direct source of support within the disability service.

Reflexive Thematic Analysis (RTA): A method of qualitative data analysis that is conducted in a flexible yet systematic way, which values the subjectivity of the researcher as a key factor of the analytical process.

Residential Service: A branch of disability services where clients live full-time alongside other clients. Frontline care staff work within the residential service to act as support.

Supported Decision-Making (SDM): A method of decision-making support which rests upon the premise that the person being supported is at the centre of the decisional process and should receive as much or as little assistance as they deem necessary during this process from a person or persons of their choosing. This term is used in this thesis rather than that of Assisted Decision-Making (ADM) to retain consistency with the international literature, as SDM is a more globally utilised term, while ADM appears to be primarily used in the Republic of Ireland (see Chapter 5).

Supervisory Staff: Professional carers who manage frontline care staff and may also directly support clients to make decisions.

List of Acronyms

ADMA: Assisted Decision Making (Capacity) Act

ADM: Assisted Decision Making

ASI: Alzheimer's Society of Ireland

CI: Citizens Information

DCSW: Direct Care Support Worker

DSS: Decision Support Service

FC: Family Carer

FCI: Family Carers Ireland

FF: Fieldfisher EU Law Firm

FS: Frontline Care Staff

HIQA: Health Information and Quality Authority

HSE: Health Service Executive

IASW: Irish Association of Social Workers

ID: Intellectual Disability

II: Inclusion Ireland

RTA: Reflexive Thematic Analysis

SDM: Supported Decision Making

SMH: St Michael's House Disability Services

SS: Supervisory Staff

Supported Decision-Making with Adults with Intellectual Disabilities, Their Family and Professional Carers
SWS: Stephen Walsh Solicitors

TBI: Traumatic Brain Injury

UL: University of Limerick

UNCRPD: United Nations Convention on the Rights of Persons with Disabilities

Chapter 1: Introduction

1.1 Chapter Summary

This chapter provides background information on intellectual disability and introduces key concepts underpinning the thesis. It begins with a brief outline of intellectual disability, followed by an overview of key concepts regarding intellectual disability and decision-making, what is meant by the term supported decision-making, and the role of supported decision-making in an international and an Irish context. The chapter concludes by outlining the rationale for the research and detailing the research project outline.

1.2 Intellectual Disability

Intellectual disability is defined by the presence of difficulty in the understanding and execution of various life domains, such as conceptual reasoning, working memory, processing speed and verbal comprehension (Zigic et al., 2023). There must also be evidence of difficulty in navigating conceptual, social, and practical skills, such as the application of knowledge, managing interpersonal relationships, self-care and health and safety (Des Portes, 2020; Zigic et al., 2023). These must be present before the age of 18, with severity now determined by the degree of ability to navigate the conceptual, social and practical skills, although the use of Intelligence Quotient (IQ) to indicate severity is still prevalent in many countries (Des Portes, 2020; Jonker et al., 2021; Zigic et al., 2023). Intellectual disability may have a significant impact on the degree of independence experienced by a person, due to relevant personal and social factors such as difficulty navigating social spaces, increased likelihood of social isolation or exclusion by the community, and an increased need for assistance in understanding and navigating practical aspects of living such as managing money, performing household tasks, or finding employment opportunities (Cvijetić et al., 2024). Lower independence has been observed in people with intellectual disabilities whose carers are less likely to support the person to make their own decisions, which in turn may lead to a decreased sense of self-determination (Mumbardó-Adam et al., 2024). Self-determination may be defined as the level of control and influence a person has over their own life. A stronger sense of self-determination may be experienced when a person feels they have made a decision based upon a deliberate, personal choice, rather than an automatic one (Ryan & Vansteenkiste, 2023). For people with intellectual disabilities, their pursuit of self-determination is linked to the historical pursuit of independent living opportunities and community integration efforts seen in literature beginning in the 1960s and 70s (Mumbardó-Adam et al., 2024). This has evolved in recent years into examining how greater self-determination may be achieved through the person being empowered through training in self-advocacy, access to a supportive community, and carers dedicated to encouraging them in decision-making, leading to a strong sense of self and a feeling of being a causal agent within their own lives (Cvijetić et al., 2024; Estreder et al., 2024). This process is often helped or hindered by the quality of support they receive from carers, and the opportunities they have to exercise personal choice in their daily lives within that support system (Morris et al., 2024). Research indicates that people with intellectual disabilities with access to supporters who encourage and support them to be causal agents in their own lives report greater life satisfaction than those who do not (Cvijetić et al., 2024; Morris et al., 2024; Mumbardó-Adam et al., 2024). In this manner, much of the literature surrounding self-determination in people with intellectual disabilities is intimately tied with that examining the mechanisms and methods of decision-making employed by, and with, this population (Di Maggio et al., 2020; Shogren & Broussard, 2011; Shogren et al., 2017; Wehmeyer & Shogren, 2016, 2017).

1.3 Intellectual Disability and Decision-Making

Decision-making may be defined as making a choice when presented with competing courses of action, following the understanding of the probable outcomes for each of these courses of action (Wehmeyer & Shogren, 2017). It forms a central element of self-determination, empowerment, and social inclusion for people with intellectual disabilities through offering them the opportunity to be causal agents in their own lives (Curryer et al., 2020; Nonnemacher & Bambara, 2011; Stancliffe, 2020; Wehmeyer et al., 2017). The right to make life decisions enables adults with intellectual disabilities to live a meaningful and independent life and leads to higher levels of life satisfaction and psychological wellbeing by fostering self-belief and confidence (Wehmeyer, 2020; Wehmeyer & Shogren, 2016). Historically, people deemed to have an intellectual disability were believed to be unable to make decisions in the same manner as those without an intellectual disability and were often segregated and placed into care facilities (Jarrett, 2015). This segregation and assumption of incapability has resulted in a deep-rooted history of paternalism, and a belief that the lives and affairs of people with intellectual disabilities should be managed by others without an intellectual disability, to prevent perceived unfavourable outcomes (Jarrett, 2015). However, this removal of personal autonomy can result in adults with intellectual disabilities feeling disempowered and may contribute to a poorer quality of life and lower life satisfaction through the perpetuation of feelings of learned helplessness, lack of self-confidence, and lack of control over their own lives (Carey, 2021; Nonnemacher & Bambara, 2011; Shogren & Broussard, 2011; Stefánsdóttir et al., 2018; Wong & Chow, 2021). For people with intellectual disabilities, a key component of autonomy in life events is the acknowledgement of their right to make their own decisions, with as much or as little assistance as they themselves determine is required (Flynn, 2020; Keys, 2017; United

Nations, 2006). However, the way this assistance is delivered impacts its overall usefulness.

There has been a historical tendency to view all people with intellectual disabilities as requiring the same type and extent of assistance in decision-making, or even to assume they are incapable of making decisions at all (Jenkinson, 1993). Jenkinson (1993) noted that the decisions made by people with intellectual disabilities are often more scrutinised and held to a higher standard with regard to their potential outcomes and quality than those made by people without intellectual disabilities, and that there is often a move to dismiss or prevent them from making decisions unless these decisions are deemed by others to be of acceptable risk (Jenkinson, 1993). This has resulted in various paternalistic practices regarding the right of persons with intellectual disabilities to make their own decisions, including the appointment of guardians, who then have the right to make decisions on behalf of the person with little requirement for their inclusion or consultation during the process (Davies et al., 2017; Giertz, 2017; Martinis et al., 2023). This is often cited as an example of so-called best interest decision-making, in which the decisions made on the person’s behalf are made with a view to what the guardian believes is best for the person, rather than what the person themselves may want, a practice which is often paired with substitute decision-making, in which decisions are made by carers on the person’s behalf without consulting the person themselves (Jenkinson, 1993). However, best-interest decision-making and substitute decision-making, though still common, are being slowly phased out in favour of more inclusive, open methods of decisional assistance (Alston, 2017; Brady et al., 2019; Kohn et al., 2012). It is now more readily acknowledged that decision-making for people with intellectual disabilities is frequently a collaborative process, with family and/or professional carers acting in the role of guide, assistant, or information gatherer, as needed (Bigby et al., 2022a, 2022b; Browning et al., 2021; Douglas & Bigby, 2020).

This process is unique to every person with intellectual disability, whose support needs vary depending on their environment, the type of decision in question, and their level of support needs (Bigby et al., 2022a; Douglas & Bigby, 2020). There is also a wider acknowledgement of the need for decision-making processes that do not require people with intellectual disabilities to undergo formal assessments and negotiations in order for the decision to be made, as not every decision made by people with intellectual disabilities requires a formal, rigorous process to explore or execute (Harding & Tascioglu, 2017). For this reason, different inclusive methods of decisional support that allow for a more informal approach are becoming more widely adopted among people with intellectual disabilities and their supporters, including supported decision-making (SDM) (Blanck & Martinis, 2018; Browning et al., 2021; Douglas & Bigby, 2020).

1.4 A Brief Note on Terms Used in this Thesis: Making Decisions Versus Making Choices

Within the limited literature available on the topic, there is a lack of consensus surrounding what is meant by making a choice versus making a decision (Brown & Brown, 2009; Harris, 2003; Stalker & Harris, 1998). Some state that there is a distinction to be made between the two, with making choices referring to the series of smaller selections made in the pursuit of a larger goal, which functions as the actual decision being made (Harris, 2003). Harris and colleagues (2003) give the example of choosing a particular university course or employment option in pursuit of a particular career path, with the career itself being the overarching decision being made in this case (Harris, 2003). However, others claim that no such difference can be claimed, and that it is a matter of semantics, with both terms free to be used interchangeably (Brown & Brown, 2009). Brown and Brown state in their 2009 paper detailing their five-step approach to choice making that choice is not distinct from decision-making as a concept, because both processes involve the person making a selection from a number of options or paths available to them (Brown & Brown, 2009). Indeed, within the literature itself, both terms are often used within the same paper to illustrate the same, or similar, points about the selection process for people with intellectual disabilities (Curryer et al., 2015; Curryer et al., 2018; Stalker & Harris, 1998; Stancliffe, 2020; Stancliffe et al., 2011). For the purpose of this thesis, I speak about the process of making decisions rather than choices in order to retain consistency of language between the general concept of decision-making and the more specific concept of SDM, which is the focus of this research project.

1.5 What is Supported Decision-Making?

SDM has many definitions both within and outside of the research context, but fundamentally rests on the premise that the person who requires support chooses someone to assist them in making decisions, with the final decision resting with the supported person (Center for Public Representation, 2022). The end goal is to afford the supported person the dignity and freedom to make decisions about their own life, without undue influence or pressure from others (Kohn et al., 2012). In this manner, SDM has been presented as an alternative to guardianship practices, as the latter are typically much more restrictive, and rely upon best interest decision-making by placing the bulk of decision-making power in the hands of the legal guardian rather than the person themselves (Kohn et al., 2012). In practice, the person with intellectual disability is at the centre of the decision-making process and selects the people they wish to include in their support circle. The composition and operationalisation of this support circle is tailored to the supported person’s needs, preferences and wishes (Bach & Kerzner, 2010; Shogren et al., 2017). The members of this support circle may include family carers such as parents or siblings, close friends and/or professional carers such as the person’s key worker, residential staff, or day or outreach staff. These supporters work with the person with intellectual disability and each other to facilitate the decision-making process in a manner of the supported person’s choosing (Shogren et al., 2017). This may be via helping the person to gather information on the prospective decision to be made before they choose a course of action on their own, assisting them in understanding outcomes, or in the case of people with communication difficulties or greater severity of intellectual disability, representing the person’s wishes based upon their knowledge of the person’s preferences and personality (Bach & Kerzner, 2010).

The majority of research on SDM to date has focused on its legal and policy implications; however, studies focused on stakeholder experiences suggest that SDM results in improved outcomes related to self-determination and life satisfaction for people with intellectual disabilities through affording them the opportunity for a collaborative relationship with their decisional supporters (Douglas & Bigby, 2020; Gudelytė et al., 2024). For example, in a longitudinal qualitative study conducted over a six-month period by Gudelyté and colleagues to examine the effects of implementing SDM as a support method in the lives of 26 L’Arche community members with intellectual disabilities and their professional carers, participants with intellectual disabilities reported feeling better able to communicate their needs effectively and experiencing more joy in their daily lives (Gudelytė et al., 2024). This was corroborated by their professional carers, who said they themselves found the support relationship more fulfilling, along with observing an increase in clients’ sense of self-advocacy and control over their own lives during support meetings (Gudelytė et al., 2024). In relation to family carers, Bigby and colleagues have conducted a number of studies showing the benefits of engaging in SDM with family members with intellectual disabilities through affording them the opportunity to see the person they support as an adult, and to foster a more meaningful relationship with them, while relieving some of their own stress and anxiety around the person’s ability to manage as an independent adult (Bigby & Anderson, 2021; Bigby et al., 2011; Bigby et al., 2022a, 2022b; Bigby, Webber, et al., 2015; Carney et al., 2023). The shift in the provision of decision-making support towards SDM has been slowly gaining traction over many years, but its main catalyst was the landmark publication of the United Nations Convention on the Rights of People with Disabilities (UNCRPD), particularly Article 12, Equal Recognition Before the Law (Series & Nilsson, 2018; United Nations, 2006). This Article states that governments should remove legal frameworks allowing substitute decision-making and should replace them with frameworks centring SDM as the designated method of decisional support (Scholten & Gather, 2017). This stipulation has caused some controversy, particularly within mental health services, with some psychiatrists arguing that in instances of greater cognitive deficit, or mental distress, it is inevitable that some people will not possess the capacity to make decisions, and as such, removing substitute decision-making entirely is neither appropriate nor possible (Freeman et al., 2015; Scholten & Gather, 2017; Szmukler, 2015). This interpretation of the Article has been refuted by law and policy experts, however, who point out that it makes reference to assessing the capacity of a person to make a decision, but stipulates that it must be conducted in a manner that takes the person’s individual circumstances into consideration, and acknowledges that a person’s right to make decisions cannot be removed indefinitely based upon the results (Arstein-Kerslake, 2016). Therefore, despite these concerns, there have been some notable steps, both nationally and internationally, to adopt an approach to decision-making that embraces SDM, and limits or removes the idea of guardianship from current legal frameworks.

1.5.1 Practical Applications of SDM in an International Context

Although many countries have taken steps to honour the premise outlined in Article 12 of the UNCRPD, the notable changes that have occurred in Australia, Canada, and the USA will be discussed here. In 2014, the Australian Law Reform Commission (ALRC) conducted an examination of all Commonwealth laws that directly impeded the ability of people with disabilities to exercise their right to legal capacity (Australian Law Reform Commission, 2014). Following this examination, they proposed a set of National Decision-Making Principles alongside guidelines to bring Australia in line with the UNCRPD in terms of legal capacity (Australian Law Reform Commission, 2014). The La Trobe Framework, created by Bigby and colleagues, uses these principles as a guide (Douglas & Bigby, 2020). This framework rests on seven steps of decisional support: 1. knowing the person, 2. identifying and describing the decision, 3. understanding will and preferences, 4. refining the decision to take into account of constraints, 5. considering if a formal process is needed, 6. reaching the decision and associated decisions, and 7. implementing the decision and seeking advocates if necessary (Bigby et al., 2022b; Douglas & Bigby, 2020). These steps were developed following an extensive literature review and qualitative investigations into the perspectives and requirements of relevant stakeholders (Bigby et al., 2022a, 2022b; Bigby, Whiteside, et al., 2019; Carney et al., 2023; Douglas & Bigby, 2020). The framework is designed with acknowledgement of the current Australian disability structure, the National Disability Insurance Scheme (NDIS), and takes into account the cultural context of the country regarding disability (Bigby et al., 2022b; Carney et al., 2023; Douglas & Bigby, 2020). A practical training programme based on this framework has been piloted and evaluated by disability care workers and health care professionals, and is currently in an implementation phase (Douglas & Bigby, 2020). The programme focuses primarily on assisting family carers in adapting to SDM as their primary support technique for adults with intellectual disabilities (Bigby et al., 2011; Bigby et al., 2009; Bigby et al., 2022a, 2022b; Douglas & Bigby, 2020). Preliminary findings indicate that family carers have found the programme to be very helpful in showing them how to make the change from more best interest approaches to decision-making to a more SDM-centred approach that encourages the person with intellectual disability to make their own decisions. They reported that the supported person displayed more self-confidence due to their change in approach, and that it led to a more respect-driven, positive relationship between them and the supported person (Bigby et al., 2009; Bigby et al., 2022a, 2022b; Carney et al., 2023; Douglas & Bigby, 2020).

Canada has been at the forefront of supporting the rights of people with disabilities to make decisions. In 1996, British Columbia passed the Representation Agreement Act, which provided a legal alternative to guardianship, the first Act in the world to do so at the time (Stainton, 2016). In more recent years, Browning and colleagues conducted research to identify common factors in SDM and decisional support experienced and practiced by Canadian people with intellectual disabilities and their supporters. Five factors were identified- 1. the experiences and attributes the person and their supporter brought to the process; 2. the quality of their relationship; 3. the decision-making environment, 4. the nature of the decision, and 5. the consequences of the decision (Browning et al., 2021). This research concluded that decision-making support is highly contextual, dependent on a complex series of factors that are highly individualised, and supporters often struggle to remain neutral during the process out of a desire to prevent an unfavourable outcome (Browning et al., 2021). This last point echoes a perspective seen on a national scale in Canada regarding Article 12 of the UNCRPD, namely concern that abolishing substitute decision-making in its entirety might put people with intellectual disabilities at risk of greater harm (Dufour et al., 2018; Stainton, 2016). Due to this, Canada has retained its substitute decision-making laws, despite having ratified the UNCRPD in 2010 (Dufour et al., 2018; Stainton, 2016; United Nations, 2023).

Similarly, the United States has also expressed concern with aspects of the UNCRPD, but unlike Canada, has thus far elected not to ratify it, despite signing in 2009, due to the belief that its own domestic laws provide more sufficient protection for people with intellectual disabilities (Grant, 2015; United Nations, 2023). Nonetheless, significant progress has been made in relation to the adoption of SDM, particularly in the states of Massachusetts, Virginia, and Georgia. The Center for Public Representation is a national organisation that provides resources and support to people with disabilities and their carers regarding SDM and exercising legal capacity (Center for Public Representation, 2022). As part of this effort, several states have undertaken research projects and pilot programmes to introduce SDM to disability services, including Massachusetts, Virginia, and Georgia (Blanck & Martinis, 2015, 2018; Martinis et al., 2023; The Arc of Northern Virginia, 2023). SDM has been adopted by 20 US states to date as an alternative to guardianship. The case for SDM reached national prominence after the landmark case of Ross and Ross vs Hatch, in which Margaret “Jenny” Hatch, a young woman with Down Syndrome, won her battle against the court system to regain her right to independence after being placed in temporary guardianship against her will (Martinis et al., 2023). This sparked a larger initiative to introduce the concept of SDM and support in independent decision-making founded by Hatch and her associates known as the Jenny Hatch Justice Project (Blanck, 2023; Martinis et al., 2023). However, due to the nature of the legal system in the USA, each state retains the right to decide its own perspective on SDM as an alternative to guardianship, and the latter continues to be the preferred method of disability support in many areas, despite great progress in others (Blanck, 2023).

1.5.2 SDM in an Irish Context

Ireland's adoption of SDM was no less rooted in its cultural and political context, and the journey to replace guardianship with a more open, person-centred approach has been slow but meaningful. According to the 2022 census, 109,288 people living in Ireland have an intellectual disability, representing 2% of the Irish population (Central Statistics Office, 2023). A survey conducted by the Health Research Board (HRB) in 2023 found that 73,927 adults with intellectual disabilities in Ireland were registered with a disability service (Health Research Board, 2023). Ninety-two percent of these service users reported living with their primary care provider, who was the person's parent(s) in 73% of cases, 41% of whom were aged 60 years or over (Health Research Board, 2023). In addition, 7,108 service users with an intellectual disability reported living in a residential setting rather than their family home (Health Research Board, 2023). Irish services are divided into a number of sectors, with some fully funded by the HSE, and some operated by other disability services on behalf of, or in partnership with the HSE. Within these services, the types of support offered are typically divided into residential, day, and outreach services. Residential services typically consist of houses of varying sizes in which services users live full-time, with professional carers in place to offer care and support within the house (Citizens Information, 2024b). Day services operate for a number of hours every weekday from morning to late afternoon, and offer access to recreational activities, social engagements, or courses which are facilitated by professional carers. Following the conclusion of the day service, service users return to their primary place of residence, which may be at home or in a residential service (Citizens Information, 2024a). Lastly, outreach services usually involve professional carers visiting service users in their home, which is usually either within the family home or in their own home where they live independently. Outreach staff generally provide assistance over the course of a short visit, and may assist service users in attending appointments, future planning, or achieving desired goals or tasks (Kare, 2024). The cultural context of older family carers forming the bulk of support for Irish adults with intellectual disabilities has been noted as a prevailing trend in the Irish context (Brennan et al., 2018; Lafferty et al., 2016; Ryan et al., 2014) and has led to a historically paternalistic attitude towards people with intellectual disabilities in Ireland (McCausland et al., 2018; Rogers et al., 2020). This is not unique to the Irish context, however, with a broader history of paternalism noted in relation to people with intellectual disabilities worldwide (Foley, 2014; McDonagh, 2006). Research indicates that this attitude was often rooted in a parental desire to protect and shield the person from perceived negative outcomes through managing their daily concerns and tasks to ensure a positive outcome (Casey, Desmond, et al., 2023a; Davidson et al., 2015). This has changed in recent years, however, with Ireland's ratification of the UNCRPD (United Nations, 2006), a convention which enshrines the right of persons with disabilities to live full, meaningful lives as part of their communities, and by the commencement of the Assisted Decision-Making (Capacity) Act (ADMA: Oireachtas, 2015) in 2023, as well as through changes in the international landscape such as the disability rights movement, and the UNCRPD.

The ADMA was signed into law in Ireland in 2015 (Oireachtas, 2015) and provides a statutory framework to assist adults experiencing difficulties with decision-making. The Act replaces the Lunacy Regulation (Ireland) Act 1871, whereby a Ward of Court gains jurisdiction over all matters relating to the Person and Estate of an individual deemed to lack mental capacity. In contrast, the ADMA articulates a range of decision-making supports and places the will and preferences of the person at the heart of decision-making (Kelly, 2017), representing a fundamental shift from traditional guardianship and substituted decision-making models in favour of an approach which encourages people requiring decisional support to seek it on their own terms in a manner that allows them to be causal agents in their own lives. In order to achieve this, a tiered system of support operated by a new government body called the Decision Support Service (DSS) has been established, which accounts for the differing levels in decisional support a person may require. Within this system, support can take the form of: i) a decision-making assistant, who helps gather information related to a decision, with the bulk of decision-making being completed by the person themselves unassisted; ii) a co-decision maker, who helps the person in making decisions throughout the entire process; or iii) a decision-making representative, who interprets the will and preferences of a person unable to directly communicate their decisions themselves during the decision-making process (DSS, 2023). This development increases Ireland’s compliance with the UNCRPD (United Nations, 2006), and has significant implications for individuals with intellectual disabilities, their families and service providers. Following an Amendment to the Act in 2022, it was commenced in April of 2023, formally removing guardianship as the primary method of decisional support for people with intellectual disabilities. The DSS was created alongside the Act and opened its doors upon its commencement. Despite these positive steps, a Red C poll taken in May 2023 showed that 67% of Irish citizens had not heard of the Act and were not aware of its purpose (Safeguarding Ireland, 2023). Furthermore, although some research has been conducted with stakeholders in Ireland regarding their experiences with SDM and other methods of support, it has largely focused on family and professional carers and their experiences of understanding or adapting to this new legislation while exploring their current support methods (Casey et al., 2023a; McCausland et al., 2019; Rogers et al., 2020).

The bulk of the literature regarding SDM in the Irish context to date has centred on theoretical or policy-related implications, particularly in the fields of health and law, such as the role the ADMA in altering policy perceptions of the capability of people with intellectual disabilities, TBI, or dementia, or how SDM can be safely implemented in healthcare settings regarding critical life decisions such the creation of advanced care directives or end of life care plans (Donnelly, 2023; Duffy & Kelly, 2023; Flynn, 2020; Kelly, 2017; Murphy & Bantry-White, 2021; Murphy et al., 2023; Ní Shé et al., 2020). However, many of the decisions people with intellectual disabilities make are related to everyday tasks such as what to wear, whom to visit, or where to go for the day do not require an extensive, formal process to execute (Harding & Tascioglu, 2017). These everyday decisions and how they are made by people with intellectual disabilities and their decision-making supporters remain largely unexplored in the Irish context, although they have been examined in other countries, such as in the Everyday Decisions Research Project in the UK (Harding & Tascioglu, 2017). This project identified areas of decision-making in the lives of people with intellectual disabilities that they required support in making. These decisions were divided into everyday decisions such as those relating to food, leisure, and activities, life decisions such as those relating to housing, education, and employment, and difficult decisions such as those relating to finances, medical, and legal issues (Harding & Tascioglu, 2017). Furthermore, no research to date in an Irish context has sought to understand how family carers, professional carers, and the person with intellectual disability themselves work together to navigate or implement these decisions, particularly in this time of legal and political change. Although many adults with intellectual disabilities in Ireland attend disability services, most continue to live at home with family carers. Therefore, it is essential in the exploration of SDM in an Irish context to consider how the person's relationship with their family and professional carers, and indeed the relationship between professional and family carers, might impact the adoption and effectiveness of SDM. In order for SDM to be fully embraced by Irish people with intellectual disabilities and their family and professional carers, it is vital that their preferences, perspectives, and experiences of giving and/or receiving decisional support are captured in order to better understand how this support might be applied in a day-to-day, informal manner, instead of focusing exclusively on formal supports and high stakes decisions.

1.6 The Rationale for the Present Research

As outlined in section 1.3 of this chapter, people with intellectual disabilities often make decisions in collaboration with their carers and disability services, who provide them with the help and support they need to do so as independently as possible and ensure they are causal agents in their own lives (Deci & Ryan, 1980; Di Maggio et al., 2020; Ryan & Deci, 2017; Ryan & Vansteenkiste, 2023). SDM has been shown to be an effective method of providing this support, through its person-centred approach and emphasis on the will and preferences of the supported person, as discussed in section 1.5 (Kohn et al., 2012; Series & Nilsson, 2018; United Nations, 2006). SDM has gained significant traction internationally due to the UNCRPD’s assertion of its benefits, with each country having its own manner of adjusting its laws and policies to reflect the UN’s recommendations, as outlined in section 1.5.1 (Blanck, 2023; Browning et al., 2021; Douglas & Bigby, 2020). National and international literature on the use of SDM, and on stakeholder experiences and perceptions of decisional support, is discussed in more detail in chapter 3, which presents a systematic review of the literature addressing perceptions and experiences of everyday decision-making among adults with intellectual disabilities, their care partners and support workers (Casey, Trayer, et al., 2023). Moreover, as discussed in section 1.5.2, although important steps have been taken in Ireland at policy and government level to remove guardianship laws and replace them with legislation founded upon the principles and values of SDM, changes in support ethos and methods have been slow to reach the daily lives of adults with intellectual disabilities and their supporters, with the majority of reform to date taking place at the level of upper management and policy (Flynn, 2020; Oireachtas, 2015;

Decison Support Service, 2023). The lack of guidance and support in understanding this new method of support outside of formal contexts represents a distinct gap in the application of SDM in an Irish context, as the majority of decision-making carried out by adults with intellectual disabilities does not require formal channels (Harding & Tascioglu, 2017). In order for SDM to be truly embraced and effective in the lives of adults with intellectual disabilities in Ireland, it is vital to understand how they and their family and professional carers currently carry out decision-making on a day-to-day basis, with a view to supporting them and their decision-making supporters to apply SDM in informal as well as formal contexts, taking into account the cultural and legal context of Ireland. Therefore, the aim of this research was to: 1. explore everyday decision-making in the lives of adults with intellectual disabilities, their family carers, and their professional carers; 2. through this exploration, establish what they consider most important during the process of decisional support; and 3. establish what they feel is most important to consider in the development of recommendations for a guide to SDM that can be used during daily decisional support, during this current time of legal and political change in decision-making legislation.

1.6.1 Thesis Outline

This thesis consists of nine chapters and describes research conducted in an iterative manner. Chapter 2 gives an account of the underpinning rationale for the qualitative nature of the project and provides an overview of the methodological areas of importance that were considered throughout. Chapter 3 consists of a systematic review of the literature to summarise the current state of knowledge on the experiences and perceptions of adults with intellectual disabilities, their family carers, and professional carers regarding support in everyday decision-making. Chapter 4 details a qualitative survey of the experiences of professional and family carers of adults with intellectual disabilities in providing decisional support during the COVID-19 pandemic. Chapter 5 details an environmental scan of online resources on SDM and the ADMA for adults with intellectual disabilities and their professional and family carers in Ireland, with the aim of identifying gaps in information, guidance, and training opportunities in SDM in the Irish context. Chapter 6 details the process and outcomes of focus groups exploring the experiences and perceptions of stakeholders [adults with intellectual disabilities, family carers and professional carers (frontline and supervisory staff)] regarding everyday decision-making and what they value most during the decisional process. Chapter 7 consists of two parts. Part 1 details what participants considered most important to include in a guide to SDM designed for their use during the focus group sessions, while part 2 describes multistakeholder feedback sessions conducted in a World Café format with the focus group participants in which they reviewed part 1's findings, and suggested recommendations for how they could be expanded upon or improved. Chapter 8 draws together the results and conclusions from Chapters 3-7 using the framework of convergence, complementarity, silence, and dissonance to identify key themes, which were then synthesised into overall recommendations for the construction of a guide to SDM for stakeholder use. The thesis concludes with Chapter 9, which consists of an overall discussion of the findings in the form of a personal reflection on the project, followed by a discussion of the theoretical and policy implications of the findings, recommendations for further research, and concluding thoughts.

Chapter 2: Methodology

2.1 Chapter Summary

This chapter will give an overview of the methodology underpinning this research. It will begin by outlining the philosophical underpinning of my work before detailing the rationale for selecting a qualitative approach to data collection, and the ethical considerations taken into account when conducting the research and data analysis. The chapter concludes with a reflection on researcher positionality within the research.

2.2 Philosophical Underpinning of the Research

This research project aimed to examine the experiences and perceptions of adults with intellectual disabilities, family carers, and professional carers regarding the execution and adoption of SDM in an Irish context. A social constructivist approach was adopted in order to centre these experiences and perceptions throughout the research process (Adams, 2006; Kim, 2001). Social constructivism in research involves an approach to investigative thinking whereby the researcher examines the interpreted reality of participants and acknowledges that this reality is as personal and individual as each included participant and reflects the diversity of lived experiences captured by the research process (Adams, 2006; Kim, 2001). The researcher collects and analyses data with a view to building a diverse and complex socially constructed landscape which allows them to capture the collective experience of the included participants without assuming that this experience will be the same for all involved (Adams, 2006; Boyland, 2019; Kim, 2001). Furthermore, the researcher remains aware of how their own interpretation and personally constructed experience might influence their analysis of the data, and through this can be conscious of, and directly utilise their own subjectivity throughout the data collection and analytic process (Boyland, 2019). In disability research, there has been a marked emphasis placed upon the researcher's acknowledgement of the role of social and cultural practices in the quality of life and social inclusion of people with disabilities (Abedi et al., 2013; Barnes, 2018; Priestley et al., 2010). For people with intellectual disabilities, societal views of their capability in decision-making have long informed the degree to which they are afforded the opportunity to participate fully in society (Young & Quibell, 2000). Therefore, when conducting disability research, it is essential to consider the cultural and social context in which it is carried out in order to better understand the experiences and perceptions of participants. In Ireland, people with intellectual disabilities largely reside in the family home, with their primary carers often consisting of an older relative, most often a parent (see chapter 1, section 1.5.2) (Health Research Board, 2023). There has been a recent legal and cultural shift in Ireland from more paternalistic approaches to decision-making towards a greater emphasis on SDM (Kelly, 2017). This combination of having an older person as the primary source of care and a legal preference towards guardianship resulted in a conservative view of the decisional capabilities of people with intellectual disabilities in Ireland, a view that has remained prevalent for many years despite frequent attempts by disability organisations and activists to alter it (Inclusion Ireland, 2021). This social and cultural context was important to consider during the research process, as it provided necessary context on how and why participants might feel a particular way about SDM as a relatively new way of executing decisional support for people with intellectual disabilities. The experiences of participants under the older system of guardianship and best interest practice would inform their perspective on the new system. Therefore, a social constructivist perspective on the research allowed for a nuanced examination of the data through consideration of the social and cultural context in which participants were situated (Adams, 2006; Kim, 2001). Furthermore, this social and cultural context also includes the interactions and relationships that people with intellectual disabilities have with their professional and family carers. As such, a rich and detailed social constructivist perspective on how they experience and receive support would not be possible without considering how the interactions between the person, their family carers, and their professional carers, as well as those between family and professional carers, informed the provision and nature of this support. Therefore, the project sought to capture the thoughts, perspectives, and experiences of these three groups to better understand how this system of support operated, and how each group's views, needs, and experiences might inform the execution of SDM in day-to-day life. To ensure a more rounded understanding of how SDM functioned in practice, it was thus necessary to acknowledge the voices of all three groups throughout the research to allow each of their perspectives to be analysed, compared, and contrasted within the context of the research question.

2.3 Rationale for a Qualitative Approach

The centring of the experiences of participants in this research process necessitated an approach which would allow for the exploration of stakeholder experiences in rich detail. In order to establish participants' current thoughts on SDM, what they felt could be accomplished with regard to SDM in the future, and how they felt the disability care system could improve its approach to decisional support, it was important to engage meaningfully and directly with the relevant populations. Therefore, a qualitative approach was chosen. A qualitative approach to research allows the researcher to centre stakeholder experiences through engaging with them directly and giving them the opportunity to describe their experiences and perspectives in their own words (Liamputtong & Rice, 2022; Van't Riet et al., 2001). The aim of this research project was not only to explore stakeholders' awareness of and engagement in SDM, but also their satisfaction with it as a method of support, how they felt about it in practice, other support methods they used, and what they required in terms of guidance and support as the landscape of decisional support continued to shift. These were not questions that could be sufficiently answered using quantitative methods, as they required a level of depth and personal reflection best captured through direct conversation with participants to thoroughly record their experiences and perceptions. Furthermore, it has been noted that in the field of disability research, qualitative methods of data collection have been shown to be more inclusive, as they afford participants the opportunity to express themselves clearly regarding the topic through imparting their feelings and experiences directly to the researcher (Liamputtong & Rice, 2022). Secondly, when engaging with a research topic concerning the experiences of a marginalised population of which the researcher is not a member, qualitative data collection methods ensure that the voice of the researcher does not supersede that of the participants themselves, as they typically encourage self-reflection and the acknowledgement of personal biases and influence on the part of the researcher (Alvesson et al., 2022; Jootun et al., 2009). In this manner, qualitative data collection methods were employed for this research project to further ensure that the preferences, experiences, and perceptions of people with intellectual disabilities, family carers, and professional carers remained the central focus of the research.

2.4 Ethical Considerations

In research involving human participants, it is necessary to consider a number of ethical aspects of data collection and participant recruitment. Researchers must adhere to an appropriate code of ethics and build a relationship with their participants based upon trust, respect, and the acknowledgement of the rights and responsibilities the researcher holds during the research process (Aluwihare-Samaranayake, 2012). All participant consent must be recorded before any data collection takes place, and the composition of the participant pool must be taken into consideration to prevent imbalance of power and maximise participant comfort and security (Råheim et al., 2016). For this research project, the Psychological Society of Ireland code of ethics along with that of Maynooth University formed the basis of the considerations made (Inclusion Ireland, 2024; Maynooth University, 2020). The participant pool included individuals without intellectual disabilities (i.e. family and professional carers), as well as those with intellectual disabilities, who in an ethical context are considered a vulnerable population (Sutton et al., 2003). Within this project, specific considerations were required for participants with intellectual disabilities (Sutton et al., 2003). While power differentials are always central to any research conducted with humans, there is a particular risk when conducting research with adults with intellectual disabilities of encouraging or influencing their responses to reflect what they believe the researcher most wants to hear (Taua et al., 2014). Furthermore, it is essential that measures are put in place to ensure that participants with intellectual disabilities are able to fully engage with and understand any materials required to be read and comprehended before consenting to participate as well as during data collection (Coons & Watson, 2013). Finally, it has been noted that people with intellectual disabilities may require more time to digest the proposed questions or topics to be discussed during qualitative research (Di Lorito et al., 2018).

Furthermore, the issue of informed consent for people with intellectual disabilities should be noted. Previous research has indicated that gatekeepers in the form of professional or family carers selecting clients for research participation may prevent people with intellectual disabilities with higher support needs from taking part in research due to assumptions made about them during the recruitment process (Crook et al., 2016). Recruitment for the focus groups and subsequent World Cafés carried out in this research project required the use of gatekeepers, as the disability organisations from which participants with intellectual disabilities were recruited would not permit direct recruitment by the researcher due to concerns regarding GDPR and safeguarding. This is a common concern among professional carers enlisted to assist in research recruitment, and historically has resulted in specific cohorts being put forward, most often clients who have good verbal communication skills with little need for communication aids (Carey & Griffiths, 2017). Therefore, the inclusion criteria for the focus groups and World Cafés, which specified people with intellectual disabilities who had experience with being supported to make decisions (see chapter 6), was being interpreted by these gatekeepers in lieu of clients themselves. It is possible, therefore, that clients with more severe intellectual disabilities, and/or alternative communication requirements, may have been pre-emptively excluded by professional carers due to assumptions that these clients lacked the ability or experience to participate. As such, the role of gatekeepers in recruitment for research with intellectual disabilities should be considered when contemplating the ethical considerations of research with this cohort, as they may inadvertently prevent the broader spectrum of intellectual disability from being represented (Carey & Griffiths, 2017; Crook et al., 2016).

In the case of participants without intellectual disabilities, considerations needed to be made regarding the composition of the focus groups for family carers and professional carers (see chapter 6 for details). It was determined that having separate focus groups for each stakeholder group would be more beneficial, as it would prevent any imbalanced power dynamic from forming between disability service staff and family carers, who might feel unable to voice concerns with the service if there were members of staff present. Furthermore, in the case of professional carers, supervisory and frontline staff members were further divided into their own focus groups, to prevent any frontline staff members from feeling reluctant to be candid about their experiences in front of a supervisor.

With these factors in mind, a number of key actions were taken throughout this research project to ensure an inclusive, open approach to recruitment and data collection. Firstly, before any recruitment or data collection took place, the two disability services in which recruitment for the focus groups and multistakeholder feedback sessions took place (see chapters 6, 7, and 8) required an application to their individual ethics committees, which involved providing a detailed account of the proposed recruitment methods, data collection methods, and reassurance that participants would be free to engage with the research for as long as they themselves chose to do so, and could terminate their relationship with the researcher at any time. Following the approval of both disability services, approval was sought from Maynooth University’s Social Research Ethics Sub-Committee, informed by the principles of ethical research as set out by the university (University, 2020). Ethical considerations made regarding participants with intellectual disabilities included ensuring all material was available in an easy read format to ensure they could engage with any necessary information in a clear, accessible way and providing contact details to allow them to contact the researcher to ask any questions they might have (see Appendix VI in Vol II). Accessibility features added included using large, clear font, straightforward, jargon-free language, and pictograms to aid understanding. The written information sheet was also accompanied by a link to a short video made by the researcher, which explained the project purpose and contents orally. When the easy read material was being constructed, the advice and perspective of a person with intellectual disability was sought, and the materials were reviewed and edited by this person before their dissemination (see chapters 6 and 7 for details). Finally, research has suggested that participants with intellectual disabilities often prefer to have a trusted supporter such as a key worker or family carer present during data collection to aid them in understanding questions and increase their feelings of security, to prevent imbalance of power between the researcher and the participants, or between participants with intellectual disabilities and family carer participants, or professional carer participants (Clarkson et al., 2009; Temple & Walkley, 2007; Timmons et al., 2011). All participants with intellectual disabilities in the present research were invited to do so if they wished. Staff members from each disability organisation assisted in the process of securing the informed consent of participants with intellectual disabilities by sitting with them beforehand and reading through the consent form with them. During data collection, all participants were reminded that they were under no obligation to continue with the research and were free to end their participation at any time. Participants with intellectual disabilities were given a short break in the middle of data collection sessions, as previous research with this cohort has indicated that they prefer to take breaks when participating in research involving collection methods such as focus groups in order to have more time to think, and to prevent undue fatigue. For the same reason, focus group sessions with participants with intellectual disabilities were also kept shorter (Temple & Walkley, 2007). For detailed descriptions of the methods of consent and data collection employed for each primary data collection phase, see the relevant sections of chapters 4 (survey), 6 (focus groups), and 7 (feedback sessions).

2.5 Researcher Positionality Within the Research Process

When conducting qualitative research, it is necessary to remain aware of your own personal experience and how it may influence your interpretation of the data (Haynes, 2012). Due to this, it is imperative that researcher bias is considered during data collection and analysis, especially if you have personal experience of the topic under investigation (Gill, 2022). This can be achieved through the practice of reflexivity within the research process (Braun & Clarke, 2019, 2021; Byrne, 2022). There are several ways in which this can be accomplished, such as keeping a diary of one’s thoughts and feelings, recording detailed memos, and employing methods of data analysis that centre reflexive practices (Alvesson et al., 2022; Braun & Clarke, 2019, 2021). With these considerations in mind, I sought to remain cognisant of my own positionality within the research and throughout data collection and analysis through acknowledgement of, and reflection on, my own experiences in relation to the topic under research. I chose to view my subjective thoughts and experiences as tools to deepen and contextualise my interpretations and conclusions, rather than seeking to remove myself from the data entirely (Byrne, 2022). I am a family member of someone with an intellectual disability. I participate in their care, and form part of their support circle. I cannot divorce myself from the thoughts, feelings, and experiences I have relating to this topic. Rather, these aspects formed a key part of my research process. They allowed me to foster a sense of empathy with my participants during data collection, and to resonate with their perspectives and experiences. I gained new perspective on my own subjective assumptions and interpretations as a family carer through my analysis of the experiences of other family carers, and by being exposed to the contrasting perspectives of professional carers and people with intellectual disabilities. Furthermore, my personal experiences encouraged me to remain open and curious during data analysis, to reflect upon my own interpretations, and to revisit and consider these interpretations when finalising my conclusions. As such, remaining aware of my own personal views and assumptions proved to be a useful component of the data collection and analytic process. However, it was also important for me to remain conscious of potential biases associated with having personal experience as a family carer of an adult with intellectual disability. When facilitating the focus groups and feedback sessions, I mitigated these biases by remaining open to hearing what all participants had to say, allowing the group to lead the conversation while I listened carefully, and taking field notes. When analysing the data, I chose to employ reflexive thematic analysis (RTA), as this method of data analysis actively encourages the researcher to utilise their own subjective thoughts and opinions as a way of gaining a more nuanced understanding of the data (Braun & Clarke, 2021). I used the memo function in MaxQDA to record my initial impressions and interrogated these impressions in light of my knowledge of the topic as a researcher. Through this rigorous and ongoing examination of my thoughts, I attempted to harness my biases and personal experiences to allow for a richer and more considered interpretation of the data.

Chapter 3: The Experiences and Perceptions of Adults with Intellectual Disabilities, Care Partners and Direct Care Support Workers of Everyday Support in Decision-Making: A Systematic Review

3.1 Chapter Summary

This chapter details the conduction of a mixed methods systematic review of the literature on the experiences and perspectives of adults with intellectual disabilities, their care partners, and direct care support workers regarding everyday decision-making. This review has been published in the *Journal of Intellectual Disabilities*; the current chapter is based on that publication (Casey, Trayer, et al., 2023). Section 3.2 gives a brief introduction to the review and describes its central aims. Section 3.3 details the methodology used. Section 3.4 describes the results. Finally, section 3.5 consists of a discussion of these results in the context of the overall topic of decision-making in people with intellectual disabilities, the strengths and limitations of the review, and recommendations for future research.

3.2 Introduction

Decision-making for people with intellectual disabilities is a popular topic among disability researchers. However, there is a lack of information surrounding how this is operationalised in everyday situations. Previous reviews of the literature on supporting the decision-making of people with intellectual disabilities have focused mainly on critical decisions such as end-of-life care, or advanced directives to address critical medical decisions (Noorlandt et al., 2020; Penzenstadler et al., 2020; Shogren et al., 2017). Reviews examining everyday decision-making have been centred around people with traumatic brain injury (TBI) (Noorlandt et al., 2020) and dementia (Kohn & Blumenthal, 2014) rather than intellectual disability; or have recruited combined samples including people with intellectual disabilities, TBI, and/or dementia (Bigby, Whiteside, et al., 2015; Penzenstadler et al., 2020; Shogren et al., 2017). The aims of this systematic review were threefold: to investigate i) how everyday decision-making is perceived and/or experienced by adults with intellectual disabilities, their care partners (including both familial and non-familial unpaid support: Daly et al., 2018) and direct care support workers (DCSWs, i.e., professional staff working directly with adults with intellectual disabilities); ii) what techniques/approaches to everyday decisional support are used by each group; and iii) what barriers and facilitators to everyday decision-making each group encountered. Within this review, an everyday decision was defined as one which any person may make any day throughout their life as a natural consequence of being an adult, outside of a critical life event such as severe illness or end-of-life care. The Everyday Decisions Project, carried out by researchers at the University of Birmingham, was used as a guide to determine what types of decisions qualified as everyday decisions (Harding & Tascioglu, 2017). This project investigated the types of decisions considered important by people with intellectual disabilities in their daily lives and showcased the wide range of decisions they might require help with (Harding & Tascioglu, 2017), including smaller, relatively trivial decisions related to food, leisure, and everyday activities, as well as more significant decisions regarding housing, education, employment and sexual health (Harding & Tascioglu, 2017).

3.3 Method

This review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines (Page et al., 2021) and was registered with PROSPERO (CRD4202170417; https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=170417).

3.3.1 Search Strategy

Electronic searches of five databases were performed: CINAHL, PsycINFO, PubMed, Scopus and Web of Science. The searches were carried out initially in May 2020 and were updated in February 2022. Searches were limited to articles published in English since January 2006, the year in which the UNCRPD (United Nations, 2006) was adopted. Search strings were developed using controlled vocabulary and/or free text search terms for each database. Bigby and colleagues’ (2015) review of decision-making support for people with intellectual disabilities and persons with TBI, and Daly and colleagues’ (2018) review of decision-making support for persons with dementia informed the wording and content of the search strings (Bigby, Whiteside, et al., 2015; Daly et al., 2018). The search strings also incorporated different terms used to refer to intellectual disability over time and across countries (Table 1).

Table 1: Search Strings Used in Review Databases

Database	**Search String**
PubMed	(("Intellectual Disability"[Mesh]) AND "Decision Making"[Mesh] OR “ Decision Making, shared” [Mesh] + year 2000 – 2020
Scopus	"intellectual* disab*" OR "intellectual* handicap*" OR "intellectual* impair*" OR "intellectual* disorder*" OR "development* disab*" OR "mental* handicap*" OR "mental* disab*" OR "mental* retard*" OR "down* syndrome*" AND "decision making"
Web of Science	(TS=("intellectual* disab*" OR "intellectual* handicap*" OR "intellectual* impair*" OR "intellectual* disorder*" OR "development* disab*" OR "mental* handicap*" OR "mental* disab*" OR "mental* retard*" OR "down* syndrome*") AND TS=("decision making")) *AND* LANGUAGE: (English). From 2000-2020

PsycINFO	intellectual* disab* OR intellectual* handicap* OR intellectual* impair* OR intellectual* disorder* OR development* disab* OR mental* handicap* OR mental* disab* OR mental* retard* OR down* syndrome* AND decision making (LIMIT: English, 2000-2020)
CINAHL	intellectual* disab* OR intellectual* handicap* OR intellectual* impair* OR intellectual* disorder* OR development* disab* OR mental* handicap* OR mental* disab* OR mental* retard* OR down* syndrome* AND decision making (LIMIT: English, 2000-2020)

3.3.2 Article Selection Criteria

Papers were eligible for inclusion if participants were i) adults (i.e., aged 18 years or above) with intellectual disability, ii) their care partners, and/or iii) direct care support workers (DCSWs: Daly et al., 2018). Papers that included care partners and/or DCSWs, but not people with intellectual disabilities, were ineligible if the participants were not directly involved in providing support in everyday decision-making. Papers containing primary data on one or more of the following topics were included: i) experiences and/or perceptions relating to providing or receiving support in everyday decision-making; ii) approaches/techniques for supporting or executing everyday decision-making; iii) barriers/facilitators to effective support in everyday decision-making. Articles focusing solely on decision-making in relation to advance care planning, hospital directives or end-of-life care were excluded.

Search results were uploaded to Mendeley citation manager (Reiswig, 2010), where duplicates were removed, then transferred to Rayyan (Ouzzani et al., 2016) for screening. The titles and abstracts were screened independently by the primary researcher (HC) and an undergraduate research assistant (AT) to establish eligibility. The full-texts of those deemed potentially eligible were then further screened by HC and AT to confirm inclusion in the final analysis. Both screening stages were followed by a review of any conflicts, and brought to a third reviewer (either LC or DD) for a final decision if required (Table 2).

Table 2: Review Inclusion and Exclusion Criteria

	Inclusion Criteria	**Exclusion Criteria**
Publication language	English	Languages other than English
Publication date	2000-2020	Prior to 2000
Target population	Adults aged 18 and over with intellectual disabilities; care partners of adults with intellectual disabilities; direct care support workers of adults with intellectual disabilities	Participants with cognitive impairments other than intellectual disabilities; direct care support workers who are not involved in decisional

		support for adults with intellectual disabilities
Study focus	How adults with intellectual disabilities, their care partners and/or direct care support workers perceive/experience supported decision making in everyday life; practical, applied techniques and approaches to supported decision-making; barriers/facilitators of supported decision making in everyday life; Conflict or complications in supported decision making experienced by care partners or direct care support workers.	Studies focusing on methods of decision-making that do not include the adult with intellectual disabilities themselves Studies focusing exclusively on advance care planning, end of life care, or terminal care decisions; Decision-making by an external agent such as a solicitor or other legal professional with no inclusion of the person with intellectual disabilities
Study type	Primary data, all research designs (qualitative, quantitative, mixed methods) Peer reviewed publications	Secondary data Non-peer reviewed publications (opinion pieces, editorials, conference abstracts, magazine articles, letters to the editor etc.) Systematic reviews

3.3.3 Data Extraction

Data extraction for the initial search in 2020 was completed by AT, and by HC for the updated search in 2022. Data extracted from each article included: author(s) name, publication year, country, study design, aim(s) and research questions, participants and sample size, data collection method, response rate, method(s) of data analysis, and findings (See Appendix I, Volume II).

3.3.4 Quality Assessment

Included articles were critically appraised independently by HC and LC using the Mixed Methods Appraisal Tool (MMAT: Pace et al., 2012), with DD consulted for any conflicts. The MMAT is designed to assess the quality of qualitative, quantitative and mixed methods publications using a single multi-category checklist. Papers are screened for relevance using two questions relating to i) the clarity of the research question and ii) whether the execution of the research allows it to be answered effectively, then further assessed using five design-specific questions depending on whether the paper is qualitative, quantitative, or mixed-methods. The quality review was conducted to aid in the critical consideration of the included articles and the credibility of their findings, and not for the purposes of exclusion (see Appendix II).

3.3.5 Data Synthesis

Content analysis was selected as the method for data synthesis. Its flexible methodology has versatile applications (Drisko & Maschi, 2016; Finfgeld-Connett, 2014; White & Marsh, 2006) and is well-suited to analysing broad research questions such as those examined in the present review. It also allows for the inclusion of papers incorporating a diversity of research methods and analytic techniques, preventing the need for using different analysis methods across qualitative, quantitative and mixed methods papers. The content analysis was conducted using an adapted version of Evans and Fitzgerald's

(2002) approach. Firstly, all included papers were read and reread by HC to establish familiarity with their outcomes and objectives. Initially, papers were grouped by HC according to which participant group(s) they included. Where more than one participant group was included, each group was analysed separately. Clusters of topics were then formed based on the initial three aims of the review (i.e. to synthesize information on the 1. experiences and perceptions of support in everyday decision-making, 2. methods of support employed or preferred in everyday decision-making, 3. barriers and facilitators to support in everyday decision-making). When a paper addressed more than one aim, it was included and discussed separately under each one. Findings under each aim were synthesised by HC by rereading the papers included and recording the main topics discussed in an Excel spreadsheet, to distil them into discrete categories. These topics were then clustered into subthemes within the main theme. The findings relating to each participant group were discussed separately under each aim.

3.3.6 Study Characteristics

After duplicates were removed, 4,062 papers were identified for abstract and title screening, of which 363 were selected for full-text screening. A final total of 81 papers reporting the findings of 76 studies were included in the review (See figure 2). Articles originated from the UK (n = 31), USA (n = 11), Australia (n = 12), Ireland (n = 7), Spain (n = 4), Sweden (n = 3), Israel (n = 2), New Zealand (n = 2) Malta (n = 2), Norway (n = 2), Canada (n = 2), Belgium (n = 1), Iceland (n = 1), and China (n = 1). Studies used either qualitative (n = 69), quantitative (n = 7), or mixed methods (n = 5) designs (see Appendix I).

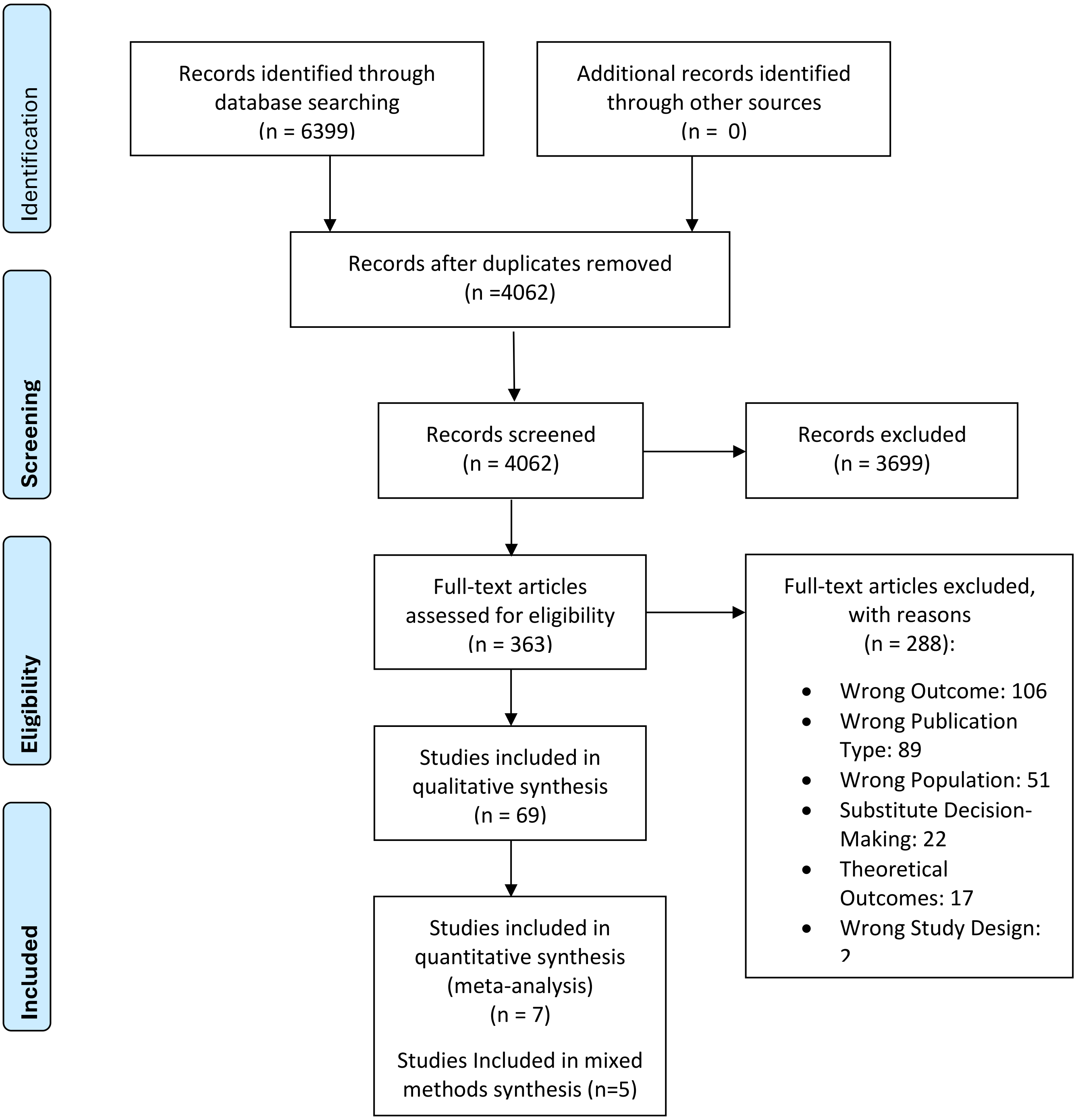


Figure 1: PRISMA Diagram of Review Process

Common methodologies employed in this systematic review for included papers included one-to-one interviews (n = 49), dyadic interviews (n = 2), focus groups (n =14), observational or ethnographic studies (n =15), surveys (n =9), and case studies (n =2). Few studies employed inclusive means of involving participants with intellectual disabilities in the data collection process. Of the few who did, these methods took the form of providing specific guidance or training such as supporting self-advocates to conduct their own research project and write an easy-read paper on its findings (Deguara et al., 2012), training participants to sit on an interview panel to select their own support workers (Johnson et al., 2012), or providing training on how to self-advocate in the form of a participatory action research project (Garcia-Iriarte et al., 2009). However, most adhered to traditional means of recruitment, participation, data collection, and analysis.

3.4 Results

There were three overarching themes identified based upon the review's three aims, and a total of six subthemes therein: 1) experiences/perceptions of everyday support for decision-making; 2) techniques/approaches to everyday support for decision-making employed (Supported Decision-Making, Other Decision-Making Techniques); and 3) barriers/facilitators of effective support in decision-making (Facilitators: Knowing the Person Well, An Inclusive Policy; Barriers: Ineffective Policy, Care Support Worker Conflicts, Underestimating the Person, Restrictions in Sexual Health Decisions).

3.4.1 Experiences and Perceptions of Support in Everyday Decision-Making

Thirty-three papers examined experiences and perceptions of support in everyday decision-making. Of these, 25 included people with intellectual disabilities as participants, 9 included care partners, and 7 included DCSWs.

3.4.1.1 People with Intellectual Disabilities

Participants with intellectual disabilities reported that they valued carer support during decision-making, but sometimes felt carers were quick to make assumptions, underestimate them, or not take their decisions seriously (Bigby, Whiteside, et al., 2019; Brotherton et al., 2020; Carey, 2021; Collings et al., 2019; Curryer et al., 2018; Lukas et al., 2018). Pressure from others to make certain choices, or having decisions made for them (Nonnemacher & Bambara, 2011; Werner & Chabany, 2016), resulted in negative perceptions or experiences of support during decision-making. Having care partners living nearby (Burke et al., 2019; Curryer et al., 2018) and being a member of a self-advocacy programme or group (Deguara et al., 2012; Gilmartin & Slevin, 2010; McCausland et al., 2018) were associated with more positive experiences. Gilmartin and Slevin (2010) reported that adults with intellectual disabilities who were members of an advocacy group found this membership empowering and felt more confident in their ability to express their preferences during Person Centred Planning (PCP) meetings. Similarly, Espiner and Hartnett (2012) found that PCP meetings which included the presence of both care partners and DCSWs allowed adults with intellectual disabilities to be more open about their goals and plans when the person leading the meeting had been trained in inclusive meeting techniques. Wong and colleagues (2021) noted that during discussions about decision-making, the scale of the decision and consideration of the safety of the person affected which group had more influence in the decisional process.

Less positive experiences were also discussed, such as being impeded in decision-making by organisational requirements to have a staff member accompany them for every activity (Larkin et al., 2018), being pressured by others to make certain decisions, or being prevented from making decisions at all (Nonnemacher & Bambara, 2011;

Werner & Chabany, 2016), which were met with frustration and unhappiness. In a paper written by members of a Maltese self-advocacy group for adults with intellectual disabilities, Deguara and colleagues (2012) reported that participants felt they were directed to take part in activities that carers thought they would like, rather than activities they themselves had expressed active interest in. In Brotherton and colleagues' (2020) investigation into why older adults with intellectual disabilities chose to retire, many participants reported that they retired because carers had asked them to do so, rather than making this decision themselves. Carey and colleagues (2021) noted that adults with intellectual disabilities who had opportunities to make their own decisions, were happier than those who did not, or could not, do this.

People with intellectual disabilities felt that occasionally, carers stepped in at times when it was not necessary or appropriate, thus impeding their ability to exercise their independence (Dowling et al., 2019; Goldsmith et al., 2013; Timmons et al., 2011). Consent was taken for granted and not directly sought in medical settings (Goldsmith et al., 2013; Sheehan et al., 2019), and decisions made in areas such as employment were often heavily directed or influenced by supporters (Timmons et al., 2011). Antaki and colleagues (2006; 2009; 2008) reported across three papers how DCSWs often disregarded choices or ideas put forward by their clients and instead used conversational techniques such as directive guiding in order to pilot them to a specific answer or offering choice while already pursuing a course of action to encourage them to choose what the support worker had already deemed to be the best option.

3.4.1.2 Care Partners

Findings indicated that care partners felt they functioned as a crucial bridge between the adult with intellectual disability and DCSWs because of their familiarity with the personality, preferences, and communication methods of the person (Bigby, Webber, et al., 2015; Burke et al., 2019). Their willingness to support the person’s choices and decisions appeared to be informed by their own personal values, and they often attempted to guide the person to an alternative if they felt the desired path was inappropriate or unsuitable. This was dictated by the conviction that they knew the person with intellectual disability best (Brady et al., 2019; Curryer et al., 2020; Mannan et al., 2011; Werner & Chabany, 2016) and by a desire to protect them (Werner & Chabany, 2016).

However, care partners were often the strongest allies of the person with intellectual disability in decision-making. In a study of decision-making among siblings by Burke et al. (2019), siblings of adults with intellectual disabilities were often outspoken supporters and defended their sibling’s right to be included and respected. Similarly, Bigby and colleagues (2011) noted care partners’ willingness to challenge decisions made by DCSWs in relation to the transition of older adults with intellectual disabilities to geriatric care settings. Finally, in a 2018 survey of Irish adults with intellectual disabilities, McCausland and colleagues observed that those who resided with care partners had more opportunities to make their own decisions than those living in residential care (McCausland et al., 2018).

3.4.1.3 Direct Care Support Workers

Many papers reported that DCSWs saw themselves as having a uniquely difficult position, often struggling to reconcile client decisions with care partners who disapproved of them (Andre-Barron et al., 2008; Bigby et al., 2011; Bigby, Whiteside, et al., 2019). At times, particularly in cases where clients had severe intellectual disabilities and were presumed incapable of making choices for themselves, support in decision-making was not offered (Bigby et al., 2009); instead, best interests decision-making approaches, informed by DCSWs' assumptions and opinions, were evident (Bigby et al., 2009; Rogers et al., 2020).

DCSWs placed greater emphasis on neutrality in support than care partners. They were aware of the influence they could have over the decisions of a person with intellectual disability they were supporting, especially if that person was noticeably attached to them (Bigby, Whiteside, et al., 2019). In addition, Bigby and colleagues (2011) reported that DCSWs were often limited by policy considerations or the physical health of the person they were supporting, and sometimes felt they had to override the person's preferences for their own safety (Davies et al., 2017). Rogers and colleagues (2020) reported that clinical psychologists who worked with adults with intellectual disabilities felt that a culture of presumed "incapacity" prevailed in their workplace, with many DCSWs inadvertently wanting to take a protective rather than empowering approach to decision-making support. These difficulties were further exacerbated by regulations, bureaucratic practices, staff shortages and time constraints (Bigby et al., 2011; Bigby, Whiteside, et al., 2019). However, DCSWs also expressed a clear desire to encourage and support clients' decision-making and independence, and frequently relied on the input of care partners to achieve this. In Bigby and colleagues' (2015) paper on sibling involvement in care and decision-making, DCSWs reported working closely with siblings to interpret what the person with intellectual disability might want to do if they could not communicate and relying on them for insight into the person.

3.4.2 Techniques and Approaches to Supporting Everyday Decision-Making

Of the 30 papers reporting approaches and techniques used to support everyday decision-making for adults with intellectual disabilities, 11 focused on SDM and included all three stakeholder groups. The remaining 19 papers explored other techniques and approaches to supporting everyday decision-making targeted towards one stakeholder group only.

3.4.2.1 Supported Decision-Making

Supported decision-making (SDM) was explicitly used or directly mentioned in 11 papers (Bigby et al., 2022a, 2022b; Bigby, Whiteside, et al., 2019; Brotherton et al., 2020; Browning et al., 2021; Buhagiar & Azzopardi Lane, 2022; Carney et al., 2023; Devi, 2013; Ledger et al., 2016; Webb et al., 2020; Werner & Chabany, 2016). Three studies focused on exploring attitudes to SDM among DCSWs and care partners (Bigby, Whiteside, et al., 2019; Ledger et al., 2016; Werner & Chabany, 2016); two focused on piloting and evaluation of training programmes to encourage the use of SDM (Bigby et al., 2022a; Buhagiar & Azzopardi Lane, 2022); and five involved explorations of techniques employed by carers and people with intellectual disabilities when engaging in SDM (Bigby et al., 2022b; Browning et al., 2021; Carney et al., 2023; Devi et al., 2020; Webb et al., 2020). Three papers detailed the application of the La Trobe Framework (Bigby et al., 2022a, 2022b; Carney et al., 2023), an Australian training programme primarily for family carer stakeholders to learn how to apply SDM in their daily lives.

3.4.2.1.1 Differences in Views Between Care Partners and DCSWs

Both care partners and DCSWs asserted that knowing the person with intellectual disability well and being familiar with their personality was of vital importance in SDM, but the applications of these beliefs differed. DCSWs favoured a more neutral approach compared to care partners, who believed their knowledge of the person meant they could determine what was best for them (Bigby, Whiteside, et al., 2019; Werner & Chabany, 2016). Werner and Chabany’s (2016) paper explored the views of Israeli parents of adults with intellectual disabilities on SDM compared to guardianship.

Parents thought SDM was unrealistic, as they did not believe their children could make their own decisions, while the adults with intellectual disabilities themselves were unsure about SDM but liked the idea of discussing options and being included in decision-making. Similarly, Ledger and colleagues (2016) conducted a survey of parents and staff who reported using SDM to support the contraceptive choices of adults with intellectual disabilities. Although respondents reported supporting an adult with intellectual disability to make decisions on this issue, the adult themselves rarely had the final say. Inclusion in decision-making was influenced by the level of support the person required, with failure to consult them being attributed to a lack of easy-read information, GP preference, and in the case of adults with high support needs, the need for medication to manage menstruation.

3.4.2.1.2 Views of Adults with Intellectual Disabilities

Webb and colleagues (2020) reported that people with intellectual disabilities felt it was important to be involved in decision-making in their own lives. Decision-making gave them a sense of confidence, but they also reported needing help at times due to previous poor decisions they felt they had made. Buhagiar and colleagues (2022) echoed this in their reporting on their financial abuse training programme. They found that people with intellectual disabilities wanted to have the final say on how much financial support they received, but agreed that they needed help to manage money effectively, through the training programme as well as from supporters.

Devi and colleagues (2020) identified three levels of decisions that they observed in their ethnographic research in a residential setting, based on the perceived level of support the person with intellectual disability required to make it: spontaneous decisions made every day, which needed very little support; mid-level decisions such as helping the person fill out a medical information form; and strategic decisions, which required more time and senior staff involvement. They concluded that this approach was in line with Article 12 of the CRPD, which stresses that the will and preferences of the person be respected in decision-making. In their study of paternalism in decisional support by family carers of adults with intellectual disabilities, Carney and colleagues (2023) also stressed the importance of Article 12 and argued that certain decision-making techniques adopted by parents when supporting decision-making were not as paternalistic in nature as they might appear. Framing the decision to highlight a particular option or narrowing the field of choice for the person were shown to increase the comfort of the supported person and prevent decisional overload.

3.4.2.1.3 The La Trobe Framework

Three of the included papers were based on the La Trobe Framework (Bigby et al., 2022a, 2022b; Carney et al., 2023) developed by Christine Bigby and colleagues to assist people with intellectual disabilities and their carers in engaging in SDM. The framework consists of seven steps: 1. knowing the person; 2. identifying and describing the decision; 3. understanding will and preferences; 4. refining the decision to take into account of constraints; 5. considering if a formal process is needed; 6. reaching the decision and associated decisions; and 7. implementing the decision and seeking advocates if necessary (Bigby et al., 2022a). In the first study, parents of adults with intellectual disabilities who completed a training programme using this framework participated in several rounds of interviews to establish if the programme led to a change in their approach to decisional support (Bigby et al., 2022a). After completing the programme, parents reported being more aware of how to use a structured approach to SDM, mitigate unconscious influence of the person, and broaden the circle of support. This contrasted with the findings of an earlier paper on parental strategies of decisional support, where parents sought to ensure they made the “right” decision out of concern and protectiveness, and controlled the types or extent of the decisions made or used their influence to guide the outcome (Bigby et al., 2022b). They also reported using their influence to encourage participation in activities they thought would broaden their child's horizons or increase their level of healthy risk, however.

Browning and colleagues' (2021) paper exploring Canadian approaches to SDM also discussed encouraging healthy risk using knowledge of the person. One DCSW participant spoke of continuing to bring a client swimming despite reluctance, as it was advised by a doctor, and the DCSW knew the client usually resisted new things but would grow to enjoy them if given time. Repeated exposure to swimming resulted in the client continuing to go to, and enjoying swimming, as the DCSW predicted.

3.4.2.2 Other Training and Techniques to Support Everyday Decision-Making

Eight papers focused on training and techniques other than SDM for adults with intellectual disabilities, nine papers discussed alternative training and techniques for DCSWs, and two papers discussed alternative training or techniques for care partners. Two papers described a formal alternative to SDM, Active Support (Beadle-Brown et al., 2008, 2012), while the remainder described less formal methods of support involving a variety of training techniques to facilitate independent decision-making in specific circumstances, such as self-advocacy and personal safety (Daniel et al., 2014; Hickson et al., 2015).

3.4.2.2.1 Adults with Intellectual Disabilities

Two papers describing training programmes for people with intellectual disabilities were focused on enhancing security and independence in residential settings. Black and colleagues (2009) provided training to support skills development among people with intellectual disabilities in communicating their rights to respect and choice. Johnson and colleagues (2012) provided interviewer skills training to enable the participation of adults with intellectual disabilities in support staff selection and recruitment. Participants reported feeling more in control of who supported them in their day-to-day activities, and better able to ensure they were supported effectively. Training programmes described by Hickson et al. (2015) and Daniel et al. (2014) focused specifically on increasing participant awareness of safe decisions to make in unsafe situations such as assault, or recognising abusive situations. Garcia-Iriarte and colleagues (2009) provided training in how to actively participate in self-advocacy groups through action projects and co-design of support tools.

Three papers detailed guidelines for researchers to follow when involving adults with intellectual disabilities in research projects. These techniques were similar to those suggested for DCSWs and care partners; namely, respecting the autonomy of the person with intellectual disability, ensuring they had full understanding of what the research would entail, and building in techniques to facilitate decision-making, such as providing questions in advance to give them more time to consider their answers or including them as co-researchers (Timmons et al., 2011).

3.4.2.2.2 Direct Care Support Workers

Nine papers discussed methods used to improve DCSWs’ knowledge of how to support the decision-making of adults with mild to moderate intellectual disability. Active Support, defined as “a practice whereby staff use an enabling relationship to facilitate the engagement of people with intellectual disabilities in meaningful activities and social relationships” (Bigby et al., 2019, p. 280), was discussed in two papers by Beadle Brown et al. (2008, 2012). Findings suggested that this approach led to an increase in the quality of support received from staff, resulting in greater engagement from the supported person.

Although adults with more severe intellectual disability were less likely to receive decisional support, four examples of approaches and techniques used to interpret decisions in such cases were included in the review (Calveley, 2012; Murphy et al., 2011; Nicholson et al., 2021; Tracy, 2015). DCSWs and care partners familiar with the adult in question reported being able to interpret bodily cues and behaviour patterns. Body language and repeated interest in activities, foods and people were considered indications of preference and were used to inform care plans for adults with severe intellectual disabilities.

Two papers described examples of effective and inclusive decision-making practices used by DCSWs. Whitehead and colleagues’ (2016) study of diabetes management demonstrated good practice in decision-making techniques through a client-led system of negotiated autonomy involving clients deciding which aspects of management they wanted help with. Additionally, Hellzen and colleagues (2018) found that encouraging adults with intellectual disabilities to voice disagreements or displeasures with staff led to feelings of empowerment and better self-advocacy.

3.4.2.2.3 Care Partners

Training for care partners was discussed in two papers (McCausland et al., 2019; Taylor et al., 2019). Like DCSWs, care partners were encouraged to improve their listening skills, understanding and ability to compromise in order to better support decision-making. One paper, which reported on a pilot programme to help care partners of adults with intellectual disabilities establish plans for future living and care arrangements, found that formal supports to ensure the adult with intellectual disability could remain at home were often lacking, necessitating a move to residential care (McCausland et al., 2019). Taylor and colleagues (2019) reported that consistency throughout the support circle was considered essential to ensure maximum effective support. However, lack of adequate professional support made facilitation of choice difficult, particularly regarding transitional events, because care partners lacked the resources necessary to support the person with intellectual disability on their own.

3.4.3. Barriers and Facilitators to Providing Effective Support in Everyday Decision-Making

Twenty-seven papers described barriers and facilitators experienced by all three participant groups in relation to supporting the everyday decision-making of adults with intellectual disabilities. Facilitators identified included having a less institutional living approach (n = 4), respect for the preferences of the person with intellectual disability (n = 5), knowing the person with intellectual disability well (n = 6), having an inclusive, flexible policy in place (n = 4), and having a policy that incorporated support for decision-making (n = 3). Barriers included inflexible policies and practices (n = 3), underestimating and not listening to the person (n = 8), and lack of familiarity with the needs of the person (n = 4).

3.4.3.1 Facilitators

In four papers, an open, deinstitutionalised approach to care was associated with greater choice, respect and decision-making opportunities for adults with intellectual disabilities in formal care settings (Devi et al., 2020; Haigh et al., 2013; Hollomotz, 2014; Williams & Porter, 2017). Respect for privacy and independence were also crucial to fostering a sense of security, freedom and decisional control for adults with intellectual disabilities in residential settings (Kåhlin et al., 2016). In the family home, involvement of care partners who facilitated adults with intellectual disabilities in expressing goals and preferences and advocating for their right to have these desires heard had a similar effect (Bigby, Webber, et al., 2015; Kåhlin et al., 2016; Wass et al., 2021; Williams & Porter, 2017).

3.4.3.1.1 Knowing the Person Well

For adults with intellectual disabilities, having access to support workers who were committed to vocal advocacy on their behalf with management and familiar with their personal wants, habits, and preferences was vital for supportive decision-making (Antaki et al., 2008; Larkin et al., 2018). Williams and Porter (2017) reported that clients valued a personalised approach to assistance and selected people to help with decisions based on familiarity, trust, and personal investment. For adults with severe to profound intellectual disabilities, having staff who were familiar with their non-verbal forms of communication or resistance was important (Nicholson et al., 2021).

3.4.3.1.2 An Inclusive Policy

Residential homes with inclusive policies were considered more respectful of residents, who reported feeling heard and included (Beadle-Brown et al., 2012; Devi et al., 2020; Petner-Arrey & Copeland, 2015). Kahlin and colleagues (2016) found that residential homes in which residents were encouraged to make decisions about how to personalise semi-private areas were better able to foster a sense of home and decisional control. Hassan (2017) demonstrated how residents' PCPs could be more effective when they incorporated activities they enjoyed. Three papers discussed inclusive practices in research with adults with intellectual disabilities. Participants said they found it easier to understand research if it was explained more slowly (Andre-Barron et al., 2008) and a support person of their choosing was available to help with their understanding (Carey & Griffiths, 2017). Trusting the researcher and their information was also important to them (McDonald et al., 2013).

3.4.3.2 Barriers

Barriers to effective everyday support in decision-making were seen at all levels of interpersonal and organisational relationships. An important factor identified in three papers was lack of familiarity with the adult with intellectual disability (Charnley et al., 2019; Fisher et al., 2009; Petner-Arrey & Copeland, 2015), which made engaging in effective decisional support more difficult. Factors that increased the likelihood of this occurring included high staff turnover (Petner-Arrey & Copeland, 2015), staff being unavailable to assist (Charnley et al., 2019), the supporter being a temporary professional brought in for decisions (Fisher et al., 2009), lack of communication at an organisational level (Charnley et al., 2019; Fisher et al., 2009) and direct guardianship practices (Gross et al., 2013; Werner & Chabany, 2016).

3.4.3.2.1 Ineffective Policies

Research examining the application of policies designed to increase independence and facilitate decision-making among adults with intellectual disabilities found that they often created problems for DCSWs. Antaki and colleagues (2009) found that disability service care policy set unrealistic standards for DCSWs that did not reflect the realities of day-to-day activities. Two studies investigated the decision-making role adults with intellectual disabilities in independent living situations assigned to organisations and professional carers found that they still viewed care workers as authority figures rather than supporters or advocates (Fullana et al., 2022; Pallisera et al., 2021).

In three papers, institutional policies regarding safeguarding, paperwork and procedures posed significant barriers to staff in supporting the everyday decision-making of clients (Devi et al., 2020; Hollomotz, 2014; Petner-Arrey & Copeland, 2015). Petner-Arrey and Copeland (2015) reported that staff were often underpaid and overworked and were expected to uphold institutional policies even if they felt they infringed on the autonomy and rights of the people they were assisting. Organisational concerns about risk were also a factor, with support workers being uncertain of how to balance the right of their clients to make choices with ensuring their safety (Hollomotz, 2014; Petner-Arrey & Copeland, 2015).

3.4.3.2.2 Care Support Worker Conflicts

DCSWs often met with resistance and conflict during interactions with clients and their care partners when attempting to support their choices (Charnley et al., 2019; Giertz, 2017; Pallisera et al., 2018). Diet was a recurring issue, with care partners wanting DCSWs to prevent residents from eating unhealthy foods and adhere to their own dietary preferences (Cartwright et al., 2015; Gill & Fazil, 2013). Further conflict was reported when care partners did not agree with decisions made by the person with intellectual disability and sought to override them. This was usually based on the premise that care partners knew them best and as such were better suited to making these decisions, and often led to the application of best interest decision-making (Charnley et al., 2019; Fisher et al., 2009; Giertz, 2017).

3.4.3.2.3 Underestimating the Person

A frequent barrier to decisional support was DCSWs' and care partners' underestimation of the ability of the adult with intellectual disability to make a decision (Pallisera et al., 2018; Petner-Arrey & Copeland, 2015). Participants with intellectual disabilities mentioned that they were often treated as if they all liked the same things purely because they had an intellectual disability (Petner-Arrey & Copeland, 2015). They reported that their actual goals and preferences were dismissed by DCSWs and care partners alike, who made incorrect assumptions about their capacity to choose (Charnley et al., 2019; Hoole & Morgan, 2011) and felt they were better equipped to make important decisions on their behalf (Ferguson et al., 2011; Gill & Fazil, 2013; Gross et al., 2013; Jingree et al., 2006; Stancliffe et al., 2011; Stefánsdóttir et al., 2018). This was coupled with service concerns about health and safety, which limited residents’ independence in certain tasks. Hollomotz (2014) reported that institutional guidelines often did not consider varying levels of ability in residents and instead employed strict blanket policies that all residents were required to obey. If these policies were breached, DCSWs were subject to disciplinary action, of which residents were aware. This underestimation and inclination to assume control appeared to be influenced by the severity of intellectual disability in some cases (Bigby et al., 2009; Murphy et al., 2011). Bigby and colleagues (2009) found that adults with severe intellectual disabilities were least likely to be supported to make decisions, with many carers asserting that it was not possible due to their inability to verbally communicate. In their paper discussing transition-aged adults with moderate to profound intellectual disability, Murphy and colleagues (2011) reported that care partners were hesitant to see them as adults, believing they still needed care and guidance.

3.4.3.2.4 Restrictions in Sexual Health Decisions

In eleven papers, adults with intellectual disabilities reported that they were often not permitted to make decisions about their sexual health. For women with intellectual disabilities, the question of pregnancy and reproductive health arose often as a source of worry and complication (Engwall, 2014; McCarthy, 2010). Two studies found that healthcare professionals were unused to engaging with patients with intellectual disabilities and frequently failed to include them in decision-making regarding their health. Accompanying DCSWs often compounded this by preventing their involvement during doctor visits (Ferguson et al., 2011; McCarthy, 2010).

Pregnancy was a source of concern for both DCSWs (McCarthy, 2010) and care partners (Jamieson et al., 2016), and often a source of fear for women with intellectual disabilities themselves (Engwall, 2014). Engwall (2014) reported that women with intellectual disabilities who participated in their study felt unable to have children because of their disability. Fear of disclosure of pregnancy due to a lack of openness with family members (Ledger et al., 2016), a tendency for parental values to influence their views of pregnancy as something unacceptable or dangerous (McCarthy, 2010), and fears of losing services and supports (Jamieson et al., 2016) were also reported.

Bigby and colleagues' 2009 paper discussing adults with severe intellectual disabilities and choice making reported that DCSWs viewed masturbation or other forms of sexual expression by residents as "that dirty thing" or "inappropriate behaviour" (p. 367), reinforcing the notion that adults with intellectual disabilities should not have same freedom to express their decisions around sexuality as those without intellectual disabilities. This was highlighted starkly by Roets and colleagues (2006), who provided a detailed account of the attempts of a young woman with intellectual disability to resist efforts to force her to have a hysterectomy due to fears she would become pregnant. The woman was supported by her Advocate (an official paid role in her native Belgium) to prevent this from occurring.

3.5 Discussion

Supporting everyday decision-making has become an increasingly important topic in policy and practice relating to adults with intellectual disabilities. The review findings indicate that adults with intellectual disabilities, their care partners and DCSWs have complex and often overlapping perceptions and experiences of support in everyday decision-making, adopt a variety of techniques and approaches to facilitate it, and encounter a range of barriers and facilitators in its implementation. Providing support in everyday decision-making is widely recognised as important, but there is a lack of consistency in the literature regarding its description and operationalisation. Although sometimes described in an inclusive manner that respects the will and preference of the person, at other times it appears purely paternalistic in execution (Fisher et al., 2009;

Scholten et al., 2021). Difficulties are particularly pronounced when the person with intellectual disability has high support needs and/or is nonverbal (Bigby et al., 2009; Calveley, 2012).

This review identified a paucity of research examining specific methods of support. In the 81 included papers, support in everyday decision-making was explored in the broader context of choice and control within the family home, encouragement (or lack thereof) of independence by support workers in residential care, or self-advocacy in the daily lives of people with intellectual disabilities, all factors that indirectly contribute to decisional support. However, there were few examples of a conscious effort to integrate a specific, tailored support process that allowed for the participation of the full support circle (Douglas & Bigby, 2020). This lack of focus on specific support could be rectified by encouraging adults with intellectual disabilities, their care partners and DCSWs to consciously integrate a method such as SDM into their daily lives through education and training. SDM was identified as the most widely used method of decisional support in 11 papers, three of which focused on the La Trobe Framework, a training initiative specifically designed to help stakeholders improve their ability to use SDM in their daily lives (Bigby et al., 2022a, 2022b; Carney et al., 2023). This framework’s approach to the implementation of SDM through training, education and stakeholder inclusion is one that facilitates engagement with SDM as a concept and brings the approaches of supporters in line with the UNCRPD.

Many of the findings in the present review echo those seen in the literature on support in everyday decision-making among people with cognitive impairments such as dementia or TBI (Bigby, Whiteside, et al., 2015; Kohn & Blumenthal, 2014; Noorlandt et al., 2020). For example, having the support of known and trusted people in making decisions, identified as being central to positive support experiences among adults with

TBI and dementia (Bigby, Whiteside, et al., 2015; Kohn & Blumenthal, 2014; Noorlandt et al., 2020), also emerged as a key factor for people with intellectual disabilities (Andre-Barron et al., 2008; Carey & Griffiths, 2017; McDonald et al., 2013) and their carers (Bigby, Webber, et al., 2015; Burke et al., 2019) in this review. Similarly, the finding that DCSWs acted as a bridge between adults with intellectual disabilities and their families, attempting to balance the wishes and desires of both parties while also adhering to service policy requirements (Andre-Barron et al., 2008; Bigby et al., 2011; Bigby, Whiteside, et al., 2019), has been observed in research involving people with cognitive impairments such as dementia (Daly et al., 2018; Donnelly, 2019; Dukes & McGuire, 2009; Mansell & Beadle-Brown, 2004). This implies that research and guidance on SDM conducted with other populations such as those with dementia or TBI may also be applicable to people with intellectual disabilities.

DCSWs' engagement in practices to support everyday decision-making seemed to largely depend on the policies of the service they worked for, and training opportunities were limited (Devi et al., 2020; Hollomotz, 2014; Petner-Arrey & Copeland, 2015). This has been noted elsewhere, as service policy is a frequently identified barrier to decisional freedom for people with TBI, mental health conditions and dementia (Davidson et al., 2015; March et al., 2013; O'Hara, 2008). Active Support shows promise as an effective approach to supporting the decision-making of adults with disabilities (Beadle-Brown et al., 2008, 2012; Mansell & Beadle-Brown, 2012). However, it has been mainly studied in residential settings with an emphasis on how it could theoretically be applied in the future, rather than through practical application. Recent studies indicate its potential application in the community (Bigby & Anderson, 2021; Bigby & Wiesel, 2015), but more research is required to examine its applicability to other care service settings and differing levels of intellectual disability. In the Irish context, at the time of data collection, no papers referring to the ADMA were identified as part of the review. However, the principles on which the ADMA is based- namely those of respecting the will and preferences of the person, and the facilitation of tiered levels of support to fit individual support requirement- are closely aligned with those of SDM. The results of this review indicate that while the ADMA is a positive step forward, more information is required from stakeholders on how this legislation has impacted their lives now that it has been fully commenced.

Ultimately, the literature indicates that people with intellectual disabilities benefit most from support in everyday decision-making that is inclusive and respectful of their will and preferences (Nonnemacher & Bambara, 2011; Whitehead et al., 2016). The findings of the present review support the view that decision-making methods such as substitute or best interest decision-making may pose a barrier to effective support (Charnley et al., 2019; Fisher et al., 2009; Giertz, 2017). The use of these methods appears to be dictated by severity of intellectual disability, with the preferences of adults with higher support needs frequently being overlooked and underestimated (Bigby, 2008; Murphy et al., 2011), as reflected in the literature on TBI (Bigby, Webber, et al., 2015; Bigby, Whiteside, et al., 2015). People with more severe intellectual disabilities were significantly underrepresented in the papers included in the present review and rarely actively participated in research even when included. Greater inclusion of adults with severe to profound intellectual disabilities in making decisions about their lives could be achieved using tailored approaches (e.g. Nicholson et al., (2021) or via communication aids (Stewart et al., 2018) or choice making technologies (Davies et al., 2003).

Although the research summarised in this review offers insights into stakeholders' experiences and perceptions of support in everyday decision-making, it was apparent there were clear gaps in the literature. Firstly, many of the findings regarding everyday decision-making were negatively oriented (Charnley et al., 2019; Fisher et al., 2009; Hollomotz, 2014; Petner-Arrey & Copeland, 2015), with research focusing on barriers to decisional support. Few of the included papers set out to identify successful approaches or factors that might help to facilitate decisional support (Bigby & Wiesel, 2015; Burke et al., 2019). This indicated the importance of examining how to resolve barriers in subsequent phases of this research, and not merely highlight them. A further aim of this project was therefore to identify what could be done to improve negative experiences and to explore positive and successful experiences of decisional support.

As part of identifying these positive experiences, it was deemed important to include all stakeholders involved in decisional support in the research in order to identify what they need and improve everyday decision-making practices. Most papers in this review included only one or two of the stakeholder groups, with only 10 papers having representation from all three groups, resulting in only a partial overview of the experiences, perceptions, or barriers and facilitators they experienced during decisional support. McCausland and colleagues (2019) also raised a vital point - namely, decisions, such as whether to remain at home or move into residential care, are heavily affected by available resources. This suggests that further government investment and community outreach may be more important than individual- or family-level interventions for future planning to be successful. It was important to discuss SDM within this project not only with each group individually, but to create a space within the overall project for the three groups to come together for further collaboration and discussion. This would ensure that the recommendations for the guide to SDM would be based within the full needs and preferences of all members of the support circle, to better understand how these members work together during the decisional process, and how the guide could remain flexible enough to accommodate these needs.

The lack of formal, clearly delineated decisional support techniques or approaches identified in the included papers represented a distinct gap in the literature. The Australian La Trobe Framework provides training for supporters to help them develop skills in supporting adults with intellectual disabilities using SDM as a technique, and has promising results (Douglas & Bigby, 2020). Some theoretical data on the approach of the National Resource Centre for Supported Decision Making in the US (NRCSD: Blanck & Martinis, 2015) has been published, but is very specific to the legal context of the individual US states it is focused on. In the American context, disability rights vary state by state, and as such there is no one organisation or movement seeking to address it, but rather a collection of individual projects addressing concerns pertaining to the state in which they are based (See chapter 1, section 1.5.1). The NRCSD acts as an online hub for these projects to share resources, commentary, and knowledge about each state's laws and policies surrounding SDM with each other and the wider disability community in order to increase awareness and understanding of each project's goals and function. This makes it a timely and useful resource for disability researchers and activists to remain abreast of what is currently ongoing in American disability research, although as discussed in chapter 1, many of these projects are seeking to implement practices that are already employed in Ireland, such as PCPs (Blanck & Martinis, 2015). The relative newness of the ADMA in Ireland means there is little infrastructure in place to help people with intellectual disabilities and their carers determine how to adapt to the new law, or to explain how to implement SDM in their lives. With this in mind, while international methods provided welcome inspiration for this project, in particular that of the La Trobe Framework, it was imperative that any recommendations for a guide were carefully crafted to align with Irish policy and procedure, as well as cultural norms and practices, provision of disability services, and the residential status of adults with intellectual disabilities within the Irish context to ensure maximum impact and useability.

3.5.1 Strengths and Limitations of the Review

This was the first review to focus exclusively on everyday decision-making in adults with intellectual disabilities and their supporters. The comprehensive search capturing the changing terminology within this research field is a key strength of this review. In addition, the inclusion of research involving adults with intellectual disabilities as well as their care partners and DCSWs allowed their different viewpoints to be represented, giving a more complex and nuanced overview of support in everyday decision-making. Most included papers involved adults with intellectual disabilities as active participants and ensured their experiences were central within the research. However, few included them as co-researchers with direct involvement in the collection and synthesis of data. Future research should seek to include adults with intellectual disabilities in this capacity. It is also important to note that the decisions described in these studies were personal decisions for the individuals, and that other kinds of decisions such as interpersonal decisions were not included. Further research is needed to determine the place of SDM in interpersonal resolution of decisional outcomes and conflict among included decision-makers. The review was limited by only including papers written in English, with most emanating from the UK, Australia, and the USA; data may be omitted from other nations where different approaches to decisional support may have been adopted.

3.5.3 Conclusion

The provision of support in everyday decision-making to adults with intellectual disabilities is a rapidly growing area of interest that is still ill-defined and under-investigated. Many studies allude to this practice without directly addressing how it is best executed. This lack of specificity indicates the need for further research on this important topic. SDM has emerged as the most widely used and investigated approach to providing support in this context, but questions remain as to how it can be applied most effectively. It is vital that adults with intellectual disabilities, their care partners and DCSWs are central to discussions surrounding support in everyday decision-making, to allow for the formation of systems and processes that acknowledge and address their needs and fit their perceptions of what is required. These groups are often addressed separately in research, even though decision-making for adults with intellectual disabilities is usually a collaborative process; the integration of their viewpoints is thus of utmost importance to allow for a more rounded, nuanced view of the topic, and the identification of an approach that works best for all involved.

Chapter 4: A Qualitative Survey on the Impact of COVID-19 on Supported Decision-Making

4.1 Chapter Summary

This chapter describes the conduction of a qualitative online survey with family carers and professional carers living in Ireland to explore their experiences and perceptions of providing support in everyday decision-making to adults with intellectual disabilities while restrictions were in place due to the COVID-19 pandemic. Material in this chapter has been published, see (Casey, Desmond, et al., 2023b). Section 4.2 gives a brief overview of the background and aims of the research. Section 4.3 describes the process of data collection and analysis using reflexive thematic analysis (RTA). Section 4.4 outlines the results of this analysis. Section 4.5 discusses these results in the overall context of the literature on SDM and details the strengths and limitations of the research.

4.2 Introduction

In Ireland, the COVID-19 pandemic resulted in the restriction of movement and social contact in order to prevent the spread of the virus. Restrictions varied in levels of severity throughout 2020 and 2021, with the strictest requiring people to remain within five kilometres of their homes (Gov.ie, 2020) and avoid meeting anyone socially indoors (Colfer, 2020). These restrictions had a significant impact on the everyday lives of adults with intellectual disabilities over and above that of the general population. As they were considered a vulnerable population, adults with intellectual disabilities were advised to self-isolate earlier than the general population (Courtenay & Perera, 2020). All recreational activities and in-person disability services stopped during this time, and those in residential homes were unable to see or visit their families (McCausland et al., 2021). Restrictions such as these meant that people with intellectual disabilities were more limited in their choice of daily activities during the COVID-19 pandemic, leading to isolation, boredom and anxiety (Ervin & Hobson-Garcia, 2020). Although some disability services continued to be delivered remotely, access appears to have been limited and/or inconsistent. In a study conducted by Inclusion Ireland, where 11 people with intellectual disabilities living at home were interviewed about their experiences during the COVID-19 pandemic, varied amounts of support from services were reported. Some received frequent phone calls from support workers while they were at home, while others said that the workers they knew well and spent time with were reassigned, leading to little contact with services (Murphy et al., 2020). A study in preparation by O’Donnell et al., in which 12 people directly involved in the development and provision of online services for disability organisations during the COVID-19 pandemic were interviewed about the process, found that factors such as lack of technological infrastructure, understaffing, lack of funding and concerns surrounding General Data Protection Regulation (GDPR) led to difficulties in establishing remote service provision (O'Donnell, 2023: In prep).

In terms of decisional support, family and professional carers play a key role in supporting people with intellectual disabilities to make decisions (Patel et al., 2021; Scheffers et al., 2021). In light of the restrictions introduced during the COVID-19 pandemic, family carers who resided in the same home as the person they support were also cut off from accessing meaningful service support as they attempted to continue their support of their loved one during these restrictions (Chadwick et al., 2013; Lafferty et al., 2016). Those whose loved ones lived in in residential services had limited access to them, and therefore could not support them to the same extent possible prior to the pandemic (Landes et al., 2020). For professional carers, the setting in which they worked determined how the pandemic affected their ability to offer decisional support, with those in day and outreach being unable to spend time with clients, while those in residential had increased time with residents due to strict lockdown protocols (Doody & Keenan, 2021). The aim of the present study was therefore to explore, using a qualitative online survey (Braun et al., 2021), how restrictions resulting from public health measures employed during the COVID-19 pandemic impacted professional and family carers' abilities to support them to make their own decisions.

4.3 Method

4.3.1 Participants

Professional and family carers of persons over 18 years with intellectual disabilities living in the Republic of Ireland were deemed eligible to participate in the survey. Sixteen responses contained sufficient information for analysis. Eight participants were professional carers and eight were family carers. Among family carers, four were male and four were female, with ages ranging from 48 to 70 years. Two were employed full-time in addition to caring duties, two were not currently employed, and the remaining four were retired. One family carer reported being the sibling of a person who lived in a residential setting, while all other family carers reported being a parent cohabiting at home with the person with intellectual disability. Among professional carers, six were female and two were male, with an age range of 36 to 63 years. Five were employed in the public sector, two were employed in semi-state companies, and one was employed in a private care company. All worked full-time, and the number of clients they cared for ranged from 5 to 43 (see Table 3).

Table 3: Survey Participant Demographic Information

Family Carers					
ID	**Age**	**Gender**	**Employment Status in Addition to Care Duties**	**Relationship to Person with Disability**	**Living Arrangement of Person with Intellectual Disability**
F1	53	Female	Employed full-time	Sibling	Residential home
F2	58	Female	Not currently employed	Parent	Cohabiting with family
F3	62	Female	Retired	Parent	Cohabiting with family
F4	63	Male	Retired	Parent	Cohabiting with family
F5	60	Male	Retired	Parent	Cohabiting with family
F6	56	Female	Not currently employed	Parent	Cohabiting with family
F7	70	Male	Retired	Parent	Cohabiting with family
F8	48	Male	Employed full time	Parent	Cohabiting with family
Professional Carers					

ID	Age	Gender	Sector	Full or Part-Time	Number of Clients Cared for
P1	56	Female	Employee, private sector	Full-time	6
P2	36	Male	Public sector	Full-time	13
P3	63	Female	Semi-state company	Full-time	8
P4	30	Female	Public sector	Full-time	9
P5	46	Female	Public sector	Full-time	3
P6	34	Male	Public sector	Full-time	4
P7	63	Female	Public sector	Full-time	43
P8	40	Female	Semi-state company	Full-time	5

4.3.2 Procedure

Ethical approval for this research was granted by Maynooth University Social Research Ethics Sub-Committee. The survey, which contained a series of open-ended questions regarding carers' experiences of supporting adults with intellectual disabilities to make decisions during the COVID-19 pandemic and associated restrictions (see Appendix III), was hosted online using Qualtrics (Boas et al., 2020). The survey questions were devised based on the systematic review detailed in chapter 3. They were formulated to reflect understanding of SDM as a method of support, as well as understanding of the evolving impacts of pandemic-related restrictions. Braun and Clarke's paper on using surveys as qualitative tools was formative in the construction of the questions (Braun et al., 2021). A link to the survey was shared across social media platforms and was sent to disability services via email for dissemination to staff or colleagues. Relevant academic experts were also contacted and asked to disseminate the link to their contacts. Data collection took place between July and December 2021. The findings were reported in accordance with the Checklist for Reporting Results of Internet E-Surveys (CHERRIES: Eysenbach, 2004) (See Appendix IV).

4.3.3 Data Analysis

Responses were transferred to Microsoft Excel and analysed using RTA (Braun & Clarke, 2019). RTA is distinct from thematic analysis in its centring of the knowledge of the researcher at the heart of the analysis. It encourages the researcher to revisit, review, and reflect upon their own understanding of the data throughout the analysis (Braun & Clarke, 2019). This reflexive method was practiced throughout the analysis to ensure trustworthiness, with the conscious application of the researcher's own thoughts and experiences in the interpretation of the data being used to strengthen conclusions rather than undermine them (Braun & Clarke, 2019). Responses were read and re-read for familiarisation with the data. Free coding was completed using colour coding and the comment feature in Excel. Codes were refined into more concise thematic categories, which were reviewed and streamlined into the final themes (Braun et al., 2021). Quotations were included to support the interpretive nature of the analysis, with participants receiving a code to indicate which cohort they were part of (F for family participants, P for professional, with the letter followed by a numerical value from 1 to 8 to distinguish between participants between and within their cohort).

When employing RTA during the analysis, I remained conscious of my own experiences of the COVID-19 restrictions as a family carer. I used Microsoft Excel's comment feature to leave memos and notes reflecting on my initial thoughts and reactions to aspects of the data, while considering my own experience as a family member of a person living in residential care. By acknowledging the perceptions and challenges of remote support that I and my family experienced during this time, it allowed me to contextualise the responses of family carer participants within the bounds of my own subjective interpretation, and to compare them with the experiences of professional carers, or other family carer participants who cohabited with the person they were supporting. Returning to my reflective comments and the raw data frequently during all stages of analysis allowed my conclusions to remain grounded in the data and prevented me from becoming fixated on a single interpretation of the data by reminding me to remain open and reevaluate these conclusions if necessary.

4.4 Results

Three main themes were identified in the data: 1. centring the person; 2. adapting to COVID-19; and 3. restricted lives.

4.4.1 Centring the Person

This theme reflects how professional (*n* = 8) and family carer respondents (*n* = 8) described their efforts to support people with intellectual disabilities by ensuring they listened to and assisted them in any way they needed before and throughout the pandemic. The emphasis was very much on the individuals with intellectual disabilities themselves and what they required to fulfil their goals and wishes.

Professional carers described how their organisations had formal approaches to support the decision-making of their clients. Person Centred Plans (PCPs), Personal Development Plans (PDPs), and Personal Outcome Measures (POMs) were mentioned as tools used to record and develop the plans and wishes of clients.

> *"We have PDPs, personal development plans for each individual, and the individual with her key workers and support of multi-disciplinary team where needed, work together to aim to achieve the ladies wishes, dreams and aims."* [P1]

Some professional carers reported receiving training to ensure the centring of their clients through the adoption of their preferred communication methods, and emphasised their organisation's ethos of respect.

> *"Rights based approach; core learning modules in induction and updates—UNCRPD and Assisted Decision-Making; staff learning includes communication, sign-language. Service values and culture focus is relationship and support frameworks (e.g., Supported Self-Directed Living) not rules & regulations (though we have them)."* [P7]

> *"To the best of our ability, we attempt to have a person-centred approach. The ethos of the organisation is 'Love and respect in every action'."* [P6]

A number of professional carers who took part reported adopting a variety of techniques in order to facilitate the choices of their clients. Techniques to establish preferences included taking note of interest expressed in certain activities, introducing options, and facilitating communication.

> *"...by sampling a variety of activities, recording interest levels and participation levels, using picture boards, communicating through Lámh [Irish keyword signing method] and giving the person options they may like as we get to know them."* [P2]

All professional carer respondents reported adopting techniques and strategies to suit the needs of their clients wherever possible.

> *“Assume capacity to make choices; each person supported by an Individualised Planning Coordinator, Key Worker, Circle of Support; each person encouraged to engage with independent advocate for their independence.”* [P7]

> *“Our organisation uses a system where people supported are represented by their peers in the interview process.”* [P8]

Family respondents reported centring their loved one in decision-making through conversation and communication. They discussed potential decisions with them and ensured they were given clear choices using simple language.

> *“Giving her choices.”* [F2]

> *“He is always asked his views on trips, feeling comfortable in certain situations.”* [F3]

One family carer respondent, whose loved one with intellectual disability lived in residential care, spoke about how the COVID-19 restrictions had affected their usual methods of support. The suspension of in-person visits meant they were less involved in their day-to-day decisions.

> *“Pre covid she would come stay with us, we called to see her regularly and we knew all the staff in her house. We were involved in her future plans and would advocate for her whenever there was a problem. We still do as much of this as we can but it definitely became more difficult during lockdown.”* [F1]

Family members detailed the types of decisions they helped their loved one to make. All spoke of everyday decisions such as clothing and outings; only one family member indicated that they helped with more significant decisions such as those related to health or interpersonal relationships.

> *"It can be something as simple as to what kind of food/clothes she wants to buy/eat to more complicated issues of helping her negotiate relationships or health decisions."* [F1]
>
> *"Clothing, personal hygiene, eating, recreational activities."* [F7]
>
> *"Plenty of warning of trips and Outings with large crowds. Offering opportunity not to participate with no feelings of disappointment."* [F2]

4.4.2 Adapting to COVID

This theme relates to how professional and family carers described their attempts to support decision-making during the COVID-19 pandemic while restrictions were in place. Professional carers reported making use of online resources to facilitate activities, but they also reported how the world of their clients became rather limited due to restriction of movement and group activities being paused. Family carers, on the other hand, reported that their loved ones received little communication or remote support from services, which led to feelings of increased isolation and limited their loved ones' social activities outside of the family home.

The internet was reported as a vital resource by professional carers. In-person activities were suspended and, as such, this was the most effective way for clients to continue to enjoy recreational activities of their choice, with varying degrees of success. Some respondents faced difficulties, such as poor internet connection or a remaining sense of isolation. However, others described the pleasure and usefulness of online classes as a source of entertainment.

> *"A lot of online activity occurred which was great e.g., zoom activities, exercise classes, music sessions, family video contact etc. however our Internet service was poor and although we have TVs etc., many times we had difficulties.*

> *Shopping for groceries, clothes etc., was very difficult for the ladies to choose online products. It was a lot of remote clinics for services and the ladies found communicating in this way difficult."* [P1]
>
> *"Some of the people supported activity sampled Boxercise online and absolutely loved it."* [P8]

The internet was also helpful in enabling clients to keep in touch with family members. The clients availed of video chat services regularly, as the restrictions prevented travel and family visits. The initial set-up of technology to facilitate contact took some time, and professional carers reported that clients were confused and upset by not being able to see their families in person.

> *"It took a number of months to get technology up to speed for everyone to keep in touch ie equipment like tablets etc. so that our people supported could use TEAMS."* [P8]
>
> *"Shopping, the ladies had limited choice as they were more dependent on staff to use technology."* [P1]
>
> *"Technology (video calls, tablets with apps etc.) needed a lot of work to get off the ground initially but very useful."* [P2]
>
> *"Family and friends contact to each individual is so important to feel loved and cared for and included, without this, without being able to go home was tough and heart breaking for many of our ladies."* [P1]

Despite the limitations described above, some professional carer respondents reported an increase in opportunity for their residents, in terms of both activity choices and independence.

Many spoke of the new hobbies and activities clients engaged in over the course of the pandemic. One discussed how the calmer schedule meant each person was more able to do the things they wanted to do, which led to a decrease in distress. They were also given more opportunities to try new activities that they might otherwise never have attempted.

> *"Lots of incidents of challenging behaviour were lowered, more person focused and less rushing around trying to fulfil activity plans/sporting groups/group events."* [P2]

> *"The menu of activities which we offer to our residents has become varied in ways which were previously unforeseen. It has forced us to adapt on extremely short notice, and many of our residents have thrived in this process."* [P6]

> *"However, some enjoyed having regular team with little rotation and learned to dine, garden, share music, do classes on-line (fitness, yoga, cooking, art, singing.......so much to do)."* [P7]

Although separation from family proved difficult for clients, professional carers reported that it also gave them more opportunities to make decisions independently.

> *"Not much impact, some positive effects also noted due to not having to fulfil families' requests to see them, meetings with families were dictated by the people we support not the families."* [P2]

> *"Have been able to make more decisions themselves."* [P5]

One respondent spoke of seeing new resilience in their clients, who adapted well to the changes.

> *"For the residents which I care for, it has led to a change in their daily lives, where many have learned to become more resilient. Many have adapted to*

> *change well, utilising technology to connect with their families and friends, as opposed to in-person visits."* [P6]

When asked how COVID-19 had led to changes in their loved ones' lives, family carers primarily discussed how the closure of services affected their ability to offer choice and activities at home. The absence of the day service and community activities usually provided by their local disability services were most commonly mentioned.

> *"Severely restricted because his day services closed for the first 21 weeks on the pandemic and only operated on a 2-day and 3-day basis for the months following. No social outlet."* [F7]

> *"Huge, our son's life was his social life and day services."* [F6]

For one respondent, their inability to visit their family member meant they were unable to support her as they usually would, which they found difficult.

> *"As we were unable to meet in person due to the restrictions, we were not involved with her the way we normally would. During times when she was upset or worried, we were dealing with her over the phone."* [F1]

Very little service support was reported by any of the family carer respondents, with only three of the eight who participated giving examples of contact with services.

> *"[Service] encourage independence but at home I find that hard to transfer. She will do it for everyone else but not her mother!"* [F2]

> *"[Name] services. Support with keyworker, social worker and psychiatrist."* [F3]

> *"Setting goals etc. [website of service given]."* [F4]

Of the remaining five family carer respondents, one expressed frustration with the lack of contact from disability services. They had previously asked for more support, but had not received it.

> *"Minimal support, we are constantly looking for more support, due to have a meeting with day services next week when I will bring it up again."* [F6]

4.4.3 Restricted Lives

COVID restrictions had a confining effect on the activities and choices of people with intellectual disabilities, according to respondents. Restriction of choice occurred as a result of group activities being cancelled and day services being shut down. Respondents also discussed the isolation and confusion experienced by the people with intellectual disabilities they supported because of social distancing and restrictions on movement.

Professional carers reported that the people they supported were bored, confused and upset by not being able to attend activities outside of their homes:

> *"The ladies love interacting in the community, and this was stopped for long period. The ladies were bored with the limited amount of activities and movement they were used to having pre covid."* [P1]
>
> *"Covid has restricted people with ID from simple stuff like going out for a coffee. Eating out. Attending a gym, going Bowling."* [P3]

An effect of greater dependency on staff was reported. As residents could not go out in the community or perform their usual tasks such as shopping or picking up medication by themselves, they became more reliant on staff to complete these tasks for them. The added complication of having to conduct all banking and shopping online meant that previously enjoyable and manageable tasks became inaccessible in some cases. This dependence was described by one respondent as being like a return to institutional practices:

> *"Lots of other scenarios occurred and the ladies eventually accepted these, but I feel they did not really understand why so many changes, it was like removing a lot of development and positive moves in our residence and we were going back to institutionalisation."* [P1]

> *"Shrinking opportunities had the effect of greater dependency—going to the shop/pharmacy for them instead of with them; the outdoor life was extremely limited."* [P7]

Two respondents also reported an increase in fear and anxiety among their clients, especially when in public due to worries over contracting COVID-19.

> *"In some cases been afraid to attend their Day Services."* [P3]

> *"When we got to go out, fear and anxiety was increased."* [P7]

Family carers discussed how the restrictions meant their loved one was unable to make their usual variety of choices, leading to feelings of distress and confusion.

> *"We used to plan activities ahead with calendar, had to put it away, this was very difficult and depressing, day services were very slow to open, only going back to 5 days next week."*[F6]

> *"Had very few choices left once covid hit."* [F2]

Some respondents said the lack of routine due to the closure of day services and government restrictions on meeting others meant their loved ones' general distress and anxiety had increased, as well as confusion over why they could not attend their usual activities.

> *"Little issues were magnified, her routine was completely changed and she had very little to occupy her."* [F1]
>
> *"The whole experience was very confusing."* [F8]
>
> *"My son suffered during the lockdown as everything he loved was curtailed. No sport and only telephonic support from his keyworker."* [F3]

4.5 Discussion

The findings of this qualitative survey indicate that the pandemic and resulting restrictions had a significant impact on the choices and freedom of people with intellectual disabilities in Ireland. Both professional and family carers noted little in-person contact with friends or family and limited activities during this period, leading to confusion, anxiety and distress. Family carers reported infrequent communication and support from disability services during this time. Research conducted in other countries highlights similar feelings of restriction, boredom and isolation among people with intellectual disabilities throughout the pandemic (Amor et al., 2021; Courtenay & Perera, 2020; Doody & Keenan, 2021; Embregts et al., 2022). Other vulnerable populations, such as people with chronic health conditions and older people, were similarly impacted (Amerio et al., 2020; Kantamneni, 2020; McAiney et al., 2021). This suggests that vulnerable groups were disproportionally affected by the restrictions. A subsequent paper by Tully and colleagues investigating the experiences of Irish people with intellectual disabilities during the pandemic showed similar findings to the present study, including feelings of frustration, boredom and isolation (Tully et al., 2024). However, in contrast to our findings, participants in Tully et al.'s (2024) study reported that caregivers employed regressive practices when it came to decisional support, and reinstated more restrictive practices such as clients having to ask for permission to leave the house, and that they felt unduly targeted by government restrictions as they were being restricted more than the general population.

The buffering impact of online communication was a key finding in the present study. Having access to the internet enabled persons with intellectual disabilities to speak to loved ones who were unable to visit, and afforded opportunities to try new activities that may not have otherwise been available to them. Previous researchers have found that using online resources, particularly communication apps, allowed people who were vulnerable or self-isolating to keep in contact with their families and friends during the pandemic, which helped to decrease feelings of loneliness and isolation (Caton et al., 2019; Nicholas et al., 2022; Puyalto et al., 2022). The literature also echoes this study’s findings on the limitations and challenges of engaging in online activities experienced by adults with intellectual disabilities. Communicating with friends and family online was not as fulfilling as seeing them in person, and difficulties were experienced in using online shopping or learning how to use the computer itself (Doody & Keenan, 2021; Embregts et al., 2022; Kremers et al., 2021; Li et al., 2021).

The finding that the pandemic often afforded greater, rather than lesser, choice to people with intellectual disabilities living in residential care settings was also notable. Although previous research found evidence of adaptability and resilience among people with intellectual disabilities and other vulnerable populations during this period, there was no evidence pertaining directly to an increase in decisional independence or support in decision-making due to the pandemic (Lake et al., 2021; Nicholas et al., 2022; Patel et al., 2021; Scheffers et al., 2021). Luckasson and colleagues (2020) wrote a theoretical paper discussing methods of maintaining independence and decisional support for people with intellectual disabilities during the pandemic, which echoes elements discussed here. Their paper included suggestions that professional services should take a flexible, holistic approach to support, should not allow safety concerns to eclipse this, and should use multifaceted techniques, including online resources, to maximise independence (Luckasson & Schalock, 2020). It appeared in the present study that family carers had a particularly difficult time implementing such measures, and a lack of resources or service support was frequently commented upon. Themes of restriction of choice and isolation featured more prominently in their responses than those of professional carers. Similarly, McCausland and colleagues reported that people with intellectual disabilities living in residential settings had greater access to, and use of, technology during the first wave of the pandemic than those living at home (McCausland et al., 2021). This highlights a potential gap in service provision for people with intellectual disabilities who attend day services or avail of outreach services.

4.5.1 Strengths and Limitations of the Research

This survey was limited by its small sample size. At the time of data collection, Ireland still had social distancing and mask wearing restrictions in effect due to COVID-19 (Lunn et al., 2024). Day services faced significant pressure to remain in contact with their clients despite few having the resources to do so remotely, and residential services were still under strict isolation and social distancing protocols, resulting in longer shifts for professional carers to minimise contact between themselves and residents (Sheerin et al., 2023). This may have contributed significantly to low engagement with the survey, as professional carers lacked sufficient time to complete it. Furthermore, as discussed in the introduction, few services had the means in place to offer remote support to the families of clients living at home during this time, which may have also resulted in decreased time for family carers to complete the survey (O'Donnell, 2023). The open-ended nature of the survey questions may also have contributed to professional and family carers’ decisions not to engage, as such questions required more time and consideration to complete in comparison to close-ended questions involving Likert scales or tick box responses (Robinson & Leonard, 2024).

However, those who did respond provided detailed replies on this under-researched topic. The survey was designed to function as a remote qualitative data collection tool rather than a traditional quantitative survey, which resulted in a sample size that was appropriate for its intended purpose. Furthermore, the open-ended questions were designed to further adapt a survey format to a qualitative data collection tool. Therefore, while statistical generalisability was not the aim, potential limitations in theoretical generalisability are acknowledged. Data pertaining to levels of disability or co-occurring conditions were not collected; these may be important considerations in future studies. People with intellectual disabilities were not included as participants in this survey due to potential issues with its online format, which is a limitation. The voices of people with intellectual disabilities should be taken into account, and future research on this topic should include them as central participants (Tully et al., 2024). The pandemic provided a unique opportunity to ask carers of people with intellectual disabilities how their strategies of support may have changed in light of unexpected national circumstances. The finding that families whose loved ones used day services had a more difficult time accessing resources to support them during this time indicated that resources for this cohort should not always be so heavily embedded in particular services, or service types.

Finally, the responses of professional carers, which indicated that they felt the people they cared for were more freely able to make choices due to reduced involvement from family members during the pandemic, indicated a latent divide between family and professional carers that was also noted within the systematic review (Chapter 3). The two groups are often addressed separately in research, preventing an opportunity for them to hear and discuss each others' views and experiences, and both often have negative impressions of the other. This apparent dynamic was considered during the analysis of the systematic review and COVID-19 survey, as well as with regard to how they might affect the subsequent research, particularly the focus groups and multistakeholder feedback sessions. From this, it was determined that while the focus groups might yield more candour if the groups were spoken to separately, removing any power differentials, such as those between supervisory and floor staff, or family carers and people with intellectual disabilities, the subsequent feedback sessions could provide an important opportunity for professional and family carers, along with people with intellectual disabilities, to speak freely about their thoughts on SDM in a group setting, in an attempt to bridge the gap between supporters. This also indicates the potential value of a guide to SDM that articulates the role and responsibilities of each member of the adult with intellectual disability's support circle in supporting their decision-making.

4.4.2 Conclusion

Although people with intellectual disabilities were limited in their everyday choices by the pandemic restrictions, professional carers reported increased opportunities to try new activities, leading to gains in independence and decision-making. This was not achieved without difficulty, as many stated that the necessary infrastructure for online and remote support was not present before the pandemic began, and it took some time before they were up and running. Furthermore, the internet proved inaccessible to service users at times, which led to a greater dependence on professional carers to carry out tasks previously completed independently. Online inaccessibility has long been discussed by people with disabilities and their supporters (Chadwick et al., 2022; Glencross et al., 2021), and, in this modern age of technology, it should be more keenly addressed to facilitate greater autonomy among people with intellectual disabilities.

Family carers reported greater restriction and isolation for their loved ones who lived with them. This has highlighted a gap in service provision and suggests that online alternatives to in-person services for those unable to access them should be developed.

Chapter 5: An Environmental Scan of Online Resources for SDM in Ireland

5.1 Chapter Summary

This chapter details the conduction of an environmental scan of online resources on SDM to determine the sources, types and quality of information that was available on this topic to adults with intellectual disabilities, professional and family carers in Ireland. Section 5.2 briefly outlines the background and rationale for the study. Section 5.3 details the general purpose of an environmental scan, the methods used to carry it out, and the use of an adapted version of the Patient Education Materials Assessment Tool (PEMAT: Shoemaker et al., 2014)) to evaluate the quality of the resources selected for inclusion (Leiva Portocarrero et al., 2015; Mahmoodi et al., 2018; Shoemaker et al., 2014). Section 5.4 details the results of the scan and outlines the overall content and quality of the resources identified. Finally, the implications of these findings are discussed regarding SDM in an Irish context, and the strengths and limitations of the study are outlined.

5.2 Introduction

Research indicates that people often consult the internet for information in order to seek knowledge on a topic of interest and better understand matters relevant to their lives (Daneback et al., 2012; Slomian et al., 2017). Carers of adults with intellectual disabilities often use the internet to locate support groups, find information on how best to support the person with intellectual disability, or to educate themselves on specific aspects of intellectual disability such as co-occurring medical conditions (Caton et al., 2019). For people with intellectual disabilities, internet usage has historically been limited by accessibility barriers, social exclusion, and carer concerns regarding safety (Chadwick et al., 2022; Chiner et al., 2017). Much of the literature on the ADMA published to date has focused on the legal framework it describes, its effect on policy, and impacts on power of attorney or acute medical decisions such as end-of-life care, with limited consideration of its implications for people with intellectual disabilities and their decision-making supporters in day-to-day life (Davies et al., 2019; Flynn, 2020; Murphy et al., 2023; Ní Shé et al., 2020). In Ireland, delays to the full commencement of the ADMA had a significant impact on the amount of available information and support (Service, 2022). Following the ADMA's official commencement in April 2023, the Decision Support Service (DSS) launched its full information campaign. However, a Red C poll performed in May 2023 reported that 67% of adults in Ireland had not heard of the ADMA; of those who had, only 4% reported having a good understanding of the Act (Safeguarding Ireland, 2023). This raises the question of how much free and accessible information may be available online for people with intellectual disabilities, their family carers, or professional carers living in Ireland in relation to SDM and its applicability to their lives. The aim of this research therefore was to investigate what kinds of online resources are publicly available to people with intellectual disabilities in Ireland and their professional and family carers about SDM and its relevance to their lives and everyday decision-making processes, as well as the quality and accessibility of the information provided (Fortune et al., 2024).

5.3 Method

5.3.1 Environmental Scan

The environmental scan conducted in the present research followed the methodology used by Leiva Portocarrero and colleagues (2015) and Mahmoodi and colleagues (2018). This approach involved combining a Google search with consultation with relevant expert academics and organisations to identify potentially relevant resources, followed by the screening of identified resources using inclusion/exclusion criteria, the extraction of data from those eligible for inclusion, and the use of a quality assessment tool to determine the quality of included resources.

5.3.2 Eligibility Criteria

Resources were eligible for inclusion if they: 1) were specifically targeted towards people with intellectual disabilities and/or their professional or family carers; 2) provided information on SDM and/or practical application of the ADMA; and 3) were applicable to their everyday concerns.

Resources were excluded if they: 1) were designed for an expert audience (i.e., if they used technical terms or acronyms that would be unfamiliar to a lay audience); 2) focused solely on decision-making in relation to advance care planning, hospital directives, or end of life care; or 3) predated the 2015 signing of the ADMA.

5.3.3 Identification of Potentially Eligible Resources

Google Trends was used to determine what phrasing was most popularly used in Ireland when searching for information on SDM and/or the ADMA. Google Trends tracks the frequency with which key words are used in Google searches and can be employed to find out the popularity of search terms over a specified period of time in a specific country (Ajbar et al., 2021; Card et al., 2021; Hassan & Gudiwala, 2022). It was found that the term “assisted decision-making” was used more frequently than “supported decision-making” in Google searches performed in Ireland since the introduction of the ADMA in 2015. Dummy searches were then carried out using criteria identified through Google’s own guide for performing the most effective searches using their Chrome web browser (Google, 2023). The final search was performed using the following search terms: “Assisted Decision Making” + Ireland. The first 100 results were extracted for screening. A second person (LC) performed the same search independently, and results were cross-referenced to identify any that were not present in both searches.

In addition, pertinent national experts and prominent organisations in the area of SDM were identified through reviewing the academic literature or news coverage of the ADMA commencement. Expert sources consulted included: 1) three academic experts in the field of SDM and disability from various Irish universities; 2) the Decision Support Service; and 3) Sage Advocacy, a national advocacy service that provides support in self-advocacy for older people and people with cognitive impairments. These sources were contacted via email to ascertain what online resources on SDM and/or the ADMA they had either created or were aware of for relevant stakeholder groups. Five out of six experts responded and provided a total of five such resources. These resources were then combined with the internet search results described previously and duplicates were removed.

5.3.4 Screening Process

Stage one of the screening process involved reading the home pages of all included resources identified from the combined expert consultation and Google search results and checking their eligibility for inclusion. In stage two of the screening process, all content to which links were provided via the home page of the remaining results were read and checked against the eligibility criteria. Following this more in-depth analysis of the content, additional reasons for exclusion were identified, including the linked content being inaccessible due to the existence of a paywall or a broken link, or providing information for an event or information session that had already taken place. This two-stage process was carried out independently by LC and HC and a consensus meeting was held to discuss any conflicts and finalise the list of included resources.

5.3.5 Data Extraction and Analysis

The application Evernote was used to extract and store the results of the Google search. Evernote is an information gathering application which allows the user to store web pages, search results, or online information using a cloud-based notebook system. This system allows users to group and categorise information saved, and to add notes or tags to the information for easier understanding and compilation (Van Arnhem, 2013). These results were merged with the resources identified by experts to compile a full list to be screened for eligibility.

An extraction table was created for the resources selected for inclusion, which included the following categories: 1) the URL of the page, 2) type of information, 3) target group(s), 4) level of accessibility, and 5) relevance to SDM and/or the ADMA (see Table 4).

5.3.6 Quality Assessment

The quality of information provided in the included resources was assessed using an adapted version of the Patient Education Materials Assessment Tool (Shoemaker et al., 2014). The PEMAT was designed to review the quality of multi-media sources of health education provided to patients based on how informative, readable, and accessible they would be to a lay audience (Vishnevetsky et al., 2018). The PEMAT allows for the analysis of mixed media resources and assessment using five topics: 1) content, 2) word choice and style, 3) layout and design, 4) use of visual aids, and 5) the actionability of the material. Within these topics, a series of statements relating to the information being assessed are rated using an 'agree'/'disagree' answer format. An answer of 'agree' indicates the source of information met the quality criteria and the source is thus awarded a score of 1 in that category. An answer of 'disagree' indicates the source of information does not meet the quality criterion, and the source is thus awarded a score of 0 in that category. To adapt the PEMAT for the purposes of the present research, statements pertaining solely to a medical context, such as calculation of dosage, were omitted, and the actionability and understandability criteria were assessed together in order to simplify the process. In the modified PEMAT, the highest possible score for text material was 19, and 18 for audiovisual material. The overall accessibility of each resource was converted into a percentage, which served as a total score (see Appendix V).

Table 4: Data Extraction Table of Online Resources Selected for Inclusion in the Environmental Scan

	Organisation	**Type of Info**	**Target Group**	**Accessibility**	**Relevance**
URL					
https://www.hse.ie/eng/about/who/national-office-human-rights-equality-policy/assisted-decision-making-capacity-act/	Health Service Executive	Government body information (HSE)	Professional Carers Family Carers Health care professional	Reasonably free from jargon Suggests further reading No easy read material	Specifically about new law Gives links to e-learning

https://inclusionireland.ie/assisted-decision-making/	Inclusion Ireland	Disability service information and educational material.	People with Intellectual Disabilities	Easy read language Video explanations Tailored towards increasing understanding	Curated info for people with intellectual disabilities to increase their understanding of act and ADM
https://alzheimer.ie/wp-content/uploads/2018/12/ASI-Position-Assisted-Decision-Making-Capacity-Act-2015.pdf	Alzheimer’s Society of Ireland	Position Paper (Alzheimer’s soc)	Family and Professional carers for dementia	Clear but no easy read language	Some relevance for people with intellectual disabilities

https://www.iasw.ie/events/312-assisted-decision-making-capacity-act-2015	Irish Association of Social Workers	Informational material (webinar)	Social workers Professional carers	Not determinable	Webinar aimed toward professionals with social work training but not the lay reader
https://www.ul.ie/engage/sites/default/files/2017,%20No%2014%20The%20Assisted%20Decision-making%20(Capacity)%20Act%20201	University of Limerick	Informational material (legal)	Legal professional Professional carer Family carer	Contains lay definitions Accessible to lay reader Not easy read	Explains in straightforward terms the legal components of ADM and how to legally apply them

5_Interpretation%20and%20Practical%20Application.pdf					
https://familycarers.ie/carer-supports/help-guidance/carers-and-capacity-briefing-for-family-carers-on-the-capacity-act	Family Carers Ireland	Resource guide	Family carers	Contains videos and slides from information sessions Aimed at family carers, lay language used Not easy read	Explains context of DSS and ADM in terms of capacity
https://www.yout	Inclusion Ireland	Informational material	Family carers Professional carers	Clear with explained jargon	Good overview of

ube.com/watch?v=VHFyULekjEg			People with ID	Video speaker goes through info slowly and explains all content making it accessible	DSS and ADM in context
https://www.citizensinformation.ie/en/health/legal_matters_and_health/advance_care_directives.html	Citizen's Information	Government information	Professional carers Family carers	Minimal jargon Not easy read	Specific to Advanced healthcare directives, but relevant to their place in ADM
https://stephenwalshsolicitors.ie/frequently-asked-questions-assisted-decision	Stephen Walsh Solicitors	Information materials	People who may need a decision making assistant Professional carers Family carers	Some jargon but straightforward No easy read	Relevant to understand changes but no practical advice

-making-capacity-act-2015/					
http://www.ruraldoctors.ie/wp-content/uploads/2017/10/assisted-decision-making-act-factsheet.pdf	Inclusion Ireland	Information materials	Professional carers Family carers	Some jargon but clear Not easy read	Relevant to understand new ADM legislation but no practical application advice
https://www.smh.ie/assets/files/pdf/easy_to_read_newsletter_-	St. Michael's House Disability Services	Informational materials	People with ID Family carers Professional carers	Easy read No jargon, fully explained, disability friendly	Relevant to help people with ID understand ADM No practical application info

_june_2019_final.pdf					
https://www.hiqa.ie/sites/default/files/2017-01/Supporting-Peoples-Autonomy.pdf	Health Information Quality Authority	Information material	Professional carers	Explained jargon No easy read	Informative for policy application in disability service
https://www.fieldfisher.com/en-ie/locations/ireland/ireland-blog/enduring-powers-of-attorney-and-	Fieldfisher EU law firm	Information material	Family carers	Jargon heavy No easy read	Displays difference between Act EPA and pre Act EPA

the-end-of-all-or-nothing					

5.4 Results

One hundred and five results were obtained in total from the combined Google search (n=100) and expert consultation (n=5). After duplicates were removed, 101 resources remained. Of these, 67 were excluded following stage one screening. Resources were excluded for the following reasons: not aimed at professional carers, family carers, or people with intellectual disabilities (n=58); made no direct mention of SDM and/or the ADMA (n=1); had no practical advice about SDM and/or the ADMA (n=3); predated the 2015 signing of the ADMA (n=2); was inaccessible due to a broken link (n=2); was an advertisement for a past event that was not recorded (n=1). Of the remaining 34 resources, 21 were excluded in the second stage of screening for the following reasons: did not provide practical everyday information on SDM and/or the ADMA (n=11); did not provide original content (i.e. linked to other organisations' resources already identified in this scan) (n=6); were behind a paywall or not otherwise publicly accessible (n=2); were designed for an expert audience (n=1); predated the signing of the ADMA in 2015 (n=1).

Thirteen resources were identified for inclusion, which originated from a variety of organisations including the Health Service Executive (HSE), Health Information and Quality Authority (HIQA), Citizen's Information (CI), Inclusion Ireland (II), the Alzheimer's Society of Ireland (ASI), the Irish Association of Social Workers (IASW), the University of Limerick (UL), Family Carers Ireland (FCI), Saint Michael's House disability service (SMH), Stephen Walsh Solicitors (SWS), and Fieldfisher EU law firm (FF). The number of links to additional information provided in each resource ranged from 0 to 6. Modified PEMAT percentages of accessibility ranged from 23.5% to 94.4%. A detailed summary of the contents of each resource, the individual percentages, and the information it linked to can be found in Appendix V.

Many of the resources were provided by health and social care organisations (HSE, HIQA, ASI, IASW) for use by professional carers working in disability services who wished to improve their current formal policy or practice in relation to SDM (n= 4). Resources aimed at family carers (n= 4) focused on how enduring power of attorney or advance care directives could be accessed under the new legislation (FF, SWS, CI, FCI). Only two resources, provided by SMH and II, were tailored towards people with intellectual disabilities and used easy read, disability-friendly formatting for their documents and audiovisual material, which focused on explaining the concept of SDM and the ADMA. All other resources were not tailored to people with intellectual disabilities, although they attempted to explain technical jargon and avoid using legal language. Seven of the resources (HIQA, CI, II, SMH FCI, UL, ASI) provided links to written materials, many of which were only available in PDF format, rendering them inaccessible to screen readers. Four resources (HSE, II, IASW, FCI) linked to audiovisual materials, all of which were well-executed and included accessibility features such as closed captions, illustrated points using visual aids, and were clearly and concisely narrated, although only II’s audiovisual materials were specifically aimed at people with intellectual disabilities. Much of the information provided across the included resources pertained to explaining the ADMA in lay terms, with a focus on how SDM could be applied under the new legislation with the help of the DSS once the Act was fully commenced, or explanations relating to key terms such as mental capacity (HSE, IASW, HIQA, SWS, FF, UL, CI). The HIQA document was the only included resource that focused on improving decisional support for people with intellectual disabilities in disability services. It was designed to act as a guide for professional carers at a service policy level to alter their current support policies to better reflect the ADMA and ensure the autonomy of service users was respected throughout the resource process. No other resource identified in this scan offered practical guidance for disability services in this manner.

5.5 Discussion

The aim of this environmental scan was to explore the type and quality of information on SDM and/or the ADMA in Ireland available online. The environmental scan facilitated this by offering a methodology that could be applied to searching for information in places other than academic databases (Gordon & Glenn, 2009; Leiva Portocarrero et al., 2015; Mahmoodi et al., 2018). The results of the scan demonstrate that although information on SDM and/or the ADMA is publicly available in Ireland, it lacks practicality and everyday relevance to people with intellectual disabilities and their decision-making supporters. HIQA was the only organisation that provided a framework designed to improve decisional support for people with intellectual disabilities. However, it was not designed with the entire support circle in mind, as it did not include steps that encouraged the inclusion of family carers in the support process. Instead, the focus was on how disability services could embed the framework in their current support policies to align them more directly with the legal obligations set out by the ADMA. Furthermore, no resources were found which explicitly provided training or guidance to carers on how to apply the concept of SDM in everyday support outside of a formal role designated in the Act such as an appointed decision-making assistant, co-decision maker, or decision-making representative, as outlined by the DSS (Decison Support Service, 2023). The DSS itself, while frequently mentioned in the resources identified, did not have any resources of its own available at the time the scan was conducted, as the Act had not yet been fully commenced. Direct advice was largely limited to very specific topics such as advance care planning and enduring power of attorney. However, as demonstrated in the systematic review (Chapter 3), many of the decisions people with intellectual disabilities require support in making are much more prosaic and less formal (Casey, Trayer, et al., 2023). This indicates that future resources on SDM and/or the ADMA must consider how SDM can play a role in more everyday situations and advise adults with intellectual disabilities and their decision-making supporters on how to apply SDM in such informal circumstances. This suggests a gap in information currently available online for those wishing to understand how SDM might be applied in their lives. Furthermore, given the relatively high cost of producing hard copy materials, this scarcity also is likely to apply to print media also. It should be noted that since the completion of this scan and the commencement of the ADMA, more resources aiding people with intellectual disabilities and their carers in understanding SDM have been made available online, including easy read materials for adults with intellectual disabilities produced by Inclusion Ireland, and a national information campaign by the DSS in partnership with people with intellectual disabilities who act as information ambassadors (Inclusion Ireland, 2021; Decision Support Service, 2023).

The results of the present study echo those of previous environmental scans highlighting gaps in the provision of information to stakeholders. For example, a number of scans pertaining to decision-making in healthcare settings have shown that the information available to patients often lacks practical advice for their target audience and instead focuses on conveying general information on the topic at hand (Leiva Portocarrero et al., 2015; Mahmoodi et al., 2018; Rowel et al., 2005; Sacco et al., 2020). In terms of intellectual disability research, previous scans reported that organisations often failed to explain how their resources and information related to important aspects of independence and support for people with intellectual disabilities and required stakeholders to read between the lines in order to establish these factors for themselves (Brown & Mallett, 2021; O'Donovan et al., 2021). An Australian environmental scan focusing on online resources available to people with intellectual disabilities who were being transferred to more independent living accommodation reported that none of the identified websites highlighted how their organisation directly enabled a transition to independent living, and instead merely listed the types of living arrangements they offered (O'Donovan et al., 2021). This echoes the findings of the present scan, in which many of the included resources provided definitions of key terms pertaining to SDM and/or the ADMA but did not explain in practical terms how they would affect the lives of the target group. Furthermore, a scan focusing on programmes to facilitate people with intellectual disabilities to find employment reported that such programmes often targeted employers and advised them on how they could meet legal requirements for the hiring of people with intellectual disabilities, with fewer designed to assist people with intellectual disabilities directly (Brown & Mallett, 2021). This is similar to the findings of the current scan, as most of the resources identified were tailored towards professional carers or organisations rather than people with intellectual disabilities themselves. This suggests that much of the information surrounding access to supports for people with intellectual disabilities fails to consider people with intellectual disabilities themselves as consumers. It is possible that this correlates with the overall difficulties faced by people with intellectual disabilities in accessing online services and reflects the paternalism often evident towards this group more generally (Glencross et al., 2021). Future efforts by Irish disability services should focus on improving the accessibility of information to people with intellectual disabilities by creating resources and practical guides tailored to them specifically, such as the Speak Up, Speak Out training guide designed by Inclusion Ireland to train people with intellectual disabilities on self-advocacy, published after the completion of this scan (Inclusion Ireland, 2024).

5.5.2 Strengths and Limitations of the Research

The primary strength of this environmental scan lies in its novelty in the present research context. It is the only research attempt that the author is aware of which endeavoured to establish what sources of information on SDM and/or the ADMA were available to Irish people with intellectual disabilities, and/or their professional and family carers. It highlighted important gaps in the information available online to stakeholders and identified the lack of accessible resources for people with intellectual disabilities regarding the topic. Furthermore, it identified current trends in the provision of information by Irish government and disability organisations during a time of great legislative change. Since the scan was completed, the ADMA was fully commenced by the Irish government, changing the volume and content of the information available online. In particular, the growing list of resources offered by the DSS was not captured here. However, the scan retains its merit through its function as a snapshot of the state of information at a particular time in the Irish context, as it attempted to integrate SDM into its legislative process. The examination of online materials only meant that it could not be determined if this scarcity of information translated to print media also, although one could speculate that it likely did given the high cost of hard copy publishing and increasing reliance on the internet for the dissemination of information. Furthermore, people with intellectual disabilities continue to face exclusion from online spaces, which may serve as an explanation for the lack of online material tailored to them directly. This can be rectified through an emphasis on the creation of more disability-friendly online resources on SDM.

5.5.3 Conclusion

The findings indicate that there is a significant gap in the provision of practical information on SDM and the ADMA to people with intellectual disabilities and their decision-making supporters in Ireland, and highlight the need to integrate the core values and goals of the ADMA into the lives of people with intellectual disabilities in Ireland, their professional carers and family carers through the development of resources designed for practical application of the principles of SDM in more everyday contexts. This could be facilitated by offering information focused on education and training in the use of SDM as a method of decisional support.

Chapter 6: Exploring the Experiences and Perceptions of Adults with Intellectual Disabilities, Family Carers, and Professional Carers Regarding SDM in the Irish Context

6.1 Chapter Summary

This chapter describes the exploration of the experiences and perceptions of SDM, the ADMA, and what methods of decisional support were most valued by people with intellectual disabilities, professional carers, and family carers in Ireland through a series of focus groups. Section 6.2 provides a brief introduction to SDM, how it pertains to people with intellectual disabilities, and its enshrinement in Irish law through the commencement of the ADMA. Section 6.3 outlines the methods employed, including the study design, ethical considerations, participant eligibility, methods of recruitment, data collection processes, and the use of reflexive thematic analysis (RTA: (Braun & Clarke, 2019) to analyse the data. Section 6.4 details the results of the focus groups separately for each participant group: adults with intellectual disabilities, family carers, supervisory staff, and frontline care staff. Section 6.5 details a discussion of the results via their collective synthesis using Bronfenbrenner’s Ecological Systems Theory as an organising framework, followed by comparisons to previous studies on the topic, and the strengths and weaknesses of this research.

6. 2 Introduction

Although SDM is growing as a method of decision-making support internationally, there remains a prevailing scepticism among some carers surrounding the ability of adults with intellectual disabilities to make their own decisions. Little research has been conducted to date on the adoption of SDM as a formally applied method of support, particularly in the Irish context (Murphy & Bantry-White, 2021). However, in light of the Assisted Decision-Making Capacity Act, 2015 (ADMA), current policies and practices in place in Ireland with respect to decisional capacity are beginning to shift (Flynn, 2020; Murphy et al., 2023). Previous research indicates that the changes the ADMA entails with respect to supporting the decision-making of adults with intellectual disabilities in Ireland have not been adequately addressed with key stakeholders, including professional carers, family carers, and people with intellectual disabilities themselves (Safeguarding Ireland, 2023). Furthermore, although the ADMA enshrines the principles of SDM in statute, little is currently known about how stakeholders view SDM as a method of decisional support, or how they already approach decision-making in their daily lives. As indicated by the results of the environmental scan detailed in chapter 5, there is a paucity of publicly available information or training available to stakeholders in Ireland that explains how to apply SDM in daily life. Therefore, the aim of this research was to explore the thoughts, opinions, and perspectives of people with intellectual disabilities, family carers, and professional carers (frontline and supervisory staff)living in Ireland on SDM, the ADMA, and what they value most during everyday decision-making.

6.3 Method

6.3.1 Study Design

This qualitative study involved conducting a series of focus groups, including 44 participants in total. Separate focus groups were conducted with: 1) adults with intellectual disabilities; 2) family carers; 3) supervisory staff working in a disability service; and 4) frontline staff working in a disability service. Eight focus groups were conducted in total, one per participant group in each participating organisation.

6.3.2 Participant Eligibility Criteria

Eligible participants were: 1) adults with intellectual disabilities aged over 18 years with experience of being supported in everyday decision-making; 2) professional carers aged over 18 years in a supervisory position whose work involved supporting clients to make everyday decisions; 3) professional carers aged over 18 years in a frontline care staff position whose work involved supporting clients to make decisions; and 4) family carers aged over 18 years involved in supporting a person with intellectual disability they cared for to make everyday decisions.

6.3.3 Participant Recruitment and Consent

Two disability service organisations facilitated recruitment of their clients, families, and staff for the focus groups. Each service catered to a broad range of support needs, including outreach, day, and residential. All participants were recruited using convenience sampling, with the assistance of a dedicated point of contact in each organisation. These points of contact distributed a study flyer and information sheet to staff and family carers via email (see Appendix VI). For participants with intellectual disabilities, an informational video created by HC was distributed to users of the organisations' day, residential and outreach services via email, along with an easy-read information sheet (see Appendix VII). The topic guide, information sheet, and consent form designed for their focus group was read and reviewed by a person with intellectual disability recruited from one of the partner organisations, who provided feedback on the readability and clarity of the documents and advised how they might be altered to ensure maximum comfort and understanding for participants. The topic guide was emailed to the key workers of participants with intellectual disabilities in advance of the focus group sessions, to allow them to become familiar with its contents and consider how they might like to answer the questions alongside their keyworker, and to give them time to contact the researcher with any questions they had if they wished, as this is recommended practice for research including participants with intellectual disabilities (McDonald et al., 2013). To ensure participant comfort, all invited to take part were asked during recruitment whether they preferred to meet in person or online via Microsoft Teams. Separate sessions were conducted with each participant group in order to mitigate concerns regarding power differentials. For example, participants with intellectual disabilities could perhaps feel uncomfortable discussing aspects of support they were unhappy with in front of family or professional carers, family carers might be concerned that professional carers would disapprove of any criticism they might have of the disability service, and frontline staff could feel reluctant to discuss aspects of their service they were unhappy with in front of supervisory staff.

Recruitment emails sent to staff and family carers contained a link to an online form hosted on Qualtrics where they could register their interest in participating and complete a consent form. A list of expressions of interest from adults with intellectual disabilities was sent to HC by the service points of contact before the focus group sessions. Their consent was recorded via paper forms (see Appendix VIII). Before each focus group session, participants were asked to verbally reconfirm their consent to participate in the focus groups, and to being audio recorded. HC reiterated the purpose of the focus group and advised participants that they were not obligated to participate in the sessions and could change their minds at any time. Participants were also reminded that they could leave the sessions at any time and could contact HC up to two months after to withdraw their consent and have data pertaining to them removed from the analysis.

6.3.4 Data Collection

Forty-four people participated across the eight sessions; demographic information is provided in Tables 5-8 in the results section. All focus groups were conducted between July 2022 and January 2023. Seven focus groups were conducted in person; six were held in venues owned by the relevant disability service and one was held in a local community centre; one focus group with supervisory staff was conducted online via

Microsoft Teams. Sessions lasted from 50 to 95 minutes (M= 78.6) and were facilitated by HC. Topic guides (see Appendix IX) tailored to each participant group were used to guide the sessions. The topic guide for participants with intellectual disabilities focused on what kinds of decisions they made every day, who they preferred to ask for help with decision-making, what methods or techniques of support in decision-making they preferred carers to use, what challenges they faced making decisions in day-to-day life, and their thoughts and impressions of the ADMA. The topic guide for family carers addressed issues relating to their experiences of supporting everyday decision-making, what methods or techniques they used to support the person to make decisions, how they felt about the approach to SDM taken by the disability organisation their loved one attended, challenges they faced in supporting the person they cared for to make decisions, and how they felt about the ADMA. The staff topic guide was used with both frontline and supervisory staff and addressed issues relating to their daily activities while caring for clients, what methods or techniques they used to support clients to make everyday decisions, how they felt about their disability service's policies or procedures relating to SDM, challenges they faced while supporting clients in everyday decision-making, and their perceptions of the ADMA. All participant groups were also asked about their preferences for a guide to SDM for use by adults with intellectual disabilities and their decision-making supporters. These findings are presented separately in Chapter 7. All focus groups were recorded with participants' consent, transcribed verbatim and anonymised by HC.

6.3.5 Data Analysis

Data for participants with intellectual disabilities, family carers, supervisory staff, and frontline care staff were analysed separately to capture each group's unique views and perspectives. The analysis was conducted using MaxQDA review software. As a family carer for an adult with intellectual disability, I was aware that I would have my own personal experiences and opinions that would impact my reading of the data. To account for this, I oriented myself through the data analytic process using the epistemological position of social constructivism (Adam, 2006; Kim, 2001). As outlined in Chapter 2, section 2.2 this orientation formed the basis of my approach to all aspects of this research project. Constructivism stipulates that the researcher should acknowledge that the reality of participants' lives is created by them and their experiences, which the researcher must be cognisant of during the analytic process (Adams, 2006; Kim, 2001). In turn, the researcher should also acknowledge that their own experiences and perceptions contribute to their understanding and analysis of participants' responses. To fulfil this, I used reflexive thematic analysis (RTA) to analyse the data (Braun & Clarke, 2019, 2021), with the exception of material pertaining directly to participants' recommendations for a guide to SDM, which was analysed and reported using a topic summary approach, described in chapter 7. RTA is a method of qualitative data analysis that actively encourages researchers to engage with their own experiences, perceptions, and reflections throughout the process. Therefore, I chose to use my personal experiences as a tool during the analytic process in order to approach the data in a constructivist manner, and afford myself the opportunity to better process and understand the thoughts and experiences of the participants by acknowledging and harnessing my own.

To fully engage with the process of RTA, the analysis was carried out in a six-step process recommended by Braun and Clarke (2019). I chose to focus on one participant group at a time, to fully immerse myself in the story each group was telling. Firstly, I transcribed each focus group myself in order to completely immerse myself in the data. Once the data were transcribed, I read and reread the transcripts. On my second reading, I used MaxQDA's internal memo feature to take notes. These notes consisted of my early thoughts and reactions to the content of the transcripts, in order to reflect upon my first impressions of the data, as well as initial observations of recurring topics I noticed among participants (Kuckartz & Rädiker, 2019). This was to fulfil step one, familiarisation with the data.

Following this, I organised the data and applied broad codes using MaxQDA's highlighter feature, in order to identify these codes by a corresponding colour. To accompany this step, I reread my memos detailing my initial observations on recurring topics to name these codes, and added a note to them identifying which initial code I felt they best captured, in order to link my own reflections and thoughts with the ongoing coding process. At this juncture I decided not to attempt to edit the codes, or only identify those that were substantial enough to encompass a theme on their own through their regular discussion or immediate relevance to the central aims. This resulted in a collection of more refined impressions of the initial content I had deemed important to consider within the data. This was to avoid becoming too narrow in my observations at this early point in the analytic process. This fulfilled step two, Initial Code Generation.

Then, I reviewed and reorganised these codes into themes. I reread my broad codes, merged those that appeared to speak to the same topic, or deleted those that did not directly relate to the research questions by reviewing my stated aims. When the codes had been consolidated, I took note of the quotes that I had added to each theme to better observe what story each theme was telling. From this, I separated out certain topics within each theme to form subthemes that I felt required their own space to be discussed, but were still distinctly connected by the overarching topic, using MaxQDA's ability to create cascading data folders. Each theme was given its own colour code with relevant quotes added to their folders highlighted within the transcript file. This allowed me to see which parts of the transcripts were connected to which theme. I also created new memo notes capturing how my thoughts and impressions of the data had changed with respect to these themes upon their generation. This fulfilled step 3, Generating (Initial) Themes.

I carried out step 4, Theme Review, by reviewing the initial themes in light of my research questions, reorganising or reworking themes that I felt were incomplete, or more akin to topic summaries, and merging or removing any themes that I found were too overlapping. I carried out this process with reference to Braun and Clarke’s (2021) observations on what should be considered quality practice in RTA. When reading each theme and subtheme, I asked myself if each theme could be considered a theme, that is a fully realised aspect of the data that merited closer discussion, or was it merely a code- a smaller, less fleshed out observation that could not stand up on its own. Also, I examined the depth and meaning of each theme by rereading my own reflective memos, and attempted to ensure it spoke to latent, interpretive aspects of the data, and did not merely summarise a topic that participants happened to discuss frequently. I reviewed subthemes in the context of their overarching theme and attempted to streamline any that were too dense or unwieldy by rereading the associated quotes and my accompanying memos to re-sort them into more manageable sections.

Following this, I read the quotes I had placed in each theme and subtheme to identify the story it was telling and ensure it was clear and relevant, both to the overarching research questions and with respect to the other themes. I took short notes regarding how each theme related to its subthemes and the other themes to observe what overarching story I was telling with respect to each participant group, and ensure that no theme or subtheme was out of place or irrelevant. I then re-examined what I had named each theme and subtheme to ensure they fully captured their content and spoke to their interpretive context, not merely the surface level context. This fulfilled step 5, Theme

Defining and Naming. Finally, before writing the results section of this chapter, I wrote a detailed summary of each theme and subtheme and read this to better understand the overall picture conveyed by each section of the data. Based upon these summaries, I then constructed the results section of the chapter, including reflections and interpretations of the meaning of the data (Braun & Clarke, 2021; Campbell et al., 2021).

6.4 Results

Findings from each participant group are presented separately with illustrative quotations for each theme. Quotes were chosen to best support the overarching conclusions made in each theme, and which complemented the interpretation of the transcripts, as outlined by Braun and Clarke (Braun & Clarke, 2019; Byrne, 2022). Quotes are labelled from P1 to P45, with acronyms to illustrate the participant group to which the speaker belonged: ID (Intellectual Disability), FC (Family Carer), SS (Supervisory Staff), and FS (Frontline Staff).

6.4.1 Adults with Intellectual Disabilities

Twelve individuals with intellectual disabilities participated across two focus group sessions (8 males, 4 females). Two main themes were identified, with five subthemes therein: Preferences for Decisional Support (Facilitating Decisions, Trust, Respecting My Voice), and Struggles in Decision-Making (Barriers and Inhibitors, Worries About Life Skills).

Table 5: Demographic Information for Participants with Intellectual Disabilities

ID	**Gender**
P1	Female
P2	Male
P3	Male
P4	Female
P5	Male
P6	Female
P7	Male
P8	Male
P9	Male
P10	Male
P11	Female
P12	Male

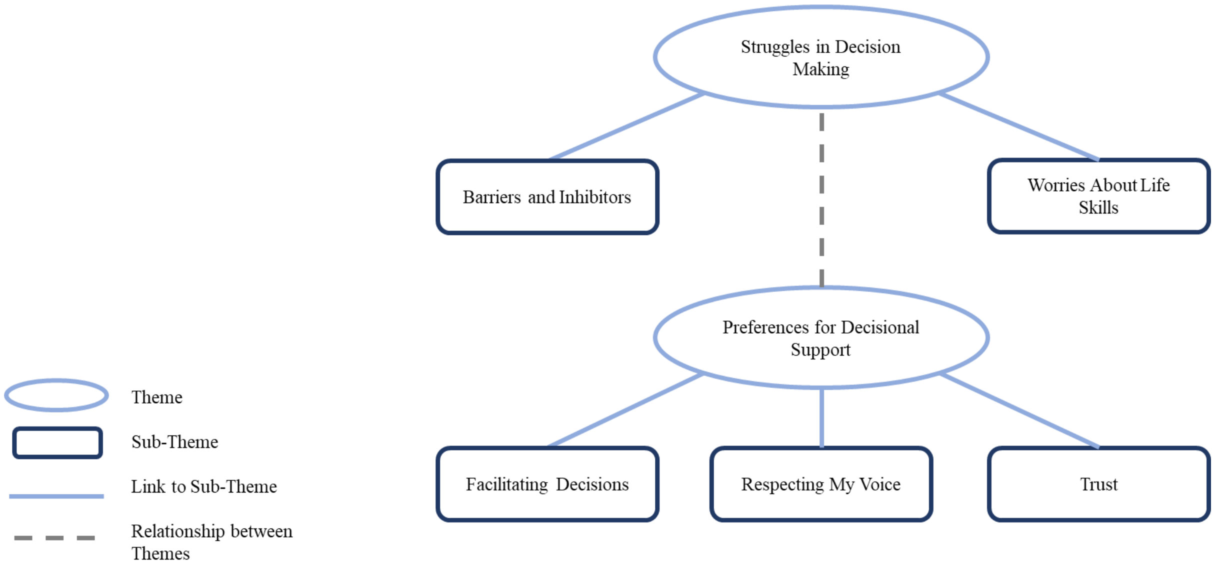


Figure 2: The Relationship Between Focus Group Themes for Participants with Intellectual Disabilities

6.4.1.1 Preferences for Decisional Support

This theme contains three subthemes and illustrates the approaches to decisional support and qualities of decision-making supporters that were most valued by people with intellectual disabilities. Subtheme one, Facilitating Decisions, discusses how these preferences were based in relationships; professional carers were relied upon for practical discussions regarding potential outcomes or to identify the individual steps of choices to be made, whereas family carer support more often took the form of reassurance through routine and practical facilitation of decisions. Subtheme two, Trust, demonstrates that it was crucially important to participants to be supported by people they knew well and trusted, and who would address all of their questions and concerns as many times as they needed without judgement or frustration. This was compounded in subtheme three, Respecting My Voice, which describes how participants felt strongly that they wished to be supported by people who would listen to them and acknowledge their desires and concerns during the decision-making process.

6.4.1.1.1 Facilitating Decisions

Participants discussed their preferences regarding support in decision-making. All commented that they preferred to be asked by their decision-making supporters directly and precisely what they would like to do, and to be the person to make the final decision at the end of any discussion. More often than not, these preferences were honoured.

> *“Em, [parents] say ‘oh what do you want to do’, and I might say go for a walk up the town or just stay home and relax, and then that’s what we do.”[P9, ID]*

Participants viewed the role of professional and family carers in the provision of decision-making support very differently. Professional carers were primarily viewed as sources of informational support during the decision-making process. Participants described how professional carers helped them to evaluate the suitability or quality of available options by breaking them down into steps they would have to take in order to achieve their desired outcome. This was helpful to participants, as they often found it difficult to keep track of the sequence of steps required to pursue a course of action. For example, one participant discussed how she often sought the support of residential staff while shopping for clothing, as when she went alone, she became overwhelmed by the available options and would end up purchasing unsuitable items. To compound this issue, she also had difficulty keeping track of receipts.

> *"So they help us pick out clothes like what my mammy used to do but now the residential staff do. So they are very good at that, because if I picked out me own clothes and I picked out something that didn't fit I lose the receipt. Like I picked out a jacket in [CLOTHING SHOP] and it fits and everything but the zip is not- it's cos [SHOP] clothes aren't made properly, and I've no receipt to return it and I have to get the jacket fixed, you see?" [P1, ID]*

Professional carers were also valued for the contextual information they provided to participants when making decisions. For example, another participant commented that he liked when staff helped him to weigh his options when planning activities by adding context or providing additional information to inform his decision-making, and felt he would make a "better" decision as a result.

> *"They might give you ideas about what's happening in the service. They might- suggest how to make it better. They might help you plan something better. Something like that." [P5, ID]*

In contrast, the support in decision-making provided by family carers appeared to be less focused on providing informational support by helping participants to evaluate the different options available to them, and more concerned with providing emotional support and enabling participants to enact their decisions with confidence. This was achieved by offering practical assistance such as providing transport and facilitating a sense of familiarity and routine. One participant took great comfort in his father driving him to and from the social engagements he liked to attend regularly. Knowing that he could rely on his father to bring him wherever he needed to go appeared to give him confidence and security in making the decision to attend these outings.

> *"So my dad will bring me from the house. And he'll drop me up and then bring me home after. And he'll be there, don't worry! My da's a good man. I know him a long time."* [P12, ID]

Knowing that family members were supportive of their decisions also helped to provide participants with confidence and reassurance. For example, one participant described how he enjoyed attending respite care, as it meant he could attend trips with his peers. Having the support of his family carers in helping him to arrange it demonstrated their approval of his decision, which facilitated a greater sense of comfort and freedom for him, as it meant he could continue to live the life he wanted while knowing his family would be there for him.

> *"They ask me do I want to go to respite or something like, the respite house I went to last time, like I said the respite has been much comfort for me to go on different trips like. So that's what they ask me to go to. But they do find it's important. And I find the same for me." [P3, ID]*

6.4.1.1.2 Trust

Participants repeatedly stressed the importance of having access to supporters who they knew and trusted when making decisions. Professional carers were treated with more reserve than family carers, whose trustworthiness was seen as a given due to their preexisting familial relationship. When discussing service staff, participants were concerned about the idea of having to rely on someone they did not know for support in decision-making and stressed that they were often reluctant to talk to new staff members about personal matters. Participants had their own metrics for when they considered a professional carer to be trustworthy, often dictated by how long they had been present within the service.

> *"Well it's easier when you know the person because you might talk to them about private things." [P5, ID]*

All participants communicated that they felt comfortable attending their disability service, and that they particularly valued having a keyworker to speak with about issues or decisions they wished to make while in attendance. Their keyworker was their preferred member of staff to seek support from, as they were seen as the most trustworthy, due to their established relationship with participants. They were also frequently mentioned as the person participants relied on during outings or activities to explain things to them, such as what money they had with them, or to read menus or other sources of information. This appeared to stem from the assertion that their keyworker was their personally assigned supporter within the service, and that it was part of their duties to assist them in matters of decision-making.

> *"[KEYWORKER] helps me to see how much money I have with me. And sometimes like, sometimes [STAFF MEMBER] sometimes [KEYWORKER] helps me with my savings." [P3, ID]*

In contrast, family carers were trusted implicitly. Unlike professional carers, however, participants were far more likely to seek approval in decision-making as well as support from family carers, who were often described as dictating the decisional process.

> *"My- my mam always makes good decisions cos it's up to my parents who organise the decision like." [P3, ID]*

Participants were more likely to speak about trusting a family carer's judgement and making decisions based upon what they asserted was best rather than in terms of trusting them to support them in making decisions independently. For example, when discussing why he chose to attend his service, one participant appeared to align his own decision-making with that of his mother and was comfortable adopting her views as his own.

> *"My mammy didn't want me to go to [OTHER SERVICE] because my aunty is already there (INT: Okay). She didn't want both of us there. (INT: Okay, did that-). She didn't want both of us there, she only wants one of us there. It's why she chose [SERVICE] and why I chose [SERVICE] too." [P2, ID]*

Participants' trust in family carers was not a given, however, and only held in familial situations that were inherently free from undue stress or conflict. For example, one participant who experienced a very difficult home life turned to professional carers rather than family for support when having to make the difficult decision to move out of her mother's house and into residential care due to issues with her mother's partner.

> *"[STAFF MEMBER] said "are you okay [P1]?" and I said "[STAFF MEMBER] I'm a bit upset I can't stand my mam's partner at home, he's actually starting rows for no reason at half two three o'clock in the morning" and she says "Okay [P1], I'll talk to [COLLEAGUE] and see about getting another house somewhere else" I- I can't stand him [STAFF MEMBER] I don't- god forbid, I don't know what I'm gonna do. And I can trust [STAFF MEMBER]." [P1, ID]*

Despite this, P1 did not view her professional carers as a decisional authority, suggesting that participants' trust in professional carers was not a given, and took time to develop.

> *"Em, kinda like I- (P6: yeah) -at the start I didn't speak to [STAFF MEMBER] because I didn't know them, now I speak to her it's no problem I know her well." [P1, ID]*

This suggests that adults with intellectual disabilities placed their trust in the closest and safest supporters available to them when choosing whose support they most valued in the decisional process.

6.4.1.1.3 Respecting My Voice

In addition to trust, participants also stressed that it was important to them that they felt listened to and respected by their supporters. Participants were quick to share incidents where they had been made to feel unimportant or dismissed, particularly by professional carers.

> *"That feels good because I find with any other service in [OTHER SERVICE] they're not treating people with respect and they're not nice to them. I find well y'know years ago I was in it with other members [NAME OF SERVICE], and I said I'm not going to this place because they don't listen to ya, and they're not very nice the way they treat ya. So I prefer where I am they listen." [P1, ID]*

Participants felt comfortable exploring how best to articulate their needs with professional carers through mutual learning and respect for what the other had to say. All participants spoke about the importance of communicating openly with their supporters to ensure they were aware of what they wanted. Some mentioned receiving training from their service providers in how to communicate more effectively and build their own listening skills so they could work together with supporters in a mutually respectful manner. One participant explained that he used social stories (i.e. comic strips depicting a relevant social situation and demonstrating the steps a service user could take to navigate the social situation successfully) alongside staff in order to communicate more effectively.

> *"[The social story is] called listening to staff. And when staff are speaking to me I listen properly and listen to the whole message, to the full message." [P8, ID]*

6.4.1.2 Struggles in Decision-Making

This theme outlines the challenges participants with intellectual disabilities described in relation to decision-making. Subtheme one, Barriers and Inhibitors, addresses barriers they encountered in attempting to exercise their right to make decisions such as overly protective carers, staff shortages and frequent staff changeover. Subtheme two, Worries About Life Skills, addresses participants' consistent worries about financial decision-making and how they would manage decision-making in the future as they and their family carers got older, while also detailing the steps they took to remedy these worries.

6.4.1.2.1 Barriers and Inhibitors

Participants were reluctant to speak openly about any negative experiences they had with decision-making, either at home or within their service. When asked if they had ever been prevented by carers from making decisions, most were unsure. Family carers were more likely to directly veto or prevent certain decisions being made, but this was often presented in a manner that underscored why the family carer was correct in their assessment of the situation, in a continuation of participants' viewing of family carers as a source of authority.

> *"INT: Okay so your mam convinced you not to do it then?*
>
> *P4[ID]: Yeah she did yeah.*
>
> *INT: Okay. And how did you feel about that?*
>
> *P4[ID]: I wasn't, what d'ya call it, I wasn't I was a little bit sad but in a few minutes I was okay about it because I understood what she meant. Yeah I just didn't realise at the time you know it took me a few minutes to just get- or not to get, you see my bearings yeah (INT: Okay), yeah."*

This pattern of changing their view of a situation to reflect that of family carers was seen among other participants, such as in P1's discussion of her initial desire to meet a man she had been talking to online, until her mother directly prevented her from doing so. She was also quick to point out that her mother was right to oppose this decision.

> *"Well one day someone text me phone and mam says- someone was ringing and she said you're not allowed to ring him and I said why amn't I not allowed to meet him mammy. Well you don't know who he is or nothing, I actually- and I said well I want to meet him and mammy said you don't know who he is he's a complete stranger and I was advised not to talk to strangers which I don't do anymore. I had an issue about it." [P1, ID]*

Barriers to decisional support regarding professional carers were distinct from those relating to family carers, and often took the form of more practical issues, such as a high rate of staff turnover, as professional carers were moved to new positions or left the service entirely. This created a sense of upheaval for participants, who commented that they found it hard to have to get to know a new keyworker every few months. These practical barriers to decision-making also occasionally took the form of physical or social factors. For example, one participant who was a wheelchair user spoke about being prevented from making decisions about where she wanted to go due to lack of accessible transportation, which was a source of frustration for her.

> *"Eh, very frustrating, yeah. Extremely frustrating. Because like the staff would ask us what do you want to do today? But the only thing we could do is go around our local town without- because like with taxis I've to book when I've to go places, book when I want to come back. And the same with the train. I have to organise to get there and the time I want to come back at so they can- so they have the ramp." [P11, ID]*

Similarly, participants who lived in residential houses with multiple occupants also mentioned that they were regularly impeded in making decisions about what they wanted to do because everyone in their household wanted to do different things, leading to disagreement. Similarly, it was mentioned that occasionally staff would not listen when participants did not want to join in with certain activities. Both scenarios led participants to feel that they had been forced into doing activities they would have preferred to avoid.

> *"Sometimes [other residents] wouldn't be a help because I want to go somewhere different." [P5, ID]*

Participants were generally quick to dismiss any suggestion that the barriers to decision-making they encountered made them overly unhappy, asserting that they were merely part of life, and were rarely willing to expand on how they made them feel.

> *Well it's when the staff got moved, but that happens in [SERVICE] unfortunately when they move staff around. And my parents were-I don't think my parents weren't happy with that but they were fine about it. It was a bit new to them. Like when [STAFF MEMBER] got moved and [STAFF MEMBER] got moved. But these things happen (P9: They do)." [P8, ID]*

6.4.1.2.2 Worries about Life Skills

Participants expressed dissatisfaction with the amount of help they required from caregivers to carry out decisions relating to certain life skills, as they appeared to feel they were something they should be managing independently. Money management was a common struggle for participants, who frequently mentioned that when shopping they found it difficult to understand prices, count out the money required to make a purchase, or ensure they had been given the correct change at the end of the transaction, occasionally causing friction with retail staff who did not understand their support needs. They commented that they preferred to have a professional or family carer present for these interactions, although they stressed that they dictated the extent of the assistance.

> *"I always ask one of the staff- my purse, and I give them permission to get the right change or the right notes out of it. I give them permission to do it. Yeah, yeah." [P4, ID]*

This desire for independence was even more evident when participants discussed their long-term financial goals. Although professional and family carers often helped them to organise their finances and keep track of their savings, knowing how to budget independently and having a plan for their own future financial matters appeared to be viewed as an important signifier of adulthood.

> *"Well we're adults so, we have to decide what we want to do, where we want to go on holidays, we have to start budgeting. Budget is really important, put a bit away every week." [P1, ID]*

As part of budgetary planning, participants often mentioned wanting to save money for larger purchases such as buying a car, or to pay their rent, in order to assert their independence. For one participant, this was often a source of anxiety, as she felt that she could not afford to spend her money on recreational activities due to a fear that she would not have enough for her bills, despite the reassurances of residential staff. She appeared to view this as interference and was displeased by what she felt were attempts to "force" her to participate in activities that she felt were financially unwise for her.

> *"...And they say but you have enough [P1], you can go and I said I didn't want to go, but they force ya I said- no this is okay I don't want to go. And then they say it's okay [P1] you don't have to go it's all sorted but you have money." [P1, ID]*

In conjunction with this, participants frequently expressed a more general worry that they relied too much on carers, particularly parents, for assistance in making decisions about their lives and wondered how they would be able to decide where to live or what to do when their parents were no longer living. All participants appeared to be acutely conscious of the fragility of their support system due to factors such as familial mortality and frequent staff turnover. This was a source of discomfort and was discussed in terms of their need to have a plan for how to manage their own lives to the greatest extent possible.

> *"P1 [ID]: I'm an adult so I have to decide to move out and be independent, because what happens if I don't have a mammy anymore and I want- touch wood not for a while but- I have to know what's going to be next to me- but I started early I started going picking up my own money and because, em, they're not always going to be around in years to come, I have to start moving out.*
>
> *P5 [ID]: It's not easy*
>
> *P1 [ID]: No it's not easy, but we're adults, we have to decide what's best."*

Although it was clear throughout both focus groups that participants valued and often enjoyed being supported in their decision-making by professional and family carers, all were determined to develop independent decision-making skills and sought out methods to facilitate this. This was reflected in their enthusiasm regarding the ADMA, although only one participant said they had heard about it prior to the focus groups. However, once its purpose was explained to the rest of the participants, they were happy to learn that their right to dictate their level of support in the decisional process was now enshrined in statute. One participant expressed that he was glad Ireland was moving forward in this way, as he recalled the restrictive care practices that used to be commonplace.

> *"So like years ago, people with disabilities used to be locked up and stuff (INT: Yes) but thank god things have changed." [P8, ID]*

During discussion of the ADMA, participants spoke about the ways they learned how to do things on their own. Enthusiasm for discovering new methods to assert their independence and participate in the wider community spoke to participants' determination to overcome their concerns regarding their reliance on others for support.

> *"Not really but I'd try it out. But if I don't like it, I don't have to do it (INT: Exactly), but it's something I haven't, something I haven't- what's it called, something that we didn't do, or something that we've never done before is something that I'd like the help out in a bank. Something to try. But if I don't like it I don't have to do it, and stick with the supermarket." [P8, ID]*

6.4.2 Family Carers

Ten family members of adults with intellectual disabilities participated across two focus group sessions (8 females, 2 males). All participants were parents of the person with intellectual disability they were caring for. Three main themes and four subthemes were identified: Factors Influencing Support (Knowing the Person, An Extended Support Circle), Barriers to Support (Conflict with Services, Relinquishing Control), and Searching for Solutions.

Table 6: Demographic Information for Family Carer Participants

ID	Gender	Age	Type of Service Accessed	Level of Intellectual Disability of Supported Person	Relationship to Supported Person
P13	Female	66	Day Service	Borderline to mild	Mother
P14	Female	80s	Day Service	Mild to Moderate	Mother
P15	Female	40s	Day Service	Severe to profound	Mother
P16	Female	65	Day service	Mild to Moderate	Mother
P17	Female	60s	Day Service	Severe to profound	Mother
P18	Female	55	Day Service	Severe to profound	Mother
P19	Male	78	Residential Service	Severe to profound	Father
P20	Male	64	Residential Service	Mild to Moderate	Father
P21	Female	71	Residential Service	Mild to Moderate	Mother
P22	Female	64	Day Service	Mild to Moderate	Mother

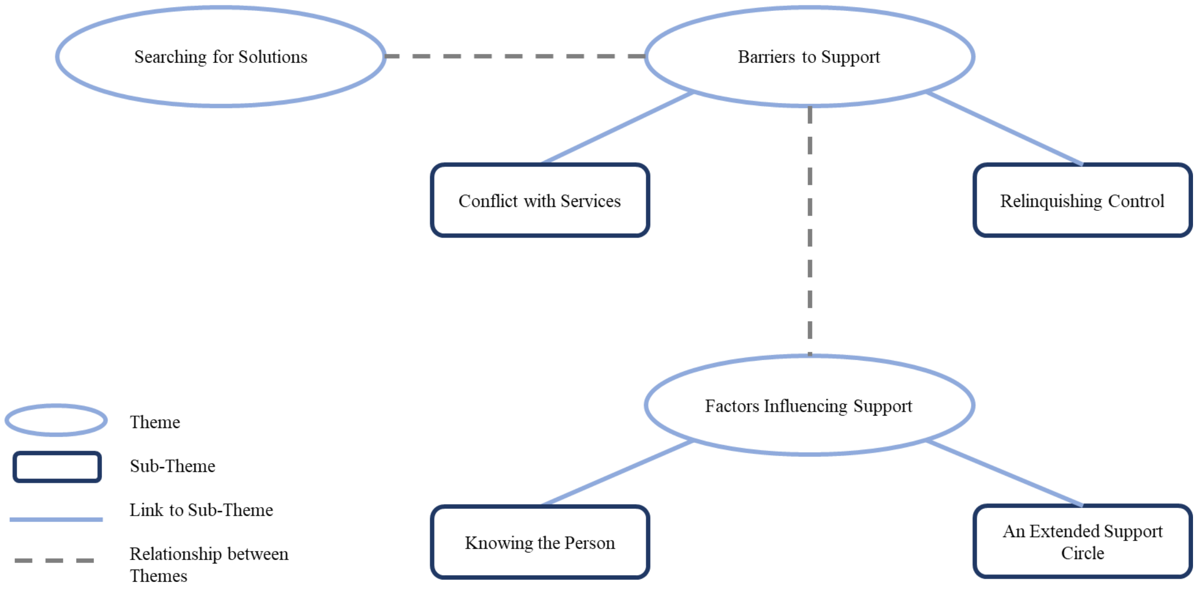


Figure 3: The Relationship Between Themes for Family Carers

6.4.2.1 Factors Influencing Support

This theme relates to the factors participants considered to be most important in supporting adults with intellectual disabilities in decision-making. Subtheme one, Knowing the Person, discussed the value of their intimate knowledge of their relation with intellectual disability, their personality, likes and dislikes, and preferences for receiving information, and how these factors informed the support they provided in decision-making. Subtheme two, An Extended Support Circle, addressed the involvement of others such as extended family and peers in providing the person with intellectual disability with the support they needed in day-to-day life, though not necessarily in decision-making, along with how this in turn led participants to develop their own support systems with other carers.

6.4.2.1.1 Knowing the Person

Participants stressed repeatedly that during decision-making, their knowledge of the person meant they could interpret body language, facial cues and vocal expressions to gain insight into how they really felt about certain topics and choices in a way that those less familiar with the person could not. These interpretations were informed by factors such as knowing what the person's usual preferred routine or interests were, or how they might express disinterest or disinclination in a particular course of action in way that a person less familiar with them might interpret as consent. Participants felt this gave them unique insight into the person, and made them their best source of support, particularly in comparison with professional carers.

> *"Yeah, it's her first thing, she'll always say Yep. But it doesn't mean yeah. And you would guess, you know what I mean- so down in, in [SERVICE] if- if they asked her some- "but she said Yeah, and- and then she didn't do anything" I'd say she said yeah, because it's just her way of saying "you're asking me something now, don't know what you're saying to me and yeah will get rid of you, end of."' [P13, FC]*

These insights were frequently communicated to professional carers by participants in an attempt to improve communication between the service and home, as most participants felt that such nuances were not considered. Participants seemed to find this frustrating, as it appeared to result in them having to work harder to understand what activity their loved one wished to participate in and help them to plan for it. For example, one participant described asking her daughter's disability service to write down any trips or planned outings in a diary that she could read when her loved one came home, because her daughter would frequently forget to tell her about these trips.

> *"I have to actually check the bag and say did you get a note from work and "well, I think I might have!" And it's either in the bag, which has sometimes happened, or it's lost somewhere up there. So I'd actually have to say to the girls "girls, if you are writing down what you're doing and [DAUGHTER] writes it down, make sure she puts the thing into the bag" as well because it's not important to her. Somebody will- she got this bus. That will happen, but how it happened? That's not her problem. So you know what I'm saying?" [P13, FC]*

Participants also felt that their unique insight into the person meant they were better able to expand their loved ones' horizons and ensure they had a variety of activities in their lives than professional carers. Some discussed how they motivated their loved one to take certain courses of action they felt were important by including an activity that they knew they particularly enjoyed. Some participants also retained their loved ones' interest during visits to town by incorporating pockets of independence into them. Others expressed incredulity or uncertainty regarding what these participants "allowed" their loved one to do, however - these were frequently the parents of an adult with intellectual disability who had higher support needs or comorbid physical disabilities. It appeared, therefore, that the degree of support offered varied among family carers, and was often dictated by their own sense of comfort and belief in their loved ones' ability to carry out certain decisions and tasks.

> *"P13 [FC]: And she would do that, yeah. Yeah. But in town now she knows [HOME TOWN] inside out. Now having said that, I'd always say check your*

> *phone [P17: Oh she can use phones?] Is the battery working? Because she'd go off for maybe half an hour and you'd be saying where is she and she won't answer the phone.*
>
> *P16 [FC]: Oh God you'd be worried then!*
>
> *P13 [FC]: And you'd have to be saying stay in [STREET] now [DAUGHTER], don't go over to Tesco's?"*

In this manner, although participants were confident that they were the best source of decision-making support for the adult with intellectual disability, this support appeared to be contingent upon what they perceived as most appropriate for their loved one, whose ability to retain information and make correct judgements they frequently questioned. The conditional nature of their support appeared to be rooted in deep concern and affection for the person, however, and participants frequently attempted to encourage courses of action that they felt would benefit their loved one, both physically and emotionally, so that they could live the life they wanted in good health and comfort.

> *"She would love to go to a restaurant. But if you said would you like to go for a walk, and if the weather was a bit windy but you still thought it was good for her- you would have to get around em, oh, you'd have to tell her there's some plan at the end of it. You must walk first! And then we go to the restaurant. So a bit of encouragement is needed to get to the end result." [P21, FC]*

6.4.2.2 An Extended Support Circle

In addition to providing support to their loved one themselves, participants spoke about how they valued and relied upon the support of others in order to ensure their loved one could live life the way they wanted. Most participants expressed concern about what would happen when they were no longer able to support their loved one to the extent they currently could and were particularly worried about what would happen after they had passed away. In this manner, extended family members were seen as having an important role to play in ensuring the person with intellectual disability could continue to live as they were currently living once participants had passed, without the undue distress they felt supporters who were less familiar with their needs and preferences would cause. They were concerned that upon their passing, these less familiar supporters could make decisions on behalf of the person with intellectual disability that would remove them from their current support system. In order to further mitigate this feared outcome, they were anxious for extended family to become established parts of their loved ones' routine before they would have to assume the role of their primary decision-making supporter to ensure they understood what their loved one would need and what their support would involve. This preselection of future supporters was seen by all participants as a decision that they needed to make in present time in order to ensure a smooth transition once they were gone. However, despite the practical, matter-of-fact tone in which it was discussed, this appeared to be a source of great concern for participants.

> *"P16 [FC]: Like in in the decision making, I think we all we all know, like if I drop dead...could be next week, could be 10 years-*
>
> *P17 [FC]: Ah you'll go on forever!*
>
> *P16 [FC]: Oh nobody goes on forever! But you know that this son or the daughter, the sister or brother that's said to me, they're going to take care of, [DAUGHTER], they should be doing that- they should be brought in now if they're available even once a year."*

In this manner, it can be seen that support for participants and for their loved one was intertwined. For the person with intellectual disability, extended family members provided variety in familial support and interaction, and were a source of community participation outside of the immediate family home. For participants, on the other hand, extended familial support was a source of relief from their care duties, and a way of securing future stability for their loved one, should they themselves become infirm or pass away.

6.4.2.2 Barriers to Support

This theme relates to the barriers and inhibitors to participants' ability to provide decisional support to their loved one described in the focus group sessions. Subtheme one, Conflict with Services, addressed how clashes with services and professional carers were common and included disagreements over appropriate support methods, lack of available resources, and professional carers' encouragement of decisions that participants felt were unsuitable. Subtheme two, Relinquishing Control, discussed how participants also struggled with letting go in decision-making, and often felt conflicted over what decisions they believed their loved one was capable of making, despite acknowledging that they were adults and needed to be treated as such during the decision-making process.

6.4.2.2.1 Conflict with Services

Clashes with services took many forms for participants. Some were due to external factors, such as a lack of available resources, which frequently resulted in participants' loved ones being unable to access needed services such as medical specialists or respite care. This meant that participants were unable to ensure their loved ones' physical comfort at times, as medical conditions went untreated, or they were unable to spend time outside of their home with their peers. Participants' own mental health appeared to be affected as a result, as they frequently stressed their own feelings of anxiety and guilt due to being unable to ensure their loved ones' continued wellbeing. Lack of access to respite care in particular was viewed as a significant stressor, as some participants did not have any other sources of relief from caring, leading to carer burnout and overwork.

> *“I went to that because I wanted to see what the story was with- do you know with respite, that’s what I asked? And sure, [SERVICE LEADER] said then you know there won’t be anything coming up before Christmas. It'll be after Christmas, but like, that's when- when he goes away, that's when I have a bit of a break.” [P15, FC]*

Linked to this was frustration with poor communication between services. Participants reported having to relay the same information repeatedly to professional carers, as previous reports did not appear to be passed along. This was often due to certain policies, including General Data Protection Regulation (GDPR). Participants seemed to view these policies with derision, and implied that services were quick to hide behind them in order to avoid taking responsibility for the lack of continuity of information. This inconsistency within services often extended to frequent staff turnover. Participants reported that they found this jarring and were often irritated by constantly having to repeat themselves to new staff members. Furthermore, there was a sense of anxiety and mistrust among participants when discussing new professional carers, as they seemed to be uncertain about whether the new person would be “a good one” or someone they would find themselves frequently at odds with during the support process.

> *“P21 [FC]: But I thought there was a database on- on special needs?*
>
> *P22 [FC]: Well if there is for my son it didn't come with him and that was GDP [sic] I was told. And when the new person came in I told them again and they'd say well don't know anything about that because GDP-*
>
> *P21 [FC]: That sounds frustrating!”*

For participants whose loved ones were in residential care, this frustration also extended to disagreements over decisions made regarding health and safety policies. Often, residential carers were not allowed to help residents with certain personal hygiene tasks their loved ones found difficult to manage independently, as the health and safety policy of the service precluded it, which occasionally meant they remained undone until participants brought their loved one to the family home for a visit, or that the decision was made by professional carers that the person must learn to do the task on their own, despite familial belief that this was unrealistic. Much like GDPR, participants appeared to feel these decisions were an excuse to avoid doing certain tasks. Those who availed of home help took a different view, however, and cited it as an unfortunate aspect of service bureaucracy.

> *"P21 [FC]: …and I would say to staff why didn't you cut [DAUGHTER]'s nails? Oh health and safety! Health and safety is used a LOT. But they bring her to-*
>
> *P18 [FC]: But I think they actually are not allowed to do things like that now like cut nails and so on, the healthcare assistants that come into the house in the morning to help with [SON]'s showers because- he's a man now and it's just me- they're not allowed to cut nails, I have to do that myself and you have to pick your moments!"*

In this manner, differences in support appeared to be dictated by the type of service participants had access to, although certain aspects seemed to be universal, such as issues regarding the passing of information pertaining to the person with intellectual disability from one professional carer to another. All participants agreed that no service seemed to be adequately prepared to provide one-to-one support for their loved one, and there was a general consensus that this perceived generic approach to care was detrimental to their loved one’s overall well-being, as it led to them having fewer options regarding what activities they would like to participate in, or a lack of ability to facilitate certain decisions.

“If I could come back to resources there. In my own case with [DAUGHTER]. She shares the house with somebody, actually the house is really divided. So there's like two parts, yeah. And eh, which I only realised they share transport. So if the other person is out and the car is not there, then [DAUGHTER] is restricted then. Do you understand? So that's resources in a sense. And what can you do about that?” [P19, FC]

6.4.2.2.2 Relinquishing Control

Although they acknowledged regularly throughout the sessions that their loved one was an adult who had preferences, wants, and goals that they wished to achieve, participants often struggled to relinquish control of their decisions. All participants frequently appeared to feel that professional carers had a habit of overestimating their loved ones’ ability to decide upon certain courses of action for themselves, contributing to unrealistic expectations or unsafe outcomes. For example, one participant whose daughter lived in a residential house described being unable to find her electric toothbrush, as he wanted to help her to brush her teeth. He was subsequently informed that a decision had been made that she would now be brushing them herself manually, which he did not believe she was sufficiently capable of doing.

> *“Now that to me showed they didn't know [DAUGHTER]. If they thought [DAUGHTER] was going to be able to brush her teeth and know what she's doing, not just put a brush up to her mouth but know what the purpose of that is? That- that was terrible to suddenly dawn on me. They don't understand [DAUGHTER].” [P19, FC]*

Those who used a day service felt professional carers’ overestimation of abilities manifested in their loved one seeking to participate in outings and activities that participants felt were unwise or unsuitable. This often resulted in conflict between them and their loved one, who would react negatively to participants’ attempts to dissuade them. They commented that they thought staff needed to exercise better judgement and avoid discussing certain plans or activities in front of clients if it would not be suitable for them. However, participants were unable to say how this suitability could be determined. They seemed to feel that professional carers lacked common sense in this area and should be able to foresee the same outcomes of certain decisions as participants themselves.

> *“P17 [FC]: Sometimes you think in [SERVICE] as well, but I think they should be able to know what's suitable without saying to them, we're all going here when you know well, it's (P16: Yeah), it's not suitable for that child, so don't be telling about it. You know, it's- you know, stop telling them they're going-*
>
> *P16 [FC]: Ah yeah, yeah.*
>
> *P17 [FC]: -somewhere when you know well it's out of their league altogether, you know, it's- it's silly!”*

In conjunction with this, participants spoke about their fear of what SDM might mean for their input in decision-making. This fear was often connected to changes in service policy, as person-centred approaches became more popular. In particular, the assertion that their loved one could choose whether or not to participate in certain activities caused much controversy. Some participants, such as in P17 and P16’s exchange above, feared that their loved one would begin to partake in every activity available, resulting in outcomes that participants did not agree with but would be unable to prevent, such as drinking or smoking. Others felt that a certain amount of encouragement was often needed to motivate people with intellectual disabilities to partake in certain activities; allowing them to decide whether or not to participate had led to a lack of organisation or social outlet. This view again appeared to stem from a mistrust of professional carers, who participants seemed to view as overly permissive in many aspects of care.

> *"I know of one parent who said I am out of my mind watching this. They can now sit on the floor and eat, there's no structure because if you say would you like to do that and they say yes they're allowed to do it, and they're kind of over 24 so you can drink a bottle of vodka- I don't know much about that so don't ask me!" [P22, FC]*

Similarly, money was frequently a source of concern for participants, and they sought to carefully manage their loved ones' financial affairs as a result. All discussed the difficulty their loved ones had in understanding the value of money, particularly in relation to knowing how much they had and how to save some of it for later. They described incidents where money was lost on days out or was spent on items participants viewed as unnecessary or excessive. The ability to tap a bank card rather than enter a PIN meant that purchases were made more easily, leading one participant to remove the tap function from her daughter's card to prevent her from going into her overdraft.

> *"But I'm a step ahead of ye on the card, I got the tap off it. Because you can tap, tap, tap up to a certain amount every day. Yeah, I think it could be gone up to since COVID- 50. Yeah. So [DAUGHTER] would tap tap, tap all day, and it'll let- it's not tapping that's the problem, it's that you go overdrawn. It will allow you go overdrawn up to €50. So [DAUGHTER] has to put in the number." [P13, FC]*

Ultimately, participants' concern surrounding control of decisions came from a scepticism and uncertainty that their loved one was truly capable of deciding things for themselves, and a mistrust of professional carers' ability to support the person as effectively as participants themselves could. They all worried about their loved one being taken advantage of, running out of money, or being hurt or disappointed by trying to do something that participants knew they would be unable to manage. The consensus was that SDM, and by extension the ADMA, needed to be employed with caution and an understanding of the person's limitations. All participants worried that it would mean their loved one could decide to do anything they wished, no matter how unwise, and that they as family members would have no right to step in. They strongly felt they should be actively involved and consulted in all decision-making to prevent unsuitable outcomes, and that professional carers should be asking them to do this.

> *"P16 [FC]: It's like what [P13] said, [DAUGHTER] decides to go somewhere, if she decides herself she'll sign the form there and then she's gone and that's it, you know?*
>
> *P13 [FC]: Well, I think it's like it has to be done in conjunction with parent or guardian and maybe the professionals giving- giving us a hand and on a more official, you know more?"*

6.4.3 Professional Carers: Supervisory Staff

Eleven supervisory staff participated across the two focus group sessions (10 females, 1 male). Two main themes and five subthemes were identified: Methods of Support (A Collaborative Support Circle, A Flexible Approach), and Challenges and Barriers (Navigating Grey Areas, Family Dynamics, Organisational Issues).

Table 7: Demographic Information for Supervisory Staff Participants

ID	Gender	Age	Job Title	Client Intellectual Disability Level
P23	Female	50	Service Manager	Mild to moderate
P24	Female	32	Programme Supervisor	Mild to moderate
P25	Female	31	Programme Supervisor	Mild to moderate
P26	Female	33	Programme Supervisor	Mild to moderate
P27	Female	34	Programme Supervisor	Mild to moderate
P28	Female	40	Supervisor	Mild to moderate
P29	Female	41	Local Service Leader	Mild to moderate
P30	Female	48	Local Service Leader	Mild to moderate
P31	Female	56	Local Service Leader	Moderate to severe
P32	Male	31	Local Service Leader	Mild to moderate
P33	Female	49	Local Service Leader	Mild to moderate

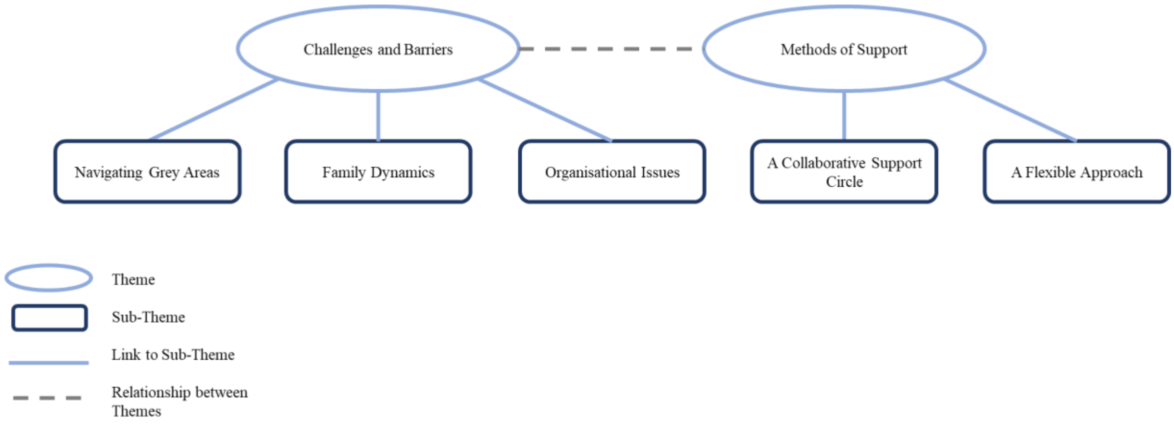


Figure 4: The Relationship Between Themes for Supervisory Staff Participants

6.4.3.1 Methods of Support

This theme details the methods employed by supervisory staff when supporting clients to make decisions and included two subthemes. Subtheme one, A Collaborative Support Circle, included ensuring there were a wide variety of supporters available to the person, whether it was family, frontline staff, themselves, or more specialised experts, providing the person with a selection of voices and perspectives to draw from when navigating decision-making. Subtheme two, A Flexible Approach, discussed taking a flexible approach to support by taking into account the personal abilities, preferences, and cultural and social context of the person during the decision-making process.

6.4.3.1.1 A Collaborative Support Circle

When supporting clients to make decisions, supervisory staff wanted to ensure they had access to more than one perspective. They noted that clients would often consult more than one person when they were attempting to decide something, and that often by the time the issue reached them, they could reinforce what the client may have already been told or give an alternative perspective, depending on what the situation required. Participants appeared to view it as an opportunity to access support for themselves also, as they could consult with the other members of the support circle and establish what they might all have been told by the client, as well as any aspects of concern or feelings surrounding the decision that the client may not have shared personally with them.

> *"Like I get a couple of phone calls a week from other or colleagues of mine would have the same calls and we would be in meetings and I would give advice or whatever and they would go oh yeah, [NAME] told me that would be a good idea as well!" [P27, SS]*

Participants regularly stated that it was as important for them to work with family carers as it was with the clients themselves, as they played a large role in the outcome of decisions, especially in day service clients. This often manifested in clear attempts to respect and include families during decisional processes and appeared to stem from wanting to avoid alienating or unduly stressing the family, as well as a desire to collaborate.

> *"And you don't want to be badgering them either, like this family I'm talking about have such a great relationship, an absolutely brilliant relationship. And they've come on a lot over the years because they were very- ah I won't go into*

> *that, but you don't want to be annoying them. They feel they're doing the very best that they can for their- son or daughter, and you kinda think sometimes that you just have to sit with it and not put a stop to it."[P33, SS]*

Participants stated that clients' quality of life could be maintained through a tailored approach to support. One participant gave the example of a client who was feeling overwhelmed by having so many decisions to make and was struggling to make even the smallest decisions. His anxiety surrounding decision-making was beginning to affect his quality of life. The participant helped to resolve this through engaging with the client's family and other support staff and helping him to make a plan each month for what he would like to do. The client's mental health improved as a result, and he felt less anxious.

> *"I suppose it can- SDM can help the people we support to live their life. Like the person earlier where decisions were causing him so much anxiety with making decisions in his life that he has people in his life, like a circle of support so his family, staff, profes- like professionals to help him make these choices because he will end up with a better quality of life at the end of it. So yeah." [P24, SS]*

6.4.3.1.2 A Flexible Approach

The assertion that support needed to be applied in a flexible manner was an important and frequently discussed theme throughout both sessions. Participants noted that some clients liked to talk about things aloud, while others were non-verbal and required the use of pictograms, sign language or familiarity with body language to infer their preferences. Different settings required differing approaches also; clients attending day services often had less contact with staff as they went home every day, whereas residential clients spent most of their time with staff, who were thus more involved in their daily decisions. This sometimes led to participants working in day or outreach services feeling undue pressure or concern over how they could effectively implement certain strategies or give the most comprehensive support during the decisional process, as they appeared to feel they had less power to support the client than residential staff, or even family carers, due to the limited time they had to spend with them.

> *"And we're trying to empower and encourage and to you know put a lot of things in place to support individuals in a very small timeframe, whereas you know if you're in residential this would probably be much easier to introduce because staff are with the individual 24/7." [P32, SS]*

Due to these varying levels of contact with clients, family dynamics were again considered when participants were adapting their approach to support in each disability service setting. Most discussed needing to take the family into consideration when attempting to support clients. Their approach to families was very individualised, from their way of delivering information regarding the decision to be considered, to their choice of language. Typically, however, they described how they would introduce the preferences of their client in a manner that they knew the family would be more receptive to, as they attempted to advocate for their client. This practice of "managing" family carers was present in the discussions of all supervisory staff participants, regardless of what setting they worked in. In this way, participants appeared to view themselves as a conduit between clients and their families, to ensure a smooth decisional process and prevent family carers from disapproving of a particular decision under discussion. Participants commented that some families were more open to suggestions from them than others, who would perhaps view such conversations as an attempt at interference.

> *"I think it depends on the family or the person. Because it's not a one size fits all. So how you might speak to one family or approach them is totally different*

> *to how you would approach another member. Because I- I know, I could, say I know I could curse to one family and that will make them comfortable because sometimes they think oh who do they think they are and it's a way of getting down to their level. And then there's others where I wouldn't dream of taking that approach with a different family. But it is...kind of putting the idea into their head?" [P30, SS]*

Furthermore, participants spoke of their own feelings and opinions, and how they affected the approach they chose to take with families. For example, one participant discussed how sometimes it was easy to fit in with what the family wanted because it was similar to the support approach she had intended to take herself, whereas at other times, in order to honour the client's voice and wishes, she had to explain their side to their family in much greater detail. However, all agreed that they tried to approach families in the best and most supportive manner possible to ensure their clients had their desired outcome. Overall, participants stressed that while their primary concern was for their client, supporting the entire family was also a necessary component of holistic support, as an antagonistic relationship with family carers could greatly hinder the decision-making process.

> *"All of our leadership styles are different, you know in how we approach things and getting to know your families and like you were saying earlier, it's about breaking down that formal barrier sometimes and getting a bit of banter. It's building trust you know, we're not just somebody coming in and dictating we're supporting them. While we want the end goal for the person, we want to support the family- to support the families as well and bring them on to move on, and move with the person." [P29, SS]*

6.4.3.2 Challenges and Barriers

This theme focused on the challenges and barriers to providing support in decision-making encountered by supervisory staff and included three subthemes. Subtheme one, Family Dynamics, included mediating family dynamics that might interfere with a client's ability to make their own decisions without undue influence. Subtheme two, Navigating Grey Areas, discussed the role of participants' own belief in a client's ability to handle certain decisions, or supporting decisions they themselves were unsure about. Subtheme three, Organisational Issues, addressed organisational factors that hindered their ability to support the person, such as service policies or a lack of available resources.

6.4.3.2.2 Family Dynamics

Despite attempts to include and support the family unit as a whole, participants regularly faced challenges in supporting decision-making due to clashes with family members, who often disagreed with participants on the ability of the client to make certain decisions. These situations required precise handling by participants, who felt at times that they had to exert more effort in persuading families to listen than supporting the client, leading to feelings of overwork and resentment.

> *"And it is a lot of plámásing, d'you know it is, sometimes you'd love to be like- people do say to me you're very straight- I'm not as straight as they'd like to think! Sometimes you'd love- you'd love to just take them and give them a shake and say will you wake up! But it's constant plámásing and placating and that can be wearing." [P30, SS]*

Misunderstandings surrounding financial matters were cited frequently by participants as an example of families' reluctance to view the reality of certain situations. In some cases, clients' Disability Allowance (DA) was placed in a family member's bank account rather than their own, with the client being given “pocket money” every week rather than having access to money whenever they might need it. Participants appeared to resent being placed in these positions, as it often meant that they had to resort to reporting the family to social services, which they were reluctant to do. However, they struggled to explain to some family carers that their refusal to allow the client to access their own finances could be construed as an abusive, or indeed illegal, action. One participant described a situation where a client’s brother would not help him set up a bank account because he was concerned the client would spend all his money. After many meetings, the brother agreed to set up a bank account for the client. However, the type of account set up meant that he still had full control over the client’s transactions.

> *“P31 [SS]: Yeah it does, like we have a particular case where the brother is kinda controlling the money and he decides to- because we were going on about the money and he needed money to go down town and to you know, to buy a coffee or whatever. But he set him up with a junior Revolut account which means-*
>
> *P30 [SS]: He still controls it!”*

Participants commented that they thought families seemed to view their loved ones’ need for help and guidance in decision-making as a hallmark of their inability to make decisions at all, rather than merely a different way of making decisions. Participants frequently mentioned the concept of the “eternal child” as an ever-present archetype that they were struggling to address with some family members, particularly those who were older. This often resulted in clients being less willing to do things for themselves or make certain decisions, because they were concerned their families would not approve. Furthermore, clients would then sometimes request that participants conceal information from their families, which they were unwilling to do, as they needed to maintain trust between the families and the service. This appeared to further increase the resentment and irritation often displayed by participants during these aspects of the discussion, as they were continually placed in the uncomfortable position of attempting to uphold the client's right to decide who was involved in the decision-making process, while also ensuring they did not alienate or anger the client's family.

> *"P29 [SS]: Well I suppose we could say they were so used to having decisions made for them, that that was a change, and when we were giving control back to the guys and saying no it's your decision you need to make choices in these different areas. And sometimes they're reluctant because it's like oh, well what would mammy say?*
>
> *P30 [SS]: Or don't tell mammy.*
>
> *P29 [SS]: Don't tell mammy! I want to do this but don't tell mammy. And we're like well no we can't do that we have to work with mammy! So that's a challenge in itself getting the guys to think a little bit differently."*

Ultimately, participants spoke about wanting to change their relationship with family carers and foster a stronger sense of support and community for the client, but found it difficult when it appeared as though the family carers themselves were reluctant to relinquish control and form part of a team. Although it was acknowledged that these actions were often taken out of concern, they nevertheless remained a source of frustration for participants. This difficulty with family carers appeared to be universal, regardless of what sector of disability service participants worked in. The concept of training for family carers in supporting decision-making was frequently discussed, as participants often felt that this aspect of their job could be resolved if the service itself was more willing to support them in educating families on why certain courses of action were necessary.

> *"And maybe it goes back again to the eternal child and wanting to have control of the purse strings...and then we realise okay well there's a little bit of learning here you know they're a new family so many we need to tailor our approach here to get- to navigate all the bits and pieces to advocate for the person. And that can be tough too you know after putting so much work in to advocate for the person and putting the effort in it can really be hard can't it?"[P23, SS]*

6.4.3.2.1 Navigating Grey Areas

Despite the frustration supervisory staff expressed regarding familial reluctance to concede control in decision-making, they also admitted to occasionally struggling to offer decisional support to clients due to their own concerns surrounding certain decisions. These complexities often arose when clients wanted to make decisions that were detrimental to their wellbeing such as eating unhealthy meals or snacks after being told by medical professionals to reduce their fat or salt intake. Participants wanted to honour medical advice but were unsure how to do so if the client did not want to adhere to it, causing them significant distress.

> *"But even down to people's diets like that's what we get a lot! It's like it's my choice- and I'm not anybody to be talking about other people's diets! But it's my choice, and then you have the family giving out about their weight you have a doctor saying they need this they need a, b and c, but yet it's their choice to eat what they want." [P30, SS]*

Participants acknowledged clients' right to make an unwise decision, however. They pointed out that people without an intellectual disability regularly ate food that was unhealthy and could do so unhindered. However, feeling responsible for clients under their care meant that participants were uneasy about not intervening when what they considered to be poor choices were being made. This seems to suggest that although participants continued to advocate for the right of people with intellectual disabilities to make their own decisions, they still struggled to overcome their own concerns, as well as balance their professional responsibilities regarding client safeguarding and wellbeing.

> *"But it's us putting it in place rather than it being an organisation thing. Like it's us seeing...[SIGHS], like I know that everybody's been deemed to have capacity but we all know there's people who genuinely aren't capable, and it's how we're supported round that. Because we all know people who genuinely couldn't manage their money, or genuinely- like you know, you know when you have the meetings and you say to the guys you have a choice there and it's like alarm bells, and you'd know the choice they're making is gonna be bad for them." [P30, SS]*

This desire to shield clients from making poor decisions was frequently tested by organisational policies, as participants were sometimes faced with determining how to explain certain courses of action in the support process to higher management. For example, reports were required for all clients that detailed the activities they had done each week. However, clients sometimes had no desire to take part in any of the activities suggested. Participants were unsure how to navigate these situations- the client should not be forced to participate, but the participants faced the possibility of upper management claiming they had not encouraged the client adequately. This was often dealt with by listing all of the options the client had been given, and explaining that they had refused them, which made participants uncomfortable, as they felt this was blaming the client. Overall, there appeared to be a great deal of frustration as participants across both services felt that policies failed to consider the grey areas of decisional support with clients.

> *"And you see you have that and then you have New Directions coming in and they want to see people's plans, wants to see people's timetables, wants to see what they're doing, em but the person doesn't want to do anything! And it's their choice! And it's a juggling exercise and a balancing act and how you're going to write that down. And it's not- and the person is still sitting there doing nothing." [P30, SS]*

6.4.3.2.3 Organisational Issues

This frustration with their respective organisations was often due to participants feeling that they were directly impeded in their attempts to provide support in decision-making to their clients, and felt ill-equipped to implement the incoming ADMA legislation. Furthermore, they were concerned that these new policies would impact their relationship with families as historically, the organisations had changed fundamental procedures and policies without informing family carers beforehand, with participants being faced with the unpleasant task of explaining to them why they had been changed, leading to further mistrust between them and family carers.

> *"Cos- because we'll ruin relationships that's what will happen, if we get all this training, and then all of a sudden we're asked to go out and deliver this training and either do the training with families and service users or whatever, we're gonna ruin relationships because we're going out pushing something that families know nothing about." [P32, SS]*

This was further reflected in participants' assertion that up to this point, they had received little guidance from their service regarding how they themselves should be providing support in decision-making to clients. Participants in one focus group stated their organisation had arranged a short online training programme for them when the ADMA was first introduced but had not provided any further guidance since then. In contrast, participants in the other focus group had received no training at all and were unable to clarify what their service planned to do in order to integrate the new legislation into their current procedures. Overall, this lack of guidance caused a palpable sense of annoyance and anxiety among both groups regarding organisational support.

> *"The- the subject is never discussed. We've done our training on [ONLINE PORTAL], like you do your training on the decision-making act on [ONLINE PORTAL], but as a conversation in a day to day or at meetings it's never in it. And maybe that's just because we're not as caught up as we should be and we need to just get going with it…" [P31, SS]*

Participants also felt this lack of guidance extended to how they should handle support in decision-making in their everyday dealings with clients. Paperwork became the focus of the decision-making process, with participants being required to document every step they took in supporting a client to make decisions. Participants viewed this as a measure implemented by upper management in an attempt to protect the disability service itself rather than to aid them in their support of clients, as the paper trail was the only aspect of support that was ever checked or managed. Once this was complete, they said it often felt as though the service considered the matter handled. This was again discussed with an undercurrent of fatigue and resentment.

> *"Yeah and it's unfortunate that that's what we're coming down to that the documentation is going to take over, and I know that in residential that is what's happened. Like I know when I used to be there on shift that, rightly or wrongly, if some of the lads got fed and their showers and their meds, it was a good day. Because the paperwork took over. And you know New Directions are looking for the evidence, they're looking for the evidence and they want it written down. And that's fine I understand it. But sometimes it's- it's taken time from doing stuff*

> *with the lads to encourage them. Sometimes you get tired and you put your hands up and go fine. Because you get tired. You do. [LAUGHS] Unfortunately." [P30, SS]*

In this manner, participants asserted that they often struggled to garner support from people at more senior levels within their organisations, who were happy to give advice but slow to take direct action. This extended to their requests for more formal assistance from social work or other specialised areas. Participants reported that procedures from senior management were often executed slowly and were more concerned with centring the family rather than the client themselves when the decisional process became more complex or stress-filled. Participants felt that in order for the ADMA to be effective and SDM to become more widely adopted, their organisations would need a more concrete, robust policy that allowed for flexibility.

> *"P31 [SS]: But we have a referral system so whether it's a behavioural support team or psychology, all the clinical team will sit down and decide who's gonna take them on. But it's only at the moment-*
>
> *P30 [SS]: It's fire fighting!*
>
> *P31 [SS]: -it's only done if it's urgent, you know? And if it's not urgent then it's waiting until you can get the staff to come and do it. But yeah you can pick up the phone and ring your social worker and say this has happened what do you think, and she'll give you advice. And it could be anything it could be oh that's a safeguarding issue or that's- you need to talk to someone else, or this that and the other."*

6.4.4 Professional Carers: Frontline Care Staff

Eleven frontline care staff members (3 males, 8 females) participated across two focus group sessions. Three main themes and four subthemes were identified: Methods of Support (A Needs-Based Approach, Decentring Family in Decision-Making), Challenges to Support (The Burden of Reality, Undermining the Cause), and Educating Everyone.

Table 8: Demographic Information for Frontline Care Participants

ID	Gender	Age	Job Title	Client Intellectual Disability Level
P34	Male	46	Programme Facilitator	Moderate to severe
P35	Female	27	Programme Facilitator	Moderate to severe
P36	Male	35	Programme Facilitator	Moderate to severe
P37	Female	30	Programme Facilitator	Borderline to mild
P38	Female	41	Programme Facilitator	Mild to moderate
P39	Female	28	Social Care Worker	Severe to profound
P40	Female	23	Staff Nurse	Severe to profound
P41	Female	28	Social Care Worker	Moderate to severe
P42	Female	34	Support Worker	Mild to moderate
P43	Male	42	Support Worker	Borderline to mild

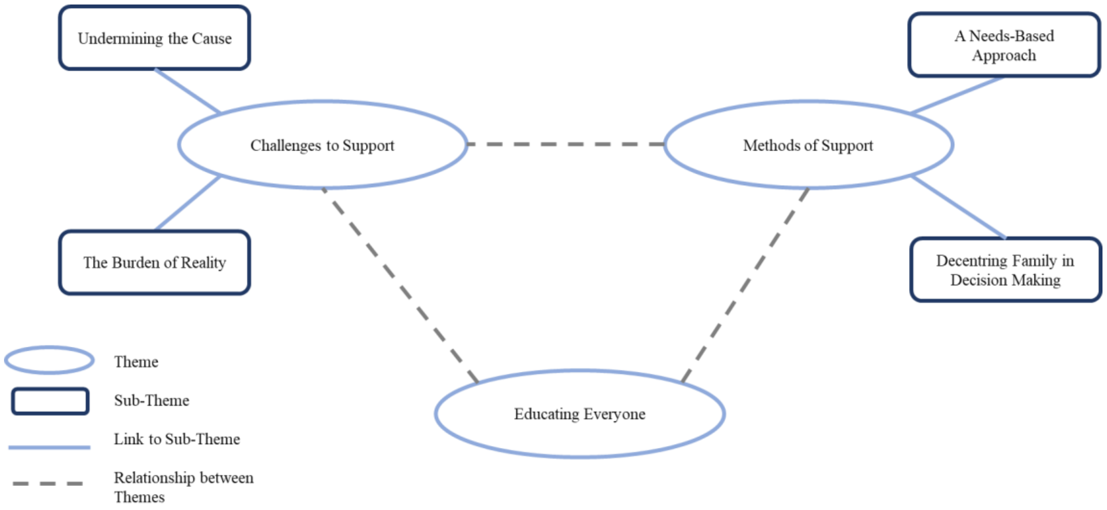


Figure 5: The Relationship Between Themes for Frontline Care Participants

6.4.4.1 Methods of Support

This theme related to the methods frontline care staff used to support their clients with intellectual disabilities. Two subthemes were identified therein. Theme one, A Needs-Based Approach, discussed centring the person to allow for a tailored approach to decision-making that took into account the client's personal preferences, background, and individual needs. Theme two, Decentring Family in Decision-Making, related to participants' attempts to decentre the wishes of the client's family during the decision-making process, while still attempting to work with them in order to help the client achieve their goals.

6.4.4.1.1 A Needs-Based Approach

Participants reported that the type and level of support they offered to clients in their decision-making was contingent upon a number of factors, including the type of service the client attended, their level of physical ability, their preferred method of communication, and the level of support they required to enact decisions. Person-Centred Plans (PCP) were an important first step employed by all service types, which were drawn up alongside the client and regularly reviewed at meetings during which short-, medium- and long-term goals were set. Other attendees at these meetings were chosen by the client. This aspect of support was provided by all participants, regardless of which setting they worked in.

> *"P36 [FS]: We already do PCPs, we already do family meetings, we already do- they invite who they want to the PCPs, whether they want the mother, father, cousin-*
>
> *P34 [FS]: Different staff members-*
>
> *P36 [FS]: Yeah it's all person-centred and they control the environment."*

These plans were then tailored to the specific needs of the clients themselves, which often varied according to the type of service they were engaged with. For example, participants working in day services described having clients who would become overwhelmed if they were presented with too many options when deciding on a course of action. Staff would then draw upon their existing knowledge of the person and present them with a pared down list of options consisting of activities or choices that the person had indicated they enjoyed in the past. This allowed the client to still make the necessary decision, but in a manner that lessened their anxiety.

> *"Yeah the only part of the thing with planners where we'd step in is if there was- if someone struggled with decision-making and having too many choices? So then we'd give a smaller amount of choices." [P35, FS]*

This method was also employed by participants working in residential services. For them, clients often wanted to make decisions that could potentially end poorly for the person, particularly regarding food, personal health or hygiene. Participants would offer an alternative route which would still allow the client to make the original decision, but in a manner that would not compromise their health or safety. One participant gave the following example of a client buying five bags of peanuts and wanting to eat them all in one sitting.

> *"...I suppose it's just about trying to give them alternative ways to have all five bags but not in the one sitting. Even though that's probably what they DO want. And like that, offering to get a bottle of coke, like a bag of peanuts and a bottle of coke. And maybe you could come back tomorrow and get another packet em...at the end of the day you're not wanting them to get sick or make bad choices with health, you're trying to advocate for good decision-making, you're*

> *trying to advocate for good outcomes for them in their decisions. Does that make sense?" [P39, FS]*

Participants from residential services often worked with clients with higher support needs, and frequently had to adhere to restrictive practices (a protocol put in place for some clients who had certain restrictions placed on their behaviour by the service out of concern for their safety) with clients who had a history of self-injurious behaviour (SIB) in the event of an adverse outcome to a decision.

> *"And we have options so he can swap cos he has restrictive practice around his clothing because it can cause certain behaviours. So we would deal with a lot of behaviours, like self-injurious behaviours that kind of thing, so it wouldn't be a case that it affects other people it only affects themselves. So it would kind of be the case that if they can't communicate and they can't describe to you what they want then they end up injuring themselves. So that's what we would have to deal with more often." [P42, FS]*

Conversely, outreach staff often worked with clients who lived in their own accommodation out in the community and were making many decisions independently. In these cases, participants reported that they would do their best to explain to the client that the outcome of their decision would be undesirable; if the client refused to heed this advice, participants would not intervene any further, instead ensuring they were available to support the client as they navigated the consequences.

> *"We would inform them of the risks of what might happen or whatever, but at the end of the day if they make that decision em to go ahead with something we would be there to support them as best we could." [P43, FS]*

6.4.4.1.2 Decentring Family in Decision-Making

Participants in day and residential settings often reported that in order to support the decision-making of clients effectively, they had to work to ensure the client remained at the centre of the decision-making process, rather than being usurped by their family. Participants had varying views on the motivation behind the observed intervening, but many felt it largely boiled down to family members fundamentally disagreeing with the client's decision or even feeling somewhat inconvenienced by it.

> *"P34 [FS]: Yeah d'you know we've had that on a couple of occasions where the decision being made is being made by the family for the family not for the person who's-....*
>
> *P36 [FS]: Or they might make a decision then the family might try to take that decision away from them [P34: Yeah], because it doesn't suit [P34: It doesn't suit] them like it could be a financial block or a- something might have to be paid for, or other reasons."*

However, other participants commented that they felt it was more about family carers' own fears regarding certain decisions. Family members were anxious that the client would not be hurt or upset, and tended to have more conservative views on which decisions or activities could result in this outcome. During a conversation about family carers being reluctant to change the address for medical appointment letters to the residential home, two participants commented that a key method they employed to address this was to remind the family that if the client did not have an intellectual disability, they would likely not be living at home and would be making their own decisions at this point in their lives. This was seen as a method of contextualising the perceived impracticality of preventing their loved one from receiving their own post in their current residence.

> *“P40 [FS]: It's nearly like control-*
>
> *P39 [FS]: Yeah just like let go. And I always try to reference it back to like if she wasn't-*
>
> *P40 [FS]: If they were verbally able to say I want to change my address it would be that bit easier-*
>
> *P39 [FS]: Yeah like if she didn't have an intellectual disability, she'd be in college and they might be living with their girlfriend or boyfriend, would you be saying no to them then?”*

The issue of family control was often raised in the context of more significant decisions, such as financial matters. Participants discussed families who were worried about their loved one losing their money or being unable to save adequately, often resulting in clients’ Disability Allowance (DA) being put in a family member’s bank account rather than in their own. This appeared to be more common for clients with higher support needs, as noted by P38, who had recently moved to a day service, having previously worked in an outreach setting.

> *“So you'd find that, like I worked in an area where they'd be very independent, and even in that area when setting up people's DA to go into their bank account I found awful resistance, but I kept going with it because they had no legal right to say what this person could do with their money, the area I'm in now I feel like I'm starting all over again. Because people are getting their DA and it's going straight into their parents' bank accounts!” [P38, FS]*

Participants were hopeful that the incoming ADMA would become a tool they could use when attempting to decentre family members from the decision-making process. An example was given by one participant of a client who often preferred to spend time in his bedroom alone and listen to music, while his mother disapproved of this and wanted him to go to the local centre and participate in activities. The participant felt the ADMA could serve to reinforce her attempts to explain that they could not force the client to attend activities if he did not want to. In this manner, participants seemed more invested in how the ADMA could be used to justify certain actions they felt they needed to take rather than what they felt it could do for the clients themselves.

> *"We were kind of stuck with he wants to sit and listen to music and mammy wants him to go out. So we were kind of stuck because we can't force him into a car. So it's kind of since the Act has come in we're a bit more conscious of that and more aware of it." [P41, FS]*

Other participants agreed with this and felt that the AMDA would serve as form of back up for them during difficult decisional processes, ensuring their clients could carry out their wishes while preventing family carers from viewing this as professional carer interference. They also felt it could be a step in the right direction for family members to change how they supported their loved ones' decision-making and gain a better understanding of why professional carers adopted particular approaches. Participants seemed to feel that their explanations alone were not enough for family carers, and viewed the ADMA as a legal push for families to take this aspect of professional care more seriously.

> *"And it's nice for them to know what's happening in [SERVICE] and in other services like if there is new policies- I mean I'm sure there is a newsletter that goes out to them but it would be nice for them to be kept informed." [P39, FS]*

Ultimately, participants saw families as a frequent obstacle to the decision-making of adults with intellectual disabilities, largely due to the fostering of dependent practices. Many observed that clients were not encouraged to do things independently at home. It was implied that there was an element of learned helplessness in clients’ apparent inability to make certain decisions at times, and that this had been encouraged, often unconsciously, by family carers out of love and a desire to protect the person. In this manner, participants felt that although family carers had played an important role in their loved ones’ development and needed to be part of the decision-making process, it should be in a less centralised manner to allow clients to live as independently as possible.

> *“Or, the other side of it is it's a lot easier at home because mammy will do everything like. And that's a huge thing because you'll find we've an awful lot of members come into us and like- spoiled rotten like! Like we went away to [COUNTRY] last week but before that we would have gone away lots last year, and parents would be getting quite stressed coming in and saying oh they need help washing their hair and all this kind of stuff and like- 90% of the time they wouldn't actually need it!” [P35, FS]*

6.4.4.2 Challenges to Support

This theme addresses the challenges and barriers participants faced when supporting clients to make decisions. Two subthemes were identified; the Burden of Reality, which focused on having to navigate situations where the decisions clients wanted to make were made difficult to execute due to their personal circumstances or participants’ own hesitation to support the decision in question; and Undermining the Cause, which addressed factors present in clients’ lives that undermined participants’ attempts to support their decision-making, such as bureaucratic processes within the service organisation, societal or cultural factors which did not acknowledge the concept of SDM, or conflict with family members.

Frontline care staff participants acknowledged that their own ability to support the decisions of their clients was occasionally challenged, particularly when they desired to make decisions that participants knew were simply not feasible due to issues such as policy, personal circumstances, or physical capability. For example, one participant mentioned a client who had been keen to move to a house in a particular area to live independently. However, when this move was completed, the client was immediately dissatisfied with the area and wanted to move to another city far away from their current home instead. They did not want to change services and still wanted the same supports they were currently receiving, however. This appeared to cause great frustration and distress for the participant, who seemed to feel the client viewed his attempts to explain these issues as a personal desire to control or restrict them.

> *"But she like- she's recently moved to a house with the help of the service, in [LOCAL TOWN], but she doesn't like [LOCAL TOWN] she wants to move to [CITY]. But don't we all? You know what I mean? And like we can't support her to do that, the government is not going to pay that rent. But you see what I mean, that is a regular complaint!" [P36, FS]*

Another participant described a situation where safeguarding concerns due to physical disability meant a client who wanted to walk to the shop by himself could not be permitted to do so. This led to staff walking behind the client rather than with him in an attempt to honour his decision on some level. However, the participant expressed significant discomfort with this, despite feeling it was necessary.

> *"Yeah, even like for example one of the lads wants to go to the shop by himself. But you know he physically needs support going up. That decision-making of I'm going to the shop by myself- but you physically cannot let him go because he*

> *could- he's not looking across roads correctly, or whatever so maybe you have to shadow him but you still have to be there!" [P41, FS]*

These examples suggest that participants often struggled with feeling they were contributing to client unhappiness by adhering to policy and safeguarding practices and felt guilty and conflicted about having to do so on occasion. Participants working in an outreach setting had similar concerns but fewer options to prevent unsafe practices from occurring. Clients usually lived outside of the service and the family home and were instead supported within the local community. Participants discussed the frustration they felt when clients demanded participants leave their homes after they became angry upon being told that their desired plan might need adjustment or reconsideration. Outreach participants also seemed to feel that they couldn't "win" with their clients at times, as they were quick to push participants away, but were then surprised and upset that participants could not simply return to see them at any time.

> *"You mentioned confrontation there, our confrontation would be more with the service users like! They might fight with you over snapchat or something and say get out! And they might throw you out of the house or something and then they give you a ring later on and be like what's the craic? And you're there like [MAKES CONFUSED FACE], d'you know? [LAUGHS]." [P43, FS]*

Participants in residential settings struggled with understanding how to support decisions clients wanted to make that would conflict with current restrictive practices, and were unsure how SDM and the ADMA would fit within that system. Their support of certain decisions had to be mitigated by other concerns such as whether the client had a restrictive practice in place, and how the outcome of that decision might affect other clients or staff within the residential home. This was met with incredulity by outreach participants, who felt that clients should be encouraged to experience the consequences of an unwise decision after the potential outcomes were explained to them. Outreach participants appeared somewhat sceptical of the need for restrictive practice, and expressed shock at the stories residential participants shared to demonstrate why it was necessary.

> *“P43 [FS]: D'you know what I mean like that's kind of the way [outreach] would kinda work that like, if you have- if you get 200 euro a week and you spend it all and you have nothing that's....*
>
> *P39 [FS]: But then the kitchen gets trashed-*
>
> *P41 [FS]: Oh it does!*
>
> *P39 [FS: And you've no peace then for the night and-*
>
> *P44 [FS]: Ah see we have none of that-*
>
> *P41 [FS]: Yeah but you know the plates are gone because the place is trashed, and all those clothes are in the bin because we've no cigarettes and he wanted more, and all the drawers are open and the clothes- that's where the clothes are living now because he didn't get what he wanted.”*

Similarly, another participant in residential support struggled to know what to do when a client was making a choice that was not being respected by a family member. She gave the example of a client who clearly did not want to speak to a family member who had arrived to visit, but the family member did not want to leave, despite the client refusing to come down to speak to them. Many participants observed that the ADMA might afford residential participants an opportunity to mitigate this by couching the client’s reaction in them deciding not to see that family member that day, however P39 stated that they were still left in a very uncomfortable position, as family members would be unlikely to react positively to this outcome.

> *"And it's a hard one, or the other one is one of his parents is sitting in our office and he doesn't want to know about it. And they're there like well are we- what are you getting for your takeaway tonight and you're just thinking he has no notion of talking back to you, and you don't know what to be at!" [P39, FS]*

Outreach participants described struggling to keep their own opinions and thoughts about certain decisions to themselves when they perceived clients making decisions they did not agree with, or occasionally that they did not believe clients understood, as they appeared to feel that they had less power to advise or support their clients compared to residential or day participants. Outreach participants struggled to know what to do about their clients' refusal to hear what they had to say, and appeared extremely tired and frustrated by these situations, as well as powerless to prevent an unfavourable outcome.

> *"…and you're there like "you've your interview for [UNIVERSITY] coming up, I can give you support for that? "Yeah, I kinda want to stay where I am" and I'm like [MAKES FRUSTRATED FACE], and he could get a good job out of it like but he wants to stay doing the CE scheme, and you're trying to explain to him then that's only for a year and they could cut you off and you're back at square one then. But he's not- he's just not listening." [P44, FS]*

Another participant working in a residential home sympathised with this feeling of frustration with a client's apparent lack of understanding but described a very different context. She explained that one of her clients was non-verbal and she was unsure if the client was making her own decisions or if she could do so at all, giving the example of deciding to go on holiday. She questioned whether the client was truly capable of understanding the choices they were being offered and expressed uncertainty about what she as a supporter should be doing to ensure that understanding was present, as to her, there did not seem to be a way to do this.

> *"So I suppose we'd be very different in our house where we have one who can verbally talk and say they want that and we can definitely assist them with that, whereas with the other person they can't- there's no wants, or cos they're nonverbal it's a bit different- like I'm not sure the other person would understand it's a holiday? That- you could be offering like you could say let's go to [CITY] or [CITY]? There's no meaning behind them two places I feel." [P39, FS]*

6.4.4.2.2 Undermining the Cause

Participants discussed various external factors that contributed to challenges in providing support in decision-making. Service policy was a significant issue that most participants brought up across both sessions. They felt that at times, organisational policy and procedure were a hindrance to clients' ability to make certain decisions. A frequent example given by residential staff was choosing where to live, a decision that residential clients were not usually given the opportunity to make. One participant gave the example of a new resident in the home she currently worked in, who had not been introduced to the current occupants before his arrival and had been in his previous home for over 20 years before being told he had to move due to his changing physical support needs.

> *"P42 [FS]: …The room's been done up but we haven't been informed about when they're coming, we haven't been given a handover or anything like that and we have to turn around and be like hey well we have to inform our lads that there's someone coming in, when they're coming in, what they're gonna be like, that's another part of informed decision making as well!*

> *P39 [FS]: That's a bit crazy isn't it, and so typical of the company! I mean just plonk the person in without warning like, seriously!"*

Participants also felt that service requirements to fill out extensive support paperwork, while necessary for evidence of service support practices and documentation of steps taken while supporting clients, nonetheless impeded the time they had to support the client. This led to participants strategically presenting an activity for clients that would allow them to complete this paperwork, a practice that all participants expressed guilt and frustration over as they felt it was manipulative. Participants appeared to be at a loss as to how to marry their desire to provide full holistic support with organisational requirements for paperwork completion. This was a key concern that some participants had surrounding the introduction of new policies stemming from the ADMA, as they were concerned that rather than it improving their ability to practically support clients in decision-making, it would instead result in a new kind of paper trail they would be required to complete.

> *"I think it will affect us as staff, because we will have to change every single policy and every single document everything that is attached to them, all the signals, even though we're doing it already, we're going to have to document everything, which means our lads are gonna lose out on one to one support because we're gonna be on a computer changing that information." [P42, FS]*

They also thought at times that clients were undermining themselves, as they would communicate a particular need or decision while in services, only to renege on the decision once at home. This resulted in some family carers believing that participants were seeking to influence clients to make certain choices, when they had in fact come from the client originally. This led to feelings of outrage and resentment towards clients at times, as participants felt they were quick to blame professional carers when family carers did not react well to certain decisions.

> *‘“[P38] wants me to get a job! I'm gonna live on my own! And I'm not doing that!" And then I have the parents ringing in like [MIMES ANGRY CALL], and I'm like that's not what I said! D'you know I said I'd support her in whatever she wanted blah blah. But d'you know will go home and absolutely dramatise everything that I have said and it'll be big family meeting then and, d'you know?’’ [P38, FS]*

It was observed by participants that this often stemmed from clients not being empowered while in the family home, due to family members not believing they had the capacity to make certain decisions. Clients would lose confidence in the decision after going home and seek to undo it upon their return to services. This was frustrating for participants, who felt that their hard work was being undone, but they also expressed great sympathy for clients for feeling this way, and seemed to view it as a sad reality of the job that they were uncertain how to fix.

> *“P35 [FS]: But imagine it's weighing us down like that like, imagine them being home and wanting things that they want like that? Like I know a lot of service users and they won't even express themselves like that at home-*
>
> *[MURMERS OF AGREEMENT]*
>
> *P35 [FS]: They come in here and it will all come out-*
>
> *P34 [FS]: Yeah it'll come flying out here, yeah!”*

6.4.4.3 Educating Everyone

This theme focuses on factors participants felt needed to be changed or adapted to empower clients to be able to make their own decisions under the new ADM legislation.

Participants commented regularly that in light of the ADMA, new training and education programmes would be hugely beneficial to everyone involved in the decision-making process for a person with intellectual disability. For themselves, they commented that they had yet to be given sufficient training or information on what the new law would mean for them and their work. This led to feelings of trepidation regarding how the ADMA might affect procedures that were already in place. They felt the training previously given did not take into account how procedures and support methods differed between service branches and were concerned that any new policies would be too broad for them to apply to their specific circumstances.

> *"P42 [FS]: Yeah it was way too broad the training like. There was nothing specific, and it didn't even give examples!*
>
> *P41 [FS]: Yeah that's very true!*
>
> *P42 [FS]: Like, relevant examples, like ones we're actually dealing with on a daily basis."*

> *"Yeah their cognitive ability the people who can understand and stuff. But I'm intrigued about how it's going to come out and like is it going to be broad. Like especially when [SERVICE] are going to have to bring out a policy around it. I'd say it's going to be a long time fixing it and making sure it's not suited just to local service or residential or one of those. So yeah, it's going to take time." [P39, FS]*

Regarding people with intellectual disabilities themselves, there was a prevailing opinion that they were not sufficiently prepared to make certain decisions under the current system. One participant spoke about running a course to help clients understand how to pay bills and was shocked to discover that many of them believed that there was a physical person who paid their bills for them rather than an electronic system.

> *"But like the bank is generous and just hands you 250 euro a week, d'you know their belief system, and this is not one person this is across the board, because you'll have 10 people doing this course and about 7 out of the 10 will come back with them answers." [P36, FS]*

These stories were common, especially among those working in day services, and were a source of concern for all participants regarding how they were going to equip their clients to make decisions under an ADMA-affected policy when they themselves had yet to be given sufficient training. Similar misperceptions held by clients were observed by outreach participants when discussing other important matters, such as sexual health. Outreach participants discussed the necessity of ensuring clients were educated on matters relating to sexual activity, as they often did not understand that it could result in accidental pregnancy. This was often complicated by a lack of understanding by clients regarding why certain actions had to be taken.

> *"And then from his side it was like reinforcing that if he didn't wear contraception that like, he was gonna be a father. And he was saying he wasn't ready and all this, so I said well then you're gonna have to wear them. So for him support is just teaching him how to cook meals em, just keeping on top of his apartment and going shopping. And basically going shopping we were buying him condoms like! [LAUGHS]" [P44. FS]*

However, in order for this education to take place, participants observed that family members and occasionally professional carers would have to be educated themselves in order to understand that clients had the right to make these decisions. Several examples of prevailing paternalistic opinions were given, such as people with intellectual disabilities lacking the ability to feel sexual desire. These opinions were met with incredulity, and at times, derision, by participants, who saw them as a barrier to the successful adoption of inclusive policies regarding clients’ rights to make decisions about these more complex topics.

> *“P38 [FS]: But everybody has those urges don't they? Well actually I was talking to a staff member the other day and I was talking about a lady and I was saying- and I hope nobody minds me talking like this here-*
>
> *P36 [FS]: No no you're fine!*
>
> *P38 [FS]: And I was saying do you think she's- so she'd be, and the word I'm gonna use is "jigging" on the chair, right? D'you know- and I was saying well maybe she's getting like an arousal from the chair. And the staff member looked at me like [MAKES DISGUSTED FACE] and they were like no sure she wouldn't have the cognitive ability for that!”*

Participants felt this sense of paternalism and perceived lack of education on such matters was enabled by management at times, especially with respect to family carers. Participants commented that upper management were quick to tell them to drop certain matters due to resistance from family carers out of a desire to protect the service’s own interests. Furthermore, participants felt that if the service ensured family carers were educated on and made aware of the process of incremental achievement that they employed when supporting clients to make decisions, they would be less inclined to worry that their loved one would suddenly be involved in situations they were not ready for.

> *“Because I'm not afraid of confrontation so I'd be there like sure I'll set up a family meeting and we'll talk through this and I'd be told oh leave it for a while. Because mammy or daddy might have been giving out! So leave it, d'you know, but I'm like that's not my job, my job is to advocate for this person, so what's the point? So in that sense, maybe am I- that's my experience.” [P38, FS]*

The scepticism surrounding people with intellectual disabilities’ ability to make decisions was also seen when participants assisted clients in navigating societal institutions, particularly banks. They reported that there was a prevailing notion among bank staff that people with intellectual disabilities needed medical proof of their capacity to open a bank account, despite this not being the case. This frequently resulted in the client being prevented from exercising their right to have their own account, despite expressing a clear desire to do so. Participants felt that incidents like these showed that Irish society as a whole still did not understand the concept of decisional support, and thus contributed to clients feeling they were incapable of making their own decisions or achieving certain goals.

> *“P38 [FS]: And you're standing there looking like well what are you talking about like nobody needs to cosign for this! And it's just like, you always assume capacity-*
>
> *P35 [FS]: That's what I said, cos I said no he'll be able to, and she was like oh well no just in case because you know down the line even-*
>
> *P38 [FS]: And she has no right to say that! “*

Ultimately, participants felt that unless relevant stakeholders and societal structures were educated in SDM and the ADMA, these new developments in disability care would go unused or be misunderstood. They felt that awareness of these new systems needed to begin early and did not think families, some professional carers, or the wider community were aware enough of the new approach to understand it clearly. Furthermore, under the current system, barriers to decision-making for adults with intellectual disabilities would continue to exist if a conscious effort to educate was not put in place.

> *"Yeah, I suppose if I look back on the education, like if I turn around to somebody and say what do you think of supported decision making, or assisted decision making they're gonna look at me and say what are you talking about [P34: Yeah]? The language is great for staff, and we can look at it, and look it up and find out all about it. But some of the lads I work with...it's just the language is what it is." [P39, FS]*

6.5 Discussion

The aim of this research was to explore the thoughts, opinions, and perspectives of adults with intellectual disabilities and their decision-making supporters (family carers and professional carers, frontline care staff and supervisory staff) regarding SDM and their preferences during the decision-making process. The findings show that these preferences often overlapped, indicating shared values in the decision-making process such as mutual respect, understanding, and a willingness to work together in order to facilitate the self-determination of adults with intellectual disabilities.

Adults with intellectual disabilities wanted to be in control of their own decisions, and valued supporters who listened to and respected what they had to say and were willing to help them to achieve their goals. However, they struggled with understanding how to enact their decisions at times, leading to a sense of anxiety and uncertainty. This resulted in a reliance on the judgement of their decision-making supporters over their own at times, particularly family carers, and concern regarding how they would manage decision-making once their family carers, who were often older parents, were no longer living. These findings mirror previous research indicating that adults with intellectual disabilities often desired opportunities to take control of decision-making but felt unsure of how to go about this. This uncertainty was mitigated through the availability of a wide range of supporters who were willing to work alongside them to help them make and carry out decisions (Bigby et al., 2022b; Buhagiar & Azzopardi Lane, 2022; Casey, Trayer, et al., 2023). Furthermore, the anxiety surrounding learning life skills, and concerns over how they would navigate decisions in the future when their family carers were unavailable, were noted stressors in previous research examining SDM in this cohort (Bigby et al., 2022b; Buhagiar & Azzopardi Lane, 2022; Casey, Trayer, et al., 2023).

Professional and family carers were in agreement that adults with intellectual disabilities should be given as much support as necessary during decision-making but disagreed on the extent and execution of that support. Supervisory and frontline staff felt that the person with intellectual disability needed to be supported and heard to the greatest extent possible in all circumstances, whereas family carers were often reluctant to completely centre them during certain decisions, such as those relating to healthcare, out of concern for their safety and well-being, and felt they needed to make these decisions in their stead. This struggle to balance the knowledge that the person they are supporting is an adult and therefore entitled to make decisions with their concerns over their ability to make good decisions has been noted in previous research with this cohort (Bigby et al., 2022a; Mannan et al., 2011; Werner & Chabany, 2016).

Family carers also felt that professional carers needed to be more selective in what they supported, and showed mistrust of their intentions at times, a mistrust that professional carers often returned in kind. This led to a continued thread of conflict between family carers and professional carers, with both groups often citing suspicion and frustration with the other. This conflict was present in all discussions, regardless of the type of disability service being accessed, or worked in, by participants. This suggests that the continued conflict between family and professional carers appears to be a function of two differing schools of thought with regard to support, rather than any one specific dynamic present in a particular section of disability services. Due to this, many professional carers felt they needed to act as mediators and interpreters between the client and their family at times, in an effort to ensure the client could achieve their desired goal without alienating family carers. These dynamics have been observed in previous research where professional carers were often bridges between the adult with intellectual disability and family carers during the decision-making process, and that adults with intellectual disabilities were quick to agree with family carers' views and opinions over their own (Andre-Barron et al., 2008; Bigby et al., 2011; Bigby, Whiteside, et al., 2019).

The findings relating to differences in decision-making support offered between types of disability services are notable. Participants reiterated throughout the discussions that flexibility and open-mindedness were vital components in effective decisional support and were often shaped by the circumstances in which that support was being provided. Day and outreach staff concerns regarding their ability to make a difference in the lives of their clients due to having less contact in comparison to residential staff and family carers resulted in a more reserved view of SDM, as they felt they lacked the proper space and time to implement it. Residential staff, however, felt constrained by the dynamics between clients within the residential home as they tried to balance the needs of all residents, and were more likely to discuss SDM in the context of factors they felt they had to consider beforehand, such as restrictive practices and SIB concerns. Previous research by McConkey and Collins (2010) examining the role of staff in supporting social inclusion similarly found that day service staff were more likely to focus on social inclusion and community participation but struggled to find adequate time and resources to follow through, while residential service staff were more likely to report prioritising personal hygiene and health and safety when supporting their clients (McConkey & Collins, 2010).

In the case of family carers, those whose loved ones were in residential care cited frustration with health and safety issues surrounding personal hygiene and changes to routine or plans being implemented in ways that made them feel pushed out or unheard, which echoes findings in the literature examining the relationship between family carers and residential staff (Chadwick et al., 2013; Kelly et al., 2020; Taggart et al., 2012). In contrast, though family carers who used day or outreach services also reported frustrations with professional carer execution of support and feeling left out of the decisional process, they were more likely to discuss how they regained control within the decision-making process due to the adult with intellectual disability residing with them directly. A scoping review examining factors determining family carer involvement and satisfaction with disability services complements this finding, concluding that family carer age, access to external support, and their confidence in being able to continue to support their loved one in the future determined how willing they were to engage with staff and work with them to support the person with intellectual disability (Lunsky et al., 2014).

Adults with intellectual disabilities who took part in the focus groups were less likely to make distinctions in support based upon service setting, but rather between professional and family carers. Family carers were seen as sources of comfort, familiarity, and affection, and the security they offered translated into an implicit trust of their judgement, whereas professional carers were viewed as a far more transient presence in their lives. This has been discussed in the literature, through categorising professional carer support as formal support, while that of family carers is termed natural support (Nuri et al., 2024). Other literature also echoes this somewhat through discussions of professional carer burnout and inadequate professional support within services leading to frequent turnover, which supports participant discussions of the ongoing issue of frequent staff changes affecting continuity of care relationships (Kozak et al., 2013).

Overall, it was apparent across the focus group sessions that people with intellectual disabilities, family carers and professional carers often honed in on similar aspects of everyday decision-making but from very different perspectives.

6.5.1 An Ecological Systems Perspective on Focus Group Data

Bronfenbrenner's ecological model of human development (Bronfenbrenner, 2000; Härkönen, 2001) was employed as an organising framework to synthesise the findings from each participant group and identify any commonalities and differences in their perspectives on decision-making (Bronfenbrenner, 2000; Härkönen, 2001). This model examines human development from the perspective of interlinked systems consisting of the microsystem (the relationship of the person themselves to their immediate environment), mesosystem (the interactions between two or more microsystems the person is involved in), the exosystem (environments in which the person is not actively involved in, but which affect their development), and the macrosystem (the larger cultural or societal system that the person lives in, affecting the functioning of the other systems) (Cala & Soriano, 2014). Previous research with adults with intellectual disabilities has examined the dynamics of their support systems using this model as an organising framework in order to examine the social and personal supports present in their lives (Cala & Soriano, 2014; Francis et al., 2020). The ecological nature of the model allows the researcher to place the person with intellectual disability at the centre of the support process and examine how their preferences and desires interact with their immediate support system, as well as the societal and cultural context within which that system is placed (Cala & Soriano, 2014; Francis et al., 2020; Jacobs et al., 2018).

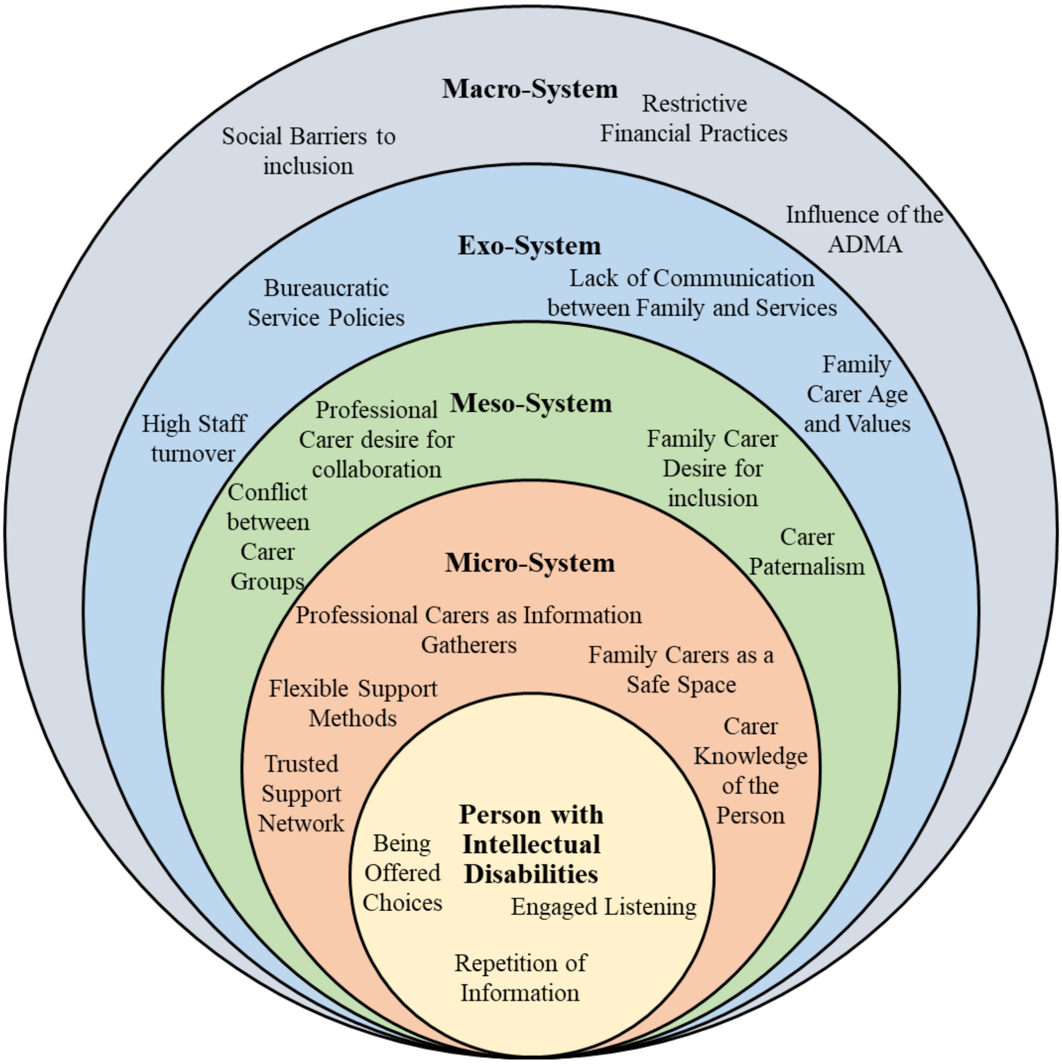


Figure 6: Bronfenbrenner Diagram Showing the Relationship Between Focus Group Participant Themes

The microsystem in this case was represented by the person with intellectual disability and their interaction with various sources of decision-making support. Interactions could be contextualised here in terms of the themes seen within the focus group data from the adults with intellectual disabilities. Having a strong network of trusted, familiar supporters during decision-making, predominantly key workers and family members, formed a key part of this system. People with intellectual disabilities' preferred methods of decision-making support, namely being offered choices, repetition of information and engaged listening, formed a core component of the supportive decision-making process. Family carers' intimate knowledge of the person's habits, preferences and desires formed a large part of this system, alongside professional carers' flexible, tailored methods of support. They viewed professional carers in a more business-like manner than family carers, trusting them to convey information and instruction on how to best achieve their goals. Family members played the role of a safe space and confidante and were seen as offering consistency and security when deciding upon a course of action.

The mesosystem could be viewed as the interaction between family and professional carers during the support process, both within and outside of the disability service. Family carer factors present here consisted of their concern regarding the methods employed by professional carers respecting decision-making, their occasional lack of confidence in the ability of the person with intellectual disability to make a decision, and their desire to form a key part of the person's support circle alongside professional carers. These offered a contrasting view to professional carers' perspectives, namely their struggle at times to convince family carers to support the person with intellectual disability to make decisions about their own lives, their reluctance to support certain decisions the person with intellectual disability wished to make, and their own desire to work with family carers to form a more complete support circle. Frontline and supervisory staff interactions were also a factor, with floor staff in particular highlighting their occasional frustration with being advised not to pursue certain avenues of support with clients due to supervisory staff concerns over mitigating the perceived irritation or disapproval of family carers.

The exosystem was conveyed through larger external factors discussed by participants, which were perceived to help or hinder the decision-making process. The policies and practices of disability services formed a large part of this system. Professional carers cited bureaucratic processes as a barrier to effective support, as they often felt the paper trail of the decisional process was more valued by the service than the process itself. Family carers also felt that the lack of communication between service providers and rigidity of health and safety practices played a significant role. All participant groups cited high staff turnover as a mitigating factor, as it broke up established relationships and led to the person with intellectual disability and their families having to explain the same personal details over and over. Family values and the age of family carers formed part of this system also- professional carers reported that older family members, particularly parents, were less inclined to be receptive to newer ideas of decision-making support.

Finally, the macrosystem could be evidenced through participant discussions of societal and cultural values that helped or hindered the decisional process. Frontline staff mentioned the issue of financial institutions being unaware of or unwilling to listen to inclusive practices and approaches to independent decision-making for adults with intellectual disabilities through the proliferation of requests for doctors' notes proving decisional capacity, or conversely, the expectation that the person with intellectual disability would be able to read or sign a contract without assistance from a trusted supporter. People with intellectual disabilities themselves corroborated this, as they viewed money as a source of distinct stress, and often discussed it in terms of a difficult life skill that they needed to learn in order to participate fully in the community. This restriction in societal participation was perpetuated at times by family carers through their attempts to limit their loved ones' access to finances out of a belief in their inability to manage money, as corroborated by professional carers who were often required to dissuade family carers from pursuing these actions, as they prevented clients from participating in their own financial decision-making. A wider societal shift was discussed by all three groups with respect to the new ADMA legislation. Participants across groups felt that it was a step in the right direction, particularly those with intellectual disabilities who felt it would give them a new sense of empowerment and control. Professional and family carers also approved of the new legislation but expressed greater confusion and concern over how it would be applied. Professional carer concerns lay in how it would alter their current work policy and environment, whereas the concerns of family carers were more rooted in scepticism of their loved ones' ability to make decisions in this way.

This synthesis shows that the feelings, experiences, and concerns of the four stakeholder groups who participated were often interlinked, and that the concerns of one group were regularly explained by the perspective of another. For example, family carers were concerned that professional carers were too quick to support the person with intellectual disability in the pursuit of complex decisions, such as where they would like to live. However, in the account of professional carers, it was explained that they carried out decisional support through a series of small, incremental steps designed to build the person's ability to implement their decision, and felt that family carers did not understand this, as they were more concerned with protecting the person. This dynamic was echoed in the manner in which participants with intellectual disabilities discussed the support provided by family versus professional carers; family support was utilised for comfort and security in decision-making, while professional carers' support was utilised for further information and instruction on how to carry out these decisions. A similar distinction has been noted in the broader social support literature, which terms the kind of support provided by family members as emotional support, while the support offered by professionals is termed as instrumental support (Arnold & Harris, 2024; Giesbers et al., 2019). Bronfenbrenner's systems theory offered a valuable lens to view how these differing types of support interact, providing an overarching, comparative perspective within the context of the life of the person with intellectual disability. Indeed, Bronfenbrenner's theory has been successfully used as an organising framework in other qualitative research pertaining to adults with intellectual disabilities and their support systems (Francis et al., 2020; Jacobs et al., 2018). However, the focus has been on how transitional stages in the lives of adults with intellectual disabilities are navigated, precluding the direct comparison of findings. Nonetheless, Francis and colleagues (2020) similarly note in their exploration of the transition experiences of Latina family carers as they assisted their loved one with intellectual disability in their move from school to the work force that the mesosystem consisted of family carers and their interaction with school support staff. The tone of this interaction often dictated how smooth the transition from school to work was, as a supportive school meant the person being supported often accessed employment far more readily than those who attended a less supportive school (Francis et al., 2020). This mirrors the present study's finding that family carers were often wary of professional carers' ability to successfully support their loved one, leading to a sense of mistrust. This in turn made professional carers less inclined to feel positive about working with family carers, resulting in less unified support circles for their loved one with intellectual disability compared to professional and family carers who were less suspicious of one another. Together, these findings indicate that a more connected support system would facilitate a greater sense of support and clarity of direction for the adult with intellectual disability.

6.5.2 Strengths and Limitations

The strength of this research lies in its comprehensive synthesis of the views of different stakeholder groups on supporting the decision-making of adults with intellectual disabilities. To the author's knowledge, this is the first such study to be conducted in an Irish context, or indeed elsewhere. A limitation of this research is that focus groups were conducted separately with each stakeholder group, preventing a multistakeholder discussion of the topic at hand and exploration of relational dynamics. However, this was a compromise based on twin concerns of mitigating power differentials and meaningfully engaging with key stakeholders in the discussions. This separation has been mitigated to some extent by the inclusion of focus group participants in subsequent multistakeholder feedback sessions, as described in Chapter 7. The use of points of contact within the participating services was a strength, as it created a close working relationship with the services themselves during the project. However, these points of contact also served as gatekeepers to recruitment, particularly with respect to participants with intellectual disabilities, which may have impacted the representativeness of this group’s views. The use of service-owned venues to carry out the focus groups might also be considered a limitation, as it might have contributed to a reluctance to be candid about certain matters relating to that service, particularly for participants with intellectual disabilities. However, it also created a positive and relaxed atmosphere for participants, as they were in a welcoming and familiar environment during the discussions. The use of Bronfenbrenner’s theory to examine the data is a strength also, as it allowed for an interconnected view of the relationship between the person with intellectual disability and the different members of their support circle. Finally, the focus groups were conducted prior to commencement of ADMA, which precluded exploration of its impact on participants’ decision-making processes. Future research exploring if or how the decision-making process for people with intellectual disabilities has changed following its implementation is thus warranted.

6.5.4 Conclusion

All participating stakeholder groups felt that the way forward in supporting the decision-making of adults with intellectual disabilities was to take a collaborative approach, with the wishes and views of the person being supported at the centre of the process. However, it was broadly acknowledged that there needed to be more open communication between the groups, particularly between professional and family carers, who were often sceptical of each others' intentions. The support in decision-making provided by each group, though different at first glance, was often complementary, and stemmed from a shared belief in the need for well-rounded support to facilitate the person to live their life in a manner of their own choosing. Adults with intellectual disabilities deeply valued supporters who listened to what they had to say and worked alongside them to help them achieve their goals, although they preferred to receive emotional support from family members, while professional carers were favoured for the instrumental support they provided. Future research pertaining to this topic should investigate how the views and perspectives of all stakeholders can be considered and adapted into a more effective support process through encouraging further conversations among all stakeholders and workshopping ideas for further training and support.

Chapter 7: Multistakeholder Focus Group Feedback Workshops using a World Café Format

7.1 Chapter Summary

This chapter describes the conduction of two World Café style multistakeholder workshops with participants from the focus group phase (see Chapter 6), in order to review and elaborate upon their key priorities for the development of a guide to SDM for use by people with intellectual disabilities and their decision-making supporters. Section 7.2 of this chapter gives a brief background and rationale for this research. Section 7.3 details the study design, participant recruitment and consent, data collection, and data analysis carried out during the study. Section 7.4 firstly details results from the focus group data regarding participants' preferences for a guide to SDM, and then the results of the multistakeholder workshops. Section 7.5 provides a general discussion of this research and its outcomes, its strengths and weaknesses, and suggestions for future research.

7.2 Introduction

There is a notable lack of resources or guidance for people with intellectual disabilities in Ireland and their decision-making supporters regarding how to best implement SDM in their daily lives, as demonstrated by the findings of the environmental scan detailed in chapter 5 of this thesis. Despite the recent commencement of the ADMA, with its emphasis on SDM, the focus of any publicly available information on this legislation thus far has been on providing information and guidance on how to implement specific legal supports such as Power of Attorney or Advance Directives, or most recently on assisting adults with intellectual disabilities in developing their self-advocacy skills (Inclusion Ireland, 2024; Decison Support Service, 2023). Currently, no resources have been developed for people with intellectual disabilities and their decision-making supporters that capture the perspectives of all members of the support circle, either in Ireland or further afield. In chapter 6, the findings of the stakeholder focus groups demonstrated how the roles and perspectives of each member of the support circle, along with the adult with intellectual disability, are intimately connected, and how a key barrier to effective decisional support is often misunderstanding or a feeling of not being heard between professional and family carers during the support process. Therefore, in order to develop a user-centred, evidence-based resource to provide guidance on SDM to people with intellectual disabilities and their supporters that takes into account the experiences and perspectives of all stakeholders, it was deemed necessary to conduct feedback sessions that would encourage conversation between all participant groups and allow for further elaboration of their shared key priorities for this resource.

In the field of disability research, active engagement in research by people with intellectual disabilities has gained increasing popularity, particularly due to a growing emphasis on ensuring policy change and research findings are informed by service user experiences and perceptions (McLaughlin, 2010). However, pitfalls of attempting to retrieve feedback can include research participants wanting to defer to the researcher as the ”expert” and therefore concealing any disagreements they may have, mistrust of the researcher’s intentions in gathering the information, and over-simplification or over-complication of the results by the researcher, leading to participants failing to understand them (Kornbluh, 2015). However, these concerns can be mitigated by utilising techniques that remove the formality from the feedback process and encourage open and honest communication between the researcher and participants, as well as between participants themselves (Raynor et al., 2018; Thomas, 2017). One such method that can be employed is that of the World Café (Bumble & Carter, 2021; Löhr et al., 2020).

The World Café approach encourages the creation of a relaxed, café-like atmosphere to allow free and open expressions of ideas, views, and discussions between participants relating to a central topic under discussion (Bazilio et al., 2020; Löhr et al., 2020; McGrath et al., 2023; The World Café, 2023). This atmosphere is encouraged through the application of the seven design principles that underpin the approach: 1) clarifying the context; 2) creating a hospitable space; 3) exploring questions that matter; 4) encouraging everyone’s contributions; 5) connecting different perspectives; 6) listening together for patterns and insights; and 7) Sharing collective discoveries (The World Café, 2023). Previous research has used this approach to facilitate conversations relating to many complex and far-reaching topics, such as domestic violence, carer harm, and representation of minority groups in research, as the focus on encouraging the coming together of diverse or perhaps conflicting perspectives on potentially difficult topics allows for the exploration of these topics in a productive, collaborative manner (Donnelly & O'Brien, 2023; Forbes et al., 2023; McGrath et al., 2023). A systematic review carried out on the use of a World Café approach with participants with intellectual disabilities noted that the application of this methodology had been successful in affording an opportunity for them to sit with family and professional carers to discuss key issues, challenges, and concerns, in a space that places emphasis on respect and active listening among participants (Bumble & Carter, 2021). This is a key strength of this methodology, as adults with intellectual disabilities have previously indicated that they often find expressing themselves in this manner to carers to be stressful and challenging, due to past experiences of feeling unheard or dismissed (see Chapter 3, Systematic Review). The review also noted the success of this methodology in encouraging participants and researchers to enact meaningful change in key disability issues based upon the outcomes of the sessions. For example, in an included paper by Raynor and colleagues examining how to increase and improve opportunities for employment among adults with intellectual disabilities, the outcomes of the World Café indicated that 97.2% of participants with intellectual disabilities found the sessions to be useful and a productive use of their time, while an average of 94.6% indicated they had identified the next steps they needed to take to improve employment opportunities for people with intellectual disabilities during their discussions (Raynor et al., 2018). This indicates that a World Café approach is an effective method of feedback collection and generation of next steps for key stakeholder groups (Bumble & Carter, 2021).

The aim of this research was thus to host multistakeholder World Café style workshops for adults with intellectual disabilities, family carers, and professional carers who had previously taken part in focus groups as part of this research project (see Chapter 6) to review and elaborate upon their key priorities for the development of a guide to SDM.

7.3 Method

7.3.1 Study Design

This study consisted of two parts. Part 1 involved analysing data from the focus groups detailed in Chapter 6 which pertained specifically to participants' views and opinions on 1) how they felt about the concept of a guide to SDM designed for their use, and 2) what factors they considered most essential for this guide in terms of its purpose, design and content. For details on the data collection methods pertaining to part 1, please refer to section 6.3 of this thesis.

Part 2 of this study involved conducting two multistakeholder workshops with individuals who had participated in the previous focus group phase. The purpose of these workshops was to review their preferences for a guide to SDM for use by people with intellectual disabilities and their decision-making supporters identified from the focus group data and discuss their shared key priorities for its construction. The workshops were conducted according to the ethos, key principles, and methodology of the World Café (Bumble & Carter, 2021; Löhr et al., 2020; The World Café, 2023). Two workshops were held in July 2023, one for each participating disability service.

7.3.2 Participant Eligibility

Participants were recruited via two partnering disability organisations, having previously taken part in focus groups as part of this research project (see Chapter 6). Four groups took part: 1) adults with intellectual disabilities who were current clients of the partnered disability services; 2) family members whose loved ones were current clients of the partnered services; 3) supervisory staff currently employed in the partnered services; and 4) frontline staff who were currently employed by the partnered services. For more detailed information on the focus group eligibility criteria and recruitment process, please refer to section 6.3.3. All participants from the previous focus group sessions were eligible to take part in the workshops, provided they had consented to their contact details being retained for follow-up and had also indicated verbally to HC at the end of the focus group sessions that they were still willing to be contacted.

7.3.3 Participant Recruitment and Consent

Ethical approval for the workshops was granted by Maynooth University's Social Research Ethics Sub-Committee and both partnered disability organisations. All professional and family carer participants who had agreed to be contacted were emailed a recruitment request by dedicated points of contact within both partnered services. Participants with intellectual disabilities were contacted via their keyworkers. All potential participants were sent an information sheet and consent form pertaining to the workshops to read and familiarise themselves with the proposed procedure, and to allow them time to ask questions if desired. The information and consent forms for participants with intellectual disabilities were in easy-read format (See Appendix IX). A list of participants who had indicated their availability to attend the workshops was given to HC by the points of contact to provide an estimated number of attendees. Consent forms were filled in by participants on the day of the workshops, with HC available to assist or answer any questions or concerns. Participant consent was reiterated verbally by all who attended before the workshops began. It was stressed by HC that participants were under no obligation to remain for the duration of the workshops and could leave at any time without giving a reason. To facilitate the comfort of participants with intellectual disabilities, they were encouraged to bring a support person (i.e. a family or professional carer) whom they trusted to help them understand and participate in the discussion if desired. A table detailing the demographics of the focus group attendees is included below.

7.3.4 Data Collection

For a description of the data collection procedure for the focus groups, please see section 6.3.5 of Chapter 6. For the World Café events of part 2, two separate workshops were held, one for each participating disability organisation. Both workshops took place in person and were open to participants from all four stakeholder groups who took part in the previous phase (i.e. people with intellectual disabilities, family members, frontline staff and supervisory staff). Any concerns relating to potential power differentials between these groups (see Chapter 6) were mitigated by applying the seven design principles of the World Café (The World Café, 2023), particularly in relation to creating a hospitable space, connecting diverse perspectives, and listening together for patterns and insights, to create a relaxed, welcoming atmosphere conducive to respectful, open discussion. The workshops started with a short presentation given by the cafe host (HC), showcasing a summary of the focus group findings for each participant group in relation to their thoughts and perspectives on the topic of SDM, as well as preliminary conclusions regarding their preferences for a guide to SDM. After this presentation, three 20-minute rounds of discussion were facilitated, with a different question highlighted at each round: 1. How do you feel about the conclusions that were made?; 2. Are there any conclusions you feel I missed?; 3. Are there any points you did not get to share last time that you would like to share now?

Each table was appointed a table host, one of three postgraduate or postdoctoral researchers from HC's university department who had agreed to assist and were Garda vetted to work with vulnerable groups. These table hosts had a dual role of facilitator and data collector, taking detailed notes during the conversations, and encouraging more discussion if they began to lag. The café host monitored all tables by walking between them and facilitating elements of discussion as they arose. At the end of each 20-minute period, the participants were encouraged to move around the room and create new groups to discuss another question. When all three questions had been discussed, participants used sticky notes provided to write down key words or phrases that they felt represented their overall thoughts and feelings about what had been discussed during the session. They then went to a whiteboard at the top of the room and stuck these onto it to graphically represent the day's discussions. The floor was then opened for any final questions, comments, thoughts or conclusions participants might have before the end of the session. The workshops were not audio recorded, as the multi-table set up would have made capturing conversations challenging to execute. This is a typical issue that arises in World Café sessions, where the detailed table notes generally form the bulk of data collection (Bumble & Carter, 2021; Estacio & Karic, 2016; Löhr et al., 2020).

7.3.5 Data Analysis

For part 1 of the data, I organised the specific recommendations of participants pertaining to the guide into discrete categories and examined them using line-by-line coding to extract key themes, the purpose of which was to create a comprehensive list for them to review during the feedback sessions. This was accomplished by using a thematic summary method which involves searching for common topics discussed within each stakeholder group, which are then summarised and organised into discrete themes (Luescher, 2005). For part 2, reflexive thematic analysis (RTA) was used to analyse the data collected during the multistakeholder workshops (Braun & Clarke, 2019). This method of analysis combines well with that of the World Café due to its emphasis on researcher mindfulness and reflexivity, while capturing the experiences and perceptions of the café attendees (MacFarlane et al., 2017; Schiele et al., 2022). For a more detailed description of how RTA was employed for the primary data analysis conducted in this thesis, see section 6.3.6 of Chapter 6. The detailed reports written up by the table hosts during the sessions were read and reread, and the keywords provided by participants on sticky notes were used to interpret their overall thoughts on the topic. I then used line-by-line coding to preliminarily organise these reports into themes using MaxQDA software (Kuckartz & Rädiker, 2019). These themes were then reviewed and revised into more refined themes, with reflection on my own interpretation and stance on the issues under discussion maintained throughout each revision through the use of the memo feature in MAXQDA.

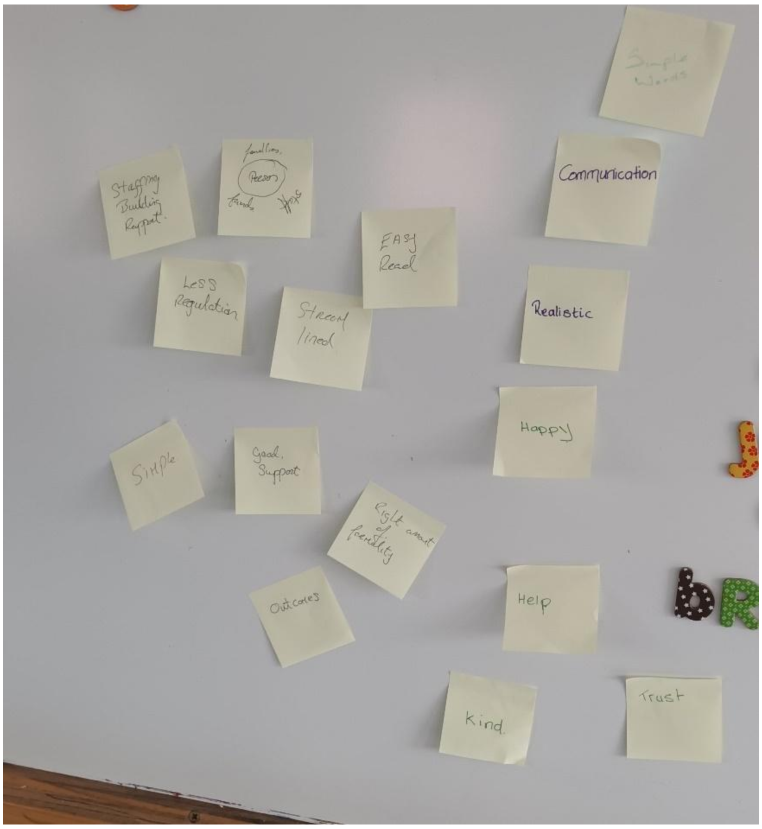


Figure 7: Sticky Notes from Café Group 1

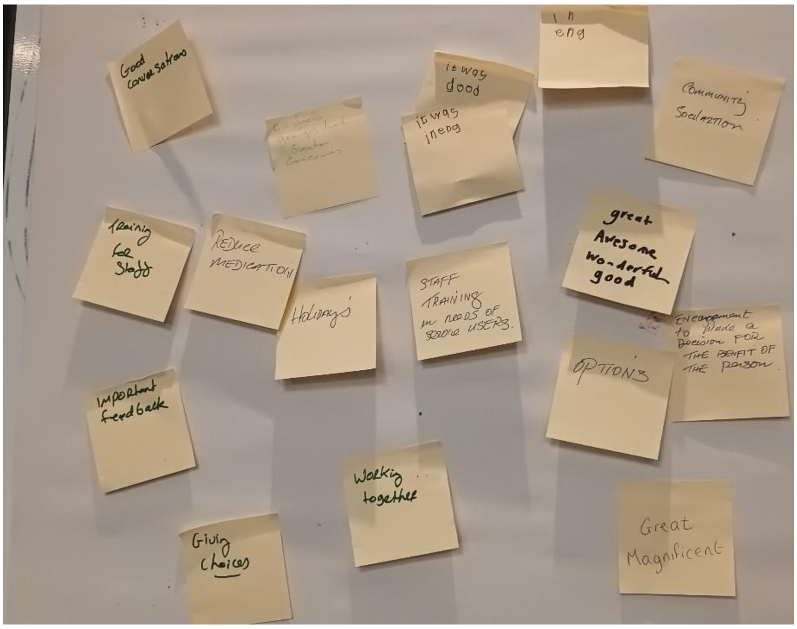


Figure 8: Sticky Notes from Café Group 2

7.4 Results

7.4.1 Part 1: Focus Group Suggestions for Guide Development

In the focus group sessions, participants were asked about their perceptions of SDM and suggestions for the construction of a guide on SDM for their use. These recommendations are presented here.

7.4.1.1 Suggestion 1: A Clear, Easy-Read Approach

Participants with intellectual disabilities all agreed that a guide to SDM would be a useful tool that they could employ to increase their independence and have more control over who supported them in day-to-day decision-making. They thought that having a guide would make it easier for them to know what to do in certain situations, as it would help them understand what the decision involved. They also liked the idea of being at the centre of decisions and expressed that they felt it was very important for them to be asked what they wanted by supporters.

> *"Eh yeah [a guide] would be handy because say someone said something to me that's hard to understand, I would say could you explain that to me much better and they'd be like- yeah em, you have to explain to me three or four times before I understand." [P1, ID]*

Participants with intellectual disabilities also stressed the importance of having a guide that was written or laid out in a way that made it easy for them to understand. They were concerned about not being able to read it on their own, or it being written in an inaccessible way.

> *"Well the guide mightn't be helpful if it's too hard (P1: No I don't think so). Or if it's in other countries, if it's in different languages and stuff." [P5, ID]*

Supervisory staff agreed that the guide would be a useful tool to have when explaining important concepts to clients, citing previous guides to COVID-19 and vaccinations as examples of good practice (Special Olympics Ireland, 2021). These easy-read guides distilled the topic under discussion into an easily understood format and helped to alleviate client concerns. Supervisory staff suggested that the guide should be printed in an easy-read format to make it more accessible to clients. Furthermore, they suggested that clients would be more likely to use such a guide if it made ample use of visual aids such as pictograms, flowcharts or visual summaries of the information, whereas they would be less likely to use it if it required them to spend a large amount of time searching for the correct piece of information.

> *"I think if it's in black and white and it's very straightforward, then whether it's staff or family, or service users, you know everybody can adapt and come back to it. So I suppose it comes down to really how straightforward it is that you're getting such a big thing down into a small thing that people can understand and that works for everybody. The problem will be if it turns out to be a big document with lots of stuff in it that throws people off. And that they can't find where they stand within it, that's where it would be a problem." [P32, SS]*

7.4.1.2 Suggestion 2: Lay Out SDM Roles and Responsibilities for All Involved

Family carer participants suggested that part of the guide could lay out the need for services to create a new role within their organisations, which participants suggested could be entitled a "decision-making assistant." As part of this suggested role, the decision-making assistant could help the person with intellectual disability to create a document, much like a PCP document, which would detail the person's likes and dislikes, goals and dreams, which the decision-making assistant could then share with the rest of the person's support system. They felt that having such a person and document would eliminate confusion or uncertainty among supporters and prevent the continual repetition of information across services, as they were certain no such database or register currently existed.

> *"Like is there no register where all this information has been kept right across the board?" [P16, FC]*

Frontline staff participants also suggested the guide should address the legality of the ADMA and the function of SDM as a support method, as well as outlining the roles and standing of the different elements of the client's support circle within it. They echoed the family carers' suggestion that services should have a designated person with advanced knowledge of SDM and the ADMA that they and family members could talk to about best practice in supporting decision-making. When told about the DSS, they expressed concern that a national body would not have the time or resources to look after every service who had a query, meaning an embedded contact person would be more beneficial.

> *"P42 [FC]: So you'd be dealing with- so that organisation would be dealing with so many other companies. It would be nice for [SERVICE] to have their own little mini one here to be able-*
>
> *P39 [FC]: Yeah someone within [SERVICE] to do that-*
>
> *P43 [FC]: Like a mediator kind of thing-*
>
> *P42 [FC]: Yeah because a lot of parents won't go to a separate company. They'll want to talk to somebody who knows their lads, who knows them like ."*

7.4.1.3 Suggestion 3: A Bridge Between Staff and Family

All supervisory staff participants were enthusiastic about having a guide to use, particularly in light of the ADMA. They felt there was a distinct lack of information currently available to them on the issue of SDM from within their own organisations and stated that having a tool at their disposal might help to clarify certain issues for them as they navigated supporting decision-making within the service. In particular, they viewed it as being a potentially valuable resource in helping them to explain to family members why a certain course of action was taken with their loved one during the decision-making process.

> *"Cos like as social care workers we all have our duty of care. And then like how...how you deal with a situation at home and you deal with a situation in work, in work you've a duty of care. So like is this going to give more of a framework that say those aren't professionals like families that are not in social care can look at and say well we're not the big bad we're going by this. So we can have a bit of a backup." [P26, SS]*

Frontline staff participants echoed this sentiment, and also expressed enthusiasm at the idea of the guide as proof of their methods to share with family carers. Participants working in residential and day services were hopeful that it could act as a source of information and education that they could use alongside clients and their families.

> *"P36 [FS]: Yeah absolutely, any tools we have-*
>
> *P38 [FS]: Any tools we have yeah, 100%, absolutely.*
>
> *P35 [FS]: It's great to have a hard copy to bring to the parents also to refer-*
>
> *P36 [FS]: To refer to, we were saying the same thing!"*

7.4.1.4 Suggestion 4: Encourage Flexibility

Family carers were concerned about what a guide would comprise, as they felt their interaction with disability services necessitated enough "box ticking" as it was and asserted that they would be unhappy if a decision-making guide was transformed into another form that had to be filled out, or another policy that staff would have to stringently enforce.

> *"If it became a rigid thing that staff were either instructed not to move outside of, or afraid to move outside of, then you're just moving back to square one. So it would have to have some kind of flexibility. You know what I mean. You don't want it to become another health and safety thing!" [P20, FC]*

Supervisory staff were similarly anxious that the guide avoid creating more bureaucratic practices, and that it focus on centring the person with intellectual disability in the decision-making process. Overall, all participants stated that they would be satisfied with a guide that could be used as needed rather than as a strict, permanent requirement, and that focused on breaking down SDM into easily understood terms for them, their clients and their families.

> *"But even like as well I suppose it will be great in that sometimes we get caught up in what the best interests for the person and what's for them and then it's like well did anybody speak to "Mary" about this? And it's like you're so busy ticking all the boxes like you talked to the mam, you talked to dad, you talked to the sister, you talked to the brother you talked to the keyworker, and sometimes you nearly forget about "Mary" in the middle of it all trying to make it all work. And this will really shine the light back on "Mary" again and make sure that "Mary" is the centre of it because sometimes you do really get caught up in all the surrounding bits and pieces." [P27, FS]*

Frontline care participants similarly stressed the need for flexibility. They felt that if the guide was constructed in such a way that it allowed for nuance and grey areas, they could see no issue with it. They were anxious that it would not do away with certain practices, however, including acknowledgement of restrictive action that needed to be taken to prevent self-injurious behaviour (SIB) or general harm, either to the person themselves or those around them. There was a strong stipulation that the guide needed to be something that enhanced their roles, but also an assertion that they believed it would take a number of years before the full benefits of either it or the new legislation were felt by those in their profession.

> *“I do think it will make our lives easier. I don't think it will make our jobs easier, but the new staff coming off the block, and the new students coming in, and the system all changes, I think they'll see a difference.” [P38, FS]*

7.4.1.5 Suggestion 5: Centre the Person with Intellectual Disability

Participants with intellectual disabilities were eager that the guide centred their need for guidance on how to begin the process of decision-making formatters of importance to them, rather than focusing on instructing their supporters. Issues that they particularly wanted the guide to address included planning trips, managing money, and how to address personal difficulties such as planning transport in the case of two participants who used a wheelchair.

> *“P8 [FC]: Getting ready to go on holidays or something?*
>
> *INT: So getting ready to go on a trip maybe?*
>
> *P8 [FC]: Yeah getting ready and preparing and being on time and things like that?”*

Family carers agreed that the person with intellectual disability was most important in the decision-making process but were concerned that they as family carers would be left out of the conversation by professional carers, and consequently decisions would be made that were not feasible in the long-term for the person with intellectual disability, or for their family as a whole. They were willing to work with professional carers in supporting the decision-making of their loved one, provided professional carers were willing to listen to what they had to say.

> *"P22 [FC]: In theory it's a wonderful idea I think, that's all I'll say. In theory it's wonderful, I think it's absolutely detrimental if it's not-*
>
> *P18 [FC]: If it's not done right.*
>
> *P22 [FC]: If parents aren't feeding into it, and especially people who are extremely knowledgeable and caring of that person. That would be a concern I'd have-*
>
> *P21 [FC]: Best interest- that would have their best interest at heart!"*

However, frontline staff felt that family carers needed to be aware that centring the person with intellectual disability meant decentring family carers and wanted the guide to reflect this. They felt that the wording of the guide should reflect that the person with intellectual disability is at the centre of its practice, not the family. Suggested ways of illustrating this were to use the term 'carer' rather than parent to refer to family, or to avoid referring to family at all and instead focus solely on the person with intellectual disability.

> *"See 'carer' because then it can be applied then to anything it's open to anything, because if you say parent then they think my child, whereas if you say carer it might just resonate with them that they actually are a carer." [P35, FS]*

Furthermore, frontline care staff concerns regarding the guide revolved around the fear that family members would react badly to it if it was not carefully constructed. Participants suggested that a focus group or panel of professional carers should be asked to review the guide once completed, as they could identify wording or phrases that might be deemed unacceptable to families. Participants stated that this fear stemmed from their own experiences of family members becoming angry with them over the handling of certain issues, which often led to the clients themselves being prevented from returning to the service for quite some time, if at all.

> *“Yeah so like, I'm the type of person like if I read something, and it gets my back up straight away- I shut down straight away. And I don't take in, I don't process things. And then I go home and I'm like ohh I wasn't right there, I should apologise. So I think what you're saying is right straight away they might go like "oh sure ahh, what the fu- sure I'm not doing that!" so I think if it's softer written, but I think if we read it first we could say it to you.” [P38, FS]*

7.4.2 Part 2: World Café Priorities for Guide Construction

The focus group findings regarding participants’ recommendations for a guide to SDM were compiled into a short PowerPoint presentation for the multistakeholder workshops. Fourteen participants took part across the two workshops. Group one consisted of five participants: two supervisory staff, two people with intellectual disabilities and one family member. Group two consisted of nine participants: two supervisory staff, four people with intellectual disabilities and three family members. Attendees have been listed below in tables 9 and 10. No frontline staff were available to participate in either group due to their unavailability on the day or having left the service since taking part in the focus groups. The small size of the first group meant they could not effectively change groups for each question- instead, open discussion was encouraged among all five participants for each round. Five key stakeholder priorities for guide construction were identified from the data collected: 1. Adding supplementary materials, 2. Maximising Flexibility, 3. Be Mindful of Existing Dynamics, 4. Be Mindful of External Barriers to the Effectiveness of a Guide to SDM, and 5. Disseminate These Findings Widely.

Table 9: List of World Café Group 1 Participants

Participant ID (As assigned in focus group chapter)	**Participant Group**	**Gender**
P8	Person with Intellectual Disability	Male
P9	Person with Intellectual Disability	Male
P21	Family Carer	Female
P30	Supervisory Staff	Female
P32	Supervisory Staff	Male

Table 10: List of World Café Group 2 Participants

Participant ID (As assigned in focus group chapter)	**Participant Group**	**Gender**
P1	Person with Intellectual Disability	Female
P4	Person with Intellectual Disability	Female
P5	Person with Intellectual Disability	Male
P6	Person with Intellectual Disability	Female
P13	Family Carer	Female

P16	Family Carer	Female
P17	Family Carer	Female
P23	Supervisory Staff	Female
P25	Supervisory Staff	Female

7.4.2.1. Priority 1: Add Supplementary Materials

All participants communicated that they found the presentation of findings from the focus groups comprehensive and well summarised, and the recommendations for the guide to SDM thorough and carefully thought out. In particular, all participants agreed that an easy-read format and inclusion of visual aids were key elements to a well-constructed and accessible guide. Supervisory staff felt an opportunity for training for all parties involved in the decision-making process should be prioritised to increase understanding of SDM and ensure the guide would be used effectively. They thought this could be supplemented with resources to complement the contents of the guide, such as worksheets, access to further courses or training, and the creation of a designated person within their service who they could contact for assistance. They suggested the guide could be broken up into subsections that would have their own leaflets or booklets that could be independently used, ideally only one to two pages long, with a summary flowchart at the end to allow for rapid use in situations that required it.

7.4.2.2 Priority 2: Maximise the Guide’s Flexibility

One staff member raised a concern regarding any clients who had additional physical disabilities which might make reading the guide independently difficult or impossible, and suggested the guide should prioritise signposting how carers could assist someone in reading and interpreting its contents without imposing their own interpretation or exerting undue influence as they did so. Family members agreed and emphasised strongly that simple language was necessary for maximum accessibility. They stated that “convoluted” language was a source of frustration for them when reading documentation and were eager to avoid the introduction of such language into the proposed document. Furthermore, they stressed the need to avoid the introduction of new forms or paperwork for them to have to fill out any time they wanted to employ the guide in daily life. They were anxious that the guide not become another box ticking exercise but instead remain a flexible, informal resource that could be consulted as desired. They also wanted to be included by staff as a key element of the person’s circle of support, and to be taken seriously as a knowledge source on the person’s needs and wants.

Both family and staff agreed that a pertinent addition to the guide would be the appointment of a permanent contact person or decision-making consultant within each disability service to ensure consistency of support. Clients agreed with the assessment that the guide should be an easy-read document using simple, straightforward language, as this would allow them to use it independently. They also commented that they would like the guide to avoid becoming another checklist that staff used to monitor their behaviour.

7.4.2.3 Priority 3: Be Mindful of Existing Dynamics

Participants’ concerns about a guide to SDM were linked to their concerns about SDM itself. Staff were concerned about how the guide would help to mitigate long-term risks to health or wellbeing for clients if their decisions might have negative consequences in those areas, such as through a poor diet, or excessive use of alcohol or cigarettes. They were unsure how much they were allowed to intervene. Similarly, staff were often faced with situations in which clients were reluctant to make a particular decision, instead stating that they were “fine” and did not feel the decision was necessary. However, these decisions were sometimes rather important and required action. This left staff in a rather precarious position at times, where they had to determine whether it was acceptable to push the client to decide one way or the other. They felt that it might be challenging for a guide to capture the nuances of such occasions. Furthermore, they were unsure about how the guide would help to foster a sense of trust in the decision-making process for both clients and family members. With family, staff noted there was mistrust of their intentions at times, which made it difficult for them to explain to family members why certain procedures were taking place. Often, staff were merely taking a small step that was part of a more far-reaching plan, but if this was not clear to family members, they would then attempt to prevent this step from occurring and were reluctant to listen to the explanations being offered. They felt that a guide needed to be constructed in a way that was mindful of the existence of these dynamics and prioritised the mitigation of such conflicts.

Family members were sceptical of the ability of a guide to assist with more complex aspects of supporting decision-making, such as when someone might lack motivation to engage in a particular activity. If the supporter is aware that the person often struggles to join in in this way, but usually enjoys the activity if pushed to go, how can this push be executed without interfering with the person’s right to choose? This element was seen in family members’ continued worries about the ability of people with intellectual disabilities to make decisions in general. They commented that the guide needed to be designed in a way that remained mindful that their loved ones were easily overwhelmed if bombarded with too much information and needed time to sit with the decision. If this time was not given, family members were concerned that they would be unable to make a decision or perhaps make an ill-advised decision, especially with respect to financial decisions. Participants with intellectual disabilities agreed with aspects of this assessment, saying that money was always a difficult topic. However, they had no additional thoughts on personal concerns about the guide in general, saying the conclusions made from the focus groups captured their preferences very well.

7.4.2.4 Priority 4: Be Mindful of External Barriers to the Use of a Guide to SDM

At times, the discussion around perceived limitations to using such a guide touched on barriers existing within the disability system, or wider society, instead of within the participants themselves. They also discussed wider, societal shifts that needed to happen in order to facilitate greater decisional freedom. Banks were cited as a prime example of this, with policies refusing to take into account the nuances of individual situations. Staff concluded that a guide to decision-making would likely be hindered by society's own incorrect and outdated assumptions on this topic. Therefore, in order to be constructed effectively, it would have to be mindful of how it could operate with respect to barriers to SDM within the wider social context.

Family members expressed similar frustrations with the system, noting the lack of funding for important resources in disability services. Furthermore, they acknowledged the impact of staff turnover, as they felt the government and society did not value the work of disability care staff, and often observed how their loved one became very attached to their keyworkers and struggled to adapt to the change when they were no longer available. They also expressed frustration regarding new policies that prevented staff from fulfilling their loved ones' wishes, with one family member citing the example of new policies preventing staff from doing overnight trips for holidays, as they were required to enact a shift change after a certain number of hours, something that was difficult to execute if the holiday was taking place some distance away from the person's home. Clients diverged on the matter of staff changes, with one participant with intellectual disability saying they did not mind when this occurred as it afforded an opportunity to meet and work with new people, whereas another participant said they found the constant changes jarring and preferred to receive support from staff members that they knew. All participants with intellectual disabilities agreed with staff and family about the stressful nature of paperwork and having to go through official processes. They were anxious to remedy this through suggesting the need for more flexibility in the guide and its procedures, as they often felt reluctant to share their desire to partake in certain activities, or make certain decisions, as they knew it would lead to them having to engage in complicated, confusing practices to do so.

7.4.2.5 Priority 5: Disseminate These Findings Widely

In terms of future approaches to the adoption of SDM, professional carers felt they were making important steps in the right direction and hoped this research could be part of that step. One service had created a special interest group dedicated to introducing SDM to the wider service along with clients and family and had run a very successful information evening for day service staff and attendees but were hoping to run a similar event for residential services soon. Higher management in both services were looking to adopt policies based upon the principles of SDM as a support method and were trying to examine which elements needed to be altered first, noting the guide and the discussions they had had as part of this research had facilitated some of these discussions already. They suggested that the guide could stipulate that clients should be freer to choose what keyworker they wanted to work with, as personality clashes could occur when assigned by others without due consideration. They also emphasised that while the services they worked for were trying to change and grow alongside current recommendations in decisional support, they would struggle to enact real change in the lives of their clients without a corresponding transformation of the wider sociocultural context.

Family carers said they felt that choosing to engage in this research project was going to pay off in the future and hoped the outcomes would help to introduce a more holistic approach to decisional support. They were anxious for the findings to be sent to the HSE or another government organisation so that it could enact real policy change. Family carers also conceded that they could already see real change, as they felt they did not have to fight or push as hard as they had to years ago for their loved ones to gain access to specialist healthcare, or disability service support outside of perfunctory matters such as food or clothing. They also commented that the discussions they had with members of staff during the workshops would never have occurred years ago, which they felt was a further sign of progress. Professional carers and clients agreed with this assessment, and suggested the current research could form the basis for new training in SDM. Clients said that overall, they felt they were listened to much more than they were in the past, and were highly enthusiastic about what the new legislation could do for them as they learned to become more independent. They were also hoping to learn how to be more confident and how to make decisions of varying importance for themselves, such as using public transport, selecting and packing their own clothing for holidays, and finding employment. Overall, the general consensus was that this conversation heralded an important next step in support for people with intellectual disabilities, and all participants were interested to see what would come of it.

7.5 Discussion

This research aimed to capture the thoughts and expereinces of participants with intellectual disabilities, family carers, and professional carers regarding a guide to SDM, and to obtain feedback on focus group data relating to the guide. Participant feedback on the preliminary guide recommendations presented was generally positive across the board, with all groups feeling the conclusions represented how they felt about SDM adequately. Certain points were reemphasised during the identification of further priorities during the feedback groups. In particular, all groups felt strongly that an emphasis on collaboration and trust needed to be baked into the guide, and that it should not transform into another bureaucratic hoop that had to be jumped through in order to achieve certain goals. These observations aligned with previous assertions noted in the focus groups, and in previous research with carers and people with intellectual disabilities, in which they discussed the barriers to effective support caused by certain bureaucratic processes in disability services (Devi et al., 2020; Hollomotz, 2014; Petner-Arrey & Copeland, 2015). However, the relationship between professional and family carers was far more cordial than the initial focus groups would have suggested, and the atmosphere in the workshops remained respectful and productive throughout. With respect to participants with intellectual disabilities, there appeared to be a certain reluctance to speak negatively of professional or family carers, or of the focus group results. They were quick to reassure all present that they were happy with the findings presented, and seemed to want to avoid discussing any part of the conversation that they may have been unhappy with through repeated assertions that they had no critiques to share, despite reassurances from carers and table hosts that they were welcome to do so. Research conducted by Jackman-Galvin and Patridge (2022) examining how person-centredness in Irish disability services is operationalised found that the prevailing cultural context of care in Ireland is one of best interest decision making and paternalistic execution of support. They suggested that this can lead to people with intellectual disabilities being reluctant to share their true feelings on decision-making due to a continued imbalance of power in decision-making (Jackman-Galvin & Partridge, 2022). Furthermore, one of the table hosts wrote in their field notes that participants with intellectual disabilities were regularly talked over by the other participants, particularly family carers, who would often make statements on their behalf and then say “isn’t that right?” in an attempt to steer their opinion. This dynamic has been observed in research pertaining to the communication styles of professional and family carers, in which it was noted that carers were often quick to make assumptions about the wishes of people with intellectual disabilities and steer them towards decisions and opinions that carers themselves thought was best (Antaki et al., 2006; Antaki et al., 2009; Antaki et al., 2008; Jingree et al., 2006). However, it must be noted that Carney and colleagues have asserted that this practice of paring down options or guiding the person in their choices is not always a paternalistic action (Carney et al., 2023).

The findings in this research echo those noted in other studies conducted on SDM, chiefly those relating to the La Trobe Framework in Australia, where family carers in particular commented that since learning about SDM through completing the La Trobe training, they felt much more confident in their loved ones’ ability to make decisions and were eager to work with them and professional carers to create a more rounded support system (Bigby et al., 2022a, 2022b; Douglas & Bigby, 2020). The recommendations of participants in the present research highlight a desire for mutual respect between support persons, to centre the person with intellectual disability during the decision-making process, and to be afforded the flexibility and understanding to utilise a guide to SDM in a manner that befits the situation at hand, rather than be required to rigidly follow a formal procedure. Other literature has noted that in the decisional process, flexibility is paramount and that it is not possible to employ precisely the same support methods with every person with intellectual disability, as each has differing support needs and methods of communication (Bigby, Bould, et al., 2019; Bigby et al., 2009; Bigby et al., 2022a; Bigby & Wiesel, 2015; Nicholson et al., 2021).

7.5.1 Strengths and Limitations

The strength of this research primarily lies in its novelty, particularly within an Irish context. The information gathered during the focus groups and workshops will be used to form the basis of a guide for stakeholders to increase their knowledge and use of SDM in an Irish setting, which will be particularly valuable in light of the recent ADMA commencement. The multistakeholder nature of the study serves as another strength, as it allowed for the collection and analysis of all perspectives of the support circle including the adult with intellectual disability themselves. This led to productive and respectful discussions of the topic, and provided a forum for them to be discussed in detail.The study was limited by the small sample size present in the first workshop, which precluded the changing of groups in the manner expected during a World Café event. Furthermore, the unavailability of any frontline care staff meant their opinions were not represented in the findings. However, the conversations that were stimulated were still productive and detailed, and led to important discussions between supervisory staff, families, and people with intellectual disabilities about a crucial topic that is frequently a source of tension in disability services. Another limitation was the noted reticence of participants with intellectual disabilities to express their views, which suggests the power differential wase not managed as effectively as hoped. Future research might mitigate this by offering training in World Café methods to participants with intellectual disabilities to ensure they are more comfortable with the format of a World Café, involving them as table hosts to encourage them to lead the discussions, or by applying other methods of data collection such as photovoice that provide more opportunities for participants with intellectual disabilities to represent their views more confidently.

7.5.2 Conclusion

The multistakeholder discussions that took place during the workshops reinforced the focus group findings. Professional carers desired clear information on what the new legislation would mean for them when supporting clients in an official capacity, and reiterated the need for family members and wider societal institutions to be brought up to speed alongside them. Family carers were anxious to establish their place in the potential new process and re-emphasised their unique and intimate knowledge of the person and their will and preferences. Participants with intellectual disabilities were pleased with the findings presented, and wanted to continue to have opportunities to learn new skills alongside supporters of their choosing. In conclusion, participants remained enthusiastic about the topic of SDM and the concept of a guide to SDM for use on a collaborative basis. Key priorities shared by stakeholders included pairing the guide with training opportunities, clarification on the roles and responsibilities of different decision-making supporters within the guide’s structure, and ensuring the guide was constructed in a manner that was mindful of existing care dynamics that would need to be integrated into a new tool. All were vehement about the need for the findings of this research project to be disseminated to relevant government bodies, as the general consensus was that it would be a wasted exercise if it were not applied as policy. These findings finish this project’s primary data analysis, and have been synthesised along with the review, survey, scan, and focus group results to form the basis for final recommendations for the construction of a guide to SDM, the details of which may be found in the next chapter (Chapter 8).

Chapter 8- Development of Recommendations for the Construction of a Guide to SDM

8.1 Chapter Summary

This chapter aims to develop key recommendations informed by the findings of this research project to be considered when developing a guide to SDM to be used by people with intellectual disabilities in Ireland and their decision-making supporters. It first details how the results from the five phases of research described in this thesis were drawn together by examining where the findings were convergent, complimentary, silent, or dissonant with respect to SDM. The discussion then further synthesises these factors through summarising and organising them into collective key recommendations for the construction of a guide to SDM. Finally the chapter discusses these recommendations with respect to previous research and forms final conclusions on the implications of the findings.

8.2 Synthesising the Five Phases

In order to amalgamate the findings from the five phases of this research project, triangulation of the results across the phases was employed (Flick, 2004; Hopf et al., 2016; Santos et al., 2020; Triangulation, 2014). Firstly, the results and conclusions from each phase were examined with respect to the overall research question, with key conclusions identified. These key conclusions were then examined with respect to each other, with differences and similarities identified (Hopf et al., 2016). This examination was then summarised by looking at how these conclusions converged (i.e. where the findings of the different research phases came to similar conclusions about the topic), where they complemented each other (i.e. where the findings of the different research phases came to different conclusions about the topic, but which were in overall agreement or reinforced each other), areas of silence within the data (i.e. potential areas of importance relating to the topic at hand that were not addressed by the research findings), and where the phase conclusions were dissonant (i.e. areas where the findings of the different research phases came to different conclusions about the topic, which were in conflict with one another) (Hopf et al., 2016). These conclusions were then further synthesised into overall key recommendations for the construction of a guide to SDM as informed by the five phases of the research project in the discussion section of this chapter.

8.2.1 Congruent Findings

There were many points of congruence across the five phases of research. The findings across all phases indicated that the person with intellectual disability should be at the centre of the decisional process. Furthermore, they indicated the need for an integrated approach to decisional support that included all members of the support system. Examples were present in the systematic review, focus groups, and multistakeholder workshops of family carers providing meaningful and necessary information to professional carers to provide greater context for the preferences and desires of the person with intellectual disability they cared for. People with intellectual disabilities expressed that trust and security with supporters was essential for them in decision-making in the review, focus groups, and multistakeholder workshops. The review, survey, focus groups, and multistakeholder workshops also showed congruence in the desire expressed by people with intellectual disabilities to be taken seriously by supporters and to learn skills that would allow them to participate as adults in wider society. Evidence was present in all five phases that bureaucratic practices hampered the ability of people with intellectual disabilities and their supporters to flexibly execute necessary steps in decisional support, whether through an overt reliance on paperwork, strict focus on formal support methods, lack of clarity on how best to proceed together to assist in decision-making, or the absence of a concrete policy within the disability service regarding decisional support. This was further supported by the congruence displayed across the five phases regarding a lack of specific methods of operationalisation of SDM in the Irish context. Finally, across the review, focus groups and multistakeholder workshops, participants emphasised their desire to understand the role they were to play within the support context. Professional carers were concerned with overstepping with family but wished to have more clarity on how they could advise them, while family carers wanted a designated person to go to when wishing to discuss SDM. People with intellectual disabilities desired having more consistent support, as high staff turnover among professional carers disrupted established relationships. This issue of service change was seen in the review, which included papers discussing the impact of poor policy within disability services, as well as in the survey in which respondents detailed struggling to maintain contact with services or clients due to a lack of remote service access.

8.2.2 Complementary Findings

Clear threads of complementary findings were present throughout the research, with common topics discussed by all stakeholders. The review outlined the distinct gap in the literature pertaining to specific examples of SDM being employed in the daily, informal decisions of people with intellectual disabilities. This was complemented by the lack of practical information on SDM for stakeholders in Ireland highlighted by the environmental scan. In continuation of this, in the focus groups all family and professional carers stressed the lack of concrete information they had access to with regard to the best way to execute SDM, which participants with intellectual disabilities agreed with through their discussion of how they were supported by carers. Finally, in the multistakeholder workshops, participants’ desire for clear guidelines, alongside a designated person within the service who they could consult regarding SDM complements this finding, as it further underscores stakeholders' desire for more concrete assistance.

Further complementary data may be observed via the discussions of the types of decisions people with intellectual disabilities were most often supported to make. The review highlighted that much of the decision-making carried out by people with intellectual disabilities was everyday in nature. This was complemented by the discussions within the survey and focus group data, where carers highlighted supporting people to pursue daily decisions such as engaging in particular hobbies they enjoyed, attending social events they wanted to partake in, or holidays they wished to go on. The findings of the multistakeholder workshops aligned with this via the assertions of participants that they felt it was important that any guide to SDM was not solely rooted in a stiff, formal process and could be used as aninformal starting point by the person themselves or anyone in their support circle. The environmental scan complements this assertion via its content revealing an emphasis on formal methods of enshrining decisions in legal documentation regarding SDM in light of the ADMA commencement, such as that of an advance care directive or enduring power of attorney, with less formal advice on SDM not found.

8.2.3 Silence within the Findings

Instances of silence were observed within the data. No discussion pertaining to the cultural context, socioeconomic factors, or prevelance of service access across the country was evident. Despite including research conducted in a number of different countries, there was little evidence within the systematic review pertaining to the impact of geographical location on opinions surrounding SDM. It should be noted that only papers written in English were included, which may have limited the cultural scope of the information included. All focus group and multistakeholder workshop participants were white Irish, precluding any discussion of the role of cultural differences in the execution of decisional support in their conversations. Within the Irish context specifically, an emphasis on an urban setting was maintained, with no exploration of rural versus urban access to resources found in the survey, environmental scan, focus groups, or feedback sessions. It is possible that knowledge of SDM and access to a stronger support system might be impacted by proximity to services. Finally, despite parental age being a distinct part of the cultural context in decisional support within the Irish context, silence was evident throughout all phases through the lack of exploration of younger versus older parents regarding the degree of their engagement with SDM, which was impeded by the age profile of included family participants, who were all older parents. It is possible this element would have added further context to discussions surrounding the uptake of SDM as a method of support. These unaddressed factors limited the ability of the research to take into account any social or cultural context that might have given a better understanding of the state and types of decisional support employed in Ireland, as well as informing a more thorough and generalisable set of recommendations for the construction of a guide to SDM. Finally, there was an absence of discussion of training for stakeholders with respect to SDM. Some training was uncovered in the review process in the form of the La Trobe Framework, however it focused solely on family and professional carers, with no corresponding training offered for people with intellectual disabilities. Subsequent phases also did not identify any current training being offered in Ireland to educate or prepare people with intellectual disabilities or their carers with respect to SDM. This highlights a gap in the current rollout of the ADMA, as education and training is required for stakeholders to afford them the opportunity to learn and apply techniques needed for effective uptake of SDM.

8.3.4 Dissonance Within the Findings

The findings were largely complementary or congruent in nature, but there were some areas of dissonance to be observed. Initial reports of the relationships between family and professional carers within the review papers, survey responses, and focus group discussions appeared to portray them as largely negative, with interactions fraught with misunderstanding and suspicion, which suggests that significant work would have to be done to ensure a smooth relationship between all members of a support circle during the decision-making process. However, the multistakeholder workshop findings contradicted this, as the discussions observed between these groups were largely positive and respectful. Both family and professional carers desired to hear what the other had to say and were open to frank discussions on the nature of each others' experiences. This would indicate that the potential for a harmonious, person-centred approach to SDM is more feasible than initial data collection would have suggested. Secondly, within the review papers, there was a noted emphasis on negative experiences for stakeholders as they discussed everyday decision-making. These results suggested that poor experiences with disability services, and negative life events were predominant for people with intellectual disabilities and their carers. The primary data collection contradicted this initial impression, however. While negative experiences were recounted, there were also many positive reports, such as in the survey when respondents reported that COVID-19 restrictions afforded people with intellectual disabilities more time to decide upon new hobbies, or in the focus groups where people with intellectual disabilities expressed their satisfaction with their support system and explained the differing roles occupied by professional and family carers in their decisional processes. This would suggest that research with people with intellectual disabilities and their supporters may benefit from focusing on the more positive aspects of their interrelationships, rather than emphasising the more problematic aspects.

8.5 Discussion

This synthesis provides a rich overview of the aspects of decisional support that are most important to people with intellectual disabilities, their family carers, and professional carers as identified in this research project. It highlights how current methods of support are operationalised by stakeholders, as well as the changes and considerations they desire to see as SDM becomes more prevelant in Ireland under the ADMA, including the continuation of person-centredness as an approach, retaining a flexible attitude to support, ensuring a user-friendly approach to resources, clarifying the role of supporters with respect to each other within the SDM process, and acknowledging the need for an informal support process for everyday decisions. SDM is fast gaining traction both in Ireland and across the world as a favoured method of decisional support, due to its emphasis on person-centredness, acknowledgement of individual needs and circumstances, and goal of empowering the supported person in selecting their own tailored decisional support circle (Arstein-Kerslake et al., 2017; Blanck & Martinis, 2018; Browning et al., 2021). However, further investigation into how the availability of resources and the cultural and socioeconomic circumstances of stakeholders might affect its function is required, as well as a greater push for tailored educational and training programmes in SDM. While Ireland has adapted to a person-centred approach to support via tools such as person-centred plans and regular meetings with supporters, there is a lack of consensus on how to enable adults with intellectual disabilities to select their own support circle (Chadwick et al., 2013; McCausland et al., 2019; McCausland et al., 2018; Murphy & Bantry-White, 2021). The transient nature of professional carers' positions within disability services is also a source of confusion and tension for people with intellectual disabilities and their family carers, as it disrupts any current support circles. Finally, no resource or training currently exists to provide clarity on how SDM might be applied by people with intellectual disabilities in Ireland and their decision-making supporters outside of a formal context. Therefore, for SDM to be applied in an effective manner in the Irish context, several key factors must be considered. Five key recommendations have thus been compiled here to reflect the synthesis of the five phases. These key recommendations seek to distill the most important common aspects identified in this research project to be considered in the development of a guide to SDM for stakeholders in Ireland.

8.5.1 Key Recommendations for the Construction of A Guide to SDM

8.5.1.1 Centring the Person

The most common preference for decisional support that arose throughout the project was the importance of centring of the will and preferences of the supported person. Effective decision-making reported in the systematic review had a common thread of respect for the voice of the person with intellectual disability. Within the COVID survey, respondents all emphasised the importance of personal plans and communication with the person during decision-making. The focus groups echoed that observation, with professional and family carers detailing methods of support based upon knowing the person well and listening to what they had to say. Participants with intellectual disabilities themselves corroborated this, and stressed the need for supporters they knew and who knew them. This key recommendation was reiterated in the multistakeholder workshops. A central tenet of SDM is allowing the supported person to choose who supports them, and what they would like to do during the decision-making process. This tenet must be remembered and enshrined within any guide created, or there is a risk of the supported person remaining unheard.

8.5.1.2 Retaining Flexibility

In order for a guide to decision-making to be effective, it must be flexible in its application. A recurring barrier across stakeholder groups in all phases of research was the issue of bureaucracy within the disability system. In the review and environmental scan, there was an emphasis placed upon formal processes of support that required meetings or documentation to execute. Participants within the focus groups and feedback sessions agreed with this. However, decision-making is an everyday process for people with intellectual disabilities. Therefore, the allowance of a more informal, day-to-day approach within the guide is an important consideration. Furthermore, disability services in Ireland come in many forms, including day services, residential services, and outreach services. These services require carers to have differing skill sets, and cater to adults with varying levels of disability. In conjunction, the guide must stress the importance of applicability with respect to the level of assistance the person being supported desires to have. Some adults with intellectual disabilities need little to no help to make a decision, while others may require help to decide during small everyday tasks. Stakeholders regularly expressed that they did not believe a one-size-fits-all approach would be possible within the remit of a guide- as such, this flexibility must be built in from the outset.

8.5.1.3 Clarify Roles of Supporters

Central to the discussion of SDM within this project was the acknowledgement of the multi-layered sources of support for people with intellectual disabilities during the decision-making process. A common theme observed within the research was a sense of disconnect and mistrust between professional and family carers. Family carers felt that professional carers did not wish to include them in conversations with the person with intellectual disability, while professional carers felt they had to balance what they thought the person wanted with preventing undue interference from family carers, whose satisfaction they often felt superceded that of their clients within the service. Often, this disagreement between professional and family carers formed the basis of a breakdown in the decision-making process, with the potential for the voice of the person with intellectual disability to be lost. Therefore, to be effective, the guide must emphasise the value of cooperation between all stakeholders. The World Café reinforces this, as when carers sat down together to discuss SDM as a topic alongside participants with intellectual disabilities, the conversations were productive, respectful, and motivated. Furthermore, by clarifying the role of different members of the support circle, cooperation can be increased by displaying the most effective way supporters can work together. In addition, the appointment of a specific SDM expert within disability services would provide a point of contact for people with intellectual disabilities and their supporters to consult in times of uncertainty.

8.5.1.4 A User-Friendly Format

A common theme among the phases of data collection was that of the accessibility of materials. The review emphasised the preference of people with disabilities for materials that they could read and understand, and for decisional processes to be conducted with their understanding in mind. The results of the environmental scan showed a dearth of accessible, easy-read material for adults with intellectual disabilities regarding SDM and its application in daily life. Similarly, in phases four and five, all stakeholder groups commented that it was far easier to read and understand information if it was presented in a jargon-free format, with accompanying infographics, pictograms, or flowcharts. With this in mind, in order for a guide to SDM to be as effective as possible, it should be formatted in a user-friendly manner. All participants in the focus groups and multistakeholder workshops indicated that they would be reluctant to use a guide that was bulky, jargon-heavy, or required in-depth specialist knowledge to understand. They also requested that the guide be broken up into discrete sections to allow for quick and easy application during practical usage. Furthermore, adults with intellectual disabilities expressed a desire to be able to use and read the guide unassisted if needed. A format that makes use of summaries, pictograms, and flowcharts would allow for a casual, user-friendly approach to SDM.

8.5.1.5 An Informal Process

All phases of this project emphasised the importance of acknowledging the everyday nature of decision-making for people with intellectual disabilities. There was a discussion throughout the research phases of the undue emphasis on formal processes when people with intellectual disabilities desired to make decisions. The review papers focused largely on difficult, negative circumstances surrounding decision-making, while the environmental scan failed to locate any day-to-day guides to decision-making. Within the focus groups and multistakeholder workshops, all participants expressed frustration with the continued insistence on formal channels of decision-making within the disability services. However, the majority of decisions made by people with intellectual disabilities do not require extensive meetings or set processes. Therefore, an effective guide to SDM would acknowledge this, and would encourage a relaxed, informal approach to decision-making.

8.6 Conclusion

Collectively, the findings of this research project highlight a lack of clarity surrounding SDM and how it can be applied in the lives of people with intellectual disabilities in Ireland, their family carers, and their professional carers. Throughout its phases, there has been a clear emphasis placed upon increasing the education and training of stakeholders with respect to SDM, while also encouraging them to draw upon their own experiences and what has worked for them with respect to support to allow for a nuanced, flexible adoption of new techniques. Future examination of this topic would benefit from wider ranging data collection to encompass all geographical and socioeconomic differences in access to disability service, and potential cultural factors that might affect how support is applied. Finally, development of these recommendations into a concrete, useable resource would allow for the creation of a necessary bridge between the current methods of support employed by people with intellectual disabilities and their supporters, and new aspects of support offered by SDM.

Chapter 9: Overall Discussion

9.1 General Discussion

SDM as a method of support offers the opportunity for fundamental change in the lives of people with intellectual disabilities, in Ireland and worldwide. Its focus on encouraging autonomy, self-actualisation, and personal empowerment through affording the person with intellectual disability the chance to be a causal agent in their own life encourages a shift away from more paternalistic or best interests approaches to decisional support, and encourages regular, ongoing conversation between the person and their support circle (Arstein-Kerslake et al., 2017; Gudelytė et al., 2024; Kohn & Blumenthal, 2014). With respect to this, the circumstances in which this research was undertaken represented a time of key change for Ireland with respect to its attitude to the right of persons with intellecual disabilities to make their own decisions. Though aspects of person-centred support have long been present here, the adoption of the ADMA has firmly enshrined this approach to support in legal statute, and has removed significant barriers to such an approach, namely that of the ward of court system (Center for Public Representation, 2022). However, there are many nuanced, complex, and often contradictory factors to be considered when discussing SDM in this context. This shift in Irish legislation has been slow to translate to relevant stakeholders and wider societal institutions (Phelan, 2023). With this in mind, the outcomes of this project indicate that adults with intellectual disabilities and their carers would value greater input into the new legislative framework are willing to work together in order to establish a more cohesive support system, and welcome the creation of a guide to assist them in executing SDM in their daily lives. However, the outcomes of this project also suggest that further groundwork is needed to enable them to engage more effectively with the new system.

Although the ADMA legislation is important to consider as a contextual factor, and has been frequently discussed throughout the research process, it is not the most important aspect of ensuring continued improvement in realising the decisional rights of Irish people with intellectual disabilities, as the majority of decisions they make are casual and do not require a legal or formal process (Harding & Tascioglu, 2017). However, conversations with stakeholders throughout the project, alongside analysis of secondary data such as the review and environmental scan, revealed that for Irish stakeholders, the concept of SDM as a support process appears to be firmly tied to the ADMA. This resulted in most participants claiming they had little understanding of SDM as a specific concept outside the bounds of this legislation, and often assumed it was itself a legal process, prompting concern that it would become another aspect of paperwork for them to engage with. This was concerning to encounter, as a key finding of this research, as discussed in chapters 7 and 8, was the need for less formal approaches to decisional support in the lives of people with intellectual disabilities, as much of their everyday decision-making precluded the need for such a formal process. An aspect of current information campaigns that might have contributed to this view of SDM as a legal process is the government’s continued emphasis on legal documentation, such as enduring power of attorney or advance care directives, rather than representing the implications of this shift in the rights of people who require assistance in decision-making, as can be seen in the results of chapter 5, the environmental scan. Furthermore, the DSS, though an important and necessary body, appears to further underscore the apparent formality of SDM through having a tiered system as set out by the ADMA, in which people requiring support must operate. In addition, there is, to date, a lack of informal advice or support for people with intellectual disabilities on their website or in their information campaigns, which may contribute to stakeholder misunderstandings regarding the purpose of SDM (Decison Support Service, 2023; Decision Support

Service, 2023). In order for SDM to be adopted with more clarity and enthusiasm by people with intellectual disabilities in Ireland and their carers, further information and resources should be developed which emphasise that SDM need not be a strict, formal process, and that it does not only exist in the context of a legal framework. The emphasis on including the whole support system and on the need for flexibility displayed in the key recommendations in Chapter 7 underscores this, and indicates a clear desire to deformalise the decisional process on the part of stakeholders.

To facilitate this needed shift in understanding of the role of SDM, further information and training for stakeholders is needed to increase engagement and understanding. In particular, professional carers repeatedly stressed the need for education and training which included family carers, not merely disability staff, or focused only the person with intellectual disability themselves, such as the new self-advocacy training, Speak Up Speak Out, recently launched by Inclusion Ireland (Inclusion Ireland, 2024). This suggestion of family carer inclusion was borne from professional carers observing that previous changes in methods of support made without the understanding and input of family carers would regularly result in families feeling pushed out and unheard. This was echoed in conversations with families themselves, who also expressed frustration at the lack of information given to them regarding the mechanics of the support process within services, and the findings from the environmental scan, which revealed a distinct lack of resources aimed at family carers or people with intellectual disabilities themselves. Previous literature has similarly alluded to this, with family carer participants often claiming that services would alter care and support arrangements with little conversation with the rest of the person’s support system (Bigby, 2008; Chadwick et al., 2013; Lafferty et al., 2016). The creation and dissemination of a resource or training programme would further underscore the key aspect of SDM as a method of support which encourages the use of a multi-layered support system of the person’s choosing, particularly as most people with intellectual disabilities have both familial and professional supports which require integration in order to function efficiently (Kohn et al., 2012; Nuri et al., 2024; Stainton, 2016). This can be seen when comparing the recommendations for the construction of such a guide or resource with the structure of pre-existing training programmes such as that of the La Trobe Framework.

The La Trobe Framework's seven-step process in supporting decision-making captures many of the aspects reported by participants in this research project (Douglas & Bigby, 2020). Establishing a support circle composed of trusted carers, placing the will and preference of the supported person at the centre of the process, consideration of a formal process only if required, researching solutions, and considering alternatives are all factors that arose within this research as well as the La Trobe research (Bigby et al., 2022a, 2022b; Douglas & Bigby, 2020). A common thread of respecting the person's right to be involved, a strong emphasis on collaboration, and a desire for the process to remain flexible and informal can be seen in both (Bigby et al., 2022a; Carney et al., 2023; Douglas & Bigby, 2020). These tenets are echoed in Browning and colleagues' paper on Canadian practices, which identified five core factors essential to an effective SDM process: the specific traits of the supported person and their supporters with respect to the decisional process, the quality of the support relationship, the environment in which the decision was being made, and the nature and consequences of the decision (Browning et al., 2021). These factors were reflected in phases four and five of this project, with particular emphasis on the need for nuance, flexibility, and a healthy collaborative approach to the process. In the US, the National Resource Center also offers such perspectives in the Arc project, located in the state of Virginia (The Arc of Northern Virginia, 2023). Within this pilot programme, an emphasis was once again placed upon the will and preferences of the person being supported above all else (The Arc of Northern Virginia, 2023).

However, although these international examples bolster the findings of this research project, the frameworks and approaches described therein are embedded within their own national contexts, and do not address all aspects of SDM. The La Trobe Framework was created with Australia’s National Disability Insurance Scheme (NDIS) in mind, a government scheme that encompasses all matters of disability in Australia, from disability allowance payments to allocation of professional care (Lloyd et al., 2023). This naturally comes with its own rules, regulations, and procedures that would affect how Australian carers and people with intellectual disabilities would contextualise decisional support on a daily basis (Horsell, 2023). Furthermore, although the La Trobe Framework offers a comprehensive, structured approach to educating carers on how to effectively support a person with cognitive disabilities in decision-making, it does not contain any resources or training for the person with cognitive disability themselves (Bigby et al., 2022a; Douglas & Bigby, 2020). With respect to the Canadian approach, although Canada was the first country in the world to enshrine the right of persons with intellectual disabilities to make decisions, the policy and practice employed there differ by province, with many continuing to allow guardianship arrangements to take place (Browning et al., 2021). This is also the case for many states in the USA, whose laws and regulations regarding the decisional rights of adults with intellectual disabilities change depending on the state body’s perspective on the topic (Blanck & Martinis, 2018; Martinis et al., 2023). As such, the National Resource Center does not have one overarching approach to SDM, and much of its resources are aimed at changing the current legal landscape of each state (Martinis et al., 2023). With respect to the Virginian pilot project, much of its focus consisted of the introduction of PCPs, a resource that has been long established in Irish disability services (The Arc of Northern Virginia, 2023). With all of this in mind, it is clear that although Ireland can, and should, take inspiration from these international examples of SDM, its unique constitution, changing legal landscape, and disability service set-up requires its own personal, tailored approach to SDM.

9.2 Implications of the research

Through the results of this research, it is clear that a gap in the provision of support in SDM for people with intellectual disabilities, their family carers, and their professional carers exists in the Irish context. Stakeholders desire more clarity, resources, and information on SDM to better understand the new legislation. With respect to this, more diverse information campaigns and educational and training programmes should be created to assist people with intellectual disabilities in Ireland and their carers in adopting the principles of SDM in their everyday lives. A further recommendation would be that the DSS examines how it might offer informal as well as formal support in the decisional process, and perhaps create resources for informal decision-making. This would assist in reducing the still prevailing misperception that all decisions made by people with intellectual disabilities require a formal, sit-down process to be executed. To model these new approaches to support, successful SDM programmes such as that of the La Trobe Framework could be used as inspiration alongside the recommendations seen in this project. The La Trobe Framework's focus on encouraging carers to think differently about how they approach support in daily life could contribute to the ongoing shift in societal attitudes regarding the ability of people with intellectual disabilities to make their own decisions (Douglas & Bigby, 2020).

Disability services could also apply the findings of this project to their current practices, and encourage further integration between family and professional carers to encourage a more rounded support circle approach. This new approach should be flexible in its execution, and allow for nuance in the application of the findings of this project in order to take into account the differing levels of support needs of people with intellectual disabilities. Services might benefit from encouraging family carers to participate in educational workshops, or roundtable discussions, in order to increase the dialogue between them and the family. This might increase the effectiveness of the support circle for the person with intellectual disability, and improve communication between respective carer groups. This research displayed that giving the different stakeholder groups the opportunity to sit down with each other, and to hear what the other has to say about providing support in decision-making, resulted in a productive, motivated outcome. Furthermore, professional carers repeatedly expressed throughout the project that family carers deserved to be included in service conversations about changes in decision support policy and practice, in order to prevent them from feeling pushed out or unimportant. This expands upon previous research into the relationship between family carers and disability services, which showed that services which prioritised communication and integration of the support network between the client’s home and their professional supporters reported more satisfaction among clients, and a more productive relationship between family and professional carers (Bigby et al., 2011; Bigby et al., 2022b; Chadwick et al., 2013).

Within the broader theoretical context, this research makes contributions to further understanding of the role played by relational dynamics in the lives of people with intellectual disabilities with respect to gaining autonomy and fostering self-determination. The provision of opportunities to act as causal agents within their own lives leads to greater life satisfaction for people with intellectual disabilities (Curryer et al., 2020; Shogren & Broussard, 2011; Wehmeyer et al., 2017). The application of methods of support by carers that encourage and facilitate autonomy and self-determination have been identified as a key factor for increasing these opportunities (Nonnemacher & Bambara, 2011; Stancliffe, 2001, 2020; Taylor et al., 2019; Wehmeyer, 2020). Many people with intellectual disabilities can and do make decisions independently; however, it is well documented that many others require more dedicated assistance to carry out decision-making in their daily lives (Shogren et al., 2017). Therefore, when examining the role of self determination in the lives of people with intellectual disabilities, the relational dynamics between the person and their support circle are fundemental in understanding the most effective means of facilitating autonomy (Dowling et al., 2019). Wong and colleagues examined the role of dynamic equilibrium in the relational dynamics between the person with intellectual disability, their family carers, and professional carers. They observed that more effective support circles consisted of those who were willing to allow the power within these dynamics to shift regularly between supporters and the person themselves as the situation required, which resulted in the person with intellectual disability having more opportunities to foster higher levels of sef-determination within these relationships (Wong & Chow, 2021). The research presented in this thesis extends our understanding of this by examining the role of supporters with respect to each other as well as to the person in need of support. Within the data, professional and family carers discussed each other in the context of how they felt their relationship affected their ability to support the person with intellectual disability. Barriers to an effective support relationship reported included family carers undermining professional carers' efforts to facilitate decisions clients wished to make by convincing them not to carry them out, and professional carers seeking to support the person in decision-making by excluding family carers from the process. Upon examination of the focus group data, the interplay between carer groups and its effect on the effectiveness of the support circle was further underscored through the finding that the barriers and facilitators identified by all three stakeholder groups were frequently alternate sides of the same coin. Therefore, it can be determined that a key implication of this research project lies in the assertion that in order to better understand how to foster self-determination and autonomy in people with intellectual disabilities, it is essential to contextualise that understanding within the relational dynamics of the support circle. All of these findings could also be applied to other groups that may require assistance in decision-making, and avail of professional or family carers to provide that assistance, such as people with traumatic brain injuries, dementia, or mental health conditions that may result in a temporary difficulty with decision-making.

9.3 Strengths and Limitations

This project’s key strength lies in its novelty and timeliness in an Irish context, and internationally. To the author’s knowledge, there is no current research encompassing stakeholder perspectives on SDM and their expectations and desires going forward. This project provides crucial information on this topic, and provides stakeholder-led recommendations for next steps in integrating SDM into Irish society. A further strength is the inclusion and integration of the views of all members of the support system- the person with intellectual disability themselves, family carers, and professional carers. This multistakeholder approach allowed the project to examine the preferences, perspectives, and needs of the entire support circle as well as the supported person, resulting in a set of nuanced recommendations and conclusions. Furthermore, it allowed stakeholders to present their current support methods, and to clarify what was currently effective for them in their lives. The process of receiving feedback from participants on the initial conclusions of the focus groups in a multistakeholder setting was also a strength displayed by the project, as it ensured that the final recommendations for guide construction were representative of the thoughts and feelings of all participants, and gave them an opportunity to discuss SDM together.

However, the project was limited by not having a fully inclusive research process where people with intellectual disabilities were involved at all stages of the research, not merely data collection and feedback. A greater emphasis on co-research would be a strong addition to any future research examining SDM in Ireland, or internationally. Furthermore, of the participants with intellectual disabilities that were included, all were considered to have a mild to moderate intellectual disability. However, family carers and professional carers of people with severe to profound intellectual disabilities were included, and communicated their perspectives on what would be required to support this cohort to make decisions through their experience as carers. Finally, the bulk of primary data collection was completed before the commencement of the ADMA in April 2023. This means that the project has been unable to encapsulate any changes that may have occurred within the included disability services, the online resources available, or the lives of participants since its commencement. However, this project represents a snapshot of a time of great change in the lives of people intellectual disabilities and their carers in Ireland, and offers a valuable record of their expectations and desires before the commencement of the ADMA.

9.4 Suggestions for Further Research

Further research into this topic should build on the recommendations set out in this thesis. An investigation into how these recommendations may be applied and and developed into a working resource is necessary, with this development taking place with the continued input and perspective of stakeholders. This future research should be fully inclusive, and employ people with intellectual disabilities as full members of the research team to be engaged at all stages of research. Methods of broad dissemination of the resource should be investigated through the creation of an accessible pilot programme that can be made available to a wide number of stakeholder groups across the country. Future conversations about this possibility should include the lobbying of government bodies responsible for disability services in order to bring the recommendations and resources to national attention, with the outcomes of this research utilised as a starting point for such conversations. More broadly, future research should endeavour to capture the positive experiences and relationships of people with intellectual disabilities with respect to SDM, and to focus more regularly on including the entire support circle in the research to better understand the role of relationship dynamics in the execution of decisional support. Furthermore, people with intellectual disabilities should be more integral to the research process, and be included as co-researchers and experts through lived experience. Inclusive research represents a key method for furthering public knowledge of the mechanisms, requirements, and future direction of research on SDM, and intellectual disability as a whole.

9.5 Conclusion

This project represents an important step towards greater use of SDM in Ireland through encouraging conversations with people with intellectual disabilities and their family and professional carers. It demonstrates the importance of communication between all stakeholders in order to facilitate a more rounded, nuanced understanding of what support looks like in practice. The inclusion of multiple members of the person with intellectual disability’s support system showed the dynamic, flexible nature of decisional support, and demonstrated that it is not a black and white process, but one that requires careful consideration of personal needs and circumstances, and an openness in conversation between all involved. The recommendations set out in this project should be carried forward and considered in future endeavours to improve the nature of decisional support in an Irish context in order to fully represent the perceptions, experiences, and needs of stakeholders. This must be the start of a productive conversation about how people with intellectual disabilities can be afforded greater respect and independence in Irish society through the use of SDM.

References

Abedi, H., Hossenigolafshani, S. Z., & Ahmadi, F. (2013). Reflection on the experiences of disabled people: The society as a cause of growth or barrier. *Journal of Qualitative Research in Health Sciences*, *2*(3), 248-260.

Adams, P. (2006). Exploring social constructivism: Theories and practicalities. *Education*, *34*(3), 243-257.

Ajbar, A., Shepherd, T. A., Robinson, M., Mallen, C. D., & Prior, J. A. (2021). Using Google Trends to assess the impact of Global Public Health Days on online health information-seeking behaviour in Arabian Peninsula. *Journal of the Egyptian Public Health Association*, *96*(1), Article 4. https://doi.org/10.1186/s42506-020-00063-w

Alston, B. (2017). Towards supported decision-making: Article 12 of the convention on the rights of persons with disabilities and guardianship law reform. *Law in Context*, *35*(2), 21-43.

Aluwihare-Samaranayake, D. (2012). Ethics in qualitative research: A view of the participants' and researchers' world from a critical standpoint. *International journal of qualitative methods*, *11*(2), 64-81.

Alvesson, M., Sandberg, J., & Einola, K. (2022). Reflexive design in qualitative research. *The SAGE handbook of qualitative research design*, 23-40.

Amerio, A., Aguglia, A., Odone, A., Gianfredi, V., Serafini, G., Signorelli, C., & Amore, M. (2020). Covid-19 pandemic impact on mental health of vulnerable populations. *Acta Bio Medica: Atenei Parmensis*, *91*(9-S), 95.

Amor, A. M., Navas, P., Verdugo, M. A., & Crespo, M. (2021). Perceptions of people with intellectual and developmental disabilities about COVID-19 in Spain: a cross-sectional study. *Journal of Intellectual Disability Research*, *65*(5), 381-396. https://doi.org/10.1111/jir.12821

Andre-Barron, D., Strydom, A., & Hassiotis, A. (2008). What to tell and how to tell: a qualitative study of information sharing in research for adults with intellectual disability. *Journal of Medical Ethics, 34*(6), 501-506.

Antaki, C., Finlay, W., Sheridan, E., Jingree, T., & Walton, C. (2006). Producing decisions in service-user groups for people with an intellectual disability: Two contrasting facilitator styles. *Mental Retardation, 44*(5), 322-343.

Antaki, C., Finlay, W., & Walton, C. (2009). Choices for people with intellectual disabilities: Official discourse and everyday practice. *Journal of Policy and Practice in Intellectual Disabilities, 6*(4), 260-266.

Antaki, C., Finlay, W., Walton, C., & Pate, L. (2008). Offering choices to people with intellectual disabilities: an interactional study. *Journal of Intellectual Disability Research, 52*(12), 1165-1175.

Arnold, C. K., & Harris, S. P. (2024). Instrumental Support: Accounts from Adults with Intellectual and Developmental Disabilities. *Journal of Developmental and Physical Disabilities*. https://doi.org/10.1007/s10882-024-09981-5

Arstein-Kerslake, A. (2016). Legal capacity and supported decision-making: Respecting rights and empowering people. *U of Melbourne Legal Studies Research Paper*(736).

Arstein-Kerslake, A., Watson, J., Browning, M., Martinis, J., & Blanck, P. (2017). Future directions in supported decision-making. *Disability studies quarterly, 37*(1).

Australian Law Reform Commission. (2014). *Equality, capacity and disability in Commonwealth laws: Summary report*. Australian Law Reform Commission.

Bach, M., & Kerzner, L. (2010). A new paradigm for protecting autonomi and the right to legal capacity. Advancing Substantive Equality for Persons with Disabilities through Law, Policy and Practice. Law Commission of Ontario.

Barnes, C. (2018). Theories of disability and the origins of the oppression of disabled people in western society. In *Disability and society* (pp. 43-60). Routledge.

Bazilio, J., Pereira, J. d. A., & Silva, E. M. (2020). Generating meaningful conversation: World Café in strategic interprofessional planning in Continuing Education. *Revista Brasileira de Enfermagem, 73*.

Beadle-Brown, J., Hutchinson, A., & Whelton, B. (2008). A better life: the implementation and effect of person-centred active support in the Avenues Trust. *Tizard Learning Disability Review*, *13*(4), 15-24.

Beadle-Brown, J., Hutchinson, A., & Whelton, B. (2012). Person-centred active support–increasing choice, promoting independence and reducing challenging behaviour. *Journal of Applied Research in Intellectual Disabilities*, *25*(4), 291-307.

Bigby, C. (2008). Beset by obstacles: A review of Australian policy development to support ageing in place for people with intellectual disability. *Journal of Intellectual and Developmental Disability*, *33*(1), 76-86.

Bigby, C., & Anderson, S. (2021). Creating opportunities for convivial encounters for people with intellectual disabilities:“It looks like an accident”. *Journal of Intellectual & Developmental Disability*, *46*(1), 45-57.

Bigby, C., Bould, E., & Beadle-Brown, J. (2019). Implementation of active support over time in Australia. *Journal of Intellectual & Developmental Disability*, *44*(2), 161-173.

Bigby, C., Bowers, B., & Webber, R. (2011). Planning and decision making about the future care of older group home residents and transition to residential aged care. *Journal of Intellectual Disability Research*, *55*(8), 777-789.

Bigby, C., Clement, T., Mansell, J., & Beadle-Brown, J. (2009). ‘It's pretty hard with our ones, they can't talk, the more able bodied can participate’: Staff attitudes about the applicability of disability policies to people with severe and profound intellectual disabilities. *Journal of Intellectual Disability Research*, *53*(4), 363-376.

Bigby, C., Douglas, J., Smith, E., Carney, T., Then, S.-N., & Wiesel, I. (2022a). “I used to call him a non-decision-maker-I never do that anymore”: parental reflections about training to support decision-making of their adult offspring with intellectual disabilities. *Disability and rehabilitation*, *44*(21), 6356-6364.

Bigby, C., Douglas, J., Smith, E., Carney, T., Then, S.-N., & Wiesel, I. (2022b). Parental strategies that support adults with intellectual disabilities to explore decision preferences, constraints and consequences. *Journal of Intellectual & Developmental Disability*, *47*(2), 165-176.

Bigby, C., Webber, R., & Bowers, B. (2015). Sibling roles in the lives of older group home residents with intellectual disability: Working with staff to safeguard wellbeing. *Australian Social Work, 68*(4), 453-468.

Bigby, C., Whiteside, M., & Douglas, J. (2015). Supporting people with cognitive disabilities in decision making–Processes and dilemmas.

Bigby, C., Whiteside, M., & Douglas, J. (2019). Providing support for decision making to adults with intellectual disability: Perspectives of family members and workers in disability support services. *Journal of Intellectual & Developmental Disability*, *44*(4), 396-409.

Bigby, C., & Wiesel, I. (2015). Mediating community participation: Practice of support workers in initiating, facilitating or disrupting encounters between people with and without intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *28*(4), 307-318.

Black, L. A., & Roberts, P. (2009). People with a learning disability as trainers: Evaluation of a values based pilot training programme. *British Journal of Learning Disabilities*, *37*(2), 129-137.

Blanck, P. (2023). Supported decision-making: emerging paradigm in research, law, and policy. *Journal of Disability Policy Studies*, *34*(1), 3-7.

Blanck, P., & Martinis, J. G. (2015). “The right to make choices”: The national resource center for supported decision-making. *Inclusion*, *3*(1), 24-33.

Blanck, P., & Martinis, J. G. (2018). The right to make choices: supported decision-making activities in the United States. *The right to make choices: supported decision-making activities in the United States*, 27-37.

Boas, T. C., Christenson, D. P., & Glick, D. M. (2020). Recruiting large online samples in the United States and India: Facebook, mechanical turk, and qualtrics. *Political Science Research and Methods*, *8*(2), 232-250.

Boyland, J. R. (2019). A social constructivist approach to the gathering of empirical data. *Australian counselling research journal*, *13*(2), 30-34.

Brady, A. M., Burke, M. M., Landon, T., & Oertle, K. (2019). Siblings of adults with intellectual and developmental disabilities: Their knowledge and perspectives on guardianship and its alternatives. *J Appl Res Intellect Disabil*, *32*(5), 1078-1087. https://doi.org/10.1111/jar.12597

Brady, A. M., Burke, M. M., Landon, T., & Oertle, K. (2019). Siblings of adults with intellectual and developmental disabilities: Their knowledge and perspectives on guardianship and its alternatives. *Journal of Applied Research in Intellectual Disabilities*, *32*(5), 1078-1087.

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative research in sport, exercise and health*, *11*(4), 589-597.

Braun, V., & Clarke, V. (2021). One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative research in psychology*, *18*(3), 328-352.

Braun, V., Clarke, V., Boulton, E., Davey, L., & McEvoy, C. (2021). The online survey as a qualitative research tool. *International Journal of Social Research Methodology*, *24*(6), 641-654.

Brennan, D., Murphy, R., McCallion, P., & McCarron, M. (2018). "What's going to happen when we're gone?" Family caregiving capacity for older people with an intellectual disability in Ireland. *Journal of Applied Research in Intellectual Disabilities*, *31*(2), 226-235.

Bronfenbrenner, U. (2000). *Ecological systems theory*. American Psychological Association.

Brotherton, M., Stancliffe, R. J., Wilson, N. J., & O'Loughlin, K. (2020). Australians with intellectual disability share their experiences of retirement from mainstream employment. *Journal of Applied Research in Intellectual Disabilities*, *33*(5), 905-916.

Brown, D., & Mallett, S. (2021). Environmental scan part 1: Current research and interventions to promote economic participation of people with disability. In: Brotherhood of St. Laurence, Melbourne. Viewed.

Brown, I., & Brown, R. I. (2009). Choice as an aspect of quality of life for people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, *6*(1), 11-18.

Browning, M., Bigby, C., & Douglas, J. (2021). A process of decision-making support: Exploring supported decision-making practice in Canada. *Journal of Intellectual & Developmental Disability*, *46*(2), 138-149.

Buhagiar, S., & Azzopardi Lane, C. (2022). Freedom from financial abuse: persons with intellectual disability discuss protective strategies aimed at empowerment and supported decision-making. *Disability & Society*, *37*(3), 361-385.

Bumble, J. L., & Carter, E. W. (2021). Application of the World Café to disability issues: A systematic review. *Journal of Disability Policy Studies*, *32*(3), 193-203.

Burke, M. M., Lee, C. E., Hall, S. A., & Rossetti, Z. (2019). Understanding decision making among individuals with intellectual and developmental disabilities (IDD) and their siblings. *Intellectual and Developmental Disabilities*, *57*(1), 26-41.

Byrne, D. (2022). A worked example of Braun and Clarke's approach to reflexive thematic analysis. *Quality & quantity*, *56*(3), 1391-1412.

Cala, V. C., & Soriano, E. (2014). Health education from an ecological perspective. Adaptation of the Bronfenbrenner model from an experience with adolescents. *Procedia-social and behavioral Sciences*, *132*, 49-57.

Calveley, J. (2012). Including adults with intellectual disabilities who lack capacity to consent in research. *Nursing Ethics*, *19*(4), 558-567.

Campbell, K. A., Orr, E., Durepos, P., Nguyen, L., Li, L., Whitmore, C., Gehrke, P., Graham, L., & Jack, S. M. (2021). Reflexive thematic analysis for applied qualitative health research. *The Qualitative Report*, *26*(6), 2011-2028.

Card, K. G., Lachowsky, N. J., & Hogg, R. S. (2021). Using Google Trends to Inform the Population Size Estimation and Spatial Distribution of Gay, Bisexual, and Other Men Who Have Sex With Men: Proof-of-concept Study. *Jmir Public Health and Surveillance*, *7*(11), Article e27385. https://doi.org/10.2196/27385

Carey, E. (2021). Aligning with the flow of control: A grounded theory study of choice and autonomy in decision-making practices of people with intellectual disabilities. *International Journal of Qualitative Studies on Health and Well-being*, *16*(1), 1857053.

Carey, E., & Griffiths, C. (2017). Recruitment and consent of adults with intellectual disabilities in a classic grounded theory research study: Ethical and methodological considerations. *Disability & Society*, *32*(2), 193-212.

Carney, T., Bigby, C., Then, S.-N., Smith, E., Wiesel, I., & Douglas, J. (2023). Paternalism to empowerment: all in the eye of the beholder? *Disability & Society*, *38*(3), 503-523.

Cartwright, L., Reid, M., Hammersley, R., Blackburn, C., & Glover, L. (2015). Food choice by people with intellectual disabilities at day centres: A qualitative study. *Journal of Intellectual Disabilities*, *19*(2), 103-115.

Casey, H., Desmond, D., & Coffey, L. (2023a). Irish mothers' experiences of providing support in decision-making to adults with intellectual disabilities: A qualitative study. *British Journal of Learning Disabilities*.

Casey, H., Desmond, D., & Coffey, L. (2023b). Professional and Family Carers’ Perspectives on the COVID-19 Pandemic and Its Impact on Supported Decision-Making with Adults with Intellectual Disabilities: A Qualitative Online Survey. *Disabilities*, *3*(2), 206-216.

Casey, H., Trayer, Á., Desmond, D., & Coffey, L. (2023). Experiences and perceptions of everyday decision-making in the lives of adults with intellectual disabilities, their care partners and direct care support workers. *Journal of Intellectual Disabilities*, 17446295231189020.

Caton, S., Koivunen, E.-R., & Allison, C. (2019). Internet use for family carers of people with intellectual disabilities: A literature review and thematic synthesis. *Journal of Intellectual Disabilities*, *23*(3), 446-468.

Center for Public Representation. (2022). *About Supported Decision-Making*. Retrieved 28/02/2023 from https://supporteddecisions.org/

Central Statistics Office. (2023). *Census 2022 Profile 4 - Disability, Health and Carers*. Central Statistics Office. Retrieved 20 June 2024 from https://www.cso.ie/en/releasesandpublications/ep/p-cpp4/census2022profile4-disabilityhealthandcarers/typeofdisability/

Chadwick, D., Ågren, K. A., Caton, S., Chiner, E., Danker, J., Gómez-Puerta, M., Heitplatz, V., Johansson, S., Normand, C. L., & Murphy, E. (2022). Digital inclusion and participation of people with intellectual disabilities during COVID-19: A rapid review and international bricolage. *Journal of Policy and Practice in Intellectual Disabilities*, *19*(3), 242-256.

Chadwick, D. D., Mannan, H., Garcia Iriarte, E., McConkey, R., O'Brien, P., Finlay, F., Lawlor, A., & Harrington, G. (2013). Family voices: life for family carers of people with intellectual disabilities in Ireland. *Journal of Applied Research in Intellectual Disabilities*, *26*(2), 119-132.

Charnley, H., Hwang, S. K., Atkinson, C., & Walton, P. (2019). ‘If I were given the chance’: understanding the use of leisure time by adults with learning disabilities. *Disability & Society*, *34*(4), 540-563.

Chiner, E., Gómez-Puerta, M., & Cardona-Moltó, M. C. (2017). Internet use, risks and online behaviour: The view of internet users with intellectual disabilities and their caregivers. *British Journal of Learning Disabilities*, *45*(3), 190-197.

Citizens Information. (2024a). *Day Centres and Day Care*. Citizens Information. Retrieved 5th September 2024 from https://www.citizensinformation.ie/en/health/health-services/health-services-for-people-with-disabilities/day-centres/

Citizens Information. (2024b). *Health Services for People with Disabilities*. Citizens Information. Retrieved 5th September 2024 from https://www.citizensinformation.ie/en/health/health-services/health-services-for-people-with-disabilities/health-services-for-people-with-intellectual-physical-or-sensory-disabilities/#85e92f

Clarkson, R., Murphy, G. H., Coldwell, J. B., & Dawson, D. L. (2009). What characteristics do service users with intellectual disability value in direct support staff within residential forensic services? *Journal of Intellectual & Developmental Disability, 34*(4), 283-289. https://doi.org/10.3109/13668250903285630

Colfer, B. (2020). Herd-immunity across intangible borders: Public policy responses to COVID-19 in Ireland and the UK. *European Policy Analysis, 6*(2), 203-225.

Collings, S., Dew, A., & Dowse, L. (2019). "They need to be able to have walked in our shoes": What people with intellectual disability say about National Disability Insurance Scheme planning. *Journal of Intellectual & Developmental Disability, 44*(1), 1-12.

Coons, K. D., & Watson, S. L. (2013). Conducting Research with Individuals Who Have Intellectual Disabilities: Ethical and Practical Implications for Qualitative Research. *Journal on Developmental Disabilities, 19*(2).

Courtenay, K., & Perera, B. (2020). COVID-19 and people with intellectual disability: impacts of a pandemic. *Irish Journal of Psychological Medicine, 37*(3), 231-236.

Crook, B., Tomlins, R., Bancroft, A., & Ogi, L. (2016). 'So often they do not get recruited': exploring service user and staff perspectives on participation in learning disability research and the barriers that inhibit it. *British Journal of Learning Disabilities, 44*(2), 130-137.

Curryer, B., Stancliffe, R. J., & Dew, A. (2015). Self-determination: Adults with intellectual disability and their family. *Journal of Intellectual and Developmental Disability*, *40*(4), 394-399.

Curryer, B., Stancliffe, R. J., Dew, A., & Wiese, M. Y. (2018). Choice and control within family relationships: The lived experience of adults with intellectual disability. *Intellectual and Developmental Disabilities*, *56*(3), 188-201.

Curryer, B., Stancliffe, R. J., Wiese, M. Y., & Dew, A. (2020). The experience of mothers supporting self-determination of adult sons and daughters with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *33*(3), 373-385.

Cvijetić, M., Kaljača, S., & Glumbić, N. (2024). The Role of Personal and Environmental Factors in Autonomous Behaviour of People with Intellectual Disability. *International Journal of Disability, Development and Education*, *71*(1), 118-133. https://doi.org/10.1080/1034912X.2021.1989669

Daly, R. L., Bunn, F., & Goodman, C. (2018). Shared decision-making for people living with dementia in extended care settings: a systematic review. *BMJ Open*, *8*(6), e018977.

Daneback, K., Månsson, S.-A., Ross, M. W., & Markham, C. M. (2012). The Internet as a source of information about sexuality. *Sex Education*, *12*(5), 583-598.

Daniel, B., Cross, B., Sherwood-Johnson, F., & Paton, D. (2014). Risk and decision making in adult support and protection practice: User views from participant research. *British Journal of Social Work*, *44*(5), 1233-1250.

Davidson, G., Kelly, B., Macdonald, G., Rizzo, M., Lombard, L., Abogunrin, O., Clift-Matthews, V., & Martin, A. (2015). Supported decision making: A review of the international literature. *International Journal of Law and Psychiatry*, *38*, 61-67.

Davies, C., Fattori, F., O'Donnell, D., Donnelly, S., Ní Shé, É., O. Shea, M., Prihodova, L., Gleeson, C., Flynn, Á., & Rock, B. (2019). What are the mechanisms that support healthcare professionals to adopt assisted decision-making practice? A rapid realist review. *BMC Health Services Research*, *19*, 1-14.

Davies, D. K., Stock, S. E., & Wehmeyer, M. L. (2003). A palmtop computer-based intelligent aid for individuals with intellectual disabilities to increase independent decision making. *Research and Practice for Persons with Severe Disabilities*, *28*(4), 182-193.

Davies, R. N., Werner, S., & Sinai, A. (2017). Guardianship and supported decision making in Israel. *Advances in Mental Health and Intellectual Disabilities*, *11*(2), 54-64.

Deci, E. L., & Ryan, R. M. (1980). Self-determination Theory: When Mind Mediates Behavior. *The Journal of Mind and Behavior*, *1*(1), 33-43. http://www.jstor.org/stable/43852807

Deguara, M., Jelassi, O., Micallef, B., & Callus, A. M. (2012). How we like to live when we have the chance. *British Journal of Learning Disabilities*, *40*(2), 123-127.

Des Portes, V. (2020). Intellectual disability. In *Handbook of Clinical Neurology* (Vol. 174, pp. 113-126). Elsevier.

Devi, N. (2013). Supported decision-making and personal autonomy for persons with intellectual disabilities: Article 12 of the UN convention on the rights of persons with disabilities. *The Journal of Law, Medicine & Ethics*, *41*(4), 792-806.

Devi, N., Prodinger, B., Pennycott, A., Sooben, R., & Bickenbach, J. (2020). Investigating supported decision-making for persons with mild to moderate intellectual disability using Institutional ethnography. *Journal of Policy and Practice in Intellectual Disabilities*, *17*(2), 143-156.

Di Lorito, C., Bosco, A., Birt, L., & Hassiotis, A. (2018). Co-research with adults with intellectual disability: A systematic review. *Journal of Applied Research in Intellectual Disabilities, 31*(5), 669-686.

Di Maggio, I., Shogren, K., Wehmeyer, M., & Nota, L. (2020). Self-determination and future goals in a sample of adults with intellectual disability. *Journal of Intellectual Disability Research*, *64*(1), 27-37.

Donnelly, M. (2019). Deciding in dementia: The possibilities and limits of supported decision-making. *International Journal of Law and Psychiatry*, *66*, 101466.

Donnelly, M. (2023). Judging Values in a Time of Transition: An Irish Perspective. In *Capacity, Participation and Values in Comparative Legal Perspective* (pp. 65-84). Bristol University Press.

Donnelly, S., & O'Brien, M. (2023). *Understanding Carer Harm*.

Doody, O., & Keenan, P. M. (2021). The reported effects of the COVID-19 pandemic on people with intellectual disability and their carers: A scoping review. *Annals of Medicine*, *53*(1), 786-804.

Douglas, J., & Bigby, C. (2020). Development of an evidence-based practice framework to guide decision making support for people with cognitive impairment due to acquired brain injury or intellectual disability. *Disability and rehabilitation*, *42*(3), 434-441.

Dowling, S., Williams, V., Webb, J., Gall, M., & Worrall, D. (2019). Managing relational autonomy in interactions: People with intellectual disabilities. *J Appl Res Intellect Disabil*, *32*(5), 1058-1066. https://doi.org/10.1111/jar.12595

Drisko, J. W., & Maschi, T. (2016). *Content analysis*. Pocket Guide to Social Work Re.

Duffy, R., & Kelly, B. (2023). Can the World Health Organisation’s ‘QualityRights’ initiative help reduce coercive practices in psychiatry in Ireland? *Irish Journal of Psychological Medicine*, *40*(2), 114-117.

Dufour, M., Hastings, T., & O'Reilly, R. (2018). Canada should retain its reservation on the United Nation's convention on the rights of persons with disabilities. *The Canadian Journal of Psychiatry*, *63*(12), 809-812.

Dukes, E., & McGuire, B. E. (2009). Enhancing capacity to make sexuality-related decisions in people with an intellectual disability. *Journal of Intellectual Disability Research*, *53*(8), 727-734.

Embregts, P. J., van Den Bogaard, K. J., Frielink, N., Voermans, M. A., Thalen, M., & Jahoda, A. (2022). A thematic analysis into the experiences of people with a mild intellectual disability during the COVID-19 lockdown period. *International Journal of Developmental Disabilities*, *68*(4), 578-582.

Engwall, K. (2014). Childfreeness, parenthood and adulthood. *Scandinavian Journal of Disability Research*, *16*(4), 333-347.

Ervin, D. A., & Hobson-Garcia, D. (2020). Community supports and COVID-19: Self-determination in a pandemic. *Intellectual and Developmental Disabilities*, *58*(6), 453-457.

Espiner, D., & Hartnett, F. M. (2012). 'I felt I was in control of the meeting': facilitating planning with adults with an intellectual disability. *British Journal of Learning Disabilities*, *40*(1), 62-70.

Estacio, E. V., & Karic, T. (2016). The World Café: An innovative method to facilitate reflections on internationalisation in higher education. *Journal of Further and Higher Education*, *40*(6), 731-745.

Estreder, Y., Martínez-Tur, V., Moliner, C., Gracia, E., & Lira, E. (2024). The voice of persons with intellectual disability: Why does autonomy support make them feel better? *Applied Psychology*, *73*(3), 1055-1070.

Evans, D., & FitzGerald, M. (2002). Reasons for physically restraining patients and residents: a systematic review and content analysis. *International journal of nursing studies*, *39*(7), 735-743.

Eysenbach, G. (2004). Improving the quality of Web surveys: the Checklist for Reporting Results of Internet E-Surveys (CHERRIES). In (Vol. 6, pp. e34): Gunther Eysenbach Centre for Global eHealth Innovation, Toronto, Canada.

Ferguson, M., Jarrett, D., & Terras, M. (2011). Inclusion and healthcare choices: the experiences of adults with learning disabilities. *British Journal of Learning Disabilities*, *39*(1), 73-83.

Finfgeld-Connett, D. (2014). Use of content analysis to conduct knowledge-building and theory-generating qualitative systematic reviews. *Qualitative research*, *14*(3), 341-352.

Fisher, K. M., Orkin, F. K., Green, M. J., Chinchilli, V. M., & Bhattacharya, A. (2009). Proxy healthcare decision-making for persons with intellectual disability: perspectives of residential-agency directors. *American journal on intellectual and developmental disabilities*, *114*(6), 401-410.

Flick, U. (2004). Triangulation in qualitative research. *A companion to qualitative research*, *3*, 178-183.

Flynn, A. (2020). Ireland: Assisted Decision-Making (Capacity) Act 2015 and Article 12 of the United Nations Convention on the Rights of Persons with Disabilities. *Julgar*, *41*, 238.

Foley, S. (2014). A Foucauldian Reading of Mothers' Views on the Paternalism/Autonomy Debate in Relation to the Sexual Practices of Their Intellectually Disabled Adult Sons and Daughters. *Irish Journal of Sociology*, *22*(2), 64-85.

Forbes, C., Alderson, H., Domoney, J., Papamichail, A., Berry, V., McGovern, R., Sevdalis, N., Rankin, J., Newburn, M., & Healey, A. (2023). A survey and stakeholder consultation of Independent Domestic Violence Advisor (IDVA) programmes in English maternity services. *BMC pregnancy and childbirth*, *23*(1), 404.

Fortune, J., Manikandan, M., Harrington, S., Hensey, O., Kerr, C., Koppe, S., Kroll, T., Lavelle, G., Long, S., & MacLachlan, M. (2024). Understanding the use of digital technologies to provide disability services remotely during the COVID-19 pandemic; a multiple case study design. *BMC Health Services Research*, *24*(1), 323.

Francis, G. L., Gross, J. M. S., Lavín, C. E., Casarez Velazquez, L. A., & Sheets, N. (2020). Facing Double Jeopardy: The Transition Experiences of Latina Family Caregivers of Young Adults With Disabilities Living in a Rural Community. *Rural Special Education Quarterly*, *39*(1), 17-34. https://doi.org/10.1177/8756870519879069

Freeman, M. C., Kolappa, K., de Almeida, J. M. C., Kleinman, A., Makhashvili, N., Phakathi, S., Saraceno, B., & Thornicroft, G. (2015). Reversing hard won victories in the name of human rights: a critique of the General Comment on Article 12 of the UN Convention on the Rights of Persons with Disabilities. *The Lancet Psychiatry*, *2*(9), 844-850.

Fullana, J., Pallisera, M., & Díaz-Garolera, G. (2022). How do people with learning disabilities talk about professionals and organizations? Discourse on support practices for independent living. *Disability & Society*, *34*(9-10), 1462-1480.

Garcia-Iriarte, E., Kramer, J., Kramer, J., & Hammel, J. (2009). ‘Who did what?’: a participatory action research project to increase group capacity for advocacy. *Journal of Applied Research in Intellectual Disabilities*, *22*(1), 10-22.

Giertz, L. (2017). Guardianship for adults with intellectual disabilities: accountant, advocate or ‘family’member?

Giesbers, S. A. H., Tournier, T., Hendriks, L., Hastings, R. P., Jahoda, A., & Embregts, P. J. C. M. (2019). Measuring emotional support in family networks: Adapting the Family Network Method for individuals with a mild intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *32*(1), 94-105. https://doi.org/https://doi.org/10.1111/jar.12512

Gill, A. (2022). Reflexivity and lived experience of out-of-home care: Positionality as an early parenthood researcher. *Affilia*, *37*(4), 664-683.

Gill, J., & Fazil, Q. (2013). Derogation of “duty of care” in favour of “choice”? *The Journal of Adult Protection*, *15*(5), 258-270.

Gilmartin, A., & Slevin, E. (2010). Being a member of a self-advocacy group: experiences of intellectually disabled people. *British Journal of Learning Disabilities*, *38*(3), 152-159.

Glencross, S., Mason, J., Katsikitis, M., & Greenwood, K. M. (2021). Internet use by people with intellectual disability: Exploring digital inequality—A systematic review. *Cyberpsychology, Behavior, and Social Networking*, *24*(8), 503-520.

Goldsmith, L., Woodward, V., Jackson, L., & Skirton, H. (2013). Informed consent for blood tests in people with a learning disability. *Journal of Advanced Nursing*, *69*(9), 1966-1976.

Google. (2023). *Refine Google Searches*. Retrieved 6/10 from https://support.google.com/websearch/answer/2466433?hl=en

Gordon, T. J., & Glenn, J. C. (2009). Environmental scanning. *Futures research methodology—version*, *3*(3).

Gov.ie. (2020). *Ireland placed on Level 5 Restrictions of the Plan for Living with COVID-19 - with a number of specific adjustments*. Department of the

Taoiseach. Retrieved 28/02/2023 from https://www.gov.ie/en/press-release/a1f21-ireland-placed-on-level-5-restrictions-of-the-plan-for-living-with-covid-19-with-a-number-of-specific-adjustments/

Grant, T. D. (2015). The UN Convention on the Rights of Persons with Disabilities (CRPD): Some Observations on US Participation. *Ind. Int'l & Comp. L. Rev.*, *25*, 171.

Gross, J. M., Wallace, L., Blue-Banning, M., Summers, J. A., & Turnbull, A. (2013). Examining the experiences and decisions of parents/guardians: Participant directing the supports and services of adults with significant intellectual and developmental disabilities. *Journal of Disability Policy Studies*, *24*(2), 88-101.

Gudelytė, U., Ruškus, J., & McCrea, K. T. (2024). 'Help me to decide': A study of human rights-based supported decision making with persons with intellectual disabilities. *American Journal of Orthopsychiatry*, *94*(3), 297-310. https://doi.org/10.1037/ort0000724

Haigh, A., Lee, D., Shaw, C., Hawthorne, M., Chamberlain, S., Newman, D. W., Clarke, Z., & Beail, N. (2013). What things make people with a learning disability happy and satisfied with their lives: An inclusive research project. *Journal of Applied Research in Intellectual Disabilities*, *26*(1), 26-33.

Harding, R., & Tascioglu, E. (2017). Everyday decisions project report: supporting legal capacity through care, support and empowerment.

Härkönen, U. (2001). The Bronfenbrenner ecological systems theory of human development. In.

Harris, J. (2003). Time to make up your mind: why choosing is difficult. *British Journal of Learning Disabilities*, *31*(1), 3-8.

Hassan, N. (2017). ‘Putting music on’: everyday leisure activities, choice-making and person-centred planning in a supported living scheme. *British Journal of Learning Disabilities*, *45*(1), 73-80.

Hassan, R., & Gudiwala, V. (2022). Evaluating the impact of global awareness days on rheumatological search interest before and during the coronavirus-19 (COVID-19) pandemic. *Egyptian Rheumatologist*, *44*(1), 75-79. https://doi.org/10.1016/j.ejr.2021.08.006

Haynes, K. (2012). Reflexivity in qualitative research. *Qualitative organizational research: Core methods and current challenges*, *26*, 72-89.

Health Research Board. (2023). *Latest Disability Data*. Health Research Board. Retrieved 20 June 2024 from https://www.hrb.ie/data-collections-evidence/disability-service-use-and-need/latest-data/

Hellzen, O., Haugenes, M., & Østby, M. (2018). ‘It’s my home and your work’: the views of a filmed vignette describing a challenging everyday situation from the perspective of people with intellectual disabilities. *International Journal of Qualitative Studies on Health and Well-being*, *13*(1), 1468198.

Hickson, L., Khemka, I., Golden, H., & Chatzistyli, A. (2015). Randomized controlled trial to evaluate an abuse prevention curriculum for women and men with intellectual and developmental disabilities. *American journal on intellectual and developmental disabilities*, *120*(6), 490-503.

Hollomotz, A. (2014). Are we valuing People's choices now? Restrictions to mundane choices made by adults with learning difficulties. *British Journal of Social Work*, *44*(2), 234-251.

Hoole, L., & Morgan, S. (2011). ‘It’s only right that we get involved’: service-user perspectives on involvement in learning disability services. *British Journal of Learning Disabilities*, *39*(1), 5-10.

Hopf, Y., Francis, J., Helms, P., Haughney, J., & Bond, C. (2016). Core requirements for successful data linkage: an example of a triangulation method. *BMJ Open*, *6*(10), e011879.

Horsell, C. (2023). Problematising disability: A critical policy analysis of the Australian National Disability Insurance Scheme. *Australian Social Work*, *76*(1), 47-59.

Inclusion Ireland. (2021). *Assisted Decision-Making*. Retrieved 07/07/2023 from https://inclusionireland.ie/assisted-decision-making/

Inclusion Ireland. (2024). *Speak Up Speak Out!* Inclusion Ireland. Retrieved 26/08/2024 from https://inclusionireland.ie/resources/speakupspeakout/

Ireland, P. S. o. (2024). *Code of Ethics*. Psychological Society of Ireland. Retrieved 16th July 2024 from https://www.psychologicalsociety.ie/footer/Code-of-Ethics-1

Jackman-Galvin, V., & Partridge, M. (2022). Relationships and power: An exploration of person-centredness in an intellectual disability service in Ireland. *Health & Social Care in the Community, 30*(6), e6294-e6302.

Jacobs, P., MacMahon, K., & Quayle, E. (2018). Transition from school to adult services for young people with severe or profound intellectual disability: A systematic review utilizing framework synthesis. *Journal of Applied Research in Intellectual Disabilities*, *31*(6), 962-982. https://doi.org/https://doi.org/10.1111/jar.12466

Jamieson, R., Theodore, K., & Raczka, R. (2016). Becoming a mother: Supported decision-making in context. *Journal of Intellectual Disabilities, 20*(4), 313-328.

Jarrett, S. (2015). The meaning of ‘community’in the lives of people with intellectual disabilities: an historical perspective. *International Journal of Developmental Disabilities*, *61*(2), 107-112.

Jenkinson, J. C. (1993). Who shall decide? The relevance of theory and research to decision-making by people with an intellectual disability. *Disability, Handicap & Society*, *8*(4), 361-375.

Jingree, T., Finlay, W. M., & Antaki, C. (2006). Empowering words, disempowering actions: an analysis of interactions between staff members and people with learning disabilities in residents' meetings. *Journal of Intellectual Disability Research*, *50*(3), 212-226.

Johnson, P., Carpenter, K., & Scarbrough-Lang, S.-J. (2012). Involvement of service users in the recruitment of staff. *Learning Disability Practice*, *15*(2).

Jonker, F., Didden, R., Goedhard, L., Korzilius, H., & Nijman, H. (2021). The ADaptive Ability Performance Test (ADAPT): A new instrument for measuring adaptive skills in people with intellectual disabilities and borderline intellectual functioning. *Journal of Applied Research in Intellectual Disabilities*, *34*(4), 1156-1165.

Jootun, D., McGhee, G., & Marland, G. R. (2009). Reflexivity: promoting rigour in qualitative research. *Nursing standard*, *23*(23), 42-47.

Kåhlin, I., Kjellberg, A., & Hagberg, J.-E. (2016). Choice and control for people ageing with intellectual disability in group homes. *Scandinavian journal of occupational therapy*, *23*(2), 127-137.

Kantamneni, N. (2020). The impact of the COVID-19 pandemic on marginalized populations in the United States: A research agenda. *Journal of vocational behavior, 119*, 103439.

Kare. (2024). *Adult Services*. Kare. Retrieved 5th September 2024 from https://www.kare.ie/adults

Kelly, B. (2017). The Assisted Decision-Making (Capacity) Act 2015: what it is and why it matters. *Irish Journal of Medical Science (1971-)*, *186*, 351-356.

Kelly, C., Craig, S., & McConkey, R. (2020). Supporting family carers of children and adults with intellectual disability. *Journal of Social Work*, *20*(5), 639-656.

Keys, M. (2017). Article 12 [equal recognition before the law]. The United Nations convention on the rights of persons with disabilities: A commentary,

Kim, B. (2001). Social constructivism. *Emerging perspectives on learning, teaching, and technology*, *1*(1), 16.

Kohn, N. A., & Blumenthal, J. A. (2014). A critical assessment of supported decision-making for persons aging with intellectual disabilities. *Disability and health journal*, *7*(1), S40-S43.

Kohn, N. A., Blumenthal, J. A., & Campbell, A. T. (2012). Supported decision-making: A viable alternative to guardianship. *Penn St. L. Rev.*, *117*, 1111.

Kornbluh, M. (2015). Combatting challenges to establishing trustworthiness in qualitative research. *Qualitative research in psychology*, *12*(4), 397-414.

Kozak, A., Kersten, M., Schillmöller, Z., & Nienhaus, A. (2013). Psychosocial work-related predictors and consequences of personal burnout among staff working with people with intellectual disabilities. *Research in Developmental Disabilities*, *34*(1), 102-115.

Kremers, E. M., Janssen, J. H. M., Nieuwboer, M. S., Olde Rikkert, M. G. M., & Peeters, G. M. E. E. (2021). The psychosocial adaptability of independently living older adults to covid-19 related social isolation in the netherlands: A qualitative study. *Health & Social Care in the Community*. https://doi.org/10.1111/hsc.13436

Kuckartz, U., & Rädiker, S. (2019). *Analyzing qualitative data with MAXQDA.* Springer.

Lafferty, A., O’Sullivan, D., O’mahoney, P., Taggart, L., & Van Bavel, B. (2016). Family carers’ experiences of caring for a person with intellectual disability. *Dublin: University College Dublin*.

Lake, J. K., Jachyra, P., Volpe, T., Lunsky, Y., Magnacca, C., Marcinkiewicz, A., & Hamdani, Y. (2021). The wellbeing and mental health care experiences of adults with intellectual and developmental disabilities during COVID-19. *Journal of Mental Health Research in Intellectual Disabilities*, *14*(3), 285-300. https://doi.org/10.1080/19315864.2021.1892890

Landes, S. D., Turk, M. A., Formica, M. K., McDonald, K. E., & Stevens, J. D. (2020). COVID-19 outcomes among people with intellectual and developmental disability living in residential group homes in New York State. *Disability and health journal, 13*(4), 100969.

Larkin, M., Unwin, G., Iyer, M., Tsimopoulou, I., Zahid, S., Malik, K., Stenfert Kroese, B., & Rose, J. L. (2018). Cultural affordance, social relationships, and narratives of independence: Understanding the meaning of social care for adults with intellectual disabilities from minority ethnic groups in the UK. *International Journal of Developmental Disabilities*, *64*(3), 195-203.

Ledger, S., Earle, S., Tilley, E., & Walmsley, J. (2016). Contraceptive decision-making and women with learning disabilities. *Sexualities*, *19*(5-6), 698-724.

Leiva Portocarrero, M. E., Garvelink, M. M., Becerra Perez, M. M., Giguère, A., Robitaille, H., Wilson, B. J., Rousseau, F., & Légaré, F. (2015). Decision aids that support decisions about prenatal testing for Down syndrome: an environmental scan. *BMC medical informatics and decision making*, *15*(1), 1-10.

Li, W., Ornstein, K. A., Li, Y., & Liu, B. (2021). Barriers to learning a new technology to go online among older adults during the COVID-19 pandemic. *Journal of the*

American Geriatrics Society, 69(11), 3051-3057. https://doi.org/10.1111/jgs.17433

Liamputtong, P., & Rice, Z. S. (2022). Qualitative inquiry and inclusive research. In *Handbook of Social Inclusion: Research and Practices in Health and Social Sciences* (pp. 1-19). Springer.

Lloyd, J., Moni, K., Cuskelly, M., & Jobling, A. (2023). National disability insurance scheme: is it creating an ordinary life for adults with intellectual disability? *Disability & Society, 38*(1), 1-20.

Löhr, K., Weinhardt, M., & Sieber, S. (2020). The "World Café" as a participatory method for collecting qualitative data. *International journal of qualitative methods*, *19*, 1609406920916976.

Luckasson, R., & Schalock, R. L. (2020). A balanced approach to decision-making in supporting people with IDD in extraordinarily challenging times. *Research in Developmental Disabilities*, *105*, Article 103719. https://doi.org/10.1016/j.ridd.2020.103719

Luescher, T. M. (2005). Student governance in Africa: Thematic summary of key literature. *Retrieved August*, *12*, 2013.

Lukas, J. F., Lizasoain, L., Galarreta, J., & Etxeberria, J. (2018). Job satisfaction among disabled people in the sheltered workshop: Differential analysis. *J Appl Res Intellect Disabil*, *31*(6), 1174-1185. https://doi.org/10.1111/jar.12492

Lunn, P. D., Timmons, S., Robertson, D. A., Julienne, H., Lavin, C., Barjaková, M., Poluektova, O., Mohr, K., Andersson, Y., & McGowan, F. P. (2024). Behavioural evidence to inform the COVID-19 pandemic response: Ireland's Social Activity Measure (SAM). *Behavioural Public Policy*, 1-15.

Lunsky, Y., Tint, A., Robinson, S., Gordeyko, M., & Ouellette-Kuntz, H. (2014). System-wide information about family carers of adults with intellectual/developmental disabilities—a scoping review of the literature. *Journal of Policy and Practice in Intellectual Disabilities*, *11*(1), 8-18.

MacFarlane, A., Galvin, R., O'Sullivan, M., McInerney, C., Meagher, E., Burke, D., & LeMaster, J. W. (2017). Participatory methods for research prioritization in primary care: an analysis of the World Café approach in Ireland and the USA. *Family practice*, *34*(3), 278-284.

Mahmoodi, N., Bekker, H. L., King, N., Hughes, J., & Jones, G. (2018). Are publicly available internet resources enabling women to make informed fertility preservation decisions before starting cancer treatment: an environmental scan? *BMC medical informatics and decision making*, *18*(1), 1-16.

Mannan, H., O'Brien, P., McConkey, R., Finlay, F., Lawlor, A., & Harrington, G. (2011). Complexities in the provision of respite care to family carers of persons with intellectual disabilities. *Disability, CBR & Inclusive Development*, *22*(2), 38-54.

Mansell, J., & Beadle-Brown, J. (2012). *Active support: Enabling and empowering people with intellectual disabilities*. Jessica Kingsley Publishers.

Mansell, J., & Beadle-Brown, J. (2004). Person-centred planning or person-centred action? Policy and practice in intellectual disability services. *Journal of Applied Research in Intellectual Disabilities*, *17*(1), 1-9.

March, E., Salzberg, M., & Hopwood, M. (2013). Acquired brain injury needs to be acknowledged at the national mental health policy level. *Aust N Z J Psychiatry*, *47*(3), 212-216. https://doi.org/10.1177/0004867412452943

Martinis, J., Harris, J., Fox, D., & Blanck, P. (2023). State guardianship laws and supported decision-making in the United States after Ross and Ross v. Hatch:

Analysis and implications for research, policy, education, and advocacy. *Journal of Disability Policy Studies*, *34*(1), 8-16.

McAiney, C., Conway, E., Koch, M., Middleton, L., Dupuis, S., Keller, H., Dupuis, K., Lee, L., Fehr, P., Beleno, R., Kuepfer, J., & Boger, J. (2021). In their own words: How COVID-19 has impacted the well-being of persons living with dementia in the community. *Canadian Journal on Aging*, *40*(4), 543-553. https://doi.org/10.1017/S0714980821000441

McCarthy, M. (2010). Exercising choice and control–women with learning disabilities and contraception. *British Journal of Learning Disabilities*, *38*(4), 293-302.

McCausland, D., Brennan, D., McCallion, P., & McCarron, M. (2019). Balancing personal wishes and caring capacity in future planning for adults with an intellectual disability living with family carers. *J Intellect Disabil*, *23*(3), 413-431. https://doi.org/10.1177/1744629519872658

McCausland, D., Luus, R., McCallion, P., Murphy, E., & McCarron, M. (2021). The impact of COVID-19 on the social inclusion of older adults with an intellectual disability during the first wave of the pandemic in Ireland. *Journal of Intellectual Disability Research*, *65*(10), 879-889.

McCausland, D., McCallion, P., Brennan, D., & McCarron, M. (2018). The exercise of human rights and citizenship by older adults with an intellectual disability in Ireland. *J Intellect Disabil Res*, *62*(10), 875-887. https://doi.org/10.1111/jir.12543

McConkey, R., & Collins, S. (2010). The role of support staff in promoting the social inclusion of persons with an intellectual disability. *Journal of Intellectual Disability Research*, *54*(8), 691-700.

McDonagh, P. (2006). Barnaby Rudge,‘idiocy’and paternalism: Assisting the ‘poor idiot’. *Disability & Society*, *21*(5), 411-423.

McDonald, K. E., Kidney, C. A., & Patka, M. (2013). 'You need to let your voice be heard': research participants' views on research. *J Intellect Disabil Res*, *57*(3), 216-225. https://doi.org/10.1111/j.1365-2788.2011.01527.x

McGrath, C., Kennedy, M.-R., Gibson, A., Musse, S., Kosar, Z., & Dawson, S. (2023). World Cafés as a participatory approach to understanding research agendas in primary care with underserved communities: reflections, challenges and lessons learned. *Research Involvement and Engagement*, *9*(1), 101.

McLaughlin, H. (2010). Keeping service user involvement in research honest. *British Journal of Social Work*, *40*(5), 1591-1608.

Morris, R., Christianson-Barker, J., Stainton, T., Mills, R., Rowley, C., Cox, J., Schroeder, M., & Hole, R. (2024). ‘They don't think I can do it’: Experiences of self-advocates, employment specialists, and employers on employment of adults with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *37*(3), e13231.

Mumbardó-Adam, C., Vicente, E., & Balboni, G. (2024). Self-determination and quality of life of people with intellectual and developmental disabilities: Past, present, and future of close research paths. *Journal of Policy and Practice in Intellectual Disabilities*, *21*(1), e12460.

Murphy, E., Clegg, J., & Almack, K. (2011). Constructing adulthood in discussions about the futures of young people with moderate-profound intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *24*(1), 61-73.

Murphy, K., & Bantry-White, E. (2021). Behind closed doors: Human rights in residential care for people with an intellectual disability in Ireland. *Disability & Society*, *36*(5), 750-771.

Murphy, T., Turley, M., Byrne, C., Clancy, N., & Browne, H. (2020). The experiences of adults with intellectual disabilities in Ireland during the Covid-19 crisis. *Retrieved from Dublin*.

Murphy, V. E., Gulati, G., Whelan, D., Dunne, C. P., & Kelly, B. D. (2023). The changing face of Capacity legislation in Ireland: algorithms for clinicians. *Irish Journal of Psychological Medicine*, *40*(2), 109-113.

Ní Shé, É., O'Donnell, D., Donnelly, S., Davies, C., Fattori, F., & Kroll, T. (2020). "What bothers me most is the disparity between the choices that people have or don't have": A qualitative study on the health systems responsiveness to implementing the assisted decision-making (capacity) act in Ireland. *International Journal of Environmental Research and Public Health*, *17*(9), 3294.

Nicholas, D. B., Mitchell, W., Ciesielski, J., Khan, A., & Lach, L. (2022). A qualitative examination of the impact of the covid-19 pandemic on individuals with neuro-developmental disabilities and their families. *Journal of Child and Family Studies*. https://doi.org/10.1007/s10826-022-02336-8

Nicholson, C., Finlay, W. M. L., & Stagg, S. (2021). Forms of resistance in people with severe and profound intellectual disabilities. *Sociol Health Illn*, *43*(3), 642-659. https://doi.org/10.1111/1467-9566.13246

Nonnemacher, S. L., & Bambara, L. M. (2011). "I'm supposed to be in charge": self-advocates' perspectives on their self-determination support needs. *Intellect Dev Disabil*, *49*(5), 327-340. https://doi.org/10.1352/1934-9556-49.5.327

Noorlandt, H., Echteld, M., Tuffrey-Wijne, I., Festen, D., Vrijmoeth, C., van der Heide, A., & Korfage, I. (2020). Shared decision-making with people with intellectual disabilities in the last phase of life: a scoping review. *Journal of Intellectual Disability Research*, *64*(11), 881-894.

Nuri, R. P., Piccone, C., Gaurav, N., Thomson, D., Pauls, R., Perry, L., & Aldersey, H. M. (2024). The Limits and Contributions of Formal Support: Service Providers' Perspectives on Balancing Formal and Natural Support for People with Disabilities and their Families in Canada. *Journal of Developmental and Physical Disabilities*. https://doi.org/10.1007/s10882-023-09944-2

O'Donnell, J. (2023). Unsticking the System: Shifting From Being Occupants of Services to Being Contributors to Virtual Services. *Maunscript in Preparation*.

O'Donovan, M., Demetriou, E., Whittle, E., Duke, Z., Aitken, T., & Guastella, A. (2021). Home and Living Options for People with Disabilities: A systematic review and environmental scan of strategies to support transition from group homes and congregate care, and those which prevent movement to congregate settings. *Sydney: Centre for Disability Studies/The University of Sydney*.

O'Hara, J. (2008). Attending to the health needs of people with intellectual disability: quality standards. *salud pública de méxico*, *50*(S2), 154-159.

Oireachtas. (2015). *Assisted Decision-Making (Capacity) Act 2015*. Retrieved 28/02/2023 from https://www.irishstatutebook.ie/eli/2015/act/64/enacted/en/html

Ouzzani, M., Hammady, H., Fedorowicz, Z., & Elmagarmid, A. (2016). Rayyan—a web and mobile app for systematic reviews. *Systematic reviews*, *5*, 1-10.

Pace, R., Pluye, P., Bartlett, G., Macaulay, A. C., Salsberg, J., Jagosh, J., & Seller, R. (2012). Testing the reliability and efficiency of the pilot Mixed Methods Appraisal Tool (MMAT) for systematic mixed studies review. *Int J Nurs Stud*, *49*(1), 47-53. https://doi.org/10.1016/j.ijnurstu.2011.07.002

Page, M. J., Moher, D., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-

Wilson, E., McDonald, S., . . . McKenzie, J. E. (2021). PRISMA 2020 explanation and elaboration: updated guidance and exemplars for reporting systematic reviews. *Bmj*, *372*, n160. https://doi.org/10.1136/bmj.n160

Pallisera, M., Vilà, M., Fullana, J., Díaz-Garolera, G., Puyalto, C., & Valls, M. J. (2018). The role of professionals in promoting independent living: Perspectives of self-advocates and front-line managers. *J Appl Res Intellect Disabil*, *31*(6), 1103-1112. https://doi.org/10.1111/jar.12470

Pallisera, M., Vilà, M., Fullana, J., & Valls, M.-J. (2021). Being in control: Choice and control of support received in supported living. A study based on the narratives of people with intellectual disability and support staff. *Journal of Intellectual & Developmental Disability*, *46*(2), 164-174.

Patel, V., Perez-Olivas, G., Kroese, B. S., Rogers, G., Rose, J., Murphy, G., Cooper, V., Langdon, P. E., Hiles, S., Clifford, C., & Willner, P. (2021). The experiences of carers of adults with intellectual disabilities during the first COVID-19 lockdown period. *Journal of Policy and Practice in Intellectual Disabilities*, *18*(4), 254-262. https://doi.org/10.1111/jppi.12382

Penzenstadler, L., Molodynski, A., & Khazaal, Y. (2020). Supported decision making for people with mental health disorders in clinical practice: a systematic review. *Int J Psychiatry Clin Pract*, *24*(1), 3-9. https://doi.org/10.1080/13651501.2019.1676452

Petner-Arrey, J., & Copeland, S. R. (2015). ‘You have to care.’perceptions of promoting autonomy in support settings for adults with intellectual disability. *British Journal of Learning Disabilities*, *43*(1), 38-48.

Phelan, A. (2023). Adult safeguarding in Ireland: a critical review of context and gaps. *The Journal of Adult Protection*.

Priestley, M., Waddington, L., & Bessozi, C. (2010). Towards an agenda for disability research in Europe: learning from disabled people's organisations. *Disability & Society*, *25*(6), 731-746.

Puyalto, C., Beltran, M., Coll, T., Diaz-Garolera, G., Figueras, M., Fullana, J., Gonzalez, C., Pallisera, M., Pujolar, J., & Rey, A. (2022). Relationships of People with Intellectual Disabilities in Times of Pandemic: An Inclusive Study. *Social Sciences-Basel*, *11*(5), Article 198. https://doi.org/10.3390/socsci11050198

Råheim, M., Magnussen, L. H., Sekse, R. J. T., Lunde, Å., Jacobsen, T., & Blystad, A. (2016). Researcher–researched relationship in qualitative research: Shifts in positions and researcher vulnerability. *International Journal of Qualitative Studies on Health and Well-being*, *11*(1), 30996.

Raynor, O., Hayward, K., Semenza, G., & Stoffmacher, B. (2018). Community Conversations to Increase Employment Opportunities for Young Adults With Developmental Disabilities in California. *Journal of Disability Policy Studies*, *28*(4), 203-215. https://doi.org/10.1177/1044207317739405

Reiswig, J. (2010). Mendeley. *Journal of the Medical Library Association: JMLA*, *98*(2), 193.

Robinson, S. B., & Leonard, K. F. (2024). *Designing quality survey questions*. Sage publications.

Roets, G., Adams, M., & Van Hove, G. (2006). Challenging the Monologue about Silent Sterilization: Implications for Self-Advocacy. *British Journal of Learning Disabilities*, *34*(3), 167-174.

Rogers, E., Pilch, M., McGuire, B. E., Flynn, E., & Egan, J. (2020). Psychologists' perspectives on supported decision making in Ireland. *J Intellect Disabil Res*, *64*(3), 234-245. https://doi.org/10.1111/jir.12712

Rowel, R., Moore, N. D., Nowrojee, S., Memiah, P., & Bronner, Y. (2005). The utility of the environmental scan for public health practice: lessons from an urban program to increase cancer screening. *Journal of the National Medical Association*, *97*(4), 527.

Ryan, A., Taggart, L., Truesdale-Kennedy, M., & Slevin, E. (2014). Issues in caregiving for older people with intellectual disabilities and their ageing family carers: a review and commentary. *International journal of older people nursing*, *9*(3), 217-226.

Ryan, R. M., & Deci, E. L. (2017). Self-determination theory. *Basic psychological needs in motivation, development, and wellness*.

Ryan, R. M., & Vansteenkiste, M. (2023). Self-Determination Theory: Metatheory, Methods, and Meaning. *The Oxford Handbook of Self-Determination Theory*, 0.

Sacco, A., Hewitt, H., & Pandya, P. (2020). Women's choices in non-invasive prenatal testing for aneuploidy screening: results from a single centre prior to introduction in England. *Arch Dis Child*, *105*(1), 47-52. https://doi.org/10.1136/archdischild-2019-317031

Safeguarding Ireland. (2023). *67% of adults have not heard of new Assisted-decision Making legislation*. Safeguarding Ireland. Retrieved 26 October 2023 from https://www.safeguardingireland.org/67-of-adults-have-not-heard-of-new-assisted-decision-making-legislation/

Santos, K. d. S., Ribeiro, M. C., Queiroga, D. E. U. d., Silva, I. A. P. d., & Ferreira, S. M. S. (2020). The use of multiple triangulations as a validation strategy in a qualitative study. *Ciencia & saude coletiva*, *25*, 655-664.

Scheffers, F., Moonen, X., & van Vugt, E. (2021). Assessing the quality of support and discovering sources of resilience during COVID-19 measures in people with intellectual disabilities by professional carers. *Research in Developmental Disabilities*, *111,* Article 103889. https://doi.org/10.1016/j.ridd.2021.103889

Schiele, H., Krummaker, S., Hoffmann, P., & Kowalski, R. (2022). The “research world café” as method of scientific enquiry: Combining rigor with relevance and speed. *Journal of business research*, *140,* 280-296.

Scholten, M., & Gather, J. (2017). Adverse consequences of article 12 of the UN Convention on the Rights of Persons with Disabilities for persons with mental disabilities and an alternative way forward. *Journal of Medical Ethics*.

Scholten, M., Gather, J., & Vollmann, J. (2021). Equality in the informed consent process: competence to consent, substitute decision-making, and discrimination of persons with mental disorders. The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine,

Series, L., & Nilsson, A. (2018). Chapter Article 12 CRPD: Equal Recognition before the Law. The UN Convention on the Rights of Persons with Disabilities,

Service, D. S. (2022). *A short video message to our potential future service users*. Retrieved 26th March from https://decisionsupportservice.ie/news-events/short-video-message-our-potential-future-service-users

Service, D. S. (2023). *Decision Support Arrangements*. https://www.decisionsupportservice.ie/services/decision-support-arrangements

Service, D. S. (2023). *Story Database*. https://www.decisionsupportservice.ie/resources/story-database

Sheehan, R., Hassiotis, A., Strydom, A., & Morant, N. (2019). Experiences of psychotropic medication use and decision-making for adults with intellectual disability: a multistakeholder qualitative study in the UK. *BMJ Open*, *9*(11), e032861. https://doi.org/10.1136/bmjopen-2019-032861

Sheerin, F., Allen, A. P., Fallon, M., McCallion, P., McCarron, M., Mulryan, N., & Chen, Y. (2023). Staff mental health while providing care to people with intellectual disability during the COVID-19 pandemic. *British Journal of Learning Disabilities*, *51*(1), 80-90.

Shoemaker, S. J., Wolf, M. S., & Brach, C. (2014). Development of the Patient Education Materials Assessment Tool (PEMAT): a new measure of understandability and actionability for print and audiovisual patient information. *Patient Education and Counseling*, *96*(3), 395-403.

Shogren, K. A., & Broussard, R. (2011). Exploring the perceptions of self-determination of individuals with intellectual disability. *Intellectual and Developmental Disabilities*, *49*(2), 86-102.

Shogren, K. A., Wehmeyer, M. L., Lassmann, H., & Forber-Pratt, A. J. (2017). Supported decision making: A synthesis of the literature across intellectual disability, mental health, and aging. *Education and Training in Autism and Developmental Disabilities*, *52*(2), 144-157.

Slomian, J., Bruyère, O., Reginster, J.-Y., & Emonts, P. (2017). The internet as a source of information used by women after childbirth to meet their need for information: A web-based survey. *Midwifery*, *48*, 46-52.

Special Olympics Ireland. (2021). *Guidance and Practical Resource Pack in Preparation for COVID-19 Vaccination Programme in Disability Services*. Retrieved 26 August 2024 from https://www.specialolympics.ie/sites/default/files/2021-02/guidance-and-practical-resource-pack-in-preparation-for-covid-19-vaccination-programme-disability-services_0.pdf

Stainton, T. (2016). Supported decision-making in Canada: principles, policy, and practice. *Research and Practice in Intellectual and Developmental Disabilities*, *3*(1), 1-11.

Stalker, K., & Harris, P. (1998). The exercise of choice by adults with intellectual disabilities: a literature review. *Journal of Applied Research in Intellectual Disabilities*, *11*(1), 60-76.

Stancliffe, R. J. (2001). Living with support in the community: Predictors of choice and self-determination. *Mental Retardation and Developmental Disabilities Research Reviews*, *7*(2), 91-98.

Stancliffe, R. J. (2020). Choice availability and people with intellectual disability. *Choice, preference, and disability: Promoting self-determination across the lifespan*, 3-26.

Stancliffe, R. J., Lakin, K. C., Larson, S., Engler, J., Taub, S., & Fortune, J. (2011). Choice of living arrangements. *J Intellect Disabil Res*, *55*(8), 746-762. https://doi.org/10.1111/j.1365-2788.2010.01336.x

Stefánsdóttir, G. V., Björnsdóttir, K., & Stefánsdóttir, Á. (2018). Autonomy and people with intellectual disabilities who require more intensive support.

Stewart, K., Bradshaw, J., & Beadle-Brown, J. (2018). Evaluating service users' experiences using Talking Mats®. *Tizard Learning Disability Review*, *23*(2), 78-86.

Sutton, L. B., Erlen, J. A., Glad, J. M., & Siminoff, L. A. (2003). Recruiting vulnerable populations for research: revisiting the ethical issues. *Journal of Professional Nursing*, *19*(2), 106-112.

Szmukler, G. (2015). UN CRPD: equal recognition before the law. *The Lancet Psychiatry*, *2*(11), e29.

Taggart, L., Truesdale-Kennedy, M., Ryan, A., & McConkey, R. (2012). Examining the support needs of ageing family carers in developing future plans for a relative with an intellectual disability. *Journal of Intellectual Disabilities*, *16*(3), 217-234.

Taua, C., Neville, C., & Hepworth, J. (2014). Research participation by people with intellectual disability and mental health issues: An examination of the processes of consent. *International Journal of Mental Health Nursing*, *23*(6), 513-524.

Taylor, W. D., Cobigo, V., & Ouellette-Kuntz, H. (2019). A family systems perspective on supporting self-determination in young adults with intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities*, *32*(5), 1116-1128.

Temple, V. A., & Walkley, J. W. (2007). Perspectives of constraining and enabling factors for health-promoting physical activity by adults with intellectual disability. *Journal of Intellectual & Developmental Disability*, *32*(1), 28-38. https://doi.org/10.1080/13668250701194034

The Arc of Northern Virginia. (2023). *Supported Decision Making Resource Library*. The Arc of Northern Virginia. Retrieved 22 December from https://thearcofnova.org/programs-services/sdm-resource-library/

The World Café. (2023). *Design Principles*. Retrieved 10th October from https://theworldcafe.com/key-concepts-resources/design-principles/

Thomas, D. R. (2017). Feedback from research participants: are member checks useful in qualitative research? *Qualitative research in psychology*, *14*(1), 23-41.

Timmons, J. C., Hall, A. C., Bose, J., Wolfe, A., & Winsor, J. (2011). Choosing employment: factors that impact employment decisions for individuals with intellectual disability. *Intellect Dev Disabil*, *49*(4), 285-299. https://doi.org/10.1352/1934-9556-49.4.285

Tracy, J. (2015). Supporting Nick to Make Decisions: An Exploration of Ways to Promote Choice and Control. *Research and Practice in Intellectual and Developmental Disabilities, 2*(1), 29-36.

Triangulation, D. S. (2014). The use of triangulation in qualitative research. Oncol nurs forum,

Tully, M., Fennelly, A., Jackman, C., Jones, T., Rojack, E., Henderson, K., & Linehan, C. (2024). 'They didn't trust us to follow the rules' – a qualitative study of how Irish adults with mild and moderate intellectual disabilities experienced the COVID-19 pandemic. *International Journal of Developmental Disabilities*, 1-12. https://doi.org/10.1080/20473869.2024.2338305

United Nations. (2006). *United Nationas Convention for the Rights of Persons with Intellectual Disabiliites: Article 12- Equal Recognition Before the Law*. United Nations. Retrieved 28/02/2023 from https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-12-equal-recognition-before-the-law.html

United Nations. (2023). *UN Treaty Body Database*. United Nations. Retrieved 18th January from https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/Treaty.aspx?Treaty=CRPD

University, M. (2020). *Maynooth University Research Ethics Policy*. Maynooth University. Retrieved 16th July 2024 from https://www.maynoothuniversity.ie/sites/default/files/assets/document/Maynooth%20University%20%20Research%20Ethics%20Policy%20%28Updated%20March%202020%29.pdf

Van't Riet, A., Berg, M., Hiddema, F., & Sol, K. (2001). Meeting patients’ needs with patient information systems: potential benefits of qualitative research methods. *International journal of medical informatics, 64*(1), 1-14.

Van Arnhem, J.-P. (2013). Unpacking evernote: Apps for Note-Taking and a repository for Note-Keeping. *The Charleston Advisor, 15*(1), 55-57.

Vishnevetsky, J., Walters, C. B., & Tan, K. S. (2018). Interrater reliability of the patient education materials assessment tool (PEMAT). *Patient Education and Counseling, 101*(3), 490-496.

Wass, S., Safari, M. C., Haugland, S., & Omland, H. O. (2021). Transitions from school to sheltered employment in Norway–Experiences of people with intellectual disabilities. *British Journal of Learning Disabilities, 49*(3), 373-382.

Webb, P., Davidson, G., Edge, R., Falls, D., Keenan, F., Kelly, B., McLaughlin, A., Montgomery, L., Mulvenna, C., Norris, B., Owens, A., & Shea Irvine, R. (2020). Service users' experiences and views of support for decision-making. *Health Soc Care Community*, *28*(4), 1282-1291. https://doi.org/10.1111/hsc.12961

Wehmeyer, M. L. (2020). The importance of self-determination to the quality of life of people with intellectual disability: A perspective. *International Journal of Environmental Research and Public Health*, *17*(19), 7121.

Wehmeyer, M. L., & Shogren, K. A. (2016). Self-determination and choice. *Handbook of evidence-based practices in intellectual and developmental disabilities,* 561-584.

Wehmeyer, M. L., & Shogren, K. A. (2017). Decision making. *Development of self-determination through the life-course*, 261-270.

Wehmeyer, M. L., Shogren, K. A., Little, T. D., & Lopez, S. J. (2017). *Development of self-determination through the life-course*. Springer.

Werner, S., & Chabany, R. (2016). Guardianship law versus supported decision-making policies: Perceptions of persons with intellectual or psychiatric disabilities and parents. *Am J Orthopsychiatry*, *86*(5), 486-499. https://doi.org/10.1037/ort0000125

White, M. D., & Marsh, E. E. (2006). Content analysis: A flexible methodology. *Library trends*, *55*(1), 22-45.

Whitehead, L. C., Trip, H. T., Hale, L. A., & Conder, J. (2016). Negotiated autonomy in diabetes self-management: the experiences of adults with intellectual disability and their support workers. *J Intellect Disabil Res*, *60*(4), 389-397. https://doi.org/10.1111/jir.12257

Williams, V., & Porter, S. (2017). The Meaning of 'choice and control' for People with Intellectual Disabilities who are Planning their Social Care and Support. *J Appl Res Intellect Disabil*, *30*(1), 97-108. https://doi.org/10.1111/jar.12222

Wong, P. K. S., & Chow, A. Y. M. (2021). Self-Determination Competencies, (Dis)Agreement in Decision-Making, and Personal Well-Being of Adults with Mild Intellectual Disabilities in Hong Kong. *Int J Environ Res Public Health*, *18*(20). https://doi.org/10.3390/ijerph182010721

Young, D. A., & Quibell, R. (2000). Why rights are never enough: Rights, intellectual disability and understanding. *Disability & Society*, *15*(5), 747-764.

Zigic, N., Pajevic, I., Hasanovic, M., Avdibegovic, E., Aljukic, N., & Hodzic, V. (2023). Neurodevelopmental disorders in ICD-11 classification. *European Psychiatry*, *66*(S1), S737-S737.

Appendices

Appendix I: Table of papers included in the Systematic Review

Author	Year	Country	Design	Participants	Data Collection	Response Rate	Method(s) of Analysis
Andre-Barron, D.; Strydom, A,; Hassiotis, A.	2008	UK	Qualitative	26 individuals; carers, adults with Intellectual Disability, clincians.	focus groups	N/A	Data transcription, tape recorded.
Antaki, C; Finlay, W.M.L; Walton, C. , Pate. L	2008	UK	Qualitative	5 men with Intellectual Disability	Ethnographic study	N/A	Conversation Analysis
Antaki, C; Finlay, W.M.L; Sheridan, E; Jingree, T; Walton, C.	2006	UK	Qualitative	20 group members and 3 staff advisors	case studies	N/A	Thematic analysis
Antaki, C; Finlay, W.M.L; Walton, C.	2009	UK	Qualitative	15 individuals with Intellectual Disability, 2 staff members.	ethnographic study	N/A	Grounded theory with discourse analysis

Beadle-Brown, J; Hutchinson, A; Whelton, B.	2008	UK	Quantitative	29 individuals with high support needs, 36 staff members.	Observational, interviews and questionnaires.	N/A	Inductive qualitative techniques
Beadle-Brown, J; Hutchinson, A; Whelton, B.	2012	UK	Quantitative	33 individuals at baseline, 31 at follow up	Observational analysis, questionnaires	N/A	EMAC-R evaluation, Momentary Time Sampling, Active support measure, short form adaptive behaviour scale, choice scale, index of partic. in daily living, index of community involvment, staff exp. and satisfaction quest., observation
Bigby, C; Bowers, B; Webber, R	2011	Australia	Qualitative	16 family members of older adults with Intellectual Disability, 17 group home staff, 17 organisational managers	semi-structured interviews, focus groups	N/A	Grounded dimensional analysis
Bigby, C; Clement, T; Mansell, J; Beadle-Brown, J.	2009	Australia	Mixed Methods	25 residents of community housing, staff, and family members, 144 direct care staff	Ethnographic Study, questionnaires	N/A	Thematic analysis, cronbach's alpha, Mann-Whitney, Kruskal-Wallis

Bigby, C., Douglas, J., Smith, E., Carney, T., Then, S. N., & Wiesel, I.	2021	Australia	Mixed Methods	18 parents	LaTrobe framework training sessions, monitoring sessions, ss interviews	N/A	coding template (Charmaz method)
Bigby, C., Douglas, J., Smith, E., Carney, T., Then, S. N., & Wiesel, I.	2021	Australia	Qualitative	23 parents	repeated ss interviews	N/A	template approach (king, chamaz), template codes based on steps 3 and 4 of LaTrobe Framework for SDM
Bigby, C; Webber, R; Bowers, B.	2015	Australia	Qualitative	14 siblings, and 17 staff members	Semi-structured interviews	N/A	Inductive qualitative techniques
Bigby, Christine; Whiteside, Mary; Douglas, Jacinta	2019	Australia	Qualitative	23 adults, mixed group of staff and family	Focus groups, one on one interviews	N/A	Thematic analysis, grounded theory coding
Black, A.B; Roberts, P.	2009	UK	Qualitative	7 people with Intellectual Disability, 119 staff members	Semi-structured interviews, training course	N/A	Likert scale, thematic analysis
Brady, Anna; Burke, Meghan; Trenton, Langdon; Oertle, Kathleen	2019	USA	Qualitative	10 adult siblings of adults with Intellectual Disability	Semi-structured one on one interviews	N/A	Grounded theory with directed analysis process

Brotherton, M., Stancliffe, R. J., Wilson, N. J., & O'Loughlin, K.	2020	Australia	Qualitative	five participants with ID	ss interviews	N/A	grounded theory coding
Browning, M., Bigby, C., & Douglas, J.	2021	Canada	Qualitative	32 (7 ID, 25 supporters)	ss interviews, observation w field notes	N/A	grounded theory coding
Buhagiar, S., & Azzopardi Lane, C.	2020	Malta	Qualitative	7 people with ID	workshop audio recorded	N/A	thematic analysis of workshop recordings
Burke, Meghan; Lee, Cheun; Hall, Sarah; Rosetti, Zach	2019	USA	Qualitative	9 sibling diads (18 participants)	Dyadic interviews, semi-structured one on one interviews with each sibling	N/A	Thematic analysis, constant comparator analysis, emergent coding
Calveley, J.	2012	UK	Qualitative	6 adults with Intellectual Disability, 17 staff members.	Participant observation, interviews, document analysis	N/A	Data analysis, transcribing.
Carey, E.	2021	Ireland	Qualitative	12 people with ID	ss interviews	N/A	grounded theory coding
Carey, E; Griffiths, C.	2017	Ireland	Qualitative	12 adults with Intellectual Disability	Interviews, one on one	N/A	Classical grounded theory methodology

Carney, T., Bigby, C., Then, S. N., Smith, E., Wiesel, I., & Douglas, J.	2021	Australia	Qualitative	110 (55 dyads, person with ID and supporter)	ss dyadic interviews	N/A	coded using Latrobe framework steps, followed by inductive thematic coding
Cartwright, Luke; Reid, Marie; Hammersley, Richard; Blackburn, Chrissie; Glover, Leslie	2015	UK	Qualitative	42 (10 service users, 10 staff carers, 10 family members, 12 facility leaders)	Semi-structured one on one interviews, focus groups	N/A	Grounded theory with constructivist methods
Charnley, H; Hwang, S.K; Atkinson, C; Walton, P.	2019	UK	Qualitative	115 individuals with Intellectual Disability	Discussion groups, observational techniques	N/A	co-inquiry study, participatory research techniques
Collings, S; Dew, A; Dowse, L.	2017	Australia	Qualitative	9 individuals with Intellectual Disability, 3 carers, 1 parent	Focus Groups	N/A	Inductive Thematic Analysis
Curryer, B; Stancliffe, R.J; Dew, A; Wiese, M.Y.	2018	Australia	Qualitative	8 adults with Intellectual Disability	Semi-structured interviews	N/A	Interpretive phenomenological analysis
Curryer, B; Stancliffe, R.J; Dew, A; Wiese, M.Y.	2020	Australia	Qualitative	8 mothers of individuals with Intellectual Disability	semi-structured interviews	N/A	Interpretive phenomenological analysis

Daniel, B; Cross, B; Sherwood-Johnson, F; Paton, D.	2014	UK	Qualitative	42 individuals with disabilites	Focus groups	N/A	Framework analysis
Davies, R.N; Werner, S.; Sinai, A	2017	Israel	Qualitative	2 social workers, 3 clinical staff, 4 lawyers	focus groups, semi-structured interviews	N/A	Thematic analysis
Deguara, M.; Jelassi, O.; Micallef, B.; Callus, A.	2012	Malta	Qualitative	7 individuals with Intellectual Disability, 30 without	Group meetings	N/A	Report Analysis of meetings
Devi, N.; Prodinger, B.; Pennycott, A.; Sooben,R.; Bickenbach, J.	2020	UK	Qualitative	10 service users, 15 support workers, 4 managers	Observations, semi-structured interviews, documentary analysis.	N/A	Institutional ethnogrpahy
Dowling, S.; Williams, V.; Webb, J.; Gall, M.; Worrall, D.	2019	UK	Qualitative	9 people with Intellectual Disability, 7 staff members	Observations, video recordings	N/A	Conversation analysis
Engwall, K.	2014	Sweden	Qualitative	19 adults, 4 with Intellectual Disability.	Semi-structured interviews	N/A	Qualitative analysis of empirical data.
Espiner, D.; Hartnett, F.M.	2012	New Zealand	Mixed Methods	10 adults with Intellectual Disability, 6 key staff workers	semi-structured interviews, questionnaires	60%	Qualitative analysis, member checking.

Ferguson,M.; Jarrett, D.; Terras, M.	2011	UK	Qualitative	4 individuals with Intellectual Disability, 13 carers.	semi-structured interviews	N/A	Thematic Analysis
Fisher, K.M.; Orkin, F.K.; Green, M.J.; Chinchilli, V.M.	2009	USA	Quantitative	262 state-licensed facilities	Self-administered surveys	65%	Exploratory factor analysis, ANOVA
Fullana, J.; Pallisera, M.; Diaz-Garolera, G.	2019	Spain	Qualitative	72 people with learning disabilities.	Focus groups	N/A	Transcript analysis, theroetical methodological framework of CDA.
Garcia-Iriarte, E.; Kramer, J.C.; Hammel, J.	2008	USA	Qualitative	16 individuals with Intellectual Disability	focus groups, participatory engagement, reflexivity	N/A	Constant comparative approach
Giertz, L.	2018	Sweden	Qualitative	14 individuals with Intellectual Disability, 14 care staff, 19 clients with LSS measures	One-on-one interviews, focus groups	N/A	Empirical data analysis, thematic analysis
Gill, J.; Fazil, Q.	2013	UK	Qualitative	6 carers	Semi-structured interviews	N/A	Thematic analysis
Gilmartin, A.; Slevin, E.	2010	Ireland	Qualitative	13 people with Intellectual Disability.	semi-structurerd interviews	N/A	phenomenological methodology, Colaizzi's 7-stage process of analysis

Goldsmith, L.; Woodward, V.; Jackson, L.; Skirton, H.	2013	UK	Qualitative	14 individuals with Intellectual Disability.	observation, semi-structured interviews.	N/A	Thematic analysis, ethnographic approach.
Gross, J.M.S.; Wallace, L.; Blue-Banning, M.; Summers, J.A.; Turnbull, A.	2012	USA	Qualitative	22 individuals with Intellectual Disability	Group interviews, individual interviews, review of support documents	N/A	Codebook development, qualitative research techniques.
Haigh, A.; Lee, D.; Shaw, C.; Hawthorne, M.; Chamberlain, S.; Newman, D.W.; Clarke, Z.; Beail,N.	2013	UK	Qualitative	20 people with Intellectual Disability	interviews, questionnaires.	N/A	Thematic analysis
Hassan,N.	2017	UK	Qualitative	4 people with Intellectual Disability, 4 support workers.	Observations, Interviews, questionnaires.	N/A	Ethnogrpahic research
Hellzen, O.; Haugenes, M.; Ostby, M.	2018	Norway	Qualitative	6 individuals with Intellectual Disability	Focus group discussion, one-on-one interviews	N/A	Qualitative content analysis, thematic analysis
Hickson, L.; Khemka, I.; Golden, H.; Chatzistyli, A.	2015	USA	Quantitative	58 individuals with Intellectual Disability	interviews, training curriculum	N/A	Statistical analysis, ANCOVA, Pearson correlations

Hollomotz, A.	2014	UK	Qualitative	29 individuals with Intellectual Disability.	Participant observation, semi-structured interviews.	N/A	Thematic analysis
Hoole, L.; Morgan, S.	2011	UK	Qualitative	7 people with disabilities.	Focus group	N/A	Thematic Analysis
Jamieson, R.; Theodore, K.; Raczka, R.	2016	UK	Qualitative	3 mothers with Intellectual Disability, 2 family members, 6 professional workers.	Semi-structured interviews	N/A	Grounded Theory
Jingree, T.; Finla, W.M.L.; Antaki, C.	2006	UK	Qualitative	8 people with ID, 5 staff members.	Video recordings, semi-structured meetings	N/A	Conversation analysis
Johnson, P; Carpenter, K; Scarbrough-Lang, SJ	2012	UK	Qualitative	30 individuals with Intellectual Disability, 2 managers	tailored training program, observation, reflective feedback	N/A	group comparison, feedback analysis
Khalin, I.; Kjellberg, A.; Hagberg, J.E.	2016	Sweden	Qualitative	15 staff members, 12 individuals with Intellectual Disability.	Semi-structured interviews, observation	N/A	Descriptive conventional content analysis
Larkin, M.; Unwin, G,; Iyer, M.; Tsimopoulou, I.; Zahid, S.; Malik, K.; Kroese, B.S.; Rose, J.L.	2018	UK	Qualitative	32 adults with Intellectual Disability	semi-structured interviews	N/A	Template analysis, phenomenological approach.

Ledger, S.; Earle, S.; Tilley, E.; Walmsley, J.	2016	UK	Mixed Methods	90 individuals	surveys	N/A	Thematic analysis, mix of open and closed questions, leading to qual and quant componants
Lukas, J.F.; Lizasoain, L.; Galarreta, J,; Etxeberria, J.	2018	Spain	Quantitative	874 persons in sheltered workshops.	Survey, semi-structured interview	N/A	Job satisfaction scale, statistical analysis
Mannan, H.; O' Brien, P.; McConkey, R.; FInlay, F.; Lawlor, A.; Harrington, G.	2011	Ireland	Qualitative	70 family members.	Focus groups, interviews.	N/A	Thematic analysis
McCarthy, M.	2010	UK	Mixed Methods	23 women with Intellectual Disability, 162 doctors.	Semi-structured interviews, survey	13.4%, 49.2%	Multistaged Narrative Analysis, Content Analysis
McCauseland, D.; Brennan, D.; McCarron, M.; McCallion, P.	2019	Ireland	Qualitative	12 families with persons with Intellectual Disability.	Semi-structured interviews	N/A	Thematic analysis, content analysis
McCauseland, D.; McCallion, P.; Brennan, D.; McCarron, M.	2018	Ireland	Quantitative	753 adults with Intellectual Disability	Intellectual Disability Supplement and Irish Longitudinal Study on Ageing.	N/A	Bivariate analysis, multiple linear regression, ANOVA.
McDonald, K.E.; Kidney, C.A.; Patka, M.	2013	USA	Qualitative	16 individuals with Intellectual Disability	semi-structured interviews, focus groups	N/A	Thematic analysis, inductive content analysis

Murphy, E.; Clegg, J.; Almack, K.	2011	UK	Qualitative	28 young people with Intellectual Disability	one-on-one interviews, observations, discussion groups, diaries and documentary analysis	N/A	Transcribing, coding framework, themes.
Nicholson, C., Finlay, W. M. L., & Stagg, S.	2021	UK	Qualitative	17 (5 service users with SPID, 12 staff)	video ethnography	n/a	description of resistence behaviours and staff responses
Nonnemacher, S.L.; Bambara, L.M.	2008	USA	Qualitative	10 adults with Intellectual Disability	semi-structured interviews	N/A	Transcribing analysis, Consensual Qualitative Research procedure, cross analysis
Pallisera, M.; Vila, M.; Fullana, J.; Diza-Garolera, G.; Puyalto, C.; Valls, M.J.	2018	Spain	Qualitative	72 advocates, 33 professionals	interviews, focus groups	N/A	Thematic analysis

Pallisera, M., Vilà, M., Fullana, J., & Valls, M. J. (2021). Being in control: Choice and control of support received in supported living. A study based on the narratives of people with intellectual disability and support staff. *Journal of Intellectual & Developmental Disability*, *46*(2), 164-174.	2021	Spain	Qualitative	19 (6 support staff, 13 people with ID)	ss interviews	N/A	qualitative directive content analysis
Petner-Arrey, J.; Copeland, S.R.	2015	USA	Qualitative	10 people with Intellectual Disability, 10 support workers.	one-on-one interviews	N/A	LeCompte Analysis, transcripts
Roets, G.; Adams, M.; Van Hove, G.	2006	Belgium	Qualitative	1 adult with Intellectual Disability and her advocate	Tape-recorded conversations	N/A	Life story research, ethnographic research.
Rogers, W.; Pilch, M.; McGuire, B.E.; Flynn, E.; Egan J.	2020	Ireland	Qualitative	15 psychologists	Semi-structured interviews	N/A	Thematic Analysis

Sheehan, R.; Hassiotis, A.; Strydom, A.; Morant, N.	2019	UK	Qualitative	14 adults with Intellectual Disability, 12 family carers, 12 paid carers.	Semi-structured interviews	N/A	Thematic Analysis
Stancliffe, R.J.; Lakin, K.C.; Engler, J.; Taub.; S.; Fortune, J.	2011	USA	Quantitative	6778 individuals with Intellectual Disability	National survey	N/A	Test-retest reliability , univariate analyses.
Stefansdottir, G.; Bjornsdottir, K.; Stefansdottir, A.	2018	Iceland	Qualitative	24 adults with Intellectual Disability, 12 support staff	Participant observation, focus group interviews.	N/A	Thematic analysis
Taylor, W.D.; Cobigo, V.; Ouellette-Kuntz, H.	2019	Canada	Qualitative	2 families with people with Intellectual Disability.	Semi-structured interviews, ethnographic observations.	N/A	Review of interview transcripts , thematic coding.
Timmons, J.C.; Hall, A.C.; Bose, J.; Wolfe, A.; Winsor, J.	2011	USA	Qualitative	15 workers, 16 individuals with Intellectual Disability, 13 family members	one -on-one interviews	N/A	Coding, theme analysis.
Tracy, J.	2015	Australia	Qualitative	1 adult with Intellectual Disability	Case study	N/A	Life story research, ethnographic research.
Wass, S., Safari, M. C., Haugland, S., & Omland, H. O.	2021	Norway	Qualitative	9 with ID	qualitative interviews	N/A	thematic analysis

Webb, P.; Davidson, G.; Edge, R.; Falls, D.; Keenan, F.; Kelly, B.; McLaughlin, A.; Montgomery, L.; Mulvenna, C.; Norris, B.; Owens, A.; Irvine, R.S.	2020	UK	Qualitative	41 individuals with Intellectual Disability or Mental Illness.	semi-structured Interviews	N/A	Thematic Anlysis
Werner, S.; Chabany, R.	2015	Israel	Qualitative	33 adults with Intellectual Disability or Mental Illness.	Focus groups	N/A	Content Analysis
Whitehead, L.C.; Trip, H.T.; Hale, L.A.; Conder, J.	2016	New Zealand	Qualitative	14 people with diabetes and Intellectual Disability, 17 support workers.	Semi-structured interviews	N/A	Thematic Analysis
Williams, V.; Porter, S.	2017	UK	Qualitative	9 adults with Intellectual Disability	semi-structured interviews	N/A	Interpretive phenomonological analysis
Wong, P. K. S.	2021	China	Qualitative	32 (13 with ID, 7 parents, 12 personnel)	focus groups	N/A	thematic analysis

Appendix II: MMAT Quality Review Tables for Systematic Review Papers

				SCREENING QUESTIONS		1. QUALITATIVE STUDIES				
Type of study	**Authors**	**Year**	**Full Citation**	**S1. Are there clear research questions?**	**S2. Do the collected data allow to address the research questions?**	**1.1. Is the qualitative approach appropriate to answer the research question?**	**1.2. Are the qualitative data collection methods adequate to address the research question?**	**1.3. Are the findings adequately derived from the data?**	**1.4. Is the interpretation of results sufficiently substantiated by data?**	**1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?**
Qualitative	Andre-Barron, D.; Strydom, A,; Hassiotis, A.	2008	Andre-Barron, D., Strydom, A., & Hassiotis, A. (2008). What to tell and how to tell: a qualitative study of information sharing in research for adults with intellectual disability. *Journal of*	Yes	Yes	Yes	Yes	Yes	Yes	Yes

			Medical Ethics, *34*(6), 501-506.							
Qualitative	Antaki, C; Finlay, W.M.L; Walton, C. , Pate. L	2008	Antaki, C., Finlay, W., Walton, C., & Pate, L. (2008). Offering choices to people with intellectual disabilities: an interactional study. *Journal of Intellectual Disability Research*, *52*(12), 1165-1175.	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative	Antaki, C; Finlay, W.M.L; Sheridan, E; Jingree, T; Walton, C.	2006	Antaki, C., Finlay, W. M. L., Sheridan, E., Jingree, T., & Walton, C. (2006). Producing decisions in service-user groups for people with an intellectual disability: Two contrasting facilitator styles. *Mental Retardation*, *44*(5), 322-343	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Qualitative	Antaki, C; Finlay, W.M.L; Walton, C.	2009	Antaki, C., Finlay, W. M. L., & Walton, C. (2009). Choices for people with intellectual disabilities: Official discourse and everyday practice. *Journal of Policy and Practice in Intellectual Disabilities*, *6*(4), 260-266.	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative	Bigby, C; Bowers, B; Webber, R	2011	Bigby, C., Bowers, B., & Webber, R. (2011). Planning and decision making about the future care of older group home residents and transition to residential aged care. Journal of Intellectual Disability Research, 55(8), 777-789.	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative	Bigby, C; Douglas, J; Smith, E; Carney, T; The, S; Wiesel, I	2021	Bigby, C., Douglas, J., Smith, E., Carney, T., Then, S. N., & Wiesel, I. (2021). Parental strategies that support adults with intellectual disabilities to explore decision preferences,	Yes	Yes	Yes	Yes	Yes	Yes	Yes

			constraints and consequences. *Journal of Intellectual & Developmental Disability*, 1-12.							
Qualitative	Bigby, C; Webber, R; Bowers, B.	2015	Bigby, C., Webber, R., & Bowers, B. (2015). Sibling roles in the lives of older group home residents with intellectual disability: Working with staff to safeguard wellbeing. Australian Social Work, 68(4), 453-468.	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative	Bigby, Christine; Whiteside, Mary; Douglas, Jacinta	2019	Bigby, C., Whiteside, M., & Douglas, J. (2019). Providing support for decision making to adults with intellectual disability: Perspectives of family members and workers in disability support services. Journal of Intellectual &	Yes	Yes	Yes	Yes	Yes	Yes	Yes

			Developmental Disability, 44(4), 396-409.							
Qualitative	Black, A.B; Roberts, P.	2009	Black, L. A., & Roberts, P. (2009). People with a learning disability as trainers: evaluation of a values based pilot training programme. British Journal of Learning Disabilities, 37(2), 129-137.	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes
Qualitative	Brady, Anna; Burke, Meghan; Trenton, Langdon; Oertle, Kathleen	2019	Brady, A. M., Burke, M. M., Landon, T., & Oertle, K. (2019). Siblings of adults with intellectual and developmental disabilities: Their knowledge and perspectives on guardianship and its alternatives. Journal of Applied Research in	Yes	Yes	Yes	Yes	Yes	Yes	Yes

			Intellectual Disabilities, 32(5), 1078-1087.							
Qualitative	Brotherton, M; Stancliffe, R.J.; Wilson, N.J.; O'Loughlin, K	2020	Brotherton, M., Stancliffe, R. J., Wilson, N. J., & O'Loughlin, K. (2020). Australians with intellectual disability share their experiences of retirement from mainstream employment. *Journal of Applied Research in Intellectual Disabilities*, *33*(5), 905-916.	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative	Browning, M., Bigby, C., Douglas, J	2021	Browning, M., Bigby, C., & Douglas, J. (2021). A process of decision-making support: Exploring supported decision-making practice in Canada. *Journal of Intellectual &*	Yes	Yes	Yes	Yes	Yes	Yes	Yes

			Developmental Disability, *46*(2), 138-149.							
Qualitative	Buhagier, S., Azzopardi Lane, C.	2020	Buhagiar, S., & Azzopardi Lane, C. (2020). Freedom from financial abuse: persons with intellectual disability discuss protective strategies aimed at empowerment and supported decision-making. *Disability & Society*, 1-25.	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative	Burke, Meghan; Lee, Cheun; Hall, Sarah; Rosetti, Zach	2019	Burke, M. M., Hall, S. A., & Rossetti, Z. (2019). Understanding decision making among individuals with intellectual and developmental disabilities (IDD) and their siblings. Intellectual and developmental disabilities, 57(1), 26-41.	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Qualitative	Calveley, J.	2012	Calveley, J. (2012). Including adults with intellectual disabilities who lack capacity to consent in research. Nursing Ethics, 19(4), 558-567.	Yes	Yes	Can't tell	Yes	Can't tell	Can't tell	Can't tell
Qualitative	Carey, E.	2021	Carey, E. (2021). Aligning with the flow of control: A grounded theory study of choice and autonomy in decision-making practices of people with intellectual disabilities. *International Journal of Qualitative Studies on Health and Well-being*, *16*(1), 1857053.	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative	Carey, E; Griffiths, C.	2017	Carey, E., & Griffiths, C. (2017). Recruitment and consent of adults with intellectual disabilities in a classic grounded theory research study: ethical and methodological considerations. *Disability & Society*, *32*(2), 193-212.	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Qualitative	Carney, T., Bigby, C., Then, S., Smith, E., Wiesel, I., Douglas, J.	2021	Carney, T., Bigby, C., Then, S. N., Smith, E., Wiesel, I., & Douglas, J. (2021). Paternalism to empowerment: all in the eye of the beholder?. *Disability & Society*, 1-21.	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative	Cartwright, Luke; Reid, Marie; Hammersley, Richard; Blackburn, Chrissie; Glover, Leslie	2015	Cartwright, L., Reid, M., Hammersley, R., Blackburn, C., & Glover, L. (2015). Food choice by people with intellectual disabilities at day centres: a qualitative study. Journal of intellectual disabilities, 19(2), 103-115.	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative	Charnley, H; Hwang, S.K; Atkinson, C;	2019	Charnley, H., Hwang, S. K., Atkinson, C., & Walton, P. (2019). 'If I were given the chance': understanding the use of leisure time by adults with learning	Yes	Yes	Yes	Yes	Yes	Yes	Yes

	Walton, P.		disabilities. *Disability & Society*, *34*(4), 540-563.							
Qualitative	Collings, S; Dew, A; Dowse, L.	2017	Collings, S., Dew, A., & Dowse, L. (2019). “They need to be able to have walked in our shoes”: What people with intellectual disability say about National Disability Insurance Scheme planning. *Journal of Intellectual & Developmental Disability*, *44*(1), 1-12.	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative	Curryer, B; Stancliffe, R.J; Dew, A; Wiese, M.Y.	2018	Curryer, B., Stancliffe, R. J., Dew, A., & Wiese, M. Y. (2018). Choice and control within family relationships: The lived experience of adults with intellectual disability. *Intellectual and developmental*	Yes	Yes	Yes	Yes	Yes	Yes	Yes

			disabilities, *56*(3), 188-201.							
Qualitative	Curryer, B; Stancliffe, R.J; Dew, A; Wiese, M.Y.	2020	Curryer, B., Stancliffe, R. J., Wiese, M. Y., & Dew, A. (2020). The experience of mothers supporting self-determination of adult sons and daughters with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *33*(3), 373-385.	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative	Daniel, B; Cross, B; Sherwood-Johnson, F; Paton, D.	2014	Daniel, B., Cross, B., Sherwood-Johnson, F., & Paton, D. (2014). Risk and decision making in adult support and protection practice: User views from participant research. *British Journal of Social Work*, *44*(5), 1233-1250.	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Qualitative	Davies, R.N; Werner, S.; Sinai, A	2017	Davies, R. N., Werner, S., & Sinai, A. (2017). Guardianship and supported decision making in Israel. *Advances in Mental Health and Intellectual Disabilities*.	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative	Deguara, M.; Jelassi, O.; Micallef, B.; Callus, A.	2012	Deguara, M., Jelassi, O., Micallef, B., & Callus, A. M. (2012). How we like to live when we have the chance. *British Journal of Learning Disabilities*, *40*(2), 123-127.	Yes	Can't tell	Can't tell	Can't tell	Can't tell	Can't tell	Can't tell
Qualitative	Devi, N.; Prodinger, B.; Pennycott, A.; Sooben,R.; Bickenbach, J.	2020	Devi, N., Prodinger, B., Pennycott, A., Sooben, R., & Bickenbach, J. (2020). Investigating Supported Decision-Making for Persons With Mild to Moderate Intellectual Disability Using Institutional Ethnography. *Journal of Policy and Practice in Intellectual*	Yes	Yes	Yes	Yes	Yes	Yes	Yes

			Disabilities, *17*(2), 143-156.							
Qualitative	Dowling, S.; Williams, V.; Webb, J.; Gall, M.; Worrall, D.	2019	Dowling, S., Williams, V., Webb, J., Gall, M., & Worrall, D. (2019). Managing relational autonomy in interactions: People with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *32*(5), 1058-1066.	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative	Engwall, K.	2014	Engwall, K. (2014). Childfreeness, parenthood and adulthood. *Scandinavian Journal of Disability Research*, *16*(4), 333-347.	Yes	Yes	Can't tell	Yes	Yes	Can't tell	Yes
Qualitative	Ferguson, M.; Jarrett, D.;	2011	Ferguson, M., Jarrett, D., & Terras, M. (2011). Inclusion and healthcare choices: the experiences	Yes	Yes	Yes	Yes	Yes	Yes	Yes

	Terras, M.		of adults with learning disabilities. *British Journal of Learning Disabilities*, *39*(1), 73-83.							
Qualitative	Fullana, J.; Pallisera, M.; Diaz-Garolera, G.	2019	Fullana, J., Pallisera, M., & Díaz-Garolera, G. (2019). How do people with learning disabilities talk about professionals and organizations? Discourse on support practices for independent living. *Disability & Society*, *34*(9-10), 1462-1480.	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative	Garcia-Iriarte, E.; Kramer, J.C.; Hammel, J.	2008	Garcia-Iriarte, E., Kramer, J. C., Kramer, J. M., & Hammel, J. (2009). 'Who did what?': a participatory action research project to increase group capacity for advocacy. *Journal of Applied Research in Intellectual Disabilities*, *22*(1), 10-22.	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Qualitative	Giertz, L.	2018	Giertz, L. (2018). Guardianship for Adults with Intellectual Disabilities: Accountant, Advocate or 'Family'Member?. *Scandinavian Journal of Disability Research*, *20*(1).	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative	Gill, J.; Fazil, Q.	2013	Gill, J., & Fazil, Q. (2013). Derogation of "duty of care" in favour of "choice"?. *The Journal of Adult Protection*.	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative	Gilmartin, A.; Slevin, E.	2010	Gilmartin, A., & Slevin, E. (2010). Being a member of a self-advocacy group: Experiences of intellectually disabled people. *British Journal of Learning Disabilities*, *38*(3), 152-159.	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative	Goldsmith, L.; Woodward, V.; Jackson, L.;	2013	Goldsmith, L., Woodward, V., Jackson, L., & Skirton, H. (2013). Informed consent for blood tests in people with a learning disability. *Journal of*	Yes	Yes	Yes	Yes	Yes	Yes	Yes

	Skirton, H.		*advanced nursing*, *69*(9), 1966-1976.							
Qualitative	Gross, J.M.S.; Wallace, L.; Blue-Banning, M.; Summers, J.A.; Turnbull, A.	2012	Gross, J. M., Wallace, L., Blue-Banning, M., Summers, J. A., & Turnbull, A. (2013). Examining the experiences and decisions of parents/guardians: Participant directing the supports and services of adults with significant intellectual and developmental disabilities. *Journal of Disability Policy Studies*, *24*(2), 88-101.	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative	Haigh, A.; Lee, D.; Shaw, C.; Hawthorne, M.; Chamberlain, S.; Newman,	2013	Haigh, A., Lee, D., Shaw, C., Hawthorne, M., Chamberlain, S., Newman, D. W., ... & Beail, N. (2013). What things make people with a learning disability happy and satisfied with their	Yes	Yes	Yes	Yes	Yes	Yes	Yes

	D.W.; Clarke, Z.; Beail,N.		lives: An inclusive research project. *Journal of Applied Research in Intellectual Disabilities*, *26*(1), 26-33.							
Qualitative	Hassan,N.	2017	Hassan, N. (2017). ‘Putting music on’: everyday leisure activities, choice-making and person-centred planning in a supported living scheme. *British Journal of Learning Disabilities*, *45*(1), 73-80.	Yes	Yes	Yes	Yes	Can't tell	Yes	Can't tell
Qualitative	Hellzen, O.; Haugenes, M.; Ostby, M.	2018	Hellzen, O., Haugenes, M., & Østby, M. (2018). ‘It’s my home and your work’: the views of a filmed vignette describing a challenging everyday situation from the perspective of people with intellectual disabilities. *International journal of qualitative*	Yes	Yes	Yes	Yes	Yes	Yes	Yes

			studies on health and well-being, *13*(1), 1468198.							
Qualitative	Hollomotz, A.	2014	Hollomotz, A. (2014). Are we valuing People's choices now? Restrictions to mundane choices made by adults with learning difficulties. *British Journal of Social Work*, *44*(2), 234-251.	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative	Hoole, L.; Morgan, S.	2011	Hoole, L., & Morgan, S. (2011). ‘It’s only right that we get involved’: service-user perspectives on involvement in learning disability services. *British Journal of Learning Disabilities*, *39*(1), 5-10.	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Qualitative	Jamieson, R.; Theodore, K.; Raczka, R.	2016	Jamieson, R., Theodore, K., & Raczka, R. (2016). Becoming a mother: Supported decision-making in context. *Journal of Intellectual Disabilities*, *20*(4), 313-328.	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative	Jingree, T.; Finla, W.M.L.; Antaki, C.	2006	Jingree, T., Finlay, W. M. L., & Antaki, C. (2006). Empowering words, disempowering actions: an analysis of interactions between staff members and people with learning disabilities in residents' meetings. *Journal of Intellectual Disability Research*, *50*(3), 212-226.	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative	Johnson, P; Carpenter, K; Scarbrough-Lang, SJ	2012	Johnson, P., Carpenter, K., & Scarbrough-Lang, S. J. (2012). Involvement of service users in the recruitment of staff. *Learning Disability Practice*, *15*(2).	Can't tell	Can't tell	Can't tell	Can't tell	Can't tell	Can't tell	Can't tell

Qualitative	Khalin, I.; Kjellberg, A.; Hagberg, J.E.	2016	Kåhlin, I., Kjellberg, A., & Hagberg, J. E. (2016). Choice and control for people ageing with intellectual disability in group homes. *Scandinavian journal of occupational therapy*, *23*(2), 127-137.	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative	Larkin, M.; Unwin, G,; Iyer, M.; Tsimopoulou, I.; Zahid, S.; Malik, K.; Kroese, B.S.; Rose, J.L.	2018	Larkin, M., Unwin, G., Iyer, M., Tsimopoulou, I., Zahid, S., Malik, K., ... & Rose, J. L. (2018). Cultural affordance, social relationships, and narratives of independence: Understanding the meaning of social care for adults with intellectual disabilities from minority ethnic groups in the UK. *International Journal of Developmental Disabilities*, *64*(3), 195-203.	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Qualitative	Mannan, H.; O' Brien, P.; McConkey, R.; FInlay, F.; Lawlor, A.; Harrington, G.	2011	Mannan, H., O'Brien, P., McConkey, R., Finlay, F., Lawlor, A., & Harrington, G. (2011). Complexities in the provision of respite care to family carers of persons with intellectual disabilities. *Disability, CBR & Inclusive Development*, *22*(2), 38-54.	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative	McCauseland, D.; Brennan, D.; McCarron, M.; McCallion, P.	2019	McCausland, D., Brennan, D., McCallion, P., & McCarron, M. (2019). Balancing personal wishes and caring capacity in future planning for adults with an intellectual disability living with family carers. *Journal of Intellectual Disabilities*, *23*(3), 413-431.	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative	McDonald, K.E.; Kidney, C.A.; Patka, M.	2013	McDonald, K. E., Kidney, C. A., & Patka, M. (2013). ‘You need to let your voice be heard’: research participants' views on	Yes	Yes	Yes	Yes	Yes	Yes	Yes

			research. *Journal of Intellectual Disability Research*, *57*(3), 216-225.							
Qualitative	Murphy, E.; Clegg, J.; Almack, K.	2011	Murphy, E., Clegg, J., & Almack, K. (2011). Constructing adulthood in discussions about the futures of young people with moderate-profound intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *24*(1), 61-73.	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative	Nicholson, C., Finlay, W. M., Stagg, S.	2021	Nicholson, C., Finlay, W. M. L., & Stagg, S. (2021). Forms of resistance in people with severe and profound intellectual disabilities. *Sociology of Health & Illness*, *43*(3), 642-659.	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Qualitative	Nonnemacher, S.L.; Bambara, L.M.	2008	Nonnemacher, S. L., & Bambara, L. M. (2011). “I'm supposed to be in charge”: Self-advocates' perspectives on their self-determination support needs. *Intellectual and developmental disabilities*, *49*(5), 327-340.	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative	Pallisera, M.; Vila, M.; Fullana, J.; Diza-Garolera, G.; Puyalto, C.; Valls, M.J.	2018	Pallisera, M., Vilà, M., Fullana, J., Díaz-Garolera, G., Puyalto, C., & Valls, M. J. (2018). The role of professionals in promoting independent living: Perspectives of self-advocates and front-line managers. *Journal of Applied Research in Intellectual Disabilities*, *31*(6), 1103-1112.	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Qualitative	Pallisera, M., Vila, M., Fullana, J., Valls, M.	2021	Pallisera, M., Vilà, M., Fullana, J., & Valls, M. J. (2021). Being in control: Choice and control of support received in supported living. A study based on the narratives of people with intellectual disability and support staff. *Journal of Intellectual & Developmental Disability*, *46*(2), 164-174.	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative	Petner-Arrey, J.; Copeland, S.R.	2015	Petner-Arrey, J., & Copeland, S. R. (2015). 'You have to care.'perceptions of promoting autonomy in support settings for adults with intellectual disability. *British Journal of Learning Disabilities*, *43*(1), 38-48.	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Qualitative	Roets, G.; Adams, M.; Van Hove, G.	2006	Roets, G., Adams, M., & Hove, G. (2006). Challenging the monologue about silent sterilization: implications for self-advocacy. *British Journal of Learning Disabilities*, *34*(3), 167-174.	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative	Rogers, W.; Pilch, M.; McGuire, B.E.; Flynn, E.; Egan J.	2020	Rogers, E., Pilch, M., McGuire, B. E., Flynn, E., & Egan, J. (2020). Psychologists' perspectives on supported decision making in Ireland. *Journal of Intellectual Disability Research*, *64*(3), 234-245.	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative	Sheehan, R.; Hassiotis, A.; Strydom, A.; Morant, N.	2019	Sheehan, R., Hassiotis, A., Strydom, A., & Morant, N. (2019). Experiences of psychotropic medication use and decision-making for adults with intellectual disability: a multistakeholder qualitative study in the	Yes	Yes	Yes	Yes	Yes	Yes	Yes

			UK. *BMJ open*, *9*(11), e032861.							
Qualitative	Stefansdottir, G.; Bjornsdottir, K.; Stefansdottir, A.	2018	Stefánsdóttir, G. V., Björnsdóttir, K., & Stefánsdóttir, Á. (2018). Autonomy and people with intellectual disabilities who require more intensive support.	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative	Taylor, W.D.; Cobigo, V.; Ouellette-Kuntz, H.	2019	Taylor, W. D., Cobigo, V., & Ouellette-Kuntz, H. (2019). A family systems perspective on supporting self-determination in young adults with intellectual and developmental disabilities. *Journal of applied research in intellectual disabilities*, *32*(5), 1116-1128.	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Qualitative	Timmons, J.C.; Hall, A.C.; Bose, J.; Wolfe, A.; Winsor, J.	2011	Timmons, J. C., Hall, A. C., Bose, J., Wolfe, A., & Winsor, J. (2011). Choosing employment: Factors that impact employment decisions for individuals with intellectual disability. *Intellectual and developmental disabilities*, *49*(4), 285-299.	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative	Tracy, J.	2015	Tracy, J. (2015). Supporting Nick to Make Decisions: An Exploration of Ways to Promote Choice and Control. *Research and Practice in Intellectual and Developmental Disabilities*, *2*(1), 29-36.	Can't tell	Can't tell	Can't tell	Can't tell	Can't tell	Can't tell	Can't tell
Qualitative	Wass, S., Safari, M.C., Haugland, S., Omland, H.O.	2012	Wass, S., Safari, M. C., Haugland, S., & Omland, H. O. (2021). Transitions from school to sheltered employment in Norway–Experiences of people with intellectual	Yes	Yes	Yes	Yes	Yes	Yes	Yes

			disabilities. *British Journal of Learning Disabilities*, *49*(3), 373-382.							
Qualitative	Webb, P.; Davidson, G.; Edge, R.; Falls, D.; Keenan, F.; Kelly, B.; McLaughlin, A.; Montgomery, L.; Mulvenna, C.; Norris, B.; Owens, A.; Irvine, R.S.	2020	Webb, P., Davidson, G., Edge, R., Falls, D., Keenan, F., Kelly, B., ... & Shea Irvine, R. (2020). Service users' experiences and views of support for decision-making. *Health & social care in the community*, *28*(4), 1282-1291.	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Qualitative	Werner, S.; Chabany, R.	2015	Werner, S., & Chabany, R. (2016). Guardianship law versus supported decision-making policies: Perceptions of persons with intellectual or psychiatric disabilities and parents. *American Journal of Orthopsychiatry*, *86*(5), 486.	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative	Whitehead, L.C.; Trip, H.T.; Hale, L.A.; Conder, J.	2016	Whitehead, L. C., Trip, H. T., Hale, L. A., & Conder, J. (2016). Negotiated autonomy in diabetes self-management: The experiences of adults with intellectual disability and their support workers. *Journal of Intellectual Disability Research*, *60*(4), 389-397.	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative	Williams, V.; Porter, S.	2017	Williams, V., & Porter, S. (2017). The meaning of ‘choice and control’for people with intellectual disabilities who are planning their social care	Yes	Yes	Yes	Yes	Yes	Yes	Yes

			and support. *Journal of Applied Research in Intellectual Disabilities*, *30*(1), 97-108							
Qualitative	Wong, P.K.S.	2021	Wong, P. K. S. (2021). Searching for a dynamic equilibrium in decision making: The voices of adults with mild intellectual disability and their significant others in Hong Kong. *Disability and Rehabilitation*, 1-11.	Yes	Yes	Yes	Yes	Yes	Yes	Yes

				SCREENING QUESTIONS		**2. RANDOMIZED CONTROLLED TRIALS**				
Type of study	Authors	Year	Full Citation	S1. Are there clear research questions?	S2. Do the collected data allow to	2.1. Is randomization appropriately performed?	2.2. Are the groups comparab	2.3. Are there complete	2.4. Are outcome assessors blinded to the	2.5 Did the participants adhere to the assigned

					address the research questions?		le at baseline?	outcome data?	intervention provided?	intervention?
Quantitative	Hickson, L.; Khemka, I.; Golden, H.; Chatzistyli, A.	2015	Hickson, L., Khemka, I., Golden, H., & Chatzistyli, A. (2015). Randomized controlled trial to evaluate an abuse prevention curriculum for women and men with intellectual and developmental disabilities. *American journal on intellectual and developmental disabilities*, *120*(6), 490-503.	Yes	Yes	Yes	Yes	Yes	Yes	Yes

				SCREENING QUESTIONS		**3. NON-RANDOMIZED STUDIES**				
Type of study	Authors	Year	Full Citation	S1. Are there clear research questions?	S2. Do the collected data allow to address the research questions?	3.1. Are the participants representative of the target population?	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?	3.3. Are there complete outcome data?	3.4. Are the confounders accounted for in the design and analysis?	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?
Quantitative	Beadle-Brown, J; Hutchinson, A; Whelton, B.	2008	Beadle-Brown, J., Hutchinson, A., & Whelton, B. (2008). A better life: the implementation and effect of person-	Yes	Yes	Yes	Can't tell	No	No	Yes

			centred active support in the Avenues Trust. Tizard Learning Disability Review.							
Quantitative	Beadle-Brown, J; Hutchinson, A; Whelton, B.	2012	Beadle-Brown, J., Hutchinson, A., & Whelton, B. (2012). Person-centred active support– increasing choice, promoting independence and reducing challenging behaviour. Journal of	Yes	Yes	Yes	Can't tell	No	No	Yes

			Applied Research in Intellectual Disabilities, 25(4), 291-307.							

				SCREENING QUESTIONS		**4. QUANTITATIVE DESCRIPTIVE STUDIES**				
Type of study	Authors	Year	Full Citation	S1. Are there clear research questions?	S2. Do the collected data allow to address the research questions?	4.1. Is the sampling strategy relevant to address the research question?	4.2. Is the sample representative of the target population?	4.3. Are the measurements appropriate?	4.4. Is the risk of nonresponse bias low?	4.5. Is the statistical analysis appropriate to answer the research question?

Quantitative	Fisher, K.M.; Orkin, F.K.; Green, M.J.; Chinchilli, V.M.	2009	Fisher, K. M., Orkin, F. K., Green, M. J., Chinchilli, V. M., & Bhattacharya, A. (2009). Proxy healthcare decision-making for persons with intellectual disability: perspectives of residential-agency directors. *American journal on intellectual and developmental disabilities*, *114*(6), 401-410.	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes
Quantitative	Lukas, J.F.; Lizasoain, L.; Galarreta, J,; Etxeberria, J.	2018	Lukas, J. F., Lizasoain, L., Galarreta, J., & Etxeberria, J. (2018). Job satisfaction among disabled people in the sheltered workshop: Differential analysis. *Journal*	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes

			of Applied Research in Intellectual Disabilities, *31*(6), 1174-1185.							
Quantitative	McCauseland, D.; McCallion, P.; Brennan, D.; McCarron, M.	2018	McCausland, D., McCallion, P., Brennan, D., & McCarron, M. (2018). The exercise of human rights and citizenship by older adults with an intellectual disability in Ireland. *Journal of Intellectual Disability Research*, *62*(10), 875-887.	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Quantitative	Stancliffe, R.J.; Lakin, K.C.; Engler, J.; Taub.; S.; Fortune, J.	2011	Stancliffe, R. J., Lakin, K. C., Larson, S., Engler, J., Taub, S., & Fortune, J. (2011). Choice of living arrangements. *Journal of Intellectual*	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes

			Disability Research, *55*(8), 746-762.							

				SCREENING QUESTIONS		**5. MIXED METHODS STUDIES**				

Type of study	Authors	Year	Full Citation	S1. Are there clear research questions?	S2. Do the collected data allow to address the research questions?	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?	5.2. Are the different components of the study effectively integrated to answer the research question?	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?
Mixed Methods	Bigby, C; Clement, T; Mansell, J; Beadle-Brown, J.	2009	Bigby, C., Clement, T., Mansell, J., & Beadle-Brown, J. (2009). ‘It's pretty hard with our ones, they can't talk, the more able bodied can participate’: Staff attitudes about the applicability of disability policies to people with severe and profound intellectual disabilities.	Yes	Yes	Yes	Yes	Yes	Yes	Yes

			Journal of Intellectual Disability Research, 53(4), 363-376.							
Mixed Methods	Bigby, C; Douglas, J; Smith, E; Carney, T; The, S; Wiesel, I	2021	Bigby, C., Douglas, J., Smith, E., Carney, T., Then, S. N., & Wiesel, I. (2021). “I used to call him a non-decision-maker-I never do that anymore”: parental reflections about training to support decision-making of their adult offspring with intellectual disabilities. Disability and Rehabilitation, 1-9.	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes
Mixed Methods	Espiner, D.; Hartnett, F.M.	2012	Espiner, D., & Hartnett, F. M. (2012). ‘I felt I was in control of the meeting’: facilitating planning with adults with an intellectual disability. *British Journal of*	Yes	Yes	No	Yes	Yes	Yes	Can't tell

			Learning Disabilities, *40*(1), 62-70.							
Mixed Methods	Ledger, S.; Earle, S.; Tilley, E.; Walmsley, J.	2016	Ledger, S., Earle, S., Tilley, E., & Walmsley, J. (2016). Contraceptive decision-making and women with learning disabilities. *Sexualities*, *19* (5-6), 698-724.	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Mixed Methods	McCarthy, M.	2010	McCarthy, M. (2010). Exercising choice and control–women with learning disabilities and contraception. *British Journal of Learning Disabilities*, *38*(4), 293-302.	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes

Appendix III: COVID-19 Survey Questions

Questionnaire

Q1 What is your age?

Q2 What gender do you identify as?

○ Male (1)

○ Female (2)

○ Non-binary (3)

○ Prefer not to say (4)

Q3 In what county do you live in?

Q4 Are you a family or professional carer for an adult(s) with intellectual disability?

○ Family carer (1)

○ Professional carer (2)

Family Carers: General Decision-Making

Q14 In your opinion, what effect has the COVID-19 pandemic had on the choice/decision-making opportunities of your family member with ID?

Q15 Supported decision-making can be defined as "*allow[ing] individuals with disabilities to make choices about their own lives with support from a team of people they choose. Individuals with disabilities choose people they know and trust to be part of a support network to help with decision-making*" (supporteddecisions.org).

Do you engage in supported decision-making with your family member with ID?

○ Yes (1)

○ No (2)

Q16 If yes, please describe how you usually engage in supported decision-making with your family member with ID. If no, please write not applicable.

Q17 Please tell us about the kinds of decisions you help your family member with.

Q18 Have you received advice or support from the HSE/other disability organisations on how to encourage independence and choice making in your family member with ID?

○ Yes (1)

○ No (2)

Q19 If yes, please describe the advice or support received. If no, please write not applicable.

Q20 Have you received advice from any organisation on how to explain the COVID-19 public health regulations to your family member with ID?

○ Yes (1)

○ No (2)

Q21 If yes, please describe the advice received. If no, please write not applicable

Family: Work and care information

Q22 In addition to your care duties, are you:

○ Employed full-time (1)

○ Employed part-time (2)

○ Not currently employed (3)

○ Retired (4)

Q23 What is your relationship to your family member with ID?

Q24 What is the living situation of your family member with ID?

○ Cohabiting with family (1)

○ Cohabiting with friends (2)

○ Residential service facility (3)

○ Long-term care facility (i.e., nursing home) (4)

○ Living independently with professional support (5)

○ Living independently with familial support (6)

Family: Not Cohabiting: Residential or Long-Term Care

Q25 Have you received updates or information from the residential or care facility about their COVID-19 policies?

○ Yes (1)

○ No (2)

Q26 How often do you receive these updates?

○ More than once a week (1)

○ Weekly (2)

○ Monthly (3)

○ Never (4)

Q27 Has your family member or any other resident contracted COVID-19?

○ Yes (1)

○ No (2)

Q28 If yes, please describe how this situation was approached by the residential or long-term service. If no please write not applicable.

Q29 Since the introduction of COVID-19 mitigation measures, how often have you been able to visit your family member with ID in the residential or long-term service?

☐ Regularly (1)

☐ Often (2)

☐ Seldom (3)

☐ Never (4)

Q30 Please provide further details here.

Family: Not Cohabiting: Cohabiting with Friends/Living independently

Q31 Has the COVID-19 pandemic affected the availability of professional support for your family member with ID living independently?

○ Not at all (1)

○ Somewhat (2)

○ Very much (3)

Q32 Please provide further details here.

Q33 Has the COVID-19 pandemic affected the availability of familial support for your family member with ID living independently?

○ Not at all (1)

○ Somewhat (2)

○ Very much (3)

Q34 Please provide further details here.

Q35 Has your family member with ID or another member of their household contracted COVID-19?

○ Yes (1)

○ No (2)

Q36 If yes, please describe how this situation was approached by the family or professional support workers. If no, please write not applicable.

Professional Carers: Work information

Q5 What setting do you work in?

○ Public sector (1)

○ Semi-state company (2)

○ Private sector as an employee (3)

○ Private sector as self-employed person (4)

○ Other (5)

Q6 Is your work full- or part-time?

○ Full-time (1)

○ Part-time (2)

Q7 How many adults with intellectual disability (ID) do you care for?

Q8 Supported decision-making is defined by supporteddecisions.org as follows:

"*Supported decision-making (SDM) allows individuals with disabilities to make choices about their own lives with support from a team of people they choose. Individuals with disabilities choose people they know and trust to be part of a support network to help with decision-making.*"

Please describe how the practice of supported decision-making is approached by your organisation/employer. If you have no information for this, please write not applicable.

Q9 Please describe any challenges you have faced in practicing supported decision-making in your workplace as a result of the COVID-19 pandemic.

Q10 In your opinion, what effect has the COVID-19 pandemic had on the independence and choice making opportunities of adults with ID in your place of employment?

Q11 In your opinion, what impact have visiting restrictions had on the independence and decision-making of adults with ID in your place of employment?

Q12 Has your place of employment experienced any cases of COVID-19 among staff or service users?

○ Yes (1)

○ No (2)

Q13 If yes, please describe how this situation was managed. In particular, we are interested to learn about any impacts on staff and/or service users. If no, please write not applicable.

Appendix IV: CHERRIES Quality Review Table for COVID-19 Survey

Item Category	*Checklist Item*	*Explanation*
Design	Describe survey design	Target population was professional or family carers of a person(s) with intellectual disabilities over 18 years living in the Republic of Ireland. This was an open survey and collected a convenience sample of participants.
IRB (Institutional Review Board) approval and informed consent process	1. IRB Approval 2. Informed consent 3. Data protection	1. Survey was approved by Maynooth University Social Science Ethics review board 2. Participants were shown an information and consent page where they were told the purpose of the survey, what their participation would involve, who approved the study, confirmation that all participation was voluntary and could be ceased at any time prior to submission of answers, what data would be stored, and who the investigator was. 3. Data was securely collected using Qualtrics an encrypted, password protected survey site. Information was accessible only to the primary investigator (HC) via a password protected Qualtrics portal hosted by the university.
Development and Pre-testing	Development and testing	Survey questions were developed using relevant literature on COVID-19 and supported decision-making. Due to the use of open-ended questions, Braun and Clarke's 2021 paper on the use of surveys as a qualitative tool was used as a guide for construction. Qualtrics allows the survey to be previewed and tested before publication. This was done by (HC) and (DD) with adjustments to layout and content made prior to publication.
Recruitment process and description of the sample having access to the questionnaire	1. Open survey versus closed survey 2. Contact mode 3. Advertising the survey	1. This was an open survey hosted on Qualtrics 2. Contact with participants was made via twitter, and via email requests to disability services, and academics in the field of disability to circulate the link among their colleagues and families of service users.

		3. The survey was advertised in a tweet from (HC)'s project twitter account, and via circulation by the above-named groups who agreed to assist.
Survey administration	1. Web/email 2. Context 3. Mandatory/voluntary 4. Incentives 5. Time/date 6. Randomisation of items or questionnaires 7. Adaptive questioning 8. Number of items 9. Completeness check 10. Review step	1. The survey was hosted on Qualtrics and distributed via a link 2. Qualtrics is a secure site used to create and host surveys. It is considered secure as it encrypts the information and uses a password protected portal linked to the institution or university the creator is associated with to ensure security of information and GDPR compliance. 3. The survey was voluntary. Participation was entirely decided by the potential participant choosing to click on the link. 4. No incentives were offered 5. The survey was open between July and December 2021 6. Due to the nature of this survey (. i.e., as a remote qualitative data collection method) randomisation of questions was not used. 8. Adaptive questioning was used based on participant confirmation of family versus professional carer, and upon family participants confirming the living arrangements of the person they cared for 8. The questionnaire was distributed over five pages for family participants, and four for professionals. 9. Completeness was checked after next or submit was clicked, with unanswered questions requesting a response before moving forward. All open-ended questions could be answered with n/a or rather not say if desired by participants. Selection of at least one response option was enforced for demographic questions. 10. Participants could not review responses
Response Rates	1. Unique site visitor	1. Qualtrics has a "prevent multiple submissions" feature

	2. View rate 3. Participation rate 4. Completion rate	which uses cookies to prevent the same person submitting data more than once 2. Not collected 3. 37 out of 37, 100% 4. 16 out of 37, 43.2%
Preventing multiple entries from the same individual	1. Cookies used 2. IP check 3. Log file check 4. Registration	1. Qualtrics applies cookies to the browser of the participant preventing the use of the survey link more than once. 2. IP addresses were not used 3. Due to the qualitative nature of the survey, open ended question responses were checked against demographic information to identify any potential duplicate entries 4. Not applicable
Analysis	1. Handling of incomplete questionnaires 2. Questionnaires submitted with atypical timestamp 3. Statistical correction	1. Only completed questionnaires were analysed. Early termination questionnaires were not analysed. All incomplete questionnaires were terminated either a. directly after the consent page was passed, or b. following input of demographic information. No incomplete questionnaire provided information that could be analysed. 2. No such questionnaires were found 3. Not applicable (qualitative survey)

Appendix V: Detailed Summary of PEMAT Results for the Environmental Scan

Health Service Executive

The HSE webpage offered a total of five links to further sources:

a. A link to Frequently Asked Questions about the Capacity Act, as compiled by the HSE themselves. This source addressed questions under two subheadings, the first relating to the Act, and the second relating to support methods under the Act. This information was designed to address questions from family or professional carers, with FAQs addressing issues such as what legal capacity meant, how to formalise ones position as a disability assistant, and what it would mean for carers currently supporting a person under guardianship. Technical terms were explained but the language was designed for professional carers in particular. No disability friendly features such as read-aloud options, large font, or an easy-read version of the information were offered. The PEMAT score for this source was 52.9%.

b. A link to a YouTube video relaying information about the Capacity Act. This video was accompanied by visual cues, narration, and closed captions. It made use of simple straightforward language, and provided explanations for any technical terms included. It was designed for all stakeholders. It included explanations of how the Capacity Act would affect the lives of people with intellectual disabilities, explained by people with disabilities and their family, and professional carers. The PEMAT score for this source was 76%.

c. A video presentation on the Capacity Act. This video was accompanied by narration, and onscreen text, but did not use visual cues. It explained technical terms used throughout, and used straightforward language. It was designed to address the concerns of professional carers and provided information on how they might apply the Capacity Act in this professional context. The PEMAT score for this source was 88%.

d. A seminar series on the Capacity Act. These videoed seminars were presented with clear narration, straightforward, language, and visual cues. All were presented alongside a sign language interpreter. The full transcript was made available for all webinars in the series, alongside the full script for any practical application examples included in the seminars, which took the form of case studies or vignettes. The webinars addressed the commencement and implementation of the Act, with topics covered including how to support someone under the Act as a professional carer, when the Decision Support Service should be contacted for assistance in supporting a person as a professional carer, the role of positive risk taking and “unwise” decisions when supporting someone as a professional carer, how a functional assessment of capacity is carried out, and respecting the role of families during decision-making support as a professional carer. As these webinars were designed for professionals, some assumptions were made regarding understanding of technical terms, though the language remained relatively straightforward. Although informative and making use of practical examples, the seminars did not offer tangible tools for applying their content. The PEMAT score for this source was 83%.

e. A further resources document. This page consisted of a full list of resources available on the Capacity Act. This list included eLearning programs available from the HSE learning portal for professional carers, the case study webinars described in section d., the FAQ page from section a, the video presentation from section b, and the explainer video from section c. The page is formatted as a PDF which is often unsuitable for eReader programs. It is presented in straightforward language, with embedded links to enable quick access to the listed resources. However it does not make use of visual aids, the active voice, or easy read language. It also listed resources that require specialised access, such as the eLearning modules. The PEMAT score for this resource was 35%.

The home page for the HSE information on the ADM Act listed all resources currently included in this list. Although it uses clear headings and straightforward language, it does not provide easy read versions of written resources, or disability access features. No explanations, visual aids, or table of contents was provided to assist in navigating the listed resources. However the page made good use of the active voice, and contained resources encouraging further investigation into the application of ADM in daily life. The PEMAT score for this resource was 47%.

Inclusion Ireland Official Website

Inclusion Ireland’s page offered a total of six links to resources on ADM:

a. A video giving information on the ADM Act to people with intellectual disabilities and family carers. This video was made to help people with intellectual disabilities understand what the Act meant for them. It was clear in its purpose and direction, made use of clear, everyday language, with explanations, narration, and captioning to aid understanding. It prominently featured people with intellectual disabilities and their families explaining what the new law would mean for them once commenced. It used visual aids to help guide understanding for viewers which reinforced the information being given in the video. The video advises how to be active in applying its included information by seeking more information on the ADM Act. It had a PEMAT score of 88%.

b. A PDF document giving a short explanation of decision-making and consent in the context of the ADM Act to people with intellectual disabilities. This document used clear headings, easy read language, and everyday language explanations of all terms and definitions mentioned. The document covers defining ADM, the ADM Act, who the act affects, definitions of capacity, how capacity is determined, and what the Act will mean for people who are currently wards of court. Although well laid out, the document does not use disability aids such as large font or read-aloud functions, and its format as a PDF makes it more difficult for eReaders to process. There were no visual aids, diagrams, or tables included to aid understanding. The document did not advise the reader of any actions that could be taken. The PEMAT score for this source was 36.8%.

c. A link to the government’s Citizen’s Information page on Wardship. This page used clear, everyday language to explain key concepts relating to the Ward of Court system, and how the ADM Act would impact those currently in its care, to professional and family carers. It used clear definitions, headings, and explanations of technical terms to convey its message. Navigation was made easier through a table of contents at the beginning of the page with live links to bring the reader down to each section. It encouraged action on the part of the reader by advising who could be contacted to investigate options for alternatives to Wardship in light of the ADM Act. It did not use visual aids, and the web page did not have accessible features such as read aloud, or font alteration. The PEMAT score was 52.9%.

d. An easy-read document on Wardship designed for people with intellectual disabilities. This document was a PDF and explained what Wardship was, how it affected people, and how it would change under the ADM Act once it was commenced. It made use of easy read language, large font, short sentences, and visual aids in the form of pictograms to reinforce the information being communicated. Further action was encouraged by the document through the inclusion of live links to further sources to aid the reader's search for information. The headings were not clear as they did not use a different font size or colour, and it lacked tangible tools to aid the reader in applying the information directly. The PEMAT score was 76.4%.

e. A webpage on ADM in everyday situations. This webpage contained links PDFS written in everyday language summarising key elements of ADM in daily life, including the summary on the ADM Act described in part a, an explanation the role of data protection under the ADM Act, an explanation of how a person can appoint an assistant to help with financial concerns, a description of the role of HIQA in supporting autonomy in everyday life, HIQA advice for obtaining financial autonomy, an explanation of the HSE's national consent policy, a summary of the Health Repayments Scheme (2006) detailing how residential staff can hold a resident's money in trust in the absence of any person to help, a summary of how SAGE can assist in supporting the autonomy of a person who requires an advocate, a summary of the medical council's policy on professional conduct and ethics for professional carers, an explanation of ADM in daily life, and a summary of actions family and professional carers can take to support decision-making in the absence of the Act being fully commenced. All of these summaries were in PDF format, made use of clear headings, everyday language, and contained plain language explanation of technical terms. All included encouragement of action on behalf of the reader through advice for how to apply the information they contained through links to branches of the HSE or government agencies mentioned and how the reader could find assistance. All PDFs were aimed at professional or family carers. None used visual aids, graphs, tables, or pictograms to reinforce information or encourage action. Although the PDFs themselves did not have any disability access features embedded in them, the webpage the PDFs could be accessed from had full disability access features including read-aloud, options to adjust the font size or contrast, pausing any animations, hiding images, or converting the page into disability-friendly text. The PEMAT score for this source was 63.2%.

f. A short webpage post on the DSS. The webpage information details very briefly the role of the DSS as it would function under the ADM Act. The short bullet point summary was written in clear everyday language, but it contained no visual aids, or advice on how to apply the information actively in their everyday life, but did provide a further link to the DSS website for more information. The webpage included disability friendly options of read aloud, contrast change, font size and spacing change, hiding of animations, and conversion to dyslexia-friendly font. The PEMAT score was 47.3%.

The home page listed all resources on ADM offered by Inclusion Ireland. Each section had a clear heading, a brief explanation of what each section would contain, and a stock picture to illustrate content. The home page has disability features of changing font size and spacing, contrast changing, read aloud, hiding animations, and conversion to dyslexia-friendly font. The PEMAT score was 47.3%.

Citizen's Information

This PDF detailed information on the ADM Act. While the purpose and direction of the PDF was clear, its layout and design was not clear, headings were present but did not visually identify themselves clearly, and the text was laid out in long sections rather than manageable chunks. The information was clearly expressed, and laid out the tiers of support outlined in the ADM Act that family carers could avail of or assume in the support of their loved ones. It also described the new procedure for advanced directives and enduring power of attorney available to all citizens. However, though informative, the PDF did not contain any calls to action or active advice on how to apply the information it contained. There were no visual aids to aid understanding, and its format as a PDF made it largely unsuitable for eReaders or other disability aids. No other disability features such as options to change contrast, font size, or font type were available, and though the language was everyday, it was not an easy read document designed for people with intellectual disabilities. The PEMAT score was 23.5%.

Alzheimer's Society of Ireland

This PDF was of the society's official position paper on the ADM Act. It stated its purpose clearly and did not contain any distracting extra information. It laid out its contents in a clear manner, using well-designed sections. It outlined the benefits and drawbacks of the ADM Act for vulnerable persons and explained how it might benefit carers. However, though the language was not inaccessible, it was inconsistent in its explanation of technical terms- they were explained in some sections, but not in others. It detailed the options available to vulnerable persons such as those with dementia, but did not do so in a manner that would be inclusive of those people themselves, as the PDF format made it incompatible with disability aids, no easy-read version of the information was provided, no visual aids were included to aid understanding, and there were no disability features for font, contrast, or read aloud included in the site. No direct calls to action were found in the document explaining how the information on the ADM Act might be applied in practice. The PEMAT score was 23.5%.

Irish Association of Social Workers

This source was a recorded webinar designed to inform social workers and other professional carers on the details of the ADM Act. The direction and purpose of the seminar was clearly established and maintained, The language used to discuss and explain the information given was clear and technical terms were explained using an engaged, active voice, and the narration was clear and ungarbled. The webinar was broken into sections allowing for easier digestion of information. The presenter used visual cues to aid understanding of the information- these cues were clearly captioned and reinforced the information they accompanied. Closed captioning was available on the recording. The webinar encouraged the listeners to actively apply the information it contained by advising them on new approaches they could take to apply the principles of ADM as they worked with and cared for people with intellectual disabilities. The PEMAT score was 94.4%.

University of Limerick

Supported Decision-Making with Adults with Intellectual Disabilities, Their Family and Professional Carers

This source was a PDF of an information booklet designed by the University of Limerick in conjunction with a care facility for older adults with cognitive difficulties detailing aspects of the ADM Act, and giving practical worked examples of how the Act might be applied in certain scenarios. The booklet was clear in its purpose and direction, with good signposting in the form of a table of contents. The information was clearly delineated into readable sections with headings in a different colour to the body of the text to emphasise sections. All text was explained, with each section containing a legislative definition (the legal definition of a term or concept) alongside what they termed the layman's definition. Some visual cues were used to explain information, such as a flow chart describing the structure of the Irish court system, but most of the booklet did not contain diagrams, tables, or visual aids to reinforce the information given. The booklet did advise on how action could be taken to apply the information it contained through the use of vignettes detailing different scenarios a carer might encounter while supporting a person to make decisions. However, it did not offer any tangible tools, or sources of aid for carers who might then encounter similar situations in their day-to-day support and seek assistance to navigate them within their organisation's policy. The PDF format did not lend itself to disability aids and the web page did not have embedded disability functions to aid readability. Though it contained lay definitions of terms, it was not written in easy-read style, as the font was small, and no visual support was given. The PEMAT score was 64.7%.

Family Carers Ireland

Family Carers Ireland (FCI) provided three resources on their webpage:

a. A recorded webinar hosted by FCI and presented by the DSS giving information to family carers about the ADM Act. The webinar's purpose and direction were clearly stated, and the information was presented in plain language, with explanations given for technical terms. Narration was given in the active voice, and was clear and ungarbled. Closed captioning was included on the video, though it was auto generated, meaning it was not accurately reflecting the content of the audio at times. Visual aids were employed to reinforce information given in the video, and to aid understanding of included content. Actionable content was included, as the video advised family carers on how they could use the DSS as they supported a person in decision-making by outlining the structure of tiered decisional support the service would offer upon opening its doors. However, no tangible tool was provided to aid family carers in directly accessing these supports, and no other instructions were provided regarding ADM application in daily life. The PEMAT score was 83.3%.

b. A PDF of the slides used in the above webinar. The slides were clear, well sectioned out, and presented their information in delineated sections that used plain language and the active voice. Visual aids included in the webinar were available in the slides to reinforce the information given, and provide aid in understanding. The slides contained the advice for action present in the audio presentation regarding resources to be accessed in the DSS but also lacked evidence of a tangible tool to aid application of given information in daily life. The PDF format presented a barrier to eReaders or other disability aids for reading, and the slides did not contain large font or other easy read qualities to aid disability inclusion. The FCI website did not provide support for disabled users in the form of embedded functions to change font type or size, contrast, or read-aloud functions. The PEMAT score was 82.3%

c. A PDF of frequently asked questions designed by FCI and the DSS for family carers. These FAQs addressed aspects of the ADM Act including tiers of support, advice on creating an advanced care directive, or enduring power of attorney, and how the DSS can provide information and advice to family carers as they continue to support a person in decision-making. The PDF had a clear purpose and direction, was written clearly using plain language and the active voice, and explained any used technical terms either in the document, or by using embedded live links to other sites explaining the term. It contained actionable material through active advice on how to access resources on creating new advanced care directives or enduring power of attorney, and provided specific instructions on how to begin these processes. It did not contain actionable advice on how to access the tiered supports for ADM when supporting a person in daily life, however. No visual aids were used to reinforce content or aid understanding. The PDF format hindered disability aids and the site did not contain disability aids such as read aloud function, font size or type changes, or contrast. The PEMAT score was 58.8%.

Inclusion Ireland YouTube Page

This YouTube video was of a webinar hosted by Inclusion Ireland and presented by the DSS to aid people with intellectual disabilities in their understanding of the ADM Act. The purpose and direction of the video was clearly stated and adhered to. The information was presented using clear, ungarbled narration, plain language, and in the active voice. Visual aids were used to reinforce the information in the video, and aid understanding. The video encouraged action by providing information on the guiding principles of ADM as outlined by the DSS, and explaining how these can be applied by carers and by the person being supported, in every day life. It also explained the role of the DSS in support, and explained the different tiers of support available. The video contained closed captions, but these were auto generated, meaning their content was inaccurate at times, depending on the quality of the audio. The PEMAT score was 88.8%.

Stephen Walsh Solicitors

This source consisted of a post on the main webpage of Frequently Asked Questions on the ADM Act as compiled by the solicitors office. The PDF stated its purpose clearly and avoided including distracting extra information. The language used was plain and straightforward, with explanations for technical terms used, but made use of the passive voice. Though easy to read, it did not make use of visual cues to reinforce content or aid understanding. The material was not easy read and was not designed for people with disabilities' use, due to the lack of visual aids, and though plain language was used, large front or easy read formatting was not employed. The website itself contained no disability aids. The material advised the reader of some action that could be taken, namely why an enduring power of attorney or advanced care directive could be of value, but did not provide any tangible tool to aid application of the information. The PEMAT score was 35.2%.

Rural Doctors Ireland and Inclusion Ireland

This source consists of an easy-read fact sheet on the ADM Act compiled by Inclusion Ireland and hosted by Rural Doctors Ireland. The purpose and direction of the PDF was clear and avoided distracting extra information. It used plain language and provided explanations for any technical terms included. The active voice was also employed. No visual aids were used to aid understanding or reinforce content, and the PDF format made the document unsuitable for screen readers. The website itself did not include any disability aids such as the read aloud function or options to change font or contrast settings. The document provided information on the Act that addressed the reader directly, but did not advise how that information could be actively applied to every day life. The PEMAT score was 47%.

Saint Michael's House Disability Services

This source was a PDF of newsletter designed to address service users attending Saint Michael's House disability services which provided information on the ADM Act. The PDF was written in easy read format with included visuals to aid understanding and reinforce the information. The information was separated into short, manageable sentence, and any technical terms were explained in plain language using the active voice. While information on the ADM Act was given, no advice or tangible tools relating to direct action on the part of the reader was included. The PDF format did not lend itself to the use of a screen reader, and the website itself did not have embedded disability friendly tools to aid reading. The PEMAT score was 76.4%.

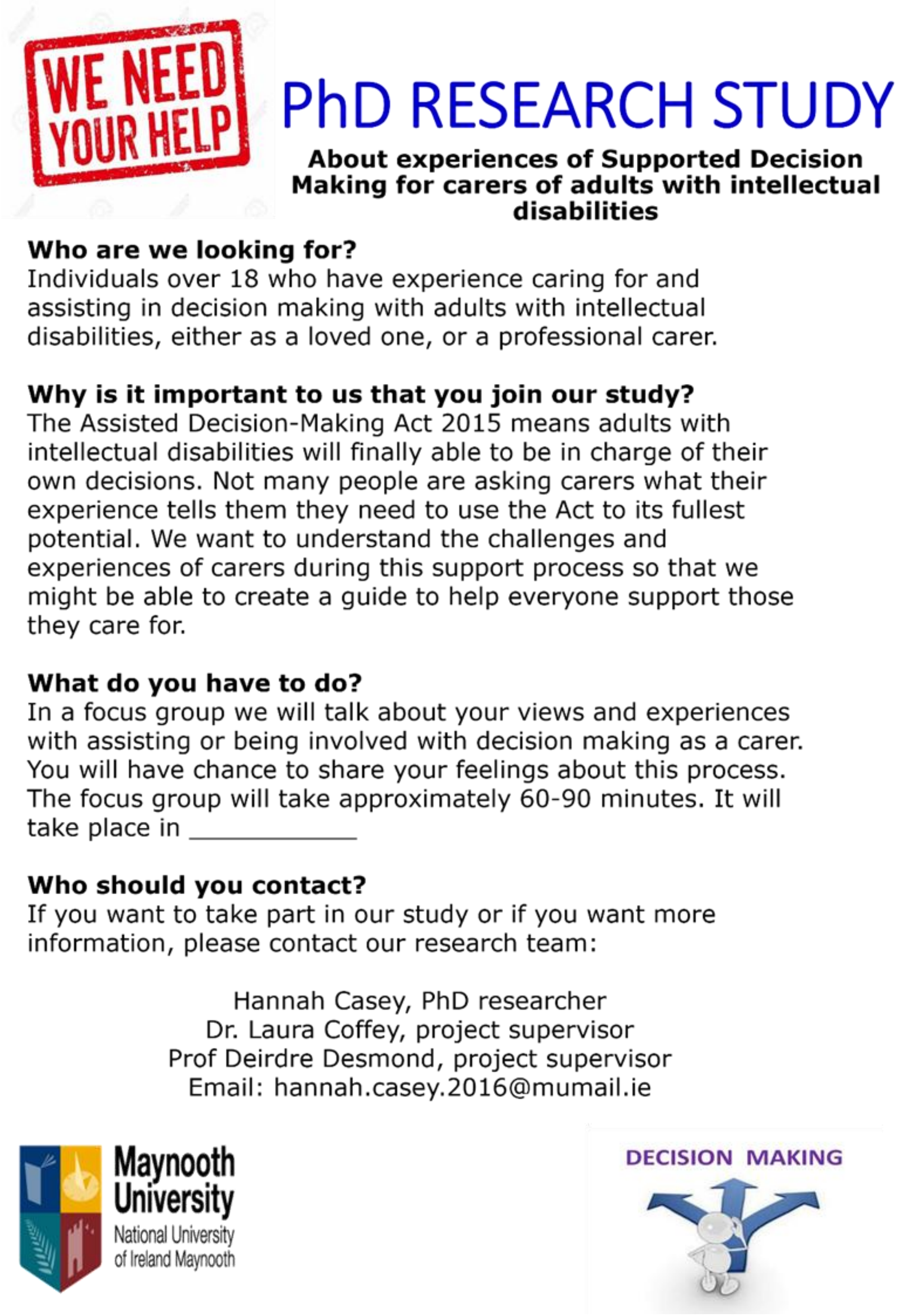
Health Information and Quality Authority (HIQA)

This source was a PDF document detailing HIQA's outline of recommendations in supporting the autonomy of people with intellectual disabilities. The document's purpose and direction was clearly stated, with the information presented in marked sections with definitive headings and explanation of technical terms where necessary. It recommended action on the part of the reader through introducing HIQA's six step recommended approach to support for autonomy for service providers: 1. Respect the person's right to autonomy, 2. Avoid prejudging, 3. Communicate appropriately to establish, explore and promote preferences, 4. Balance rights, risks and responsibilities, 5. Agree person centred supports, and 6. Implement and evaluate supportive actions. This was accompanied by a visual aid in the form of a flow chart, and applications were suggested through case studies using examples of each step being used. The document was designed to be used by professional carers- while the language was not inaccessible, it made assumptions of a baseline level of knowledge in places, and did not always explain certain terms or acronyms. The document was also very long, at 60 pages. It was not designed for adults with intellectual disabilities, and the recommended policy on autonomy was recommended at a service policy level rather than as a tool to be actively used in conjunction with family carers or the person being supported. The PDF format of the document would prevent ease of use with a screen reader, and the host website did not have any disability friendly tools embedded within it to aid reading. The PEMAT score was 58.8%.

Fieldfisher EU Law Firm

This source was a blog post hosted on the blog of Fieldfisher's Irish services page discussing the new policies surrounding enduring power of attorney under the ADM Act. The blog post's purpose and direction were clear, every day language was used and technical terms were explained. Action was to the reader through the outlining of how to create an enduring power of attorney once the ADM Act commenced. However, no tangible tool was offered or suggested as to who to contact or how to proceed with this course of action. No visual aids were employed to aid understanding or reinforce the information being conveyed. The blog was written in the passive voice and did not address the reader directly when suggesting action to be taken. The website did not have embedded disability aids for reading the blog post. The PEMAT score was 35.2%.

Appendix VI: Flyer for Professional and Family Focus Group Participant Recruitment



PhD RESEARCH STUDY

About experiences of Supported Decision Making for carers of adults with intellectual disabilities

Who are we looking for?
Individuals over 18 who have experience caring for and assisting in decision making with adults with intellectual disabilities, either as a loved one, or a professional carer.

Why is it important to us that you join our study?
The Assisted Decision-Making Act 2015 means adults with intellectual disabilities will finally able to be in charge of their own decisions. Not many people are asking carers what their experience tells them they need to use the Act to its fullest potential. We want to understand the challenges and experiences of carers during this support process so that we might be able to create a guide to help everyone support those they care for.

What do you have to do?
In a focus group we will talk about your views and experiences with assisting or being involved with decision making as a carer. You will have chance to share your feelings about this process. The focus group will take approximately 60-90 minutes. It will take place in ____________

Who should you contact?
If you want to take part in our study or if you want more information, please contact our research team:

Hannah Casey, PhD researcher
Dr. Laura Coffey, project supervisor
Prof Deirdre Desmond, project supervisor
Email: hannah.casey.2016@mumail.ie

Appendix VII: Easy-Read Information Sheet and Consent Form for Focus Group

Recruitment of Participants with Intellectual Disability

Information Leaflet

WE NEED YOU!

For our research study:

WHAT DO YOU THINK ABOUT SUPPORTED DECISION-MAKING?

You are invited to take part in our research,
about supported decision-making.

What is a decision?

A decision is when you choose what you would or would not like to do about something, or which thing you would like best. It can be a small choice, like what you would like to wear, or where to go on holiday. It can be a bigger choice too, like where you want to live.

What is supported decision-making?

Supported Decision Making is a way for you to ask for help with decisions if you need it. The important part is you choose who will help, and how much they help.

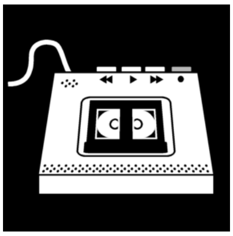
Examples of people you might choose are:

- Your mum or dad
- Your brother or sister
- Someone else from your family, like an aunt or uncle
- A staff member from your home or centre
- Your key worker

How does this research work?

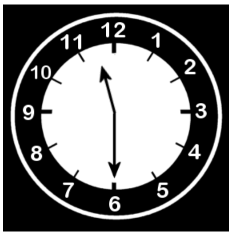
A researcher will invite you to come and talk to them in a group called a focus group. This will be a group of people who also need help with decisions sometimes. You will all talk in the group about some questions the researcher will ask you together.

You will be given the questions beforehand so you can ask someone to help you read them and think about what you might like to say.



The researcher will record your answers, using a voice recorder.

How long will it take?



The focus group will take about 1 hour. We will take a break in the middle, and you can ask for another break at any time if you need it.

Why do we want to interview you?

For our research it is very important,
to hear about your experiences. We want to know what you think of the support you get in decision-making every day.
With your information we want to make a guide to help you and the people who help you know what to do, if a decision is hard, or you are not sure what to do next.

We would like to know for example:

- Your age
- What kind of decisions you might need help with

- Who you ask to help you with those decisions
- What kind of things help you the most when making decisions

Will anyone else know what you tell us?

We will keep all your personal information private, and will only tell someone if you tell us that you have been hurt, or are not being looked after properly. This is because we want to make sure you are safe.

Your name will not be in any report.

The researcher will change your name and any personal things you tell her about yourself so she can write about it. She will write about it in a journal article (a place for other researchers to read about what she found out) and in her PhD thesis (a report she is writing for the university).

Your name and personal information will be changed by September the 30th 2022.

Are there any risks involved?

We do not know of any risks that taking part in this research may cause for you. If you feel worried or stressed at any time during the research, you can take a break, or even tell us you would rather not continue.

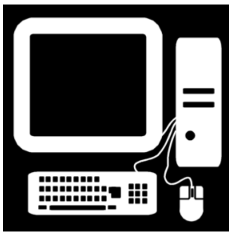
Where Will the Group Take Place?

The group will take place in X at X o'clock. If you have to travel to meet us, we will give you back any money you had to spend to get there.

What if we can't meet in person?

Because of COVID-19, we might have to meet online. If we do, we will use a computer meeting place called Teams. To make sure you can come to

the meeting, we will ask ORG to help you use a computer to join in.



You will be sent an invitation in you email to click on so you can join the meeting.

What happens after the focus group?

The recording will be saved on a computer. The researchers will study all the information. They will use the information to make a guide to help you and the people who support you if you are finding it hard to make a decision. They will also write about the focus group for a journal (to tell other researchers about it) and for Hannah's PhD (to tell the university about it).

You can view the findings of the focus group if you want. The recording will be kept for 10 years on the computer and then deleted.

If you want, you can participate in a workshop where the researchers will show you the supported decision-making guide they made using what you have told them.

In this workshop, you can comment on the guide and tell us if you think it is good or bad.

Have you got any questions?

If you have any questions or complaints during the research, discuss this with your care staff or family.

You can also tell ORG about it directly

You can always contact one of the researchers:

Hannah: email to hannah.casey.2016@mumail.ie

Laura: email to laura.coffey@mu.ie

Deirdre: email to deirdre.desmond@mu.ie

Would you like to join in this research?

Talk about it first with family or friends,

and decide if you want to join in this focus group.

You don't have to, only if you want to.

You can also change your mind,

and stop at any time.

No: I do not wish to join

You don't have to do anything.

Yes: I do wish to join

Fill in and sign the consent form.

Give it back to the researchers.

You can do this together with your support staff or family member.

If you sign the consent form,

and send it back to the researchers,

you agree to to join in this research.

Thank you very much!

Hannah Casey

Dr Laura Coffey

Professor Deirdre Desmond

Consent Form to join the research

WHAT DO YOU THINK ABOUT SUPPORTED DECISION-MAKING?

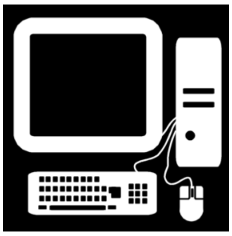
Please read the information below and sign this consent form if you agree to take part in this research.

I agree with the following statements:

	I have read the information leaflet about this research	☐
	I understand what I am being asked to do for this research	☐

	Any questions that I had, were answered.	☐
	I know who to contact if I have any other questions.	☐
	I know that it is my choice to take part in this study.	☐
	I understand that I do not have to answer questions I don't feel happy with.	☐
	I understand that - I will take part in a focus group - The researcher is going to audio record the group. - The researcher may use my information as explained in the information leaflet.	☐

		
	I understand that I can stop taking part in this study and leave it when I want to. I do not have to give a reason.	☐
	I understand that all information I give during this study will be kept safe and private. I understand that I should keep other people's information safe and private after I talk to them in this group. I understand that if the researchers learn that I am being hurt or not looked after properly, they will need to tell someone to help keep me safe.	☐

	I will not be named in any reports.	☐
	I understand that there are no known risks with this study.	☐
	I understand I can view the outcomes of the focus group if I want.	☐
	I understand that after September the 30th 2022, my information will have been changed to stop people who read about the focus groups from knowing who I am. I understand that this means I cannot ask the researcher to take out my information after this date.	☐
	I give permission to be contacted after the focus group for the workshop as explained in the information leaflet:	Yes ○ ○ No

Your consent:

My name:………………………………………………………………………………...........................
..

My signature:

……………………………………………………………………………………………................
....

Date of today:......……………………………………………………………….........................

To be completed by the researcher:

Statement of investigator's responsibility**:** I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

Investigator's signature: …………………………… Date: …………..…

If you are not happy with how this focus group has been done, you can tell the Maynooth University Ethics Committee about it. They can be contacted by email research.ethics@mu.ie or by telephone +353 (0)1 708 6019. They will listen to any complaints you may have in a kind and respectful way.

The person in charge of making sure your information stays private is the Data Protection Officer. Her name is Ann McKeon. Her office is in Humanity House, room 17, in Maynooth University. You can email her at dataprotection@mu.ie if you have any worries. You can read about how Maynooth University keeps peoples' information safe at https://www.maynoothuniversity.ie/data-protection.

Topic Guide: Service Users

1. Welcome

	I would like everyone to say their name, so we all get to know each other
	A “decision” is when you choose what you would or would not like to do about something. It can be a small choice, like what you would like to wear, or where to go on holiday. It can be a bigger choice too, like where you want to live.

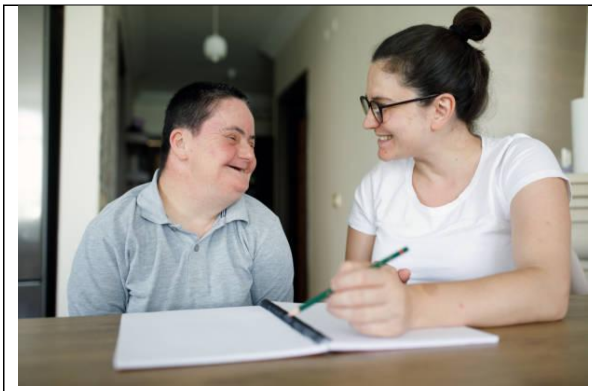
	What kind of decisions do you make every day?

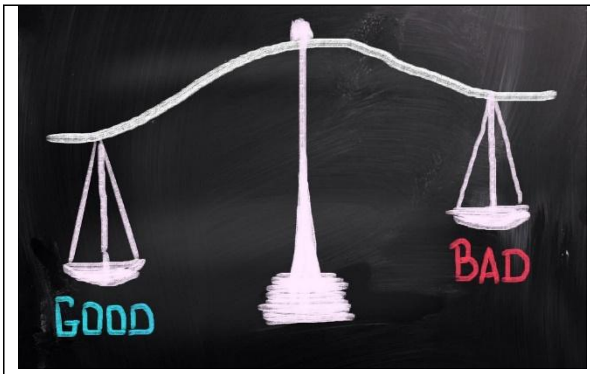
2. Your Thoughts about Decision-Making

	When you want to make a decision, who do you ask for help?
	Why did you pick that person?

	Supported Decision Making is a way for you to ask for help with decisions if you need it. The important part is you choose who will help, and how much they help. What do you think about this idea?

3. How Decision-Making Works for You

	What kind of things do your supporters do to help you make decisions?

	What are the good parts of the support you get in making decisions? What are the bad parts?
	Have you had times where people did not like a decision you wanted to make? Can you tell me what happened?

	There is a new law in Ireland called the Assisted Decision Making Act. This law says that everyone is allowed to make their own decisions, to choose who helps them, and to say how much help they would like. What do you think about this law? Have you heard of it before?

4. Your Thoughts on a Decision-Making Guide

	We are talking to you today because we want to make a guide for you and the people who help you make decisions. This guide will help you and the people supporting you if a decision is hard, or you are not sure what to do next.
	Would you like it if you had a guide to use?
	Do you think this guide would help you and your supporter?
	What kind of things would you like the guide to help you with?

	Can you think of any reasons why the guide might not be helpful?

Topic Guide: Family Carer

1. Icebreaker

I would like everyone to introduce themselves to the group, and say why they are here
Who is the person you support? Tell me a bit about them

2. Personal experience of SDM

Are you familiar with Supported Decision Making as an approach? It is defined by the Center for Public Representation as a process which "allows individuals with disabilities to make choices about their own lives with support from a team of people they choose."
Has anyone ever helped you carry out SDM, or support in general?
How do you feel about the overall concept of SDM?

3. SDM in Practice

Do you have a particular way of approaching SDM with your loved one?
What works well for you in support and what does not work so well?
How do you feel about the Assisted Decision-Making Capacity Act? Do you know what it aims to do?
Have you experienced any particular challenges or barriers to SDM?

4. SDM guide/framework

If a guide/framework were to be given to you, what would you like it to contain?
Do you think you would make use of it?
What challenging aspects of SDM would you most like it to address?
Do you think there would be any problems with such a guide?

Topic Guide: Staff/Professional Carer

1. Icebreaker

Can everyone introduce themselves and say what their job title is?

How many clients do you support in your role?

What are you most eager to discuss today?

2. Aspects of the Job

Does your organisation have a specific approach to support?

Are there any challenges you face because of this approach?

Has the approach to support in decision-making changed in light of the 2015 Capacity Act?

3. SDM in theory

Are you familiar with Supported Decision Making as an approach? It is defined by the Center for Public Representation as a process which “allows individuals with disabilities to make choices about their own lives with support from a team of people they choose.”

What do you feel SDM can/cannot do for your clients?

How do you feel about the Assisted Decision Making Capacity Act? Do you know what it aims to do?

4. SDM in practice

What are the challenges in carrying out SDM with your clients?

Are there steps you feel should be taken to improve the current approach?

Do you feel you receive enough guidance in how to best support them?

5. SDM guide/framework

If a guide/framework were to be given to you, what would you like it to contain?

Do you think you would make use of it?

What challenging aspects of SDM would you most like it to address?

Do you think there would be any problems with such a guide?

Appendix IX: Easy-Read Information Sheet and Consent Form World Café

Participants with Intellectual Disabilities

Information Leaflet Participants

WE NEED YOU!

For our research study:

WHAT DO YOU THINK ABOUT OUR FOCUS GROUP RESULTS ABOUT SUPPORTED DECISION-MAKING?

You are invited to take part in our research,

about supported decision-making.

What is a Decision?

A “decision” is when you choose what you would or would not like to do about something. It can be a small choice, like what you would like to wear, or where to go on holiday. It can be a bigger choice too, like where you want to live.

What is supported decision-making?

Supported Decision Making (SDM) is a way for you to ask for help with decisions if you need it. The important part is you choose who will help, and how much they help.

Examples of people you might choose are:

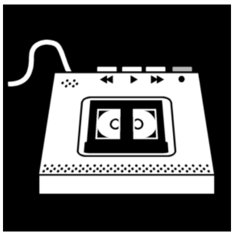
- Your mum or dad
- Your brother or sister
- Someone else from your family, like an aunt or uncle
- A staff member from your home or centre
- Your key worker

How does this research work?

A few months ago, Hannah came and talked to a group of you about what they thought about SDM. We have put the things they told us together and have used them to make suggestions on how we think you would like a guide to help you and your supporters know what to do when you are making a decision to look.

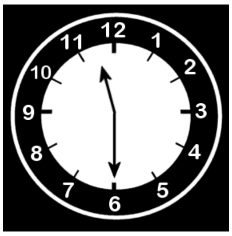
For this new part of the research we want to show you these suggestions, and to ask you if you think they are good.

You will be given the questions beforehand so you can ask someone to help you read them and think about what you might like to say.



You will sit with families and staff from [SERVICES] at a table and talk about what you think about the focus group results. You will be asked to swap groups three times, one for each question. These groups will be led by researchers who work with Hannah in the university who have agreed to help her. The researcher will record your answers by writing down notes about what has been said.

How long will it take?



The workshop will take an hour and thirty minutes. We will take a break in the middle, and you can ask for another break at any time if you need it.

Why do we want you to come back?

For our research it is very important,
to hear what you think about our results.
They will be made into a guide for you to use with your supporters, and we want to make sure we have fully understood everything you told us.
With your help, we can make sure this guide is useful for many people in Ireland like you.

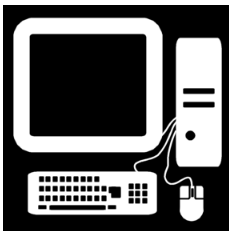
We would like to know for example:

- If you think the focus group results have included everything you think is important about SDM
- If you think there is anything important about SDM that we missed
- If you have anything else you would like to add to our results that should be included when we are making the guide.

Will anyone else know what you tell us?

We will keep all your personal information private, and will only tell someone if you tell us that you have been hurt, or are not being looked after properly. This is because we want to make sure you are safe.
Your name will not be in any report.
Your information will be changed when we write about the workshop for a journal (a place for other researchers to learn about the research) or in Hannah’s PhD Thesis (where she will tell the university about it).You can leave the session at any time if you are not comfortable taking part, but once it is over you cannot ask Hannah to take out any of your parts. This is because the sessions will have everyone working together to answer the questions, so she will not be able to work out which parts you might have put in by yourself.

“It must be recognised that, in some circumstances, confidentiality of research data and records may be overridden by courts in the event of litigation or in the course of investigation by lawful authority. In such circumstances the University will take all reasonable steps within law to ensure that confidentiality is maintained to the greatest possible extent.” This means that if a judge or the police tell Maynooth University that they need to see the data from this project, the university will have to give it to them.



Are there any risks involved?

We do not know of any risks that taking part in this research may cause for you. It is possible that talking about SDM and how you feel about being supported in your decisions might make you feel sad or stressed. If you do, you can take a break for as long as you want, or even leave the session completely. You can do these things any time you want with no need for explanation.

What happens after the workshop?

The notes will be saved on a computer.

The researchers will study all the information.

They will use the information to change and make the guide better and more useful for everyone.

You can view the outcomes of the workshop if you want.

Have you got any questions?

If you have any questions or complaints during the research, discuss this with your care staff or family.

You can also tell ORG about it directly

You can always contact one of the researchers:

Hannah: email to hannah.casey.2016@mumail.ie

Laura: email to laura.coffey@mu.ie

Deirdre: email to deirdre.desmond@mu.ie

Would you like to join in this research?

Talk about it first with family or friends,
and decide if you want to join in this workshop.

You don’t have to, only if you want to.

You can also change your mind,
and stop at any time.

No: I do not wish to join

You don’t have to do anything.

Yes: I do wish to join

Fill in and sign the consent form.

Give it back to the researchers.

You can do this together with your support staff.

If you sign the consent form,

and send it back to the researchers,

you give permission to join in this research.

Thank you very much!

Hannah Casey Dr Laura Coffey Professor Deirdre Desmond

Consent Form to join the research

HOW DO YOU FEEL ABOUT OUR FOCUS GROUP RESULTS?

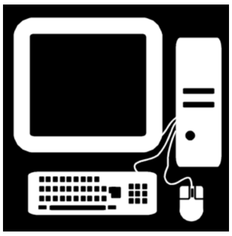
Please read the information below and sign this consent form if you agree to take part in this research.

I agree with the following statements:

	I have read the information leaflet about this research	☐
	I have understood what I am being asked to do for this research	☐
	Any questions that I had, were answered.	☐
	I know who to contact if I have any other questions.	☐

	I know that it is my choice to take part in this study.	☐
	I understand that I do not have to answer questions I don't feel happy with.	☐
	I understand that - I will take part in a feedback workshop - The researcher is going to write notes about the group. - The researcher may use my information as explained in the information leaflet.	☐

	I understand that I can stop taking part in this study when I want to. I do not have to give a reason.	☐
	I understand that all information I give during this study will be kept safe and private. I understand that I should keep other people's information safe and private after I talk to them in this group. I understand that if the researchers learn that I am being hurt or not looked after properly, they will need to tell someone to make sure I can get help.	☐
	I will not be named in any reports.	☐

	I understand that there are no known risks with this study.	☐
	I understand I can view the outcomes of the workshop if I want.	☐
	I understand that after August 31st, my information will have been changed to stop people who read about the workshop from knowing who I am. I understand that this means I cannot ask the researcher to take out my information after this date.	☐

Your consent:

My name:………………………………………………………………….......

My signature:

…………………………………………………………………………….

Date of today:.......……………………………………………………….........

....

Date: ……………………………………………………………….................................
....

To be completed by the researcher:

Statement of investigator's responsibility**:** I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

Investigator’s signature: ……………………………

Date: ……………..………………………..

If you are not happy with how this focus group has been done, you can tell the Maynooth University Ethics Committee about it. They can be contacted by email research.ethics@mu.ie or by telephone +353 (0)1 708 6019. They will listen to any complaints you may have in a kind and respectful way.

The place in charge of making sure your information stays private is Maynooth University, Maynooth, Co. Kildare. The office is in Rye Building, room 27, on north campus in Maynooth University. You can email them at dataprotection@mu.ie if you have any worries. You can read about how Maynooth University keeps peoples’ information safe at https://www.maynoothuniversity.ie/data-protection.

Appendix X: University Ethical Approval Confirmation Letters

MAYNOOTH UNIVERSITY RESEARCH ETHICS COMMITTEE
MAYNOOTH UNIVERSITY,
MAYNOOTH, CO. KILDARE, IRELAND

Dr Carol Barrett
Secretary to Maynooth University Research Ethics Committee

18 May 2022

Hannah Casey
Department of Psychology
Maynooth University

Dear Hannah,

The Social Research Ethics Sub-committee has reviewed the ethical protocol for your project: **The perceptions and experiences of adults with intellectual disability regarding supported decision-making: A qualitative study** and we would like to inform you that ethical approval has been granted.

Any deviations from the project details submitted to the ethics committee will require further evaluation. This ethical approval will expire on 31/05/2023.

Kind Regards,

Dr Carol Barrett
Secretary,
Maynooth University Research Ethics Committee

C.c. Dr Laura Coffey, Department of Psychology
Professor Deirdre Desmond, Department of Psychology

MAYNOOTH UNIVERSITY RESEARCH ETHICS COMMITTEE
MAYNOOTH UNIVERSITY,
MAYNOOTH, CO. KILDARE, IRELAND

Maynooth University
National University
of Ireland Maynooth

Dr Carol Barrett
Secretary to Maynooth University Research Ethics Committee

17 December 2021

Hannah Casey
Department of Psychology
Maynooth University

Dear Hannah,

The Social Research Ethics Sub-committee has reviewed the ethical protocol for your project: **The perceptions and experiences of professional and family carers of adults with intellectual disability regarding supported decision-making: A qualitative study** and we would like to inform you that ethical approval has been granted.

Any deviations from the project details submitted to the ethics committee will require further evaluation. This ethical approval will expire on 31/07/2022.

Kind Regards,

Dr Carol Barrett
Secretary,
Maynooth University Research Ethics Committee

C.c. Prof Deirdre Desmond, Department of Psychology
Dr Laura Coffey, Department of Psychology

Reference Number
SRESC-2021-2454603

MAYNOOTH UNIVERSITY RESEARCH ETHICS COMMITTEE
MAYNOOTH UNIVERSITY,
MAYNOOTH, CO. KILDARE, IRELAND

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Professor Deirdre Desmond, Department of Psychology

MAYNOOTH UNIVERSITY RESEARCH ETHICS COMMITTEE
MAYNOOTH UNIVERSITY,
MAYNOOTH, CO. KILDARE, IRELAND

Dr Carol Barrett
Secretary to Maynooth University Research Ethics Committee

30 June 2023

Hannah Casey
Department of Psychology
Maynooth University

Dear Hannah,

The Social Research Ethics Sub-committee has reviewed the ethical protocol for your project: **Developing a Guide on Supported Decision-Making for Adults with Intellectual Disabilities and their Supporters: A Feedback Session with stakeholders using a World Café format** and we would like to inform you that ethical approval has been granted.

Any deviations from the project details submitted to the ethics committee will require further evaluation. This ethical approval will expire on 30/06/2024.

Please note: all projects now require an end of project report which is attached. Please complete and upload the end of project report to your RIS ethics record after the project end date.

Kind Regards,

Dr Carol Barrett
Secretary,
Maynooth University Research Ethics Committee

c.c. Prof. Deirdre Desmond, Department of Psychology
Dr Laura Coffee, Department of Psychology

Reference Number
SRESC-2023-36302