SUPPORTING ADULTS WITH A LEARNING DISABILITY TO MAKE HEALTH DECISIONS

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Abstract

People with learning disabilities have historically been denied opportunities to make decisions about all aspects of their life, including their health. They are likely to have increased health needs yet often have poor healthcare experiences and outcomes. The *Mental Capacity Act* 2005 underpins decision-making in England and Wales. Principle 2 of the Act requires all practicable steps to be taken to support an individual to make their own decision. Whilst there has been a lot of interest in supporting decision-making since the United Nations Convention on the Rights of Persons with Disabilities in 2006, supporting health decision-making has received less attention. A review of the literature found limited rich data pertaining to supporting health decision-making. Little is known about how adults with a learning disability want to be supported to make health decisions, and what facilitates and hinders supporting health decision-making in line with the Mental Capacity Act.

Social constructionism underpinned an interpretivist, qualitative research study, which used accessible research methods. The research aimed to understand supporting health decision-making according to the experiences and perspectives of those that the Mental Capacity Act is intended to serve. Forty-eight people participated: 19 adults with a learning disability took part in interviews or focus group discussions, six family members and 16 healthcare staff were interviewed, and nine student nurses completed a pilot online survey. Data were analysed using reflexive thematic analysis.

Two overarching findings suggested that participants with a learning disability wanted to make their own health decisions, however whilst there was evidence of good practice, not everyone had a positive experience. Synthesis of the developed themes suggested that three factors are significant in enabling support for health decision-making with adults who have a learning disability. Firstly, all those involved need to have a good understanding of the Mental Capacity Act, “Mental

Capacity Act literacy”. Secondly, those involved need to understand the health decision to be made, “Health literacy”. Thirdly, healthcare staff need to respect individuals with learning disabilities, recognising them as decision-makers, “Valuing Individuals”. When one of these is missing, supporting health decision-making can either not happen or be a negative experience for all concerned. When all three are in place, appropriate support can result in individuals with a learning disability developing confidence in making and implementing their own health decisions.

Glossary

Accessible Information	Information which can “be read or received and understood by the individual or group for which it is intended” (NHS England, 2017, p. 6).
Best Interests decision	In line with the *Mental Capacity Act* 2005, a decision made by others in the individual’s best interests when the individual has been assessed as lacking mental capacity (Office of the Public Guardian, 2007).
Decision-making	“…the act of choosing among competing courses of action based on an understanding of the probable outcomes of those courses of action” (Shogren *et al.* 2017, p.149).
Easy read	‘Easy read’ involves written information in short sentences accompanied with images to illustrate text (NHS England, 2017).
Intellectual disability	“A significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development” (World Health Organisation, 2017). “Intellectual disability” is often used internationally whilst ‘learning

	disability’ (see below) is more commonly used in England and Wales.
Learning difficulty	Learning difficulties affect one aspect of learning, but do not affect intellectual ability. Learning difficulties include dyslexia, ADHD and dyspraxia. Learning difficulties are often confused with learning disabilities, which do affect intellectual ability (Mencap, 2023).
Learning disability	Learning disability “…includes the presence of: a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with; a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development.” (Department of Health, 2001, p.14). Terminology currently used in England and Wales.
Mental capacity	“The ability to make a decision about a particular matter at the time the decision needs to be made” (Office of the Public Guardian, 2007, p.282).
Mental capacity assessment	Determines if an individual has the mental capacity to make the decision in question at the time the decision needs to be made. Requires an individual to be able “to communicate the decision (this does not have

	to be verbally), understand the information relevant to the decision, retain the information, and weigh up the information to reach a decision” (Office of the Public Guardian, 2007, p.45).
Reasonable adjustments	“Under the *Equality Act* 2010 public sector organisations have to make changes in their approach or provision to ensure that services are accessible to disabled people as well as everyone else. Reasonable adjustments can mean alterations to buildings by providing lifts, wide doors, ramps and tactile signage, but may also mean changes to policies, procedures and staff training to ensure that services work equally well for people with learning disabilities.” (Public Health England, 2020).
Supporting and substituted decision-making	Supporting decision-making is “an approach to decision-making that involves providing a person with impaired decision-making ability the support they need to make their own decision. It is often contrasted with substitute decision-making, where a decision is made on behalf of a person who is unable to make that decision.” (Victorian Law Reform Commission, 2012, p.xviii).

Healthcare staff in this thesis include anyone employed in a health or allied health professional role including doctors, nurses, support workers and care workers.

The term 'supporter' is used to indicate the person who is providing support to an adult with a learning disability to make a health decision.

Chapter 1: Introduction

This thesis uses a qualitative methodology and accessible research methods to explore the practice of 'supporting decision-making' in relation to health decisions with adults (aged eighteen and over) in England who have a learning disability. This first chapter commences by introducing the *Mental Capacity Act* 2005 as this legislation provides the basis for supporting decision-making practice in England and Wales, and therefore the context for this research. A definition of decision-making is provided, as are key terms as they are introduced. Definitions of key terms are also included within the Glossary. The rationale for focusing on supporting health decision-making with adults who have a learning disability will be discussed, along with a statement about language. In recognition of my role within this research in making decisions about all stages of the research and in shaping the research findings, I also introduce my position towards the end of this chapter for transparency and context, although a more detailed discussion is in Chapter 10. Chapter 1 concludes with the research aim and research questions, before an outline of this thesis is presented with a brief overview of the content of each chapter.

1.1. Decision-making legislation in England and Wales: *Mental Capacity Act* 2005

Decision-making legislation differs across the United Kingdom (UK). The *Mental Capacity Act (Northern Ireland)* 2016 and the *Adults with Incapacity (Scotland)* Act 2000 are the decision-making legislation in Northern Ireland and Scotland respectively. In England and Wales, the *Mental Capacity Act* 2005 (hereafter, MCA) is the statutory framework which underpins decision-making practice. It is based on five statutory principles:

1. "Capacity should be assumed;

2. all practicable steps should be taken to support an individual to make their own decision;
3. an individual can make an unwise decision;
4. if an individual does not have capacity, decisions should be made in the person's 'best interests'; and
5. the least restrictive decision should be taken"

(Office of the Public Guardian (OPG), 2007, p.19).

Consultation for the MCA began in 1989 with a review of Anglo-Welsh decision-making legislation by the Law Commission (1995a, 1995b). This was in response to the culmination of changes in national social policy and increased awareness of rights for disabled people (Law Commission, 1995b), supported in part by the United Nations Declaration on the Rights of Disabled Persons (United Nations, 1975). The Law Commission (1995b) identified that whilst there was established legislation for financial decision-making, case law had highlighted a disparity in English law concerning medical decision-making for individuals who lack mental capacity to make decisions for themselves. This, the Law Commission (1995b) stated, resulted in medical decisions being left "to some rather uncertain provisions of common law" (p.6). The Law Commission (1995b) recommended the introduction of one piece of decision-making legislation with a clear definition of mental incapacity (Law Commission, 1995a). This led to the publication of a Green paper in 1997: Who Decides? Making Decisions on Behalf of Mentally Incapacitated Adults (Lord Chancellor's Department, 1997), and the subsequent White paper: Making Decisions (Lord Chancellor's Department, 1999), which was the basis for the succeeding Mental Capacity Bill (2004). The initial focus on 'mental incapacity' was reframed to a focus on 'mental capacity'. (Appendix 1: Timeline of consultation). The *Mental Capacity Act* 2005 was implemented in England and Wales in 2007. The Mental Capacity Act 2005 Code of Practice (CoP) (OPG, 2007) supports application of the Act, providing guidance for those who are working with adults who may lack mental capacity to make their own decisions.

The MCA requires the provision of support to enable individuals to make their own decisions, whilst also ensuring safeguards for people who are assessed as not having the mental capacity required to make their own decision. The concept of ‘mental capacity’ therefore distinguishes individuals who are viewed legally as being able to make their own decision, regardless of whether others consider the decision to be wise, with those for whom the decision is made by others in their best interests (OPG, 2007).

‘Mental capacity’ is defined as:

> “The ability to make a decision about a particular matter at the time the decision needs to be made” (OPG, 2007, p.282),

emphasising that decision-making capacity is both time and decision specific. Accordingly, an individual might be able to make some decisions but not others and/or might have capacity at certain times but not others (OPG, 2007). Consequently, mental capacity might fluctuate and, in line with the MCA, should be regularly assessed.

The MCA sets out a two-stage assessment of capacity. Firstly, it asks whether an individual has an “impairment of, or a disturbance in the functioning of, the mind or brain”, which secondly, prevents them from making a specific decision at the time the decision is required to be made (OPG, 2007, p.46). If the answer to both these questions is ‘yes’, the individual is deemed not to have capacity to make the decision in question. There is however an inherent tension in implementing the MCA, as an assessment of capacity may be triggered and/or influenced by what is perceived to be an unwise decision. In the event a person is assessed as lacking capacity, a ‘best interests’ process is invoked, which involves a decision being made by others in the individual’s best interests, where the least restrictive option should be chosen based on the individual’s preferences (OPG, 2007).

1.2. The significance of Principle 2 of the MCA to healthcare practice

With regards to healthcare, a mental capacity assessment, which determines if an individual has the mental capacity to make the decision in question at the time the decision needs to be made, is the responsibility of the person proposing the treatment or intervention (OPG, 2007). In clinical healthcare settings, this commonly places the responsibility for assessing mental capacity on doctors and healthcare staff such as nurses, allied health professionals and healthcare assistants. In residential settings, the responsibility often falls to support staff or care assistants and personal assistants. The professional and educational backgrounds of staff with responsibility for applying the MCA in their daily practice therefore varies considerably (as will be discussed further in Chapter 2).

To be assessed as having the mental capacity to make the decision at the time it needs to be made, an individual is required to:

1. “Communicate the decision (this does not have to be verbally)
2. Understand the information relevant to the decision
3. Retain the information
4. Weigh up the information to reach a decision” (OPG, 2007, p.45).

Assessment of capacity is therefore an integral part of the MCA, with healthcare staff required to assess capacity prior to the treatment or health decision being made.

However, in line with the underpinning statutory principles of the MCA, prior to assessment of capacity, Principle 2 of the MCA stipulates that,

> “A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success” (OPG, 2007, p.19).

This places an onus on healthcare staff to support individuals to make their own decision **before** an assessment of mental capacity is undertaken (OPG, 2007).

1.3. Supporting decision-making

The second principle of the MCA is generally referred to as "supported decision-making" (House of Lords, 2014, p.41). As the first principle of the MCA is a 'presumption of capacity', it follows that decision-making support should be provided before capacity is assessed. UK parliament undertakes post-legislative scrutiny to evaluate if new legislation has achieved its intended outcome(s) (DeVrieze, 2017). In 2013/14, the House of Lords post-legislative scrutiny evaluation of the MCA found that whilst the MCA was generally "held in high regards" (p.6), there were several failings with implementation. In relation to Principle 2, the House of Lords found that,

> "Supported decision-making, and the adjustments required to enable it, are not well embedded" (House of Lords, 2014, p.8)

stating that supporting decision-making was "rare in practice" (p.41), particularly in healthcare. Harding and Taşcioğlu (2018) suggested that less focus on Principle 2 in the MCA and the MCA Code of Practice (OPG, 2007) had resulted in limited development in the implementation of supporting decision-making in practice.

The United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) (2006) was the catalyst for international interest in 'supporting decision-making' (Kohn and Blumenthal, 2014), advocating for people with disabilities to have the same rights and freedoms as non-disabled citizens (UN, 2006). The CRPD seeks to place disability rights on the international agenda, with the involvement of persons with disabilities in decision-making processes considered fundamental. Article 12 of the CRPD advocates for supporting decision-making recognising that in order to make decisions, mechanisms of support need to be available:

> "Supported decision-making can take many forms. Those assisting a person may communicate the individual's intentions to others or help him/her understand the choices at hand. They may help others to realize that a

> person with significant disabilities is also a person with a history, interests and aims in life, and is someone capable of exercising his/her legal capacity." (UN Handbook for Parliamentarians, 2007, p.90-91).

Whilst there is no formal, agreed definition (Mental Welfare Commission for Scotland, 2016), Davidson *et al.* refer to supporting decision-making as the,

> "…process of supporting people, whose decision-making ability may be impaired, to make decisions and so promote autonomy and prevent the need for substitute decision-making" (2015, p.61).

There is a consensus that supporting decision-making should be a person-centred and facilitative process that enables an individual to make their own decision (National Institute for Health and Care Excellence (NICE), 2018; UN CRPD, 2006).

The UK ratified the UN CRPD in 2009 (House of Lords, 2014). However, the UN expressed concern in 2017 regarding the lack of supporting decision-making for disabled people in the UK, advocating the need for research to advance knowledge, practice and policy in this area (UN, 2017a). The UK responded saying that it was,

> "…considering recommendations from the Law Commission to amend the Mental Capacity Act to better ensure the person's wishes and feelings are the prime consideration in any 'best interest' decision and to introduce a framework for supported decision making." (UN, 2017c, p.7).

Highlighting the importance of developing an evidence base to inform the development or revisions of a framework for supporting decision-making in line with Principle 2 of the MCA. The 'best interest' decision process is beyond the focus of this research; however, the findings may have relevance in ensuring the person's wishes and feelings remain at the centre of the 'best interest' decision process.

1.4. Definition of decision-making underpinning this research

A definition of ‘decision-making’ is required to provide context. The MCA Code of Practice (OPG, 2007) does not include a specific definition. However, in line with the MCA, to be deemed to have capacity to make a decision, an individual is required to understand the information relevant to the decision; retain and weigh up the information to reach a decision, and to communicate this to others (OPG, 2007). This is similar to the definition proposed by Shogren *et al.* (2017) following a synthesis of literature,

> “…the act of choosing among competing courses of action based on an understanding of the probable outcomes of those courses of action” (p.149).

This definition differentiates the concept of ‘choice’ from ‘decision-making’. Whilst making a choice is part of the decision-making process, the act of ‘choosing’ might not involve consideration of the probable outcomes of the choices available. Whereas ‘making a decision’ necessitates an understanding of the probable outcomes of the choices, therefore requiring the individual to understand the options available and the likely consequences. Shogren *et al’s.* (2017) definition of ‘decision-making’ underpins my research as it is in line with a mental capacity assessment under the MCA (OPG, 2007) whereby an individual is required to “understand the information relevant to the decision” and to “weigh up the information to reach a decision” (OPG, 2007, p.45) in order to be assessed as having mental capacity to make their own decision.

1.5. Rationale for focus on supporting health decision-making with adults who have a learning disability

Using data from Public Health England (2016) and the Office for National Statistics (2020), Mencap (2023) estimate there are approximately 1.5 million people in the UK who have a learning disability. In the UK, ‘learning disability’,

> "…includes the presence of: a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with; a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development." (Department of Health (DH), 2001, p.14).

Individuals who have a learning disability may have fluctuating or diminished mental capacity (OPG, 2007), and as a population group are likely to require more frequent application of the MCA (Willner *et al.* 2012). People make decisions all the time, from daily perhaps seemingly trivial decisions such as what to eat or what time to go to bed, to larger, more consequential decisions such as whether to move house or have medical treatment. Decision-making for all people (regardless of age and ability) is fundamentally based on support from others (Arstein-Kerslake, 2016; Bigby, Whiteside & Douglas, 2015; Curryer, Stancliffe and Dew, 2015; Weller, 2014), with decision-making support deriving from a variety of people depending on the decision to be made (for example, family and friends, colleagues, healthcare professionals) (Arstein-Kerslake, 2016). However, individuals with a learning disability are often more reliant on others, such as paid staff to support them with decision-making (van der Meulen *et al.* 2018). This means decision-making can be more complicated as individuals are often already in dependent relationships (Arstein-Kerslake, 2016; Bigby, Whiteside & Douglas, 2015; Weller, 2014), whilst also not necessarily having had developmental opportunities to acquire decision-making skills (Wehmeyer and Abrey, 2013).

As will be discussed further in Chapter 2, people with learning disabilities face more health inequalities and have poorer health outcomes than those without a learning disability (Health Services Safety Investigations Board, 2023; NICE, 2021; University of Bristol, 2019; Equality and Human Rights Commission, 2016; Emerson and Hatton, 2014; Heslop *et al*. 2013; Michael, 2008; Mencap, 2007; Disability Rights Commission, 2006). Yet, generally, there has been an under-representation of people with learning disabilities in healthcare and/or medical research (Bishop *et al.* 2024; Strickler and Havercamp, 2023; Hamilton *et al.* 2017) as well as a paucity of focused learning disability nursing research (Williams *et al.* 2010). For example, a scoping review in 2009 by Griffiths, Bennett and Smith revealed a limited evidence-base for learning disability nursing practice, highlighting limited literature representing the experiences and perspectives of people with learning disabilities. Without meaningful inclusion, under-representation is likely to continue, with recommendations made to improve practice potentially falling short of meeting the needs of the population they are intended to benefit.

1.6. Statement about language

"What we call people matters" (Lemay, 2012, p.125), with the language used often a reflection of the social views at that point in time (Cluley, 2018; Gates and Mafuba, 2016). Internationally, the term "intellectual disability" is now widely used. In England and Wales, "learning disability" continues to be used. Although this has not been without debate (Gates and Mafuba, 2016), as for example, "learning difficulty" has often been the preferred term used by self-advocacy groups (Goodey, 2015). In 2015, Goodey suggested that whilst the term "intellectual disability" had been embraced by academics, most people with a learning disability in England would not recognise it. As I am a Registered Learning Disability Nurse working in England, "learning disability", the term used commonly in England and Wales, is the one I have chosen to adopt throughout this thesis - except for in interview and focus group transcripts and quotes where the 'voice' of participants is reported verbatim.

1.7. Personal position

I have been a Registered Learning Disabilities Nurse for over twenty years. I worked in clinical practice for the first part of my career, and since 2013 I have worked as a Senior Lecturer in a University nursing department. I have a family member who has a learning disability, although I did not know Mark (pseudonym) had a learning disability until 2014. I explore my personal position in greater depth in Chapter 10 as my background, professional and personal experiences have informed, influenced and shaped every stage of this research; from the choice of research topic to the design, methodology and methods I have chosen to use.

1.8. Research Aim and Research Questions

1.8.1. Research Aim

The aim of this qualitative study is to explore how adults with a learning disability in England are supported to make health decisions, with a focus on how this population, as well as family members and healthcare staff, “make sense” of the process of supporting decision-making and **how** supporting health decision-making is implemented in ‘real world’ contexts.

This study draws on international supporting decision-making literature but focuses on the application of Principle 2 of the *Mental Capacity Act* 2005, to consider implications for policy and practice for **how** supporting health decision-making with adults who have a learning disability can be improved and further developed. The aim is to provide evidence-based recommendations for advancing practice in this area.

1.8.2. Research questions

Research question:

In line with the *Mental Capacity Act* 2005, how are adults with a learning disability supported to make health decisions?

With sub-questions:

- How do adults with a learning disability want to be supported to make health decisions?
- What facilitates supporting health decision-making with adults who have a learning disability?
- What hinders supporting health decision-making with adults who have a learning disability?

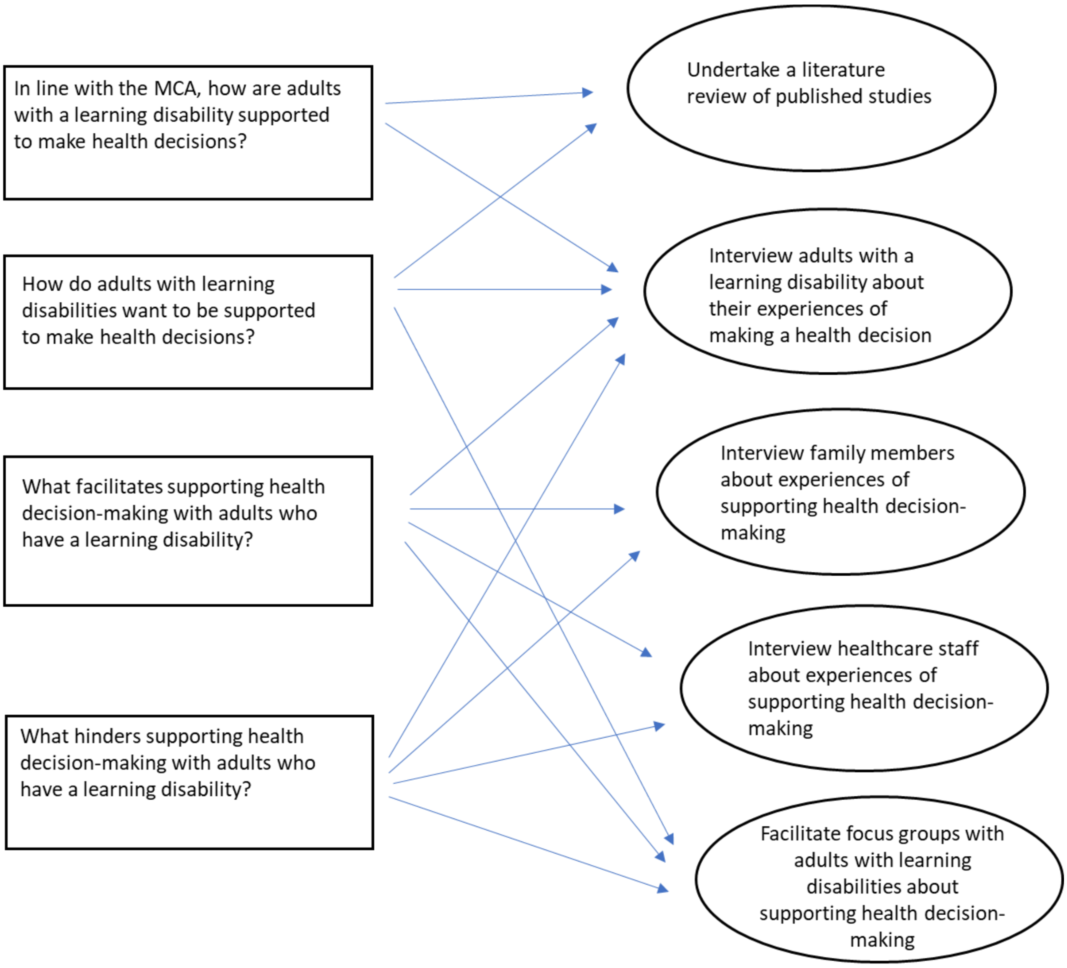


Fig 1.1: Outline of how research questions and phases of the research link

1.9. Outline of the thesis

Chapter 2: Background and Context – this chapter considers the historical context of learning disability policy and practice, recognising the importance of the wider historical, sociocultural and political circumstances which have shaped and continue to influence decision-making practice for adults with learning disabilities in England.

Chapter 3: Literature Review - presents the findings from a literature review exploring 'supporting health decision-making with adults who have a learning disability', identifying current understanding of supporting decision-making as well as gaps in knowledge and understanding.

Chapter 4: Methodology and Methods - discusses the underpinning philosophy including the ontological and epistemological assumptions which guide this research along with the methodology, which provides the overarching structure. Methods are also presented and discussed for each part of the research.

Chapter 5: Perspectives of adults who have a learning disability – this chapter presents the findings from semi-structured interviews with adults who have a learning disability about their experience of being supported to make a health decision.

Chapter 6: Perspectives of family members – this chapter presents the findings from semi-structured interviews with family members about their experiences of supporting health decision-making with their family member who has a learning disability.

Chapter 7: Perspectives of healthcare staff – this chapter explores the findings from interviews with a range of healthcare staff who support health decision-making with adults who have learning disabilities as part of their daily practice. It also incorporates pilot survey data from learning disability nursing students.

Chapter 8: Focus groups with adults who have a learning disability – this chapter presents the findings of three focus groups, which asked adults who have a learning disability about how they want to be supported to make their own health decisions.

Chapter 9: Discussion - this chapter considers how the findings from the four datasets (discussed in Chapters 5-8) collectively advance our understanding of supporting health decision-making with adults who have a learning disability in England. This chapter draws out similarities as well as tensions, providing an overview of what facilitates as well as hinders supporting health decision-making with adults who have learning disabilities.

Chapter 10: Reflexivity – in this chapter, I consider how my position has shaped and influenced this research, from informing my research aim and questions, influencing decisions regarding epistemology, ontology and methodology as well as shaping my approach to recruitment, data collection, data analysis and the dissemination of findings.

Chapter 11: Conclusion and implications – this chapter concludes the key research findings considering implications for policy and practice and making recommendations for further research.

Chapter 2: Background and Context

2.1. Introduction

This chapter provides the background to the research aim and questions outlined at the end of Chapter 1. It starts with a summary of the historical context of learning disability policy and practice, recognising the importance of the wider historical, sociocultural and political circumstances which have shaped and continue to influence decision-making practice for people with learning disabilities in England and Wales. It discusses the rationale for focusing on health decision-making, reviewing some of the findings from research studies and reviews which have evaluated the impact of MCA training on healthcare staff knowledge, understanding and practice. Two of the key concepts underpinning supporting decision-making practice, self-determination and autonomy, are then considered.

2.2. Historical, sociocultural and political context

The history of learning disability is complicated (Jarrett and Walmsley, 2019), exacerbated in part by changes in definitions and terminology related to 'learning disability' (Goodey, 2015) and compromised as most people labelled with having a learning disability "leave virtually no written historical account" (Jarrett and Tilley, 2022, p.133). The result being that the voices of people who have a learning disability are largely absent from the historical narrative. It is important to reflect on how the wider historical, sociocultural and political context has and continues to influence and shape decision-making practice with people with a learning disability in order to locate and position this research (Braun and Clarke, 2022). Context is important, as Goodey (2015) advocates that "without such an understanding, we operate in the dark" (p.1).

2.2.1. Twentieth century

In the early twentieth century, eugenic ideology prevailed. *The Mental Deficiency Act* 1913 categorised people with a learning disability as “mentally deficient” (Jarrett and Walmsley, 2019), and people were often viewed as a threat or as “objects of disgust” (Richards, 2020, p.502). People with learning disabilities were dehumanised and often segregated from mainstream society in colonies (Series, 2022; Goodley, 2017; Goodey 2015), which were newly built or developed from the 19th century asylums (Race, 2007). Jarrett and Walmsley (2019) refer to this as a “controlling and excluding era” in the history of learning disability policy and practice in the UK (p.177), where people were denied basic human rights (McClimens and Richardson, 2010) including rights to make their own decisions. Following the atrocities related to the eugenics ideology during World War II, the eugenics movement lost favour (McClimens and Richardson, 2010; Race, 2007). The establishment of the National Health Service in 1948 meant that colonies were renamed as hospitals (Gates and Mafuba, 2016), with the medical model dominating during this period (Series, 2022). Learning disability was viewed as something that needed to be treated or cured (Edwards, 2012). Jarett and Walmsley (2019) commented that the conditions in long-stay hospitals were not significantly different from colonies in the early part of the 20th century. Individuals with learning disabilities continued to be dehumanised (Goodey, 2015); for the majority, decisions about all aspects of their lives were made, by others (Power, Lord and DeFranco, 2013).

‘Normalisation’ originated in the late 1950s in Scandinavia before spreading across Western countries (Emerson, 1992). It challenged the way people with learning disabilities were viewed, advocating for equal rights and “normal” living conditions (Emerson, 1992). Whilst normalisation opposed the ideas of eugenics and the medical model (McClimens and Richardson, 2010), Emerson (1992) highlighted that early approaches did not challenge the segregation of people with learning disabilities. Normalisation was developed later by Wolfensberger (1972) who argued for integration and valued social roles for people with learning disabilities, challenging the portrayal and perception of people with learning disabilities and the dehumanising practices of segregation and historical stigmatising attitudes. In the UK, principles of normalisation influenced the 1971 White Paper: Better Services for the Mentally Handicapped (Department of Health, 1971), which advocated for care to be provided in the community rather than long-stay hospitals.

In the 1960s and 1970s, abuse within long-stay hospitals was highlighted (Department of Health & Social Security, 1978, 1971, 1969), adding to a growing momentum challenging the oppression of people with disabilities more generally (Goodley, 2017). The UN Declaration on the Rights of Disabled Persons (1975) added impetus internationally. In the UK, the conclusion of a 'Report of the Committee of Enquiry into Mental Handicap Nursing and Care' (Jay, 1979) embraced the principles of normalisation, recommending that people with learning disabilities "should live in small family-type groups […], making their own decisions" (p.140). There was consensus that people with a learning disability should be able to have an "ordinary life" and treated with respect and "accepted as having equal value" (King's Fund, 1982, p.14).

The later *Community Care Act* 1990 added further impetus, moving money away from long-stay institutions to social services (Power, Lord and deFranco, 2013), although this was motivated in part by a desire to cut costs by closing NHS beds (Race, 2007). People with and without disabilities campaigned against the notion of charity, wanting legislative reform that gave disabled people rights and protection from discrimination (Lewis, 2020). In the UK, years of campaigning by disability groups led to the initiation of the *Disability Discrimination Act* 1995 [which has since been repealed and replaced with the *Equality Act* 2010 in Scotland, England and Wales], protecting people with physical and/or mental impairments against discrimination (Lewis, 2020). In the late 20th century, self-advocacy groups expanded, aiming to specifically empower (Miller and Keys, 1996) individuals with a learning disability to have a voice (Walmsley and The Central England People First History Project Team, 2014). The premise of self-advocacy was, and continues to be, about "speaking up" and "making [other] people listen" (Walmsley *et al.* 2014, p.35), and has been suggested as one mechanism to support people with learning disabilities to make their own decisions (Finn, Smith and Stein, 2022).

2.2.2. Twenty-first century

In 2001, the first learning disability White Paper for 30 years was published in the UK, setting out a strategy for learning disability for the 21st century. ‘Valuing People’ (Department of Health, 2001) focused on the empowerment of people with a learning disability, with four key underpinning principles: rights, independence, choice and inclusion. Interestingly, the focus of Valuing People was on “choice”,

> “Like other people, people with learning disabilities want a real say in where they live, what work they should do and who looks after them. But for too many people with learning disabilities, these are currently unattainable goals. We believe that everyone should be able to make choices. This includes people with severe and profound disabilities who, with the right help and support, can make important choices and express preferences about their day to day lives.” (Department of Health, 2001, p.24).

Six-years later, the MCA was implemented, decision-making legislation stipulating that capacity should be assumed, with individuals supported by “all practicable steps” to make their own decisions (OPG, 2007, p.19). The premise of the MCA is that if an individual has support to make their own decisions, they are more likely to have ‘mental capacity’ and be able to live more independently, gaining what Weller (2014) referred to as the “threshold for citizenship” (p.298) in many Western societies.

Deinstitutionalisation was associated with many improvements for people with learning disabilities, particularly in relation to social inclusion (Emerson, 2004), and Quality of Life indicators (McCarron *et al.* 2019; Howard and Spencer, 1997). However, the pace of change has been slow. Some institutional cultural attitudes and practices associated with long-stay hospitals transferred to community living environments (Series, 2022; Power, Lord and deFranco, 2013; Mansell and Beadle-

Brown, 2010; Power, 2010), perpetuating the perspective that people with learning disabilities were dependent on others and unable to make decisions for themselves. This was reflected in a series of cases of institutional abuse across a range of services commissioned to serve people with a learning disability, highlighting that discriminatory practices, and more specifically “dehumanising attitudes”, persisted towards individuals with a learning disability (Jarett, 2022, p.124). Cases of abuse (e.g., Cornwall Partnership NHS Trust (Commission for Healthcare Audit and Inspection, 2006); Sutton and Merton Primary Care Trust (Commission for Healthcare Audit and Inspection, 2007; Flynn, 2007); Winterbourne View, South Gloucestershire (Bubb, 2014; 2016; Care Quality Commission, 2011); and Whorlton Hall, County Durham (Social Care Institute for Excellence, 2022) exposed ongoing examples of how people with learning disabilities continued to be treated with disrespect and as non-autonomous individuals by those who were paid to support them. This suggested that, despite the introduction of legislation and a change in overarching policies and rhetoric, the attitudes of some of those responsible for supporting people with a learning disability had not changed; in addition, there was a lack of checks and balances.

In 2019, Logeswaran *et al*. published a Rapid Literature Review to update the seminal review regarding the social identities of people with learning disabilities by Beart, Hardy and Buchan (2005). 16 articles were retrieved, with findings suggesting that most participants associated the label of having a learning disability with negative connotations. In 2018, Dixon, Smith and Touchet found that many people with a learning disability continued to experience negative attitudes, public stigma and discrimination. Despite changes in political discourse and a policy shift from segregation towards inclusion, independence, choice and rights (Department of Health, 2001), people with a learning disability have remained one of the most marginalized and stigmatized groups within society (Gates, 2019; Equality and Human Rights Commission, 2016; Ali *et al.* 2016, 2012; Goodey, 2015; Emerson and Hatton, 2014; Powers, Lord and deFranco, 2013; Jahoda *et al*. 2010).

2.3. Rationale for focus on health decision-making

Qualitative research is about "meaning and meaning making" and as such the context of research is important (Braun and Clarke, 2019, p.591). My decision to focus on health decision-making was influenced in part by my background as a Registered Nurse alongside evidence highlighting that despite people with a learning disability having greater and more complex health needs, they are more likely to contend with health inequities and have poorer health experiences and outcomes (Health Services Safety Investigations Board, 2023; NICE, 2021; University of Bristol, 2019; Equality and Human Rights Commission, 2016; Emerson and Hatton, 2014; Heslop *et al*., 2013; 2014; Michael, 2008; Mencap, 2007; Disability Rights Commission, 2006). A seminal study in 2013, the Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD), identified that people with learning disabilities were more likely to die prematurely than people without a learning disability because of systemic healthcare failings (Heslop *et al.* 2013). These included delays in diagnosis and treatment, as well as failures in making "reasonable adjustments" (a requirement of the *Equality Act* 2010). CIPOLD also suggested that poor adherence and understanding of the MCA was a contributory factor to people with a learning disability dying prematurely (Heslop *et al.* 2014; 2013).

Following the publication of the CIPOLD report in 2013, a national Learning Disability Mortality Review (LeDeR) Programme was established with the aim of improving the lives of people with a learning disability. As part of the LeDeR programme, multi-agency reviews were initiated following the death of a person with a learning disability. The aim of the mortality reviews was to learn from those involved in the care of the individual in the period leading to their death, to identify modifiable factors that may improve standards and ultimately the quality of services (University of Bristol, 2019). The LeDeR reports published in 2020 and 2021 by University of Bristol and in 2022 and 2023 by King's College London (White *et al.* 2023; 2022) continue to identify concerns that the Principles of the MCA are not being consistently applied in healthcare practice. The 2020 report highlighted that some families were not aware of the MCA, which LeDeR concluded should have provided some protection and empowerment for the individual and their family (University of Bristol, 2021). In the recent reports published in 2022 and 2023 (White *et al.* 2023; 2022), a lack of adherence to the MCA was identified with examples of the MCA being “poorly understood” or poorly “implemented” in practice alongside gaps in MCA documentation (White *et al.* 2022, p.49).

2.3.1. Healthcare staff knowledge and understanding of the MCA

Despite the MCA being statutory, guidelines being available (e.g., NICE, 2018; OPG, 2007), and mandatory training in place, there has been a plethora of literature highlighting potential limitations of MCA training for health and social care staff (Jenkins *et al.* 2020; Marshall and Sprung, 2018; Willner *et al*. 2013; Gough and Kerlin, 2012; Phair and Manthorpe, 2012). Whilst none of this literature specifically focuses on knowledge and understanding of Principle 2, it questions the impact MCA training has had on overall implementation of the Act in practice settings, which has been described in some circumstances as being a “tick box” exercise (Scott *et al.* 2020, p.238). A qualitative study in 2014 exploring the experiences of seven clinical psychologists found that participants felt MCA training was “too basic” (Waliji, Fletcher and Weatherhead, 2014, p.118), with one participant reporting that they had known more about the MCA than the facilitator. More recently, in a literature review by Jenkins *et al.* (2020) exploring the impact of MCA training on staff practice, only two of the 16 included studies provided details about the MCA facilitators or trainers, meaning it is not possible to know the qualifications or background of those facilitating MCA training. From the synthesis of the 16 studies Jenkins *et al.* (2020) found that there was sometimes an expectation for MCA training to be cascaded within teams or healthcare settings. The authors suggested this might result in people who either did not feel confident or who may not be competent, left with responsibility for facilitating MCA training to other staff. Potentially raising questions about the validity of MCA training facilitated.

Overall, the literature suggests that MCA training is more likely to be effective if it is based on real-life scenarios which are relevant to the area of practice of the staff (Jenkins *et al.* 2020; Hincliff-Smith *et al.* 2017; Marshall and Sprung, 2016), as well as if staff can apply their learning in practice soon after participating in MCA training (Jenkins *et al.* 2020). Following an evaluation of MCA training with NHS staff in 2013, Willner *et al.* proposed that formal training should be considered as part of a multipronged approach, suggesting that whilst formal training raises MCA awareness, staff then need to access online MCA resources for further guidance as well as being able to access a "MCA champion" (p.99), who can provide real-time support and guidance in practice settings. More recently, Jenkins *et al.* (2020) suggested that training is likely to be only one part of improving MCA application in practice settings. Jenkins *et al.* (2020) highlighted tensions between the ethos of the MCA (i.e., the underpinning principle of promoting decision-making autonomy) and long-established health professional cultures (for example, of beneficence and protection). Echoing the House of Lords findings in 2014. This suggests that, for the MCA to be applied consistently within healthcare practice, changes in working practices and attitudes are required (Jenkins *et al.* 2020; Marshall and Sprung, 2018; House of Lords, 2014), which cannot be addressed by training alone (Jenkins *et al.* 2020).

In an evaluation of mental capacity knowledge of staff working specifically in learning disability services in 2012, Willner *et al.* found that staff (health professionals and social workers) working in Community Learning Disability Teams were more likely to have improved MCA knowledge compared with "generic NHS staff" defined by Willner *et al.* as "staff providing services to the general public" (p.34) as well as qualified nurses working in residential services with people with a learning disability. Willner *et al.* (2012) suggested that those working in Community Learning Disability Teams were more likely to encounter regular, daily capacity issues with a wide range of different individuals, providing opportunities for these staff not only to apply the MCA in their daily practice but to develop expertise. Conversely, Willner *et al.* (2012) and Dunn, Clare and Holland (2010) found that staff working in learning disability residential services -staff with a nursing qualification (Willner *et al.*) as well as unqualified, support staff without a health or social care professional qualification (Dunn, Clare and Holland)- were less likely to have adequate knowledge and understanding of capacity issues and decision-making in line with the MCA. Of note, Willner *et al.* (2012) found that staff working in residential learning disability settings paradoxically reported to feel confident with the MCA, proposing that confidence is not necessarily a good indication of mental capacity knowledge and understanding. Dunn, Clare and Holland (2010) suggested a discrepancy between MCA legislation and practice in residential learning disability services, highlighting a legislation-practice gap. These studies are over 10-years old, and they explored mental capacity knowledge and understanding more broadly, often with a focus on mental capacity assessments, however it is likely that the findings also relate to staff knowledge, understanding and practice in relation to Principle 2 of the MCA.

2.3.2. Alternative interpretations of Principle 2 of the MCA

Jenkins *et al.* (2020) and Marshall and Sprung (2018) suggested that the MCA is often misunderstood and applied inconsistently in healthcare practice, echoing the findings of CIPOLD (Heslop *et al.* 2014; 2013); House of Lords (2014) and subsequent LeDeR reports (White *et al.* 2023, 2022; University of Bristol, 2021, 2020). Scott *et al.* (2020) undertook a systematic review to explore practitioners' experience of implementing the MCA. The review was not exclusive to learning disability services, however, it provides potentially significant insights into different interpretations of Principle 2 of the MCA. A thematic synthesis of the nine qualitative studies retrieved led Scott *et al.* (2020) to suggest that the MCA principles were generally "becoming successfully embedded in practice" (p.240). In relation to Principle 2 specifically, Scott *et al.* suggested that staff were using different methods to "maximise an individual's decision-making capacity" (p.240).

Methods included providing extra time, adapting communication, building rapport and delaying assessments, which are all recommended in the MCA Code of Practice (OPG, 2007). However, in the main section of the review, the use of different methods is incorporated within the third theme identified by Scott *et al.* (2020) as "doing the [mental capacity] assessment justice" (p.237). Application of Principle 2 is therefore discussed as part of undertaking a capacity assessment rather than as a preceding activity in its own right, i.e., of supporting an individual to make their own decision **before** their capacity is assessed. Scott *et al.* (2020) identified how liaising with others who knew the person well and gathering information helped **staff** "prepare for the capacity assessment" (p.237) rather than in supporting the **person** to make their own decision. There is a similar discussion of supporting decision-making in a literature review undertaken by Jayes *et al.* (2020). Jayes *et al.* (2020) retrieved 20 qualitative studies to explore how health and social care professionals assessed mental capacity. Through a process of thematic analysis, the authors identified four themes across the included studies; the third theme is titled, "supported decision-making" where the authors suggested,

> "The studies included in this review provide evidence about the ways that professionals supported people to maximise their decision-making abilities **during** capacity assessments" (p.2803). [bold added].

This identifies several aspects of good practice including gathering information to inform the assessment, helping staff prepare to undertake the assessment as well as making adjustments to support the individual appropriately during the capacity assessment. However, like the review by Scott *et al.* (2020), Jayes *et al.* (2020) appear to be viewing supporting decision-making as part of an assessment of capacity rather than as a preceding activity to support the individual to be in a position to make their own decision. Both reviews focused on preparing or helping staff to prepare for the assessment rather than on supporting the patient. This raises two potential concerns. Firstly, this appears incongruent with Principle 2 of the MCA, which as outlined in Chapter 1, stipulates,

> “A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success” (OPG, 2007, p.19).

Suggesting that steps should be taken to support an individual to make their own decision **before** an assessment of capacity, therefore suggesting an alternative interpretation of Principle 2. Secondly, the interpretations of Scott *et al.* (2020) and Jayes *et al.* (2020) suggest that the underpinning values guiding staff practice might not be in keeping with the values of the Act. The MCA Code of Practice (OPG, 2007) makes it clear that the Act is to empower individuals to make their own decisions. However, the interpretations communicated in the literature reviews by Jayes *et al.* (2020) and Scott *et al.* (2020) focus on the role of supporting decision-making in helping staff prepare for a capacity assessment rather than on supporting the individual to make their own decision. Scott *et al.* (2020) explicitly identified supporting decision-making as helping staff prepare for mental capacity assessments, using this as part of their evidence for saying that the Principles of the MCA appear to be embedded in practice. This raises questions as to how healthcare staff are understanding and applying Principle 2 of the MCA within their daily practice when working with individuals who may lack capacity to make their own decisions.

Overall, inconsistent application of the MCA continues to be identified as a cause for concern in the quality of healthcare provision for people with learning disabilities (e.g., Health Services Safety Investigations Board, 2023; White *et al.* 2023, 2022; University of Bristol, 2019; Heslop *et al.* 2014; House of Lords, 2014). NICE guidance (2018), ‘Decision-making and mental capacity’, was commissioned because of the House of Lords report in 2014 which, as discussed in Chapter 1, suggested supporting decision-making was “rare” in practice (p.41). NICE stipulate the guidance should be read in conjunction with, and not in place of the MCA Code of Practice (OPG, 2007), issuing broad advice, such as,

> "Practitioners should increase the person's involvement in decision-making by using a range of interventions focused on improving supported decision-making" (NICE, 2018, s.1.2.14).

There is a focus on communication, emphasising the responsibility of all health and social care professionals and carers who work with people who use health and social care services to support individuals to make their own decisions, providing principles in line with the Code of Practice (OPG, 2007). However, little is known about **how** people with a learning disability want to be supported to make their own health decisions or what the barriers and facilitators of supporting health decision-making are in relation to application of Principle 2.

A qualitative study in Scotland asking people with a learning disability if supporting decision-making can be a safe and realistic alternative to substitute decision-making found that the majority of the 128 participants wanted to make their own decisions (People First (Scotland) & Animate, 2017). However, the study found that a prevailing focus on mental capacity rather than supporting decision-making continued to limit decision-making opportunities for people with learning disabilities (People First (Scotland) & Animate, 2017), a finding which appears to be echoed in the more recent literature reviews undertaken by Jayes *et al.* (2020) and Scott *et al.* (2020).

2.4. Concepts associated with supporting decision-making

Carney (2014) discussed the complexities and challenges with the conceptualisation of supporting decision-making, suggesting that the meaning is often unclear, which Carney (2014) suggested is made more difficult as internationally there are different models and approaches adopted. Across the international and national literature and guidance, there is a consensus that supporting decision-making should be a person-centred and facilitative process that enables an individual to make their own decision (Zhang *et al.* 2019; NICE, 2018; Bigby, Whiteside and

Douglas, 2015; Davidson *et al.* 2015; OPG, 2007; UN, 2007; UN CRPD, 2006), with two key concepts associated with supporting decision-making: self-determination and autonomy.

2.4.1. Self-determination

Self-determination is a psychological construct concerned with the degree to which people are “actors in their own lives, rather than being acted upon” (Wehmeyer and Abrey, 2013, p.399). Despite being a debated concept (Wehmeyer, 2004), self-determination has been associated with improved quality of life and is often discussed in association with supporting decision-making (Shogren *et al.* 2018). Decision-making is identified as one of many skills (along with choice-making, problem-solving, goal setting) associated with the concept of self-determination (Burke *et al.* 2020). Wehmeyer and Abrey (2013) suggest that people with a learning disability have been found to be “less self-determined" (p.400) than their non-disabled peers, however they emphasise that this finding is not in relation to capacity to become self-determined but instead due in part to a lack of opportunities to develop decision-making skills.

A case study by McLeod (2017) exploring alternatives to guardianship for a young man with a learning disability in the United States of America (USA), suggested that preparing for self-determination should start from birth to enable individuals’ opportunities to develop decision-making skills. Whilst McLeod (2017) is a single case study meaning there may be limits to the transferability of the findings to other contexts, it is reflective of wider literature emphasising the importance of providing opportunities for individuals to develop and practice decision-making skills (Burke *et al.* 2020; Algozzine *et al.* 2001). Research about self-determination has often focused on the effect of educational interventions in schools on supporting students to become more ‘self-determined’ (Burke *et al.* 2020). Burke *et al.* (2020) undertook a meta-analysis of literature published since the original work by Algozzine *et al.* (2001) examining the effect of interventions to promote self-determination skills in school settings with students with a range of disabilities. Caution is required when reviewing the findings due to different terminology used internationally. The majority of the participants were identified as having either a learning disability (39%) or an intellectual disability (24%) (Burke *et al.* 2020, p.181). A learning disability in America equates to the term 'learning difficulty' used within the UK (Gates and Mafuba, 2016), meaning that some caution is required when drawing conclusions from the results as data from participants with a 'learning disability' may not be transferable to the population of people with a learning disability in England and Wales, who my research is focused on. Burke *et al.* (2020) however found that published research findings suggest educational interventions promoting self-determination can be effective, whilst identifying limitations in current research quality recording limiting the interpretation of results.

Whilst research has focused on interventions in school settings (Burke *et al*. 2000), self-advocacy groups might offer opportunities to develop self-determination skills for adults with learning disabilities. Fenn and Scior (2019) undertook a literature review exploring the psychological and social impact of self-advocacy groups, finding that empowerment and increased confidence were reported benefits of membership (confidence reported in 8 of 12 studies identified; empowerment in 4 of 12 studies). Fenn and Scior (2019) suggested that this is not surprising given the premise of self-advocacy, which is about "speaking up" and "making people listen" (Walmsley *et al.* 2014, p.35). Miller (2015) highlighted the impact a self-advocacy group had on organizational change in a low-secure service for men with a learning disability and mental health needs, suggesting that groups can promote wider service or organizational change as well as being associated with benefits for individuals. Whilst the Miller (2015) evaluation was in one NHS service in England, a qualitative study by Anderson and Bigby (2017) exploring the effects on social identity of membership in self-advocacy groups in Australia and the UK had similar findings. Anderson and Bigby interviewed 25 members across six self-advocacy groups, with the findings suggesting that self-advocacy membership can "create opportunities for change" (p.113). Miller (2015) suggested consideration is needed for funding of self-advocacy groups as well as for skilled external facilitation

(Anderson and Bigby, 2017) to ensure groups are not used for the agendas of others (Bigby, 2015). However, membership of self-advocacy groups might be one mechanism for developing self-determination in adults who have a learning disability.

2.4.2. Autonomy and choice-making

Autonomy is discussed as a component of self-determination (Shogren *et al.* 2018). It is often discussed with a focus on independence. Although dated, Wehmeyer (1992) suggested autonomy was about “acting in accordance to one’s own priorities or principles” (p.305). More recently, Watson (2023) has suggested that supporting decision-making “moves to a relational understanding of autonomy” (p.359), which recognises the wider context for people with a learning disability who are often in dependent relationships with carers. Watson (2023; 2016) advocates that those supporting an individual with a learning disability (specifically a severe or profound learning disability) need to be responsive to the formal and informal communication of the individual in order for the individual’s will and preferences (or priorities and principles) to be acknowledged and acted upon. (This will be discussed in further depth in Chapter 3).

Being able to make choices is discussed as part of being autonomous (Shogren *et al.* 2018). Since the origins of the principles of normalisation and social role valorisation (Wolfensberger, 1972), choice has featured significantly within policy directives in the field of learning disabilities, with the promotion of choice being central to O’Brien’s five service accomplishments (O’Brien and Tyne, 1981) and one of the four underpinning principles in ‘Valuing People’ (Department of Health, 2001). However, despite choice featuring heavily in policy, evidence suggests that whilst there have been developments and improvements, people with a learning disability continue to have restrictions of choice in their everyday life (Carey, 2020; Gjermestad *et al.* 2017; Hollomotz, 2014; Ferguson, Jarrett and Terras, 2010). Hollomotz (2014) found for example that whilst it appeared that adults with a learning disability were making more decisions, they were often making decisions by choosing from a predetermined set of restricted options as opposed to having genuine “free choice”. In 2010, Ferguson, Jarrett and Terras explored opportunities for people with a learning disability to make choices in Scotland. 17 participants were interviewed; 13 paid carers and four people with a learning disability. The authors explain that whilst they had intended to include more people with learning disabilities, it was not possible due to potential participants not meeting the language or understanding level required to participate in the study. It is unclear if reasonable adjustments were used to make the study more accessible, however the reason for non-participation appears incongruent with the study’s aim of exploring people’s opportunities of “making choices”. The findings, however, suggested that although people with learning disabilities were making choices about everyday life, they were still principally relying on others for choices about healthcare. Ferguson, Jarrett and Terras (2010) suggested that carers needed to better understand choice making in order to be able to support people with a learning disability to make their own healthcare choices.

Gjermestad *et al.* (2017) undertook a systematic review of international literature, retrieving 12 qualitative studies exploring everyday life in residential settings from the perspective of adults with learning disabilities. The findings suggested that whilst people with a learning disability want to have agency over their lives and have hopes and dreams for their futures, it can be difficult to exercise choice and control over their lives due in part to staff attitudes and the organisation (or standardisation) of services. Of note, Gjermestad *et al.* (2017) highlighted that the majority of participants in the retrieved studies had a mild learning disability and were members of self-advocacy groups, suggesting that self-advocacy groups in themselves may not be the panacea to developing decision-making autonomy.

Carey (2020) undertook a grounded theory study exploring choice making with 12 individuals with a learning disability attending day centres in Ireland. Carey (2020) found that individuals with a learning disability often lived in controlling environments, which made exercising choice and autonomy about a range of life choices challenging. Individuals with a learning disability were continuously negotiating between what was important to them and the concern of the environment or setting. Carey (2020) concluded by emphasising the importance of people with a learning disability having opportunities to make choices in order to fulfil aspirations of UN CRPD (2006), suggesting a need for "structured forums within supportive services where matters of choice and control can be creatively discussed and debated" (p.14).

2.5. Summary

In summary, historical policies and agendas have restricted the decision-making opportunities and rights of people with learning disabilities (Powers, Lord and deFranco, 2013; Power, 2010). People with a learning disability continue to face marginalisation and experience high levels of health inequalities (NICE, 2021). In England and Wales, the MCA provides the legislative framework stipulating that capacity should be assumed and individuals should be supported to make their own (health) decisions (OPG, 2007). However, the application of the MCA has been found to be inconsistent and poorly implemented, with the findings of the House of Lords (2014) and the UN (2017b) reporting that the UK is lacking in regards to supporting decision-making practice. In recent literature reviews there appears to be some confusion regarding Principle 2 of the MCA, with some authors discussing it in relation to supporting staff to prepare for mental capacity assessments (e.g., Jayes *et al.* 2020; Scott *et al.* 2020) rather than focusing on the provision of support to enable the individual to make their own decision. If individuals are supported by "all practicable steps […] to make their own decision" (OPG, 2007, p.19), they are more likely to develop decision-making autonomy and self-determination. It is timely to research supporting health decision-making in line with the MCA. If the facilitators and barriers specifically relating to the MCA's second principle of supporting decision-making with adults who have learning disabilities are understood, evidence-based recommendations and initiatives can be developed to improve this area of practice.

Whilst Chapter 2 has presented the historical, cultural and policy background to the research aim and questions, Chapter 3 will discuss the findings of a review of empirical research literature focusing on supporting health decision-making with adults who have a learning disability.

Chapter 3: Literature Review

3.1. Introduction

This chapter collates and synthesises the research literature on supporting health decision-making with adults who have a learning disability.

3.2. Background and design

In 2018, when I commenced this PhD research, seven literature reviews had already been published exploring international evidence pertaining to supporting decision-making (Ryan, 2018; Bigby *et al.* 2017; Shogren *et al.* 2017; Bigby, Whiteside and Douglas, 2015; Davidson *et al*. 2015; Kohn and Blumenthal, 2014; Werner, 2012) (A summary of each review is presented in Appendix Two). Each published review included international literature and referred to the UN CRPD (2006) as part of the context for the review. Each adopted a different methodology with a distinct focus and aim. Whilst four focused on people with a learning disability (Ryan, 2018; Bigby *et al*. 2017; Kohn and Blumenthal, 2014; Werner, 2012), three included other population groups in addition to those with learning disabilities (Shogren *et al.* 2017; Bigby, Whiteside and Douglas, 2015; Davidson *et al.* 2015). All seven included literature discussing all types of decision-making, including literature pertaining to substituted as well as supporting decision-making. The heterogeneity of the methodologies employed made it difficult to synthesise the results, however the overall findings of the seven reviews identified a limited evidence-base, suggesting a need for further empirical research using robust methodologies to inform future supporting decision-making policy and practice. Reviewing these literature reviews informed the development of my initial scoping review of published and grey literature at the start of my PhD.

3.3. Initial scoping review

Design and scoping review questions

In 2018/2019, after reviewing the seven published literature reviews, I developed and undertook a scoping review following the five-stage framework by Arksey and O'Malley (2005) focusing on UK literature (my initial scoping review protocol is in Appendix Three). Literature review questions were developed using the Population, Concept and Context framework (Peters *et al.* 2017): Population being adults (aged 18 and over) with a learning disability; Concept being supporting decision-making; and Context being health/healthcare:

1. What is the literature about supporting health decision-making with adults who have learning disabilities?
2. What does the evidence tell us about how supporting health decision-making is being facilitated with adults who have a learning disability, and the experiences of those involved?
3. Are supporting decision-making models being used? Is so, which ones and is there evidence of effectiveness?

Identifying relevant studies and study selection

The literature search was an iterative process, which culminated in the development and refinement of keywords (Table 3.1), and the selection and search of 12 electronic databases (discussed later with the final databases used presented in Table 3.2 below) as well as a search of grey literature via Google. I am grateful to Philip O’Shaughnessy, subject librarian at UWE, Bristol, who was generous with his time in 2018/2019 in supporting me to develop my search strategy. We spent hours independently running and re-running searches with different search terms to ensure search terms were suitably specific, whilst also refining my eligibility criteria (which will be discussed later) so we both made similar judgements about inclusion when scanning titles and abstracts of retrieved items.

Table 3.1. Keywords

Population		Concept		Context
“learn* disab*” OR “learning diff*” OR “Intellect* impair*” OR “Intellect* disab*” OR “Develop* disab*” OR “Develop* impair*”	AND	“Support* decision-making”	AND	Health* OR treatment*

The results of database searches were exported to RefWorks. When searching grey literature, I looked through initial pages until results were similar or irrelevant. Whilst the search of grey literature identified a plethora of guidance and promotion of supporting decision-making, it identified no new primary research studies, reports or evaluations, which had not already been identified via the database searches. I also contacted authors who were publishing work about either supporting decision-making specifically or about evaluation or application of the MCA. The seven literature reviews (Ryan, 2018; Bigby *et al.* 2017; Shogren *et al.* 2017; Bigby, Whiteside and Douglas, 2015; Davidson *et al*. 2015; Kohn and Blumenthal, 2014; Werner, 2012) were used for snowballing. Reference lists were scanned for potential items meeting my eligibility criteria (Table 3.3). In 2019, one of my supervisors (SD) and I independently assessed each retrieved full-text document against the predetermined eligibility criteria. If there were queries about whether a paper met the inclusion criteria, this was discussed before a decision was reached. This happened for articles where several populations of people (for example, people with dementia or acquired brain injury and people with learning disability) and/or wider decisions (for example, financial and everyday decisions as well as, or sometimes comprising health decisions) were included. My discussions with SD focused on whether the article findings for health decisions by people with a learning disability could be extracted.

The findings of my initial scoping review identified limited evidence of supporting health decision-making in the UK, informing my research questions (as outlined at the end of Chapter 1) and the design of my research (which will be discussed in Chapter 4).

3.4. Updated literature review

Throughout my PhD, I have continuously returned to the published literature. Since 2018, there has been an increase in the research published reflecting international and national interest in advancing supporting decision-making practice for people with cognitive disabilities. I formally re-ran my searches in June and July 2023 when I was nearing the end of data analysis. This led me to widen my literature review to incorporate international studies, and studies that included health decision-making. I drew on the strengths of my initial scoping review search strategy, to undertake a literature review using a systematic approach in January 2024. The design, methods and findings of this updated review are discussed here. My reflections on this process are discussed in Chapter 10.

3.4.1. Search strategy

The updated search used the same key terms developed in my initial scoping review (see Table 3.1 above).   Ten electronic databases were selected, informed by my initial scoping review, due to their relevance to the subject matter: AMED (Allied and Complimentary Medicine), ASSIA (Applied Social Services Index and Abstracts), BND (British Nursing Database), CINAHL Plus (Cumulative Index to Nursing and Allied Health Literature), Embase, IBSS (International Bibliography of the Social Services), Medline, PsycINFO, SCOPUS*, and Social Policy and Practice (Table 3.2 below).

Table 3.2. Databases

Database	**Last Date Searched**	**Number of hits**
AMED (Allied and Complementary Medicine)	11.01.2024	1
ASSIA (Applied Social Services Index and Abstracts)	10.01.2024	272
BND (British Nursing Database)	11.01.2024	209
CINAHL Plus (Cumulative Index to Nursing and Allied Health Literature)	10.01.2024	40
Embase	11.01.2024	53
IBSS (International Bibliography of the Social Services)	11.01.2024	64
Medline	10.01.2024	57
PsycINFO	10.01.2024	66
SCOPUS*	11.01.2024	68
Social Policy and Practice	11.01.2024	35

Results of the updated literature search were recorded in Excel, and duplicates removed and recorded using the PRISMA Extension for Scoping Reviews (Tricco *et al.* 2016) (fig 3.1. below). I scanned titles and abstracts of retrieved material to see if they met the inclusion criteria, identifying articles as either YES / MAYBE / NO. At this stage, material identified as 'NO' was disregarded. If an item was identified as 'YES' or 'MAYBE', the full text was retrieved. I assessed each item retrieved independently based on the eligibility criteria presented in Table 3.3. The initial scoping review had focused on UK literature, whereas the updated review included international literature.

Table 3.3. Eligibility criteria

Inclusion	Exclusion
Participants to have a learning disability, as defined by the Department of Health (2001).	Participants without a learning disability (as defined by Department of Health, 2001).
Aged 18 and over.	Participants aged 17 and under.
Published evidence including reports and evaluations, with "supporting decision-making" focus.	Focus is decision-making on behalf of adult(s) rather than **by** or **with** adult: surrogate decision-making/substitute decision-making/guardianship/professional decision-making/family/carer decision-making.
	Conclusion of study is that improved supporting decision-making is required rather than being focus of the paper.
	Focus is on providing guidance to healthcare staff based on mental capacity legislation, rather than evidence of supporting decision-making being applied/implemented in practice.
Health/healthcare/treatment/medical decisions included.	Health/healthcare/treatment/medical decisions are not included, therefore papers where decision-making focus is on: relationships, finance, research participation, employment, transition, education, leisure activities including holidays, accommodation, everyday choices such as what to wear, what to eat.
2007 (MCA was implemented) – Jan 2024	Pre-2007

3.4.2. Data extraction and quality appraisal

Data were extracted from each included item. I initially developed the data extraction table, from one I had used in 2017 when I had undertaken a literature review about what staff learn from MCA training for a MSc module I was taking. I extracted data from each item as represented in Table 3.4 below. Retrieved items were appraised using the CASP (2019) tool for qualitative research (Table 3.5 below).

3.4.3. Search outcomes

Sixteen items were retrieved. 15-were articles reporting on qualitative research, and one was a report (Davidson *et al.* 2018). The report by Davidson *et al.* (2018) had been retrieved in my initial scoping review; the findings had since been published in two journal articles (Webb *et al.* 2020a; 2020b). I decided to use the original report (rather than the two published articles) as I had already extracted and coded data from the report.

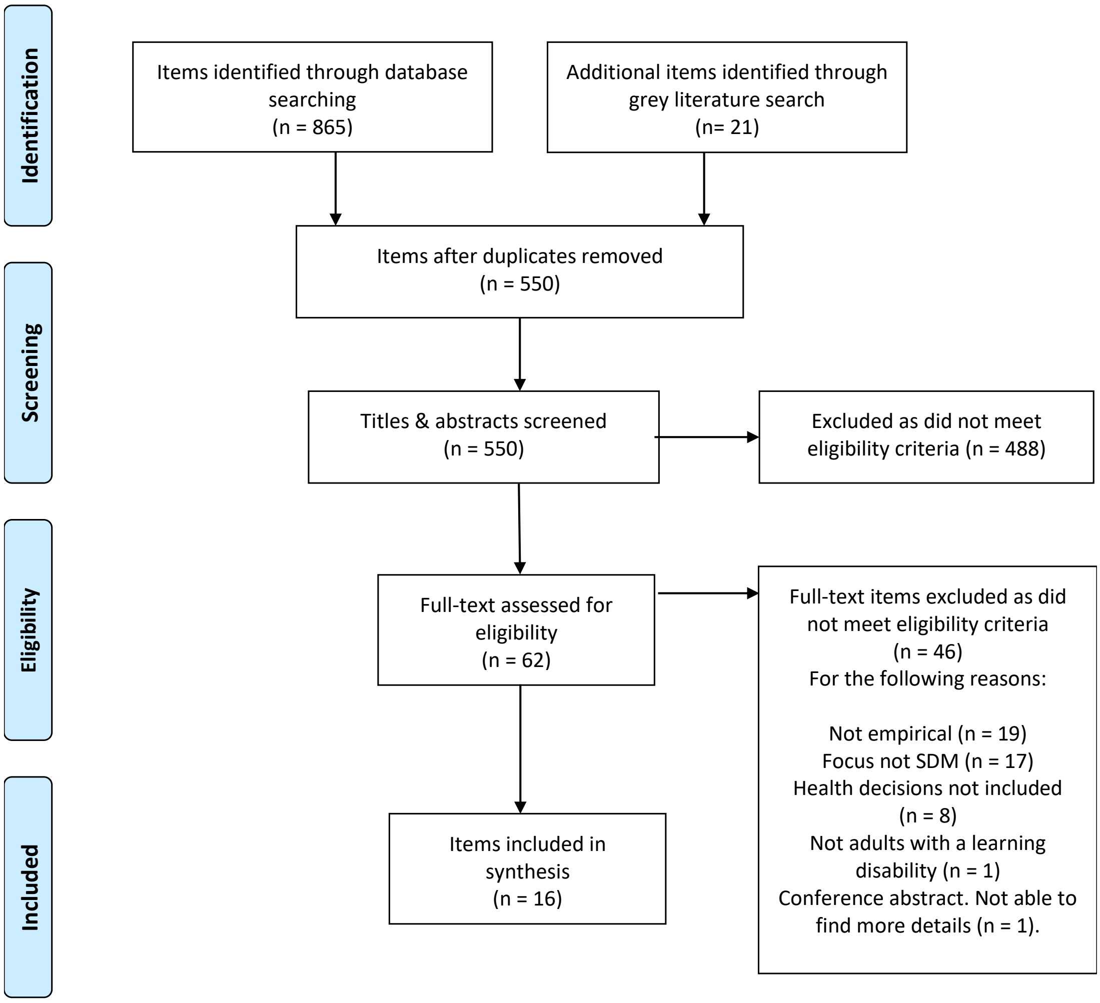


Fig 3.1. PRISMA flow chart showing process of selecting items

Table 3.4. Data Extraction 1 of 4

Author(s) / Year	Design	Geography	International/National context	Phenomena	Setting	Participants (Sampling)
Bigby *et al*. (2022b)	Exploratory qualitative (social constructionist)	Australia	UN CRPD	All decisions including health. To understand parents' experiences & strategies of supporting decision-making	Community	23-parents of adult children with learning disabilities (Purposive)
Bigby, Whiteside and Douglas (2019)	Exploratory qualitative (social constructionist)	Australia	UN CRPD	All decisions including health	Community	11-family members & 12-disability workers (Purposive)
Browning, Bigby and Douglas (2021)	Qualitative (Constructivist Grounded Theory)	Canada	UN CRPD Representation Agreement [British Columbia] & Microboards	All decisions including health. Aim to understand how decision-making support is provided in Canada.	Community	7-individuals with a learning disability & 25-supporters (Purposive & theoretical)
Carney *et al.* (2023)	Qualitative (social constructionist)	Australia	UN CRPD	All decisions including health	Community	55 Dyads: Individual & a parent (33) or family/friend (5) or paid worker (16) (Purposive)
Casey, Desmond and Coffey (2023a)	Exploratory qualitative	Ireland	UN CRPD Assisted Decision Making (Capacity) Act 2015 Ireland	All decisions including health. Exploring experiences of mothers of providing decision-making support.	Community	7-mothers of adult children with learning disabilities (Purposive)
Casey, Desmond and Coffey (2023b)	Exploratory qualitative	Ireland	UN CRPD Assisted Decision-Making (Capacity) Act [Ireland]	Exploring impact of Covid 19 restrictions on supporting decision-making.	Community	8-family members and 8 professional carers (Purposive)
Davidson *et al.* (2018)	Qualitative - Inclusive design	Northern Ireland, UK	UN CRPD Mental Capacity Act (Northern Ireland) 2016	All decisions including health	Community	41 adults with mental health problems or a learning disability (20 from Mencap NI) (Purposive)
Devi *et al.* (2020)	Institutional ethnography	England, UK	UN CRPD MCA	Everyday decisions including health	Residential	10-adults with learning disabilities, 15-support workers & 4-residential setting managers (Convenience/snowballing)

Table 3.4. Data Extraction 2 of 4

Author(s) / Year	Data collection	Data analysis	Findings/Authors' conclusions
Bigby *et al*. (2022)	Multiple semi-structured interviews	Deductive & inductive coding - Template approach to analysis	Findings reinforce the complexity & multifactorial nature of decision-making. Important to support parents to reflect on how they support decision-making. Authors suggest accountability mechanisms for supporting decision-making practice & parental involvement in disability support systems.
Bigby, Whiteside and Douglas (2019)	Semi-structured interviews or focus groups	Inductive thematic analysis & grounded theory line-by-line coding	Supporting decision-making is "complex & demanding" (p.406). Self-reflection should be built into 'supporting decision-making' training. Challenges for supporters to navigate include the supporter "being neutral, managing risks, avoiding influence & foreclosing options by being realistic too soon" (p.406-7).
Browning, Bigby and Douglas (2021)	Semi-structured interviews, observations & field notes	Constructivist grounded theory methodology	Decision-making is a "complex, dynamic and multifactorial process" (p.147). Support for decision-making is influenced by experiences & attributes of the person & the supporter, the quality of the relationship, the decision-making environment and the nature and consequences of the decision being made.
Carney *et al.* (2023)	Semi-structured interviews	Interpretive. Deductive & inductive coding	Suggest moving from paternalism to empowerment is "highly difficult, nuanced and subjective" (p.503). Instead, focus might be better placed on training of supporters.
Casey, Desmond and Coffey (2023a)	Semi-structured interviews	Thematic analysis (Braun and Clarke, 2006)	Mothers have a vital role in supporting decision-making. Participants in this study were supportive of the rights of their adult children to make their own decisions, yet they were often "hesitant to fully relinquish control in an effort to protect and guide them" (p.1).
Casey, Desmond and Coffey (2023b)	Online survey	Reflexive thematic analysis (Braun and Clarke, 2021)	People with learning disabilities had their choices curtailed during Covid-19 restrictions. Carers reported "increased opportunities to try new activities, leading to gains in independence and decision-making" (p.214).
Davidson *et al.* (2018)	Semi-structured interviews	Thematic/content analysis approach	Decision-making is central to people's lives; people want to be supported to make their own decisions. Findings emphasise the need for support to be individualized. Time is identified as an important factor, as process can take longer. Three things make decision-making harder: the type of decision, the role of other people & what the outcome might be (p.43).
Devi *et al.* (2020)	Semi-structured interviews, observations & documentary analysis	Textual & ethnographic analysis process	Organisational processes can be a barrier to supporting decision-making. Authors suggest that supporting decision-making may be improved through amending "documentation and processes (…) and through greater emphasis on the relationships & understanding between the support workers and service users." (p.154).

Table 3.4. Data Extraction 3 of 4

Author(s) / Year	**Design**	**Geography**	**International/National context**	**Phenomena**	**Setting**	**Participants (Sampling)**
*Douglass *et al.* (2023)	Exploratory qualitative	Bristol, UK	Not stated	Infant feeding decision-making	Community	4-women with learning disabilities (Purposive)
*Dowling *et al.* (2023)	Qualitative - Descriptive design	England, UK	Not stated	Infant feeding decision-making	Health settings (NHS)	7-healthcare professionals (Purposive)
Harding and Taşcioğlu (2018)	Qualitative	England & Wales, UK	UN CRPD/MCA	Everyday decision-making, which included health	Community	15-disabled people, 6-supporters, 25-social care professionals (Purposive & snowballing)
Jamieson, Theodore and Raczka (2016)	Qualitative - Grounded Theory	London, UK	Not stated	Pregnancy and motherhood	Community	3-mothers with learning disabilities, 2-family members & 6-professionals (Theoretical)
Rogers *et al.* (2020)	Exploratory qualitative design (Social constructionist)	Ireland	UN CRPD/ Assisted Decision Making (Capacity) Act 2015	All decisions including health. To explore key issues of decision-making capacity	Voluntary sector	15-Clinical psychologists (Purposive / snowballing)
Sheahan, Bigby and Douglas (2023)	Qualitative - Case study design	Australia	UN CRPD/ Medical Treatment Planning and Decisions Act 2016 (Vic)	Advance Care Planning – prospective decisions relating to end of life care	Community	3 people: individual, GP and supporter (Purposive)
Watson (2016)	Qualitative – Multiple case study (interpretative)	Australia	UN CRPD	Decision-making - people with severe/profound learning disabilities	Community or residential	5 people with severe or profound learning disabilities
Watson, Wilson and Hagiliassis (2017)	Qualitative. Action Research/Multiple Case study design	Australia	UN CRPD	All decisions but focus of paper is on a decision about end-of-life care	Community or residential	5 people with severe or profound learning disabilities (focus on one individual) & 23-supporters

Table 3.4. Data Extraction 4 of 4

Author(s) / Year	Data collection	Data analysis	Findings/Authors' conclusion
*Douglass *et al.* (2023)	Focus group & photo elicitation	Reflexive thematic analysis & Critical visual analysis	Accessible health information needs to account for differences in terms of understanding, visual literacy and cultural taste, as well as being freely available to support decision-making about infant feeding.
*Dowling *et al.* (2023)	Semi-structured interviews	Reflexive thematic analysis (Braun and Clarke, 2022)	Historical & cultural considerations influence support provided. There are several competing topics to discuss with pregnant women. Authors' suggest a suite of accessible resources is needed.
Harding and Taşcioğlu (2018)	Interviews	Thematic analysis (Braun and Clarke, 2006)	Whilst people were supported to make everyday decisions, more complex decisions (including health decisions), were likely to be less well supported. Supporting decision-making requires developments in regulations, policies as well as "social change" (p.1).
Jamieson, Theodore and Raczka (2016)	Semi-structured interviews	Grounded theory methodology	Quality of relationships with supporters is key. Three themes were identified: 1) power/powerlessness; 2) qualities of support network/need for reasonable adaptations; and 3) decision-making is an emotional and relational process.
Rogers *et al.* (2020)	Semi-structured Interviews	Thematic analysis (Braun and Clarke)	Supporting decision-making is a process that adults with learning disabilities continue to be excluded from. Paternalistic attitudes & organisational systems and policies are identified as barriers to supporting decision-making.
Sheahan, Bigby and Douglas (2023)	Semi-structured interviews	Constant comparison (Grounded theory coding & template approach)	Limitations of the Medical Treatment Planning and Decisions Act 2016 (Vic) for people with severe learning disabilities. Authors' suggest need for more institutional support for supporting decision-making and education initiatives for medical professionals. The La Trobe Framework is suggested as a useful guide to decision support in this context.
Watson (2016)	Interviews, focus groups, questionnaires & observational data	Qualitative content analysis	Supporting decision-making with people with severe or profound learning disabilities is an "interdependent and complex process" (p.7). Person expresses their will & preference using informal communication methods & supporter responds by "acknowledging, interpreting and acting on" expressions. Emphasis on responder responsiveness.
Watson, Wilson and Hagiliassis (2017)	Interviews, discussion groups, observations & document review	Colaizzi's (1978) seven stages of data analysis (p.1026).	There is a "strong association between supporter responsiveness (…) and relational closeness" (p.1032) in providing decision-making support for individuals with a severe or profound learning disability.

Table 3.5. Quality Appraisal 1 of 2

Checklist for qualitative research (CASP, 2019)	Bigby *et al.* (2022b)	Bigby, Whiteside and Douglas (2019)	Browning, Bigby and Douglas (2021)	Carney *et al.* (2023)	Casey, Desmond and Coffey (2023a)	Casey, Desmond and Coffey (2023b)	Davidson *et al.* (2018)	Devi *et al.* (2020)
Was there a clear statement of the aims of the research?	√	√	√	√	√	√	√	√
Is a qualitative methodology appropriate?	√	√	√	√	√	√	√	√
Was the research design appropriate to address the aims of the research?	√	√	√	√	√	√	√	√
Was the recruitment strategy appropriate to the aims of the research?	√	√	√	√	√	√	√	√
Was the data collected in a way that addressed the research issue?	√	√	√	√	√	√	√	√
Has the relationship between researcher and participants been adequately considered?	Not discussed	Not discussed	**Not discussed in this paper	Not discussed	Not discussed	To some extent	Not discussed	Not discussed
Have ethical issues been taken into consideration?	√	√	√	√	√	√	√	√
Was the data analysis sufficiently rigorous?	√	√	√	√	Not clear	Not clear	√	√
Is there a clear statement of findings?	√	√	√	√	√	√	√	√
Is the research valuable?	√	√	√	√	√	√	√	√

Table 3.5. Quality Appraisal 2 of 2

Checklist for qualitative research (CASP, 2019)	*Douglass *et al.* (2023)	*Dowling *et al.* (2023)	Harding and Taşcioğlu (2018)	Jamieson, Theodore and Raczka (2016)	Rogers *et al.* (2020)	Sheahan, Bigby and Douglas (2023)	Watson (2016)	Watson, Wilson and Hagiliassis (2017)
Was there a clear statement of the aims of the research?	√	√	√	√	√	√	√	√
Is a qualitative methodology appropriate?	√	√	√	√	√	√	√	√
Was the research design appropriate to address the aims of the research?	√	√	√	√	√	√	√	√
Was the recruitment strategy appropriate to the aims of the research?	√	√	√	√	√	√	√	√
Was the data collected in a way that addressed the research issue?	√	√	√	√	√	√	√	√
Has the relationship between researcher and participants been adequately considered?	To some extent	To some extent re data collection	Not discussed	√	To some extent	Not discussed	**Not discussed in this paper	Not discussed
Have ethical issues been taken into consideration?	√	√	√	√	√	√	√	√
Was the data analysis sufficiently rigorous?	√	√	√	√	√	√	√	√
Is there a clear statement of findings?	√	√	√	√	√	√	√	√
Is the research valuable?	√	√	√	√	√	√	√	√

*I co-wrote these articles. Articles reported on research I had been involved in.

**These articles report on PhD research, where further details pertaining to methodology are discussed in greater depth.

3.4.4. Synthesis

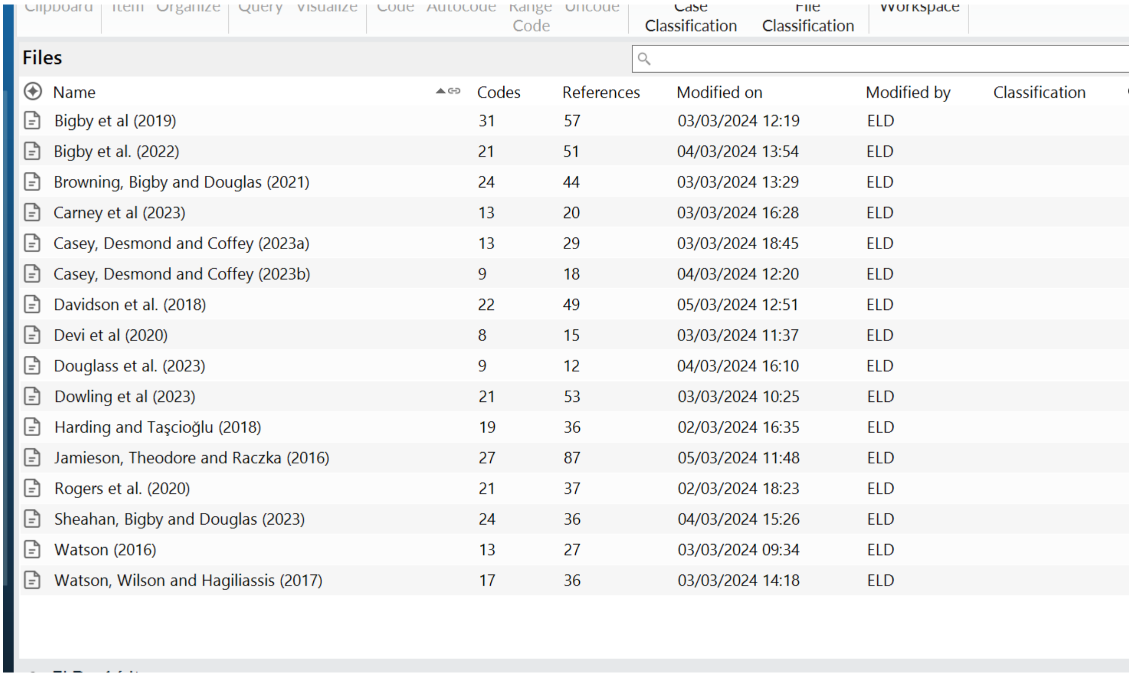
The approach I used for synthesis was informed by the results of my initial scoping review in 2018/19. All the items retrieved had used a qualitative design, leading me to use Thomas and Harden's (2008) approach to thematic synthesis. This typically involves three stages, however when I re-ran the searches in 2024 I was synthesising the findings of published literature **after** having collected and analysed my own data. By the time I started formally synthesising the data in 2024 I had also read most of the retrieved articles several times. Some items (e.g., Davidson *et al.* 2018; Jamieson, Theodore and Raczka, 2016) I had initially coded in 2019 using the line-by-line coding method by Thomas and Harden (2008). I had co-authored two of the included studies so also knew these very well (Douglass *et al.* 2023; Dowling *et al.* 2023), as they were reporting on research I had been involved in. With all other items, whilst I had not systematically coded them previously, I had read them when they had initially been published, so I felt familiar with all the 16 items.

When I started the process of synthesis, I found that I was comparing the findings of the retrieved items with the data from my PhD research. In order to tell the story of the published research, I needed to stay closer during synthesis to the original articles as opposed to moving to my interpretation of the data, which I felt was being shaped by the analysis I had undertaken of my research data. I therefore decided that I needed to adopt a more descriptive, semantic approach to synthesising the published data rather than an interpretative one. I subsequently only used the first two stages (not the third stage) of Thomas and Harden's (2008) approach to data synthesis. Using the first two stages enabled me to be systematic and thorough, remaining close to the original data to make connections between the findings of the 16 items.

Stage 1: Line-by-line coding

I copied the text from the original “Results” or “Findings” section of each retrieved item into a separate Word document, which I uploaded into NViVO 12 (QSR International) (Fig 3.2.). For one article (Watson 2016) this was a combined section discussing the empirical research findings and implications.

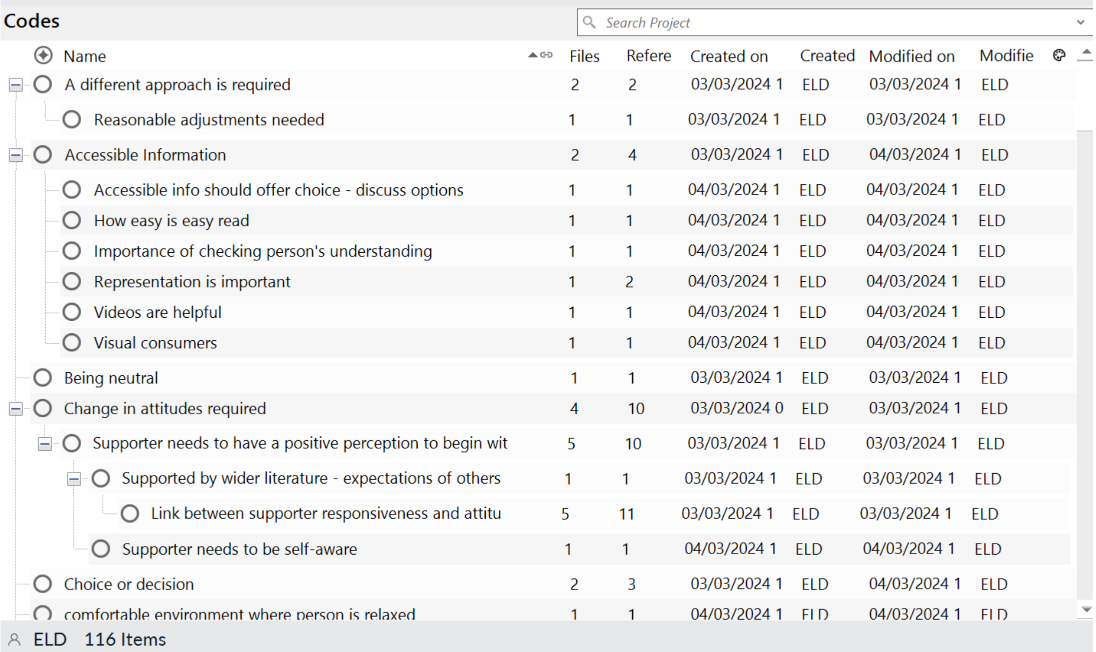
Fig 3.2. A file for each retrieved item, uploaded to NVivo for coding



Name	Codes	References	Modified on	Modified by	Classification
Bigby et al (2019)	31	57	03/03/2024 12:19	ELD	
Bigby et al. (2022)	21	51	04/03/2024 13:54	ELD	
Browning, Bigby and Douglas (2021)	24	44	03/03/2024 13:29	ELD	
Carney et al (2023)	13	20	03/03/2024 16:28	ELD	
Casey, Desmond and Coffey (2023a)	13	29	03/03/2024 18:45	ELD	
Casey, Desmond and Coffey (2023b)	9	18	04/03/2024 12:20	ELD	
Davidson et al. (2018)	22	49	05/03/2024 12:51	ELD	
Devi et al (2020)	8	15	03/03/2024 11:37	ELD	
Douglass et al. (2023)	9	12	04/03/2024 16:10	ELD	
Dowling et al (2023)	21	53	03/03/2024 10:25	ELD	
Harding and Taşcioğlu (2018)	19	36	02/03/2024 16:35	ELD	
Jamieson, Theodore and Raczka (2016)	27	87	05/03/2024 11:48	ELD	
Rogers et al. (2020)	21	37	02/03/2024 18:23	ELD	
Sheahan, Bigby and Douglas (2023)	24	36	04/03/2024 15:26	ELD	
Watson (2016)	13	27	03/03/2024 09:34	ELD	
Watson, Wilson and Hagiliassis (2017)	17	36	03/03/2024 14:18	ELD	

The first step of synthesis involved line-by-line coding of each item. As suggested by Thomas and Harden (2008) I used an inductive approach, identifying codes in response to the data rather than trying to answer my review questions at this point (Fig 3.3.) I undertook several coding sweeps trying to make sure I had looked at all data equally from across the 16 retrieved items. For items that were not exclusively about people with a learning disability (Davidson *et al.* 2018; Harding and Taşcioğlu, 2018) or exclusively about health decision-making (Carney *et al.* 2023; Casey, Desmond and Coffey, 2023a; 2023b; Browning, Bigby and Douglas, 2021; Rogers *et al.* 2020; Bigby *et al.* 2022b; Bigby, Whiteside and Douglas, 2019; Davidson *et al.* 2018; Harding and Taşcioğlu, 2018), as far as was possible I tried to focus synthesis on the data that was specifically about adults with a learning disability and supporting health decisions. This is the reason why some studies have fewer codes identified (Fig 3.2.) At the end of this stage, I had identified 142-codes.

Fig 3.3. Example of initial codes identified



Name	Files	Refere	Created on	Created	Modified on	Modifie
A different approach is required	2	2	03/03/2024 1	ELD	03/03/2024 1	ELD
Reasonable adjustments needed	1	1	03/03/2024 1	ELD	03/03/2024 1	ELD
Accessible Information	2	4	03/03/2024 1	ELD	04/03/2024 1	ELD
Accessible info should offer choice - discuss options	1	1	04/03/2024 1	ELD	04/03/2024 1	ELD
How easy is easy read	1	1	04/03/2024 1	ELD	04/03/2024 1	ELD
Importance of checking person's understanding	1	1	04/03/2024 1	ELD	04/03/2024 1	ELD
Representation is important	1	2	04/03/2024 1	ELD	04/03/2024 1	ELD
Videos are helpful	1	1	04/03/2024 1	ELD	04/03/2024 1	ELD
Visual consumers	1	1	04/03/2024 1	ELD	04/03/2024 1	ELD
Being neutral	1	1	03/03/2024 1	ELD	03/03/2024 1	ELD
Change in attitudes required	4	10	03/03/2024 0	ELD	03/03/2024 1	ELD
Supporter needs to have a positive perception to begin wit	5	10	03/03/2024 1	ELD	03/03/2024 1	ELD
Supported by wider literature - expectations of others	1	1	03/03/2024 1	ELD	03/03/2024 1	ELD
Link between supporter responsiveness and attitu	5	11	03/03/2024 1	ELD	03/03/2024 1	ELD
Supporter needs to be self-aware	1	1	04/03/2024 1	ELD	04/03/2024 1	ELD
Choice or decision	2	3	03/03/2024 1	ELD	04/03/2024 1	ELD
comfortable environment where person is relaxed	1	1	04/03/2024 1	ELD	04/03/2024 1	ELD

Stage 2: Identifying descriptive themes

The second stage is to identify descriptive themes (Thomas and Harden, 2008). I looked for relationships between the data to group the original codes together to develop themes (Table 3.6).

Table 3.6. Example of codes and descriptive themes

Codes	Descriptive themes
Medical decisions described as more complex decisions Decision gets harder support reduces Harder as more abstract Harder as more to understand Health decisions can require more support Deferred to someone else - person's wishes discounted Passed to senior staff who might not know person so well Person wants more support from people they know Making the right decision - managing uncertainty with health decisions	Health decisions are hard due to complexity and uncertainty
Relational closeness Supporter being there Talking it over Pacing of information Picking up subtle cues Supporter needs to have a positive perception to begin with Make reasonable adjustments Make information accessible Comfortable environment where person is relaxed Consistency of information is important	Quality of the relationship between the supporter and person with a learning disability is important
Not being confident decision makers - lack of experience Outcomes of previous decisions inform next decision It's not fair Choice taken away Desire for choice Ask me what I think Developmental nature of decision-making - need opportunities to learn Difficult to make big decisions under pressure	Tensions between paternalism and empowerment
Being set up to fail rather than supported Change in attitudes required Presumption of capacity but culture of incapacity Protection rather than empowerment People seen as children due to prejudices of others Unthinking paternalism or unchangeable realities of life Paternalism / Weak paternalism Additional surveillance	

3.5. Findings

This section presents the findings of the synthesis in response to the review questions.

3.5.1. What is the literature about supporting health decision-making with adults who have learning disabilities?

An overview

Five of the items were reporting on research that had been undertaken in England/Wales where the MCA is the underpinning legislation (Douglass *et al.* 2023; Dowling *et al.* 2023; Devi *et al.* 2020; Harding and Taşcioğlu, 2018; Jamieson, Theodore and Raczka, 2016). Three were reporting on research undertaken in Ireland (Casey, Desmond and Coffey, 2023a; 2023b; Rogers *et al.* 2020), where the Assisted Decision-Making (Capacity) Act [Ireland] is the underpinning legislation. One study was undertaken in Northern Ireland (Davidson *et al.* 2018) before implementation of the *Mental Capacity Act (Northern Ireland)* 2016, which, similar to the MCA, stipulates:

> “The person is not to be treated as unable to make a decision for himself or herself about the matter unless all practicable help and support to enable the person to make a decision about the matter have been given without success” (*Mental Capacity Act (Northern Ireland)* 2016, Section 1).

Six of the included items were reporting on research undertaken in Australia (Carney *et al.* 2023; Sheahan, Bigby and Douglas, 2023; Bigby *et al.* 2022b; Bigby, Whiteside and Douglas, 2019; Watson, Wilson and Hagiliassis, 2017; Watson, 2016). Since the introduction of the UN CRPD, Australian academics have undertaken research exploring supporting decision-making with populations who have a cognitive disability, which has included people with an acquired brain injury or learning disability (Bigby *et al.* 2022a; Douglas and Bigby, 2020; Bigby, Whiteside and Douglas, 2019; 2015; Bigby *et al.* 2017; Knox, Douglas and Bigby, 2017; 2016a;

2016b; 2015; 2013; Douglas, 2013). The work by Bigby and colleagues has resulted in what Douglas and Bigby (2020) advocate is the first evidence based supporting decision-making framework: ‘La Trobe Support for Decision Making Practice Framework’. The framework offers a structure for supporting all types of decisions with anyone who has a cognitive disability and is currently being evaluated in Australia (Douglas and Bigby, 2020). Three of the papers included in my review are part of the evaluation, with each of them reporting on a sub-section of data from the larger study (i.e., Carney *et al.* 2023; Bigby *et al.* 2022b; Bigby, Whiteside and Douglas, 2019). Much of the earlier research focused on people with cognitive disability following traumatic brain injury (Knox, Douglas and Bigby, 2017; 2016a; 2016b; 2015; 2013; Douglas, 2013). Whilst there are likely to be some parallels with supporting decision-making with individuals who have had a brain injury and those who have a learning disability, some of the historical and contextual factors are different. People with a learning disability might not have had many opportunities to develop decision-making skills (Wehmeyer and Abrey, 2013) whereas somebody with an acquired brain injury has usually lived a life before the injury where they have had opportunities to make their own decisions. This Carney *et al.* (2023) suggest can at least be used as a “reference point” (p.518) for the person’s preferences following brain injury.

The final article retrieved is from Canada (Browning, Bigby and Douglas, 2021). At the time I was planning my doctoral research, Canada had been recognised as an international leader in supporting decision-making. Some Canadian provinces and territories incorporated ‘supporting decision-making’ as part of decision-making legislation, which preceded the UN CRPD. As an example, in British Columbia, the *Representative Agreement Act* 1996 is a formalised legal agreement, whereby an individual appoints a representative to support decision-making (Stainton, 2016; Gooding, 2013; Gordon, 2000). This approach is markedly different from the requirements of Principle 2 of the MCA in England and Wales where all health and social care staff have a responsibility to take “all practicable steps (…) to support an individual to make their own decision” (OPG, 2007, p.19). The Canadian approach is therefore not readily transferable to England and Wales without changes to Anglo-Welsh decision-making legislation.

Study design and sample

All sixteen included items used a qualitative methodology, with all but one using semi-structured interviews and/or focus groups to collect data. The exception was Casey, Desmond and Coffey (2023b) who used a qualitative online survey during Covid-19 restrictions. Four also collected data via observations; observations and documentary analysis (Devi *et al.* 2020; Watson, Wilson and Hagiliassis, 2017), observations and field notes (Browning, Bigby and Douglas, 2021) and observations and questionnaires (Watson, 2016), with Douglass *et al.* (2023) using photo elicitation.

Sample sizes and participants varied (Table 3.4), reflecting the wide range of different people likely to be involved in supporting health decision-making with adults who have a learning disability across a range of services. Two were focused on the perspectives of people with a learning disability. Davidson *et al.* (2018) asked people with learning disabilities about their experiences and preferences for support for decision-making, whilst Douglass *et al.* (2023) facilitated a focus group with four women with learning disabilities specifically about infant-feeding decision-making.

A larger number of the retrieved items included the experiences or perspectives of adults with learning disabilities and their supporter(s). The Australian paper by Carney *et al.* (2023) reports on a subset of data from the larger, ongoing evaluation in Australia including 55 dyads consisting of an individual with a learning disability and their supporter, who was either a parent (33), family/friend (5) or paid worker (16). Also, in Australia, Sheahan, Bigby and Douglas (2023) used a case study to explore prospective decision-making for an advanced care directive including a woman with a learning disability, the GP and the supporter (who was a family friend). Watson, Wilson and Hagiliassis (2017) and Watson (2016) drew on empirical research findings from Watson's PhD research, which included five individuals with a severe or profound learning disability and 25 supporters, 23 were paid support staff and eight were unpaid. The Canadian study by Browning, Bigby and Douglas (2021) included seven adults with learning disabilities and 25 supporters. Supporters included family members, support workers, members of the person's circle of support, financial and healthcare representatives. In England, Jamieson, Theodore and Raczka (2016) interviewed three mothers with a learning disability, two family members and six health or social care professionals about decision-making support about pregnancy and motherhood. Devi *et al.* (2020) used institutional ethnography methodology, including 10 adults with a learning disability living in residential or independent living settings and paid staff, who were either support workers or managers with responsibility for supporting decision-making. Harding and Taşcioğlu (2018) spoke to disabled people, including participants with learning disabilities as well as other "intellectual disabilities" (p.1), supporters (including family members, personal assistants, a care worker and a volunteer) and social care professionals.

Other items focused on the experiences and perspectives of family members. Family members often have a unique informal role in providing support for decision-making. Bigby *et al.* (2022b) included 23 parents and Casey, Desmond and Coffey (2023a) study offered insights from the experiences of seven Irish mothers of adult children who had a learning disability. Two articles included family members and paid staff. Casey, Desmond and Coffey, (2023b) included professional carers, whereas Bigby, Whiteside and Douglas (2019) included paid staff from day programmes as well as paid support staff and house coordinators from the living setting. Only two items focused on the perspectives and experiences of healthcare professional staff; clinical psychologists (Rogers *et al.* 2020), and midwives, health visitors and learning disability nurses (Dowling *et al.* 2023).

3.5.2. What does the research evidence tell us about how supporting health decision-making is being facilitated with adults who have a learning disability, and the experiences of those involved?

Are we supporting people to make choices or supporting people to make their own decisions?

Different interpretations of supporting decision-making are evident within the retrieved literature, reinforcing the view of Carney in 2014 that "supporting decision-making" is not a term with a universal definition or shared understanding. For example, the Irish article by Casey, Desmond and Coffey (2023b) has a title of "supported decision-making", specifying that the article is about supporting decision-making in the abstract, background and introduction sections. However, the 16 participants (8-professional and 8-family carers) appear to mostly refer to 'choice' rather than 'decision-making' in their answers. This study was exploring the impact of the Covid-19 pandemic on supporting decision-making using a qualitative online survey to collect data. The data reported is limited in detail and depth. It is subsequently unclear if the data collection method has limited the depth of the participants' responses or whether the answers are reflective of participants' equating supporting "choice" to be the same as supporting "decision-making". Whilst choice is an important aspect of decision-making, as has been discussed previously, it is one component of decision-making rather than being equivalent to decision-making in itself. In the Australian article by Carney *et al.* (2023), a person with a learning disability and their supporter discuss a "decision" about having a vagal nerve stimulator implemented for epileptic seizures. However, Carney *et al.* (2023) tentatively conclude that the individual appears to have been given a choice by their supporter, which they are happy to make, rather than the opportunity to make an informed decision as the benefits and risks of the procedure have not been discussed with the individual.

It is feasible that a tendency to revert to “choice” rather than “decision-making” persists. This might be a result of the focus on “choice” in key philosophies and policies that have shaped learning disability services in the later part of the 20th and the beginning of the 21st century. As discussed in Chapter 2, principles of normalisation (Wolfensberger, 1972), O’Brien’s five service accomplishments (O’Brien and Tyne, 1981) and person-centred planning (Department of Health, 2001) have influenced learning disability services. All emphasise “choice”, offering a potential explanation as to why choice appears at times to be the default position as opposed to “decision-making”.

Health decisions are hard due to complexity and uncertainty

Five items focused exclusively on an aspect of health decision-making, including pregnancy (and motherhood) (Jamieson, Theodore and Raczka, 2016); infant feeding (Douglass *et al.* 2023; Dowling *et al.* 2023); end-of-life care (Watson, Wilson and Hagiliassis, 2017) and Advance Directives (Sheahan, Bigby and Douglas, 2023). All other items whilst incorporating health decisions explored supporting decision-making more generally, which could include every day decisions like what to wear, what activities to do, what to eat; as well as financial, legal, relationship and accommodation decisions (Carney *et al.* 2023; Casey, Desmond and Coffey, 2023a; 2023b; Bigby *et al.* 2022b; Browning, Bigby and Douglas, 2021; Devi *et al.* 2020; Rogers *et al.* 2020; Bigby, Whiteside and Douglas, 2019; Davidson *et al.* 2018; Harding and Taşcioğlu, 2018; Watson, 2016). The study by Devi *et al.* (2020) whilst including health decisions, focused most of the ‘Findings’ section on a decision to go on holiday. Consequently, rich data pertaining to supporting health decision-making is limited. Whilst there has been a perfusion of interest in supporting decision-making since the UN CRPD (2006), supporting health decision-making appears to have received less attention.

Where taxonomies of decision-making are suggested, health decisions are included in multiple categories. For example, as “every day” and “major” decisions in the study by Davidson *et al.* (2018, p.28) and as "spontaneous, mid-term and strategic decisions" by Devi *et al.* (2020 p.147). The distinction between a health decision falling within a category appears to depend on how easy the decision is perceived to be and the level of support required (Devi *et al*. 2020; Davidson *et al.* 2018) as well as the potential impact of the decision on other areas of the person's life (Davidson *et al.* 2018). In comparison, Harding and Taşcioğlu (2018) categorised health decisions in only one category; "difficult" decisions (p.4). The authors suggested that complexity makes health decisions difficult due to them often requiring an individual to understand more complex and potentially abstract information. Harding and Taşcioğlu (2018) found that whilst individuals wanted more support to enable them to make their own health decisions, levels of support available paradoxically reduced rather than increased for difficult decisions (which was not found to be the case for everyday decisions, which were identified by participants as easier decisions to make).

In some articles, health decisions were passed to more senior colleagues (Bigby, Whiteside and Douglas, 2019; Harding and Taşcioğlu, 2018). In the Australian paper by Bigby, Whiteside and Douglas (2019) a member of staff passed on a decision pertaining to a woman having a hysterectomy to their manager and to the Public Advocate, viewing this decision as beyond their sphere of responsibility; "So, no, sorry, not my gig" (Bigby, Whiteside and Douglas, 2019, p.400). In the Australian case study by Sheahan, Bigby and Douglas (2023), the supporter (a family friend) feels comfortable to support Mary (a woman with a learning disability) to make an Advance Directive, but refers the sections concerning future medical treatment to the GP, feeling this "required more understanding than she had of treatment options" (p388-9). The GP is part of the supporting decision-making arrangement so referring this to the GP is successful in continuing to keep Mary at the centre of the decision-making process and supporting Mary to make her own health decisions, illustrating a positive case study of supporting health decision-making. However, English authors suggest that in some circumstances, deferring decisions to others risks it becoming a form of substitute rather than supporting decision-making (Devi *et al.* 2020; Harding and Taşcioğlu, 2018), as the decision is moved further away from the individual with a learning disability rather than keeping the individual central to the decision-making process.

Family members also identified additional complexities with supporting health decision-making compared with supporting everyday decisions. Health decisions were associated with being more complex, with an increased risk resulting in what appears to be a tendency towards paternalistic behaviours and attitudes. For example, in the paper by Casey, Desmond and Coffey (2023a) Irish mothers would "step in" (p.5) to make health decisions for their adult children. A similar finding was identified in Australia by Bigby *et al.* (2022b) with one parent explaining that health decisions can be challenging due to the uncertainty of not knowing which option might be better (aligning potentially to the abstract nature of some health decisions that Harding and Taşcioğlu highlighted). Family members were concerned about the consequences of health decisions on the long-term wellbeing of their loved one, expressing concern that their loved one might not be able to understand the consequences of the health decision (Casey, Desmond and Coffey, 2023a; Bigby *et al.* 2022b). Family members talked about having to "nudge" the person in the "right direction" (Casey, Desmond and Coffey, 2023a, p.6) or to offer a curtailed set of choices for the individual to choose from (Bigby *et al.* 2022b).

There are tensions between paternalism and empowerment

In the Irish study by Rogers *et al.* (2020) some of the 15 clinical psychologists who participated in semi-structured interviews suggested that despite efforts to support decision-making with adults who have learning disabilities, medical decisions made by a person with a learning disability could be "disregarded by medical professionals" (p.238) and passed on to someone else to make. An example discussed was consent forms being passed to an individual's Next of Kin to complete and sign. This is not legal practice in line with the MCA, and in the studies from the UK which included participants with a learning disability, people with a learning disability reported that they wanted to make their own decisions (Douglass *et al.* 2023; Davidson *et al.* 2018*;* Harding and Taşcioğlu, 2018; Jamieson, Theodore and Raczka, 2016). Participants with a learning disability discussed feeling disempowered and angry when others made decisions which affected them (Davidson *et al.* 2018; Jamieson, Theodore and Raczka, 2016). This affected trust and was discussed as having a detrimental impact on future relationships with health and social care staff (Jamieson, Theodore and Raczka, 2016).

Negative experiences of supporting decision-making in the UK were often linked to the perceived discriminatory attitudes of health and social care staff (Dowling *et al.* 2023; Davidson *et al.* 2018; Jamieson, Theodore and Raczka, 2016). In the Australian paper by Bigby, Whiteside and Douglas (2019), whilst supporting decision-making was recognised by some family member participants as part of daily life, some paid staff (who either worked in day programmes or the living setting) highlighted how supporting decision-making can be compromised by staff attitudes. The findings suggest that some people with a learning disability continue to live within paternalistic environments, which limit and narrow decision-making opportunities rather than support them. The findings of the Irish study by Rogers *et al.* (2020) suggest that one barrier to supporting decision-making practice is overcoming the prejudices people have about individuals with a learning disability, suggesting that there is “a presumption of capacity but a culture of incapacity” (p.238).

In the English study about decision-making in pregnancy, power for decision-making was discussed as being with the health and social care professionals rather than with the person with a learning disability. Jamieson, Theodore and Raczka (2016) interviewed women with learning disabilities, family members and health and social care professionals. They found that decisions had frequently been made by the professional staff resulting in individuals with a learning disability feeling despondent; judged by others; and as though their wishes regarding their pregnancy and early motherhood had been ignored. In the English article by Dowling *et al.* (2023) whilst positive examples of supporting infant feeding decision-making were identified, health professionals reported that they felt women with learning disabilities did not always have an opportunity to decide how they wanted to feed their baby. The healthcare professionals interviewed suggested that breastfeeding was not always seen as a viable option and therefore not discussed, with one participant saying that due to potentially discriminatory attitudes women with learning disabilities were "getting a really raw deal at the moment" (p.4). This was felt to be exacerbated by how hard it can be for healthcare professionals to support decision-making whilst working within maternity pathways, which were described as "rigid" and inflexible (Dowling *et al.* 2023, p.5). A lack of flexibility in service provision was also highlighted by Jamieson, Theodore and Raczka (2016), which was discussed as negatively impacting on opportunities to support decision-making.

Staff members in some of the articles discussed the dilemmas they faced in wanting to respect an individual's choice or decision whilst feeling obliged to follow organisational and service policies, which were felt in some circumstances to constrain what was possible (Carney *et al.* 2023; Browning, Bigby and Douglas, 2021; Jamieson, Theodore and Raczka, 2016). Staff discussed what was described as a "fine line" in the Canadian study by Browning, Bigby and Douglas (2021, p.143), feeling pressure to meet the obligations and priorities of the service they worked for whilst also respecting the preferences of the individual with a learning disability. Trying to navigate this "fine line" resulted in some staff presenting information and leading discussions in a way that prompted the person being supported "to do something that [they] didn't want to do" (Browning, Bigby and Douglas, 2021, p.143).

Difficulties between honouring an individual's wishes whilst also having a Duty of Care were also identified in several papers (Casey, Desmond and Coffey, 2023a; Bigby *et al.* 2022b; Browning, Bigby and Douglas, 2021; Rogers *et al.* 2020; Bigby, Whiteside and Douglas, 2019; Jamieson, Theodore and Raczka, 2016). An example in the article by Bigby, Whiteside and Douglas (2019) concerns a woman with epilepsy who is at risk of falls due to seizures but does not want staff with her all the time. Rogers *et al.* (2020) highlights the complex ethical issues involved, which include managing risk, and balancing neglect versus Duty of Care, autonomy and self-determination. It is suggested that supporting decision-making is a “process with limits” (Rogers *et al.* p.239), which was also the perspective of mothers in the article by Casey, Desmond and Coffey (2023a). Whilst the seven participants welcomed the new Assisted Decision Making (Capacity) Act in Ireland, they were cautious of how it would work in real-life settings, saying there was a need for decisions to be "realistic" (p.5) and "restricted" (p.6). Whilst caution is required as this data is not focused exclusively on health decision-making, it does suggest that the attitude of the supporter(s) is important in supporting decision-making practice in either restricting decision-making (as is reflected in this data) or actively supporting it, which will be discussed next.

The attitude and responsiveness of the supporter is significant

It is recognised that the supporter brings their own experiences, assumptions, values and beliefs to the process (Browning, Bigby and Douglas, 2021) adding another layer of complexity to supporting decision-making. The attitudes and assumptions of the supporter influence their ability and also their approach to supporting decision-making (Casey, Desmond and Coffey, 2023a; Dowling *et al.* 2023; Browning, Bigby and Douglas, 2021; Devi *et al.* 2020; Rogers *et al.* 2020; Bigby, Whiteside and Douglas, 2019; Davidson *et al.* 2018; Watson, Wilson and Hagiliassis, 2017; Jamieson, Theodore & Raczka, 2016; Watson, 2016). This requires the supporter to be self-aware of their influence on the process and in how they are presenting information to the person they are supporting. In the papers by Browning, Bigby and Douglas (2021) and Bigby, Whiteside and Douglas (2019) some support staff were aware of the influence and power they had over the process.

The only two papers to focus on supporting decision-making with people with a severe or profound learning disability are by Watson, Wilson and Hagiliassis (2017) and Watson (2016) both stemming from Watson's PhD research in Australia. People with a severe or profound learning disability are more likely to communicate using informal and unintentional forms of communication such as body language, gestures, facial expressions and vocalisations, rather than words, which can make supporting decision-making even more complex (Watson, 2016). Watson's research findings suggest that supporting decision-making should focus on the responsiveness of the supporter. Watson found that if the supporter perceives that the person with a severe or profound learning disability can make a decision, the supporter is more likely to detect and respond to the individual's expressions of preference(s). The suggestion is that the focus of supporting decision-making with individuals who have a severe or profound learning disability should therefore be on the responsiveness of the supporter (Watson, Wilson and Hagiliassis, 2017; Watson, 2016). Watson (2016) advocates that focusing on the supporter rather than the person being supported is in line with the social model of disability and the UN CRPD as it is not expecting the individual with a learning disability to change but instead focusing on the behaviour and actions of the supporters which are amenable to change and development (Watson, 2016).

Interestingly, whilst Watson (2016) and Dowling *et al.* (2023) are focusing on different populations of people with a learning disability (individuals with a severe or profound learning disability/people with a mild learning disability) and very different health decisions (decision-making generally/infant feeding decisions), there is some similarity between the findings. Both stress the significance of a truly person-centred, individualised approach where the focus should be on the supporter changing their approach and behaviour to be more responsive to the individual they are supporting. The significance of the supporter's response is also highlighted in the paper by Browning, Bigby and Douglas (2021) in being able to empower the individual to have decision-making autonomy. This requires the supporter to be interested in the person with a learning disability; to believe the person with a learning disability can make their own decisions or express their preferences; and to change their behaviour (as the supporter) in response to the person who has a learning disability they are supporting.

The quality of the relationship matters

The importance of the quality of the relationship was emphasised in most of the items retrieved (Casey, Desmond and Coffey, 2023a; 2023b; Dowling *et al.* 2023; Sheahan, Bigby & Douglas, 2023; Browning, Bigby and Douglas, 2021; Davidson *et al.* 2018; Watson, Wilson and Hagiliassis, 2017; Jamieson, Theodore and Raczka, 2016; Watson, 2016), highlighting the emotional and relational aspects of decision-making. It does not matter who the relationship is with, nor necessarily the role and skills of the supporter but the quality of the relationship (Davidson *et al.* 2018). Decision-making (and supporting decision-making) is an emotional and relational process (Watson, Wilson and Hagiliassis, 2017; Jamieson, Theodore and Raczka, 2016; Watson, 2016) with emphasis placed on the importance of a positive relationship (Davidson *et al.* 2018; Jamieson, Theodore and Raczka, 2016), which involves knowing the person well (Sheahan, Bigby and Douglas, 2023) or spending time getting to know the individual (Dowling *et al*. 2023; Bigby, Whiteside and Douglas, 2019; Watson, Wilson and Hagiliassis, 2017; Watson, 2016).

Watson, Wilson and Hagiliassis (2017) discussed the relationship between the supporter and the person being supported in terms of “relational closeness”. They found that supporters who felt they were “intimate” or “very close” (p.1032) to the person they were supporting were more likely to know about the person’s history, which they used to inform support for decision-making. The case study by Sheahan, Bigby and Douglas (2023) provides a positive experience of an individual with a learning disability (Mary) being supported to make an Advance Directive with her friend (Sandy) and Mary’s GP. Sandy knows Mary well and would be deemed to have "relational closeness" (Watson, Wilson and Hagiliassis, 2017) to Mary, being able to use knowledge of Mary’s history to inform the approach she takes to support Mary to make her own decisions.

Developing a trusting relationship (Browning, Bigby and Douglas, 2021; Bigby, Whiteside and Douglas, 2019; Davidson *et al.* 2018); having historical knowledge

(Bigby *et al.* 2022b; Watson, Wilson and Hagiliassis, 2017); and working in partnership with the person and their circle of support (Dowling *et al.* 2023; Bigby, Whiteside and Douglas, 2019; Davidson *et al.* 2018; Watson, Wilson and Hagiliassis, 2017; Watson, 2016) are therefore emphasised as important. Bigby *et al.* (2022b) also highlights the importance of listening to the person to find out and then validate their views to increase their confidence in being able to make their own decisions.

3.5.3. Are supporting decision-making models being used? Is so, which ones and is there evidence of effectiveness?

In Australia, La Trobe Support for Decision Making Practice Framework (Douglas and Bigby, 2020) is currently under evaluation. Notably, La Trobe framework has not yet been applied specifically in healthcare settings (Sheahan, Bigby and Douglas, 2023), although articles included in this review do include aspects of health decision-making (Carney *et al.* 2023; Sheahan, Bigby and Douglas, 2023; Bigby *et al.* 2022b; Bigby, Whiteside and Douglas 2019). Also, in Australia, Watson has developed a suite of training resources focused on encouraging supporters to respond to expressions of will and preference by individuals with a severe or profound learning disability. The Australian research collectively suggests that supporter training is likely to be an important aspect of developing supporting decision-making practice, as well as highlighting the importance of peer-support for supporters.

The Irish article by Casey, Desmond and Coffey (2023b) and the English article by Devi *et al.* (2020) identified person-centred planning as one formal approach used by organisations providing services to people with learning disabilities. Whereas Casey, Desmond and Coffey (2023b) provides evidence of staff knowledge (what they should do) collecting data from eight professional carers via an online survey, Devi *et al.* (2020) use of an ethnographic methodology provides insight into the application of person-centred planning tools to support decision-making. Devi *et al.*

(2020) suggest that person-centred planning can be an effective way of supporting decision-making, however, as the study is not focused on health decisions, it is not clear how effective person-centred planning is, or could be, for supporting health decision-making. Jamieson, Theodore and Raczka (2016) developed a model: Model of supported decision-making in pregnancy/motherhood (p. 323) based on the themes identified from their findings, although there is no evidence that this has been evaluated. Therefore, whilst the research evidence is growing, research specifically focused on supporting health decision-making is limited as is the evidence from England and Wales with regards to application of supporting decision-making in line with Principle 2 of the MCA.

3.6. Discussion

In one of the seven literature reviews (Appendix Two), Shogren *et al.* (2017) advocated that those researching supporting decision-making should articulate the definition of "decision-making" they are using. This is important as "choice" appears to be used interchangeably with "decision-making" within some of the papers retrieved. This might stem from philosophies underpinning learning disability service provision in Western countries focusing, until recently, on "choice" rather than "decision-making". Highlighting the need to ensure "supporting decision-making" research is on supporting decision-making rather than offering choice.

Health decisions are identified as difficult decisions in many of the items retrieved. The difficulty is associated with the quantity of often complex information an individual must understand to be able to make a decision, alongside the often-abstract consequences of health decisions which can have a long-term impact on future health and wellbeing (Casey, Desmond and Coffey, 2023a; Sheahan, Bigby and Douglas, 2023; Bigby *et al.* 2022b; Bigby, Whiteside and Douglas, 2019; Harding and Taşcioğlu, 2018). This suggests that focused research on how to support people with a learning disability to make health decisions is required, as well as exploration as to how adults with a learning disability **want** to be supported to make their own health decisions.

There appears to be a tension between staff (those who are professionally qualified and those working as support or care workers) wanting to empower people with learning disabilities to make their own decisions and working within what are described as restrictive and rigid pathways or organisational structures. Paternalistic attitudes and practices appear to permeate current practice. Staff also find it hard to support people to make their own decisions whilst maintaining their Duty of Care, with concerns about navigating the line between neglect and empowerment. To develop supporting decision-making practice, it is therefore important for further research to include staff members so that these tensions can be better understood and solutions explored.

The research focusing on people with a severe or a profound learning disability (Watson, Wilson and Hagiliassis, 2017; Watson, 2016) is helpful in focusing on the responsiveness of the supporters. Watson (2016) suggests that how supporters respond and behave in response to an individual's communication is amenable to change through educational or training initiatives. There is a link here with other findings (for example, Carney *et al.* 2023; Bigby *et al.* 2022b; Dowling *et al.* 2023) whereby supporting decision-making requires the supporter to adapt their attitude and approach; requiring them to start with the belief that the person they are supporting is able to make a decision or to communicate their preference (Dowling *et al.* 2023; Watson, Wilson and Hagiliassis, 2017; Watson, 2016).

Person-centred planning and/or La Trobe framework (Douglas and Bigby, 2020) might ultimately be helpful to inform supporting health decision-making with adults who have a learning disability in England and Wales. However, what appears to be missing is a clear understanding of what facilitates and hinders supporting health decision-making in relation to the MCA with adults who have a learning disability. Given the legislation in place and guidelines available, it is not clear what else needs to be in place (whether this be policies, training or resources) to enable supporting health decision-making to be applied consistently in daily practice with adults who have a learning disability. It is likely that whilst ‘supporting decision-making’ is underrepresented in the literature, it is happening in practice as Gordon suggested in 2000. A gap in the empirical evidence is therefore identified in terms of **how** people with a learning disability want to be supported to make their own health decisions and what enables and/or hinders supporting health decision-making in line with Principle 2 of the MCA.

3.7. Strengths and limitations

A strength of this review is that the initial search strategy was developed iteratively over several months with a subject librarian. Findings from the included items have been synthesised using line by line coding informing the identification of descriptive themes using the systematic approach by Thomas and Harden (2008). This provides us with a reference point of what is known as well as the gaps. Studies from England and Wales specifically focusing on supporting health decision-making are limited. Indeed, there is a paucity of empirical evidence focused on supporting health decision-making generally with adults who have a learning disability. This resulted in the search being expanded to include studies **including** health decisions rather than health decision-making being the focus of the research. Whilst I tried to focus my synthesis on the findings of each item relating to health decision-making, this was challenging. Caution is therefore required with the transferability of some findings to health decision-making. This is similar for items including participants with other cognitive disabilities, which is challenging as different terminology is used for ‘learning disability’ by researchers in different settings and countries. Therefore, whilst the findings provide a useful foundation, they may not readily be transferable to supporting individuals with a learning disability (in line with the Department of Health, 2001, definition) in making health decisions in England and Wales (where the MCA is in place).

3.8. Summary

This review was interested in the empirical evidence for supporting health decision-making with adults who have a learning disability. Sixteen items were retrieved meeting the eligibility criteria, however most explored support for making all decisions, with limited in-depth data about specifically supporting health decision-making with adults who have a learning disability. Only five of the retrieved items were from England and Wales. Whilst the principles of supporting decision-making can be debated internationally, national approaches need to correspond with national laws, and to work within existing healthcare settings and structures. In Chapter 4 my research design and approach are discussed, along with the methodology and methods, which provide the overarching structure and steps taken for each part of my research.

Chapter 4: Methodology and Methods

4.1. Introduction

Chapter 3 outlined the findings identified from a literature review exploring evidence of supporting health decision-making. Rich data pertaining to supporting health decision-making is limited. Whilst there has been a perfusion of interest in supporting decision-making since the UN CRPD (2006), supporting health decision-making appears to have received less attention. A gap in the empirical evidence was identified in terms of how people with a learning disability want to be supported to make their own health decisions. This PhD research therefore aimed to explore how adults with learning disabilities are supported to make informed health decisions, seeking to understand what facilitates and hinders the supporting decision-making process from the perspectives of adults with learning disabilities, family members and healthcare staff. In this chapter, the epistemological and ontological positions underpinning this research will be presented, along with the methodology, which guides the overall research approach. The methods employed in each of the phases of the research will then be discussed.

4.2. Overview

My PhD is an interpretivist qualitative research project, which seeks to understand supporting health decision-making in practice according to the "...meanings, interpretations and experience of the persons" (Denzin, 2010, p.25) that Principle 2 of the MCA is intended to serve. My research is underpinned by a moderate social constructionist epistemology (drawing principally on the ideas of Burr, 2015 and Gergen, 2001, 2015), using accessible research methods. It is important to begin by articulating the epistemological and ontological positions, identifying my assumptions about knowledge and reality, as these underpin all decisions taken with regards to research design, methodology and methods.

4.3. Social Constructionism

Epistemology is the theory of knowledge; the study of how we know what we know (Willig, 2013). Essentially, it is concerned with what makes knowledge ‘true’ and therefore how it can be produced (Crotty, 2014). Epistemology underpins and directs all aspects of the research design and is crucial in designing a study that generates new knowledge. Constructionism suggests that rather than being created, knowledge is constructed (Crotty, 2014), and therefore built-up and developed over time, scaffolded from an individual’s experiences and from the context and networks in which the person is situated. Social constructionism focuses on understanding phenomena in light of where and how they exist (Gergen, 2001, 2015; Edley, 2001), suggesting that it is not possible to understand what is “true”, or to understand an individual’s “reality” without taking into account the wider context that the phenomenon is part of and has been constructed by (Burr, 2015; Gergen, 2015). The social, cultural and historical context therefore shapes the construction of meaning about a phenomenon, and it is these aspects that are important to consider and understand in the construction of new knowledge (Burr, 2015).

Social constructionists have been described by Willig (2013) as being on a continuum ranging from radical to moderate. Radical constructionists are interested in the ways a person constructs and uses language to convey meaning at a specific point in time within a specific social context (Willig, 2013), whereas moderate (or less relativist) constructionists, are interested in how the construction of a specific reality relates to the wider sociocultural context in which the reality takes place. Willig suggests that moderate constructionists are seeking to understand and make sense of participants’ experiences in relation to the broader social and cultural context.

As discussed in Chapter 2, people with a learning disability continue to face marginalisation and oppressive health and social care practices, supported in part by historical as well as current policies and agendas (Powers, Lord and deFranco, 2013). To be able to make sense of peoples' experiences and perspectives in relation to supporting health decision-making, it was felt important to consider these wider historical, sociocultural and political factors. A moderate social constructionist epistemology enables data to be viewed considering these wider influences, informing all stages of the research process, placing individual experiences within context, with the aim of enabling understanding and new insight. This was important when exploring 'supporting decision-making' in the field of learning disabilities. Without acknowledging and more importantly taking the historical and wider social and cultural aspects into account, it was likely to result in the interpretation of experiences and perspectives in isolation. At best, as Gergen (2001) suggests, this might lead to a partial or incomplete understanding of the phenomenon, and at worst, misleading or irrelevant understanding. With both outcomes, partial or misleading understanding, it might not be possible to make recommendations for how practice and policy could be improved in a meaningful way. A social constructionist approach would hopefully facilitate the study's findings to have social relevance, by considering the significance of the broader context.

I have been influenced by the writing of Gergen (2001, 2015) and Burr (2015), who advocate that social constructionism requires the researcher to adopt a critical stance to the meaning and understanding of phenomena, emphasising that nothing is value-free or independent but instead a manifest of the influencing social, historical and cultural context in which the subject of interest is situated. I started this PhD by considering how the political and sociocultural history of learning disability has influenced and shaped current decision-making practice and legislation (as discussed in Chapter 2) as well as reflecting on my motivation to explore supporting health decision-making (as will be discussed in Chapter 10). This guided my decision to recruit an advisory group to inform each stage of my research, as well as influencing my decision to use a qualitative methodology using accessible research methods (as detailed below). I wanted to undertake ethical research which empowered people with a learning disability to make informed decisions about participation in my research and, if they chose to, to be able to participate in a meaningful way. It also informed my decision to adopt an inductive approach to data analysis and to think about how to communicate my research findings in an accessible way, so that they are understandable to the population they were intended to serve.

4.4. Critical Realism

Whereas epistemology is the theory of knowledge, ontology is concerned with the nature of reality, essentially what exists (Crotty, 2014). My research is underpinned by the philosophical ontological assumptions of critical realism (Danermark *et al.* 2015). Critical realism suggests that there is a constructed reality based on an individuals' relationships and experiences; essentially, there

> "…exists both an external world independently of human consciousness, and at the same time a dimension which includes our socially determined knowledge about reality." (Danermark *et al.* 2015, p.6-7).

The external world can be known through an individual's interpretations of it (Danermark *et al*. 2015). These interpretations can be identified and provisional "truths" obtained. Accordingly, reality is not observable, instead knowledge is constructed based on intrinsic and extrinsic factors and must be interpreted to identify mechanisms that connect the multiple and varied realities (Mauthner and Doucet, 2003).

In my research I have sought multiple experiences of supporting decision-making with the intention of enabling a wider perspective to inform the construction of new understanding and knowledge. I have considered connections between individuals' accounts and the social practices and interactions within which the reality took place (extrinsic factors) (Burr, 2015), with the aim of enabling understanding and new insight into the mechanisms which facilitate and hinder supporting health decision-making in practice.

4.5. Making research accessible

An important aspect of my research design was to make my research accessible to people with a learning disability. I was guided initially by the literature on inclusive research. 'Inclusive research' is a term originally used by Walmsley in 2001 in relation to including people with learning disabilities meaningfully in the research process. People with learning disabilities continue to be underrepresented within research (Bishop *et al.* 2024; Strickler and Havercamp, 2023; Hamilton *et al.* 2017). If evidence-based recommendations are to meaningfully serve this population, it is imperative that their experiences and perspectives inform new understandings and shape practice recommendations. Whilst it is acknowledged that there is no "right" way to do research inclusively (Nind, 2020), the design of my research draws on accessible research principles (Nind, 2020; Walmsley and Johnson, 2003), which are based on values rather than a particular research approach or methodology (Nind, 2008). It is recognised that undertaking research accessibly can take longer and is usually more expensive (Nind, 2020). However, using accessible research methods can enable successful recruitment and involvement of participants to generate findings which have individual and societal benefits (McDonald *et al.* 2016). The aim of my research was to inform future supporting decision-making practice by developing an in-depth understanding of how adults with a learning disability are supported to make health decisions and how they want to be supported in this process, making accessibility an essential part of my research design.

Inclusive research incorporates a continuum from recruiting people in an advisory capacity to people having control and leading the study. Recruiting people with a learning disability as consultants (Hollomotz, 2018) or as advisory group members (Ellis, 2018; Powers, 2017) is an approach used in studies guided by inclusive research principles. I decided to recruit an advisory group at the beginning of my

PhD to give advice regarding methods, co-produce accessible materials to facilitate recruitment and meaningful data collection, and inform data analysis and the dissemination of my research findings.

I recruited advisory group members via my local networks. I had initially planned on recruiting six advisory group members: two people with lived experience of having a learning disability; two family members with a loved one with a learning disability; and two healthcare professionals. Due to financial constraints, I was able to recruit three individuals: one person with lived experience; one family member; and one healthcare professional. We had eight advisory group meetings. The timing of meetings corresponded with pivotal points of the research process (see PhD research timeline in Appendix Four). Each meeting lasted for between two and three hours. Meetings were all face-to-face apart from one held on online due to the Covid restrictions in place at the time (16.12.2020).

In consultation with my advisory group, I spent significant time planning how to make my research accessible to adults with learning disabilities. This is in line with the growing body of research literature (for example, Nind, 2020; Hollomotz, 2018; Powers, 2017; Nind and Vinha, 2016; Aldridge, 2015; 2007; Crook *et al.* 2015; Bigby, Frawley and Ramcharan, 2014; Chapman, 2014; Strnadova *et al.* 2014; Koenig, 2011; Walmsley and Johnson, 2003), which emphasises the need for researchers to be person-centred, considering the abilities of each research participant and subsequently using appropriate methods to collect meaningful data. The methods employed needed to be suitably flexible to enable individuals with a learning disability to participate in the research if they chose to.

For my study, this included the adoption of accessible recruitment and data collection methods, which will be discussed in more detail below but included:

- the development of ‘easy read’ (NHS England, 2017) research information leaflets (Hollomotz, 2018),

- a person-centred consent process often involving one or more meetings and discussions for the prospective participant and I to get to know each other prior to data collection (Arksey and Knight, 1999),
- a person-centred approach to facilitating interviews. For example, as suggested by Hollomotz (2018) being prepared to ask a series of closed questions, requiring a YES/NO or one-word response, rather than purely open-ended questions, which some individuals might find abstract and therefore difficult to answer.

4.6. Qualitative Methodology

Methodology refers to the framework in which research is conducted for the knowledge and understanding gained to be valid and meaningful (Willig, 2013). Nind (2020) observes that whilst inclusive, accessible research has been influenced by qualitative methodologies, it does not have to be qualitative. However, to understand and make sense of current practice, the voice and perspective of individuals with a learning disability, family members and healthcare staff was important to hear to understand how factors and contexts facilitated, as well as hindered, supporting health decision-making in practice. Accordingly, a qualitative methodology was chosen, with the aim of gathering in-depth data about how people with a learning disability want to be supported to make their own health decisions and the factors which facilitate as well as hinder supporting health decision-making.

Hanson, Balmer and Giardino (2011) suggest that qualitative research questions often commence with the investigators "curiosity about something they have observed or experienced" (p.376). The subject matter and research question for this PhD originated initially from my observations in practice as a Registered Nurse between 2003 and 2013. My observations were reinforced when I read the House of Lord's Select Committee post-legislative report in 2014, which found that supporting decision-making was rare in practice, and the later finding of the UN

CRPD (2017a, 2017b, 2017c) that further research was required for supporting decision-making practice to be improved. My curiosity in this area has also been shaped, over several years, by discussions with adults who have learning disabilities, family members of people with a learning disability and student nurses I have taught, as well as from personal experience of having a family member who has a learning disability (which I will discuss further in Chapter 10).

4.7. Quality

Debates continue about how to ensure quality in qualitative research (Morse, 2018). Trustworthiness, credibility, transferability and confirmability often replace traditional, positivist measures of rigour, such as internal and external validity and reliability (Denzin and Lincoln, 2018). Trustworthiness relates to the overall quality and the faith readers should have in the research findings (Rolfe, 2006), encompassing credibility (which is aligned to internal validity within quantitative research), dependability (associated with reliability), and transferability (which is akin to external validity). Braun and Clarke (2023) additionally suggest influence is considered in place of bias, recognising the researcher's active engagement and subjectivity as being crucial to a rich interpretative and creative understanding of the phenomena being studied. However, rather than researchers who use qualitative methodologies adopting a uniformed set of criteria in order to demonstrate quality and rigour, which often do not reflect the philosophical orientation of the research (Braun and Clare, 2022), there is growing support for a more nuanced approach which judges each piece of research on its own merits (Reicher, 2000).

Cresswell and Miller (2000) suggest that whilst member checking, triangulation, peer review and audits are often discussed in terms of ensuring rigour in qualitative studies, not all are required, and the approach(es) selected to demonstrate credibility ultimately depends on the underpinning philosophical assumptions of the research. As I became immersed in using Braun and Clarke's reflexive thematic analysis (2013, 2018, 2022) (discussed in more detail below), I was influenced by their notion that quality was about "immersion, creativity, thoughtfulness and insight" (2022, p.268) and I undertook the strategies discussed below to improve the trustworthiness and credibility of my research.

4.7.1. Critical discussions

Norris (1997, p.174) suggests qualitative researchers should discuss their research design, methods and findings with "critical friends" as a way of identifying their biases and assumptions as well as exploring alternative viewpoints and positions. Whilst Norris' writing is dated, this is also a strategy suggested by Braun and Clarke (2022) and Cresswell and Miller (2000). From the start of my PhD I have engaged in regular supervision, where my supervisory team have continuously challenged me to consider alternative approaches, questioning my decisions about methodology and methods, and querying my implicit assumptions and thinking with regards to data analysis, especially the initial findings I have identified from each data set. I have also had the privilege of being able to discuss my research design, methods and findings with my advisory group, who have given advice about how to make my research accessible as well as keeping me grounded in focusing on what is important to people with a learning disability and their families, again continuously encouraging me to consider different viewpoints and perspectives. Braun and Clarke (2023) advocate insight from multiple researchers and reflexive discussions to "enhance understanding, [whilst] supporting the development of analytical skills" (p.708). Ongoing critical discussions with my supervisory team and advisory group have helped me to remain curious, to be open to different and alternative ideas and perspectives, and to continuously consider how I am influencing and shaping the research process and findings. Some examples are discussed in Chapter 10.

4.7.2. Reflexive journaling and a transparent audit trail

Reflexivity was central to the design of my research for me to identify, consider and challenge my assumptions, as well as to continuously consider how I was influencing and shaping every stage of the research process. During data analysis I kept a 'log' (in the form of 'memos' in NVivo – discussed in more detail below) of the reasons for the decisions I had made. This is discussed as being crucial in research where the researcher is active in the research process and is recognised as being part of the "co-construction" of knowledge (Burr, 2015; Tracy, 2013). This was important when collecting data via interviews and focus groups as my presence and ability to develop an appropriate relationship and rapport with each participant directly influenced the data I collected (Elmir *et al*. 2011). My role in the construction of knowledge could not be underestimated. Several authors (Braun and Clarke, 2022; 2013; Connelly and Peltzer, 2016; Rolfe, 2006) suggest researchers should present a clear audit trail in a reflexive diary to demonstrate quality of research and trustworthiness of findings. I found making notes in my reflective diary in conjunction with keeping an audit trail using Memos within NVivo of the decisions I made, along with the rationale for each decision, helpful especially as this research spanned several years. This is discussed in greater depth, with examples in Chapter 10.

4.7.3. Allowing time for data analysis

Trainor and Bundon (2021) emphasise the importance of ensuring adequate time for thematic analysis to be reflexive and transparent. Pragmatically, Braun and Clarke (2022) suggest doubling the amount of time originally planned for analysis, highlighting that good quality interpretative analysis which goes beyond data descriptions, takes time. Partly for pragmatic reasons (working whilst undertaking this PhD part-time) I was able to allow plenty of time for the analysis. I analysed each data set over a period of time, often returning to analysis several weeks or months (or in the case of the interview data with individuals with a learning disability and family members, years) later. Each time I analysed data, I wrote myself notes as memos in NVivo recording my thoughts at that time about each transcript, the rationale for why I had linked codes, and my thoughts and rationale for how I was developing semantic codes into latent codes and then themes. When returning to analysis, this approach enabled me to review the original data and to review the codes and themes I had developed as well as to make sense of my decisions (this I discuss further, with examples in Chapter 10). Each time I returned to data analysis I tried to look at the data from different perspectives, which was informed by the critical discussions I had with my supervisory team and advisory group.

4.8. Methods

Methods refer to the techniques employed in undertaking the research (Willig, 2013). Qualitative data were collected using three methods: semi-structured interviews with adults with a learning disability, family members and healthcare staff; focus groups with adults with a learning disability and an online qualitative survey of student nurses. Sample, recruitment, data collection, data analysis and ethical considerations will now be discussed.

4.8.1. Sample: sampling approach

To recruit individuals with the necessary experience, purposive sampling was used throughout, which is typical in qualitative research aiming to generate new understandings about phenomena (Patton, 2015; Braun and Clarke, 2013). Patton (2015) advocates that ‘purposive sampling’ is an umbrella term, (including convenience and snowballing techniques) involving the recruitment of individuals who meet pre-agreed criteria (see Table 4.1 below), so that they can share insight into the phenomena in question. This approach to sampling was appropriate, aligning with the study’s aim, questions and epistemological perspectives, which sought information from people with lived experience of either making their own health decisions with support (adults with a learning disability) or supporting adults with learning disabilities to make informed health decisions informally (family members) or in a professional capacity (healthcare staff). I reflect on my approach to purposive sampling in Chapter 10.

Table 4.1. Sampling criteria

Participants with a learning disability		**Family members**		**Healthcare staff**	
Criteria	**Rationale**	**Criteria**	**Rationale**	**Criteria**	**Rationale**
Diagnosis of, or self-identifies as having a learning disability	Identified population of study	Family member of an adult with a learning disability	In line with the MCA Code of Practice (OPG, 2007), if a person is assessed as not having capacity, "close relatives…" (p.66) should be consulted in the decision-making process	Works with individual(s) who has/have a diagnosed learning disability as a part of their daily practice	Identified population of study
18 years of age or over	Age in line with MCA Code of Practice (OPG, 2007, p.216), young people are 16-17; and children aged below 16	Family member of an adult 18 years of age or over	Age in line with MCA Code of Practice (OPG, 2007, p.216), young people are 16-17; and children aged below 16	Works with adults who are 18 years of age or over who have a learning disability	Age in line with MCA Code of Practice (OPG, 2007, p.216), young people are 16-17; and children aged below 16
With complex or multiple health needs (as identified by individual)[1]	Likely to have regular contact with health professionals/need to make health decisions on a regular basis	Family member of an adult who has complex or multiple health needs (as identified by family member)	Likely to have regular contact with health professionals/need to make health decisions on a regular basis	Works in healthcare/health environment as part of daily practice	Focus of research is health decision-making
Have some verbal communication (to be assessed during consent process)	To be able to participate in interviews/focus groups	Have some verbal communication (which will be assessed during consent process)	To be able to participate in interviews	Have some verbal communication (which will be assessed during consent process)	To be able to participate in interviews
Able to give informed consent or has a personal or professional consultee	In line with MCA				

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[1] Criteria used for interviews but not for focus groups

4.8.2. Sample size

Whilst sample size in qualitative research is debated (Hagaman and Wutich, 2017), there is consensus that it should be decided in advance as part of the research plan (Mason, 2010), generally being small enough to be manageable yet large enough to obtain data which answers the research question (Sandelowski, 1995). Robinson (2014) advocates it being both a theoretical and pragmatic decision, whilst Morse (2000) emphasises the importance of considering the nature of the topic, as well as the potential quality and quantity of data.

Guest, Bunce and Johnson (2006) advocate saturation as the ‘gold standard’. Whilst there are different types of saturation (theoretical, data, theme) the term is generally defined as “no new information” (Guest, Bunce and Johnson, 2006, p.59) or as “information redundancy” (Braun and Clarke, 2021, p.201). Barbour (2001) suggests the concept of saturation has been reinforced in part due to its inclusion in qualitative checklists such as CASP (Critical Appraisal Skills Programme, 2019) and COREQ (Tong, Sainsbury and Craig, 2007), resulting in it becoming synonymous with qualitative research (O’Reilly and Parker, 2012). Mason (2010), who advocates saturation as a guiding principle, also recognises that sample size should reflect the research aim and objectives, suggesting saturation might not be the only viable approach to determining sample size in qualitative studies. O’Reilly and Parker (2012) suggest transparency and congruence with methodology is more important than saturation. This is a view supported by Braun and Clarke (2021) who advocate strongly against saturation, arguing that saturation aligns to a positivist or realist approach whereby data are a window to truth and findings are waiting to be discovered by the researcher (i.e., when a certain number of people are interviewed, no new findings will be identified). This is incongruent with the underpinning assumptions of reflexive thematic analysis, in which the researcher has an active role in interpreting and constructing meaning from the data (Braun and Clarke, 2019). My qualitative, exploratory research was seeking in-depth, rich data about an under-researched area of practice. The aim was to advance understanding of supporting health decision-making with adults who have a learning disability to inform future practice and policy developments. Using accessible research methods to ethically and meaningfully include participants with a learning disability, which requires more time and resources (Nind, 2020) outweighed having a larger number of participants. The decision about sample size was therefore partly pragmatic, shaped by the accessible research design.

My initial plan was to recruit six adults with a learning disability, six family members and six healthcare staff for interview, resulting in a total of 18 individuals, from three different groups. At the beginning my intention was to collect data from equal sized groups so no one had a louder 'voice'. Blaikie (2018) encourages researchers who use interpretative qualitative methodologies to be guided by the iterative nature of the study, so whilst sample size was agreed initially as part of the research plan, there was flexibility, with the number of interviews being reviewed after each set of data had been collected to check that data had provided "textured understanding" (Sandelowski, 1995, p.183) of supporting health decision-making. 'Textured understanding' pertained to gathering the perspectives of people who Principle 2 of the MCA is designed to serve (individuals who have a learning disability, family members and healthcare staff) in a range of settings. Sample size increased from the initial plan of 18 to 48 as the research progressed. This increase was in response to emerging findings, which is discussed in more detail in Chapter 10. In the end, 19 adults with a learning disability (collected via interviews and focus groups); 6 family members; 16 healthcare staff; and 7 student nurses who completed a pilot survey participated (Table 4.2).

Table 4.2. Sample size: Number of participants – planned and actual

Participant	**Planned at start of PhD**	**Actual number at end of PhD**
Adults with a learning disability	6 (interviews)	7 (Interviews) 12 (participants in focus groups)
Family members	6 (interviews)	6 (interviews)
Healthcare staff	6 (interviews)	16 (interviews)
Student nurses	None	7 (survey responses)
Total	**18 (interviews)**	**48 (via interviews, focus groups and survey responses)**

4.8.3 Recruitment

Recruitment of individuals with a learning disability for interview

For interviews with adults with a learning disability, recruitment was from an existing social group in the Southwest of England. The group had a large, diverse membership and met on a regular basis. The group was also based within commuting distance from where I was based, which meant that I could be person-centred in my approach to both recruitment and data collection. At the time of recruitment (June-July 2019), the group had a membership of approximately 60-adults who had a learning disability, with paid staff facilitating formal and informal events and activities. Members had varying levels of learning disability, ages and backgrounds. Some members lived in supported living, some in residential or nursing homes, and some in the family home. Some members attended social group sessions independently whilst others were supported by paid carers. My decision to recruit from this group was to try to hear the voices of individuals from different backgrounds, who lived in a variety of settings, who had different strengths and abilities; however, who were homogenous in terms of the criteria identified in Table 4.1 above.

Recruitment for interviews commenced on 01.07.2019. The ‘easy read’ research information leaflet (Appendix Five) was distributed to members of the social group via the staff team, who invited prospective participants to contact me if they were interested in participating in the study. In addition to the dissemination of research information leaflets, I attended pre-group social sessions where group members met in a café for a drink and chat before the scheduled group started. This was a voluntary and informal “drop-in” session, whereby group members would arrive up to an hour before the scheduled session to meet friends. I attended these informal gatherings to introduce myself and the study, and to talk through the research information leaflet if people wanted to. I attended the pre-group informal session on different days of the week in an attempt to recruit a diverse group of individuals, as different group sessions were targeted towards individuals with different abilities.

I attended five pre-group social sessions between 01.07.2019 and 09.07.2019. The intention had been to attend more, however there was a lot of early interest in my research from people who met the study’s inclusion criteria. In discussion with one of my supervisors, I made the decision to focus on meeting and talking to people who had already expressed an interest, rather than to continue trying to recruit more people. Six participants were recruited as a result of meeting me at a pre-group informal meeting, and one participant was recruited as they phoned me having seen a research information leaflet, which had been disseminated via the social group’s internal communication channels. Seven people who met the eligibility criteria expressed interest in participating in the study between 01.07.2019 and 12.07.2019.

In addition to these seven participants, after initially showing interest and talking to me to discuss the study, five other people actively declined to take part due to a range of reasons. This gave me confidence that prospective participants had understood relevant information about the study. Some of those who chose not to participate (whilst not asked to) gave me reasons for their decision, which I felt demonstrated they had given the research thought and made a decision based on the information I had provided. For example, one person said that they did not have the time to be interviewed, and another person said that they did not want to discuss a health decision with me. Others expressed an interest initially, however subsequently indicated that they did not wish to be interviewed. One person, for example, initially said yes, but when they arrived for the interview on a later date (as had been arranged), said that they no longer wanted to be involved in the study. I reflect on my approach to recruitment in Chapter 10.

Recruitment of family members for interview

To recruit family members, information about the study was disseminated via UWE's Family Carers Network by the Public Involvement Administrator and Advisor on two occasions (14.10.2019; 06.11.2019). Prospective participants were e-mailed the research information sheet and consent form. When prospective participants contacted me, we initially had a phone conversation where I explained the purpose of the study, and individuals were able to ask questions. During this conversation, if the person wanted to participate a date, time and venue was agreed. Five family members contacted me, three of whom decided to participate. Three additional participants were recruited as a result of snowballing/chain sampling where participants who consented to be interviewed disseminated the study details to wider contacts via networks which they were associated with.

Recruitment of healthcare staff

To recruit qualified and non-qualified healthcare staff with experience of supporting adults with a learning disability to make health decisions, I sent out e-mails with information about the study via my existing professional and academic networks, including Avon and Wiltshire Positive Behaviour Support Network; Avon Learning Disabilities Education and Research Network; and the UK and Ireland Learning Disability Academic Nursing Network. I also sent information to my colleagues and to organisations that provide services to and for people with a learning disability. People who saw the original e-mail were encouraged to forward and share the information more widely among their own networks.

The recruitment e-mail included my contact details, a copy of the Participant Information and consent form, inviting healthcare staff with experience of working with people with learning disabilities to contact me if they are interested in participating in the study. When potential participants contacted me, I asked if they had any questions or wanted to talk about the study. Each participant therefore had opportunity to ask questions and have those questions answered (either via e-mail conversation or a phone conversation) before deciding whether to take part. Following this, if individuals responded saying they wanted to participate, I asked them to e-mail me a completed consent form. A date and time for the interview was then arranged at the convenience of the individual.

Recruitment of individuals with a learning disability for focus groups

Focus groups were face-to-face, so recruitment was focused on the areas of Bristol, South Gloucestershire, Wiltshire and Somerset for practical and cost reasons. In January 2023, information about the study was disseminated through local support and self-advocacy groups, as well as independent and voluntary sector organisations providing support and services to and for people with learning disabilities in these geographical areas. Information about the study was also disseminated via professional networks, such as via learning disability nurses working across services in these areas in an attempt to reach a wider range of people who might be interested in participating.

Prospective participants were advised to contact me if they were interested in participating in the study. Some people contacted me independently expressing an interest, at which time I offered to either meet in person or to have a telephone conversation to discuss the study. A couple of prospective people subsequently decided not to participate. For most prospective participants, a member of staff who worked with the person initially contacted me, at which time I offered to meet with the individual(s) to introduce myself and to talk about the study, as well as sending out the Participant Information Sheet and Consent Form. If people wanted to participate after having had time to look through the information and ask questions, a date and venue was agreed.

4.8.4 Data Collection

Interviews

Interviews are frequently used in qualitative research (Holloway and Galvin, 2017). However, Brinkmann (2018) warns against them being adopted without due consideration, emphasising that interviews are far from being an easy and quick data collection method. I decided to use interviews as they were congruent with my research question, underpinning philosophy and methodology. Interviews offered the opportunity to gather rich, descriptive data from participants who had relevant experience (Brinkman and Kvale, 2018). They allowed me to be flexible in my approach to asking questions depending on the needs of each participant (Hollomotz, 2018) as well as enabling me to ask critical and probing questions as a way of gaining a deeper understanding of what participants said (Brinkman and Kvale, 2018).

To answer my research question, it was imperative that people with a learning disability could participate in a meaningful way in my research. Interviews were a data collection method with the required flexibility in both structure (for example, we could have several short interviews on different days) and facilitation (for example, I could ask questions in different ways depending on the needs of each participant) to meaningfully include people with a learning disability within the study.

Brinkmann (2018) suggests that whilst the structure of interviews is a continuum between unstructured and structured approaches, in practice most interviews fall somewhere within the middle. To make my research accessible, following discussion with my advisory group, a semi-structured interview was selected, with a topic guide developed to guide the interview conversation. Topic guides enabled relevant questions regarding people's experiences and perceptions to be sought whilst supporting a flexible approach (Holloway and Gavin, 2017), as discussed above, so that both open and closed questions could be asked depending on the needs of the participant. Additionally, interviews offered the opportunity to seek clarification from participants, and therefore enabled the interpretation process to commence during the interview itself, as suggested by Butler (2005).

Interviews with individuals who have a learning disability

For six participants, the interview was completed in one setting; whilst one participant was interviewed over two separate days, one week apart. Rather than personal choice this was out of necessity due to support arrangements, and due to the timing of transportation for the participant to return home. The duration of the interview time ranged from 21 minutes to 1 hour 22 minutes. All participants gave consent for the interview to be audio recorded, which was discussed as part of the consent process (and which will be discussed in more detail below). The interviews were also video recorded, with the intention of analysing body language and non-verbal communication however, due to issues with software, four did not record properly, resulting in a decision to delete all footage. As all interviews were also audio recorded no data were lost because of discarding the videos.

To facilitate participation (Frankena *et al.,* 2019), all participants had the choice of bringing somebody with them for the interview (for example a key worker, family member or friend). This was in the research information leaflet and discussed throughout the consent process. It was explained that participants could bring somebody into the interview with them, but that I was interested in the participants' views and not those of their support person. It was also explained that participants could attend the interview alone. None of the participants chose to bring somebody with them into the interview.

The venue for each interview was negotiated with the participant. Four individuals chose to be interviewed at the venue of the social group they attended, usually before or after a scheduled group session, and three chose to be interviewed at Glenside campus, UWE, Bristol. I reimbursed travel costs for those who incurred additional costs to attend the interview.

Interviews with family members

Informed consent was sought at the beginning of each interview. The topic guide (Appendix Six), written in consultation with the Advisory Group, provided the framework for each interview. Five interviews were facilitated in total with six people. Three interviews were face-to-face (two individual and one dyad), between November and December 2019. One interview was planned for March 2020 but was postponed due to Covid-restrictions and my related 6-month suspension from PhD study. Two interviews were facilitated online via BlackBoard Collaborate™ in late November and early December 2020. Each participant chose to be interviewed in their own home. All participants gave consent for the interview to be audio-recorded. Duration of interviews ranged from 37 minutes to one hour and 34 minutes.

Interviews with healthcare staff

Most Interviews (n=15) with staff were facilitated between 17.06.2021 and 16.07.2021. Interview dates and times were negotiated and arranged so that they were convenient for the participant, which meant some interviews took place in the evening or at weekends. All participants chose to be interviewed via Microsoft Teams and gave consent for interviews to be recorded. Interviews were between

23 and 55 minutes in length, with interviews on average taking 40-minutes. Interviews were semi-structured. Whilst the topic guide (Appendix Seven) was used, interviews were flexible to enable additional probing questions to be asked in relation to what participants said.

One final interview was facilitated on 13.09.2023. This staff member had attended one of the focus groups to support the participation of individuals with a learning disability. The staff member had made some interesting comments, which I felt were of potential benefit to my wider research, however as the focus groups were focused on the views of people with a learning disability, it had not been appropriate for me to ask probing questions of the staff member at that point in time. Following the focus groups, I discussed this with my supervisory team and sought an ethics amendment, which was granted on 08.08.2023 (Table 4.3. below) to invite this member of staff for an interview via Microsoft Teams.

Survey

My initial research plan included conducting a short, cross-sectional online survey (via Qualtrics) to find out how healthcare staff were supporting adults with a learning disability to make health decisions. The online survey questions were co-written with my advisory group and included five questions about how staff were supporting individuals with a learning disability to make health decisions before asking participants to complete some demographic information (Appendix Eight shows the survey protocol and questions). I envisaged that the survey would take approximately 15 minutes to complete and for the link to be disseminated via my existing professional and academic networks, including Avon and Wiltshire Positive Behaviour Support Network; Avon Learning Disabilities Education and Research Network; and the UK and Ireland Learning Disability Academic Nursing Network, as well as to my colleagues and to organisations that provide services to people with a learning disability. People who saw the original e-mail were encouraged to forward and share the information more widely among their own networks. As suggested by

Braun and Clarke (2013), to gather feedback re clarity of instructions, wording and ordering of questions, I piloted the survey with learning disability nursing students during a conference day at Glenside campus, UWE, Bristol on 16.12.2019, before I planned to launch the survey more widely in March 2020. I had ethical approval to include responses from the pilot survey in data analysis (Table 4.3 below).

The intention was to find out how supporting decision-making was being facilitated in healthcare practice. It was not aiming to collect representative or generalisable data. Neither was it necessarily aiming to collect examples of good practice. The intention was to try to find examples of supporting health decision-making to inform the development of interview questions to ask staff. At the end of the survey, there was an additional question asking if they would be interested in participating in a telephone interview.

Due to the Covid-19 pandemic, I did not launch the survey across the UK as planned. Whilst I had collected pilot data from student nurses in December 2019, when I came to launching the survey to healthcare staff, the first lock-down had started and I took a 6-month break from PhD study due to the pandemic. On returning to PhD study, my primary aim was to complete family member interviews, which I subsequently analysed along with an initial analysis of the pilot survey responses. This analysis made me reflect on the purpose of the survey. Because I was seeking in-depth data, which explained not only how staff were supporting health decision-making but also why they used a particular approach and if and how they felt it was effective, I decided to pause the launch of the survey and instead invite staff for interviews. Following data analysis of the staff interviews, in discussion with my supervisory team and advisory group, I subsequently decided not to pursue with disseminating the survey but instead to use the time I had left to facilitate focus groups with people with a learning disability. This is discussed in more detail in Chapter 10.

Focus groups

Focus groups were not part of my original research plan. However, between 23.03.2020 and 31.05.2022, I suspended my PhD studies for a total of 15-months (not consecutively) for Covid-related reasons (see PhD research timeline in Appendix Four). When I returned to looking at the interview data from adults with a learning disability in 2023, it was post-pandemic and 4-years after the initial interviews had been facilitated. I wanted to explore individuals' views in a post-pandemic environment as well as to enable more people with a learning disability to give their views about support to make health decisions. Rather than replicating the original data collection method, which focused on gathering in-depth data via semi-structured interviews about one experience of making a health decision, I decided to ask adults with a learning disability more generally about what they thought enabled supporting health decision-making as well as exploring potential barriers and challenges. I wanted to generate discussion and to hopefully gather the views of individuals from different backgrounds, so I chose to use focus groups.

There was initially a lot of interest from people with a learning disability and staff working in learning disability services, which led me to apply for an ethics amendment (see Table 4.3 below) to facilitate more than three focus groups. However, in the end I facilitated three focus groups in total, two in Bristol and one in Somerset, between 27.01.2023 and 08.03.2023 (I reflect on recruitment to focus groups in greater depth in Chapter 10). Whilst I planned for the first focus group to be facilitated in Bristol, the venue of the other two was decided in negotiation with participants. 12 individuals participated in total, three participants in each of the first two focus groups (FG1 and FG2), and six participants in FG3. None of the participants dropped out of the study. Participants were invited to bring a support person with them if they wished. Three support people (all staff members) attended focus groups; one support person in FG1 and two in FG3. The person's role was to support the participant, not to contribute to the focus group discussion, which was discussed as part of the consent process.

My approach to the design and facilitation was informed by my previous experience of co-facilitating a focus group with a similar participant group (Douglass *et al*. 2023). Each focus group followed the same structure and format. The first 30 minutes were used for introductions and informal conversations about the research to create a comfortable environment and to support decision-making about participation. In my previous experience of facilitating a focus group I had worked with a team of researchers, which meant that three of us were present during the focus group. This we reflected had helped us to ensure the consent process was person-centred. It also enabled us to have a distress protocol so that in the event of a participant becoming distressed, support could be provided. Following ethical approval, I therefore recruited two research assistants to support the focus groups. This meant we were able to give time to talk to participants on a one-to-one basis. We spent time talking through the Participant Information Sheet and privacy notice information with each participant in a way that was meaningful to them. Consent was sought at the end of this discussion for participation in the focus group and for providing some demographic information (which is presented in Chapter 8, Table 8.1). The next hour was used for the focus group discussion. I facilitated each focus group with flexibility to enable a person-centred approach. For example, breaks were incorporated at different points in each focus group in line with the preferences of those participating. A topic guide was used to structure the focus group discussion (Appendix Nine) with additional probing questions asked depending on the nature and content of discussion in each group. The last 30 minutes of each focus group were used for general discussions and to confirm consent (after participants were aware of what they had discussed).

4.8.5. Data Analysis

In this section I discuss data analysis, starting with my approach to transcription, and my decisions to use NVivo to organise data and to use Braun and Clarke's

(2013, 2018, 2022) approach to thematic analysis, which in their recent writing is called, ‘reflexive thematic analysis’ (Braun and Clarke, 2022, 2023).

Transcription

I chose to transcribe all the interview and focus group data myself. The transcription process was time-consuming, but valuable in enabling immersion in the data, which is an important aspect of familiarisation in line with the first phase of Braun and Clarke’s (2022) approach to thematic analysis. I was aware that transcription is not a value-neutral process, so I initially adapted Braun and Clarke’s (2013) transcription approach for consistency. During transcription, I anonymised data. Names were removed, and specific locations and services were generalised to prevent re-identification. For example, “St James’ Surgery” (fictious example) would be changed to “GP Surgery”, “Dr Bhurton” changed to “GP” or “health professional” depending on the context and possibility of re-identification. As a novice researcher, I was acutely mindful of my ethical responsibilities to ensure the anonymity of participants was protected and always erred on the side of caution when transcribing data. If participants disclosed any personal information such as where they worked or details of specific operations or healthcare procedures, where I considered there was a potential risk of re-identification due to a combination of factors in the account, this detail was not transcribed or was generalised to ensure anonymity. As part of the consent process, I informed all interview participants that I would not use their name and when I transcribed the interview, I would call them a letter followed by a number; in focus groups, participants all chose a pseudonym.

Use of computer assisted qualitative data analysis software

Once transcribed, anonymised transcripts were uploaded to NVivo 11 or NVivo 12 (depending on year data were collected) (QSR International). The use of Computer Assisted Qualitative Data Analysis Software (CAQDAS) in qualitative research is viewed cautiously by some writers (e.g., Brinkmann, 2018; Cope, 2014) with concerns about potential for the researcher to become detached from the data (Banner and Albarran, 2009). I decided to use NVivo after I had chosen to use thematic analysis, as a tool to support my data analysis process rather than influencing which method of data analysis I used. NVivo supported data analysis as I was able to keep all data in one place alongside reflexive 'memos' detailing why I had coded data in a particular way or had initially developed a theme, capturing my thinking at different stages in the research process. I was able to easily retrieve original data from transcripts when I was reviewing latent codes and themes, which I often did years after the initial analysis. It also meant I could share data alongside my coding and thinking about developing themes with my supervisory team at key stages of analysis, facilitating critical questioning and scrutiny, whilst supporting my reflexivity.

Reflexive thematic analysis

I chose to use Braun and Clarke's (2022; 2018; 2013) approach to thematic analysis as I wanted to inductively analyse what participants said to capture shared meanings in and across the data sets: interviews with adults with learning disabilities; interviews with family members; interview and survey responses from healthcare staff; and focus groups with adults with learning disabilities. This "theoretically flexible" method of thematic analysis appealed to me as it enabled me to take a broader view and interpretation of findings by considering them within a wider social context; therefore, congruent with a social constructionist epistemology and appropriate to answering my research questions. Braun and Clarke (2016) contend that themes are not in the data, waiting to be unearthed by the researcher, but instead are a way for the researcher, through a reflexive and interpretative process to create a unifying concept that links the data together. Themes are developed from the researcher's own position and interpretations and should "tell a story" about the phenomena of interest, which "contributes some or many facets to our understanding(s) of the issue" (Braun and Clarke, 2022, p.120).

When I was initially planning this research, I was guided by earlier writing by Braun and Clarke (for example, 2006 and 2013) to inform my approach. However, Braun and Clarke have developed their approach to thematic analysis whilst I have been working on my PhD. I have used more recent guidance as it has been published to inform the process I have taken. For example, in 2006, whilst Braun and Clarke discussed “searching for themes”, they now prefer **“**generating themes” in a move away from a view that themes are in the data, waiting to be found, but are instead generated through active engagement, subjectivity and influence from the researcher (Braun and Clarke, 2019, p.593).

Reflexive thematic analysis involves six (often iterative) phases, where all data is coded, and through an active process of interpretation by the researcher, themes are developed across data to find shared meaning (Braun and Clarke, 2022). Reflexivity is central to analysis, with the researcher actively considering how their own assumptions are informing and shaping the analytical process (Braun and Clarke, 2023). Whilst the six phases of data analysis are discussed below sequentially, phases overlapped and were continuously being reviewed up until the point of writing my thesis in February 2024.

Phase 1

Facilitating the interviews and focus groups and transcribing the data helped the first analysis phase of familiarisation as I felt immersed in the data. Following guidance by Braun and Clarke (2022; 2018) I repeatedly read transcripts, writing memos in NVivo to capture my initial thoughts about what was going on in each transcript. I also tried to articulate my assumptions at this stage as well as how my assumptions were potentially influencing and shaping my understanding of what participants had said. To facilitate this process, I found it helpful to answer Braun and Clarke’s (2013) seven questions for each interview transcript, which I documented as memos in NVivo (examples are included in Appendix Ten).

Phase 2

The second phase of analysis involves the identification of codes, whereby I looked at each transcript separately and coded anything in the transcript that seemed interesting (Braun and Clarke, 2018). At this stage, as suggested by Braun and Clarke (2013), I tried to look at all data equally and coded everything of possible significance. Braun and Clarke (2022; 2018) advocate that researchers should aim to code all data initially at a semantic level, defined as a code that describes or represents the data's surface level of meaning. I explain in subsequent chapters the semantic codes I identified for each data set. (Examples of excerpts of coded transcripts are in Appendix Eleven). For all data, I undertook several rounds of coding. Coding often spanned several weeks or months to code anything that appeared significant in each transcript to help me answer my research questions.

Phase 3

Phase 3 involves the generation of initial themes. Braun and Clarke (2022) advise that this is where the codes should be organised into over-arching themes, whereby the researcher joins ideas from individual transcripts with one central organising concept. The central concept should tell a story "about particular patterns of shared meaning across the dataset" (Braun and Clarke, 2019, p.593). When working through this phase, I considered the relationship between individual codes and continually looked back at the original transcripts to ensure that developing themes aligned with the original data. Braun and Clarke (2018) are critical of researchers adopting this approach to reflexive thematic analysis and concluding analysis with the identification of themes, informed only by semantic codes. Instead, they advocate active interpretation of what the data means at a deeper level. This is referred to as the identification of 'latent' codes, which instead represent interpretative meaning (Braun and Clarke, 2022). It is these latent codes which eventually inform the identification of themes, so an important part of the analysis is the interpretative process in moving from semantic to latent codes. This is where data were analysed and interpreted through a social constructionist lens, whereby consideration was given to the wider social, cultural and historical context. Examples of semantic codes, latent codes and developed themes are described for each interview group and for the focus groups in subsequent chapters. This phase was helped by regular conversations with one of my supervisors (SD) and my advisory group.

Phase 4

Phase 4 requires the researcher to review the potential themes. I found it helpful to ask the following questions as suggested by Braun and Clarke (2018) at this stage:

- Is this a theme?
- Is there a central organising concept?
- What is the quality of this theme?
- What are the boundaries of this theme?
- Are there enough meaningful data to support this theme?
- Are the data too diverse / wide-ranging?
- Do themes work in relation to a) coded extracts and b) entire datasets?

As advocated by Braun and Clarke (2022) I continued to revisit and review potential themes in each dataset up until I started writing up my thesis in February 2024. I was mindful that the themes I developed should connect “ideas and concepts” to answer my research questions (Connelly and Peltzer, 2016, p.53). I was trying to link component parts to make a “meaningful whole” (DeSantis and Ugarriza, 2000, p.362), essentially to capture the “shared meaning” (Braun and Clarke, 2023, p.700) to develop and advance understanding of the phenomena (Connelly and Peltzer, 2016). Illustrations from my data will be illustrated in Chapters 5-8 where analysis of the individual data sets are discussed, as well as in Chapter 10 where I reflect on the overall process I adopted throughout my research.

Phase 5 and phase 6

Phase 5 concerns the naming of themes for which Braun and Clarke (2018) suggest writing a description at the start of each theme. This again was an iterative process, which I continuously reviewed up until the point of writing my thesis. Finally, phase 6 is writing up the findings. I approached collection and analysis of interview and focus group data, as four separate, independent data sets. The findings are therefore discussed in the subsequent chapters as follows:

Chapter 5: Interview data from individuals with a learning disability
Chapter 6: Interview data from family members
Chapter 7: Interview data from healthcare staff and pilot survey data from learning disability student nurses
Chapter 8: Focus group data

To enable conclusions and recommendations I discuss the findings from all four data sets collectively in Chapter 9.

4.8.6 Ethics

To answer the research questions, data collection, as discussed above, was separated into smaller studies, with the findings from one informing the specific approaches and/or questions to be asked in the next. Therefore, applications to the University of the West of England Faculty of Health and Applied Sciences Research Ethics committee for ethical approval were completed and submitted separately for each study as identified in Table 4.3.

Table 4.3. Ethical approval details

Study description	Ethical approval details including amendments
Interviews with adults with learning disabilities and family members	Ethical approval was granted [UWE REC REF No: HAS.19.05.175] on 24.06.2019 (Appendix Twelve). As a result of Covid-19 restrictions, amendment to permit remote interviews online for family member interviews was applied for on 02.10.2020 and granted on 08.10.2020 (Appendix Thirteen).
Qualitative survey	Ethical approval was granted [UWE REC REF No: HAS.19.11.061] on 12.12.2019 (Appendix Fourteen).
Interviews with healthcare staff	Ethical approval was granted [UWE REC REF No: HAS.21.01.087] on 26.05.2021 (Appendix Fifteen). An amendment to increase the number and role of participants was applied for on 21.06.2021 and granted on 22.06.2021 (Appendix Sixteen). A later amendment to interview one more member of staff was applied for on 28.07.2023 and granted on 08.08.2023 (Appendix Seventeen).
Focus groups with adults with learning disabilities	Ethical approval was granted [UWE REC REF No: HAS.22.11.036] on 03.01.2023 (Appendix Eighteen). A later amendment to facilitate more focus groups was applied for and granted on 26.01.2023 (Appendix Nineteen).

4.8.6.1. Ethical approaches for recruitment and developing accessible materials

In accordance with the *Equality* Act 2010, service providers are required to make ‘reasonable adjustments’ for people with disabilities to have access to services and information. For all staff working within the NHS and adult social care, there is an additional legal duty to follow the Information Standard (NHS England, 2017) to ensure information is ‘accessible’, which is defined as:

> “Information which is able to be read or received and understood by the individual or group for which it is intended” (p.6).

The provision of accessible information is also recognised as an integral aspect of making research accessible to individuals who have a learning disability (Walmsely, 2004), and is stipulated in the ‘consensus statement on how to conduct inclusive health research’ by Frankena *et al.* (2019). To support prospective participants to make informed decisions about whether to participate in my research, it was important to ensure all documents disseminated as part of the recruitment process, as well as documents used for seeking consent, were accessible. Reasonable adjustments were made to the recruitment, consent processes and interviews/focus groups to support decision-making about participation. The following, which will be discussed in more detail below, were developed in partnership with my advisory group:

- ‘Easy read’ research information leaflet
- accessible consent form
- accessible privacy notice information
- adaptable topic guide questions so that questions could be asked in a way that met the individual participant’s needs
- Pictorial ‘healthcare’ and ‘feelings’ prompt cards to support interview discussions

‘Easy read’ research information leaflet

An accessible research information leaflet (see Appendix Five) was co-developed with my advisory group in ‘easy read’. ‘Easy read’ involves written information in short sentences accompanied with images to illustrate text (NHS England, 2017), and is often advocated for use by and for people with a learning disability (Leeds and York Partnership, 2021; Chinn, 2020). Whilst some small-scale studies have suggested limitations with ‘easy read’ (Douglass *et al.* 2023*;* Buell *et al.* 2020;

Hurtado, Jones and Burnston, 2014), Chinn (2020), in a study exploring how ‘easy read’ health information was used in healthcare practice, suggests that ‘easy read’ can both aid communication and support understanding if consideration is given to how the information is used, and in what context. In discussions with my advisory group, ‘easy read’ was considered to be a good way of initially presenting the research information, whilst being mindful that prospective participants were also likely to need somebody to discuss the information with them before making a decision about participation.

The ‘easy read’ research information leaflet was developed to provide information to prospective participants, which could be discussed with a support worker, friend or family member, or with me as part of the recruitment and consent process. It was designed and formatted in accordance with best practice guidelines (NHS England, 2017; Mencap, 2002) with images on the left-hand side, and minimal text presented in short sentences (Tahoma, size-16 font) on the right. I initially drafted text, which was then discussed and adapted with my advisory group.
Images used in the leaflet were selected as part of an advisory group meeting on 06.06.2019 from ‘Easy on the I’ (Leeds and York Partnership NHS, 2021). ‘Easy on the I’ is an online free database containing images, which have been co-developed with people who have a learning disability in line with the Accessible Information Standard (NHS England, 2017). I also included a recent photograph of myself on the research information leaflet, so that prospective participants would know what I looked like.

Consent form

The language used in the consent forms for interviews and focus groups with people with a learning disability were modified slightly in discussion with my advisory group with the aim of making it clearer for prospective participants (Appendix Twenty). The consent form was disseminated at the time the interview or focus group were arranged to be completed at the beginning of the interview or focus group.

Accessible privacy notice

To comply with GDPR requirements, a Privacy Notice must be given to all research participants before data can be collected (University of the West of England (UWE), 2019). At the time the resources were being developed, UWE's privacy notice was not in a format accessible to prospective participants with a learning disability. Consequently, it was questionable as to if it would support informed decision-making as prospective participants were unlikely to have been able to understand the content. As well as being in breach of the *Equality Act* 2010, it would have been tokenistic to include the privacy notice without making it more accessible. Adapting the privacy notice was challenging as I did not have ownership over the content. I therefore sought guidance from the Data Protection and Records Manager at UWE to discuss and agree how I could communicate the core information in a more accessible way so that it was lawful but also meaningful to prospective participants. Consequently, on 10.07.2019, following conversation with one of my supervisors and the Data Protection and Records Manager, it was agreed that six key points (Table 4.4) could be discussed with participants prior to interviews or focus groups commencing as part of the consent process.

Table 4.4. Making the privacy notice information accessible

The following points were discussed with each participant before the interview commenced:

1. UWE is the 'data controller', e.g. UWE is responsible for looking after your data ('data' means your information – so, everything you tell me on the consent form and everything you tell me as part of the interview). UWE has to stick to the rules / laws to look after your information.
2. Why we are collecting data (i.e. purpose of research: this involved reading through the research information leaflet, which was repeated at the beginning of each interview).
3. Lawful basis of processing data (e.g. we will only collect and use your data with your permission – if you say 'yes'. Saying 'yes' is also called 'giving your consent'). You can change your mind.
4. Sharing of data (who outside of UWE is personal data shared with) – e.g., our conversation will be recorded, and I will write down everything that we have said today, but when I do this, I will not write down any of our names. What I write down is called a "transcript" – this is a written version of our conversation but with nobody's name in it. The transcript will be shared with my 3 teachers – Sally Dowling, Julie Mytton and Andy Gibson.
5. How long is data kept? (The data will be kept for 10 years)
6. Participants rights and how to exercise them (If you change your mind, you need to contact me, Emma Douglass – telephone number and e-mail address given on the research information leaflet).

Without making these adjustments to the privacy notice, this could have been a tokenistic activity as opposed to an opportunity for participants to consider their rights and make an informed decision about participation in the study. I have not found any literature about how other researchers are making privacy notices accessible to people with learning disabilities.

4.8.6.2. Ethical approaches for data collection

Consent

Seeking informed consent from prospective participants with a learning disability was undertaken as a process (Carey and Griffiths, 2017), with time built-in so that I could spend time building a rapport with prospective participants (Carey and Griffiths, 2017; Elmir *et al.* 2011; Cameron and Murphy, 2007; Arksey and Knight, 1999) before seeking consent or collecting data. Cameron and Murphy (2007) emphasise the importance of researchers ensuring prospective participants have time to make an informed decision and spending time to ensure individuals understand what they are consenting to. This involved spending time with each participant before an interview or focus group was arranged in order to talk about the study and to answer prospective participants' questions. It was important that prospective participants had the opportunity to discuss the study to support understanding and decision-making.

For the interviews, I met six of the participants on two occasions before an interview was arranged. These meetings were informal, and all were arranged as part of the pre-group informal sessions, providing an opportunity to discuss the study as well as for us to begin to get to know each other. It also enabled the participant to decide where and when they wanted the interview to take place. One participant was not recruited via pre-group sessions. This participant contacted me by telephone indicating interest. A meeting was arranged with them prior to an interview date and time being arranged as they wanted to see what I looked like (the photograph on the research information leaflet was reported to make me look “scary”, however on meeting face-to-face, the participant said that I did not look so scary in real life and they were therefore happy to be interviewed). In addition to one face-to-face meeting, this participant phoned me on several occasions between indicating an interest in participating and the interview date.

Telephone calls were all to ask questions and to seek clarification on aspects of the study.

For focus groups, a person-centred approach to discussing the research and talking through the privacy notice was enabled with the support of two research assistants (as discussed above).

Pre-interview or focus group discussions, consent was sought at two specific time-points:

1. Following discussions about the study at the point the interview or focus group was arranged; and
2. At the beginning of each interview or focus group

Additionally, confirmation of consent was sought at the end of each interview or focus group. It was possible that participants might not have been part of a research interview or focus group before, and therefore might not have known what to expect. Consent was therefore confirmed at the end of interviews and focus groups to ensure ‘informed consent’, whereby the participants knew what they had said and could make a decision as to whether they wanted information to be included in the study. Consent was sought and given by all participants who were interviewed and who participated in the focus groups.

Topic Guide

Strnadova *et al.* (2014) discussed the development of an inclusive research team with four women with a learning disability and four academic researchers in Australia, identifying that involvement in writing the interview protocol was particularly useful. The authors’ noted that the women with learning disabilities were able to offer suggestions “based on their lived experience, asking questions which had not occurred to the academic researchers” (p.191). Draft topic guide questions for my study were initially informed by the literature review, before being discussed with the advisory group on 06.06.2019. As a result of the advisory group feedback, questions were simplified, and some language altered to make questions more accessible (Appendix Twenty-one).

Pictorial prompt cards – used in interviews

Nind and Vinha (2016) suggest the use of visual devices and resources to guide interview discussions as a way of enabling meaningful participation. As an example, Hollomotz (2018) and Bigby, Frawley and Ramcharan (2014) used a pictorial topic guide to aid participation during interviews. This was discussed with my advisory group but as recruitment was from a diverse population with regards to ability, developing a pictorial topic guide that would be meaningful for each individual participant was not considered to be viable. Instead, I drew on my skills and experience of working with people with learning disabilities to adapt my communication with regards to how I asked and responded to questions.

In line with the aim of the study, I wanted participants in interviews to select a health decision that was important and significant to them. The advisory group felt that it might be challenging for participants to identify a health decision to focus on, and so we decided to incorporate health image cards as part of the interview. These cards were approximately 8cm by 10cm, printed in colour, depicting a wide range of possible health decisions including having a health check; blood test; colonoscopy; cervical screening; going to the dentist; healthy eating; changing medication; going into hospital; and having an anaesthetic (Appendix Twenty-two). Additionally, "feelings" cards, representing emotions such as happy, sad, angry, frustrated, surprised, pride, were used. The prompt cards were used as part of the interview to support the participant to decide what health decision they wanted to discuss, as well as how they had felt at different stages of the decision-making process. Images from 'Easy on the I' were used for all prompt cards.

Distress Protocol

A distress protocol identifies what the researcher should do if a participant becomes distressed within an interview or focus group, in order that the participant receives appropriate support. The distress protocol used was amended from the protocol developed by Davidson *et al.* (2018). I shared this with my advisory group on 06.06.2019 when some small refinements were made following discussions. If a participant were to become distressed within an interview, the interview would be paused. The participant would then have the opportunity to discuss their concern before deciding whether to resume or end the interview. The distress protocol was initially developed for the semi-structured interviews and was amended later to be used in the focus groups (Appendix Twenty-three).

4.9. Summary

This chapter has discussed the philosophical position, the overall design and methodology and methods used for this research. Social constructionism and critical realism underpin the research design, which is guided by accessible research principles and methods, informing my approach to recruitment, data collection and data analysis. Discussions with my advisory group have informed the approach used for recruitment and data collection, as well as influencing and shaping data analysis. In the following chapters 5-8, the findings of the data collected from interviews with adults who have a learning disability (chapter 5); interviews with family members (chapter 6); interviews with healthcare staff including the pilot survey data from student nurses (chapter 7); and focus groups with adults with learning disabilities (chapter 8) will be presented and discussed.

Chapter 5 - Perspectives of adults who have a learning disability

"They cannot tell me what to do"

5.1 Introduction

Chapter 4 discussed how adults with learning disabilities were recruited to participate in semi-structured interviews. This chapter firstly presents information about the participants, all of whom talked to me about an experience of making a health decision. Detail about the reflexive thematic analysis process adopted to answer my research questions is discussed, before the themes developed from the data are presented.

5.2. Participants

Seven adults (three men, four women) aged between 30 and 56 participated in face-to-face interviews. All participants lived in Bristol; five lived with family and two in supported living. Six participants identified as White British; one participant identified as being "Mixed Race". All communicated verbally, were able to make an informed decision to participate, choosing to be interviewed without a support person with them. Participants chose to talk about one-off, major health decisions such as whether to have surgery, as well as health lifestyle decisions, involving long-term behaviour change. Health decisions discussed by participants included: change of contraceptive; having surgery or a medical device fitted; having an annual health check; losing weight and eating a healthier diet. Interview participants (P) are identified as P1-P7 when quotations are used below.

5.3. Data analysis

Following transcription and familiarisation of the data (as discussed in Chapter 4), I identified 84 initial (semantic) codes across the seven transcripts, with descriptive code titles, such as: “facilitators of supporting decision-making”; “difference of opinion”: “learning through attendance at social group”; “learning through attendance at a college course”; “practical support from family member”; “having a choice”; “not having a choice”, “favoured attributes of support person”. At the end of this phase, I met with one of my supervisors, SD, to critically discuss my initial coding. We discussed where there were commonalties between participants’ experiences as well as where there was variance. For example, whereas most data indicated that individuals felt they had the opportunity to make their own decision with support, one participant felt they had not had the opportunity to make their own decision as a result of what they considered was inadequate support.

After meeting with SD, I undertook two further "coding sweeps". This was to ensure that all data relevant to a code were collated, each data item had been carefully considered, and that code names were illustrative of what the data represented as well as answering my research questions, which focused on how individuals with learning disabilities were supported to make health decisions and the factors that either facilitated or hindered the process. This took time and was disrupted by the Covid-19 pandemic and my personal circumstances, which resulted in my PhD being suspended between March and September 2020.

Initial codes often reflected the question I had asked in an interview (e.g., “facilitators of supporting decision-making” was similar to a question on the interview topic guide). As discussed in Chapter 4, Braun and Clarke (2013) advocate the importance of moving semantic codes to latent codes, which provide an interpretative meaning of the data. Using a social constructionist lens, initial data codes; “learning disability can be a hidden disability”, “learning disability as being different”, “people with a learning disability not being valued” and “emotional pain caused by bullying” were at this point, collectively organised as a latent code; “disability as part of identity”, which I recognised was shaped by my personal experiences (I reflect on this in Chapter 10). The semantic codes, “having a goal” and “making decisions”, were grouped together to generate the latent code “demonstrated agency/autonomy”; and the codes, “MCA perceived as punishment”, “MCA awareness”, and “not having a choice” were collectively “recognition of rights” (Table 5.1). The third stage of analysis involves the generation of initial themes (Braun and Clarke, 2022). “Demonstrated agency/autonomy” was initially a central theme with “recognition of rights” and “disability as part of identity” as sub-themes. I created visual concept maps in PowerPoint to help illustrate and represent the relationship between latent codes and developing themes to help me make sense of the relationships between latent codes and developing themes (examples are in Appendix Twenty-four). I also continued to use memos in NVivo to capture my reflections and developing ideas to help make sense of how I was shaping data analysis (which I discuss further in Chapter 10). At this stage I had five potential themes, which after further development and review (phase five of Braun and Clarke’s 2022 approach), ultimately resulted in four “refined, defined and named” themes (p.108), which are discussed next.

Table 5.1. Theme development examples

Examples of semantic codes	**Examples of latent codes linking semantic codes**	**Themes developed**
Having a choice Having a goal Making decisions Being determined	Demonstrated agency / Demonstrated autonomy	Understanding decision-making ‘rights’ can support health decision-making autonomy
MCA perceived as punishment MCA awareness Not having a choice People can’t tell me what to do	Recognition of decision-making ‘rights’	
Learning disability can be a hidden disability Learning disability as being different People with a learning disability not being valued Emotional pain caused by bullying	Disability as part of identity	Disability identity impacts health decision-making experiences
Learning through attendance at social group Learning through attendance at a college course Watching DVD of procedure Easy read leaflet was helpful	Being informed Accessible Information	We need opportunities to understand the decision that needs to be made
Difference of opinion Practical support from family member Favoured attributes of support person Feeling lost Talk it through with Mum or Dad/Sibling/God/Friend	Matrix of support	Informal validation helps us to make our own health decision

5.4 Findings

Four inter-related themes were developed from the data in response to my research questions: 1: Understanding decision-making ‘rights’ can support health decision-making autonomy 2: Disability identity impacts health decision-making experiences; 3: We need opportunities to understand the decision that needs to be made; and 4: Informal validation helps us to make our own health decision.

5.4.1. Theme 1: Understanding decision-making “rights” can support health decision-making autonomy - "*They cannot tell me what to do*"

This theme captures that participants were aware and understood their ‘rights’ in relation to decision-making, referring to the MCA when discussing their experiences. Participants spoke about their right to know information; to decide what happened to their body; and the importance of individuals with a learning disability having a ‘voice’.

All but one participant demonstrated autonomy (appearing to act in accordance to one’s own priorities and principles) with some participants referring to the MCA in relation to the health decision they were talking to me about. Decisions were often made with support from others, however crucially appeared to be ultimately the decision of the participant themselves. Self-awareness appeared to support health decision-making autonomy. One participant discussed how they decided what information to disclose on a health questionnaire prior to attending an annual health check. P4 indicates at the beginning of the interview that they drink alcohol, however, later in the interview reflects that they might not always complete the question about alcohol consumption accurately,

> Int: So (the health questionnaire) comes to your house from the surgery (…) Does it ask you anything else?
>
> P4: Do I drink (…) I used to try to put it down properly but [laughs] it’s hard to... hard to say ...

Another participant reflected that they were inactive: “I like sitting at home doing nothing” (P5), which appeared to contribute to their decision to lose weight. Setting goals also appeared to be beneficial. The following participant reflected that being determined to achieve their goals helped them to make their own health decisions, whilst also recognising they sometimes required support,

> “Uh... well I’ve got this sort of determination within me, if I want to set myself upon a certain goal, I aim for it (…) But with support in the background if I need it” (P7).

Participants’ autonomy in making the health decision appeared to have been supported by a recognition of their rights. In the following excerpt, the participant felt that they should have been informed about the healthcare intervention in advance, feeling that they had been made to have the health intervention against their will,

> “…and she was like ‘no, it is for your own good’, and I went ‘how is it for my own good, doing something against my will when I don’t know about it?’” (P2)

Another participant spoke more positively about their experiences, stating that healthcare professionals are only able to give advice,

> “…when I have my health check to make sure it’s alright. They can advise me, and that's all that they can do. They cannot tell me what to do.” (P4)

Some participants also said that whilst many people with a learning disability could make their own decisions, some people with more “complex needs (or) extreme disabilities” (P7) might not be able to. Participants were aware that they could make their own decisions, identifying that they could make an unwise decision, whilst recognising that they might need support to understand the potential consequences. One participant was particularly knowledgeable about the MCA, which they referred to at several points during the interview. When asked, P6 explained that they had learnt about the MCA via a house meeting where they lived, whereby they had looked at "…easy read all about the Mental Capacity Act" which they said they had found helpful.

Whilst participants mentioned the MCA, it was not always referred to in a neutral way. One participant felt strongly that they were not given the opportunity to make their own decision. This participant perceived that the healthcare staff had "used the Mental Capacity Act on [them]", taking away their choices and making them "look thick" (P2) rather than as a mechanism to support them to make their own decision. This individual became emotional at points during the interview saying that they felt angry and frustrated. In contrast, when participants perceived their rights to have been upheld, having been supported to make their own decisions, feelings and outcomes were likely to have been positive,

> "It makes me happy, and also it makes me feel really good about myself" (P6).

5.4.2. Theme 2: Disability identity impacts health decision-making experiences - "*People like me, people with learning difficulties"*

This theme captures that having a learning disability appeared to be a core part of the identity of participants, reflected in how individuals spoke or referred to themselves and others throughout the interview. Participants spoke in relation to how having a learning disability affected health decision-making, as well as how it impacted and shaped their wider life experiences.

Generally, participants referred to having a learning disability in a neutral, often pragmatic way. For example, P6 talked about some people with learning disabilities being able to make their own choices, whilst saying that others might need more support,

> "…it is 'cos some people with special needs have mental capacity act and make own choices about what they do and some people lack mental capacity act, they have, someone ... decision in their own best interests." (P6)

Whilst speaking about seeking and receiving support from a friend in relation to a health decision that they had to make, P5 referred to themselves and their friend as having the same “condition”. This was considered helpful as it enabled them to understand how each other felt, promoting trust,

> “I’ve got [learning disability] right, so um meeting another person with the condition, [friend] knows how I feel, and I know how [they] feel, and I trust [them] a lot.” (P5)

One participant spoke about the difference between a visible and hidden disability, considering their learning disability to be a hidden disability. P7 recognised that having a learning disability was part of who they were, whilst referring to being “different”,

> “Some of these emotions are part of my hidden disability. […] A hidden disability is when you have a disability which is not physical but hidden so you look just the same as everybody else but slightly different and I can’t help the way I was born different.” (P7)

Whilst a learning disability was often spoken about neutrally, some participants reflected that at times having a learning disability might have negative implications on how health professionals behaved towards them, therefore impacting decision-making opportunities as well as experiences. In the following excerpt, P7 is explaining that sometimes healthcare staff have spoken to their carer or parent rather than them,

> “Yes, because too often, people like me, people with learning difficulties have... had their … carer been... had themselves been talked over the doctor talks to their carer instead of the patient, that’s uh.... the person with the learning difficulty.” (P7)

One participant reflected on a doctor suggesting to their mum when they were young that their life would be restricted. They recognised that their mother had disregarded the doctor’s perspective whilst also reflecting that the doctor was wrong,

> "And some doctors can be not nice. One said to my Mum that I wouldn't go out to … out … out places... I would always have to stay in and she said, 'you're lovey doving my [child]...' and like... the doctor got that wrong." (P4)

Having a learning disability could result in being treated differently, with health professionals not explaining health decisions to support informed decision-making. One participant associated not having the opportunity to make their own health decision and therefore not having control of what happened to their body with having a learning disability,

> "Like useless... like powerless... like it's my body but I've got no control over what happens to it. (…) Why... why is it just because I've got a learning disability why haven't I got the right to know? It's my body." (P2)

Regardless of whether individuals referred to having a learning disability in a neutral way or in association with being treated differently, having a learning disability appeared to be a core part of the identity of most participants, which impacted on both their experiences and opportunities to make health decisions.

5.4.3. Theme 3: We need opportunities to understand the decision that needs to be made - *"…if I don't understand it, it's not going to be easy*"

What was apparent from all participants was that they needed and wanted opportunities to understand the health decision that they needed to make. The methods to support individuals to understand the decision were varied and diverse. There appeared to be a distinction between one-off, potentially irreversible decisions such as having an operation, and 'smaller' or longer-term decisions that were made more frequently such as whether to attend routine health appointments or to make lifestyle changes, requiring a longer-term behaviour change.

All participants said that they needed to be informed about the decision so that they could understand what it entailed. Some individuals reflected that they sometimes did not understand health information. When participants spoke confidently about the decision that they made, they were more likely to be able to explain the decision in the interview, providing details and demonstrating that they understood the possible consequences. In most cases, understanding had been facilitated, in part, by discussions with different (and often more than one) healthcare staff:

> "Well I went into hospital for a check-up and they said I needed an operation and so went to see a nurse and she explained all about what would happen in the operation and then at another stage we saw the surgeon that was going to do my operation." (P1)

For one-off decisions, healthcare professionals were likely to be involved in the provision of information. Doctors and nurses were often referred to by participants, with discussions appearing to facilitate the participant's understanding, supporting their ability to make an informed decision. When healthcare professionals had discussed the decision, participants also found this to be reassuring, helping them to trust the person,

> "I trust him a hell of a lot more … [lots of background noise] and like he... like he hasn't lied saying yeah it's gonna work, he's like gave me like in a way worser odds to prepare me." (P2)

For decisions related to routine screening, healthy eating and weight loss, information supporting decision-making was more likely to stem from structured activities, such as college courses or social group activities. Active participation and social learning appeared to have been significant in the learning of information about health, which participants were able to draw on sometimes years after the actual event or activity. Others had acquired information through life experiences,

> Int: (…) How did you know that it's healthy to lose weight?
>
> P4: It's helpful and it's healthy
>
> Int: Did anyone tell you that [name]?
>
> P4: No, I worked it out myself.

P2 wanted to know more about the healthcare procedure that they had been told they needed. They actively sought information from the Internet explaining to me that not understanding the procedure caused them anxiety and distress. P2 talked about looking for additional information on the Internet (for example health websites and Facebook) when they felt information from healthcare professionals was not forthcoming, demonstrating autonomy in finding information to inform health decision-making. This participant recognised that this might not be the best place to find information saying, "…you can also find scary stuff…" (P2).

In summary, having opportunities to understand the health decision was important for all participants and a core part of supporting decision-making.

5.4.4. Theme 4: Informal validation helps us to make our own health decisions - *"Just being there, really"*

Informal support appeared to be significant in validating decision-making, by enabling participants to process and work through different options and outcomes before arriving at a decision. Individuals were more likely to speak positively about their experiences of making a health decision, as well as the outcomes of the decisions they had made if they had an informal support person or social network to discuss it with. Those without an informal support network almost appeared to get lost in the decision-making process. Informal support was distinct from formal support and regarded as being from non-paid supporters; participants spoke about Mums, Dads, siblings, Aunts, Nans, and friends. One participant also spoke about God. Often, informal support was part of a wider formal network,

> "But with support in the background if I need it. […] Well if things go wrong or if I get into problems or any difficulty or if it's something that I'm unsure about […] I know I've got [name of person at social group] and my mum and I've got the staff at [place name]." (P7).

Those who appeared better able to navigate formal support mechanisms often had strong informal support. For example, the following individual accessed information about the health decision, which was whether to have a major operation, from a variety of healthcare professionals including a doctor, surgeon, hospital nurse and two community learning disability nurses. In-between meeting with these professionals’, informal support appeared to be significant in helping P1 make their own decision,

> Int: so you had (nurse) who you knew already, and she had helped you before you said?
>
> P1: Yeah
>
> Int: and then you spoke to your mum?
>
> P1: Yeah… and my Dad
>
> Int: and your Dad. Ummm, so speaking to those three people… that was helpful?
>
> P1: Yeah and I also talked to … (second nurse) who is ummm… he is a nurse at (place name) and umm he helped me also
>
> Int: How did he help?
>
> P1: Umm… he came to my house um and made sure I… if I understood what was going on.

Several participants spoke about their Mum being a source of emotional or practical support, as well as a source of information,

> “Um yes [knew there was a tablet] because my Mum told me about [tablet], they’re really good to stop become, reduce periods.” (P6)

Family members and friends appeared to offer "softer", often emotional support, which could be difficult to articulate, but appeared to make a significant difference in supporting individuals to make a health decision,

> “Just being there, really” (P4).

Informal supporters offered opportunities for further discussion, clarification and reassurance. One participant appears to be talking about ‘making sense’ of decisions by talking it through, “explaining” it to their Mum, who then explains it back to them (P3). Participants were self-aware, reflecting on the input of their informal supporter,

> Int: and was it your decision to take that medication?
>
> P4: yeah and a bit of mum, but it was a little bit of mum as well but it was right to go on it.

Informal support appeared to enable participants to navigate the challenges and difficulties of formal mechanisms of support to help them make their own health decisions.

5.5. Summary

This study is the first that I am aware of, specifically exploring supporting health decision-making with adults with a learning disability in England. Four central aspects, discussed as themes above, appear to be significant aspects in either facilitating or hindering supporting adults with learning disabilities to make their own health decisions (as represented as parts of a jigsaw in fig 5.1 below): Disability-identity; Being informed; Awareness of decision-making ‘rights’ and Informal validation from a trusted person.

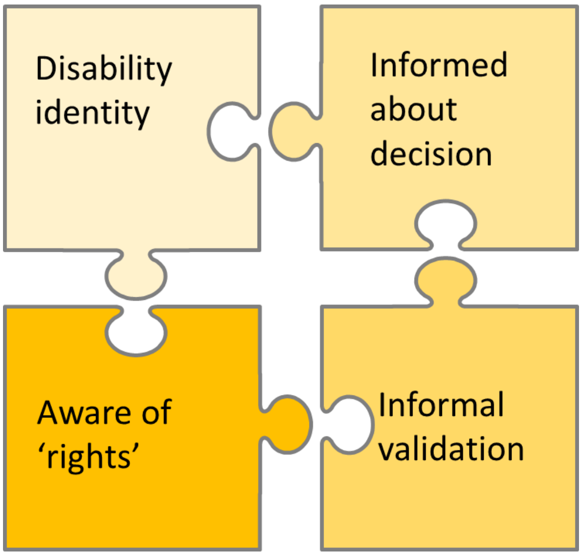

Fig. 5.1. Four central aspects of supporting decision-making from interviews with adults who have a learning disability

These four themes reflect the experiences of adults who have a mild learning disability, who were able to participate in a semi-structured interview. In Chapter 6, the experiences of families who have a loved one with a more severe or profound learning disability or a learning disability with complex needs will be discussed.

Chapter 6: Family members experiences and perspectives of supporting health decision-making

"…we each have expertise that is needed to be brought to the table to get this good outcome"

6.1 Introduction

Chapter 5 discussed the perspectives of seven adults with mild learning disabilities about their experience of being supported to make a health decision. This chapter moves on to consider the perspectives of family members. Family members were invited to participate to understand the experiences of supporting health decision-making with people who have a more severe or profound learning disability or a learning disability with more complex needs. Demographic information about the participants is presented to provide context before the data analysis process and findings are discussed.

6.2. Participants

A total of six family members were interviewed in five interviews: one dyad (a mother and a father) and four individual interviews (three mothers and one sibling). Three interviews were face-to-face pre Covid (two individual and one dyad) and two interviews were facilitated online due to Covid restrictions.

Five individuals with a learning disability were discussed (four sons and one brother), aged between 20 and late 40s. The individuals all had a learning disability and complex health and/or sensory needs, living in bespoke, specialist accommodation with 24-hour staff support. All individuals were identified by family members as having limited capacity to make their own health decisions, requiring ongoing support from others. All family members who participated in interviews had a good understanding of the MCA, referring to their right to contribute to supporting decision-making.

6.3. Data analysis

Following a process of familiarisation with the transcripts, initial coding identified 93 codes. I undertook two further ‘coding sweeps’, resulting in 116 semantic codes. I then looked at data with a social constructionist lens to develop latent codes. Before progressing to the generation of initial themes I met with my supervisor, SD, to reflect on the process, which was useful in considering where there was overlap across codes. This led me to amalgamate codes with a similar meaning. For example, "Family members need knowledge"; "Information (to support decision-making) not being shared with family members"; "Is consent informed?" were grouped together to generate the latent code “Potential conflict – differences of opinion”. “Family members have clinical overview nobody else has”; “Family member as advocate”; “Knowing the individual” were grouped collectively as “Family member expertise” (Table 6.1).

Phase 4 involved the development and review of potential themes. As well as a second discussion with my supervisor and my advisory group, I kept memos in NVivo reflecting on how I was potentially influencing the data as both a Registered Learning Disabilities Nurse and from the perspective as a family member of an individual with a learning disability (I reflect on some examples in Chapter 10). After a process of reflection and interrogation of data, themes were named (phase 5) and written up (phase 6) as will be discussed below.

Table 6.1. Theme development examples

Examples of semantic codes	**Examples of latent codes linking semantic codes**	**Themes developed**
Lack of trust MCA not being followed / Poor practice Family carers more likely to honor MCA principles Is consent informed? Support staff not able to provide reliable health information	Staff lack knowledge / understanding of the Act Support staff lack knowledge / understanding of health issues	Staff sometimes lack knowledge and understanding to support health decision-making
Wanting an ordinary life for loved one Family members have clinical overview nobody else has Family member as advocate Family know the individual Family have 'know how'	Family member expertise Emotionally attached	Listening to family expertise supports health decision-making
Can only share knowledge if you are in the loop Fight to get things done Family members need knowledge Information not being shared with family members Need for honesty and/or transparency Partnership/collaborative working with profs	Potential conflict – differences of opinion Need to recognise / value differences of opinion	Work with us, not against us
Flexibility required People with learning disabilities not being treated well Pleased with outcome, but decision-making was frustrating Waiting lists are long Decision-making process takes a long time	It takes time: "It just drags on"	Applying the MCA can lead to further disadvantage

6.4. Findings

Healthcare decisions discussed in the interviews included: starting new and/or changing medication; having annual health checks or GP appointments; having general anaesthetic for investigations or treatment; and investigating the presentation of ongoing, atypical epileptic seizures. Four inter-related themes were developed through the process of analysis: 1. Staff sometimes lack knowledge and understanding to support health decision-making; 2. Listening to family expertise supports health decision-making; 3. Work with us, not against us; and 4. Applying the MCA can lead to further disadvantage.

6.4.1. Theme 1: Staff sometimes lack knowledge and understanding to support health decision-making - "*support workers who are not very savvy*"

This theme encapsulates that all but one participant felt that healthcare staff were not always best placed to support health decision-making with individuals who had a severe or profound learning disability or an individual with a learning disability and complex needs. Examples applied equally to support staff (unregistered care staff who were often working in residential services without a formal health qualification or registration) as well as clinical health staff (such as doctors and nurses). This was due to staff being perceived as often lacking knowledge and understanding about either the medical or health issue(s) and/or the MCA. Participants discussed several incidents where they considered healthcare staff had not adequately applied decision-making legislation in their practice, despite being aware that healthcare staff had attended MCA training (saying it was a mandatory requirement). In the excerpt below, F6 reflects on an occasion when they believe that their loved one who has a learning disability (pseudonym Fred in transcript below) has not given consent to a new medication, but where the psychiatrist's letter records that consent has been given,

> “I would be concerned about the level of consent because when the.. when the psychiatrist originally talks about it, he talks about it in an interview and it’s all very quick, and he says, “You want to do that Fred?” and Fred says “Yeah” as Fred says “yes” to most things that the doctor says. Um, you never really know how much he [Fred] understands. And then in the letter it always says that he’s given consent.” (F6)

Some participants felt that the responsibility for supporting health decision-making often fell with the family members and support staff,

> “I do think it’s very much up to the family and the support workers more than really he gets from the doctor.” (F6)

Support staff (including personal assistants) work with the individual with a learning disability on a daily basis. They are more likely to be unqualified/unregistered, and/or someone who may have limited health and/or MCA knowledge and experience. There was concern expressed throughout the data about how a limited knowledge and understanding of health issues could subsequently affect ability to provide reliable information at health consultations (such as with GPs) to support informed health decision-making about the individual with a learning disability,

> “…, reliant upon what’s described by the staff and so on and that’s uh not always reliable I don’t think, so you have front line member staff, care support workers who are not very savvy…” (F3)

Examples were given by participants of when they considered that both a lack of medical or health knowledge and a lack of understanding of how to apply the MCA in daily practice, resulted in their loved ones receiving what they perceived to be a sub-standard quality of care. One participant felt that their loved one had not been involved in the decision-making process at all. This they believed was due to a combination of the support staff not providing an accurate presentation of the health issue in the first instance to a GP (resulting in what they felt was medication being prescribed unnecessarily) as well as the MCA not being followed. The individual with a learning disability (pseudonym, Harry) did not like things on his skin. However, a medication had been prescribed by the GP in the form of a ‘patch’. Harry had then continuously removed the patch. The family believed the support staff had then placed the patch on Harry’s back so that he was unable to reach it (and presumably pull it off). The participant felt strongly that in this case - in line with the MCA – that Harry’s preferences should have been at the centre of the decision, and a Best Interests decision should have been made as having the patch on his skin had caused Harry distress.

> “…that’s the bit that’s worrying, that despite providing training around the Mental Capacity Act, despite talking about the least restrictive option, and all of those sorts of things, people continue to do that type of thing to someone with a learning disability (…) it didn’t occur to them that, that was wrong and they shouldn’t be doing it.” (F2)

Although several family members provided examples of when they believed that staff had not followed the MCA, this perspective was not shared by all family members interviewed. One participant felt that the support staff had a crucial role in supporting health decision-making with their family member who had a severe learning disability and complex needs,

> “…because they will get to know that person as well hopefully as you, do you know what I mean? The only thing they don’t get obviously is the emotional, I mean they do in a roundabout way because they obviously care for the person they are working for but they’re the people – the PA, the support worker.” (F1)

6.4.2. Theme 2: Listening to family expertise supports health decision-making - *“I hold the history”*

This theme was consistent across all data. It encapsulates that family members have expertise, described as an “intense knowledge” (F2), developed over a lifetime of knowing and supporting the individual with learning disabilities. Often nobody else has this knowledge and expertise, family members therefore “…*hold the history*” (F2 and F4), knowing what has happened previously, what has been successful as well as having found solutions to challenges. Some family members spoke about this in terms of being more like a ‘care coordinator’, with a “clinical overview” (F5) of all aspects of the individual's health needs, informed by the individual’s history. Family members felt strongly that their in-depth, comprehensive, holistic knowledge and expertise should support the decision-making process:

> “…I hold the history (…) and it’s really important for somebody that can’t communicate, or understand the implications of something, that they listen to those that know them best.” (F2)

Family members spoke about emotional attachment as marking their relationship with the individual as different to paid staff. Family members do not view themselves as a separate entity to the individual with a learning disability, but an integral representation of the individual's voice in the decision-making process. This was discussed in terms of being an intimate relationship. Supporting decision-making is something family members have been doing throughout the individual's lifetime, it is nothing new “…but now has a name and people think it's a good idea” (F5); in essence, for family members, supporting decision-making simply reflects their everyday life experiences.

Family members spoke about how their expertise means that they have a different perspective or insight, which can support health decision-making, often contributing something that would not be picked up by staff. For example, family members might detect subtle cues that suggest pain or discomfort, as well as having learnt ways of supporting the individual, which staff might not notice or be aware of:

> "…which we observe and the staff don't because they're quite subtle and staff teams aren't used to that…" (F3)

Family members want their loved one to be supported to be involved in decision-making. A range of approaches were discussed as being potentially useful. Intensive interaction (Hewett, 2018) was described by one participant, whilst social stories™ (Gray, 1994) were discussed by others. The crucial aspect of whichever approach used was that it was person-centred, tailored to the individual, often having been adapted and developed over years. However, there were times when participants felt their role was to articulate and represent the 'voice' of their loved one, which should be given credibility as part of supporting decision-making by healthcare staff.

Family members spoke about wanting to share their knowledge and expertise with healthcare staff as part of supporting decision-making, which they thought would improve the health outcomes for their loved one.

> "I'm trying to do a non-verbal communication book up because my worry is that they [staff] don't understand how to support his communication the same way I did..." (F1)

> "I wrote um a health passport and tried to explain some of the adaptations we'd need…" (F6)

The participants who spoke to me however recognised that not all family members are the same, suggesting that it is the role of the healthcare staff to ask the right questions in order to support health decision-making:

> "I'm sure there are little gems of information that make it easier all round." (F4)

6.4.3. Theme 3: Work with us, not against us - "…we each have expertise that is needed to be brought to the table to get this good outcome"

This third theme embraces the hope and aspiration family members have for genuine partnership working between healthcare staff and families. Participants recognised that in order to get the best outcomes for the individual with a learning disability, collaborative, partnership working with healthcare staff was essential:

> "…it's about that understanding of, (…) that we each have expertise that is needed to be brought to the table to get this good outcome." (F5)

Family members are committed to supporting health decision-making both with and for their loved one, and want to be treated with respect and recognised as equals in the decision-making process. Whilst they want to be actively involved in supporting decision-making, they spoke about their views not always being respected by healthcare staff, resulting at times in feeling that they had to become "interfering" (F3) or "pushy" (F4) in order to get things done.

Conflict between healthcare staff and family members predominately appeared to stem from healthcare staff and family members having different opinions about the health needs of the individual with a learning disability. Conflict between family members and individuals with a learning disability was conversely not mentioned. Participants spoke about healthcare staff having one perspective as to what should happen and not being willing to discuss alternative perspectives offered by family members. For example, one family member recognised the expertise the staff had in their son's health condition but described them as being "arrogant" (F3) in not working collaboratively with the family and listening to what the family had to offer,

> “So that level of understanding was not there (pause) and, and going into rather um… difficult territory I think the clinicians were quite well-informed but they… were quite arrogant” (F3).

Another participant spoke about family members being viewed as "thorny people" (F5) by healthcare staff, rather than understanding they wanted their views and perspectives to be taken into account to support the process and make sure that their loved one’s preferences remained at the centre of decision-making. Feelings in relation to differences of opinion appeared to be exacerbated by the complexity of the health decision that needed to be made. For example, one family member discussed the need to investigate the pattern and presentation of seizures in order to ensure appropriate anti-epileptic treatment was prescribed. Seizures were mainly occurring during night-time hours so the family felt that video-recording was an appropriate option to establish seizure pattern and presentation, whereas healthcare staff felt that this was an infringement on the individual’s human rights.

Of note, family members felt that they were more likely to adhere to policy and MCA principles compared with healthcare staff, eroding trust. Participants discussed feeling frustrated that they were not always given full and up-to-date information about the health status of their loved one in order to be able to support informed health decision-making. Feelings of distrust were exacerbated when family members felt they were not kept informed,

> “So, you lose trust.” (F4)

Some participants said that because healthcare staff had not shared information with them, they had pursued ‘Freedom of Information’ requests to find out information they felt had been kept from them. Not having information resulted in family members feeling unable to support informed decision-making,

> “…so, we feel we were badly let down in terms of the Mental Capacity Act, and not being kept informed about his experiences…” (F3)

Conflict between healthcare staff and family members often resulted in feelings of frustration. When examples were given in interviews, language used to describe the situation was often associated with a “battle” (F3) or a “fight to get things done” (F1). Family members felt conflict had resulted at times in their loved one receiving poor and sub-optimal standards of healthcare. Navigating this was considered particularly challenging for family members,

> “So, this is a tricky, it’s a tightrope walk you know and um not everyone wants to listen to your, to your, to what needs to be done….” (F5)

Participants felt strongly that they should be respected and treated as equals in supporting decision-making discussions. Only by working in genuine partnership with healthcare staff, based on mutual respect, would decision-making benefit the person with a learning disability. All family members interviewed spoke about wanting to make changes so that there was more respect for the views of family members and better partnership working between healthcare staff and family members.

6.4.4. Theme 4: Applying the MCA can lead to further disadvantage - *“…the frustration sets in then because it just drags on*”

Time was consistently referred to by all participants in reference to all aspects of supporting health decision-making, both with and for an individual with learning disabilities and complex needs. However, this theme is complicated and nuanced, family members were not simply saying supporting decision-making requires more time, but suggesting that the length of time it can take to implement the MCA results in the person with a learning disability being potentially further disadvantaged.

Participants talked about the prolonged length of time it can take for healthcare staff to get to know the individual with a learning disability (particularly if family members are not involved) in order for health needs to be initially identified. This initial assessment process can delay initial healthcare appointments, investigations and/or treatment, often causing prolonged discomfort, pain and/or anxiety for the individual with a learning disability. Once a health issue has been identified, lengthy waiting lists also exacerbate the time the process of decision-making takes to reach the point where an individual is actually put on a list for a medical investigation or treatment,

> "…he was referred (by the GP) but we just sort of joined the queue … And it was a long queue, and, and we thought this is not right because… it had been going on for such a long time…" (F3).

In essence applying the MCA appropriately meant that it could take longer for the individual with a learning disability to receive much needed medical investigations and/or treatment. This was a cause of frustration. Time was paradoxically also identified as a reason for why some healthcare staff do not adhere to the MCA, discussed in terms of potentially putting healthcare staff off from implementing it correctly,

> "…people [healthcare staff] don't want to be spending the time doing it in the right way sometimes." (F2)

Neither approach seemed satisfactory, and family members were often left feeling frustrated with the decision-making process.

Supporting health decision-making with individuals who have more complex needs takes time, especially if the individual has had previous negative experiences. One participant reflected that it can take years to get supporting decision-making right, especially if individuals have had poor healthcare experiences previously as this means more time is required to build and develop trust with new staff and healthcare services,

> "…it's taken 20 odd years to get to that point. Um so there are no quick fixes around people with autism and learning disabilities who have had a tough time out there… (…) I often think that that's why they call us patients." (F5).

Time is important in ensuring the person is supported to be involved and for their preferences to be at the heart of the decision-making process. For example, information presented in alternative formats as discussed in theme two above, such as by using social stories™, or using alternative methods of communication, such as intensive interaction. However, additional time can inadvertently result in the individual experiencing prolonged symptoms, resulting in what might be considered as further disadvantage. Additionally, the length of time it can take might actually discourage staff and/or family members from wanting to follow the MCA principles and processes.

6.5. Summary

As intended in the research design, the family members perspectives reflect the experiences of adults who have a more severe or profound learning disability or a learning disability with complex needs. All family members spoke about the individual with learning disabilities not being able to understand many healthcare decisions due to the nature of their learning disability, therefore needing lots of support and the involvement of people who knew them well to ensure that the individual's 'voice' was heard within the decision-making process. This is in contrast to the adults with learning disabilities who participated in interviews (as discussed in Chapter 5) and, as will be seen, those who participated in focus group discussions (see Chapter 8), who had mild-moderate learning disabilities and were able to talk to me about their experiences and preferences.

Four themes were developed from the interview data in answer to my research questions. Healthcare staff were perceived by family members as sometimes lacking knowledge and understanding to support health decision-making, either in relation to the MCA and/or health conditions/issues. Family members have expertise that healthcare staff do not have about their loved one, which means healthcare staff should listen to what family members say to support health decision-making. Families want to work in partnership with healthcare staff to support decision-making and enable good health outcomes for their loved one. Paradoxically, the time it can take to apply the MCA properly can result in either healthcare staff being deterred from using it, or the individual with a learning disability being further disadvantaged, with prolonged symptoms.

In Chapter 7, the views and perspectives of healthcare staff and pilot survey data from learning disability student nurses will be discussed.

Chapter 7: Staff perspectives of supporting adults with a learning disability to make health decisions

"We often think we're doing the best for our patients... but it might not be what the patient wants"

7.1. Introduction

Chapters 5 and 6 discussed the themes developed from interview data with adults who have a learning disability and family members. In Chapter 7, the findings from semi-structured interviews with healthcare staff and the pilot results of a qualitative online survey completed by learning disability nursing students will be explored. Details including demographic data and details of professional experience are provided for the staff who participated, before the themes developed from the data are discussed.

7.2. Participants

Sixteen healthcare staff participated in semi-structured interviews, and seven learning disability nursing students completed an online qualitative survey pilot. Demographic information is presented in Table 7.1 for interview participants and in Table 7.2 for participants who completed the survey.

Interview participants are identified as S1-S16 and survey respondents S17-S23 when quotations are used below.

Table 7.1. Sample characteristics of interview participants

Interview sample characteristics	Number of participants
Sex as identified by participant	
Female	14
Male	2
Ethnicity	
White British	15
Other	1
County participant works in	
Bristol	3
Cornwall	1
Devon	1
Dorset	1
Merseyside	2
Somerset	1
South Gloucestershire	5
Wiltshire	2
Type of service participant works in	
Acute Hospital	3
Community Learning Disability Team	3
Council/Social Care	2
Criminal Justice Service	1
Nursing Home	1
Residential/domiciliary care services	5
Supported-Living Service	1
Years of experience working with people with a learning disability	
1-5 years	7
6-10 years	3
11-20 years	0
21-30 years	2
Over 31 years	4
Professional qualification/job role	
Adult nurse	3
Commissioner	1
Learning disability nurse	7
Midwife	1
Registered home manager	1
Support worker/team leader	3

Table 7.2. Sample characteristics of survey participants

Survey sample characteristics	Number of participants
Sex as identified by participant	
Female	7
Male	0
Ethnicity as identified by participant	
English	1
Mixed Black/White British	1
White British	4
No response given	1
Country of residence	
England	6
Wales	1
Current role	
Student learning disabilities nurse (year of study was not asked for in the pilot survey)	7

7.3. Data Analysis

Data from both the qualitative survey responses and the interview transcripts were analysed following the six-step process outlined by Braun and Clarke (2022; 2018; 2013) as discussed in Chapter 4. Familiarisation and initial coding sweeps were undertaken between July and September 2021 and revisited in June 2022 (following a suspension of PhD studies between Sept 2021 and May 2022). In June 2022, further coding sweeps were undertaken resulting in 205 semantic codes, where codes aligned closely to the original data. Codes were revisited, transcripts re-read and further coding sweeps undertaken, resulting in some initial codes being renamed and merged. Codes were then grouped together, which started the process of theme development, where codes moved from being semantic. When initial themes had been identified, critical discussions with one of my supervisors (SD) informed the boundaries of these themes and how codes linked together (Table 7.3: Theme development examples).

Table 7.3. Theme development examples

Examples of codes		**Theme development**	
Examples of Semantic codes	**Examples of Latent codes**	**Initial themes**	**Developed Theme**
Advocating for individual Ask individual who they want involved Build trust Continuous support Family involvement Knowing somebody’s wishes Take process at person’s pace Support staff views disregarded Support staff get left out Change communication approach Continuity and repetition important Respecting an individual's wishes	Advocating for the rights of an individual Aggression can be misinterpreted Supporter needs to be realistic Building on individual's strengths Needs to be the right person to support decision-making Need to involve the right people (those who know individual well) Making yourself available Learning from what has worked before Learning from what hasn’t worked before	Support person needs to be present – “Being there” / “Being open” / “Being available” to understand the individual	Understanding the person is at the heart of supporting decision-making
Need accessible information Staff don’t always understand Need to share accessible resources It takes time to find/develop accessible resources DVD helpful Easy read leaflets can be helpful Pictures can be demeaning Easy read can be demeaning	Accessible information only part of the process Accessible resources support understanding Need for more individualized accessible resources to support decision-making Need for more accessible resources to support decision-making for all involved	Let’s make health information simpler	Let’s make healthcare information accessible for everyone

Examples of codes		**Theme development**	
Examples of Semantic codes	**Examples of Latent codes**	**Initial themes**	**Developed Theme**
Conflict Different opinions to hospital staff Different opinions within the team Feeling responsible for MCA application GP lacks knowledge Frustrations with medical staff Ask him, don't tell him! MCA applied by paramedics MCA applied well in community MCA applied well in acute hospital MCA applied well in residential home MCA not applied well	Staff lack knowledge and/or understanding Lack of knowledge, understanding **and** confidence MCA application relies on value base of staff or service or organization MCA application requires knowledge and understanding MCA requires expertise MCA decision-making knowledge limited in wider healthcare services	It's a mixed bag – supporting decision-making requires a 'whole system' approach	MCA knowledge and understanding are paramount in order to support health decision-making
People with learning disabilities being written off People with learning disabilities not being valued Being denied healthcare interventions and services Support staff not being listened to Support staff views being disregarded Respect for different opinions	MCA application is about attitude of staff member Staff value base informs decision support provided for/to individual Good working relationships with other professionals facilitates supporting decision-making MCA increasing inequality rather than reducing it Who is valued in society		Respect is required for all involved in the supporting health decision-making process

Examples of codes		Theme development	
Examples of Semantic codes	**Examples of Latent codes**	**Initial themes**	**Developed Theme**
It can be frustrating but positive Supporting some decisions can be incredibly difficult, but not a reason not to do it Taking time initially can save time with later decisions It takes time Small steps I feel like I failed	It doesn't always work first time MCA application relies on professional curiosity MCA application in daily life is complex - not linear It's an iterative process	Supporting decision-making is tough but do-able	You don't always get supporting decision-making right first time

Table 7.4. Health decision discussed by interview participants

Primary health decision discussed	Sex of individual with a learning disability	After supporting decision-making did individual with a learning disability have capacity to make the decision?	Learning disability as reported by participant
Anxiety intervention	Male	Yes	Mild
Blood test due to increased seizure activity	Female	No	Moderate-severe
Cataract removal	Male	Yes	Mild-Moderate
Cervical screening	Female	Yes	Mild-moderate
Dental work	Male	Yes	Mild
Flu / Covid Vaccines	Male	No	Profound and Multiple
Liver biopsy	Male	Yes	Mild learning disabilities with complex needs
Percutaneous Endoscopic Gastrostomy (PEG) fitted	Male	No	Moderate learning disabilities with complex needs
Podiatrist appointment	Male	Yes	Complex needs
To have an annual health check	Male	No	Moderate learning disabilities
To smoke	Male	No	Complex needs
To take over the counter analgesics	Male	Yes	Mild with complex needs
Treatment for breast cancer	Female	Yes	Mild-moderate
Treatment for cancer	Male	Yes	Mild
Treatment for a fractured bone	Male	No	Severe
Vagal Nerve Stimulation surgery	Female	Yes	Mild

7.4. Findings

A range of decisions were discussed (see Table 7.4 above) in interviews with 16 healthcare staff who work with adults with a learning disability as part of their daily practice. Most decisions discussed (12/16) were in relation to men, who were described by the participant as having complex health needs.

Five themes were developed from reflexive thematic analysis of the data: 1. Understanding the person is at the heart of supporting decision-making; 2. Let’s make healthcare information accessible for everyone; 3. You don’t always get supporting decision-making right first time; 4. MCA knowledge and understanding are paramount in order to support health decision-making; and 5. Respect is required for all involved in the supporting health decision-making process.

7.4.1. Theme 1: Understanding the person is at the heart of supporting decision-making - *“...the most important thing is to really understand the person”*

The essence of the first theme is that everything the member of staff does to support decision-making needs to revolve around the individual’s strengths and preferences. The staff member has an active and ‘enabling’ role. What is most significant is the approach taken by the member of staff (comparable on my reflections to their bedside manner), which relies on the staff member taking the time to “really understand the person” (S3). Notably, this does not necessitate knowing the person with a learning disability at the beginning of the process. Whilst knowing the individual in advance of the decision needing to be made can be helpful, what appears to be most important is the development of a trusting relationship between the staff and the individual with a learning disability, which often includes liaising with the individuals’ wider support network (i.e., those people who do know the person well). Healthcare staff participants talked at length about the importance of knowing or getting to know the individual. It is through understanding the person that approaches to supporting decision-making can be tailored to their strengths, abilities and needs. By knowing **or** getting to know the individual, staff were also able to learn from what had or had not worked well in the past. This enabled staff to adapt their approach and to be in a more informed position to provide support which met the needs of the individual,

> “...I had to be very careful about um how I did it with him, uh, I had to keep it at a very light sort of touch sort of thing, you know (…) the importance of pacing of information, not sort of overloading him with information” (S10).

Where the decision allowed, for example a non-urgent decision such as having a flu vaccination or an annual health check, participants advocated that the process of providing support for the individual to make their own decision should be at the individual's pace. This was discussed as maximising an individual’s capacity to make their own decision by spending time with the individual, revisiting the decision with the person as required and using different approaches and methods to facilitate the individual’s understanding. Participants emphasised the importance of repetition as well as consistency of information provided. This often involved multiple conversations with the individual. As not all participants had long-term relationships with the individual, working in partnership with the wider support network so that all involved were able to give and discuss information about the decision in a consistent way was essential:

> “...we put a little folder together (…) so, at any point she [individual with a learning disability] could go and have a look at it, um, speak to staff [who were supporting individual on a daily basis] ...” (S8)

Participants frequently spoke about the importance of understanding the individual so that emotional as well as practical support could be provided to support the individual to make the healthcare decision:

> "The gentleman in question is absolutely petrified of going to any health appointments and so some of the work (…) was around um talking through and validating his feelings and his worries and anxieties..." (S9)

The importance of staff being person-centred in their approach was emphasised. It was significant in terms of **how** staff supported decision-making but also in relation to evidencing the individual's decision. For example, one participant explained how video was used to document the decision of an individual who did not use verbal methods of communication:

> "...we could see how upset she portrayed when we were talking about [procedure], and how she became so irate in her body movements, (…), her volume, change of the tones of the sounds she was making, um… And we used them [videos] to evidence that we could show that she was saying yes or no in her way." (S4)

Whilst the importance of working in partnership with family members to understand the individuals' preferences and strengths was highlighted, some participants were working with individuals who did not have family or in situations where the family did not want to be involved – these individuals were more likely to be older and living in residential settings. When someone did not have family, support staff or personal assistants (staff working with an individual daily, often over years) were identified as being ideal to support decision-making. If the individual did have family involved, different opinions between staff and family members could lead to conflict, complicating supporting decision-making. However, where different opinions between staff and families were discussed, most participants spoke about finding ways of resolving potential conflict, as well as staff recognising a need to respect where the different perspective or potential conflict stemmed from,

> “…it may be that there, there is a conflict but it’s from a very caring, nurturing and uh, a very you know, fearful place…” (S9)

In summary, theme 1 captures the active, enabling role healthcare staff have, which is based on understanding the individual so that a person-centred approach to supporting decision-making can be used. Significantly, this does not necessitate staff knowing the individual with a learning disability in advance of the decision needing to be made, but does often rely on staff working in partnership with those who do know the person well.

7.4.2. Theme 2: Let’s make healthcare information accessible for everyone - *“...why can’t we make it simpler?”*

This second theme focuses on the need to make health information more accessible for individuals who have a learning disability as well as for the staff who are supporting the individual to make a decision. The use of accessible information to support decision-making was identified by all 23 participants, with many emphasising the need for accessible resources to be freely and easily available to healthcare staff. The member of staff’s role was more than simply offering choice, it was about facilitating understanding of the healthcare procedure or intervention so that the individual could make an informed decision about what they wanted to happen. Therefore, in order to support an individual with a learning disability to understand the decision at hand, the member of staff needed to understand the procedure or intervention.

> “...it would have been really difficult for me to go away and go and speak to him and get his understanding if I didn’t necessarily understand it myself so making sure we’re given all the necessary information, and all the necessary, like pros and cons etc., um just so that we can relay that information more effectively um…” (S13).

Accessible information was routinely used to support the individual with a learning disability to understand the medical procedure or intervention being proposed, as well as being used by members of the wider support network and the staff themselves to increase their understanding. Participants highlighted that it is often support staff or personal assistants who are the best people to support decision-making. Yet these people, whilst knowing the individual with a learning disability well, might have limited medical and health knowledge. The complexity of health procedures and interventions was therefore discussed as a potential barrier to supporting decision-making,

> "…you know it's even for me as a person with capacity, it's really difficult to make decisions about our own health… and you know I think some… somewhere along the line that person has to really, really, fully understand the health decision that's to be made" (S2)

Understanding the procedure or intervention involved understanding the rationale for the procedure or intervention as well as the potential risks and benefits. Examples discussed as complex included a decision whether to have a Percutaneous Endoscopic Gastronomy (PEG) tube fitted and Vagal Nerve Stimulation (VNS) surgery. Some interventions and procedures were considered especially complex because the risks and potential benefits were possible but not definite, as well as affecting people differently,

> "…every day's a school day when it comes to this piece of kit [VNS] […] it was a bit of an unknown thing to [know] how [individual] would respond [to having a VNS] and how it would be for her. It's not the same for everyone, it's very individual…" (S2).

The use of 'easy read' information and videos or DVDs were mentioned by participants as being particularly useful in facilitating understanding, as was the use of "flash cards with pictures on" (S6). Participants however expressed frustration that accessible resources were not always freely available and the time it takes to develop an accessible resource, especially sourcing suitable, freely available images and pictures. Due to individual needs, abilities, cultural tastes and preferences, staff discussed that it was sometimes challenging to find appropriate accessible health resources or images that they could use. Some participants suggested it would be helpful to have an online “picture bank” (S15) of a variety and diversity of different, accessible resources and images that staff could freely access to support decision-making, rather than individual staff working in separate services/organisations/localities all developing their own versions, potentially wasting time by duplicating work:

> “...around the country [staff] are all doing very similar things, you know, I’ve done a lot around Covid vaccination, and I created a whole form (…) and then I realised that actually somebody else had done a much better one (…) that was 3 or 4-hours’ worth of work that was just gone because I didn’t know that somebody else was doing it” (S3).

> “I couldn’t find anything available in easy read format for the, the treatments that were being offered at that time, um, there were often pictures um and certain captions of things that you could grab at, so I put them all together and also made it relevant to her” (S4).

Whilst there was consensus across the data about using accessible information to support decision-making, one participant gave an example of one individual they supported who found accessible information “demeaning” (S10). This emphasises the importance of understanding the individual and supporting decision-making in a person-centred way.

7.4.3. Theme 3: You don’t always get supporting decision-making right first time - *“...trial and error… until we exhaust a number of options...”*

The third theme relates to the **process** of supporting decision-making, which was identified as an iterative and flexible process with "no guarantee[s]” (S10). Despite developing a trusting relationship with a focus on understanding the individual’s preferences, strengths and needs, attempts by the staff to support an individual to make their own decision did not always work first time. Frequently participants discussed how an initial attempt to support decision-making had been ineffective in facilitating the individual with a learning disability to understand the decision. Participants talked about the importance therefore of “exhausting” (S4, S11) multiple different methods and approaches to support the individual to make their own decision. Supporting decision-making was discussed in terms of being “tough” (S1) and/or “challenging” (S3, S7, S11) due to this iterative process which required supporters to try multiple different approaches, which may or may not end with the individual being able to make their own decision. One participant reflected on a process where they first used a Social Story™ (Gray, 1994) to support an individual to make a decision about whether to have an annual health check. This was not effective as, whilst the individual was interested in the character in the story, this approach did not facilitate understanding about an annual health check. A video was then tried, but with limited effect in facilitating understanding. After multiple different approaches were tried, the outcome of a capacity assessment was a Best Interests decision, which demonstrated sound application of the MCA. However, the participant said they felt professionally “like a failure” (S11) for not having been able to support the individual to make their own decision.

Participants suggested the need for “professional curiosity” (S2), for the supporter to keep asking questions and being open and willing to try different approaches. A “toolbox” (S11) of resources and practical approaches and ideas was a suggestion to help supporters think about different ways they could support decision-making as well as providing reassurance that no approach comes with a guarantee that it will work:

> “...that list is endless, you have to, you know you can think so far out of the box sometimes to try and make sure that you are exhausting every opportunity to make sure they are empowered to make that decision” (S4).

Time was discussed as a core aspect of this iterative process. Individuals often required time to understand and process information pertinent to the decision. Whilst it was recognised that some decisions needed to be made quickly, this was not the case for all decisions. Some participants felt that decisions were often “rushed or not considered” (S3), especially in busy healthcare settings, which participants felt resulted in individuals with a learning disability being denied opportunities to be supported to make their own decisions. Participants suggested that if time was invested in supporting decision-making initially, it often saved time at a later date. Participants gave examples of how the people they had supported had learnt and gained confidence in making their own decisions whilst developing trust in healthcare professionals and services. This, they felt, had increased the independence of the person with a learning disability, reducing the need for additional support in the future:

> “The outcome was very positive, it was brilliant, yeah you know and she, we don’t even now support her when she comes to the outpatient clinic” (S4).

Interviewees gave examples when difficult decisions were required, emphasising that it was important for staff supporting decision-making to be realistic in recognising that individuals with a learning disability like all people might change their mind. Difficult decisions were described in terms of it being anxiety provoking, possibly due to fear of the healthcare intervention or procedure, with the potential for the individual to display aggressive behaviour as a result of anxiety or distress. These participants reflected that after individuals had been supported to make and execute the “difficult” decision, feelings of anxiety and distress were often replaced with feelings of pride and elation, almost celebratory, with the individual being glad they had made the decision. Supporting individuals to make a healthcare decision was frequently discussed in terms of being a challenging, iterative process, but one that is ultimately rewarding for both the individual with a learning disability and the supporter:

> "...it is very, very rewarding" (S12).

Enabling individuals with a learning disability to have opportunities to practice making decisions was also emphasised. Practice opportunities were discussed as needing to be part of everyday life with the individual’s usual, everyday support network, so that when an individual needed to make a health decision, they had prior experience of making decisions. Exposure to daily decision-making, such as deciding what to wear, what to eat etc., developed decision-making confidence which was beneficial when individuals were faced with a healthcare decision which was often more complex with more significant consequences.

Theme 3, in summary, captures the essence that supporting decision-making is an iterative and complex process, which does not always work first time. However, supporting someone to make their own health decision can ultimately be a rewarding process which increases an individual’s independence.

7.4.4. Theme 4: MCA knowledge and understanding are paramount in order to support health decision-making - “*I think a lot of staff don’t understand it*”

Whilst there were positive examples of good practice within the data:

> “...there’s lots of good work (…) where things are done in the right way” (S2),

poor supporting decision-making practice was often associated with the treating clinician having what was perceived as poor or limited knowledge and/or understanding of the MCA. Most of the healthcare staff who spoke to me felt a strong sense of responsibility to ensure the MCA was applied appropriately, feeling that implementation of the MCA more widely across healthcare services was viewed as a "tick box" (S7, S11, S13) exercise as opposed to a person-centred process. This was a source of frustration for several of the staff who viewed the MCA as a tool for positive change:

> "...if it's used properly, [the MCA] is a tool to maintain … human rights" (S5).

Participants cited examples where the treating clinician had said they were "not qualified to do a capacity assessment" (S5), whereas in line with the MCA, the treating clinician is responsible for the capacity assessment (OPG, 2007).   Some participants expressed dissatisfaction about a perceived lack of MCA knowledge by those they identified as being in more senior positions:

> "It also surprises me on how many consultants and doctors don't understand the Mental Capacity Act (…) oh my goodness, yeah, you're so far up the tree ahead of me professionally and I'm advising you on how you should follow a consent process, it, yeah, it's shocking really." (S15)

There was consensus that MCA training was a crucial aspect of raising awareness and improving supporting decision-making practice, "...it's obviously educating the staff..." (S7). Participants advocated that everybody "coming in contact with that patient" (S4) should receive regular training to ensure the patient's journey through the health service was supported in line with legislation.

Some participants were in positions where they facilitated MCA training for healthcare professionals (these participants tended to be staff with professional qualifications working in community or acute healthcare settings). These participants expressed strong views on the content and delivery of training, advocating the need for face-to-face, synchronous MCA training (online or in-person) rather than asynchronous e-learning, which often involved "clicking through a screen and answering questions" (S4) without reflexive discussion and/or real case examples. Having an experienced and passionate trainer/facilitator was also suggested as essential for training to be effective:

> "...they go on, do their e-learning, MCA e-learning, but I don't know, until you've actually got someone coaching and showing and you know, knowing how to make those conversations, (…) they don't get that from an e-learning. They get that from someone who strongly… is passionate about it and advocating it and promoting it..." (S2)

Concerns were also raised by some staff, particularly those who had worked in more than one organisation, about the reliability and validity of information provided at mandatory MCA training. One participant explained how they had received contradictory information from attending two different mandatory MCA training sessions, facilitated by different organisations. Given their experience, this participant suggested that MCA training should be standardised to reduce the risk of staff receiving conflicting or potentially inaccurate advice, advocating that the people facilitating MCA training needed to have expertise in what they were teaching:

> "I think nationalise training so, nationalise standards for trainers" (S3).

In addition to formal training, several participants identified a need for informal ongoing support, valuing having a mentor or a colleague to de-brief and have reflexive discussions with. These were often informal arrangements, where an experienced member of staff had offered to support less experienced staff or where the staff member had sought out a colleague for advice:

> “I don’t expect to get it 100% right every single time but I’ll learn from each experience (…) and that additional peer support (…) making sure that I’ve got somebody who I can go back to um and ask advice from.” (S7)

Staff also spoke about challenges for family carers when adult children transition from children to adult services, advocating that families need MCA training as part of transition to prepare them for supporting their adult child to make decisions.

Theme 4 captures the perspective of the staff interviewed that the MCA is generally not well understood by healthcare staff resulting in a “mixed bag” (S5) of supporting decision-making practice. Mandatory MCA training was identified as pivotal, although participants suggested that training in its current form requires review. Informal mechanisms of support, such as peer support, reflexive discussions, and somebody to contact for advice were suggested as particularly helpful in improving supporting decision-making practice.

7.4.5. Theme 5: Respect is required for all involved in supporting health decision-making – *“there needs to be more joint working”*

This final theme captures the importance of mutual respect for all persons involved. Participants said that, at times, respect for individuals with a learning disability and for staff supporting individuals with a learning disability, was lacking; identifying this as a potential barrier to supporting health decision-making taking place.

Several participants felt that staff with experience of supporting people with a learning disability were often left with the responsibility for the application of the MCA, rather than the treating clinician. Lack of MCA knowledge and understanding was identified (as discussed in theme 4 above), with some participants suggesting that examples of poor practice also reflected wider values and attitudes of healthcare staff towards people with learning disabilities, raising potential concerns about what was perceived as discriminatory practice:

> “those with learning disabilities were pushed to the bottom of the list...” (S1).

Staff discussed examples where they felt individuals with a learning disability were “...written off... [or seen as] a number in a bed without any views, without a voice” (S1) or “...not always listened to” (S12). Some interview participants gave examples of when they felt a lack of capacity had incorrectly been perceived as an individual refusing or declining a healthcare intervention or treatment. Whilst others discussed examples when health interventions or treatments were implemented without any support provided to enable the individual to make their own decision:

> “...very much off the cuff sort of comments about, ‘oh this person lacks capacity, so we’ll just go ahead with that’...” (S11)

‘Do Not Attempt Resuscitation’ (DNAR) orders and ‘Treatment Escalation Plans’ (TEP) were discussed as examples whereby some interview participants felt a blanket decision had been made by one clinician without any attempt at supporting the person to make their own decision, or discussing it with family members or support staff who knew the person well, as required by the MCA:

> “I’ve seen TEP forms, DNAR forms that look really suspect to me (…) family technically haven’t signed it; GP hasn’t signed it...” (S2)

Some participants also expressed frustration at feeling they had not been respected by healthcare staff who were in more senior positions. This resulted in examples where the participant felt the individual with a learning disability had not been supported appropriately, as the people who knew and understood the individual had not been consulted:

> “I’ve had situations in the past where … I’ve been to a hospital and I’ve been told, ‘oh, but you’re just a carer, I’m a nurse’ or, ‘you’re just a carer, I’m a doctor’” (S13).

Where participants discussed positive examples of supporting decision-making, respect for colleagues and healthcare staff from different disciplines was more likely,

> “(the consultant) listened, ‘cos originally it was just like, “oh she mustn’t, she hasn’t got capacity”, that was the first thing that was said um, and we were like, “no, we feel she has got capacity”, but we just need some time for her to process it, so, um, and he agreed with us, and he did listen, it was good.” (S4)

Some participants suggested more learning disability expertise was required across healthcare settings for sustainable improvements to be made, although there was no agreement about how this should be facilitated:

> “...the hospital [learning disability] liaison team should be working 24-hours a day… eekk… [laughs] um, probably they should have a learning disability nurse potentially on every ward possibly or at least learning disability nurses available.” (S2)

However, this was not the view of all. Some participants suggested that to improve supporting decision-making practice rather than “preach[ing] to those who are already aware of (…) the issues (…)” (S9), more partnership working was required across healthcare agencies, organisations and healthcare professional groups, with respect to the staff who had experience and specialism in learning disabilities. Partnership working across disciplines, as well as “role modelling” good practice was advocated.

Current MCA documentation was also discussed in terms of potentially perpetuating attitudes hindering supporting decision-making, as the focus of the documentation was often felt to be on recording the outcome, i.e., whether a person has capacity or not, rather than how an individual has arrived at the decision and what support has been provided:

> "I find from experience there is little in documentation about how people have come to decisions. Like yes, they may have understood and made healthcare decisions but often not documented the support that was given." (S22)

In summary, a lack of respect for people with a learning disability and those supporting them was identified by interview participants as a cause for concern, with the suggestion that this hindered supporting decision-making practice. Whilst some participants felt there was a need to increase the number or availability of learning disability nurses, others advocated for more partnership working and sharing of expertise, as well as a review of current MCA documentation. Overall, respect for all persons involved was seen as essential.

7.5. Summary

This chapter has discussed the findings from interviews with healthcare staff and pilot survey responses from learning disability nursing students. The data from healthcare staff and student nurses demonstrates a mixture of good and poor experiences of supporting adults with a learning disability to make health decisions. The data provide valuable insights, contributing to our understanding of what the key factors are likely to be to supporting decision-making being a good experience, i.e., one that reflects the MCA Code of Practice (OPG, 2007). These factors are healthcare staff understanding the person; health information pertaining to the decision to be made being understandable to the person and those supporting them; understanding that supporting decision-making is an iterative process, which doesn’t always work the first time; as well as the need for all healthcare staff to understand the MCA so that they can apply it in daily healthcare practice; and partnership working, which centres on respect for all involved.

The next chapter discusses the findings from three focus group discussions with adults who have a learning disability.

Chapter 8: Focus Group Findings

"...it's not just awesome, it feels like you're being (...) your own PM Prime Minister"

8.1. Introduction

Chapters 6 and 7 discussed the findings from interviews with family members and healthcare staff and Chapter 5 presented the findings from seven in-depth interviews with adults with learning disabilities. The interviews with adults with learning disabilities were facilitated in 2019, pre-Covid-19 pandemic, asking participants to talk in detail about an experience of making their own health decision with support. In this Chapter, the views of adults with learning disabilities collected via focus groups in 2023, following the Covid-19 pandemic, will be presented and discussed. Focus group participants were asked how they wanted to be supported to make health decisions with regards to what was helpful and unhelpful in supporting them to make health decisions rather than being asked to talk about making one health decision in detail.

8.2. Participants

As discussed in Chapter 4, twelve adults were recruited to participate in three focus groups. All focus group participants identified as having a learning disability. I did not ask participants to identify a level of learning disability, however the focus group data reflects individuals who have a mild-moderate learning disability (based on my assessment). To ensure the anonymity of participants, demographic data is presented for all three focus groups combined (Table 8.1). Participants all chose a pseudonym to use during the focus group discussions; the names chosen by participants appear below when direct quotes are used.

Table 8.1. Demographic information about focus group sample

Characteristics of focus group sample	Number of participants
Age	
20-39	7
40-59	5
Gender as identified by participant	
Female	5
Male	7
Place of Residence	
Bristol	3
Somerset	8
South Gloucestershire	1
Type of Residence	
Residential	2
Supported Living	2
Family home	2
Private tenancy	3
Own property	1
Other	2
Does participant have support when attending health appointments?	
Yes	8
Sometimes	2
No	2
Of the 10 participants who have support; who does participant choose to support them?	
Support worker (paid member of staff)	6
Family member	3
Health liaison worker	1

8.3. Data Analysis

Similar to the analysis of interview data, I first familiarised myself with the focus group data before undertaking a series of coding sweeps. I was interested in exploring how participants made sense of health decision-making and how they wanted to be supported to make their own health decisions. At the end of the third coding sweep, I had a total of 71 semantic codes. Codes at this stage were semantic, closely aligning and representing what the participants had said. For example, “don’t use jargon”, “choice of how information is provided”, “wanting to understand” and “supporter helps understanding of health information”.

When thinking about themes I initially considered recurring codes (i.e., aspects that were frequently discussed by several participants across all three focus groups) before thinking about the unifying concept, trying to identify the key idea that joined together individual codes (Braun and Clarke, 2022). For example, the codes above were collectively joined as a potential theme: “supporter as translator” (which later became “supporter as interpreter”). This was one of four potential themes identified at this stage, along with “decision-making know-how"; “developing confidence is key to decision-making"; and “assumptions about people with learning disabilities”. Further critical discussions were held with my supervisor (SD), before consideration of potential themes.

My interpretation was central to the process of thinking about themes that told “a situated story” (Braun and Clarke, 2022, p.295) about the essence of supporting health decision-making practice and how focus group participants wanted to be supported to make their own health decisions. This resulted in the development of three themes as illustrated in Table 5.2. Two codes, “don’t use jargon” and “use plain English” were subsequently incorporated into two themes (highlighted in bold in Table 8.2 and discussed below).

Table 8.2. Example of codes supporting each theme

Example of Codes	**Developed Theme**
Supporter helps understanding of health information Concern about misunderstanding Wanting to understand / Wanting to sound things out Hard vs. easy decisions to make Trust in supporter is an important part of supporting decision-making Choice of how information presented as accessible is different for everyone **Don't use jargon. Use plain English**	Supporter is an interpreter of health information
Decision-making know-how Working towards making own decisions **or** I make my own decisions Making own decisions is awesome Knowledge about health needed to make a decision Support groups can be helpful Support person(s) can give you confidence Problem solving – weighing up information to make a decision	Health literacy helps develop confidence to make and implement decisions
Health professionals should know what they are doing Unhelpful assumptions about people with a learning disability Poor healthcare experiences Experience of over shadowing Listen to us. Talk to me not my support person. Look at me Qualities required of health professionals **Don't use jargon. Use plain English**	Health professionals need to be prepared for having a patient who has a learning disability

8.4. Findings

Three themes were developed from the focus group data in answer to my research questions about what facilitates and hinders supporting health decision-making with adults who have a learning disability: 1: The supporter is an interpreter of health information; 2: Health literacy helps develop confidence to make and implement health decisions; and 3: Health professionals need to be prepared for having a patient who has a learning disability. These themes will now be discussed.

8.4.1. Theme 1: The supporter is an interpreter of health information – *"…just in case the doctor says something that I don't really understand, and the staff then can explain it in a way that I do"*

This first theme focuses on the role the supporter has as an interpreter of health information between the health professional and the individual with a learning disability. This was discussed by participants as essential. Most participants valued having the supporter with them at health appointments as this enabled them to discuss the decision following the health appointment; "...because we discuss things later" (Jet). It required the supporter to have skills and expertise in making information accessible, in effect to be able to communicate health information provided by health professionals (which participants highlighted was often confusing and challenging to understand) into accessible information, which enabled participants to make sense of the information so that they could make an informed decision. The supporter's role as an interpreter appeared to be an integral factor in supporting individuals to make their own health decisions:

> "...if you don't understand what they're [health professional] saying then having somebody else there… who can explain to you 'cos sometimes it is, understand some of their jargon [hum] that they come out with and if you're not sure…" (Orlando)

> “Well, I did understand what happened ‘cos they [supporter] explained to me...” (Elton).

The role of the supporter(s) as interpreter(s) of health information appears pivotal in supporting decision-making, as participants discussed not always being able to understand what health professionals told them. In the following excerpt, Jet reflects on an occasion when they did not take a supporter with them to a health appointment which resulted in them misunderstanding the information given by the doctor, leading to unnecessary worry and anxiety:

> “I remember going to the doctors on my own and not quite understanding what the doctor had said and he said I needed a biopsy (…) I didn’t get it, so I went home terrified saying ‘awwwww, I’ve got cancer, I’ve got cancer’ and if I had a member of staff with me at the time, they would have explained ‘no, it’s not what that…, but it’s something else’” (Jet).

Some participants described experiencing anxiety and doubt, expressing concern about potentially making the “wrong” decision (Lavender Lily). When probed, making a wrong decision was discussed in terms of the participant not understanding what the healthcare professional had said to them, resulting in them making what they felt was the wrong decision due to a misunderstanding of pertinent health information. However, potential misunderstandings could be avoided with involvement of the supporter. Participants described how it was helpful when they didn’t feel sure that they had understood the relevant information to be able to talk the decision through with their supporter(s) following the health appointment. Doing this reduced the chances of them misunderstanding the information given by the health professional, therefore reducing anxiety. Ed and Elton also discussed how it can be helpful if health professionals write key information down or write it in an e-mail so that they can share and discuss it with their supporter(s) at a later time,

> Elton: Yeah. So, like if you're, if you're in there for example and they tell you all that, you've got to remember that memory and that
> Ed: Yeah, and it's good to write it down
> Elton: It's good to write it down maybe on your phone or maybe they send you an e-mail… or maybe they write it down
> Ed: yeah
> Elton: …or print it on a piece of paper for you [or give it to your staff] [overlapping]
> Ed: [Yeah, you're remember it then like] [overlapping]

Talking the decision through with the supporter either as part of, or after the health appointment was discussed as important in terms of ensuring participants had understood the information to be able to make a decision. This did appear to vary, however, from individual to individual as well as depending on how hard the decision was to make. There was some consensus about the difference between an 'easy' and a 'hard' decision. Easy decisions were identified as ones where there was a clear need (e.g., suspected broken arm causing pain), proposed intervention (x-ray at the hospital) followed by treatment (arm put in plaster cast), whilst 'hard' decisions required participants to think more in order to weigh up all the required information. Changes to medication for long-term conditions as well as decisions about diagnostic interventions, which could be "scary" (Freddie) (e.g., brain scan), were identified as being 'hard' decisions, requiring more discussion and collaboration with the supporter(s). Lavender Lily described how they discussed a decision and the information relating to the decision with their supporter(s) to check that they had understood it correctly,

> "to see if I've got the right end of the stick (…) Because I might be wrong, so I'll double check if it's right..." (Lavender Lily).

Several participants said that the use of jargon by health professionals, defined as "words you don't understand, complicated words and sentences about the medication or about your health" (Lavender Lily), made it hard to understand health information provided. The use of "jargon" by health professionals is an aspect of both this theme and theme 3 (as discussed below). In relation to this theme, it highlights the importance of health information being accessible to the patient. When probed about what makes information accessible, participants often found this difficult to articulate. There was lots of discussion in all focus groups but little consensus as participants expressed different needs and preferences. Some participants preferred information to be written down in short sentences, some preferred 'easy read', some preferred to have the original "long document" (Will), whilst others preferred pictures, with one participant identifying a preference for photographs.

The consequences of participants not understanding health information pertinent to the decision combined with the complexity of making information accessible, appears to make the role of supporter(s) as health interpreter(s) a significant factor in supporting adults with a learning disability to make their own health decisions.

8.4.2. Theme 2: Health literacy helps develop confidence to make and implement health decisions - *"... I wouldn't say boo to a goose but now they can't shut me up"*

This second theme was a recurring discussion point in all focus groups. Participants appeared to be well informed about their rights and health issues in general, they were aware that decision-making capacity can fluctuate, and discussed how they sought and used support when making health decisions. Having underpinning knowledge and understanding of health issues as well as an understanding of the right to make their own decisions appeared to be empowering, enabling individuals to have confidence to make and implement their own decisions. Knowing what to expect at routine health interventions such as an annual health check was discussed as increasing confidence in decision-making as participants were prepared.

Many (but not all) of the focus group participants attended a social or support group of some description specifically for adults with learning disabilities. These groups were often referred to as the place where participants had learnt about health issues or health information as well as decision-making rights, which helped individuals to feel confident in making and implementing their own health decisions,

> "It's a healthy, making sure [chuckles] you lose a bit of weight, (…) I think [name of group] kind of thing give me the confidence get the uh… make my own choice or whatever" (Jonathan).

Orlando highlighted that it was through attendance at a social group that he had learnt about what to expect from annual health checks, reflecting that this had supported him to develop knowledge and understanding of health issues along with their decision-making rights. This was discussed in terms of giving confidence to make health decisions and crucially to implement their decision,

> "...because before I came to [social group] I wouldn't say boo to a goose but now they can't shut me up" (Orlando).

Some participants discussed how confidence to make your own health decisions develops over time, as well as identifying a link between having confidence in their supporter(s) knowledge and understanding and feeling confident in themselves as decision-makers. Participants were discerning about who they selected to support them with health decision-making. Participants explained how they chose supporter(s) whom they knew, trusted and had confidence in that person's knowledge and understanding of health or health-related issues. For example, Jane discussed how she chooses somebody from the GP surgery to support her with health decision-making as this person understands the health issue(s) as they “work in health” (Jane). Whilst Elton discussed how he chooses people to support him based on the person’s experience and how good he thinks they are at their job,

> “...I wouldn’t just go with unregulars (…) she [supporter] knows what she’s doing, she’s very good at that... (…) You’ve got to feel confident with [supporter]” (Elton).

Having an underpinning knowledge and understanding of health issues, helped develop participants’ confidence to make and implement their own health decisions. Making health decisions was for some something to strive towards, and frequently discussed in terms of becoming independent, being accountable and having control over their lives,

> "...it's not just awesome, it feels like you're being (...) your own PM Prime Minister" (Cinnamon).

8.4.3. Theme 3: Health professionals need to be prepared for having a patient who has a learning disability – *“…health professionals should know what they’re doing”*

Some participants reflected on their poor experiences of healthcare services, which for some had caused considerable anxiety. Jane reflected her experience of having had asthma initially mis-diagnosed as anxiety. Jane discussed how the failure to recognise her asthma resulted in an emergency hospital admission, while Freddie discussed an occasion when he had been told by the GP surgery that his medication was being stopped. He reflected on the anxiety this caused him as he knew that he needed these tablets to keep him well. Freddie talked about how having his Mum's support had enabled him to calm down and to be able to speak to the GP to resolve the error:

> "I suppose she [Mum] was there and, and she said 'don't worry' and I told the doctor off but any[way], he was fine with it and actually laughed... I didn't have to change my tablets (...) because it was like, the surgery had got it wrong." (Freddie)

The supporter in this example was Freddie's advocate, empowering him to take control and challenge what he had been told by the receptionists by discussing it with the doctor in order to have his medication continued.

Participants discussed the expectations placed on them, as patients, to be prepared for health appointments. Examples given were completing a form before having an annual health check and taking a urine sample with them to an appointment, but participants highlighted that there should also be an expectation that the health professional is prepared for the appointment with them. One negative healthcare experience identified was discussed in terms of healthcare staff not being prepared for the appointment:

> "...people should know what they're doing when you go for a health check or, or, or um an operation because I had, I went for my blood test, they didn't know it was for my [condition] … um they thought it was for something different and I ended up in hospital [hum / ok] so they should, professionals, health professionals should know what they're doing" (Lavender Lily).

When participants reflected on experiences where the health professionals were aware and prepared for their appointment, experiences were more likely to be discussed positively. Jonathan for example talked about it being helpful that health professionals and services are already aware that they have a learning disability before they arrive. Participants, however, differentiated between health professionals being aware of their learning disability as being helpful in contrast to health professionals having negative views and making unhelpful assumptions about them because they have a learning disability:

> "I think some doctors can treat people with learning disabilities as an imbecile and stupid (…) we're not, talk to us" (Jet).

> "I think accusations on people with a learning disability or Autism (…) I think people are quick to decide (…) [people assume] ' you can't speak for yourself and you can't have a choice, you don't make decisions' (…) and that is absolutely disgusting" (Cinnamon).

Participants expressed concern for people who might not have the same skills and support as they have, for example people with more severe learning disabilities and those who do not use verbal methods of communication. Participants suggested that health professionals should learn to be able to support people with different needs:

> "If people can't speak, by being able to, people who work in health learning about people who can't speak (pause) and people with severe disabilities, meeting their needs (pause) (…) for them [health professionals] to be able to learn about the needs of people who can't speak" (Jane).

Some participants suggested that all people working within healthcare environments, including receptionists who are often the first people a patient sees, should have "better training" (Orlando). There was consensus as to what health professionals need to do to improve how they support people with different needs. Several participants spoke about the need for health professionals to be "kind" (Freddie) and "non-judgmental" (Will), to speak clearly (Ed), to give choices (Cinnamon) and to listen to what the patient says (Ed). Two examples discussed in all focus group discussions, which made participants frustrated, were health professionals using jargon, which the participants could not understand (discussed in theme 1 above in relation to accessibility of health information) and the health professional talking to their supporter rather than them:

> "…they're more focused on the carer than they are on the patient, and that's not good, that's not good (…) he was talking to my Mum, and he wasn't talking to me and I'm the one having the procedure done for God's sake." (Cinnamon)

Several participants discussed ways in which they were trying to actively challenge what they perceived as poor practice. For example, some participants discussed how they were trying to remedy this by having their support person sit behind them in appointments to encourage the health professional to talk to them rather than their supporter.

8.5. Summary

Without exception, focus group participants wanted to make their own health decisions, which they often referred to as being (or working towards being) independent. They discussed that they needed support to make health decisions, which they sought from people (supporters) whom they trusted and perceived to be knowledgeable about health. These findings illustrate **how** adults with a learning disability want to be supported to make their own health decisions. They wanted their supporter to help them interpret what was discussed as it was often complex health information. They felt that learning about health and decision-making rights had helped them to develop confidence in not only in making a health decision but also acting on and implementing their decision. Focus group participants also felt strongly that health professionals should be prepared for having a patient who has a learning disability.

The synthesised findings from all four data sets: interviews with adults who have a learning disability; family members; healthcare staff including survey responses from student nurses; and focus group discussions, will now be discussed in Chapter 9.

Chapter 9: Discussion - The significance of my research findings

9.1. Introduction

This chapter discusses the significance of my research findings. Whilst chapters 5-8 focused on the developed themes from the individual data sets, this chapter considers how the findings from the four datasets collectively advance our understanding of supporting health decision-making with adults who have a learning disability in England, drawing out similarities as well as tensions. In table 9.1. below, the themes developed from the data are presented in response to the research questions. Collectively, the developed themes suggest that a combination of three central factors facilitate supporting health decision-making with adults who have a learning disability: MCA literacy, health literacy and valuing individuals (Table 9.2). It is when there is an absence of one or more of these that supporting health decision-making is likely to be hindered.

This chapter commences with a discussion of the two key overarching findings from analysis of the data collected: 1. Participants with a learning disability wanted to make their own health decisions; and 2. There was evidence of good practice in supporting health decision-making but not everyone had a good experience, before a discussion of each of the three factors is presented.

Table 9.1. Research questions and developed themes in response to questions

Research Question(s)	**Findings from Developed Theme(s)**
What supports adults with a learning disability to make their own health decisions? How do adults with a learning disability want to be supported to make health decisions?	• Understanding decision-making 'rights' (Chapter 5) • Opportunities to understand the decision that needs to be made (Chapter 5) • Having informal validation (Chapter 5) • Having a supporter to interpret health information (Chapter 8) • Health literacy helps develop confidence to make and implement health decisions (Chapter 8)
What facilitates supporting health decision-making with adults who have a learning disability from the perspectives of adults with a learning disability, family members and healthcare staff?	• MCA knowledge and understanding are paramount in order to support health decision-making (Chapter 7) • Health professionals being prepared for having a patient who has a learning disability (Chapter 8) • Understanding the person is at the heart of supporting decision-making (Chapter 7) • Listening to family expertise supports health decision-making (Chapter 6) • Work with us [families], not against us (Chapter 6) • Respect is required for all involved in the supporting health decision-making process (Chapter 7) • Disability identity impacts health decision-making experiences [so can both facilitate or hinder supporting health decision-making] (Chapter 5) • Let's make healthcare information accessible for everyone (Chapter 7)
What hinders supporting health decision-making with adults who have a learning disability from the perspectives of adults with a learning disability, family members and healthcare staff?	• Disability identity impacts health decision-making experiences (Chapter 5) • Staff sometimes lack knowledge and understanding to support health decision-making (Chapter 6) • Applying the MCA can lead to further disadvantage (Chapter 6) • You don't always get supporting decision-making right first time (Chapter 7)

9.1.1. Overarching Finding 1: Participants with a learning disability wanted to make their own health decisions

This research started with the premise that supporting decision-making was a requirement of Principle 2 of the MCA, and therefore did not ask people if they thought it was a good idea. Without exception, all of the participants with a learning disability who contributed to my research wanted to make their own health decisions, which they often referred to as being, or working towards being, independent. Participants did not want other people to make health decisions for them. This finding corresponds with the psychological construct of 'self-determination', which as discussed in Chapter 2 is concerned with the degree to which people are "actors in their own lives, rather than being acted upon" (Wehmeyer and Abrey, 2013, p.399); or as Cinnamon, in one of the focus group discussions said was like "...being (…) your own PM Prime Minister".

Carney *et al.* (2023) suggest it is difficult to assess "whether support actually helps someone with a cognitive disability to achieve their will or preferences" (p.503). Whilst this can be more challenging when working with people who have more severe or profound learning disabilities as will be discussed later, the participants with a mild or moderate learning disability in my study were able to discuss numerous examples of **how** support had enabled them to achieve their will, preferences and goals with regards to their health. Wehmeyer and Abrey (2013) advocate that capacity to become self-determined can increase with the right support, which underpins Article 12 of the UN CRPD (2006). My findings support this, suggesting that with the right support people with a learning disability can develop confidence in making and implementing their own health decisions.

As intended in the research design, the family member participants reflect the experiences of supporting adults who have a more severe or profound learning disability or a learning disability with complex needs (Chapter 6). This is in contrast to the adults with a learning disability who were interviewed (Chapter 5) and those who participated in the focus groups (Chapter 8), who were more likely to have a mild or moderate learning disability and to be able to talk to me about their experiences and perspectives. Healthcare staff spoke about experiences of supporting individuals with different learning disabilities, ranging from mild to profound and multiple learning disabilities (Chapter 7). As has been highlighted previously in the published literature (Watson, Voss and Bloomer, 2019; Watson, Wilson and Hagiliassis, 2017; Watson, 2016), people with a severe or profound learning disability have different support needs. Watson (2016) advocates the focus should be on the responsiveness of the supporter rather than the individual with a learning disability. My research findings support this suggesting that families and healthcare staff are in a good position to ensure the individual's preferences remain at the heart of the decision-making process by being tuned in and responsive to the individual's formal and informal methods of communication.

9.1.2. Overarching Finding 2: There was evidence of good practice in supporting health decision-making but not everyone had a good experience

One of the original motivations for my PhD research was The House of Lords post-MCA legislative scrutiny report, which advised that supporting decision-making was "rare in practice" (House of Lords, 2014, p.41). Later, the UN (2017a) suggested the UK was lacking in supporting decision-making practice advocating that more research was required to advance knowledge, practice and policy in this area. Whilst these reports were published over seven years ago, hence potentially reflecting dated practice, literature from England (Health Services Safety Investigations Board, 2023; Devi *et al.* 2020; Harding and Taşcioğlu, 2018; Jamieson, Theodore and Raczka, 2016) has continued to suggest that supporting people with learning disabilities to make their own decisions requires improvement. This was also my personal perspective from my experiences as a Registered Learning Disabilities Nurse in clinical practice and my observations of having a family member with a learning disability.

My research illustrates numerous positive examples of supporting health decision-making, from the perspectives of healthcare staff and from adults who have a learning disability. Whilst this might be related to the use of purposive sampling and respondent bias, my findings provide some evidence that supporting health decision-making can be done well in busy healthcare environments. People with learning disabilities spoke positively about situations when they felt they had been effectively supported to make their own health decision(s). This however was not the experience of all. Many of the family members, who were talking about experiences of supporting health decision-making with people who had a more severe or profound learning disability and/or complex needs, expressed concerns. Family members were concerned that the individual’s wishes and preferences were not always at the centre of the decision-making process, which they felt was due in part to healthcare staff not always understanding how to apply the MCA in their practice. They discussed examples when they felt staff had not worked in partnership, or consulted with the family who knew the individual with a learning disability well. Family members also questioned if the application of the MCA might result in further health inequalities for individuals who have a learning disability (as will be discussed later).

Healthcare staff provided examples of where they had either supported an individual to make their own health decision or supported the decision-making process to ensure that an individual’s will and preferences were at the heart of the decision-making process. They spoke about the potential benefits of supporting someone to make their own health decision surpassing the immediate value of improving the health experience and outcome for the individual they were supporting with that decision. Longer-term impact was highlighted such as an increase of trust in healthcare staff and services, which combined with an increase in the individual’s confidence could result in the person being more independent and requiring less support in future healthcare appointments. Examples were provided where creative solutions had been used to support someone with a more moderate or severe learning disability to be involved in their health decision-making and to evidence either the person’s decision or the person’s will and/or preference, which then informed the decision-making process. Family members spoke about how using approaches specifically tailored to an individual with a more severe or profound learning disability, such as Intensive interaction (Hewett, 2018) or social stories™ (Gray, 1994), can help support an individual to be involved and at the centre of the decision-making process.

Much of the published literature on supporting decision-making, as discussed in Chapter 3, has incorporated a broad spectrum of decisions (e.g., Carney *et al.* 2023; Casey, Desmond and Coffey, 2023a; 2023b; Bigby *et al.* 2022b; Browning, Bigby and Douglas, 2021; Rogers *et al.* 2020; Bigby, Whiteside and Douglas, 2019; Davidson *et al.* 2018; Harding and Taşcioğlu, 2018; Ryan, 2018; Bigby *et al*. 2017; Shogren *et al.* 2017; Bigby, Whiteside and Douglas, 2015; Davidson *et al.* 2015; Kohn and Blumenthal, 2014; Werner, 2012) whereas my study appears to be unique in focusing specifically on health decisions in relation to Principle 2 of the MCA. Published literature has suggested that there might be a difference in supporting decision-making practice depending on the complexity of the decision to be made (Devi *et al.* 2020; Harding and Taşcioğlu, 2018). Whilst focus group participants in my study articulated differences between what they considered to be 'hard' and 'easy' health decisions to make, interview and focus group participants spoke about a range of health decisions identifying examples of positive supporting decision-making regardless of the complexity of the decision. My findings suggest that it is likely to be a combination of the presence or absence of three key factors, discussed below, that either enable or hinder supporting health decision-making rather than the complexity of the decision itself.

9.2. What my research contributes to our understanding

In line with the findings of the work by Douglas and Bigby (2020) which explored supporting decision-making more generally, and Harding and Taşcioğlu (2018) who explored supporting decision-making in England and Wales, my findings suggest that several aspects are required for supporting decision-making to be implemented consistently and applied in a meaningful way. Health decisions are rarely made in isolation. In addition to the person with a learning disability, they frequently involve several healthcare staff, often from different professional groups, working across different settings, as well as family members and support staff or personal assistants. When supporting decision-making was discussed positively by participants, multiple factors appeared to be involved whereas when it was discussed negatively and with frustration, multiple aspects appeared to be absent.

From my research findings, the three key factors (Fig 9.1) which appear to be significant in supporting health decision-making with adults who have a learning disability are: MCA literacy; Health literacy; and Valuing Individuals. Table 9.2. below demonstrate how the developed themes align to these three factors, which will subsequently be discussed.

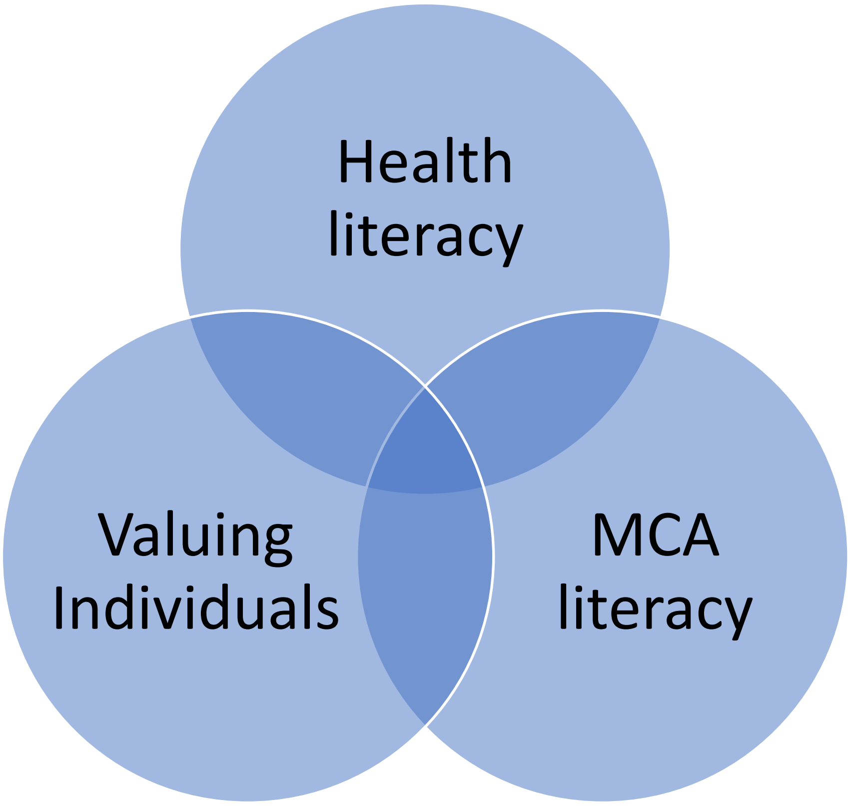

Fig 9.1. The three key factors required to enable supporting health decision-making with adults who have a learning disability

Table 9.2. Showing how developed themes align with the three factors identified

Developed themes from datasets	**Enablers or barriers to supporting health decision-making in line with Principle 2 of the MCA**
Understanding decision-making ‘rights’ can support health decision-making autonomy (Chapter 5) MCA knowledge and understanding are paramount in order to support health decision-making (Chapter 7) Staff sometimes lack knowledge and understanding to support health decision-making (Chapter 6) You don’t always get supporting decision-making right first time (Chapter 7) Informal validation helps us to make our own health decision (Chapter 5)	MCA Literacy
We need opportunities to understand the decision that needs to be made (Chapter 5) Let’s make healthcare information accessible for everyone (Chapter 7) The supporter is an interpreter of health information (Chapter 8) Health literacy helps develop confidence to make and implement health decisions (Chapter 8)	Health Literacy
Disability identity impacts health decision-making experiences (Chapter 5) Applying the MCA can lead to further disadvantage (Chapter 6) Health professionals need to be prepared for having a patient who has a learning disability (Chapter 8) Understanding the person is at the heart of supporting decision-making (Chapter 7) Listening to family expertise supports health decision-making (Chapter 6) Work with us, not against us (Chapter 6) Respect is required for all involved in the supporting health decision-making process (Chapter 7)	Valuing Individuals

9.3. Mental Capacity Act literacy

Adapting the definition proposed by Sørensen *et al.* (2012) for health literacy (which will be discussed below), I suggest that 'Mental Capacity Act literacy' describes people's knowledge, motivation and competence to access, understand, appraise, and apply Mental Capacity Act legislation and guidance in daily healthcare practice. My research findings suggest that MCA literacy is a core factor for enabling supporting health decision-making practice with adults who have a learning disability. In essence, healthcare staff need to access MCA education or training, and to understand the legislation to be able to make judgements in their daily practice about how to apply the Principles for the benefit of the individual patient.

9.3.1. MCA knowledge and understanding

Concerns about healthcare staff misunderstanding the MCA or not having the confidence to apply it in their practice were widespread across my data. Misunderstandings about the MCA appeared to be a barrier to supporting decision-making practice in healthcare settings, with the potential to cause conflict among healthcare staff themselves; between healthcare staff and family members; and/or between people with a learning disability and healthcare staff. Some of the recent work by Bigby *et al.* (2022a) in Australia has focused on the training of family members in supporting decision-making. Notably, in my study, it was the family members who suggested that healthcare staff required more training in supporting decision-making, a recommendation which was also advocated by the healthcare staff themselves. Family members specifically referred to healthcare professionals, who they perceived misapplied the MCA in their practice, as well as unqualified support staff who they felt did not realise when their practice was in contradiction to the Act. A cause of conflict for the healthcare staff who spoke to me was associated with **other** healthcare staff, who were perceived as not always having a good understanding of the MCA and/or the confidence to apply it in their practice, which has been highlighted in previous research (e.g., Waliji, Fletcher and Weatherhead, 2014). Similar to the findings of Davidson *et al.* (2018), participants with a learning disability who contributed to focus group discussions specifically sought out staff who they perceived to be “good at their job” to support them with health decision-making, seeming to choose staff who they felt knew what they were doing and so were better able to support them. Knowledge and understanding of the MCA appears to be a significant factor in enabling supporting health decision-making practice.

Whilst good practice was evident, my findings suggest decision-making practice is not consistently in line with Principle 2 of the MCA due to a lack of knowledge and/or confidence in applying the MCA by healthcare staff. The ‘legislation-practice’ gap, which has been identified in previous research (for example, Jenkins *et al.* 2020; Dunn, Clare and Holland, 2010 as discussed in Chapters 2), persists. Participants (family members and healthcare staff) in my research gave examples of when they perceived capacity had been incorrectly assumed (meaning that individuals could be receiving health interventions against their wishes), had been used incorrectly as a reason not to provide a healthcare intervention or simply not applied at all. These examples echo the House of Lords (2014) scrutiny report findings. They also raise doubts about the content and quality of MCA training for healthcare staff and question if the MCA could be further increasing health inequalities for people with learning disabilities. The potential for policies to inadvertently increase health inequalities has already been discussed within the context of public health initiatives (Emerson and Hatton, 2014) and is a further justification for the need to focus on factors which can improve supporting decision-making practice across healthcare practice.

With regards to healthcare staff knowledge and understanding of the MCA, my findings concur with the published literature (Jenkins *et al.* 2020; Marshall and Sprung, 2018; Willner *et al*. 2013; Gough and Kerlin, 2012; Phair and Manthorpe, 2012), questioning the quality and reliability of the content and format of some of the current mandatory MCA training on offer to healthcare staff. As reflected in previous literature (eg., Jenkins *et al.* 2020) asynchronous e-learning packages were identified by many of the staff participants as being largely ineffective. Some staff for example reflected on how they and their colleagues might go straight to answering the questions to 'complete' the MCA mandatory training e-package rather than working through each of the suggested sections. Asynchronous e-learning might also potentially further perpetuate a misconception that application of the MCA is a "tick-box" activity as has been found in previous research in relation to MCA training more generally (Scott *et al.* 2020; Marshall and Sprung, 2016).

My research findings also raise some potential concerns with face-to-face MCA training, suggesting that current face-to-face synchronous training also can perpetuate confusion about the Act. Some healthcare staff participants discussed how they had received conflicting guidance in different MCA training sessions, with the quality of the training appearing to depend on who the training was facilitated by and how the 'trainer' had interpreted how the Act should be implemented. This point requires further exploration but potentially suggests the need for nationalised standards for MCA education and training, and a set of agreed national proficiencies for those who are facilitating MCA training to ensure quality of content and delivery.

My research findings suggest that MCA education initiatives need to move beyond a high-level discussion focusing on communication with regards to Principle 2. They need to include a discussion about the values underpinning this Principle of the MCA; emphasising the legal requirement for healthcare staff to support an individual to make their own health decision **before** a capacity assessment is considered; as well as accentuating the iterative nature of supporting decision-making as a process. Other suggestions for improvement include making sure MCA training is grounded in real-life anonymised case scenarios, which illustrate **how** individuals can be supported to make their own health decisions as well as making training interactive and discussion based. This finding is in line with recommendations from published literature reviews exploring more general application of the Act in association with MCA training (Jenkins *et al.* 2020), decision-making with older people (Hinsliff-Smith *et al.* 2017) and community nursing (Marshall and Sprung, 2016).

9.3.2. Supporting decision-making is an iterative process

My findings support the findings of the studies by Rogers *et al.* (2020) and Bigby, Whiteside and Douglas (2015) emphasising the iterative and often complex process of supporting health decision-making. Multiple attempts and different approaches are required, none of which are guaranteed to work. My findings illustrate several examples of Principle 2 of the MCA being applied well in 'real life' busy health settings. However, healthcare staff discussed sometimes finding the iterative process one of the most challenging aspects of supporting health decision-making, not always knowing when they had done enough. In one example, a community nurse reflected how they felt they had "professionally failed" when supporting decision-making had not been effective in facilitating an individual to make their own health decision despite having tried several different approaches -in partnership with the individual's mother- over a number of weeks. Some staff who participated in my research appeared to view a Best Interest decision as "failure" as opposed to the appropriate 'next step' in line with the MCA.

The flexibility of Principle 2 in promoting a person-centred approach may paradoxically be one of its weaknesses with regards to implementation. My research findings suggest there is sometimes confusion and/or anxiety about what "all practical steps" looks like and what it means in 'real life' contexts. It seems important therefore to prepare staff for the reality that attempts to support decision-making might not always work first time or work at all. The iterative nature of supporting decision-making should be emphasised as part of MCA training and guidance so that healthcare staff are prepared for the realities and 'messiness' of the process, as well as having opportunities to consider and discuss examples of what “all practicable steps” looks like, using ‘real life’ health case study scenarios.

9.3.3. Awareness of rights can support decision-making but only if the individual is in a position to act on them

Whilst my research findings question the MCA knowledge and understanding of healthcare staff (as discussed above), the knowledge and understanding of the participants who had a learning disability (in interviews and focus group discussions) was impressive. The individuals who spoke to me recognised that they had decision-making ‘rights’, which included being able to make their own decisions, to have support to understand information to make a decision, and to have the right to make an unwise decision if they understood the possible consequences. Participants also spoke about how people with different types of learning disability require different levels of support with decision-making. In the study in Northern Ireland by Davidson *et al.* (2018) participants were aware of their rights, however overall, there is an absence of literature concerning what people with a learning disability know or understand about their decision-making rights in line with the MCA. Literature regarding knowledge and understanding of the MCA has to date focused on staff (for example, Jenkins *et al.* 2020; Willner *et al.* 2013; Gough and Kerlin, 2012; Phair and Manthorpe, 2012; Dunn, Clare and Holland, 2010). This study might be the first in identifying the knowledge and understanding that some people with a learning disability have in relation to the MCA decision-making legislation; with my findings suggesting that understanding of decision-making rights might be a facilitative factor in supporting health decision-making autonomy. However, if people understand their decision-making rights and feel these are denied them, this can cause feelings of anger and resentment, potentially leading to conflict as will be discussed next.

Whilst mainly positive examples of supporting decision making were identified in the interviews with adults who have a learning disability, one participant felt that the MCA had been used against them, denying them the opportunity of making their own health decision. This person’s experience is incongruent with the underlining principles of the Act itself, which promotes autonomy underpinned by a presumption of capacity. This person’s experience aligns with the findings from some of the family members, who felt that the MCA had not been applied well by the staff who were working with their loved one. Where an individual or a family member perceived either their rights, or the rights of their loved one had inappropriately been denied or restricted, feelings of anger, resentment, and powerlessness were reported. This echoes the findings of the study by Davidson *et al.* (2018) and Jamieson, Theodore and Raczka (2016) in which participants who had not felt supported to make their own decision(s) felt angry and frustrated. My research findings question if in some cases individuals with a learning disability and family members might have a better understanding of the MCA compared with the healthcare staff. This could potentially lead to a mistrust of healthcare professionals and potential conflict.

Young and Quibell (2000) contend that whilst rights have been used in an attempt to redress injustices, ‘rights’ in themselves do not address the foundations on which the inequities originate, arguing that to act on one’s ‘rights’, one must be in a position which enables this to happen. Applying this to health decision-making, whereby the responsibility for applying the MCA resides with the healthcare staff proposing the treatment or intervention; regardless of how well informed the individual or family member is about their decision-making rights, the power ultimately remains with the healthcare staff. The staff are therefore in a position where they can either enable or prevent an individual to act on their rights. To rectify this, healthcare staff need to have adequate knowledge and understanding of the MCA to be able to apply it in their daily practice as well as positive and empowering attitudes about people who have a learning disability (and their supporters), as will be discussed later in this Chapter in section 9.5: Valuing Individuals.

9.3.4. Informal support is important

Informal support and validation were important to people with a learning disability and healthcare staff who participated in my research.

9.3.4.1. Informal support for people with a learning disability

Participants with a learning disability in my research demonstrated self-awareness, recognising their strengths as well as identifying that they needed support with decision-making from different people at different times. This support often came from a family member or a friend, whilst one participant spoke about God. Support for health decision-making depends on wider social and environmental circumstances, with context being significant. This aligns to supporting decision-making literature (Carney *et al.* 2023; Dowling *et al.* 2023; Sheahan, Bigby and Douglas, 2023; Bigby *et al.* 2022a; 2022b; Browning, Bigby and Douglas, 2021; Douglas and Bigby, 2020; Rogers *et al.* 2020; Bigby, Whiteside and Douglas, 2019; Davidson *et al.* 2018; Harding and Taşcioğlu, 2018; Watson, Wilson and Hagiliassis, 2017; Jamieson, Theodore and Raczka, 2016; Watson, 2016; Bigby, Whiteside and Douglas, 2015), which has consistently identified the importance of the **supporter**. In my study, paid healthcare staff were talked about as being both helpful and unhelpful in supporting decision-making. From my data, what appeared to potentially differentiate positive and negative experiences of health decision-making was having at least one trusting relationship with an informal (not paid) support person who was around during the process and at the time the decision needed to be made. Participants with a strong relationship with an informal support person appeared to be better able to navigate the complexities and often non-linear processes involved in health decision-making, or to have some resilience to it. The part informal supporters play appears to be in validating the individual in making their own decision, and in helping with the actual decision-making process, which participants said could be complex and confusing. Having an informal supporter acted as a “sounding board”, appearing to boost confidence, validating that the individual was able to make the required decision, and in essence **supporting** the individual to make their own health decision.

It appears from my research data that individuals without this unofficial support are potentially missing out on this informal process of ‘making sense’ of the decision to be made. In contrast to predominantly positive decision-making examples discussed by individuals with a learning disability, one person, without an informal support network, appeared to struggle to understand and navigate the complexities of the decision-making process. This participant felt that the MCA had been used by healthcare staff “against them”. This might suggest that the informal supporter plays an important role in supporting the person to ‘make sense’ of both the decision to be made and of the decision-making process itself. This requires further exploration, potentially raising the question as to how this “informal” supporter role can be replicated for those without robust informal support networks.

9.3.4.2. Informal support for healthcare staff

It was not only people with learning disabilities who appear to benefit from having an informal support person or informal support network. As well as mandatory MCA training and formal support (for example, clinical supervision), informal support was valued by the healthcare staff who participated in my study. Similar to participants with a learning disability, healthcare staff found the iterative process of supporting decision-making complicated.   Peer-support, reflexive discussions and impromptu advice from experienced colleagues, often sought informally, appeared to be invaluable in developing staff competence and confidence in supporting people with a learning disability to make their own decision(s). This supports previous research findings (for example, Carney *et al.* 2023; Bigby, Whiteside and Douglas, 2019; Bigby, Whiteside and Douglas 2015) corroborating the recommendation which has previously been made of having MCA workplace champions for staff to access in their routine daily practice as situations arise (Jenkins *et al.* 2020; Ratcliff and Chapman, 2014; Willner *et al.* 2013).

9.4. Health literacy

Alongside MCA literacy, health literacy appears to be important in supporting health decision-making. Following a systematic review of health literacy definitions and models, Sørensen *et al.* (2012) proposed the following definition,

> "Health literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course." (p.3).

In line with this definition, four competencies are required to be 'health literate': being able to access, understand, appraise and apply health information in everyday life. A lower health literacy level has been associated with poorer health outcomes (Paasche-Orlow and Wolf, 2007; DeWalt *et al*. 2004), and improving health literacy has been suggested to be a factor for improving health outcomes (Finlay *et al.* 2016). A recent systematic review found that whilst most research on health literacy has centred on adults with learning disabilities, it has focused on the first two health literacy competencies, accessing and understanding health information, without much consideration of the last two competencies of appraisal and application (Turnbull *et al.* 2023). Participants with a learning disability in my research, whilst not formally assessed, demonstrated face-value health literacy. Participants were able to discuss health interventions, which they clearly understood, demonstrating through interview or focus groups discussions how they had used this information to make and implement their own health decisions. Having access to health information and the support to understand relevant information appeared to facilitate confidence in making and implementing health decisions.

Significantly, the health literacy of the supporter(s) (who may or may not have a health qualification) appeared to be equally important to that of the individual with a learning disability. Focus group participants were discerning about who they chose to support them to make health decisions, articulating the importance of being able to choose a person whom they perceived to be knowledgeable about health. What is evident from the focus group data is that the individual needs to have confidence in their supporter(s), which appears to be linked to the health literacy of the supporter as perceived by the individual. This is likely to be significant as many people with learning disabilities are supported by staff who may have no formal health education. Health literacy for both the individual and the supporter(s) therefore appears to be a potentially important factor for supporting health decision-making.

9.4.1. Accessible Information

When participants with a learning disability talked about having been supported to make their own health decision, they were well-informed about the decision they made. This was demonstrated by the individual being able to explain the decision and implications of making and not making the decision during the interview or focus group discussion. The people who spoke to me identified a wide range and variety of information sources used to inform their health decision-making. Information sources included college courses; self-advocacy and social groups; monthly house meetings where they lived; healthcare professionals (doctors, surgeons, nurses including community learning disability nurses); non-qualified paid support staff; work preparation schemes; friends; and family members. Individuals also found television programmes and watching specifically produced DVDs about operations and medical procedures particularly useful. Whilst some people with a learning disability preferred information in ‘easy read’, others preferred ‘long documents’. At other times, people were unable to remember exactly where they had acquired health information. This tended to be for lifestyle decisions such as to lose weight or eat healthily, which might emphasise the ongoing importance of ensuring public health campaigns are accessible to people with learning disabilities, which has been previously identified by Emerson and Hatton (2014).

The need for accessible information has been identified within published research findings to support decision-making (for example, Dowling *et al.* 2023; Davidson *et al.* 2018; People First (Scotland) and Animate, 2017; Jamieson, Theodore and Raczka, 2016) as well as being a key recommendation in the MCA Code of Practice (OPG, 2017) and NICE guidance (2018) and a requirement of the *Equality Act* 2010. All 23-healthcare staff and student nurse participants in my research reported to use accessible information when supporting individuals to make health decisions. They discussed using a range of accessible information, with videos or DVDs and 'easy read' being frequently identified as having been used with good effect in supporting decision-making. However, the people with a learning disability who spoke to me had very different preferences and views as to what they find 'accessible', meaning that the provision of accessible information is not necessarily straight-forward nor easy to do well. My findings support previous work by Mander (2016), suggesting that accessible information is only likely to be effective in supporting decision-making if it is used as part of a person-centred process which focuses on the individual's strengths and preferences. Challenges were also highlighted by healthcare staff in terms of accessing suitable 'accessible' health resources, resulting in staff often having to develop their own accessible information. This finding suggests that at a time when healthcare services are under a lot of financial and workforce pressure (The King's Fund, 2023; 2022), many staff are potentially investing time in developing accessible resources, which somebody else may have already developed, therefore duplicating work. This finding echoes the findings found in my previous research focusing on infant-feeding decision-making with women with learning disabilities (Douglass *et al.* 2023; Dowling *et al.* 2023), which recommended an 'accessible resource bank' where generic and anonymised accessible resources could be uploaded and freely shared to save duplication of work.

9.4.2. Staff want accessible health information too

My research findings also suggest that it is not **only** people with a learning disability who require accessible health information. Family members suggested that support staff (who were likely to be unqualified and unregistered staff working in residential or supported living services, often with limited health education) were not able to reliably support their loved ones due to the staff not having a good understanding of health conditions or health interventions. Notably, some staff also reported that either they or staff they worked with, found it challenging to support an individual with a learning disability to make a health decision due to the complexity of some health decisions. It is well known that people with a learning disability are more likely to have multiple and complex health needs (NICE, 2021). What the findings of my research contribute is that accessible health information can be equally helpful for staff, as well as people with a learning disability. As one of the healthcare staff participants said:

> "...why can't we make it [health information] simpler?"

As discussed in Chapter 3, previous research suggests that when decision-making is passed to others it risks becoming a form of substitute rather than supported decision-making (Devi *et al.* 2020; Harding and Taşcioğlu, 2018). My findings suggest that it is often unqualified support staff who are in the best position to support an individual to make a health decision, however they may themselves have limited health knowledge. It is therefore important that these staff can also acquire accessible information to support them to understand the health condition or procedure, so that in turn they can provide effective support to the individual. This is reinforced by the findings from the focus group discussions, which as will be discussed next, suggest that the supporter often plays a significant part in making health information accessible, by taking on the role of a health interpreter.

9.4.3. The supporter’s role as an interpreter of health information

My focus group findings suggest that the supporter plays an important role as an interpreter of health information. The definition of an interpreter is,

> “Someone whose job is to change what someone else is saying into another language” (Cambridge Dictionary, 2023, p.403).

In the context of supporting decision-making, the supporter is interpreting medical or health language into an accessible form that the person they are supporting is able to understand. In line with previous research (Watson, 2016) which has highlighted the role of the supporter in ‘interpreting’ what the person with a learning disability is communicating, my research emphasises the role the supporter has in interpreting what the healthcare professional is saying to the person with a learning disability. As discussed previously, the importance of making health information accessible is not new. However, my findings highlight the complexity of the supporter’s role: They require a good level of health literacy as well as the ability to interpret medical information provided by health professionals into an accessible form that the individual with a learning disability can understand.

Many organizations providing health and social care services for people with learning disabilities recruit staff who may have limited previous experience in working with people with learning disabilities coupled with limited formal health or communication education and training. The Care Quality Commission (CQC) (2019) have previously highlighted concerns about the care provided to people with a learning disability, reporting that CQC inspectors found many learning disability services had employed staff who lacked “the skills, training, experience or clinical support” (p.6) to provide appropriate care and support. Poor retention of unqualified staff working in learning disability social care services has been linked in part to low pay (Stevens *et al.* 2021). In parallel, there has been concerns raised about the reduction in learning disability nursing numbers in England (Royal College of Nursing, 2021). The inconsistent practice in supporting individuals with learning disabilities to make their own health decisions could in part be a symptom of an under-trained, under-skilled, under-experienced workforce, with limited time, who are at the 'front line' of supporting adults who have a learning disability and are expected to perform what appears to be a complex role.

9.4.4. Social groups

As noted in Chapter 2, self-advocacy groups have been identified previously as being significant in supporting decision-making practice with people with learning disabilities. The findings of my research support this, whilst also suggesting that a variety of different ‘social groups’ (not just self-advocacy groups) might have a role in supporting decision-making autonomy. Many (but not all) of the individuals with learning disabilities who participated in my research were members of one or more social groups. I use the term “social groups” here to include the varied and assorted types of groups that individuals referred to within interviews and focus group discussions (which I appreciate might not be how groups view themselves). Some groups were facilitated in the supported living or residential settings where people lived, whilst others were more formal groups which were facilitated in the community separate and independent to the person’s living and support arrangements. Individuals with learning disabilities have different abilities and preferences, meaning it is unlikely that one type of social group will work or be of interest to everyone. My findings are therefore potentially helpful in signifying that it is more likely to be the core values underpinning the ‘social group’ and the bringing of people together that are important rather than the specific group attended. Social learning appears to be helpful, with the individuals who spoke to me welcoming the opportunity to learn and to talk about health information with peers.

My findings reinforce the promotion and development of facilitating ‘social groups’ as one way of supporting health decision-making autonomy. It appears that groups can have a key role in facilitating learning and education about health. Turnbull *et al.* (2023) suggest the research focus with regards to health literacy has been on access and understanding, leading to a widely held, but unsubstantiated assumption, that being able to access and understand health information results in application. My findings, albeit from a small study using purposive sampling, suggest that one way in which support groups might facilitate health decision-making is in helping people to learn about health and decision-making rights whilst also empowering individuals to act on these rights. All participants appeared to be knowledgeable about the health issues affecting them; an example discussed which had relevance to all focus group participants was annual health checks. Annual health checks are a public health initiative to reduce health inequalities (Department of Health and Social Care, 2018) and should be available to all individuals with a learning disability from the age of 14 (National Health Service, 2019). Participants explained how they had used information learnt from one of a variety of social groups they had attended to make and implement health decisions in relation to annual health checks.

9.5. Valuing individuals

The third factor which can either facilitate or be a barrier to supporting health decision-making is the attitude and assumptions made by healthcare staff. My findings support the published literature (e.g., Dowling *et al.* 2023; Rogers *et al.* 2020; Davidson *et al.* 2018; Jamieson, Theodore and Raczka, 2016) suggesting that negative assumptions held about people with learning disabilities by ‘others’ can be a barrier to supporting health decision-making. The study by Davidson *et al.* (2018) found negative experiences were more likely to be associated with “attitudes to disability” (p.44), whilst Rogers *et al.* (2020) study of 15 clinical psychologists suggested that there was “a presumption of capacity but a culture of incapacity” (p.238) due to perceptions about people with a learning disability not being able to make their own decisions. Participants (adults with learning disabilities, family members and healthcare staff) in my research talked about how they felt the negative attitudes and assumptions made by some healthcare professionals continue to impact on the health decision-making experiences and outcomes for people who have a learning disability.

9.5.1. Disability Identity

Concerns about discriminatory attitudes of healthcare staff in meeting the needs of people with a learning disability are not new and were part of my initial rationale for focusing on health decision-making. Some focus group participants talked specifically about the negative impact on them, discussing incidents when they felt health professionals had made unhelpful assumptions about people with a learning disability. As discussed in Chapter 2, in a literature review exploring attitudes towards individuals with disabilities, Wilson and Scior (2014) found implicit negative biases were common about people with a learning disability even among care staff who were paid to support individuals. Skowron (2016) contended that legislation is only one part of the picture, advocating that other measures are required to enable supporting decision-making, linking with Young and Quibell's (2000) perspective that 'rights' are only one part of the jigsaw. The need for wider staff training initiatives to raise awareness of the needs of people with learning disabilities have already been identified with the Oliver McGowan training that is now mandatory for all health staff (Health Education England, 2022). What remains to be seen is what impact this will have on changing what appear to be at times persistent negative attitudes and assumptions about people with a learning disability held by some healthcare staff.

For individuals who have a learning disability, one aspect which appears to be significant in supporting health decision-making autonomy is that of identity. Having a learning disability was a core part of individual identity, and a strong 'sense of self' seems to have been important in each of the participant's ability to make their own health decision(s). My research participants openly acknowledged their learning disability; it was part of who they were. Self-stigma was not evident. Whilst many people spoke about experiencing some form of discrimination from others due to having a learning disability, most discussed social interactions positively. It might be that these positive social interactions enabled participants to reject negativity associated with having a learning disability. This potentially links to the “web of interdependency” and relational autonomy as discussed by Kong and Keene (2018, p.44). In this way, the positive social relationships, discussed by participants, might have enabled individuals to feel supported to make their own health decisions, but also, at a more fundamental level, acted as a kind of “buffer” against social stigma. Individuals who do not have such a strong and robust support network, potentially might not have this same “buffer”. Identity and ‘sense of self’ might have been facilitative of individuals being able to demonstrate autonomy in health decision-making. As Young and Quibell (2000) suggest,

> “…when people know who they are, where they come from, and who they could be, their roles in society become more clear, more flexible, and hopefully more meaningful. In such a narrative, it is suddenly possible for the agents within to be ‘given their dues’, to have justice done to them.” (p.761).

By knowing who they are, being aware of their past as well as their strengths and opportunities, it is possible that this facilitated individuals in my study in being able to know and to also act on their rights. This also potentially resulted in responder bias whereby the people who chose to participate in my study were more likely to have the confidence that arises from having a ‘sense of self’. In recognising that the participants in my study are not representative of all adults with a learning disability, and that decision-making is not autonomous for all, the question therefore is how to understand these aspects so that they can be transferred and promoted to supporting decision-making more widely with people with learning disabilities.

9.5.2. Partnership working and respect

As discussed above health decisions are rarely made in isolation; often involving several people from different organisations and settings. All family members spoke about their loved one not being able to understand some health decisions due to the severity of their learning disability. The involvement of people who knew the person well was therefore a significant factor in ensuring that the individual's 'voice' was heard and at the centre of the decision-making process, as advocated in the MCA Code of Practice (OPG, 2007). The importance of 'knowing the person' is reflected in wider supporting decision-making literature (for example, Sheahan, Bigby and Douglas, 2023; Bigby *et al.* 2022b; Harding and Taşcioğlu, 2018; Watson, Wilson and Hagiliassis, 2017). In a paper exploring family members and staff experiences of supporting decision-making generally in Australia, knowing the individual well was identified as crucial (Bigby, Whiteside and Douglas, 2019). 'Knowing the person' is the first step of The La Trobe decision-making framework (Douglas and Bigby, 2020). For individuals with severe or profound learning disabilities, who might not be able to make their own decision, it is recognised that family members can offer invaluable information to support the decision-making process (Watson, Wilson and Hagiliassis, 2017; Watson, 2016). In the context of health decisions, my findings offer reassurance that whilst knowing the person is important, it does not matter necessarily if the healthcare staff do not know the person in advance of the decision needing to be made. For example, learning disability liaison nurses working in acute settings often do not know the individual before they are involved in supporting decision-making. What appears to be important is that the healthcare staff work in partnership with the individual, and also with the individual's wider support network to "get to know" the person so that supporting decision-making can build on the individual's strengths and preferences.

Conflict between healthcare staff and family members was identified as a potential barrier to supporting health decision-making in interview data from healthcare staff and family members. Many family members felt as though they were not kept informed, which subsequently excluded them from meaningful involvement. Healthcare staff were more likely to speak about the **potential** for conflict rather than actual conflict with family members, emphasising the importance of trying to understand the family's perspective and to find common ground. Healthcare staff participants identified that without doing so there was a potential for conflict to occur. Conflict, or the potential for conflict, has been discussed within the wider literature (for example, Rogers *et al.* 2020; Bigby, Whiteside and Douglas, 2019). There is recognition (OPG, 2007) that partnership working has the potential to deliver the best outcomes, whilst poor relationships can be a barrier to supporting decision-making (Jamieson, Theodore and Raczka, 2016). Sullivan and Hang (2018) advocate the importance of finding common ground in order for the valuable insights of family members to be heard. In England and Wales, recognition of the role of family members is already endorsed in the MCA Code of Practice (OPG, 2007), and part of NICE guidelines (2018). However, my findings suggest that tensions persist requiring further work to embed partnership working between healthcare staff and families in order to support health decision-making with individuals who have a severe or profound learning disability or a learning disability with complex needs.

The healthcare staff and family members who spoke to me were keen to find solutions. Healthcare staff themselves advocated for staff to try to understand the potential origins of different perspectives. There was, for example, appreciation in the staff data that most family members just wanted the best for their loved one, with recognition that families may have had previous negative experiences resulting in them having a distrust of healthcare services. Family participants suggested that family members should be viewed as “equal” to clinicians, with both roles (clinician and family member) being respected: whereas healthcare staff brought medical and healthcare expertise to the table, the family member brought expertise about their loved one, and only by working in partnership could the best outcome be found.

Most of the healthcare staff who spoke to me appeared to value different opinions, especially when supporting an individual with a more severe or profound learning disability to make a health decision. Where there was respect for different opinions (and an understanding of the reasons for the different opinions), partnership working appeared to be more effective in achieving the best outcome for the individual with a learning disability. However, family member participants recognised that not all family members are in a position to articulate the needs of their family member, which can be confounded by a power imbalance between healthcare professionals and family members. There was consensus across the family member data that the knowledge and expertise the family member has could be explored and extrapolated if healthcare staff asked the right questions, recognising the information that the family bring. This places the onus for involving the family member in supporting decision-making with healthcare staff. This seems reasonable for qualified and registered healthcare staff, who should have received training and who should be working within professional codes of conduct that endorse partnership working (for example, the Nursing and Midwifery Council, 2018). However, it is less clear how this aligns with unqualified and unregistered support staff, who often provide most of the day-to-day support to individuals with a learning disability. Some of these staff might not have received much if any training or education on working in partnership with family members. Staff may not feel confident to discuss health issues with families, which is likely to be exacerbated if the staff are not confident about the healthcare decision that needs to be made; and further intensified if they do not feel confident with their knowledge and understanding of the MCA. Previous supporting decision-making research suggests that in residential services where frontline staff do not have the required knowledge or do not feel confident in supporting decision-making or it is part of the localised policy, decisions can be passed to more senior staff (Devi *et al.* 2020; Harding and Taşcioğlu, 2018). However, senior staff do not always know the person with a learning disability well resulting in decisions being moved further away from the individual who should be at the centre of the decision-making process (Harding and Taşcioğlu, 2018). My findings concur with previous research that it is often the staff who are working with the individual on a daily basis, who are the best people to support an individual to make their own health decision. However, these staff do not always have the necessary knowledge and skills to do this effectively. What appears clear is that support staff need to be included in discussions about the health decisions themselves so that they understand the health decision that needs to be made. Being able to read accessible information about the health decision was welcomed by support staff. They also need to be able to develop their confidence in the application of the MCA with support, through for example shadowing and coaching opportunities with more experienced colleagues or senior member of staff. To support communication and the passing on of information, it may be beneficial to add a “how I like to be supported to make health decisions” to already existing and widely used documentation such as Hospital Passports, Health Passports, Communication Passports, Person Centred Plans and annual health check documentation, so that learning can be shared.

9.5.3. The need for flexibility within care pathways

Time was identified as a challenging aspect of supporting decision-making: it can take time for healthcare staff to get to know an individual with a learning disability and then it takes time to support decision-making. This finding is reflective of wider literature (for example, Casey, Desmond and Coffey, 2023a; Dowling *et al.* 2023; Rogers *et al.* 2020; Bigby, Whiteside and Douglas, 2019; Davidson *et al.* 2018). However, what is emphasised in my findings is that on top of the often-protracted time involved in supporting decision-making (if the MCA and Code of Practice is implemented correctly), individuals might then have to join lengthy waiting lists for the treatment or investigation. Family member participants discussed how this can result in individuals living in pain or discomfort for a long, extended period of time. This finding is potentially significant and requires further exploration. It suggests that application of the MCA has the potential to lead to further health inequity without reasonable adjustments being made to care pathways. The CIPOLD report (Heslop *et al.* 2013) identified that people with a learning disability were dying prematurely as a result of failures in systemic healthcare processes. It might be necessary to consider for example developing parallel care and treatment pathways for individuals this affects to mitigate against the extended time it takes to apply the MCA before a decision is reached. This is similar to the findings of the study with seven healthcare staff exploring infant feeding decision-making with women who have a learning disability by Dowling *et al.* (2023), where participants suggested that the rigidity of maternity pathways can make it difficult for professionals to work in a person-centred way, necessary for supporting women with a learning disability to make their own decisions. My PhD research findings continue to highlight a potential tension between “rigidity” of care pathways in place and the application of the MCA and reasonable adjustments as required by the *Equality Act* 2010.

9.6. Summary

In line with the findings of previous research exploring supporting decision-making more generally, my findings add weight that many factors are required for supporting decision-making to be applied in a meaningful way. Health decision-making is complex and health decisions are rarely made in isolation; often several different organisations and healthcare professionals are involved. Three key factors appear to be significant in the application of supporting health decision-making: MCA literacy; health literacy and valuing individuals, which requires healthcare staff to be prepared and to have a positive attitude towards people with a learning disability, valuing and supporting individuals to make their own decisions.

In the next Chapter, I discuss how my personal and professional position has shaped and influenced all aspects of this research.

Chapter 10: Reflexivity

10.1. Introduction

Reflexivity has been central to my PhD research from the start. I realise now, at the point of trying to write my thesis, how “messy” my reflexivity process has been. I have three reflexive diaries full of notes and observations from different stages of my research, usually written when I have been grappling with aspects to do with epistemology, ontology and methodology. I have a log of reflexive e-mails I have sent myself, mostly written during recruitment or data collection, for example when I was waiting for a participant to arrive before an interview. I have some more formally written reflexive entries written as Word documents and typically (but not always) more structured reflexive thoughts that I have written after reading published literature or following meetings with my Advisory Group or interviews/focus groups. I have copious reflexive notes typed as memos in NVivo, capturing my thoughts and observations throughout data analysis. These are the most organized of my reflexive notes; in date order with a title and colour coded text. I also have voice notes which I recorded when driving to capture ideas ‘as they occurred’, which were useful at the time in securing my thoughts, but probably the least helpful to me now. It has been a tortuous experience listening back to audio recordings as I cannot stand listening to my own voice.

Although I have shaped and influenced every aspect of this research, feeling fairly comfortable to articulate this in discussions with my supervisory team, advisory group and in progress reviews, writing this up in a way that is accessible to the reader without detracting from the key points of each chapter has been a challenge. So, whilst I believe reflexivity has been central to my research, it has been messy and the aspect I have found most difficult to write up in my thesis for others to read and make sense of. In this chapter, I try to present how my position has shaped and influenced this research in an ordered and structured way to make it accessible for the reader.

10.2. My approach

Finlay (2008) encourages qualitative researchers to make “a deliberate and informed choice of route” (p.6) about their process of reflexivity. I found the work of Finlay (2008; 2002) helpful in making an informed decision about research reflexivity following early discussions with my supervisor, SD at the start of my PhD. From the five approaches discussed by Finlay (2008) I have used two central approaches, which Finlay identifies as introspection and mutual collaboration. Introspection is explained in terms of the researcher recognizing how their personal experiences have shaped the research (Finlay, 2002). Researchers are compelled to move beyond emotional introspection of personal experiences and instead to use their personal experiences as a catalyst “for interpretations and more general insight” (Finlay, 2008, p.8). In this way, introspection is used to make links between the researcher’s personal experiences, the experiences of participants and the wider context. As well as informing my research aim and questions, my personal experiences have influenced decisions regarding epistemology, ontology and methodology as well as my shaping my approach to recruitment, data collection, data analysis and the dissemination of my findings, as discussed below.

Mutual collaboration enables multiple perspectives to inform and influence the research methods adopted and the interpretation of data (Finlay, 2002). I have discussed my approach to recruitment and data collection as well as my interpretations of data during analysis with my advisory group. These discussions have shaped my thinking, prompting me to reconsider and at times refine my approach and initial interpretations of data.

10.3. Positioning myself within this research

I have been a Registered Learning Disabilities Nurse for over 20 years (10 years working in clinical practice before moving to nurse education). My interest in decision-making started when I was undertaking my pre-registration nursing degree between 2000-2003 (before the implementation of the MCA). I continuously questioned as a student nurse how I would feel if I was not able, or viewed as unable, to make my own decisions. Decision-making at the time seemed to me to be at the heart of person-centred nursing, which was the dominant concept underpinning the learning disability nursing curricula at that time. I was influenced by the "Once a Day" good practice guidance from the Department of Health (1999), specifically the section focused on consent. This underpinned my choice of pre-registration dissertation topic, which I wrote on 'Assessment of decision-making competence' in 2003. Since qualifying as a Registered Nurse, the MCA has been implemented and I have been influenced by working and listening to individuals with a learning disability to gradually move away from focusing on the 'assessment of capacity' to 'supporting decision-making'.

From a personal perspective, a member of my extended family has a learning disability (living with minimal paid support in a house he has lived in for most of his life). It is a complicated situation which I have found hard to write about here as it is not my story to tell but, as it has influenced my research and 'world view', is included for transparency. Whilst I always knew Mark (pseudonym) existed, I have never met him. I only found out Mark had a learning disability when my aunt (who was an incredible person and a memorable part of my childhood) died over 10 years ago, at which time my Mum took on a role as one of Mark's 'family carers'. I have since found out that when Mark was born in the 1960s, my auntie was told that she could either send Mark to a long-stay hospital or keep him at home without any other support. My aunt, apparently without much hesitation but with, what now seems to me, probably a lot of anger and resentment towards "services", kept Mark at home with her. Mark outlived my aunt. Mark was left living on his own, hundreds of miles away from his extended/wider family; he was not known to services; there was no plan in place; and he had a vehement distrust of "services" who to this day he believes will take him away and lock him up.

My experiences influence every decision I have made throughout this research as ultimately "... all ways of understanding are culturally and historically relative" (Burr, 2015, p.4). From the outset it has been important to me to have an equal balance of perspectives from people with a learning disability and family members/staff. My starting point was to ask people with a learning disability how they had been supported to make a health decision. In essence, as well as this research being informed by literature and most notably the House of Lords (2014) findings that supporting decision-making was "rare" in practice, it has also been motivated, and shaped, by my professional and personal experiences.

10.4. What language / terminology to use

I am aware that as a person without a learning disability who is writing about people who have a learning disability, the language I use requires careful consideration. As Lemay (2012) reminds us language is powerful, having the potential to perpetuate old approaches and ways of thinking if not used knowingly and thoughtfully. According to the writing by McClimens (2005), my use of language risks reflecting **my** concerns more than the population it is hoped to serve and benefit, i.e., people who have a learning disability, who are a heterogenous and diverse population of individuals. I have been mindful of my choice of language, frequently revisiting my decision to use 'learning disability'. There has not been a consensus or an obvious preference expressed by the people who have participated in, or contributed to my research, who have used several terms, often interchangeably (learning disability, learning difficulty, special needs), and so I have decided to use the language which is currently used in England and Wales, i.e., 'learning disability'. I have done this to reflect the practice and policies, which provide the context to my research findings, whilst recognising that this term will likely change in time.

10.5. Questioning my epistemological and ontological position

On revisiting the writing of Denzin (2010) following a 6-month break in my PhD due to the Covid-19 pandemic, I questioned if I had clearly articulated my epistemological, ontological and methodological positions. The catalyst for this was reading work by Denzin (2010) and Cresswell and Miller (2000) which appeared to suggest a constructivist paradigm is different to a critical paradigm. I questioned if there was a difference with social constructionism (as opposed to constructivism) and why my research could not be critically interpretivist, looking at data through a social constructionist lens. I found myself repeatedly returning to what epistemology and ontology really mean in terms of **my** research – with epistemology being about the theory of knowledge (Willig, 2013): Do we know things? And **how** do we know things? I have been attracted to looking at the data through a social constructionist lens – we can know things, but what we know is influenced by multiple social contexts (historical, political, cultural) as well as individual contexts. It seemed to me that history, social policies and cultural beliefs have influenced (or perhaps prejudiced) the life experiences of people with learning disabilities. For research about supporting decision-making to be meaningful and for the findings to have relevance and applicability in real health settings, consideration of the wider social context and influences shaping the data appeared to me to be essential.

I also realised how my own feelings about my family were entwined in my attraction to social constructionism. Although I will never 'truly' know (as I only found out about Mark after my aunt's death), I suspect that my aunt's experiences when Mark was born and very young shaped the life my aunt subsequently adopted for herself and Mark. Mark has a vehement (and I use that word knowingly) distrust of "services", particularly social services. He will not let social workers in his house and if a visitor tells him that they are a social worker, he becomes angry, hostile and agitated. This presents as aggressive behaviour, making those around him feel unsafe. It has significantly limited the support available to

Mark at times as it has been recorded that “Mark refused or declined services”. I believe Mark’s presentation is not a refusal of services, but Mark communicating that he is scared. He is scared that this person will take him away (“lock him up”) as this is what he has spent his life hearing from those who loved him and he loved most. Mark is left with a legacy of believing that ‘services are bad as they might take him away or lock him up’, created (I believe) by the responses my aunt received when Mark was young, and what appear to have been several traumatic experiences in Mark’s early life. Our histories and the contexts in which we live shape who we are and how we know. My experiences have undoubtedly shaped the epistemological position I adopted in this research.

Ontology is concerned with the way of knowing or the nature of reality (Willig, 2013), which I understand to be – perhaps simplistically – on a continuum with positivism on one end and relativism on the other. I struggle with both of these extremes, I do not believe reality (what is real, perceived to be “true”) can necessarily be observed directly and objectively with there being ‘one truth’ or ’one version’ to discover or to find. However, I also struggle with the extreme of relativism. Whilst I do believe everyone has a different (interpreted) reality, I also believe that there must be ‘something’ that is shared in people’s different, varying realities, or in their interpreted realities that links them together, and it is by thinking about what this ‘unifying thing’ is that we can advance our understanding and be in a stronger position to influence future practice. So, in line with my research, among the multiple, varied realities, which participants have interpreted, there must be some “thing” or “things” that connects them, which Mauthner and Doucet (2003) discuss in terms of “something [being] out there” (p.421).
When analysing data, I did so with the assumption that there is “something there”, something to be constructed and developed across the data (and the data sets), something that can provide us with some insight into supporting decision-making practice and more importantly help our understanding of how practice can be developed and improved. When looking at data, I was doing so from both a moderate social constructionist epistemological perspective (how has the participant’s way of thinking being constructed in line with the person’s wider social

network and shaped by wider healthcare practices) and also from a critical realist ontological position, in that I think there is “something there” to provide insight into current practice and more importantly to inform solutions going forward.

10.6. Keeping up with the literature

By far, the most challenging aspect of undertaking this PhD research has been working as a solo researcher (rather than as part of a team), struggling at times to keep up with literature being published and to know where to boundary eligibility criteria for my literature review. At times, this has seemed like my nemesis, something that I cannot ignore but have not known how to keep abreast of. My initial scoping review and reading of the literature informed my research question and approach to recruitment, data collection and data analysis. Later, analysis of my data informed the way I subsequently read, interpreted and used more recent literature in my extended review as well as informing how I was looking at the data I collected. Through continuously returning to the literature I have been able to reappraise my ideas and question my ways of thinking.

What I initially thought of as a limitation, I now think has been a strength. A more iterative approach to literature reviews is advocated by Braun and Clarke (2022), who suggest that qualitative researchers should consider writing the final version of the literature review towards the end of their data analysis. Whilst this was not what I had planned to do, this is what I ended up doing. Braun and Clarke’s (2022) writing gave me some confidence in the iterative process I had taken. My literature review presented in Chapter 3, I hope, provides a more contextualised appraisal of what is known about supporting health decision-making with adults who have a learning disability, enabling me to situate my research findings in what is already known. However, using this approach meant that when I synthesised the findings from the literature retrieved, I was doing so after I had collected and analysed my own research data. This meant that my interpretations and developed thinking was influencing and shaping my synthesis of the published literature. It also meant that two articles I co-authored were included in the synthesis. At an early stage I tried to use a narrative approach to data synthesis of the published literature however, I found that I was skipping some data and focusing on the content that connected or affiliated with me and my research findings rather than considering all of the data equally. I therefore chose to revert back to using what I found to be a more structured method of thematic synthesis; line-by-line coding (Thomas and Harden, 2008). This approach necessitates looking at every line of the data from each retrieved item and coding all data ‘equally’. Using this approach helped me to reduce my influence on what was important and instead to remain focused on what was included in the Findings sections of each retrieved paper. I also found NViVO helpful in doing this as it kept an audit trail of my thinking and decisions.

10.7. Sampling and recruitment, and the consequences of my decisions

As discussed in Chapter 4, I used purposive sampling (Patton, 2015). Recruitment was shaped by my personal values as well as pragmatic reasons. Whilst pragmatically I planned data collection for months of the academic year when my teaching timetable was less busy, due to my personal values I also did not want to turn anyone away from participating in my research (see Excerpt 10.1 and 10.2 below). Both of these aspects potentially shaped my sample. In 2019, at the time I was recruiting individuals who had a learning disability for interviews (see Excerpt 10.2 and 10.4 below) I felt I was recruiting a heterogeneous sample of people who had different abilities, experiences and perspectives. However, the participants I recruited in effect were the first people who responded to me, so on reflection potentially reflected people who were more likely to feel confident in making their own decisions, influencing my sample and therefore my data. It is probably not a coincidence that people who wanted to participate in my research were living in settings or accessing support groups that encouraged the development of decision-making autonomy by providing opportunities for individuals to gain confidence in being able to make and implement their own decisions, including health decisions. I chose to use the term “social groups” to include opportunities where people with a learning disability came together to talk about many topics (including health and the MCA) to talk it through and make sense of it. Whether the group was a formal drama group, speaking-up group or self-advocacy group which the person accessed separately from where they lived or was a group set up within a residential or supported living setting, such as monthly meetings, these groups were often referred to when I asked participants how they knew something or where they had learnt about the MCA. This has resulted in my data reflecting the experiences and perspectives of people with a learning disability who have had opportunities to develop decision-making autonomy.

Excerpt 10.1. E-mail I sent to myself during recruitment of adults with a learning disability for semi-structured interviews

To:Emma Douglass

Wed 26/06/2019 17:47

Went to XXX for 10am. […]

People started arriving for 11 o'clock group. Spoke to three people initially, showing them the leaflet and offering to talk it through. One woman said "no" as she was "fed up of speaking about health matters" and one gentleman said "no" because he had too much on at the moment and not the time to be interviewed. Although not helpful for the study's recruitment, this I felt was positive for two principle reasons. One, both individuals appeared to understand enough about the study in order to make a decision. The decision was appropriate and indicated that each individual had understood enough about the study in order to make a decision, one because of the time involved and one because the interview would be about health. Secondly, I felt positive that both individuals had felt able to say "no".

The third individual, a woman, appeared keen to be involved and said a definite "yes". However, in order to confirm informed consent (understanding as well as retention of information), I said that I would return next Wednesday to talk about the study again and to see if she still wanted to be interviewed. I gave her a research information leaflet to look at and we agreed to meet at 10am next Wednesday to discuss further.

More people arrived so I spoke to people individually. Most people listened, took a leaflet and did not give a definite response one way or other. One woman said she might be interested, whilst another person repeated everything I said to him. When I asked him questions afterwards about what I wanted to talk about, he said that he did not know. Another gentleman was interested but said he wanted to discuss it with his carer first. I said that I thought this was a good idea, and that I would return next week. He asked me if I could speak to his carer and then let him know what his carer thought. I said that he needed to talk to his carer and then to come back to me if he was interested in being involved, and that I could speak to him and his carer together. I wasn't aware at the time but he went to talk to his carer at that point, and returned to me just before 11am to say "yes" (the carer spoke to me later). As I had done with the first person, I said I would return next Wednesday so that we could discuss the study again and arrange a time for the interview.

I spoke to one gentleman who had his carer with him. The gentleman said he would be interested but the carer said that they would have to check with his Mother first. I encouraged the gentleman to take a leaflet, think about it, talk about it with people he trusted and that I would return next week.

I left the remaining leaflets with one of the XXX staff to give out at the Friday group, and several leaflets for XXX to hand out at the XXX Group.

Plan is to return Monday at 1030, and next Wednesday at 1000 to continue talking about the project. If the two people who said "yes" today are still interested, I will discuss a date for each interview as I do not want to turn anyone away who says they want to participate.

Excerpt 10.2. Excerpt from e-mail sent to myself during recruitment of adults with a learning disability for semi-structured interviews

> 10.07.19 - Since Friday I have considered whether to progress with interviewing people who have expressed an interest in being interviewed or to continue with recruitment. I think that giving each of the 9 people who have expressed interest in being interviewed an opportunity to be interviewed would be beneficial for two reasons. Firstly, the heterogeneity of the people who have come forward. People are from a range of different social groups/workshops. As each social group/workshop has a different purpose/aim, by recruiting people from a range of groups, I am hopefully more likely to recruit a heterogeneous sample of people who have different abilities/experiences/perspectives. I think this diversity will add to the richness of data collected in terms of representing different views and perspectives. Secondly, I am recruiting from a potentially "hard to reach" population, where many individuals I talk to either do not have phones/e-mail, or choose not to use phones/e-mail, or are living in accommodation, where communal phones lines make it challenging to contact people. Therefore, although lots of effort has gone into timetabling interviews at a time/date that is convenient to the person and at a location of their choosing, it is possible that not all 9 people will attend for interviews at designated times. Also, probably more significantly, I don’t want to turn anyone away. If someone has expressed an interest and taken the time to talk to me, I want to be able to interview them if they decide they want to be involved. I want this to be a positive experience for them and not an experience in which they feel ‘turned away’ or worse, rejected. If this is a negative experience, they might not put themselves forwards in future which would limit future opportunities.

When I started recruitment for focus groups, I tried to disseminate information about my research to reach a wider group of people. I wanted to recruit people from different backgrounds, and was keen to recruit people who lived in residential settings as published research (for example, Devi *et al.* 2020; Willner *et al.* 2012; Dunn, Clare and Holland, 2010) suggested residential settings might be more restrictive with regards to supporting individuals to make their own decisions. However, recruitment of people in residential settings often required the involvement of “gatekeepers”. This proved to be a frustrating process as I do not think that some prospective participants ever found out about my research. I struggled to get ‘buy in’ from gatekeepers (see excerpt 10.3 below). My focus group sample was again skewed to people who were living in environments where there appeared to be a strong ethos promoting individuals to make their own decisions.

Excerpt 10.3. Section from reflexive notes made during focus group recruitment

10.02.2023: […] …my feelings of frustration and annoyance are high. It is hard enough trying to do research, but it just feels like there are so many additional obstacles to overcome when trying to recruit people with a learning disability from residential settings. I have to penetrate what feels like layers of gatekeepers, who ultimately hold all the power. It strikes me that if I fail in making a strong case to gatekeepers, people with a learning disability potentially don’t even get to hear about the research or opportunities available.

It occurs to me that by making information accessible I might have failed to provide enough information for gatekeepers. One gatekeeper has e-mailed me saying that no one they know in their organisation/service setting will be able to talk for 2 hours. I responded explaining how the focus groups were structured, with 2-hours being so people could have lots of breaks and be supported to participate in a truly person-centered way. I now wonder if this is the problem across the board – the information I have sent out was meant to be ‘accessible’ but as it is going to gatekeepers and not people with a learning disability themselves, it is not detailed enough for gatekeepers who then might dismiss it instantly. Gatekeepers are all busy people, and it is just one more thing that they do not have time to think about.

The gatekeeper then responded to my initial e-mail saying that the people with a learning disability where they work would not be able to travel to Bristol. I replied suggesting we have a phone conversation, saying that we could travel and have the focus group nearer to where the people live or if convenient/appropriate, in the residential facility itself. After feeling as though I had offered solutions to the first two challenges, the gatekeeper asked if the decision-making had to be in relation to ‘health’. When I said it would have to be in relation to health decisions as health decision-making was the aim/topic of my research, they said that nobody where they worked would be able to participate as nobody wanted to talk to me about their health. I had no way of overcoming this – as health decision-making is the focus of my research. Leaving me to question if the people living in this setting had actually ever been given a genuine choice of whether or not they wanted to participate.

10.8. Data collection

I chose to use an inductive approach to my research design, which meant that whilst I had a plan at the beginning of my PhD, it was open to change and amendments as my thinking developed in line with data collection and data analysis. For example, my decision to recruit family members of an individual with a more severe or profound learning disability and/or complex needs was cemented through the initial interviews I facilitated with adults who had a learning disability. Whilst I had hoped to recruit a heterogenous sample, I realised that due to my approach to recruitment (discussed above) that the people I interviewed shared similar characteristics (Excerpt 10.4).

Excerpt 10.4. E-mail I sent myself during month I was interviewing adults with a learning disability

To:Emma Douglass

Tue 16/07/2019 18:46

Deliberately chose not to use gatekeepers and to recruit from a large social group as I wanted to recruit a heterogeneous sample of participants who lived in different settings with different levels of support etc. However, sample is ultimately very similar in some characteristics.

Also, ongoing difficulties in contacting people. Many people who expressed an interest in participating do not have a phone. One person who is keen to participate doesn't like to use the telephone. Nobody who I have spoken to so far who wants to be involved uses e-mail for communication. 2 people I have already interviewed actively used and had mobile phones (P2 and P3), whilst one person had a landline (P4). For others, it was a matter of meeting before groups and arranging to meet at a later stage (P1, P5 and P6), which worked for these four people who were subsequently interviewed. However, for others this was problematic when people did not arrive at times previously discussed/arranged, as I had no way of contacting people, which has skewed my sample? For P7 this was overcome as P7 had expressed interest in the study to staff, who then relayed this interest to me, therefore I did not feel like I was breaching person's confidentiality when I asked staff member to relay a message back to P7 to confirm date, time and venue of interview. However, this did subsequently potentially exclude a couple of other people from being interviewed as I did not see them again, and had no method of contacting them outside of the social group. As these people had talked to me fairly privately about participation, I did feel it was a breach of confidentiality, or possibly pressure by asking staff to relay information, the result in being they were not interviewed - but I am not convinced that these people did not want to be interviewed - therefore is this a further barrier to inclusion?

One could say that people had my contact e-mail address and phone number so could contact me if they were interested, however nobody I met used e-mail, and only one of the people subsequently interviewed contacted me directly by phone from reading the leaflet. Everyone else expressed interest through face to face discussions at pre-workshop social sessions. In order to meaningfully include people with a learning disability in research, need to consider how to recruit in a more inclusive and appropriate way - not sure I achieved it this time despite trying!?

Also challenges of achieving a heterogeneous sample - all people who were interviewed:

- used verbal method of communication (although to a range of abilities)
- were mobile and ambulant
- were relatively independent – although this is a subjective term and one I question… independence is on a continuum…
- either lived in the family home or in supported living accommodation - therefore nobody living in residential homes

I felt a deep sense of responsibility to "do right" by the people who participated in my research. Whilst I felt this responsibility during all stages of the research process, I felt this more intensely during data collection when individuals shared their experiences with me (Excerpt 10.5), which cemented the importance of de-briefing opportunities throughout data collection and analysis.

Excerpt 10.5. Section from an e-mail I sent myself following family carer interview

To:Emma Douglass
Title: PhD Family interview thoughts following interview
Tue 17/12/2019 17:11

Facilitated a family interview today. The interview was far longer than the previous ones, and one that I struggled to navigate/direct, especially at the beginning. However, what the participant did discuss was a healthcare decision, and on reflection (although at the time I felt that I wasn't doing a good job as an interviewer) I think by the end, the interviewee had explained the process of a healthcare decision spanning decades and involving several layers of complexity. If I had wanted a straight pathway then I would have perhaps used a more quantitative approach, this interview data is rich, does ultimately answer the research questions but took longer to uncover / pull out.

It was harrowing to hear some of the content of the interview and I found myself responding with facial expressions and sympathetic body language. Is this OK to do? As a researcher, should I be aiming to remain neutral? Is this possible when hearing such vivid and upsetting experiences. Need to discuss this with Sally.

I went though many emotions throughout this interview - empathy, sadness, disgust and shame at the way this individual had been treated and ultimately let down by services that I was (and still am) part of, also admiration for the family. I cannot even begin to put myself in the family's shoes, and listening to their responses put the concerns I have about my own family into perspective. How can we be living in a society where individuals are treated so badly, almost as non-humans, de-humanised? How does this happen? Why do things go so wrong? Throughout, and following the interview, I question how families find the strength to keep going and to keep fighting. Where does this strength and courage come from?

I also feel responsible and part of the problem. When the interviewee was talking about their loved one being in a service with qualified learning disability nurses, I felt shame and responsibility, like real, personal responsibility for the way in which this individual had been treated. It was the most emotionally challenging interview I've done. I feel a great sense of responsibility about my research findings and to ensure I do justice when analysing the data (which seems now like a cold way to view someone's life / real experience).

My initial plan had been to undertake a qualitative survey of healthcare staff. This was interrupted due to Covid-19 pandemic as discussed in Chapter 4. However, the decision to change from a qualitative survey to semi-structured interviews with staff was shaped by reflecting on my thinking from the data I had already collected in line with published literature and through collaborative reflexive discussions with my supervisory team and advisory group (Excerpt 10.6).

Excerpt 10.6. Entry from reflexive diary on 09.11.2020, written at a point where I was revisiting my interest in focusing on Principle 2 of the MCA as well as my decision to move from a survey to interviews with healthcare staff

09/11/2020: Writing about moral status, Silvers (2012) identifies inherent difficulties in attempting to measure and categorize an individual's mental capacity, suggesting that even if valid measures existed, measuring capacity fails to appreciate and value an individual's full capacity. Therefore, does the focus on mental capacity assessment serve to further discriminate and devalue individuals who have a learning disability rather than support individuals to have a voice with decisions that affect them?

"…valuing inclusiveness proceeds on the assumption that every kind of entity possesses prima facie considerability" (Silvers, 2012, p.1021). Silvers suggests an **inclusive social approach** as opposed to an approach, which measures and judges, "…with each of us attending to the possibility of casting others as potential partners in collaborative enterprises, and to the challenge of devising innovative ways of cooperating with different kinds of individuals" (Silvers, 2012, p.1021). Richards (2020) argues that in light of continuation of abuse scandals (e.g., Winterbourne View, Whorlton Hall) person-centred care as it is currently understood, is "out of date" as it relies on individuals being viewed as People First. However, due to the stigma and de-humanisation of people with learning disabilities in our culture, person-centred principles might be taught and promised, but practice falls short of providing sound person-centred support to individuals with learning disabilities. Richards (2020) refers to our cultural history where people are "objects of disgust or fear, and indeed pity and misfortune" (p.502). Instead advocating for an embracement of disability. This was where I started this research, the underpinning of my PhD, to find ways of supporting healthcare decision making through creativity, inclusion and partnership working – accepting people as people and finding ways to support decision-making.

My starting position -for this research (which has moved from my pre-reg Dissertation which was on assessment competence) was that the focus should be on supporting individuals to make their own decisions rather than assessing capacity – influenced by my experience as an RNLD and Mark. I wonder how much focus is put into supporting an individual to make a decision in healthcare daily practice compared with undertaking capacity assessment? The MCA published literature appears to focus on capacity assessment rather than supporting decision-making, but I need to go back and re-run my initial searches to check if this is still the case.

Lemay (2012) appears to be talking about “competence” as a continuum between intelligence on one side and stupidity on the other. Whilst making the case that “we learn what we have the **opportunity** to learn, and what the **context** requires” (Kegan, 2012, p. 70 as cited by Lemay, 2012, p.127). Suggesting we are all products of our environments and of all the experiences and mistakes which we have made, or have been made to us. Context and opportunity appear to be fundamentally important. Reading this text returned me to considering who has the right to assess capacity/competence of another human being? What are we judging / assessing? By assessing competence, we have a measurement / structure. Whereas if we instead focused on supporting an individual to make their own decisions, or to contribute to decision-making, would we have a structure / measurement? Need to provide opportunity whilst “enabling” (not sure if this is the correct word?) the context. But what is the context? If Lemay (2012) is right, and competence is a continuum between intelligence and stupidity, where does this leave us in terms of assessing an individuals’ decision-making capacity? Especially if assessing an individual with profound or severe learning disabilities, who we know may not have capacity to make a specific decision. This links to Watson’s (2016) research in Australia about focusing on the supporter’s responsiveness to the individual’s communication methods to detect/identify the person’s preferences. Otherwise are we simply setting the individual up to fail by the requirement of completing a capacity assessment (form filling / documentation) process? The process is required by the commissioning organisations, for example, CQC and local policies and procedures to evidence capacity has been considered and assessed, however by asking staff to complete capacity assessments in certain circumstances, when individuals do not have capacity, are we furthering the de-valuation of this person by again asking staff to evidence that somebody does not have capacity rather than looking at **how** the person could have input/involvement/inclusion in decision-making process? Reading the work by Klotz (2004) makes me think about people being ultimately set up to fail, and the importance of actually listening to what people with a learning disability think and have to say. The work by Bogdan and Taylor (1982), which Koltz discusses, resonates with an Einstein quote I use when facilitating a session with new student learning disabilities nurses about the use of terminology and labelling:

> "Everybody is a genius. But if you judge a fish by its ability to climb a tree, it will live its whole life believing that it is stupid."

How does the process of assessing capacity help to support people to make their own decisions? Instead, is the process pathologising people further as being "incompetent"? What is the purpose/function of this? Instead of supporting people to make decisions, and to be actively involved in the decision-making process, are we further de-humanising people, who are already viewed as being different by having label of "learning disability"? What purpose does this process serve?

How does assessing capacity help in valuing the individual and supporting decision-making independence/autonomy? Is this yet another example of devaluing practice? Lemay (2012) suggests "the cloak of competence" is a backhanded insult (p.128). Reading work by Lemay made me question **why** I started my interest in this topic by looking at capacity assessment? Is it merely a reflection of what Western society holds as important, society's values? IF capacity / competence were not valued within society, what would the implications be? Do staff evidence what mechanisms of support have been put in place/implemented to support the individual to make their own decision in the

> first place? Where is the focus in practice? On evidencing the assessment of competence or on evidencing supporting decision making? The next stage needs to be exploring staff perspectives and experiences and I am now convinced that interviews rather than my survey is the right approach. The survey responses from the pilot are useful and interesting to an extent but provide superficial detail, whereas interviews would enable additional probing to try to understand the actual experiences and perspectives of healthcare staff…

My decision to facilitate focus groups was influenced by my thinking during interviews with staff members (Excerpt 10.7).

Excerpt 10.7. E-mail I sent myself on 25.06.21 (whilst preparing for 5th staff interview)

> To:Emma Douglass
> Fri 25/06/2021 09:12
> Title of e-mail: PhD – what's needed – idea for next step after staff interviews
>
> A number of times now people have spoken about the need for supporting decision-making to be wider than just learning disability nurses, which is a theme within the family member data as well. Education is often suggested, as is the need for case scenarios and examples.
>
> What I also question is the documentation the treatment provider has to complete when a decision needs to be made in relation to a patient who may not have capacity. What does the treatment provider/healthcare staff have to document/complete? And is this focused on the outcome, i.e., what the decision is, or the assessment, rather than the support provided before a capacity assessment has been completed?
>
> Could I audit documentation? How would I do this? Would an audit of documentation be more helpful to this research rather than a survey of staff opinions/perceptions? How could I access/see the documentation individual Trusts / services use? Could I contact MCA leads in Trusts and ask for blank

copies of documentation for example? I recall what someone once said to me when I was a nurse involved in implementing CPA across services: To change behaviour, have to change working practices. To change working practices, have to change policies and protocols, so maybe ultimately documentation? Not sure staff survey will be required following the staff interviews? Will have to review after completing and analysing the data…

Also wonder if I should consider facilitating a focus group(s) with adults with learning disabilities to canvass more opinions / perspectives? Especially about what people find helpful to support them to make decisions generally rather than asking to share an experience (as I did in the interviews?)

10.9. Data analysis

I grappled with how to ensure quality in my research especially at the beginning of my PhD. Connelly and Peltzer (2016) advise nurse researchers who are undertaking qualitative research to try “to understand and not to prove something” (p.54). This advice has been at the forefront of my mind throughout, but particularly when analysing data. Braun and Clarke (2023) have more recently written about the need for the researcher to have “thoughtful knowingness” (p.701) when undertaking reflexive thematic analysis. It has been my aim to achieve and evidence this; for my research to be “interpretative and positioned”, by ensuring my approach to using reflexive thematic analysis was done “knowingly” (Braun and Clarke, 2023, p.698). I have tried to be aware of my influence and how it has shaped my interpretations of the data. I have attempted to consider how my personal position has influenced every stage of analysis, but especially the way I have looked at the data to develop themes. I initially found the article by Frith and Kitzinger (1998) helpful in trying to unpick my assumptions about what people say not being a reliable depiction of their actions and/or behaviours but rather an interpretation of their experiences of supporting decision-making in the context of the settings in which it takes place. Data is not transparent. It in itself is not a window, it is not transparent, which shows what happens; “there is no objective truth" (Denzin, 2010, p.23), instead it has been interpreted and constructed, and I have had a role in shaping this construction in the interviews and focus group discussions.

As one example, a core component of the learning disability nursing programme on which I teach is about the importance of accessibility of information, in which 'easy read' is often promoted as one way of making information accessible. A recent exploratory qualitative research study I was involved in questioned the accessibility of "accessible" information (Douglass *et al.* 2023*;* Dowling *et al.* 2023; Johnson *et al.* 2022). It was important not to let this cloud my thinking when analysing data – I was aware of the risk of looking for findings which agreed with the content of seminars I taught or with the findings of my previous research. I tried to mitigate against this by following Braun and Clarke's (2022) advice – reading, re-reading and re-reading transcripts, making notes in the 'memo' section of NVIVO and documenting my thinking at each phase of analysis. I met with one of my supervisors (SD) who also looked at the raw data, my codes and initial themes in NVIVO, asking critical questions of my thought processes. I also discussed the themes I was developing with my advisory group, who acted like a 'sounding board', helping me to make sense of my interpretations of the data.

A second example is the theme I developed relating to 'identity' from the interviews with individuals who have a learning disability: 'the importance of identity – having a learning disability as being a core part of identity' was one of the initial themes I developed. I was initially confident with this theme, however the more I thought about it, the more I questioned if I had developed this as a theme as a result of my personal experience; was I more sensitive to issues relating to identity because of my aunt and Mark? On reflection, I felt my aunt had almost hidden Mark away due to her fear of "services" which, it seemed to me, had probably stemmed from her initial fear of Mark being taken away from her when he was young. Therefore, was I focusing on identity and potentially seeing it and elevating it beyond how it was positioned within the actual data. Again, reflexive notes and memos documenting my thinking at different points (relating to the data), critical discussions with my supervisor and advisory group helped me to make sense of this theme. At first, I thought it was a positive aspect – that the people with a learning disability who spoke to me had a positive self-identity, which had supported them to make their own health decisions. Discussions with my advisory group made me question the link with identity and participants being part of a social group. Through mutual collaboration with my supervisor and advisory group, as well as repeatedly looking back at the original data, I reflected that whilst having a learning disability did appear to be significant in each participant's health decision-making experiences, this was not necessarily a positive aspect (see excerpt 10.8 below). Instead disability identity influenced supporting decision-making and it was dependent on other factors and contexts whether this was either facilitative or a barrier.

Excerpt 10.8. Memo in NVivo capturing developing thoughts in relation to the potential theme concerning identity

21.05.21– Disability is part of identity, "People like me, people with learning difficulties" – but is this positive like I initially thought? Revisiting and questioning my initial thoughts – am I seeing what I want to see? - feedback from team and discussion with advisory group have made me question… Looking back at data… Not always… Having a learning disability does appear to be a central part of the identity of participants. I initially thought this reflected how individuals spoke or referred to themselves… some participants spoke in relation to how having a learning disability affected decision-making, but also about how having a learning disability impacts/shapes wider life experiences – how 'others' see them/view them/speak to them – "One [healthcare professional at the hospital] I don't really get on with is as she talks to me like I'm a toddler…" (P2). When P1 talks about it being helpful to watch a DVD of somebody with a learning disability having the same operation as they needed. This by contrast to P2 is spoken about in an unemotional and matter-of-fact / neutral way – "…she [nurse] showed me a DVD of someone with learning difficulties having the same kind of operation as I had […] … he seemed quite happy about it…”

Generally, participants referred to having a learning disability in a neutral, often practical way. For example, P6 talks about some people with learning disabilities being able to make their own choices, whilst saying that others need more support from others, “Yes, it is ‘cos some people with special needs have mental capacity act and make own choices about what they do and some people lack mental capacity act, they have, someone ... decision in their own best interests” (P6).

P5 talks about it being helpful to talk about health decisions with a friend who has the same learning disability as they do, “I’ve got [learning disability] right, so um meeting another person with the condition, [friend’s name] knows how I feel, and I know how he feels, and I trust him a lot”. Trust? Understanding? Shared experience in both having the same learning disability, which is neither positive nor negative, just how it is / matter of fact. Importance of shared understanding and common ground.

P7 refers to being “different” but also having a learning disability is interwoven throughout transcript and appears to be spoken about with acceptance? Neutrality? – just part of who they are, but does impact / affect decision-making support – they need some support sometimes and know who to approach for support (support is sought from several people – both informal and formal).

So, whilst having a learning disability is more often spoken about, as it seems to me ‘neutrally’, it does impact decision-making support. E.g., P2/P7/P4 - negative implications in how health professionals behave towards people, “And some doctors can be not nice”; “but mainly like because you’ve got learning difficulty like people act like... like you don’t count and like you don’t know what you're talking about”.

Regardless of whether participants refer to having a learning disability in a neutral way or in association with being treated differently, participants identify as having a learning disability as part of who they are, which appears to have an impact on health decision-making /support for health decision-making.

10.9.1. Continuously questioning myself: Am I seeing what I want to see in the data?

I have tried to be aware of how I have shaped the development of themes when analysing data. I followed guidance from Braun and Clarke (2013) detailing my initial thoughts (examples in 10.9 and 10.11 excerpts below) and also keeping a log of how my thinking was changing and developing and why (examples in 10.8 above and 10.10 excerpt below).

Excerpt 10.9. A memo in NVivo capturing initial thoughts about one of the family member transcripts

Supporting decision-making is often left with family members and support staff. Healthcare professionals, in this participant's experience, might be inclined to say/write that her family member has given consent when she doesn't think he has understood enough to be able to give valid consent. This has caused concern in the past, resulting in the family developing easy read material to help inform individual about the decision in question.

Participant thinks that development of easy read information has supported family member's ability to make a decision. Consent/decision-making is not a black-and-white issue, it is a process (takes time) and there is a need to provide information so that family member with a learning disability has an opportunity to understand. Development of easy read information is left with family members as in participant's experience, it has not been instigated/supported by healthcare professionals.
Key aspects from this transcript:
-Decision-making is a process.

-Support for individual with a learning disability often left with family members.

-Participant became aware of consent when psychiatrist wrote a letter saying family member had given consent when participant felt that family member did not understand anything about the new medication.

-Participant wants family member to be informed/supported to be involved in decision-making so that he doesn't acquiesce. Wants him to be able to question authority. Wants him to be safe.

-Participant speaks about not going through a supporting decision-making process for all decisions. Family member trusts family and support staff so will go along with what they suggest. It is my reflection that this makes participant in turn more aware of family member’s potential tendency to acquiesce, motivating the family to support him to make his own decisions (including saying ‘no’) where possible.

Participant is committed to her family member; wants the best for him; wanting him to be involved in decisions that affect him. Ultimately wants to protect and empower.

What kind of world is 'revealed' through their account?

A world where family and support staff take much of the responsibility for supporting decision-making and healthcare professionals take little. This "world" relies on family members learning or knowing information in order to be able to support their loved one. Knowledge and information become powerful tools.

Excerpt 10.10. NVIVO Memo: Review of potential themes from family member data

28-05-21: Following discussion with Sally yesterday and further reflection, I have revisited potential themes today, interrogating the data, asking if the quotes are part of the theme I have assigned them to (whereby they provide detail, contributing to the development of that theme) or if they are telling us something different.

Potential theme “Sharing information”: On review, I potentially influenced this being a theme in its own right due to my work as a nursing academic/lecturer whereby we teach about accessible information, so it is on my radar. Additionally, easy read information has helped my family member in the past to make decisions for himself, and I could empathise with the participant. However, on further review, data (quotes from all participants) represents sharing information with person with a learning disability to support decision-making and **also** with healthcare staff. I originally thought this (sharing information/accessible information) was a theme in its own right but on review there isn’t enough in the data to represent a “fully developed” theme (in line with writing by Braun and Clarke recently in 2021 and 2019 articles). Instead I think it might be split into two aspects: sharing information with individual with a learning disability to help individual to make a decision (I now question if this links more with the family’s expertise / them knowing the individual) **and** sharing information with staff to help staff support decision-making (maybe linking more with partnership working?). Family members share information with their loved one as they want their loved one to be supported to be involved in decision-making. They want the best for their loved one, and strive to do anything to support this. It is part of everyday family life. Whereas, when family members speak about sharing information with staff, it is in the context of knowing/reflecting/thinking they know more about their loved one than the staff and wanting to share this information to enable partnership working with staff teams/healthcare professionals. This is still motivated by a desire for their loved one to have to have a good quality service, but is in the context of recognising that they have a lot of knowledge/history that staff do not have/know. Therefore, on reflection, I think this is part of the Family Expertise theme - family members have this expertise and knowledge, and want to share this with others so that their loved one can have the best outcomes possible.

Excerpt 10.11. E-mail I sent myself following staff interview – when making initial notes about what the participant had said

To:Emma Douglass

Thu 24/06/2021 15:04

Have just undertaken the 4th staff interview, 4th learning disability nurse, this time working in an acute setting. Questioning myself slightly as the interview lasted just less than 30-minutes, questioning my interviewing skills... I will need to listen to recording but participant was articulate, concise, and succinct with answers, speaking through a comprehensive example of where they had supported an adult with a learning disability to make a healthcare decision.

Reflecting on interview content, some of the same themes come up - that of time and staff training/education - but not for learning disability nurses, but wider healthcare staff / teams - this has been mentioned by several participants now including family members.

Easy read developed by nurse, so it was personal to individual, which was helpful.

Nurse worked with carers who knew individual well. They didn't know person in advance so needed to work with those who did. Nurse reflected that family members can be significant but only when they are involved and spend time with individual. Otherwise, care staff might be more appropriate. [-this was also mentioned in one of the family members interviews I think – need to look back / check what was said].

Nurse also spoke about need for examples / case studies of supporting decision-making - to help/facilitate staff to support healthcare decision-making. Otherwise possibly an abstract concept? This came up with one other staff interview - difficult to interpret MCA potentially, so examples might improve practice.

Wider healthcare staff important - needs to be wider than learning disability services. Importance of education (MCA and learning disability). Also, importance of supporting care teams with anxiety they might experience when supporting decision-making.

I read an article published by Carney *et al.* (2023) after I had finished analysing all of my data. I read it with interest. Carney *et al.* (2023) question if choice is decision-making and also critically discuss the line between empowerment and paternalism. The findings resonated with me as they reflected some of my personal and professional experiences and thoughts at the start of this PhD, prompting a reflection that when I started interviewing people with a learning disability, this is what I had anticipated my findings would suggest. Reading the Carney *et al.* article and revisiting my initial reflections prompted me to revisit my original data (one more time) from interviews with adults with a learning disability and focus group discussions. Had I seen something in the data that was not really there? Had I misinterpreted choice as decision-making autonomy? On revisiting the data, my reflections continued to be that participants were overall able to talk about what was involved in the decision(s) they discussed, referring to potential or actual advantages and disadvantages of the decision they were making, and the support they had received. This I therefore concluded demonstrated decision-making as opposed to making a choice (which did not necessitate an understanding of the options available). For example, in an interview P6 decides to attend cervical screening even though they know it is uncomfortable and makes them anxious as they have learnt it is important to check for abnormal cells, which they appear to "weigh up" in order to make a decision,

> "…been invited to have a smear test with cells not healthy, not abnormal […] …and also female support worker goes with me.... and also um... also um... …also smear test, [I] get um... um … um distressed, then they can support [me] by distracting [me] […] have to be really relax so it's easy for person

> who does it, put the cold instrument inside you just to take some cells out […] If [I] have a... if [I] have support... make right choices... if [I] make unwise choice, [I] need support with it to understand what the consequences will be" (P6).

Whilst P7 talks about their decision to have a mammogram,

> P7: …mammogram first – you have to be reach 50s or upwards to have a mammogram... um, I wasn't worried about that 'cos I knew it had to be done to ensure I haven't got any like breast cancer or any abnormalities … and uh the tests took place at [place name]
>
> Int: Ok. And how did you know that you... that it was important to have a mammogram?
>
> P7: Ah... well I know about mammograms [from support group attended] […] And that was when my first mammogram was in [date] um when I first turned 51 and a letter came through the post with a leaflet explaining what the mammogram was about […] I didn't feel any discomfort […] um I thought at a certain age I've got to have that test done.

These two interviews are markedly different from P2, who feels that they were not able to make an informed decision due to not being given the relevant information,

> "I didn't know anything like about it and um... I didn't know any..., I didn't know anything about it... and (name of nurse) said like oh I'll get like you a date like to find out about it, like to talk about it and all that, and like a date came but it was..., she arranged for it to be put in [to have intervention]. I didn't..., I weren't told, I didn't know what was involved... what it would be like or anything... and um... and I … and I like I got there thinking that like I was going to find out about it and I found out it was going to be done […] Like at first I was like "no" I was like; "you said it was about finding out about it" and she was like "no, it is for your own good", and I went "how is it for my own good, doing something against my will when I don't know about it?" […] I didn't really have a ... didn't really have a choice. I … actually I

> think I said “no, I don’t want it” and she used the Mental Capacity Act on me that I didn’t know what was good for me. […] I hate that thing [The Mental Capacity Act] …‘Cos it like takes choices away from you […] and certain people in the past have used it to make me look like you're... like thick... Like you don’t know night from day... and I was like I didn’t agree with having it done…” (P2).

P2 felt that they should have been supported to understand the procedure before having the opportunity to make a decision about whether to have it. They discuss looking on the Internet for information, which they find challenging as they find a lot of “scary stuff” about the procedure on Facebook sites that makes them feel more anxious. They are seeking information that they think will help them understand the decision that needs to be made.

Similarly, in the focus group discussions, participants talk about the importance of the healthcare professional explaining the decision and providing enough information to enable them to make a decision. They also talk about the importance of the healthcare professional checking they have understood the information provided, to check that they have made an informed decision,

> Jet: them [healthcare professionals] giving their opinions and telling you what you should be doing and what you shouldn’t be doing, that doesn’t help at all (…) um, it is better for them to explain, say, not say this is what you should do, they should explain why they’ve said it but sometimes they don’t (pause)
>
> Int: So, not telling you what you should do but letting, giving you the information
>
> Jet: yeah… […] I think the other thing is um… them thinking that we understand things when we don’t, but… assume that [Lavender Lily: yeah] we understand, um, sometimes we don’t bu… doctors, some doctors [Lavender Lily: yeah] can assume that you understand and we don’t and

> they get a bit “aghh” or “you should” sort of thing [Lavender Lily: yeah] attitude. [Indistinguishable from room: mmm]
>
> Int: So, checking that you’ve understood*?*
>
> Lavender Lily/Jet: Yeah.

Participants were able to discuss and describe decisions. They also said whether they felt they had made their own decision (with support) or felt that they had been denied the opportunity to make their own decision. For me, the interview and focus group data suggests that participants were aware of their rights; wanted to have adequate information about the advantages and disadvantages as well as what was involved in order to inform the healthcare decisions they were making. Where possible they sought informal support from a person (or people) they trusted to discuss and weigh-up the decisions they were faced with. Carney *et al.* (2023) suggests that,

> “…empowerment and paternalism cannot readily be read from the expressed views of the person being supported (as a rights perspective would favour in designing accountability measures)” (p.512).

This might be the case in some circumstances, however in line with the MCA and a presumption of capacity, the views and perceptions of the person being supported should arguably be part of the design of any evaluation measures of decision-making autonomy. The individuals who volunteered to participate in my research were able to say if they felt they had made an informed decision or been prevented from doing so.

10.10. Research findings

My research findings now seem common sense. Of course, staff need to understand the MCA to be able to confidently apply it in their practice; of course, those involved (either making the decision or supporting the process) need to have a good understanding of the health decision that needs to be made; of course the values and assumptions of healthcare staff about people with a learning disability are significant in underpinning their practice; and of course respect for all involved and partnership working is essential. These aspects make sense, so much so that they have made me question and re-question and re-question my research question(s), design, and methods. Have I just generated data that has found out what appears to be common sense? However, whilst on reflection the findings seem like common sense, they were not what I necessarily expected when I commenced this research. At the beginning I was expecting more people with a learning disability to talk about negative experiences of supporting decision-making, and healthcare staff to report challenges that made supporting health decision-making impractical or unfeasible in certain situations. The data I have collected and analysed, however, is both more balanced and more nuanced than I anticipated at the beginning, reflecting both positive and negative examples of supporting health decision-making. This has enabled me to unpick what factors appear to be instrumental in facilitating **or** hindering supporting health decision-making in real life contexts.

From the beginning, it was important to me to make my research findings accessible to people with a learning disability. In February 2024 whilst I was writing up my thesis I was invited to share and discuss my findings with a self-advocacy group, which generated a lot of lively discussion (the PowerPoint slides I used to facilitate this session are in Appendix Twenty-Five). To reach a larger audience, I am currently working with Misfits theatre group in Bristol (https://misfitstheatre.com/) to co-produce a short film of my research findings with adults who have a learning disability. At the time of writing we are working on finalising the script (the current draft script is in Appendix Twenty-Six), with filming due to start in June 2024.

10.11. Summary

Reflexivity has been central to every aspect of this research. My background and life experiences have shaped and influenced every part of this study from the research aim and questions to the methods I have chosen to use. In this chapter I have tried to provide examples, using excerpts from my reflexive diaries, e-mails and NVivo memos, to illustrate and discuss my influence in shaping this research in what I hope is a transparent and accessible way.

In Chapter 11, the final chapter, I will conclude by summarising what my research findings contribute to our understanding of supporting health decision-making with adults who have a learning disability in line with Principle 2 of the MCA. I will consider the strengths and limitations of my doctoral research, suggesting implications for practice and recommendations for future research.

Chapter 11: Conclusion and recommendations

11.1. Conclusion

The aim of this qualitative research was to explore how individuals with a learning disability are and want to be supported to make health decisions. This study is the first that I am aware of, to focus on supporting health decision-making with adults with a learning disability in England in line with Principle 2 of the MCA. It contributes to our understanding of how supporting health decision-making can be improved in practice settings but also the potential barriers that can hinder people with learning disabilities from being supported to make their own health decisions.

11.2. What my research contributes to our understanding

My research findings advance our understanding of the facilitators and the barriers to supporting individuals to make health decisions. Through pilot survey responses, and interviews and focus groups with a total of 48-people, the findings of my research demonstrate how supporting people with learning disabilities to make health decisions can happen as part of daily life and can be done well. The adults who participated in my research spoke passionately about how they wanted to make their own health decisions identifying that, as is the case for most of us, sometimes they require support to do so. Many of the adults interviewed or who contributed to focus group discussions spoke about how good it feels to make their own health decisions, saying that it increases their confidence and makes them feel in control of their life. Correspondingly, healthcare staff suggested supporting health decision-making can have further benefits such as developing trust in healthcare staff and services which in future can mean some people need less support to access healthcare. My research builds on previous findings of the importance of 'knowing the person', however provides reassurance suggesting that people can still be supported appropriately to make health decisions even when the health professional does not know the person and might have just met them – which is often the case with health decisions.

Three factors appear to be significant in either facilitating or hindering supporting health decision-making: MCA literacy; health literacy; and valuing individuals (Fig 11.1). From my findings, it appears that when these are in place (i.e., healthcare staff are knowledgeable about the health decision to be made; they are confident in applying the MCA in their practice; they have positive attitudes towards people with a learning disability and work respectfully with the person, family members and other staff), adults with a learning disability can be supported to make their own health decision(s) or remain at the centre of the decision-making process. However, when one or more of these falls short, my research findings suggest that health decision-making can be a negative and unpleasant experience for all concerned, often resulting in feelings of anger and frustration, leading potentially to conflict and distrust of healthcare staff and services.

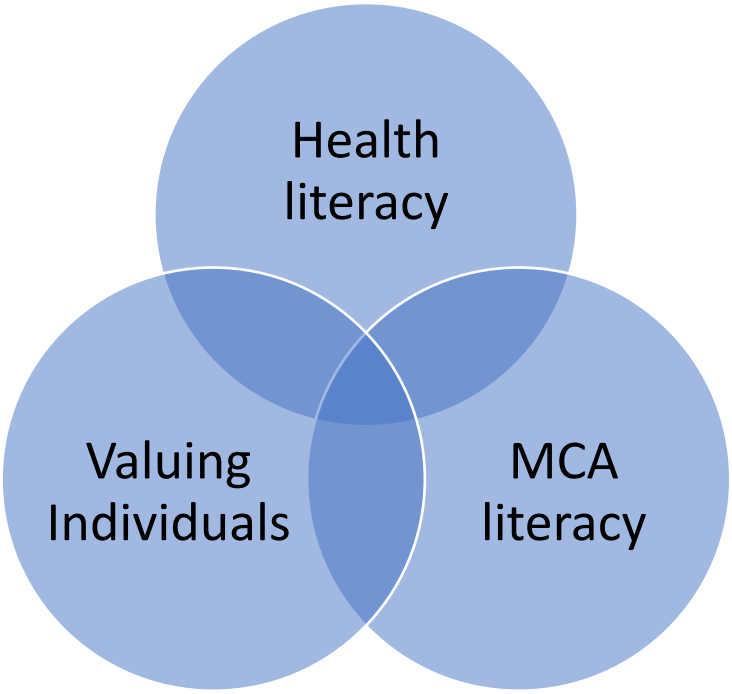

Fig 11.1. The three key factors required for supporting health decision-making

11.3. Strengths

An advisory group informed every stage of this research, especially in informing recruitment and data collection as well as offering invaluable insights in discussions during data analysis, specifically theme development. The use of accessible research methods has facilitated the experiences of 19 adults with learning disabilities to be included, informing us about how they want to be supported and what they find most helpful and why. A strength of the focus group data is that participants were recruited from a range of settings and living arrangements, which suggests that promotion and commitment to supporting decision-making can be achieved in a range of accommodation settings. The experiences of family members contribute to our understanding of potential tensions when supporting an individual with a more severe or profound learning disability or an individual with a learning disability and complex needs. Healthcare staff participants worked in a range of settings, including the criminal justice system, community teams, acute hospitals, nursing homes, residential homes and commissioning, with the findings having potential relevance and application to a range of services and settings where individuals with a learning disability should be supported to make their own health decisions.

Reflexive thematic analysis has enabled data to be interpreted from a moderate social constructionist position; meaning that the data have been considered in relation to complexities of healthcare settings and the multiple people often involved. Findings are likely to have relevance to 'real health' contexts and the recommendations (drawn from the findings) can be applied to 'real world' health practice.

11.4. Potential limitations

This is a qualitative study, using purposive sampling. It is possible that people with a learning disability who chose to participate had an interest in decision-making or confidence from self-identity and informal support that enabled them to make decisions. Their views and experiences therefore do not reflect all people with a learning disability. Notably, the individuals with a learning disability who participated had a high level of awareness of the MCA, which may not reflect knowledge and understanding of the Act in the wider population. In the initial semi-structured interviews with individuals with a learning disability, the requirement for consent for video recording might have excluded some people from participating, potentially skewing the participant group.

The staff who participated in interviews were all working with adults with a learning disability, having developed expertise in applying the MCA in their daily practice and in supporting people with a learning disability to make health decisions. The family members who participated were well informed and knowledgeable about the MCA, which is unlikely to be the case for all family members of an individual with a learning disability. My findings therefore do not necessarily transfer to wider families of people with a learning disability.

Most participants (people with learning disabilities, family members and healthcare staff) identified as being White British, so whilst providing valuable insights, my findings are not necessarily transferable to people from other ethnic groups. Future research should purposively recruit people from other backgrounds to provide insights into the experiences and preferences of a diverse population.

11.5. Implications for practice and policy

The implications of my research findings are the significance of MCA literacy, health literacy and the attitudes of healthcare staff towards people with a learning disability.

MCA literacy: Education, training and guidance

MCA education, training and guidance for healthcare staff should emphasise the importance of supporting decision-making, so that there is more than just a discussion about communication. Communication is important, but only one part of supporting an individual to make their own health decision. The focus in MCA education, training and guidance should be on the rationale, meaning and value of supporting decision-making in healthcare settings – placing emphasis on the responsibility all health staff have in supporting an individual to make their own decision (unless the decision is urgent) **before** a capacity assessment is considered. MCA training and educational initiatives for healthcare staff should be interactive and discussion based, with reference to real scenarios to demonstrate what “all practical steps” looks like in different cases, settings and situations, with involvement of individuals with lived experience.

Develop health and hospital passports to include supporting decision-making

Currently, NHS Trusts and Independent Voluntary Organisations use various documentation for Person Centred Planning, Health Passports and Hospital Passports. Different formats are also used for Annual Health Checks. To improve communication of how to support decision-making, one suggestion is for organisations to add a “how I want to be supported to make health decisions” section to the documentation that is already in use (rather than adding new documentation).

Audit and inspections

Routine governance and inspections by regulators such as CQC should include supporting decision-making as part of audits of MCA documentation across healthcare settings to emphasise the legal requirement to support decision-making before capacity is assessed.

Health literacy

Increase availability of accessible health information by including it alongside routine health information provided to the public. For example, the National Health Service website in England provides information for many health conditions including symptoms and treatment options (National Health Service, no date). An accessible version of content could be included on this site to make health information more easily available.

Mandatory learning disability awareness training for healthcare staff

The Oliver McGowan mandatory training is currently being implemented across health settings with the aim of improving knowledge and understanding of supporting an individual who has a learning disability. The National Oliver McGowan training team in collaboration with lead trainers, trainers and co-trainers to evaluate the content and quality to inform regular updates and revision to the training.

Development of flexible care pathways

Consider developing parallel care and treatment pathways for individuals with a learning disability to mitigate against the extended time it can take to apply the MCA before a care or treatment decision is reached. This would require involvement of numerous stakeholders including commissioners, healthcare professionals and people with a learning disability and their families.

11.6. Recommendations for further research

The findings of my research represent the experiences and perspectives of the participants, and as discussed above do not necessarily reflect the wider population of adults who have a learning disability. Further research is therefore required. I envisage next steps would include the following:

1. Evaluation of MCA mandatory training offered to healthcare staff, including the frequency, duration, delivery, background of facilitator(s), content and outcomes, to identify what is effective and how outcomes can be improved. The findings of the evaluation should inform policy of MCA mandatory training across healthcare practice.

2. In conjunction with an evaluation of MCA training, evaluation of the mental capacity documentation used in healthcare settings to identify how supporting decision making is recorded to learn what works and how outcomes for supporting decision-making can be improved. The findings of the evaluation of mental capacity documentation should inform future policy in relation to documentation used in healthcare settings.

3. Develop evidence-based case studies illustrating how individuals can be supported to make their own health decision as well as how this learning can be used to inform best interest decisions if required. Case studies could be added to the Code of Practice and/or MCA guidance and education and training resources.

4. Exploration of the role of support groups to supporting people with a learning disability in developing decision-making autonomy. This learning could then be applied more widely in other settings to reach and impact more people with a learning disability.

5. Research using a qualitative design to explore the process of supporting decision-making for a health decision where the participants (for example, the individual with a learning disability, the informal supporter or family member and healthcare staff involved) are linked. To consider using videos to capture non-verbal communication as this might be helpful if participants use informal and alternative methods of communication, however this requires careful consideration as it might potentially deter prospective participants from participating.

6. Research in an acute setting to explore the supporting decision-making process and the role of the learning disability liaison team.

7. Oliver McGowan training is due to be implemented to all healthcare students at the University of the West of England in the next 3-years. To embed a process and outcome evaluation of the Oliver McGowan training as part of implementation to identify what can be improved and to assess training outcomes on delegates knowledge and understanding as well as attitudes towards people with a learning disability.

11.7. Summary

The participants with a learning disability who participated in this research all wanted to make their own health decisions, with support. The family members who participated wanted their loved ones to be supported to be involved in the decision-making process, wanting to work in partnership with healthcare staff if their loved one was not able to make their own health decision.

Through a social constructionist lens, reflexive thematic analysis has enabled the development of themes from each of the data sets. The developed themes provide insight, contributing to our understanding of what works and why it works, informing us of the factors and context that appear to be significant in enabling adults with learning disabilities to be supported to make health decisions. They point to the need for changes:

- Healthcare staff require a good working knowledge of the MCA, so that they can apply it in daily practice.
- Individuals with a learning disability need to have opportunities to develop decision-making skills and also to improve their health literacy.
- The staff supporting people with a learning disability to make their own decisions require opportunities to understand the health decision that needs to be made.
- All those involved need to start with a presumption of capacity, valuing individuals with a learning disability as decision-makers; and

- Where individuals require more support, healthcare staff need to work in partnership with the people who know the person well, valuing the contribution of all involved.

In conclusion, my research findings suggest that if staff (professionally qualified and registered healthcare staff as well as support staff and personal assistants) are MCA and health literate, valuing individuals with a learning disability as ‘decision-makers’, they are more likely to be able to take “all practicable steps” (OPG, 2007, p.19) to support individuals with a learning disability to make their own health decision(s). In circumstances when an individual is not able to make their own decision, what has been learnt through the supporting decision-making process can be used to guide and inform the decision that is subsequently made in the person’s best interest(s) so that the individual’s will and preferences can remain at the heart of the decision-making process. In the words of Cinnamon:

> Making your own health decision is “not just awesome, it feels like you're being (...) your own PM Prime Minister".

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APPENDIX ONE: Timeline of consultation leading to MCA

1989	Review of decision-making legislation for people who might lack capacity by the Law Commission.
1995	Law Commission recommended there to be one piece of decision-making legislation
1997	Green paper published: Who decides? Making decisions on behalf of mentally incapacitated adults
1999	White paper published: Making Decisions
2003	Draft bill published: Mental Incapacity Bill
2004	Bill introduced: Mental Capacity Bill - change from Incapacity to Capacity was Recommendation 99 of the Joint Committee on the Draft Mental Incapacity Bill
2005	MCA introduced
2007	MCA implemented in England and Wales

APPENDIX TWO: Summary of published literature reviews

Author (DATE) Country of Origin	**Type of review & question or aim**	**Population**	**Exposure**	**Outcomes**	**Author(s) recommendations**
Werner (2012) Israel	Systematic Review of international literature: Has the enactment of the UN CRPD translated into opportunities for autonomous and supported decision-making among individuals with a learning disability?	Individuals with a learning disability	Supported and substitute decision-making (all decisions).	27-studies retrieved. 4 focusing on healthcare decision-making; 3 of these were about substituted rather than supported decision-making. The 4th paper focused on making choices. All 4 studies suggested involvement in healthcare decision-making was poor.	1.Development of practical working decision-making models to guide practice. 2.Development of decision-making skills among people with learning disabilities. 3.Supported decision-making training for professionals. 4.Promotion of person-centred planning.
Kohn and Blumenthal (2014) USA	Literature review: To evaluate if supported decision-making empowers adults with a learning disability to make their own decisions.	People with a learning disability who are ageing	Appears to be all decision-making, but not explicit.	Limited empirical research available.	Further research is recommended to find out: 1. How supporters & individuals with a learning disability engage with each other? 2. How different techniques influence the decisions made & if individuals with learning disabilities feel satisfied with & empowered by the process? 3. To what extent and under what conditions is supported decision-making coercive? 4. Do supported decision-making processes result in decisions that are substantively different than the decisions reached under surrogate decision-making models and if so, what is the nature and impact of these differences? (Kohn and Blumenthal, 2014, p.S42).

Author (DATE) Country of Origin	**Type of review & question or aim**	**Population**	**Exposure**	**Outcomes**	**Author(s) recommendations**
Bigby, Whiteside and Douglas (2015) Australia	Literature review. Exploring the barriers and enablers of support for decision-making.	People with a learning disability or an acquired brain injury.	All types of decision-making.	Few studies focused on support for decision-making. Authors suggest findings are indicative of "small body of literature reflecting a weak evidence base with few robust designs or large scale studies" (p.13).	Need for more methodologically robust empirical research, or large-scale designs exploring support for decision-making.
Davidson *et al*. (2015) UK	A broad Rapid Evidence Assessment. To provide an overview of the available evidence relevant to supported decision-making in order to develop supported decision-making in mental health services.	Not specific, all populations	All decision-making including supported decision-making and substitute decision-making.	Overarching theme from literature is the need to develop supported decision-making in order for people with various disabilities to be able to make their own decisions.	Evidence regarding implementation and impact of supported decision-making is limited but literature supports practice development and further research of supported decision-making approaches.
Bigby *et al.* (2017) Australia	Scoping review of evaluations of formal, funded supported decision-making projects for adults with a cognitive disability being piloted in Australia.	People with a learning disability.	Supported decision-making. All decisions.	5 supported decision-making programmes identified. Programmes can be effective in supporting people to make decisions but there are challenges around boundaries, enrolling supporters, and expectations.	Although no detail relating to costs, authors' remark on the likely expense of formal decision-making programs such as these.

Author (DATE) Country of Origin	**Type of review & question or aim**	**Population**	**Exposure**	**Outcomes**	**Author(s) recommendations**
Shogren *et al.* (2017) USA	Literature review "to identify what is known about contextual factors, demands, and supports that influence supported decision-making" (p.146)	Mental health, learning disability and people who are ageing.	All decisions.	Overarching theme from literature is the need to develop practice-based supported decision-making frameworks.	Importance of adopting a specific decision-making definition to guide research, and of identifying contextual factors influencing decision-making capacity.
Ryan (2018) Ireland	Set out to undertake a systematic review, however ended up undertaking an "eclectic" review due to limited literature (p21). Aim to "identify the evidence base related to how family carers support persons, living with profound intellectual and multiple disabilities, in decision-making" (p.283).	Family carers of individuals with a profound intellectual and multiple disabilities.	All decision-making.	Limited literature. Gap in the literature re evidence base of how family carers support people with profound learning disabilities to make decisions.	There is a need "for more explicit research informed by evidence as to the processes of supported decision-making, implementation and evaluation of such processes to inform future policy." (p.300).

APPENDIX THREE: Initial scoping review protocol

Written on: 04.10.2018.

Title

Supporting Adults with a Learning Disability to make healthcare decisions: A Scoping Review

Review Questions

1. What is the literature about supporting health decision-making with adults who have learning disabilities?
2. What does the evidence tell us about how supporting health decision-making is being facilitated with adults who have a learning disability, and the experiences of those involved?
3. Are supporting decision-making models being used? Is so, which ones and is there evidence of effectiveness?

Objective

The objective of this scoping review is to summarise the body of literature currently available in order to;

- Establish what type of literature exists
- Ascertain the disciplinary/professional background from where the literature originates
- Explore the current evidence base for how adults with a learning disability are supported to make healthcare decisions
- Identify if decision-making models (or tools) are being used to support adults with a learning disability to make health decisions
- If decision-making models (or tools) are being used, how have these been developed? Have they been evaluated? Who have they been designed for, and thus identify if adults with different types of learning disability are equally represented
- Identify whether there are gaps in the literature

- Identify implications for my research

Background

People with disabilities have and continue to be marginalised in society (Harpur, 2012). Weller (2014, p.298) suggests that in Western societies, mental capacity has been "a threshold requirement for citizenship", therefore excluding many disabled people from exercising their rights and freedoms. Mental capacity is defined as "the ability to make a decision" (Office of the Public Guardian (OPG), 2007, p.41), with the act of "decision-making" requiring an individual to "weigh up" alternative options in order to reach a decision, which they are then required to communicate (OPG, 2007).

People make decisions all of the time, from daily perhaps seemingly trivial decisions such as what to eat or what time to go to bed, to larger, more momentous decisions such as whether to apply for a new job, move house, get married or have medical treatment. In England and Wales, the *Mental Capacity Act* (MCA) (2005) provides a statutory framework for decision-making. The MCA is based on a provision of support to enable individuals to make their own decisions, whilst also providing a framework for when adults do not have capacity to make their own decisions (OPG, 2007).

The MCA came into force in England and Wales in 2007, and is based on five principles: capacity should be assumed; all practicable steps should be taken to support an individual to make their own decision; an individual can make an unwise decision; if an individual does not have capacity, decisions should be made in the person's 'Best Interests'; and the least restrictive decision should be taken (OPG, 2007). The second principle of "support in decision-making" is to enable individuals to make their own decisions by providing all feasible help. In recognition that the first principle is that of a "presumption of capacity", decision-making support should be provided before capacity is questioned.

There is now international acknowledgment that people with disabilities should have the same rights and freedoms as non-disabled citizens. The United Nations Convention on the Rights of Persons with Disabilities (UN CRDP) (2006) outlines the necessity for support to be provided to enable individuals to make their own decisions, recognising that in order to make decisions, mechanisms of support need to be available. Although it has been identified that the MCA is not completely compatible with the UN CRDP (Beadle-Brown, 2015), the MCA's second principle requiring all practicable steps to be taken to support decision-making is in line with the UN CRPD. This places an onus on health and social care professionals and paid support staff to support adults with a learning disability to make their own decisions.

People with a learning disability represent approximately 1.2 million people in the UK (Hatton *et al*. 2016). In the UK, learning disability,

> "…includes the presence of: a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with; a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development." (Department of Health, 2001, p.14).

Whilst some people with severe learning disabilities may lack capacity to make many decisions, others may, with the right support, be able to make their own decisions concerning many areas of their life (OPG, 2007). However, Hollomotz (2014) found that although it might appear that adults with a learning disability are now making more decisions, they are often making decisions by choosing from a predetermined set of restricted options as opposed to having genuine "free choice". A small-scale qualitative study exploring healthcare choice-making by Ferguson, Jarrett and Terras (2010) found that adults with learning disabilities often felt that "others" were responsible for making healthcare decisions rather than seeing themselves as the decision-maker. Therefore, despite changes in political discourse and a policy shift from segregation towards empowerment, inclusion, independence and rights (Department of Health, 2001), people with a learning disability continue to face barriers often resulting in restricted opportunities to make their own decisions.

Decision-making for all people (regardless of age and ability) is fundamentally based on support from others (Bigby, Whiteside & Douglas, 2015; Arstein-Kerslake, 2016; Curryer, Stancliffe and Dew, 2015; Weller, 2014), with decision-making support deriving from a variety of people depending on the decision to be made (for example, family and friends, trusted colleagues, healthcare professionals) (Arstein-Kerslake, 2016). However, for people requiring daily support from others to meet health and social care needs, such as is the case for many adults with a learning disability, decision-making can become more complicated as these people are often already in dependent relationships (Bigby, Whiteside & Douglas, 2015; Arstein-Kerslake, 2016; Weller, 2014). Whilst the MCA requires all health and social care staff – regardless of role and seniority – to understand and apply the MCA in order to support individuals to make their own decisions, research on staff knowledge and understanding of the MCA has been concerning (Beadle-Brown, 2015). Findings suggest that professional knowledge and understanding is limited (Heslop *et al.* 2014; Evans, Warner and Jackson, 2007); MCA implementation is inconsistent (Beadle-Brown, 2015; Heslop *et al*. 2014; House of Lords, 2014); and formal MCA training has marginal effect on improving staff knowledge and understanding (Willner *et al.* 2013; Phair and Manthorpe, 2012; Sawhney, Mukhopodhyay and Karki, 2009). These findings raise concerns about the application of the MCA in practice, with one study suggesting poor adherence to the MCA contributes to the premature deaths of people with a learning disability (Heslop *et al.* 2014).

Whilst an agreed definition of supporting decision-making appears elusive (Carney, 2014), what is clear is supporting decision-making should be a person-centred and facilitative process that enables an individual to make their own decision (Bigby, Whiteside and Douglas, 2015; UN CRDP, 2006; MCA, 2005).

It remains ambiguous as to how the second principle of the MCA, of taking all "practicable steps to support decision-making" is being accommodated currently in healthcare practice. It is not clear what processes are being used to enable supporting decision-making or what models/resources are currently in use and whether these are effective.

Systematic reviews are appropriate when answering a specific, focused question (Aromataris and Munn, 2017), however this is an area of practice which includes a variety of diverse literature from an array of different disciplines. Literature might include research (qualitative and quantitative), evaluations of tools/models used in practice and/or reports. For these reasons, a scoping review seems more appropriate in order to meet this study's objective of summarising the body of literature currently available. The findings will hopefully enable future research and service development activities to focus on areas where there are gaps, as well as to learn from, and build on, what already exists.

A preliminary search using four databases - Joanna Briggs Institute (JBI); Cochrane Database of Systematic Reviews; CINAHL Plus; and PsychINFO – was undertaken on 26.07.2018 revealing no scoping reviews had been conducted specifically addressing the questions for this review. Seven literature reviews have been published, using different methodologies and with different aims and questions.

Protocol development

This protocol has been developed using the JBI guidance for the development of Scoping Reviews (Peters *et al.* 2017) in conjunction with PRISMA guidelines for Scoping Reviews (PRISMA-SCR) as written in the checklist in Tricco *et al.* (2016) online paper.

The intention is for this draft protocol to be revised through discussions with supervisory team, advisory group and research and subject librarians at UWE.

Search strategy

Research librarians and a subject librarian will contribute to the development of the search strategy.
Search strategy will follow JBI three-step search strategy (Peters *et al.* 2017) consisting of an initial search in CINAHL Plus and PsycINFO to identify and refine search terms before undertaking a second search using 14 electronic databases. Electronic databases have been identified in consultation with a subject librarian as all being relevant to the topic under exploration. Databases identified are listed below;
On the EBSCO platform: AMED; CINAHL Plus; PsycINFO; and Medline
On Proquest platform: ASSIA (Applied Social Services Index and Abstracts); BND (British Nursing Database); IBSS (International Bibliography of the Social Services); and Sociological Abstracts
On OVID platform: Embase; Social Policy and Practice
On Elsevier platform: SCOPUS*
Cochrane
NICE Evidence
TRIP+ (Turning Research into Practice)
The next step will involve a supplementary search to identify additional papers through snowballing from reference lists of retrieved papers.
Authors who have published in this area may be contacted for further information.

Eligibility Criteria

Participants: Adults >18 years of age (in line with the MCA Code of Practice) who have a learning disability (as defined in Government White Paper; *Valuing People* (Department of Health, 2001, p.14).

Concept: Supporting Decision-making

Context: Healthcare. Any country in the UK. Although the MCA only applies to England and Wales, the UK has been found to be lacking in support for decision-making by the United Nations (2017). Scotland has the Adults with Incapacity Act (2000), and the Assisted Decision-Making Capacity Act (2015) is the underpinning legislation in Northern Ireland.

Date: 2007 – September 2018. The MCA was implemented in April 2007 in England and in October 2007 in Wales.

Types of sources: Open.

Selection of Sources of Evidence

Duplicate references will be removed. The title and abstract of each article will be read whilst referring to the eligibility criteria by two reviewers. All articles meeting the eligibility criteria will then be retrieved and the full text read to ensure that the paper meets all eligibility criteria. At this point, all papers meeting the criteria will be charted on a charting table based on the extraction table I used in a previous review. In the event of disagreements, discussions will be held with the supervisory team.

Synthesis of Results

Narrative synthesis following guidance by Popay *et al.* (2006) will be used to synthesise data retrieved. Narrative synthesis uses a text-based approach, with the aim of "telling a story" from the findings of the included literature (Popay *et al.* 2006, p.5).

Narrative synthesis has been selected for the following reasons;

This review aims to provide a summary and synthesis of existing empirical literature for knowledge support rather than decision support (Popay *et al.* 2006). A Scoping Review has specifically been chosen to map the current empirical literature as well as to identify gaps.

Literature included is likely to include research (qualitative and quantitative) and evaluations, therefore a flexible method of synthesising different data is required. Literature is likely to originate from a range of professions, and to be published in a diverse range of publications, which narrative synthesis will accommodate.

Presentation of Results

The PRISMA flow diagram will be used to present the papers retrieved.

Results will be presented in a descriptive, narrative format aligning to answering this review's questions and objectives (as stated above).

APPENDIX FOUR: PhD Timeline

	Sep 18-Feb 19	Mar/Apr 19	May/June 19	July/Aug 19	Sept 19	Oct 19-Feb 20	Mar-Aug 20	Sept-Dec 20	Jan-Apr 21	May-Aug 21	Sept 21-May 22	June-Aug 22	Sept-Dec 22	Jan-March 23	April-July 23	Sept-Nov 23	Jan 24	Feb-May 24	June-Aug 24
Scoping (literature) Review	■	■	■		1-month suspension (personal circumstances)		6-month suspension (Covid)				9-month suspension (Covid related)				■		■		
Advisory Group Meetings	Set up		x2			x2		x1						x1	x1			x1	
Ethical Applications			■			■				■			■	■					
Develop recruitment & data collection resources		■	■																
Recruitment & consent			■	■															
Individual Interviews			■	■															
Family Interviews						■		■											
Initial Data Analysis								■	■										
Staff survey pilot						■													
Staff Interviews										■									
Initial Data Analysis										■		■	■						
Focus groups														■					
Initial Data analysis														■	■				
Synthesis of data sets																■			
Writing thesis																		■	
Co-production of film																			■

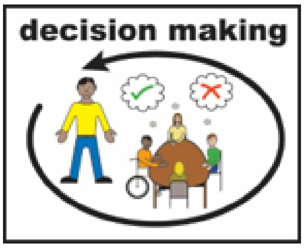
APPENDIX FIVE: Accessible research information leaflets

For Interviews:

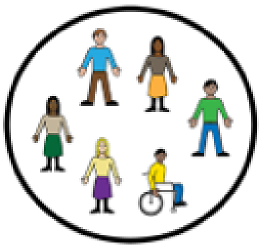
V3. Without location or date

Research Information: Supporting healthcare decision making

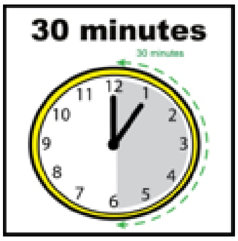
Introduction

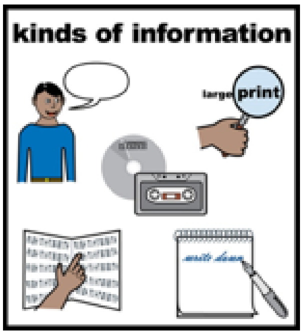
	My name is Emma Douglass. I am a student researcher.
	I want to find out how adults with a learning disability make decisions…
	…about their health.

Participant Information for adults who have a learning disability: Supporting Healthcare Decision Making with Adults who have a Learning Disability. Images from https://www.learningdisabilityservice-leeds.nhs.uk/easy-on-the-i/ "**All symbols copyright © LYPFT**".

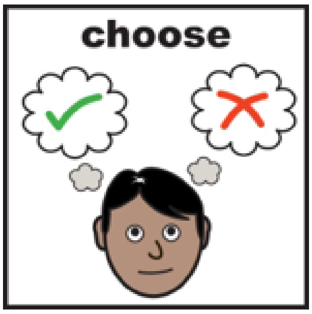
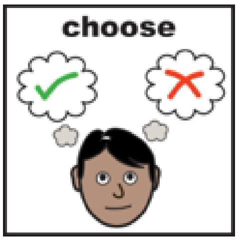
	I would like to talk to 6 adults who have a learning disability

What will happen to me if I take part?

	I will come to talk to you at ….. We might need to talk more than once but you will decide.
	I will ask you questions for about 30 minutes Each time we meet.

	I will use an audio-recorder to help me remember what we talk about But I will ask you if that is OK.
	I will use a video recorder But I will ask you if that is OK.

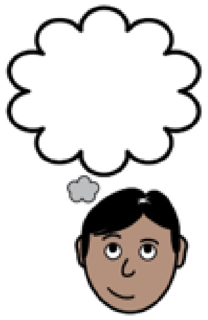
Do I have to take part?

	It is your choice. You decide if you want to take part.
	You can say No if you don't want to talk to me.

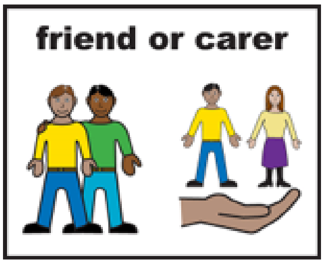
Can I stop being part of the study?

 	Yes you can change your mind.

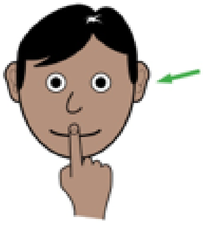
What is good about taking part?

	You will be able to talk about your experiences of making a health decision. You can say what you think.

What is difficult about taking part?

	Some people worry about talking to new people.
	You can bring somebody with you when we talk.

What will happen to the information I give?

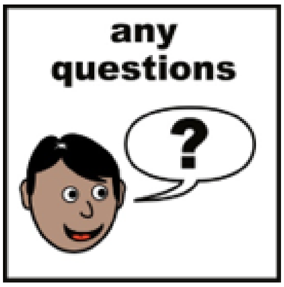
	I will collect information from everyone I talk to. I will record what everyone tells me But I will not use your name.

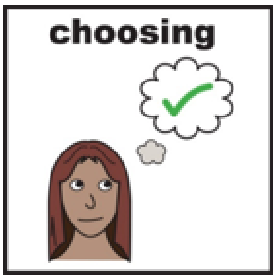
Where will the information I give be kept?

	Personal information will be kept private. Only people doing the study will be able to look at what we talked about.

What happens after we have talked?

	I will write about what I have found out. I will write down the information for magazines. I will also talk to people about it. But I will not use your name when I do this.

	**Any questions?** **Contact me:** **Emma Douglass** **Emma2.Douglass@uwe.ac.uk** **0117 328 8495**

	**If you would like to take part,** **Contact me:** **Emma Douglass** **Emma2.Douglass@uwe.ac.uk** **0117 328 8495**

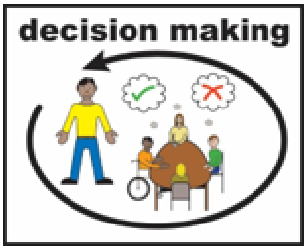
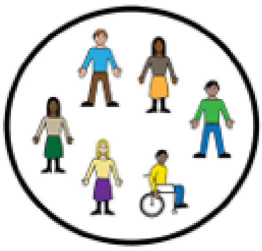
For Focus Groups:

UWE Bristol | University of the West of England

V3. Without location or date

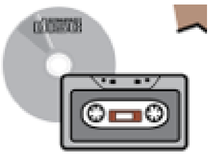
Research Information: Supporting healthcare decision making

Introduction

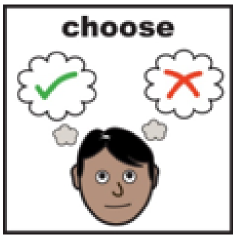
	My name is Emma Douglass I am a student researcher
	I want to find out how adults with a learning disability make decisions about their health
	I would like to talk to a group of people This is called a 'focus group'

Participant Information for adults who have a learning disability: Supporting Healthcare Decision Making with Adults who have a Learning Disability. Images from https://www.learningdisabilityservice-leeds.nhs.uk/easy-on-the-i/ **"All symbols copyright © LYPFT"**.

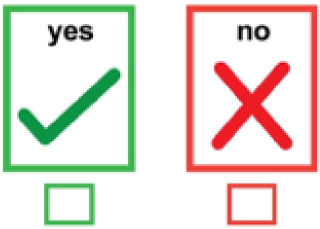
What will happen to me if I take part?

	We will meet in … We will talk in a group It will take 2-hours
	I will ask you how you think people should be supported to make their own health decisions
	I will use an audio-recorder to help me remember what we talk about But I will ask you if that is OK

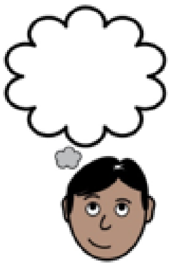
Do I have to take part?

	It is your choice You decide if you want to take part
	You can say No if you don’t want to talk to me

Can I stop being part of the study?

	Yes - you can change your mind

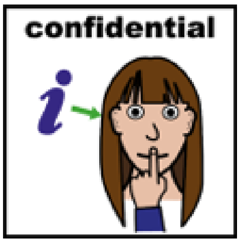
What is good about taking part?

	You can tell me how you think people should be supported to make their own health decisions

What is difficult about taking part?

	Some people worry about talking to new people
	You can bring somebody with you when we talk

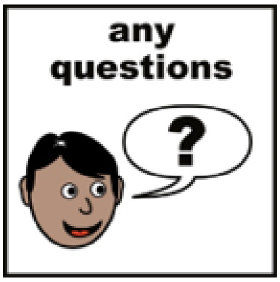
What will happen to the information I give?

	I will listen to what people tell me I will record what everyone tells me But I will not use your name

Where will the information I give be kept?

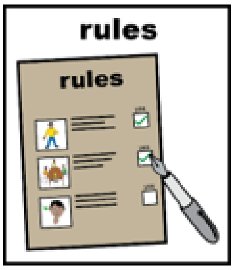
	Everything you tell me will be kept private Only people doing the study will be able to look at what we talked about I will not use your name

What happens after we have talked?

	I will write about what I have found out I will write down the information for magazines I will also talk to people about it But I will not use your name when I do this
	**Any questions?** **Contact me:** **Emma Douglass** **Emma2.Douglass@uwe.ac.uk** **0117 328 8495**

	**If you would like to take part,** **Contact me:** **Emma Douglass** **Emma2.Douglass@uwe.ac.uk** **0117 328 8495**

V3. Without location or date

	This focus group is for a research project I have permission to do this research from UWE’s ethics committee (UWE REC REF No: HAS.20.07.205) which checks that I am following the rules

APPENDIX SIX: Topic guide for interviews with family members

V1. 29/04/19

Indicative Topic Guide for Interviews with family carers

The following are the broad questions that will be asked during interviews.

Prior to interviews, these questions will be adapted in line with feedback from the advisory group in order to make them accessible for participants.

1. Tell me about one occasion when a *healthcare decision** had to be made either by or for your family member with a learning disability.

    1. What was the decision?

2. Why *did this healthcare decision need to be made?*

3. How was this decision made?

    - What was considered when making this decision?
    - What influenced the decision?
    - Who else was involved? Why were they involved? How were they involved?
    - How did you feel about the process of making this decision?
    - How did you feel about the outcome?

4. How was your family member supported to make the decision?

    - What things were considered when making the decision?
    - What influenced the decision making process?
    - Who else was involved?
    - How did you feel about the process and outcome?

4\. Have you heard of “supporting decision making”?

5\. What is your understanding of “supporting decision making”?

6\. How would you like your family member to be supported in future to make healthcare decisions?

7\. As a family carer, what support do you need/would you find useful to support your family member to make healthcare decisions?

*Healthcare decisions might include whether to make/attend a GP/nurse/dentist/optician appointment; have a blood test; start/change medication; attend screening; have an annual health check.

APPENDIX SEVEN: Staff Interview research questions and topic guide

Research Questions

What can we learn from healthcare staff who have had experience of supporting adults with a learning disability to make healthcare decisions?

- What approaches to supporting decision-making are staff using in practice?
- What facilitates healthcare staff to support adults with learning disabilities to make healthcare decisions?
- What are the barriers to supporting decision-making in healthcare practice?
- What supporting decision making tools and/or aids are being used?

Topic Guide

V1. 14/01/21

Indicative Topic Guide for interviews with healthcare staff

The following are the broad questions that will be asked during interviews.

1. Tell me about one occasion when you supported an adult with a learning disability to make a healthcare decision.
    - What was the decision?

2. Why did this healthcare decision need to be made?

3. How was the individual with a learning disability involved/supported to make the decision?

    - What things were considered?
    - Who else was involved?
    - Were any decision aids / tools used to facilitate this process?
    - If so, what were these and were they helpful? How? Why?

4. How was the decision made?

    - What was considered when supporting the person to make this decision?
    - What influenced the decision?
    - Who else was involved? Why were they involved? How were they involved?

    - How did you feel about the process of making this decision?
    - How did you feel about the outcome?

5. In your experience, how do you think adults with a learning disability should be supported to make healthcare decisions?

  - Who should be involved in supporting healthcare decision-making?

6. As a member of healthcare staff, what do you need/would you find useful to facilitate you to support healthcare decision-making?

Is there anything else you want to say / add?

APPENDIX EIGHT: Survey protocol and questions

Written October 2019

Project Proposal:

Staff survey: How are healthcare staff supporting adults who have a learning disability to make healthcare decisions?

Background

People with a learning disability represent approximately 1.2 million people in the UK (Hatton *et al.,* 2016). Despite changes in political discourse and a policy shift from segregation towards empowerment, inclusion, independence and rights (Department of Health, 2001), people with a learning disability remain a vulnerable group. This is particularly evident within healthcare, where this population face health inequalities and experience poorer health outcomes (Emerson and Hatton, 2014; Heslop *et al*., 2013; Michael, 2008; Mencap, 2007). In response to reports of discriminatory healthcare practice (e.g., Michael, 2008; Mencap, 2007; Disability Rights Commission, 2006) the 'Confidential Inquiry into Premature Deaths of People with Learning Disabilities' (CIPOLD) (Heslop *et al.,* 2013) was commissioned. Despite people with a learning disability having greater and more complex health needs, CIPOLD found that this population are more likely to die prematurely as a result of systemic healthcare failings. These include delays in diagnosis and treatment, as well as failures in making "reasonable adjustments" (as required by the *Equality Act* 2010). CIPOLD also identified that poor adherence and understanding of the *Mental Capacity Act* (MCA) (2005) was a contributory factor to people with a learning disability dying prematurely.

The MCA was implemented in England and Wales in 2007, and is based on five principles: capacity should be assumed; all practicable steps should be taken to support an individual to make their own decision; an individual can make an unwise decision; if an individual does not have capacity, decisions should be made in the person's 'Best Interests'; and the least restrictive decision should be taken (Office of the Public Guardian (OPG), 2007).

Whilst the MCA stipulates that healthcare staff should support decision-making (Office of the Public Guardian, 2007), a House of Lord's (2014) report found limited evidence of this happening in practice. The United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2017) and the National Institute for Health and Care Excellence (2018) suggest that this is an area requiring further research in the UK; specifically, to explore how supporting decision making can be improved across UK healthcare practice.

A scoping review, undertaken in 2018/19 as part of this PhD study, identified only two published papers reporting on supported health decision making with adults who have a learning disability in the UK. Therefore, this project hopes to find examples of how healthcare staff are currently supporting adults who have a learning disability to make healthcare decisions.

Aim of Study

The aim of this study is to find out how staff in the United Kingdom are currently supporting adults who have a learning disability to make healthcare decisions. The findings will contribute to a larger study exploring supporting healthcare decision making with adults who have a learning disability.

Research Questions

How are healthcare staff supporting adults who have a learning disability to make healthcare decisions? Specifically;

- What approaches are being used?
- Are decision aid tools being used? If yes, which tools?
- What is the participant's understanding of "supported decision making"?

Definitions

"**Learning disability** includes the presence of: a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with; a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development." (Department of Health, 2001, p.14).

Methodology

Research design and rationale

A literature review (undertaken as part of this PhD in 2018/19) of published and grey UK literature found limited evidence of supported healthcare decision-making happening in practice. Only two published papers (one qualitative study and one report) were retrieved; Davidson *et al*. (2018) and Jamieson, Theodore and Raczka (2016). A search of grey literature, whilst identifying a plethora of guidelines, advice and promotional materials, did not identify evidence of supporting decision-making actually happening with adults who have a learning disability in UK healthcare practice. This finding corroborates the findings of the House of Lords (2014) scrutiny report, however Davidson *et al*. (2018) and Gordon (2000) suggest that whilst supported decision-making is likely to be underrepresented in the literature, it has been happening in practice for some time. This appears therefore to be a gap in the literature.

Consequently, the intention is to use a short, cross-sectional online survey (via Qualtrics) to find out how UK based healthcare staff are currently supporting adults who have a learning disability to make healthcare decisions.

The survey will ask five questions about supporting healthcare decision-making, before seeking demographic data. The survey should take approximately 15-minutes to complete.

It is anticipated that the findings from the survey will inform a subsequent phase of the PhD study, which will interview healthcare staff about their experiences of supporting adults who have a learning disability to make healthcare decisions.

Pilot

As suggested by Braun and Clarke (2013), in order to gather feedback re clarity of instructions, wording and ordering of questions, the survey will be piloted in December 2019. The intention is to pilot the survey at UWE's Learning Disability Nursing Programme Day on Monday 16th December 2019, which typically includes some Registered Learning Disability Nurses, students from all 3 years of the learning disability undergraduate nursing programme (approximately 60) and academic nursing staff.

My intention is to make necessary modifications to questions following the pilot, but also to include pilot data in survey data analysis.

Indication of interest in being invited for a telephone interview

[This won't be included in pilot survey].

At the end of the survey (excluding pilot survey), the participant will be asked if they would be interested in participating in a telephone interview between May and July 2020 (ethical approval for telephone interviews to be submitted at a later date, as survey responses will inform interview questions). If interested, the participant will be able to click on a link where they will be able to provide a contact e-mail address. This will be in a separate Qualtrics survey to ensure that this personal identifiable data is kept separately from responses to the survey questions. In this way, the survey responses will remain anonymous.

Sampling and recruitment

The aim is to reach as many healthcare staff working within the learning disability field across the UK as possible. The sample is not intended to be representative of a healthcare staff group or geographical area, instead it seeks to gather a wide variety of views (Braun and Clarke, 2013). For a survey of this type and design, Braun and Clarke (2013) suggest a response of between 10 and 50.

The survey will be aimed at healthcare staff who work with adults who have a learning disability in the UK. Healthcare staff may include: Allied Health Professionals; Dentists; Doctors; Healthcare Support Workers / Healthcare Assistants / Care Staff; Managers; Midwifes; Psychologists; Registered Nurses; and Student Nurses.

For the pilot, prospective participants will be registered nurses, nurse academics and pre-registration learning disability student nurses from UWE. This might increase the number of student nurses who complete the survey compared to other healthcare staff groups, however as the aim of this survey is to find examples of supporting decision-making in practice and not to collect representative or generalisable data, this will not impact on the usefulness of collected data.

The online survey will be disseminated via the following methods, with those who see the original tweet or e-mail being encouraged to forward and share the survey link among their own networks:
Avon and Wiltshire Positive Behaviour Support Network
Avon Learning Disabilities Education and Research Network
'LIDNAN' network, which is a UK and Ireland Learning Disability Academic Nursing Network LIDNAN
RCN South West
Twitter – using the "UWELDNurse" twitter account
Placement mentors who supervise UWE undergraduate learning disability nursing students (this covers the South West of England)

Data Collection

Data collection will be via an online Qualtrics survey. The online survey will include five questions about supporting decision-making before asking participants to complete some demographic data. It is envisaged that the survey will take approximately 15-minutes to complete.

Data Analysis

Descriptive data analysis will be used for closed questions and demographic data. Thematic analysis (Braun and Clarke, 2013) will be used to identify patterns in the qualitative data.

Data collected via the pilot will be included in data analysis.

Ethical Issues

This proposal will be submitted to UWE's Faculty of Health and Applied Sciences Ethics committee for approval.

Pilot of survey via the UWE Learning Disability Nursing Programme Day will be voluntary, with prospective participants being informed that they do not have to partake without giving a reason or detriment. I intend to discuss the survey at the end of a taught session (before a break) so students feel under no pressure or obligation to participate. As students know me, they may feel they want to participate to help me out, I will therefore emphasise that participation is voluntary and anonymous so I will not know who has participated and who has not. I will also emphasise that there will be no detriment to students whether they decide to participate or not to participate. If students do partake in the pilot, all survey responses will be anonymous. In the pilot survey, participants will not have the option of providing an e-mail address for a future interview. Students will instead be asked to give feedback about the clarity of instructions, wording of questions and ordering of questions. In Question 3 of the survey (attached) participants are given the option to e-mail me copies of decision aid tools that they use in practice. For the pilot, students will not be given the opportunity to e-mail me documents, but instead there will be instructions for how students can upload copies of documents anonymously to the Learning Disability Nursing Programme BlackBoard site if they want to. Consequently, no participant will be able to be identified through either completion or non-completion of the survey.

Following the pilot, participants will be recruited via online forums, Tweeter and e-mail.

Participants are not considered to be vulnerable. Prospective participants will all be healthcare staff or healthcare students who work with adults who have a learning disability. Some respondents may be known to the researcher through a professional capacity such as registered nurses working in the South West of England, however participation in the survey will be voluntary and all survey responses will be anonymous.

UWE's Data Privacy Notice and the Participant Information will be included at the start of the survey, along with instructions of how to complete the survey. Participants will have to click to acknowledge they have read the privacy notice and participant information to continue with the survey.

At the end of the survey, participants will be given the option of providing a contact e-mail address if they are interested in a future telephone interview. If participants choose to provide a contact e-mail address, they will do so in a separate Qualtrics survey. This is to ensure anonymity of survey responses. E-mail addresses will be kept separately to the survey responses (as a separate survey data set). All participants who have provided a contact e-mail address will be e-mailed in April/May 2020 with information about the telephone interviews. At this point, they will be able to decide whether or not they want to take part. Personal data (e-mail) will be stored on an Excel spreadsheet and stored and accessed via password protected computers at Glenside and one UWE laptop. All computers are protected by a firewall. Staff interviews will require separate UWE ethical approval as questions will be informed by the data collected as part of this survey.
Data will be stored in line with UWE's policies and procedures, and GDPR.

Survey Questions

The following will be in QUALTRICS.

Title

Staff survey: How are healthcare staff supporting adults who have a learning disability to make healthcare decisions?

Pre-participation information (Participant Information Sheet)

See Participant Information Sheet: Staff Survey (separate document here but in Qualtrics the Participant Information is at the start of the survey), before the data privacy notice and the consent page.

[Participant has to click to say they have read the Participant Information before being able to proceed]

See Privacy Notice: Staff Survey (separate document here but in Qualtrics the Privacy Notice is at the start of the survey), after the Participant Information and before the consent page.

[Participant has to click to say they have read the Privacy Notice before being able to proceed]

Consent

- I have read and understood the Participant Information
- I agree that anonymised quotes may be used in the final report of this study
- I understand that my participation is voluntary
- I understand that I am free to withdraw at any time until the data has been submitted, without giving a reason
- I agree to take part in the research

[Participant has to click to say they consent before being able to proceed]

Instructions on how to complete and answer questions

- All questions should be answered from your perspective as a healthcare member of staff, or as a student working in a practice placement.
- All questions are specific to the care/support of adults who are aged 18 and over, and who have a learning disability.
- Please provide as much detail as possible without giving any patient/service user identifiable details such as peoples' names and place names.
- Write answers in your own words.
- There are no right or wrong answers.
- This survey should take approximately 15-minutes to complete.

- Thank you for taking the time to read this.

Main body of survey

Q1. Using your own words, what is “supported decision making”?

FREE TEXT

Q2. In your role as a member of healthcare staff (or student nurse), please provide examples of how you support adults who have a learning disability to make healthcare decisions. Please use your own words. Give as much detail as possible about the approaches you use without providing any patient/service user identifiable information.

FREE TEXT

Q3. Decision aid tools can facilitate decision-making and may include resources such as leaflets, objects of reference and interactive media (Elwin *et al.* 2006). When supporting an adult who has a learning disability to make a healthcare decision, do you use decision aid tools?

DROP DOWN – YES / NO

[If No, will go straight to Q4].

Q3b. [If Yes] Please tell me about the decision aid tool(s) that you use.

Please describe the decision aid tool(s) in as much detail as you can.

Tell me the name of the tool; who the tool was developed/produced by (if you know this information); the authors of the tool; and the date it was developed.

If it is a tool you or colleagues have developed, please tell me why you developed it and how you have used it.

Alternatively, you can e-mail me a copy of decision aid tool(s) that you use: Emma2.Douglass@uwe.ac.uk. If you do this, please make sure all service user/patient identifiable information is removed.

Q4. Think about a specific example of when you have supported an adult who has a learning disability to make a healthcare decision. With this example in mind, please tell me what else you do to support decision-making?

FREE TEXT

Q5. Is there anything else you would like to add, or any other questions I should have asked you about supporting adults who have a learning disability to make healthcare decisions?

FREE TEXT

DEMOGRAPHIC QUESTIONS

In order to learn the range of people taking part in this survey, please could you answer the following demographic questions.

Q1. Which of the following best describes your current position?

DROP DOWN LIST
Allied Health Professional > 1a
Dentist
Doctor > 1b > 1bi
Healthcare Support Worker / Healthcare Assistant / Care Staff
Manager
Midwife
Nursing Associate
Psychologist
Registered Nurse > 1c
Researcher
Student Nurse > 1d
Other – FREE TEXT TO EXPLAIN

Q1a. Please select which Allied Health Professional group from the following list.

Art Therapist
Drama Therapist
Music Therapist
Chiropodist / Podiatrist
Dietician
Occupational Therapist
Operating Department Practitioner
Orthoptist
Osteopath
Paramedic
Physiotherapist
Prosthetist / Orthotics
Radiographer
Speech and Language Therapist

Q1b. Do you work in primary or secondary care?

Primary Care
Secondary Care
Other – FREE TEXT TO EXPLAIN

Q1bi. In what discipline do you work (tick all that apply)?

CAMHS
General Practice
Learning Disabilities
Mental Health
Occupational Health
Psychiatry
Other – FREE TEXT TO EXPLAIN

[Participants who complete this question, will then answer Q3 as Q2 will not apply].

Q1c. What is your nursing registration?
Registered Adult Nurse
Registered Children's Nurse
Registered Learning Disability Nurse
Registered Mental Health Nurse
Other – FREE TEXT

Q1d. Which field of nursing?
Student Adult Nurse
Student Children's Nurse
Student Learning Disability Nurse
Student Mental Health Nurse
Other – FREE TEXT

Q2. Which of the following best describes where you currently work?
DROP DOWN LIST
Brain Injury Unit
Community
Education
Hospital Liaison
Hospital Ward > Q2b.
Independent Voluntary Sector
Nursing Home
Primary Care
Residential Home
Social Services
Other – FREE TEXT

Q2b.

Acute

Brain Injury

Learning Disability

Medical

Mental Health

Neurology

Surgical

Other – FREE TEXT

Q3. In which country of the United Kingdom is the majority of your experience?

DROP DOWN LIST

England

Northern Ireland

Scotland

Wales

Q4. In total, how long have you worked with adults who have a learning disability?

DROP DOWN LIST

12 months or less

More than 1 year and less than 5 years

More than 5 years and less than 10 years

10 years or more

Q5. How do you describe your racial/ethnic background?

FREE TEXT

Q6. Gender?

DROP DOWN LIST
Female
Male
Prefer not to say
Prefer to self-describe - FREE TEXT

Q7. How old are you?
DROP DOWN LIST
18 to 24
25 to 39
40 to 59
60 plus
Prefer not to say

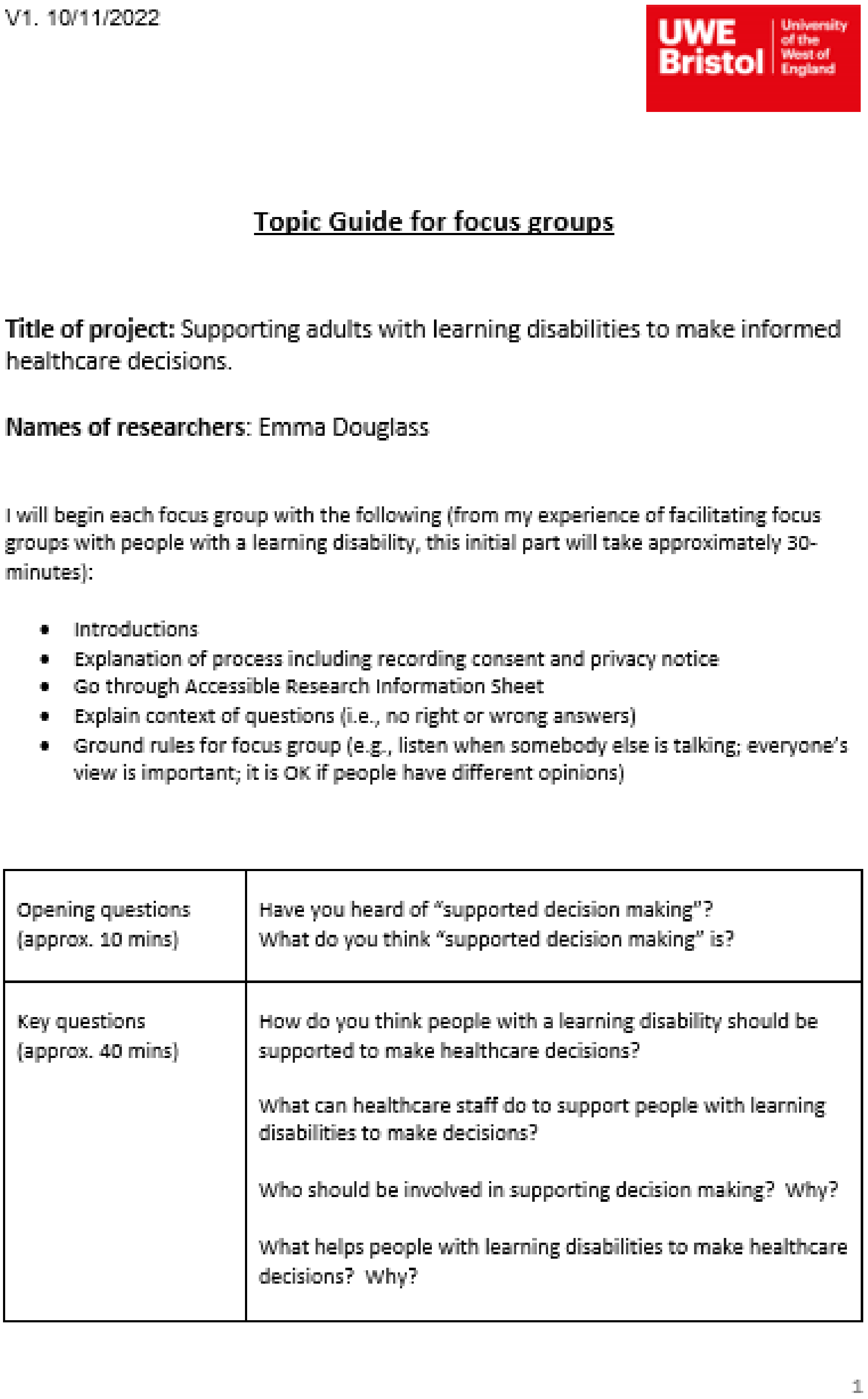
Thank you. You have now completed all survey questions.

In the next phase of this PhD research I will be recruiting staff for telephone interviews about their perspectives and experiences of supporting adults who have a learning disability to make healthcare decisions. It is anticipated that telephone interviews will take place between May and July 2020. If you are potentially interested in having a telephone interview, please click the following link where further information will be provided and you will be able to provide a contact e-mail address if you wish to.
Please note that if you decide to give an e-mail address, this data will be separated from your survey responses so your survey responses will remain anonymous.

Link to separate survey where participant will be able to provide e-mail address if they are potentially interested in participating in a telephone interview.

Thank you for completing this survey.

APPENDIX NINE: Focus group topic guide



V1. 10/11/2022

Topic Guide for focus groups

Title of project: Supporting adults with learning disabilities to make informed healthcare decisions.

Names of researchers: Emma Douglass

I will begin each focus group with the following (from my experience of facilitating focus groups with people with a learning disability, this initial part will take approximately 30-minutes):

- Introductions
- Explanation of process including recording consent and privacy notice
- Go through Accessible Research Information Sheet
- Explain context of questions (i.e., no right or wrong answers)
- Ground rules for focus group (e.g., listen when somebody else is talking; everyone's view is important; it is OK if people have different opinions)

Opening questions (approx. 10 mins)	Have you heard of "supported decision making"? What do you think "supported decision making" is?
Key questions (approx. 40 mins)	How do you think people with a learning disability should be supported to make healthcare decisions? What can healthcare staff do to support people with learning disabilities to make decisions? Who should be involved in supporting decision making? Why? What helps people with learning disabilities to make healthcare decisions? Why?

1

	What doesn't help / stops supported decision making happening in practice?
Ending question (approx. 10 mins)	Is there anything else you want to say about supporting people with a learning disability to make healthcare decisions that we haven't talked about?

Timings of focus group discussion run to approx. 60 mins to allow plenty of time if participants want to have break(s).

At the end of the focus group discussion, 30-minutes has been timetabled to allow for:

- A short comfort break
- Opportunity for participants to ask questions
- Confirmation of consent
- De-brief(s) as necessary

APPENDIX TEN: Braun and Clarke’s (2013) initial questions

Braun and Clarke’s seven “Questions to ask when reading the data” (2013, p.205) for each interview transcript, which were captured in memos in NVivo.

Example 1: Individual interview

How does a participant make sense of their experiences?

P Initially selected lots of cards, but most were in relation to having an annual health check, so eventually decides to talk about their decision to have an annual health check and GP appointment around ongoing health condition. This person did not arrive at the interview already having decided what they wanted to talk to me about, which is different to the other people I have interviewed so far who have all arrived knowing what they wanted to talk to me about. Whilst focus of discussion is annual health checks, P talks about linked/related decisions such as to lose weight and eat more healthily; decision not to smoke as had seen family member smoke (and family member died so had seen what smoking can do to a person); and decision to take medication – which appears to have been supported by doctor being "brilliant" as the doctor had explained side-effects in a way P understood. Doctor is spoken about in high regard as the doctor listens and is understandable.

How might a participant make sense of their experiences in this way (and not in another way)?

This person has a strong support network around them – formal and informal. Family provides important informal support in enabling (not sure if ‘enabling’ is the right word? Encouraging? Supporting? Validating?) P to make their own decisions. P trusts the staff at the GP surgery and speaks highly of them. The support network (informal and formal) appears to give P confidence in who they are and their ability to make their own decisions, providing information in an understandable way so P can weigh up the options).

In what different ways do participants make sense of supporting healthcare decision-making?

Family is important in supporting decision making, particularly in relation to practical aspects such as completing forms and making appointments.

Participant knows what to expect from an annual health check (again link with understanding decision to be made - similar to previous interviews – the importance of understanding the decision that needs to be made and feeling prepared). Current health staff (doctor and nurses at the GP surgery) are nice and understandable.

P says supporting person needs to be kind, helpful and understandable.

How 'common-sense' is their story?

When listening to P speak, their story is ‘common sense’. But why do I find it to be refreshing, when it is ‘common sense’? I wonder how common sense it is to people with a learning disability generally.

How would I feel if I was in this situation? (Is it different from or similar to how the participant feels, and why might that be?)

P feels making their own decisions is just a part of life. I found this interview refreshing in how trivial P was in talking about making health decisions (taking it in their stride / part of ‘normal’ everyday life, not a big deal / no one can tell P what to do), which I relate to. Aspects of this interview made me smile along with P when they were talking, especially when P referred to not always being completely honest about the information they provide on health forms about drinking alcohol.

What assumptions do participants make in talking about the world?

People with a learning disability have support to make their own health decisions. Others (family members / doctors / nurses) can give information and advice but cannot tell person with a learning disability what to do – it is the person’s decision ultimately.

What kind of world is 'revealed' through their account?

A world I want to live in! A world where individuals can be supported in a way that enables them to reach their potential (which P talks about in the interview) and to make their own decisions. A world where people with a learning disability can have a good quality of life, doing things they want to do, having friends / informal networks / relationships with others etc., etc., because their health needs are well-managed and supported appropriately - ("The good things in life" / links with social role valorisation potentially?)

Example 2: Family interview

How does a participant make sense of their experiences?

F is well-informed and pivotal in the life of her son. Throughout, focus is on the need for collaborative working between healthcare professionals and family members, with the knowledge and expertise family members have, being respected as equal to that of the healthcare worker(s). For it is the family member who *knows* the individual and who is trying to ensure the individual's voice is heard and at the centre of decision-making. For F, this is crucial when individuals, like her son, have severe learning disabilities and are not able to necessarily consent and represent themselves.

All family members want is for the individual to have an ordinary life.

How might a participant make sense of their experiences in this way (and not in another way)?

F is balanced in understanding/respecting the differences in the knowledge of healthcare professionals and families. From what F says, it seems that there have been less than positive experiences in the past but F is focused on raising awareness and promoting truly collaborative working where family views and perspectives are respected.

Participant is articulate and well-informed. They are aware of legal framework, as well as having a good knowledge of how services work. Rather than become negative about healthcare staff or situations, F is trying to make a difference and to be a catalyst for change.

In what different ways do participants make sense of supporting healthcare decision-making?

Collaboration / working in partnership is essential.

Family carers should be valued and respected rather than seen as difficult people.

It is a long process / takes a long time.

It is important so individual can have an ordinary life, based on their preferences and what is important to them.

Individuals with a severe or profound learning disabilities need people involved who really *know* them.

How 'common-sense' is their story?

As a reader / interviewer / researcher / nurse, the story appears to me to be "common sense". A mother wanting her child to have an ordinary life and to be treated with respect, with the adult child’s preferences at the heart of all decision-making.

How would I feel if I was in this situation? (Is it different from or similar to how the participant feels, and why might that be?)

From what F says, it seems that life has not always been easy and there have been less than optimal experiences in the past. It appears F has focused on ensuring her son is supported appropriately by a team that have his best interests at heart, whilst F has continued to be involved in decision-making, representing her son's voice - as her son does not always have capacity. I think I would feel more jaded and less positive than this person, who appears to me to have taken negative situations and focused on making positive change. I find this commendable, admirable especially as this must be exhausting and all-consuming at times.

What assumptions do participants make in talking about the world?

-People with a learning disability have the right to an ordinary life. Family members are pivotal to ensuring this happens. Family is important.

-But not all healthcare staff want/are comfortable to work collaboratively with family members / -Family members are seen as being difficult.

What kind of world is 'revealed' through their account?

-A world that isn’t fair – a world where people with a severe or profound learning disability can have a rough time / they are not always treated with respect or dignity.

-Building relationships and good communication are therefore crucial.

-It is important to involve individual throughout and to use appropriate approaches (in this case "social stories") to ensure individual is supported to contribute/be involved/at the centre of the decision-making process.

-If somebody has a severe learning disability, family members are crucial in supporting the individual’s preferences to be at the centre of health decision-making.

-Some individuals with severe or profound and multiple learning disabilities might need others to make decisions in order that they can receive timely, good quality healthcare, to have an “ordinary life”.

-Central to this is the family member’s knowledge/expertise being viewed as important as healthcare professionals,

-Where collaborative working happens, individuals can receive good quality healthcare **but** this takes time and dedication - especially on the part of the family member.

Example 3: Staff working in residential/domiciliary care services

How does the participant make sense of their experiences?

S comes across as being experienced and having learnt from a long career as a nurse, supporting lots of different individuals who have a learning disability and complex needs, as well as supporting lots of staff, depending on their position / role within the organisation in which they work. S is reflexive when speaking, saying that they have not always "*been as good as I should have been*" (in relation to making information accessible and supporting decision-making) - which has similarities with SX interview - SX had not been qualified for many years but had had different roles and was reflexive that they were learning every day and might not have got things right each time. S also discusses supporting decision-making in the wider context of life, with pragmatism and realism, recognising that not all of us will make what are considered the "right" decisions despite knowing that it is probably in our best interest, for example, when making decisions to eat healthily. We all might relapse and change our minds - in this context, as well as in context of supporting an individual with a learning disability who they know well, S talks about supporting health decision-making being a long-term venture, continuous in nature and to be taken at the individual's pace. Says something along the lines of, '*I'll be doing this until I retire*' or similar - need to recheck transcript for accurate quote. No quick fixes is similar to family member data.

How might a participant make sense of their experiences in this way (and not in another way)?

S's views and experiences are clearly based on years of experience as a nurse and working with people who have a learning disability, and also with reflections from personal life and world-view.

In what different ways do participants make sense of supporting healthcare decision-making?

S talks about the importance of thinking about individual at centre of process and the individual's needs.

The importance of partnership working with different teams, for example Community Learning Disability Team and GP, whilst at all times having consent of individual.

The importance of relationship with family member(s).

Support staff are crucial, but might need further education / support due to limited health knowledge / experience.

It's important to find the 'right' person to support specific decisions - based on the needs of the person with a learning disability (not the needs of the service or staff).

Accessible information can be useful, but needs to be tailored to individual you are working with - this gentleman for example would find images to illustrate text demeaning. These details are important to understand / know for supporting decision making to be effective / successful.

How 'common-sense' is their story?

Yes, it is 'common sense' when reflecting on the interview discussion.

What strikes me from this interview is the need to engage critical thinking about use of accessible information to support decision-making.

Also, this interview highlights that support staff, crucial to supporting decision-making, might have limited understanding of health issue themselves, therefore do we need to think about making health information accessible just as much for staff as well as individuals with a learning disability? How can we expect support staff (who are not paid much, and who are often at the bedrock of supporting people with a learning disability to make daily healthcare decisions) to support decision-making if they too do not understand the health decision that needs to be made? Are there links here with family carer data findings about decisions whether to include/work with families left with support staff, who might not have good understanding or might feel threatened by family members?

How would I feel if I was in this situation? (Is it different from or similar to how the participant feels, and why might that be?)

This person’s story resonated with me in many ways. I think I have similar feelings to those expressed in this interview.

What assumptions do participants make in talking about the world?

People are people, we might know what is best for us, but we might not. We might make a decision to stop doing something because we know it is good for us to stop doing it, but we might relapse. Human beings are fallible and complex.
Supporting decision making needs to be realistic and pragmatic, around the needs of the individual.
We don't all get it right every time, it's a continuous learning process.

What kind of world is 'revealed' through their account?

A kind, thoughtful world. One where people with a learning disability are treated with respect and dignity and have their needs met in a person-centred, holistic way. One where there is partnership working, and at times alternative methods of support are used to ensure the person with a learning disability remains in and at the centre of the decision-making process.

Example 4: Staff working in acute setting

How does the participant make sense of their experiences?

Supporting individuals to make their own decisions (the participant refers to this as "empowering" the individual to make their decision) can and should be done, it takes a different approach and attitude. S spoke about a decision where they went 'above and beyond' to ensure an individual's wishes were respected. The individual did not use verbal communication, communicating instead via informal methods of communication such as body language.

How might a participant make sense of their experiences in this way (and not in another way)?

Individuals are not consistently supported to make their own decisions, so more education is required for healthcare professionals, support/care staff and wider staff such as receptionists etc., in order to ensure all individuals can be supported to make their own decisions. Although this takes longer initially (process rather than a 'one off'), it builds trust and confidence for all involved (individual with a learning disability, support/care staff, healthcare professionals) so that future decisions might be easier and require less additional support.

In what different ways do participants make sense of supporting healthcare decision-making?

The need for education / training is a theme throughout this transcript, facilitating education and training for acute hospital staff, support/care staff, other organisations, as well as self. This interview seems different to SX (S and SX are both hospital learning disability liaison nurses working in big, busy acute hospitals as part of small learning disability liaison nursing teams - but in different counties in England). Whereas S speaks throughout about the need for education and support for others to develop supporting decision-making, seeing it as their role to facilitate/provide this, SX appears frustrated that consultants/doctors (other healthcare staff?) do not have knowledge and understanding about the MCA and ask them questions / seek clarification. S talks about learning from the experience they discussed with me, and the learning changing their own clinical practice.

How 'common-sense' is their story?

It makes sense - participant is part of a small team, which cannot be involved in supporting every decision - it is therefore more appropriate (essential) for participant to focus some of their time on supporting / educating / training others to support people with a learning disability to make healthcare decisions.

How would I feel if I was in this situation? (Is it different from or similar to how the participant feels, and why might that be?)

I hope I would be as effective as this person. I think this is a really good example of excellent supporting decision-making practice. The nurse appears very proud of this example, and I would be too - it demonstrates what can be achieved, illustrating the short and long-term positive effects and benefits of supporting an individual to make their own decisions.

In other interviews, people have said examples would be useful as a reference/guide (to make supporting decision-making less abstract). This would make an excellent example.

What assumptions do participants make in talking about the world?

People with a learning disability can and should be supported to make their own decisions.

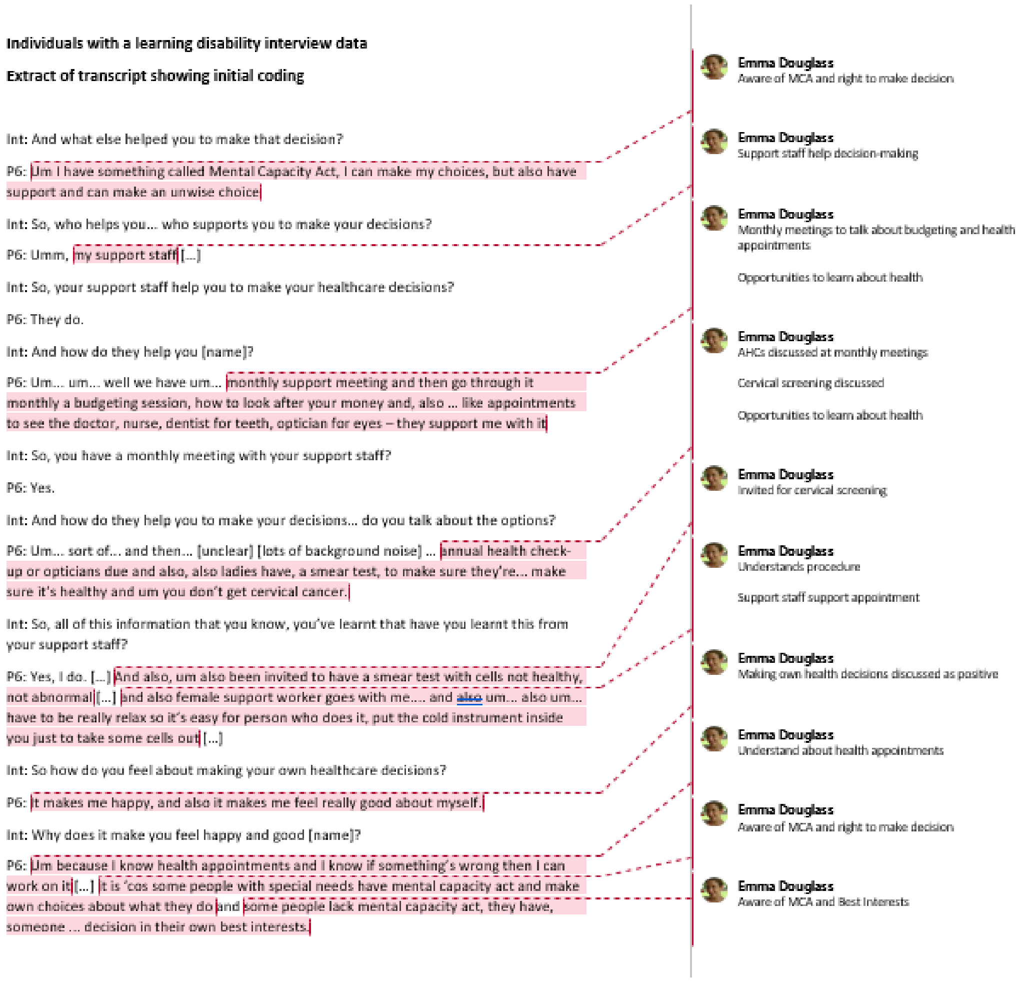
Healthcare professionals (consultant in this example) are ready / happy to work with liaison nurses to support decision-making, but might see this as the nurses' role rather than their own.

Support decision-making and making reasonable adjustments are everybody's responsibility regardless of job role and seniority, not niche role of liaison nurses / specialist teams.

What kind of world is 'revealed' through their account?

A world where health and care staff can learn from each other. Supporting decision-making is a process, which takes time, from which all people involved can learn, grow and develop.

APPENDIX ELEVEN: Data Analysis – Examples of coding



Individuals with a learning disability interview data

Extract of transcript showing initial coding

Int: And what else helped you to make that decision?

P6: Um I have something called Mental Capacity Act, I can make my choices, but also have support and can make an unwise choice

Int: So, who helps you… who supports you to make your decisions?

P6: Umm, my support staff […]

Int: So, your support staff help you to make your healthcare decisions?

P6: They do.

Int: And how do they help you [name]?

P6: Um… um… well we have um… monthly support meeting and then go through it monthly a budgeting session, how to look after your money and, also … like appointments to see the doctor, nurse, dentist for teeth, optician for eyes – they support me with it

Int: So, you have a monthly meeting with your support staff?

P6: Yes.

Int: And how do they help you to make your decisions… do you talk about the options?

P6: Um… sort of… and then… [unclear] [lots of background noise] … annual health check-up or opticians due and also, also ladies have, a smear test, to make sure they're… make sure it's healthy and um you don't get cervical cancer.

Int: So, all of this information that you know, you've learnt that have you learnt this from your support staff?

P6: Yes, I do. […] And also, um also been invited to have a smear test with cells not healthy, not abnormal […] and also female support worker goes with me…. and also um… also um… have to be really relax so it's easy for person who does it, put the cold instrument inside you just to take some cells out […]

Int: So how do you feel about making your own healthcare decisions?

P6: It makes me happy, and also it makes me feel really good about myself.

Int: Why does it make you feel happy and good [name]?

P6: Um because I know health appointments and I know if something's wrong then I can work on it […] It is 'cos some people with special needs have mental capacity act and make own choices about what they do and some people lack mental capacity act, they have, someone … decision in their own best interests.

Emma Douglass
Aware of MCA and right to make decision

Emma Douglass
Support staff help decision-making

Emma Douglass
Monthly meetings to talk about budgeting and health appointments

Opportunities to learn about health

Emma Douglass
AHCs discussed at monthly meetings

Cervical screening discussed

Opportunities to learn about health

Emma Douglass
Invited for cervical screening

Emma Douglass
Understands procedure

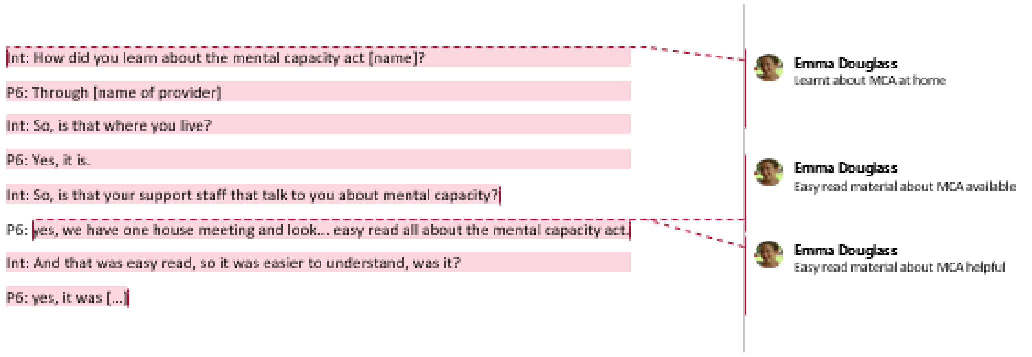
Support staff support appointment

Emma Douglass
Making own health decisions discussed as positive

Emma Douglass
Understand about health appointments

Emma Douglass
Aware of MCA and right to make decision

Emma Douglass
Aware of MCA and Best Interests



Int: How did you learn about the mental capacity act [name]?

P6: Through [name of provider]

Int: So, is that where you live?

P6: Yes, it is.

Int: So, is that your support staff that talk to you about mental capacity?

P6: yes, we have one house meeting and look… easy read all about the mental capacity act.

Int: And that was easy read, so it was easier to understand, was it?

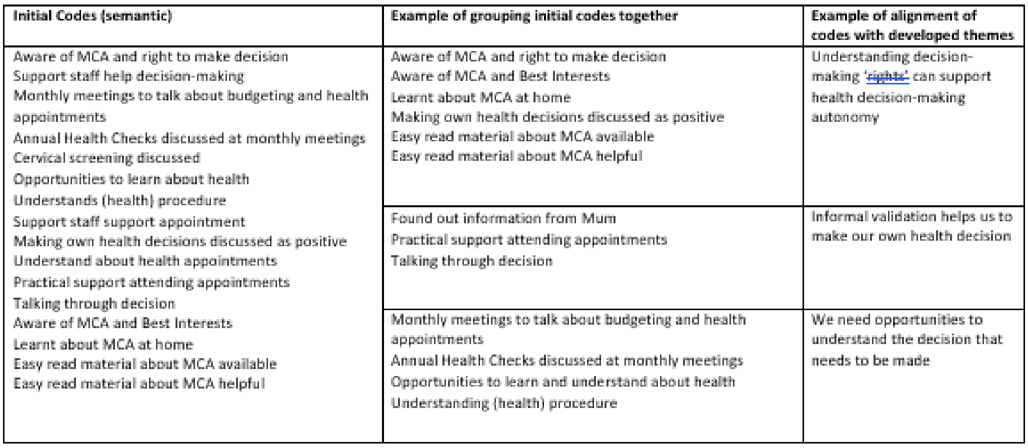
P6: yes, it was […]

Emma Douglass
Learnt about MCA at home

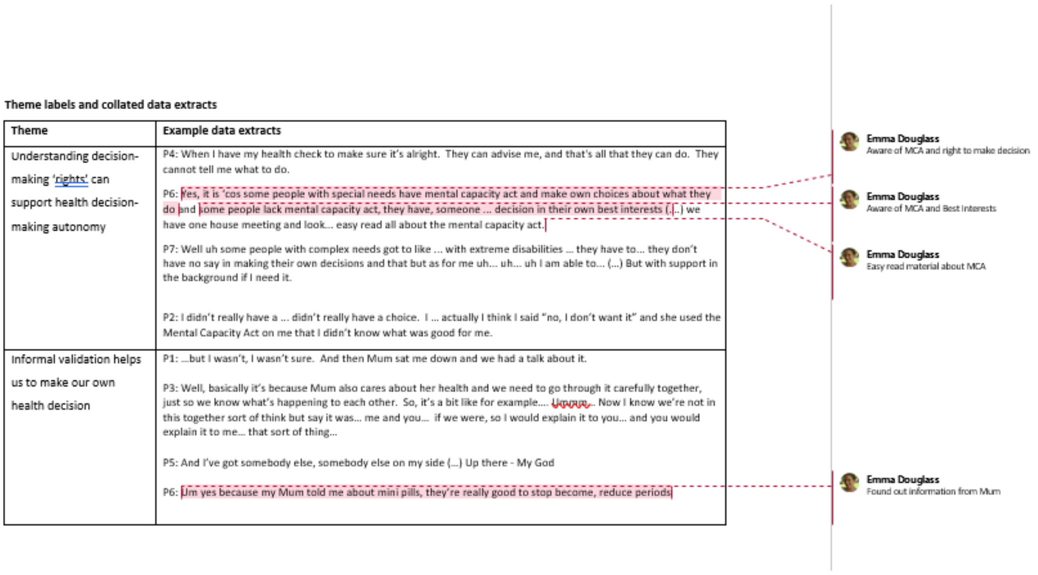
Emma Douglass
Easy read material about MCA available

Emma Douglass
Easy read material about MCA helpful

Example of how initial codes were grouped and developed into themes



Initial Codes (semantic)	Example of grouping initial codes together	Example of alignment of codes with developed themes
Aware of MCA and right to make decision Support staff help decision-making Monthly meetings to talk about budgeting and health appointments Annual Health Checks discussed at monthly meetings Cervical screening discussed Opportunities to learn about health Understands (health) procedure Support staff support appointment Making own health decisions discussed as positive Understand about health appointments Practical support attending appointments Talking through decision Aware of MCA and Best Interests Learnt about MCA at home Easy read material about MCA available Easy read material about MCA helpful	Aware of MCA and right to make decision Aware of MCA and Best Interests Learnt about MCA at home Making own health decisions discussed as positive Easy read material about MCA available Easy read material about MCA helpful	Understanding decision-making 'rights' can support health decision-making autonomy
	Found out information from Mum Practical support attending appointments Talking through decision	Informal validation helps us to make our own health decision
	Monthly meetings to talk about budgeting and health appointments Annual Health Checks discussed at monthly meetings Opportunities to learn and understand about health Understanding (health) procedure	We need opportunities to understand the decision that needs to be made



Theme labels and collated data extracts

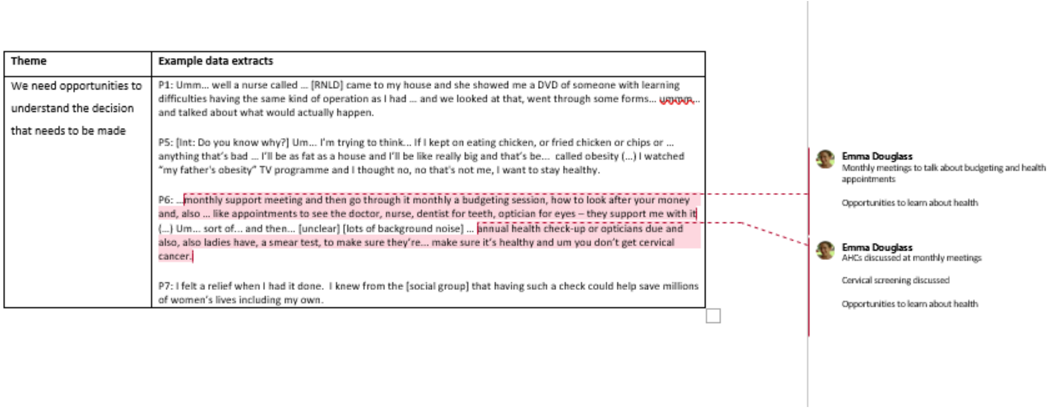
Theme	Example data extracts
Understanding decision-making 'rights' can support health decision-making autonomy	P4: When I have my health check to make sure it's alright. They can advise me, and that's all that they can do. They cannot tell me what to do. P6: Yes, it is 'cos some people with special needs have mental capacity act and make own choices about what they do and some people lack mental capacity act, they have, someone ... decision in their own best interests (...) we have one house meeting and look... easy read all about the mental capacity act. P7: Well uh some people with complex needs got to like ... with extreme disabilities ... they have to... they don't have no say in making their own decisions and that but as for me uh... uh... uh I am able to... (...) But with support in the background if I need it. P2: I didn't really have a ... didn't really have a choice. I ... actually I think I said "no, I don't want it" and she used the Mental Capacity Act on me that I didn't know what was good for me.
Informal validation helps us to make our own health decision	P1: ...but I wasn't, I wasn't sure. And then Mum sat me down and we had a talk about it. P3: Well, basically it's because Mum also cares about her health and we need to go through it carefully together, just so we know what's happening to each other. So, it's a bit like for example.... Ummm... Now I know we're not in this together sort of think but say it was... me and you... if we were, so I would explain it to you... and you would explain it to me... that sort of thing... P5: And I've got somebody else, somebody else on my side (...) Up there - My God P6: Um yes because my Mum told me about mini pills, they're really good to stop become, reduce periods

Emma Douglass
Aware of MCA and right to make decision

Emma Douglass
Aware of MCA and Best Interests

Emma Douglass
Easy read material about MCA

Emma Douglass
Found out information from Mum



Theme	Example data extracts
We need opportunities to understand the decision that needs to be made	P1: Umm… well a nurse called … [RNLD] came to my house and she showed me a DVD of someone with learning difficulties having the same kind of operation as I had … and we looked at that, went through some forms… ummm… and talked about what would actually happen. P5: [Int: Do you know why?] Um… I'm trying to think… If I kept on eating chicken, or fried chicken or chips or … anything that's bad … I'll be as fat as a house and I'll be like really big and that's be… called obesity (…) I watched "my father's obesity" TV programme and I thought no, no that's not me, I want to stay healthy. P6: …monthly support meeting and then go through it monthly a budgeting session, how to look after your money and, also … like appointments to see the doctor, nurse, dentist for teeth, optician for eyes – they support me with it (…) Um… sort of… and then… [unclear] [lots of background noise] … annual health check-up or opticians due and also, also ladies have, a smear test, to make sure they're… make sure it's healthy and um you don't get cervical cancer. P7: I felt a relief when I had it done. I knew from the [social group] that having such a check could help save millions of women's lives including my own.

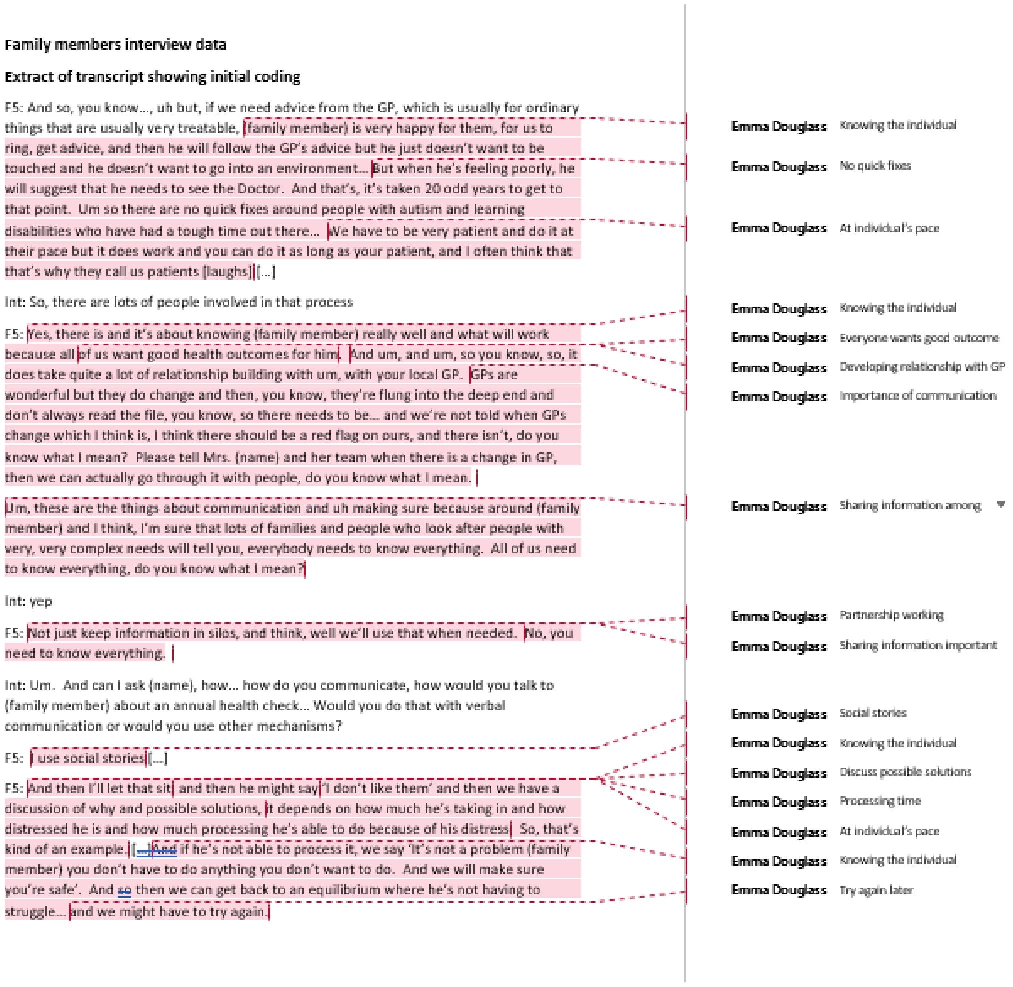
Emma Douglass
Monthly meetings to talk about budgeting and health appointments

Opportunities to learn about health

Emma Douglass
AHCs discussed at monthly meetings

Cervical screening discussed

Opportunities to learn about health



Family members interview data

Extract of transcript showing initial coding

F5: And so, you know…, uh but, if we need advice from the GP, which is usually for ordinary things that are usually very treatable, (family member) is very happy for them, for us to ring, get advice, and then he will follow the GP's advice but he just doesn't want to be touched and he doesn't want to go into an environment… But when he's feeling poorly, he will suggest that he needs to see the Doctor. And that's, it's taken 20 odd years to get to that point. Um so there are no quick fixes around people with autism and learning disabilities who have had a tough time out there… We have to be very patient and do it at their pace but it does work and you can do it as long as your patient, and I often think that that's why they call us patients [laughs] […]

Int: So, there are lots of people involved in that process

F5: Yes, there is and it's about knowing (family member) really well and what will work because all of us want good health outcomes for him. And um, and um, so you know, so, it does take quite a lot of relationship building with um, with your local GP. GPs are wonderful but they do change and then, you know, they're flung into the deep end and don't always read the file, you know, so there needs to be… and we're not told when GPs change which I think is, I think there should be a red flag on ours, and there isn't, do you know what I mean? Please tell Mrs. (name) and her team when there is a change in GP, then we can actually go through it with people, do you know what I mean.

Um, these are the things about communication and uh making sure because around (family member) and I think, I'm sure that lots of families and people who look after people with very, very complex needs will tell you, everybody needs to know everything. All of us need to know everything, do you know what I mean?

Int: yep

F5: Not just keep information in silos, and think, well we'll use that when needed. No, you need to know everything.

Int: Um. And can I ask (name), how… how do you communicate, how would you talk to (family member) about an annual health check… Would you do that with verbal communication or would you use other mechanisms?

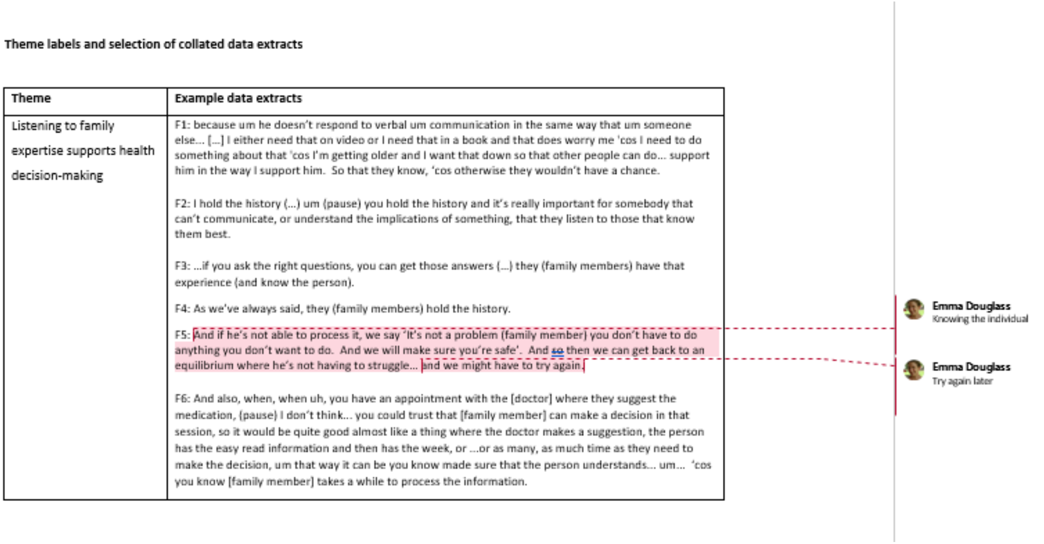
F5: I use social stories […]

F5: And then I'll let that sit and then he might say 'I don't like them' and then we have a discussion of why and possible solutions, it depends on how much he's taking in and how distressed he is and how much processing he's able to do because of his distress. So, that's kind of an example. […] ~~And~~ if he's not able to process it, we say 'It's not a problem (family member) you don't have to do anything you don't want to do. And we will make sure you're safe'. And so then we can get back to an equilibrium where he's not having to struggle… and we might have to try again.

Emma Douglass Knowing the individual
Emma Douglass No quick fixes
Emma Douglass At individual's pace
Emma Douglass Knowing the individual
Emma Douglass Everyone wants good outcome
Emma Douglass Developing relationship with GP
Emma Douglass Importance of communication
Emma Douglass Sharing information among
Emma Douglass Partnership working
Emma Douglass Sharing information important
Emma Douglass Social stories
Emma Douglass Knowing the individual
Emma Douglass Discuss possible solutions
Emma Douglass Processing time
Emma Douglass At individual's pace
Emma Douglass Knowing the individual
Emma Douglass Try again later

Example of how initial codes were grouped and developed into themes

Initial Codes (semantic)	Example of grouping initial codes together	Example of alignment of codes with final developed themes
Knowing the individual No quick fixes Everyone wants good outcome Developing relationship with GP Importance of communication Sharing information among support team/GP important Partnership working Sharing information important Social stories to facilitate understanding Discuss possible solutions Processing time At individual's pace Try again later	Knowing the individual Social stories can facilitate understanding Discuss possible solutions Processing time At individual's pace Try again later	Listening to family expertise supports health decision-making
	Everyone wants good outcome Developing relationship with GP Importance of communication Sharing information among support team/GP important Partnership working Sharing information important	Work with us, not against us

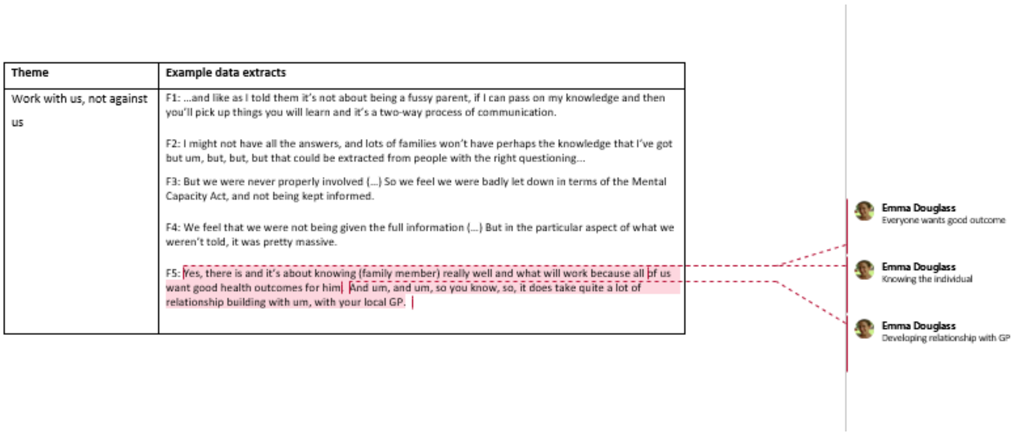


Theme labels and selection of collated data extracts

Theme	Example data extracts
Listening to family expertise supports health decision-making	F1: because um he doesn't respond to verbal um communication in the same way that um someone else… […] I either need that on video or I need that in a book and that does worry me 'cos I need to do something about that 'cos I'm getting older and I want that down so that other people can do… support him in the way I support him. So that they know, 'cos otherwise they wouldn't have a chance. F2: I hold the history (…) um (pause) you hold the history and it's really important for somebody that can't communicate, or understand the implications of something, that they listen to those that know them best. F3: …if you ask the right questions, you can get those answers (…) they (family members) have that experience (and know the person). F4: As we've always said, they (family members) hold the history. F5: And if he's not able to process it, we say 'It's not a problem (family member) you don't have to do anything you don't want to do. And we will make sure you're safe'. And so then we can get back to an equilibrium where he's not having to struggle… and we might have to try again. F6: And also, when, when uh, you have an appointment with the [doctor] where they suggest the medication, (pause) I don't think… you could trust that [family member] can make a decision in that session, so it would be quite good almost like a thing where the doctor makes a suggestion, the person has the easy read information and then has the week, or …or as many, as much time as they need to make the decision, um that way it can be you know made sure that the person understands… um… 'cos you know [family member] takes a while to process the information.

Emma Douglass
Knowing the individual

Emma Douglass
Try again later

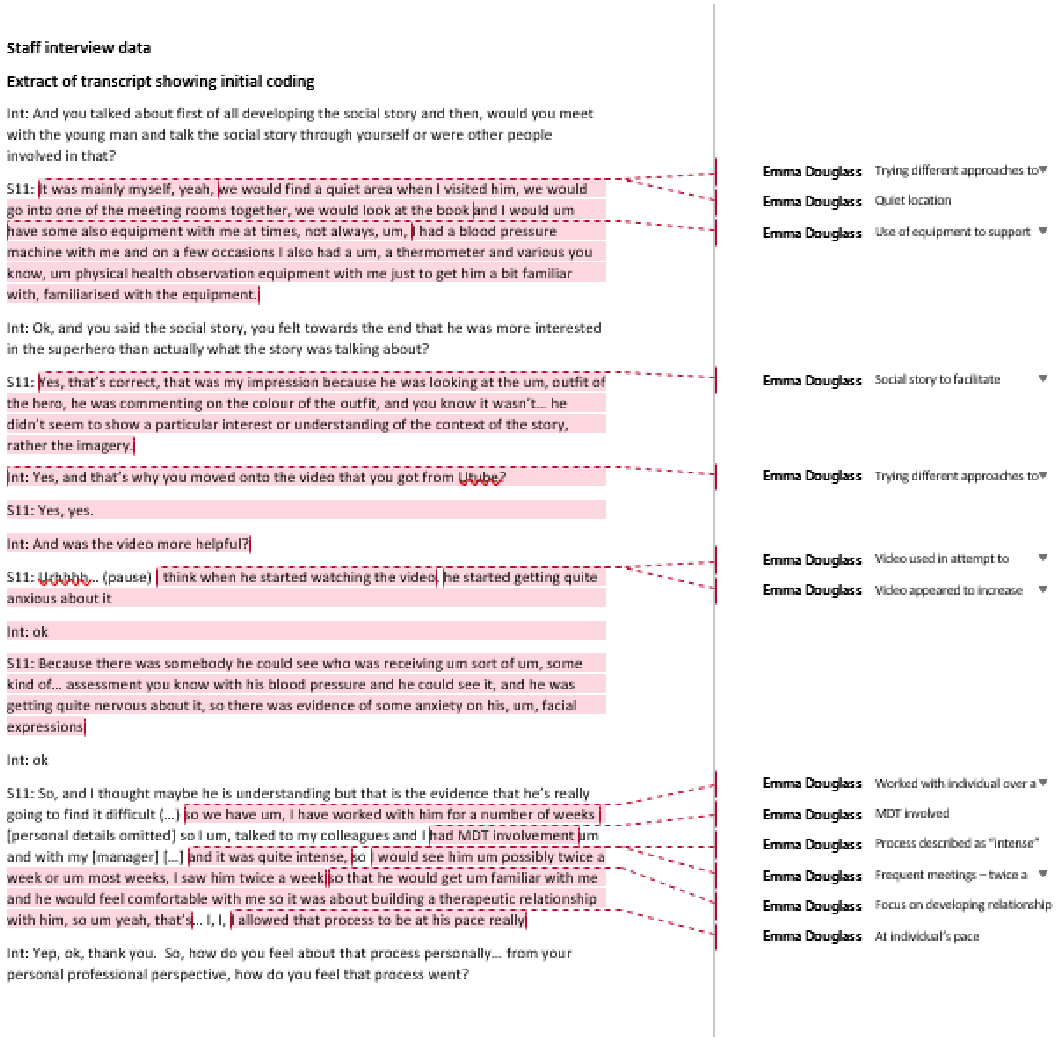


Theme	Example data extracts
Work with us, not against us	F1: …and like as I told them it's not about being a fussy parent, if I can pass on my knowledge and then you'll pick up things you will learn and it's a two-way process of communication. F2: I might not have all the answers, and lots of families won't have perhaps the knowledge that I've got but um, but, but, but that could be extracted from people with the right questioning… F3: But we were never properly involved (…) So we feel we were badly let down in terms of the Mental Capacity Act, and not being kept informed. F4: We feel that we were not being given the full information (…) But in the particular aspect of what we weren't told, it was pretty massive. F5: Yes, there is and it's about knowing (family member) really well and what will work because all of us want good health outcomes for him. And um, and um, so you know, so, it does take quite a lot of relationship building with um, with your local GP.

Emma Douglass
Everyone wants good outcome

Emma Douglass
Knowing the individual

Emma Douglass
Developing relationship with GP



Staff interview data

Extract of transcript showing initial coding

Int: And you talked about first of all developing the social story and then, would you meet with the young man and talk the social story through yourself or were other people involved in that?

S11: It was mainly myself, yeah, we would find a quiet area when I visited him, we would go into one of the meeting rooms together, we would look at the book and I would um have some also equipment with me at times, not always, um, I had a blood pressure machine with me and on a few occasions I also had a um, a thermometer and various you know, um physical health observation equipment with me just to get him a bit familiar with, familiarised with the equipment.

Int: Ok, and you said the social story, you felt towards the end that he was more interested in the superhero than actually what the story was talking about?

S11: Yes, that's correct, that was my impression because he was looking at the um, outfit of the hero, he was commenting on the colour of the outfit, and you know it wasn't… he didn't seem to show a particular interest or understanding of the context of the story, rather the imagery.

Int: Yes, and that's why you moved onto the video that you got from Utube?

S11: Yes, yes.

Int: And was the video more helpful?

S11: Uhhhh… (pause) I think when he started watching the video, he started getting quite anxious about it

Int: ok

S11: Because there was somebody he could see who was receiving um sort of um, some kind of… assessment you know with his blood pressure and he could see it, and he was getting quite nervous about it, so there was evidence of some anxiety on his, um, facial expressions

Int: ok

S11: So, and I thought maybe he is understanding but that is the evidence that he's really going to find it difficult (…) so we have um, I have worked with him for a number of weeks [personal details omitted] so I um, talked to my colleagues and I had MDT involvement um and with my [manager] […] and it was quite intense, so I would see him um possibly twice a week or um most weeks, I saw him twice a week so that he would get um familiar with me and he would feel comfortable with me so it was about building a therapeutic relationship with him, so um yeah, that's… I, I, I allowed that process to be at his pace really

Int: Yep, ok, thank you. So, how do you feel about that process personally… from your personal professional perspective, how do you feel that process went?

Emma Douglass Trying different approaches to

Emma Douglass Quiet location

Emma Douglass Use of equipment to support

Emma Douglass Social story to facilitate

Emma Douglass Trying different approaches to

Emma Douglass Video used in attempt to

Emma Douglass Video appeared to increase

Emma Douglass Worked with individual over a

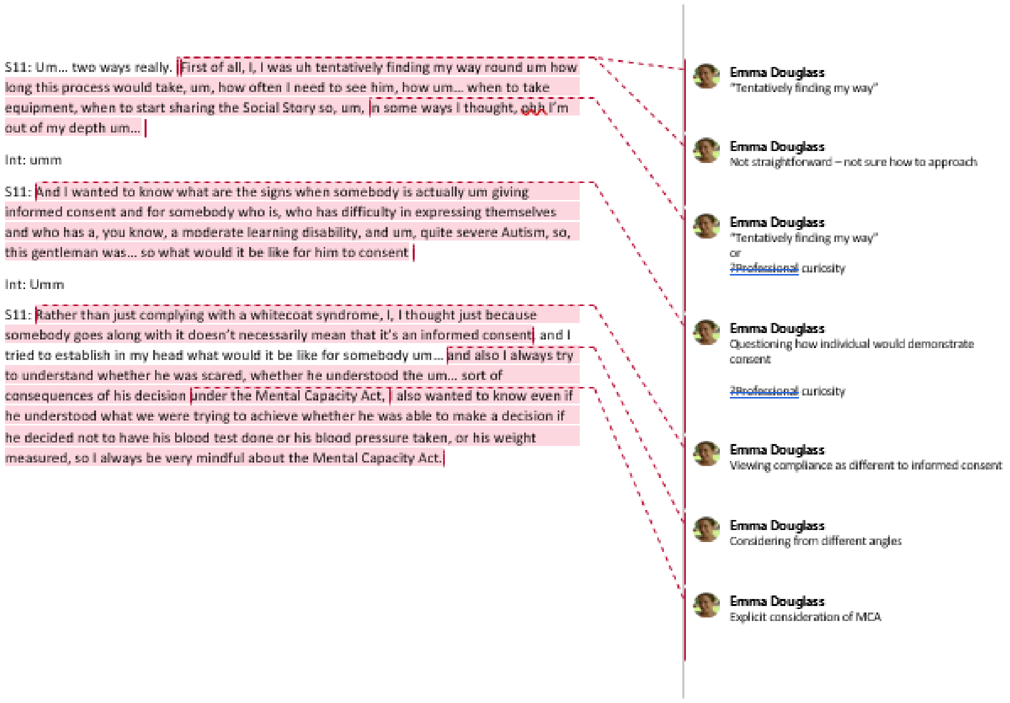
Emma Douglass MDT involved

Emma Douglass Process described as "intense"

Emma Douglass Frequent meetings – twice a

Emma Douglass Focus on developing relationship

Emma Douglass At individual's pace



S11: Um… two ways really. First of all, I, I was uh tentatively finding my way round um how long this process would take, um, how often I need to see him, how um… when to take equipment, when to start sharing the Social Story so, um, in some ways I thought, ohh I'm out of my depth um…

Int: umm

S11: And I wanted to know what are the signs when somebody is actually um giving informed consent and for somebody who is, who has difficulty in expressing themselves and who has a, you know, a moderate learning disability, and um, quite severe Autism, so, this gentleman was… so what would it be like for him to consent

Int: Umm

S11: Rather than just complying with a whitecoat syndrome, I, I thought just because somebody goes along with it doesn't necessarily mean that it's an informed consent, and I tried to establish in my head what would it be like for somebody um… and also I always try to understand whether he was scared, whether he understood the um… sort of consequences of his decision under the Mental Capacity Act, I also wanted to know even if he understood what we were trying to achieve whether he was able to make a decision if he decided not to have his blood test done or his blood pressure taken, or his weight measured, so I always be very mindful about the Mental Capacity Act.

Emma Douglass
"Tentatively finding my way"

Emma Douglass
Not straightforward – not sure how to approach

Emma Douglass
"Tentatively finding my way"
or
~~?Professional~~ curiosity

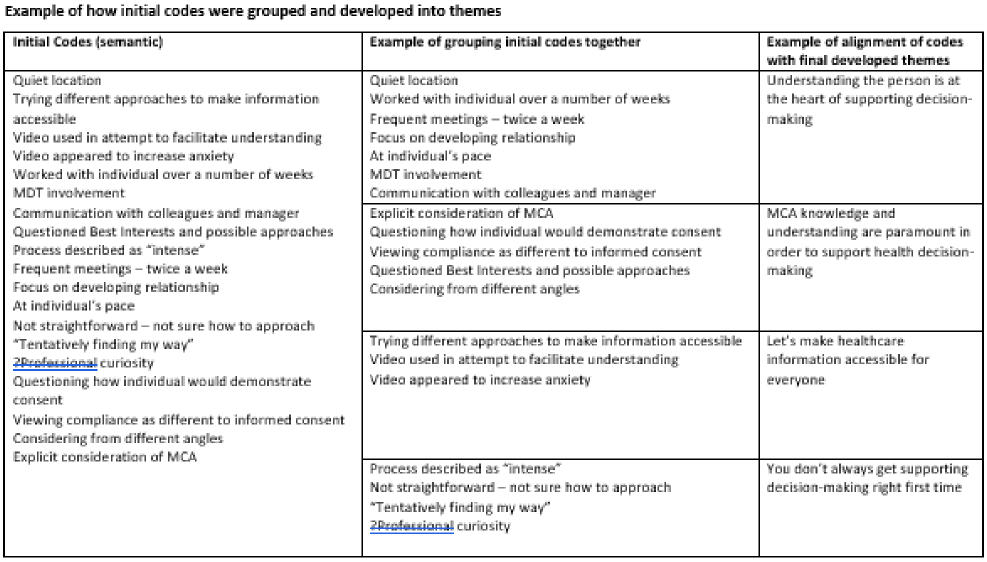
Emma Douglass
Questioning how individual would demonstrate consent

~~?Professional~~ curiosity

Emma Douglass
Viewing compliance as different to informed consent

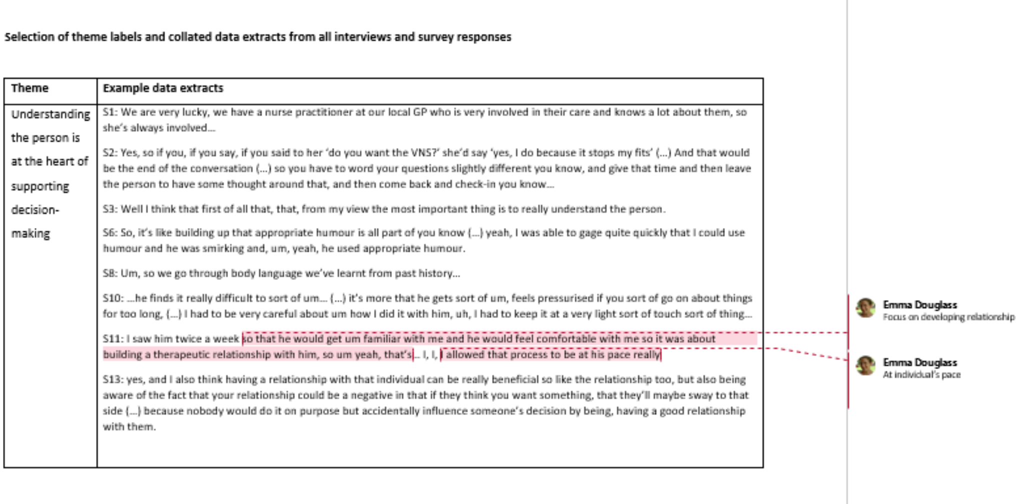
Emma Douglass
Considering from different angles

Emma Douglass
Explicit consideration of MCA



Example of how initial codes were grouped and developed into themes

Initial Codes (semantic)	Example of grouping initial codes together	Example of alignment of codes with final developed themes
Quiet location Trying different approaches to make information accessible Video used in attempt to facilitate understanding Video appeared to increase anxiety Worked with individual over a number of weeks MDT involvement Communication with colleagues and manager Questioned Best Interests and possible approaches Process described as "intense" Frequent meetings – twice a week Focus on developing relationship At individual's pace Not straightforward – not sure how to approach "Tentatively finding my way" ~~?Professional~~ curiosity Questioning how individual would demonstrate consent Viewing compliance as different to informed consent Considering from different angles Explicit consideration of MCA	Quiet location Worked with individual over a number of weeks Frequent meetings – twice a week Focus on developing relationship At individual's pace MDT involvement Communication with colleagues and manager	Understanding the person is at the heart of supporting decision-making
	Explicit consideration of MCA Questioning how individual would demonstrate consent Viewing compliance as different to informed consent Questioned Best Interests and possible approaches Considering from different angles	MCA knowledge and understanding are paramount in order to support health decision-making
	Trying different approaches to make information accessible Video used in attempt to facilitate understanding Video appeared to increase anxiety	Let's make healthcare information accessible for everyone
	Process described as "intense" Not straightforward – not sure how to approach "Tentatively finding my way" ~~?Professional~~ curiosity	You don't always get supporting decision-making right first time

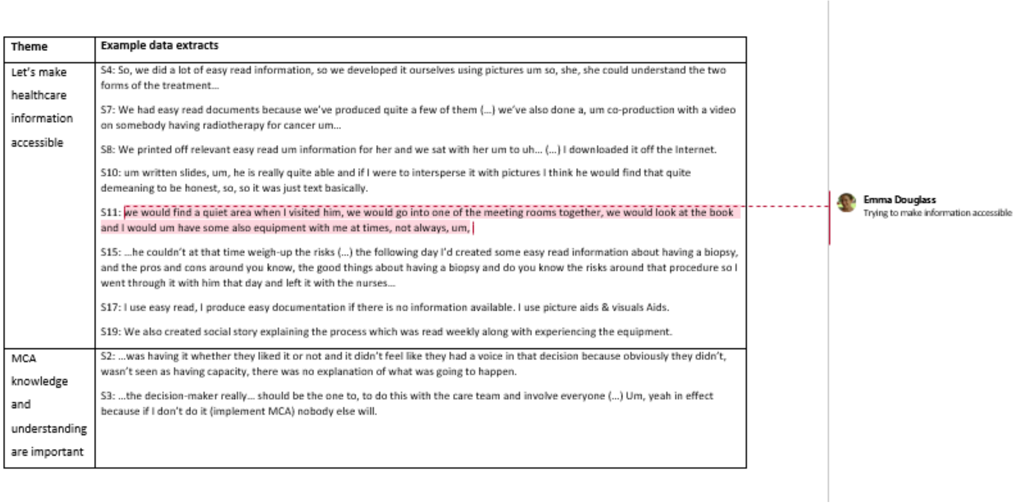


Selection of theme labels and collated data extracts from all interviews and survey responses

Theme	Example data extracts
Understanding the person is at the heart of supporting decision-making	S1: We are very lucky, we have a nurse practitioner at our local GP who is very involved in their care and knows a lot about them, so she's always involved… S2: Yes, so if you, if you say, if you said to her 'do you want the VNS?' she'd say 'yes, I do because it stops my fits' (…) And that would be the end of the conversation (…) so you have to word your questions slightly different you know, and give that time and then leave the person to have some thought around that, and then come back and check-in you know… S3: Well I think that first of all that, that, from my view the most important thing is to really understand the person. S6: So, it's like building up that appropriate humour is all part of you know (…) yeah, I was able to gage quite quickly that I could use humour and he was smirking and, um, yeah, he used appropriate humour. S8: Um, so we go through body language we've learnt from past history… S10: …he finds it really difficult to sort of um… (…) it's more that he gets sort of um, feels pressurised if you sort of go on about things for too long, (…) I had to be very careful about um how I did it with him, uh, I had to keep it at a very light sort of touch sort of thing… S11: I saw him twice a week so that he would get um familiar with me and he would feel comfortable with me so it was about building a therapeutic relationship with him, so um yeah, that's… I, I, I allowed that process to be at his pace really S13: yes, and I also think having a relationship with that individual can be really beneficial so like the relationship too, but also being aware of the fact that your relationship could be a negative in that if they think you want something, that they'll maybe sway to that side (…) because nobody would do it on purpose but accidentally influence someone's decision by being, having a good relationship with them.

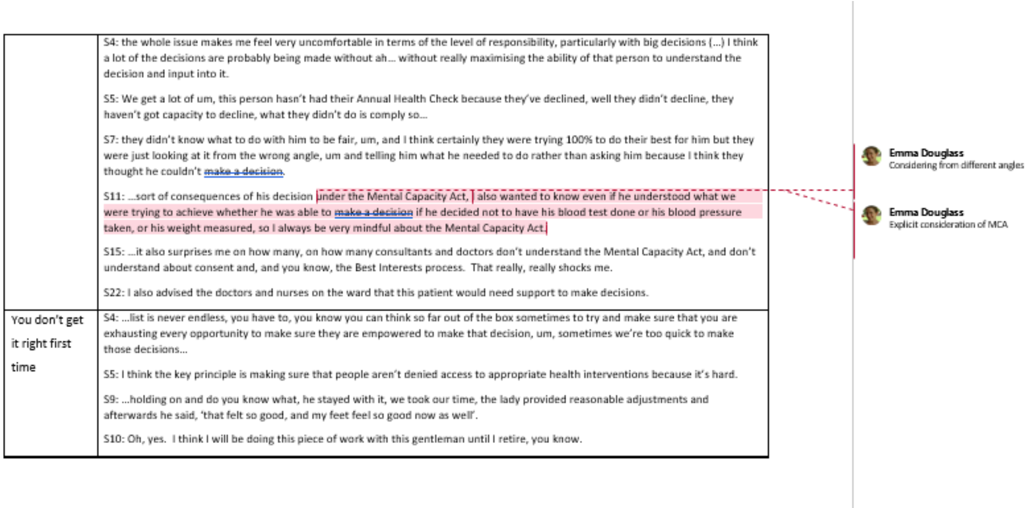
Emma Douglass
Focus on developing relationship

Emma Douglass
At individual's pace



Theme	Example data extracts
Let's make healthcare information accessible	S4: So, we did a lot of easy read information, so we developed it ourselves using pictures um so, she, she could understand the two forms of the treatment… S7: We had easy read documents because we've produced quite a few of them (…) we've also done a, um co-production with a video on somebody having radiotherapy for cancer um… S8: We printed off relevant easy read um information for her and we sat with her um to uh… (…) I downloaded it off the Internet. S10: um written slides, um, he is really quite able and if I were to intersperse it with pictures I think he would find that quite demeaning to be honest, so, so it was just text basically. S11: we would find a quiet area when I visited him, we would go into one of the meeting rooms together, we would look at the book and I would um have some also equipment with me at times, not always, um, S15: …he couldn't at that time weigh-up the risks (…) the following day I'd created some easy read information about having a biopsy, and the pros and cons around you know, the good things about having a biopsy and do you know the risks around that procedure so I went through it with him that day and left it with the nurses… S17: I use easy read, I produce easy documentation if there is no information available. I use picture aids & visuals Aids. S19: We also created social story explaining the process which was read weekly along with experiencing the equipment.
MCA knowledge and understanding are important	S2: …was having it whether they liked it or not and it didn't feel like they had a voice in that decision because obviously they didn't, wasn't seen as having capacity, there was no explanation of what was going to happen. S3: …the decision-maker really… should be the one to, to do this with the care team and involve everyone (…) Um, yeah in effect because if I don't do it (implement MCA) nobody else will.

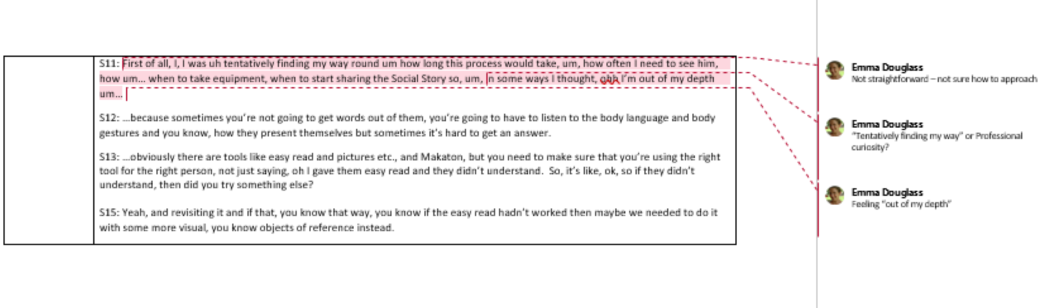
Emma Douglass
Trying to make information accessible



	S4: the whole issue makes me feel very uncomfortable in terms of the level of responsibility, particularly with big decisions (…) I think a lot of the decisions are probably being made without ah… without really maximising the ability of that person to understand the decision and input into it. S5: We get a lot of um, this person hasn't had their Annual Health Check because they've declined, well they didn't decline, they haven't got capacity to decline, what they didn't do is comply so… S7: they didn't know what to do with him to be fair, um, and I think certainly they were trying 100% to do their best for him but they were just looking at it from the wrong angle, um and telling him what he needed to do rather than asking him because I think they thought he couldn't ~~make a decision~~. S11: …sort of consequences of his decision under the Mental Capacity Act, I also wanted to know even if he understood what we were trying to achieve whether he was able to ~~make a decision~~ if he decided not to have his blood test done or his blood pressure taken, or his weight measured, so I always be very mindful about the Mental Capacity Act. S15: …it also surprises me on how many, on how many consultants and doctors don't understand the Mental Capacity Act, and don't understand about consent and, and you know, the Best Interests process. That really, really shocks me. S22: I also advised the doctors and nurses on the ward that this patient would need support to make decisions.
You don't get it right first time	S4: …list is never endless, you have to, you know you can think so far out of the box sometimes to try and make sure that you are exhausting every opportunity to make sure they are empowered to make that decision, um, sometimes we're too quick to make those decisions… S5: I think the key principle is making sure that people aren't denied access to appropriate health interventions because it's hard. S9: …holding on and do you know what, he stayed with it, we took our time, the lady provided reasonable adjustments and afterwards he said, 'that felt so good, and my feet feel so good now as well'. S10: Oh, yes. I think I will be doing this piece of work with this gentleman until I retire, you know.

Emma Douglass
Considering from different angles

Emma Douglass
Explicit consideration of MCA

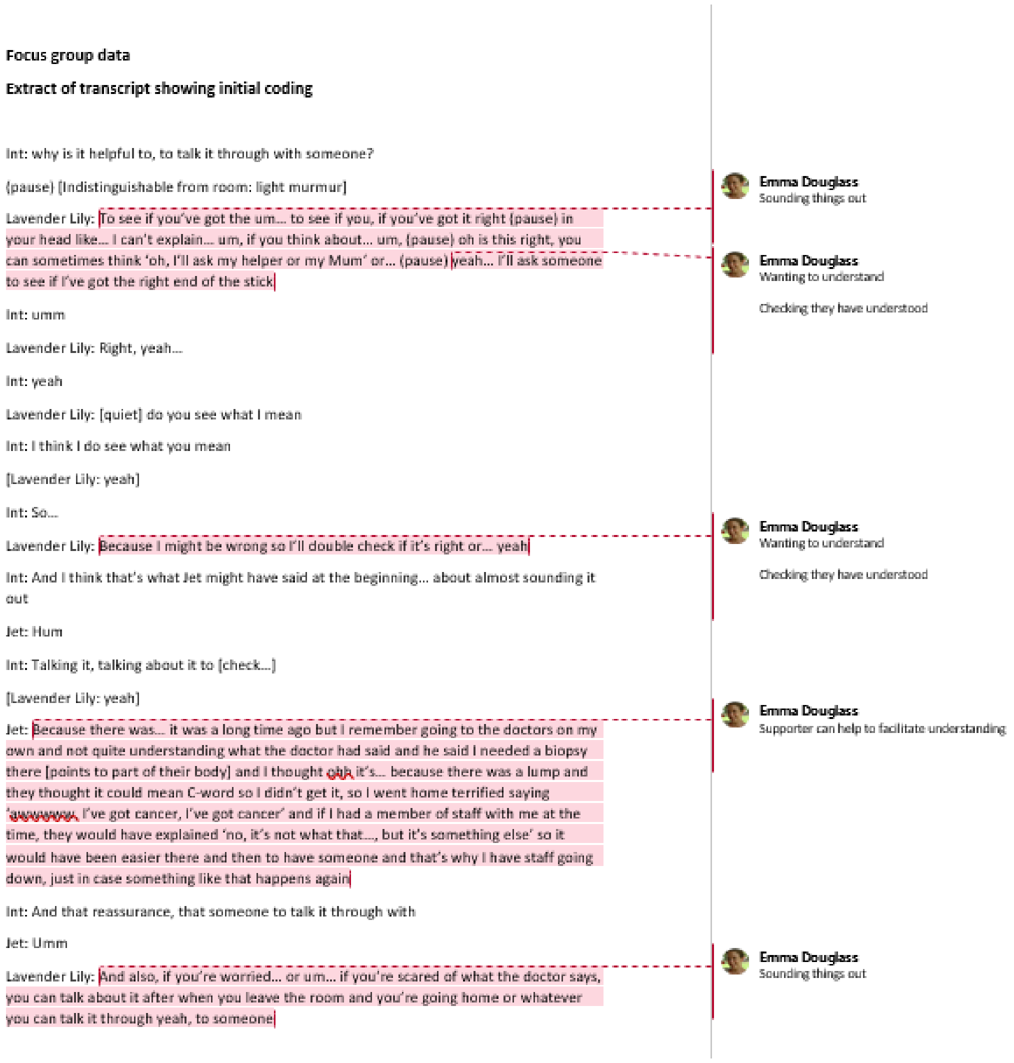


	S11: First of all, I, I was uh tentatively finding my way round um how long this process would take, um, how often I need to see him, how um… when to take equipment, when to start sharing the Social Story so, um, in some ways I thought, ohh I'm out of my depth um… S12: …because sometimes you're not going to get words out of them, you're going to have to listen to the body language and body gestures and you know, how they present themselves but sometimes it's hard to get an answer. S13: …obviously there are tools like easy read and pictures etc., and Makaton, but you need to make sure that you're using the right tool for the right person, not just saying, oh I gave them easy read and they didn't understand. So, it's like, ok, so if they didn't understand, then did you try something else? S15: Yeah, and revisiting it and if that, you know that way, you know if the easy read hadn't worked then maybe we needed to do it with some more visual, you know objects of reference instead.

Emma Douglass
Not straightforward – not sure how to approach

Emma Douglass
"Tentatively finding my way" or Professional curiosity?

Emma Douglass
Feeling "out of my depth"



Focus group data

Extract of transcript showing initial coding

Int: why is it helpful to, to talk it through with someone?

(pause) [Indistinguishable from room: light murmur]

Lavender Lily: To see if you've got the um… to see if you, if you've got it right (pause) in your head like… I can't explain… um, if you think about… um, (pause) oh is this right, you can sometimes think 'oh, I'll ask my helper or my Mum' or… (pause) yeah… I'll ask someone to see if I've got the right end of the stick

Int: umm

Lavender Lily: Right, yeah…

Int: yeah

Lavender Lily: [quiet] do you see what I mean

Int: I think I do see what you mean

[Lavender Lily: yeah]

Int: So…

Lavender Lily: Because I might be wrong so I'll double check if it's right or… yeah

Int: And I think that's what Jet might have said at the beginning… about almost sounding it out

Jet: Hum

Int: Talking it, talking about it to [check…]

[Lavender Lily: yeah]

Jet: Because there was… it was a long time ago but I remember going to the doctors on my own and not quite understanding what the doctor had said and he said I needed a biopsy there [points to part of their body] and I thought ohh it's… because there was a lump and they thought it could mean C-word so I didn't get it, so I went home terrified saying 'awwwww, I've got cancer, I've got cancer' and if I had a member of staff with me at the time, they would have explained 'no, it's not what that…, but it's something else' so it would have been easier there and then to have someone and that's why I have staff going down, just in case something like that happens again

Int: And that reassurance, that someone to talk it through with

Jet: Umm

Lavender Lily: And also, if you're worried… or um… if you're scared of what the doctor says, you can talk about it after when you leave the room and you're going home or whatever you can talk it through yeah, to someone

Emma Douglass
Sounding things out

Emma Douglass
Wanting to understand

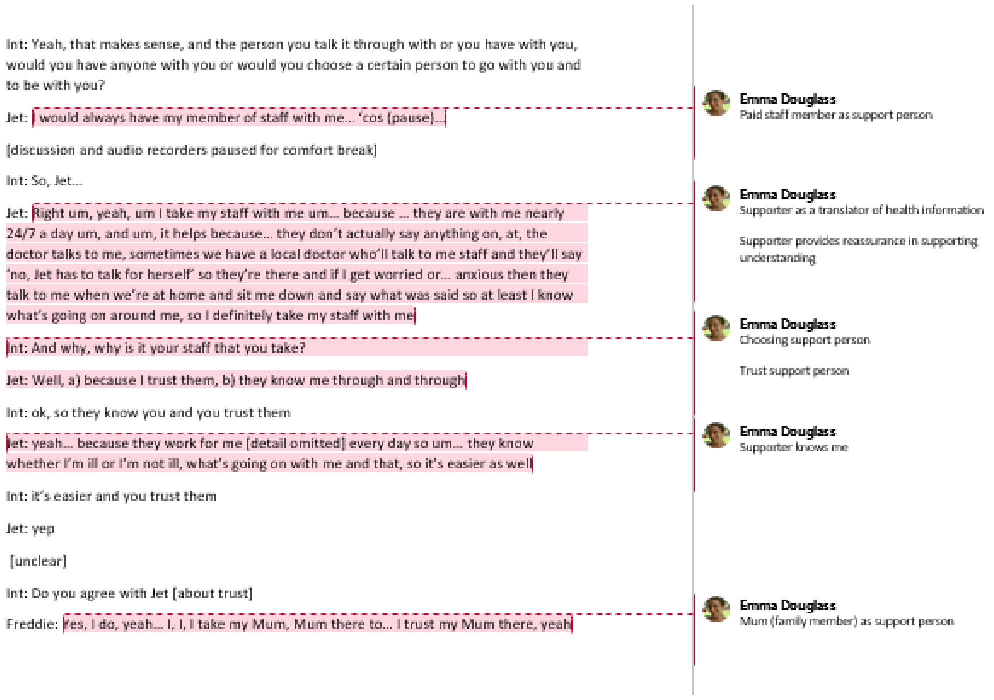
Checking they have understood

Emma Douglass
Wanting to understand

Checking they have understood

Emma Douglass
Supporter can help to facilitate understanding

Emma Douglass
Sounding things out



Int: Yeah, that makes sense, and the person you talk it through with or you have with you, would you have anyone with you or would you choose a certain person to go with you and to be with you?

Jet: I would always have my member of staff with me… 'cos (pause)…

[discussion and audio recorders paused for comfort break]

Int: So, Jet…

Jet: Right um, yeah, um I take my staff with me um… because … they are with me nearly 24/7 a day um, and um, it helps because… they don't actually say anything on, at, the doctor talks to me, sometimes we have a local doctor who'll talk to me staff and they'll say 'no, Jet has to talk for herself' so they're there and if I get worried or… anxious then they talk to me when we're at home and sit me down and say what was said so at least I know what's going on around me, so I definitely take my staff with me

Int: And why, why is it your staff that you take?

Jet: Well, a) because I trust them, b) they know me through and through

Int: ok, so they know you and you trust them

Jet: yeah… because they work for me [detail omitted] every day so um… they know whether I'm ill or I'm not ill, what's going on with me and that, so it's easier as well

Int: it's easier and you trust them

Jet: yep

[unclear]

Int: Do you agree with Jet [about trust]

Freddie: Yes, I do, yeah… I, I, I take my Mum, Mum there to… I trust my Mum there, yeah

Emma Douglass
Paid staff member as support person

Emma Douglass
Supporter as a translator of health information

Supporter provides reassurance in supporting understanding

Emma Douglass
Choosing support person

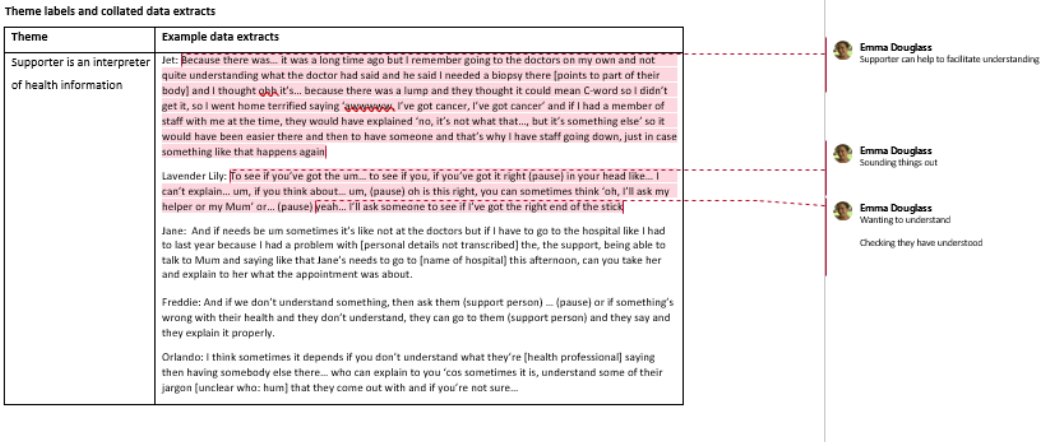
Trust support person

Emma Douglass
Supporter knows me

Emma Douglass
Mum (family member) as support person

Example of how initial codes were grouped and developed into themes

Initial Codes (semantic)	Example of grouping initial codes together	Example of alignment of codes with final developed themes
Sounding things out Wanting to understand Checking they have understood Supporter can help to facilitate understanding Paid staff member as support person Supporter as a translator of health information Supporter provides reassurance in supporting understanding Choosing support person Trust support person Supporter knows me Mum (family member) as support person	Supporter is a translator of health information Role of support person to help understanding of health information	Supporter is an interpreter of health information



Theme labels and collated data extracts

Theme	Example data extracts
Supporter is an interpreter of health information	Jet: Because there was… it was a long time ago but I remember going to the doctors on my own and not quite understanding what the doctor had said and he said I needed a biopsy there [points to part of their body] and I thought ohh it's… because there was a lump and they thought it could mean C-word so I didn't get it, so I went home terrified saying 'awwwww, I've got cancer, I've got cancer' and if I had a member of staff with me at the time, they would have explained 'no, it's not what that…, but it's something else' so it would have been easier there and then to have someone and that's why I have staff going down, just in case something like that happens again Lavender Lily: To see if you've got the um… to see if you, if you've got it right (pause) in your head like… I can't explain… um, if you think about… um, (pause) oh is this right, you can sometimes think 'oh, I'll ask my helper or my Mum' or… (pause) yeah… I'll ask someone to see if I've got the right end of the stick Jane: And if needs be um sometimes it's like not at the doctors but if I have to go to the hospital like I had to last year because I had a problem with [personal details not transcribed] the, the support, being able to talk to Mum and saying like that Jane's needs to go to [name of hospital] this afternoon, can you take her and explain to her what the appointment was about. Freddie: And if we don't understand something, then ask them (support person) … (pause) or if something's wrong with their health and they don't understand, they can go to them (support person) and they say and they explain it properly. Orlando: I think sometimes it depends if you don't understand what they're [health professional] saying then having somebody else there… who can explain to you 'cos sometimes it is, understand some of their jargon [unclear who: hum] that they come out with and if you're not sure…

Emma Douglass
Supporter can help to facilitate understanding

Emma Douglass
Sounding things out

Emma Douglass
Wanting to understand

Checking they have understood

APPENDIX TWELVE: Ethical Approval for interviews

This appendix has been removed as it contains personal information.

APPENDIX THIRTEEN: Ethical amendment for family member interviews

This appendix has been removed as it contains personal information.

APPENDIX FOURTEEN: Ethical approval for online survey

This appendix has been removed as it contains personal information.

APPENDIX FIFTEEN: Ethical approval for interviews with healthcare staff

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APPENDIX SIXTEEN: Ethical amendment 1 for interviews with healthcare staff

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APPENDIX SEVENTEEN: Ethical amendment 2 for interviews with healthcare staff

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APPENDIX EIGHTEEN: Ethical approval for focus groups

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APPENDIX NINETEEN: Ethical amendment for focus groups

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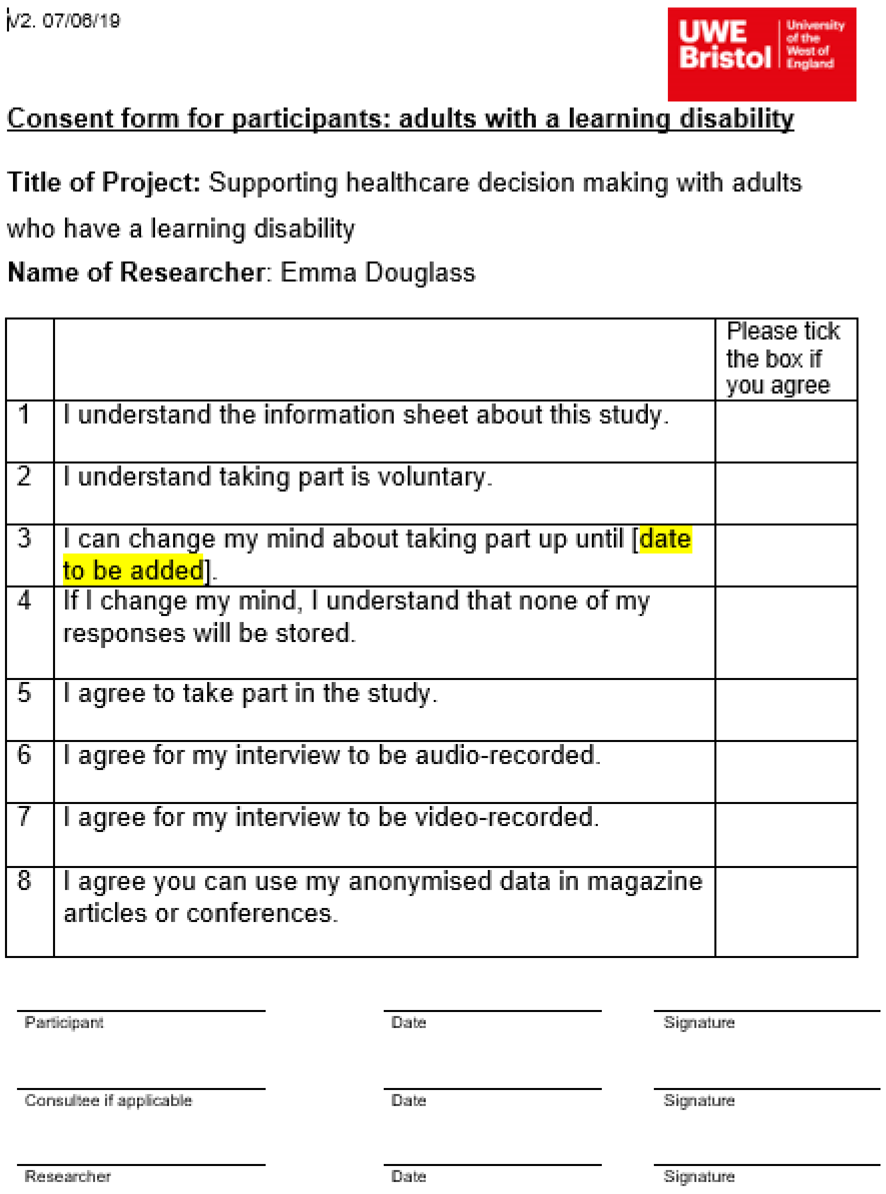
APPENDIX TWENTY: Consent form templates

For Interviews:



V2. 07/06/19

UWE Bristol University of the West of England

Consent form for participants: adults with a learning disability

Title of Project: Supporting healthcare decision making with adults who have a learning disability

Name of Researcher: Emma Douglass

		Please tick the box if you agree
1	I understand the information sheet about this study.	
2	I understand taking part is voluntary.	
3	I can change my mind about taking part up until [date to be added].	
4	If I change my mind, I understand that none of my responses will be stored.	
5	I agree to take part in the study.	
6	I agree for my interview to be audio-recorded.	
7	I agree for my interview to be video-recorded.	
8	I agree you can use my anonymised data in magazine articles or conferences.	

Participant Date Signature

Consultee if applicable Date Signature

Researcher Date Signature

V2. 14.12.22**Consent form for focus groups**

Title of Project: Supporting adults with learning disabilities to make informed healthcare decisions

Name of Researcher: Emma Douglass

		Yes	No
1	I understand the information sheet about this study.		
2	I understand taking part is voluntary. This means it is my decision. I can say 'no'.		
3	I can change my mind about taking part up until [date to be added, 1-month after focus group].		
4	If I change my mind, I understand that you will delete everything I have told you.		
5	I agree to take part in the focus group.		
6	I agree for the focus group to be audio-recorded.		
7	I agree you can use my anonymised data in magazine articles or conferences. This means that you might write about what I said, but you will never use my name.		

Participant	Date	Signature
Consultee if applicable	Date	Signature
Researcher	Date	Signature

APPENDIX TWENTY-ONE: Topic guide

V3. 10/07/19. Indicative Topic Guide for Interviews with participants who have a learning disability

The following are the broad questions that will be asked during interviews.

During interviews, questions may be rephrased in order to meet individual participant needs. Picture cards will also be used as prompts. These will include pictures representing a wide range of different healthcare decisions and images representing different emotions. Images are from “Easy on the I”.

SEEK CONSENT / GDPR PRIVACY NOTICE

- **UWE (the university I work at) is responsible for looking after the information you give me and for sticking to the rules.**
- **We are collecting data/finding out information about how people with a learning disability make healthcare decisions. I want to understand how people make healthcare decisions so that I can find out what could be done differently to make this better.**
- **We will only collect and use your data with your permission, so if you say “yes”.**
- **Your personal data will only be shared with my teachers at UWE. Nobody else.**
- **Information will be kept until the end of my study, up to 10 years.**
- **If you have any concerns about your information, you can talk to me or to my teacher – Sally Dowling.**

2. Have you made a healthcare decision? [*Image cards to be used as prompts on table*]

   Let's look at the images on this table – these are some of the ideas that you may have had to make a decision about… A decision you can remember well / remember a lot about.

Break if needed - resume

3. Can you tell me about …?

   - Why did you need to make this decision?
   - What did you have to think about when making this decision?
   - What helped you make this decision?
   - Was anything unhelpful? What? Why?
   - Who else was involved?
   - How did other people involved help you make this decision? Was this helpful/unhelpful? Why? How?

   - How did you feel about making this decision? (*You can use more than one word to explain how you felt). [Image cards to be used as prompts* – Why did you choose this picture?*]*
   - How did you feel about what happened after you made this decision? (*You can use more than one word to explain how you felt). [Image cards to be used as prompts]*

4. How would you like to be supported in future to make healthcare decisions?

- Who would you like to help you? Why?
- How would you like (person) to help you?

5. “Supporting decision making” is a new term being used. I wonder whether you have heard of it?

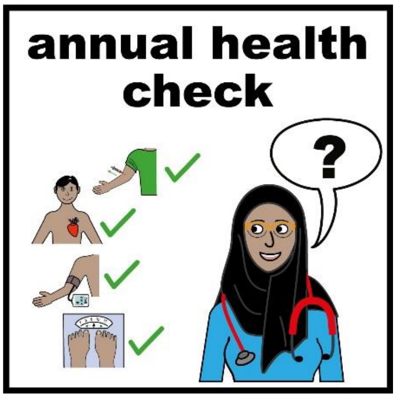
6. What do you think “supporting decision making” is?

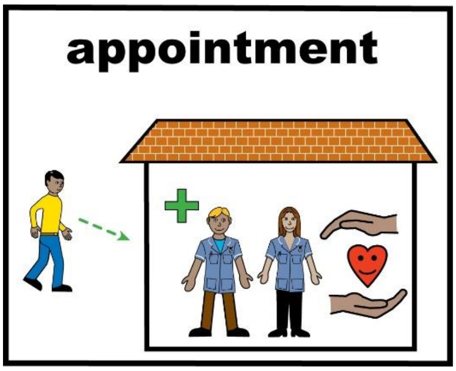
CONFIRM CONSENT

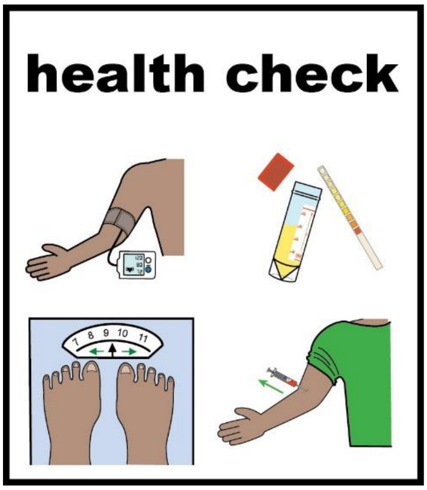
Can I ask you a few more questions?

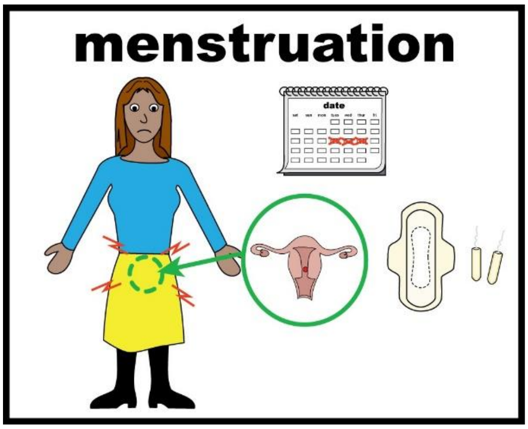
1. How old are you?
2. Sex?
3. Ethnicity?
4. Have you got a job?
5. Which groups do you attend [at the social group]?
6. Are you married? Have a boy/girlfriend?
7. Do you have children?
8. Who do you live with?

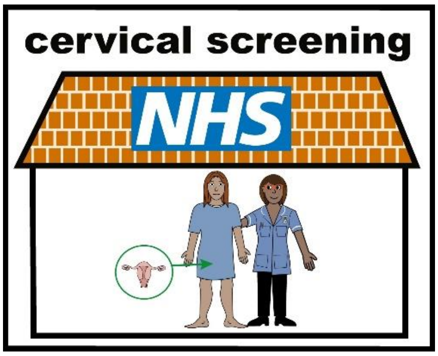
APPENDIX TWENTY-TWO: Example of pictorial cards used in interviews

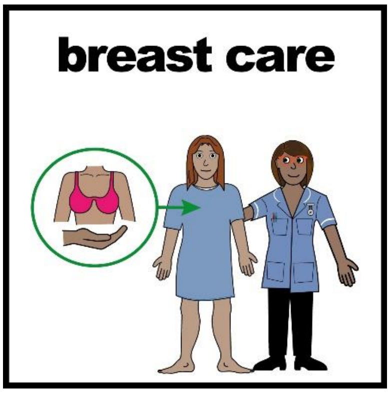




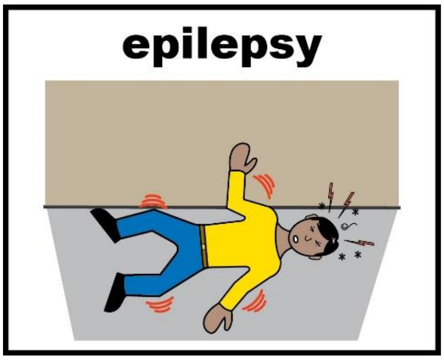


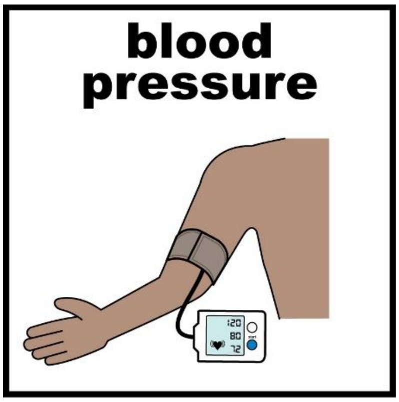


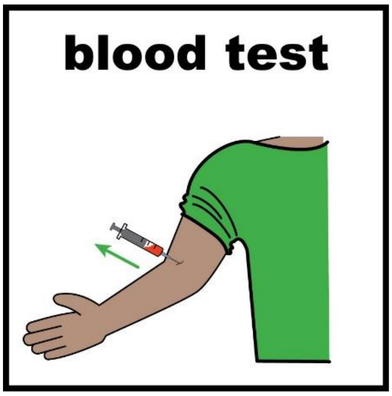


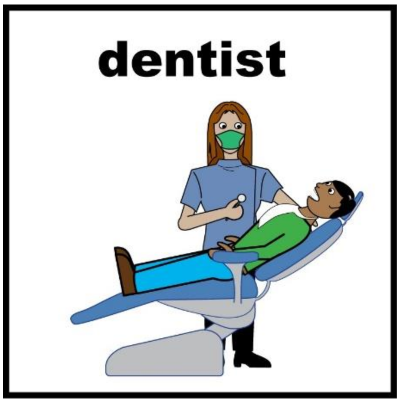


Images are from easyonthei image bank: www.easyonthei.nhs.uk.









Images are from easyonthei image bank, www.easyonthei.nhs.uk.

APPENDIX TWENTY-THREE: Distress Protocol

Distress Protocol to be used for focus groups (adapted from a published Distress Protocol used in a study by Davidson *et al.* 2018, p.57).

Pre-Data Collection

- The researcher will explain the areas that will be covered in the focus group and be mindful of the potentially personal and emotive nature of the topic.
- The researcher and research assistants will be ready to respond with sensitivity and compassion to any expressions of distress.
- Participants will be reminded that they can choose what and what not to speak about in the focus group discussion.
- Participants will be reminded that there are no right or wrong answers.
- Participants will be reminded that they do not have to comment or answer any questions if they do not want to.
- Participants will be reminded that they can ask for a break during the focus group.
- Participants will be reminded that they can leave the focus group at any time if they want to.

Stage 1 Initial response

- If a participant becomes distressed during the focus group, they can discuss their concerns with the researcher or one of the research assistants in the first instance. There will be the researcher and at least one research assistant present to enable this to happen.
- The researcher and research assistant(s) will provide immediate support and will ask the participant if they need to take a break from the focus group or leave the focus group if required.
- If required, a comfort break can be facilitated for all participants.

Stage 2 Review

- If the participant feels able to continue with the focus group, return and resume focus group (and upon completion, conclude the focus group with 'Stage 4: distress debriefing' with distressed participant).
- If the participant feels unable to continue with the focus group, go to 'Stage 3: further response'.

Stage 3 Further action

- Facilitate a focus group 'comfort break' for all.

- The researcher will determine the nature of the participants' distress and provide further immediate support.
- If the participant is experiencing distress but is not deemed to be at risk to themselves or others, the participant will be encouraged to speak with either their GP or a member of the direct care team in their service for further advice/support. Or the researcher will offer, with participant consent, to contact either of these services on their behalf.
- If the participant is deemed to be at risk to themselves or others the researcher will inform a member of the service immediately for further advice / support.

Stage 4 Debriefing

For all participants who exhibit distress during the interview process:

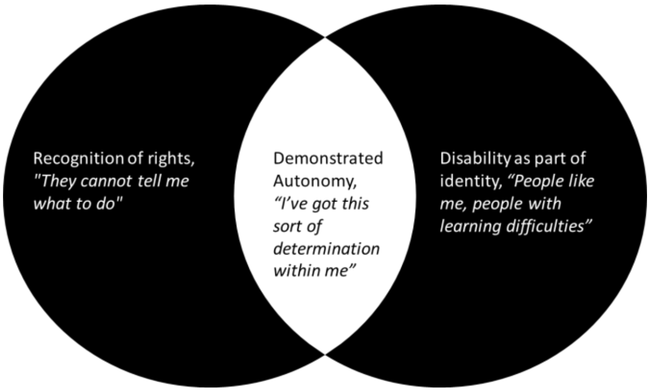
- The emotive nature of any aspects of the interview will be acknowledged.
- The researcher will ask the participant how they are now feeling.
- The researcher will ensure the participant feels safe and able to go about their day.
- The researcher will provide information about potential supports and encourage the participant to contact their GP or their service if they experience further episodes of increased distress in the hours / days following the interview.

Reference:

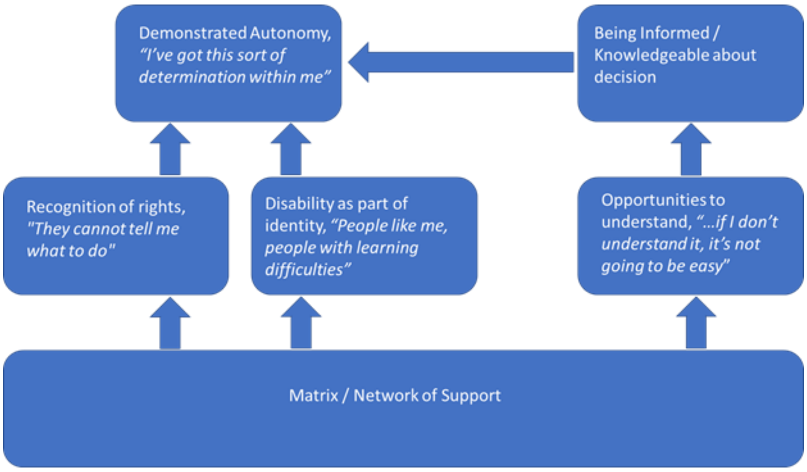
Davidson, G., Edge, R., Falls, D., Keenan, F., Kelly, B., McLaughlin, A., Montgomery, L., Mulvenna, C., Norris, B., Owens, A., Shea Irvine, R. and Webb, P. (2018) *Supported decision making - experiences, approaches and preferences*. Belfast: Praxis Care, Mencap and Queens' University Belfast, p.57.

APPENDIX TWENTY-FOUR: Examples of concept maps

Data analysis: theme development



Example 1: 23.10.20: Analysis of interview data with adults with a learning disability. Visual representation created in PowerPoint to illustrate relationships between developing potential themes.



Example 2: 6.10.20: Visual representation created in PowerPoint to illustrate relationships between developing potential themes.

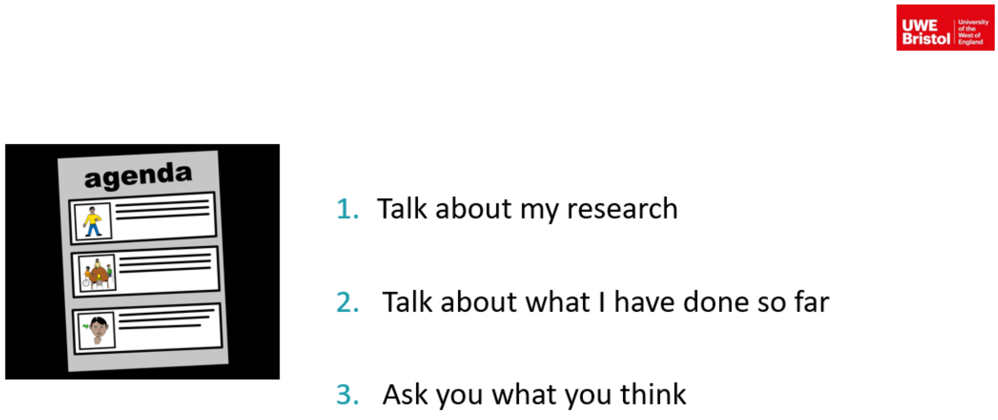
APPENDIX TWENTY-FIVE: PowerPoints slides used when talking about research findings with a self-advocacy group

Research findings

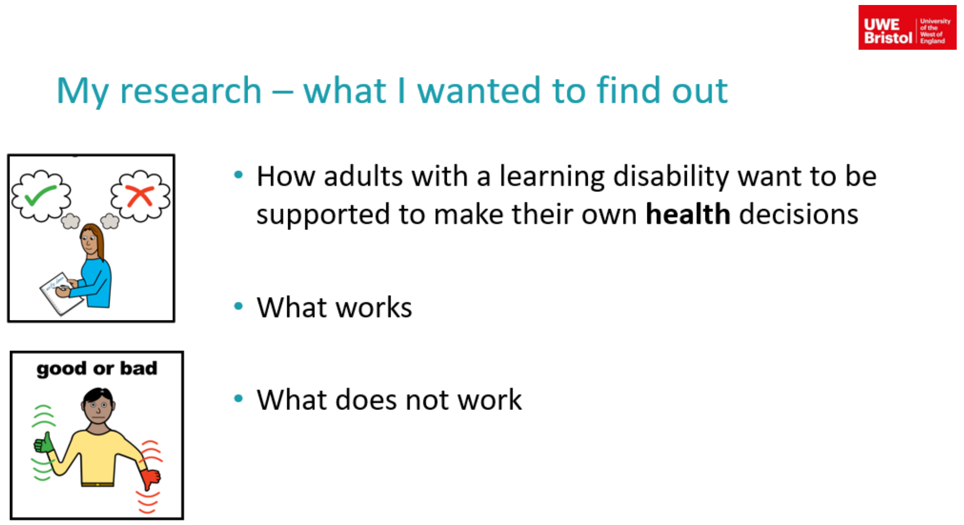
February 2024

Emma Douglass

All images in this PP are from: easyonthei image bank,
www.easyonthei.nhs.uk

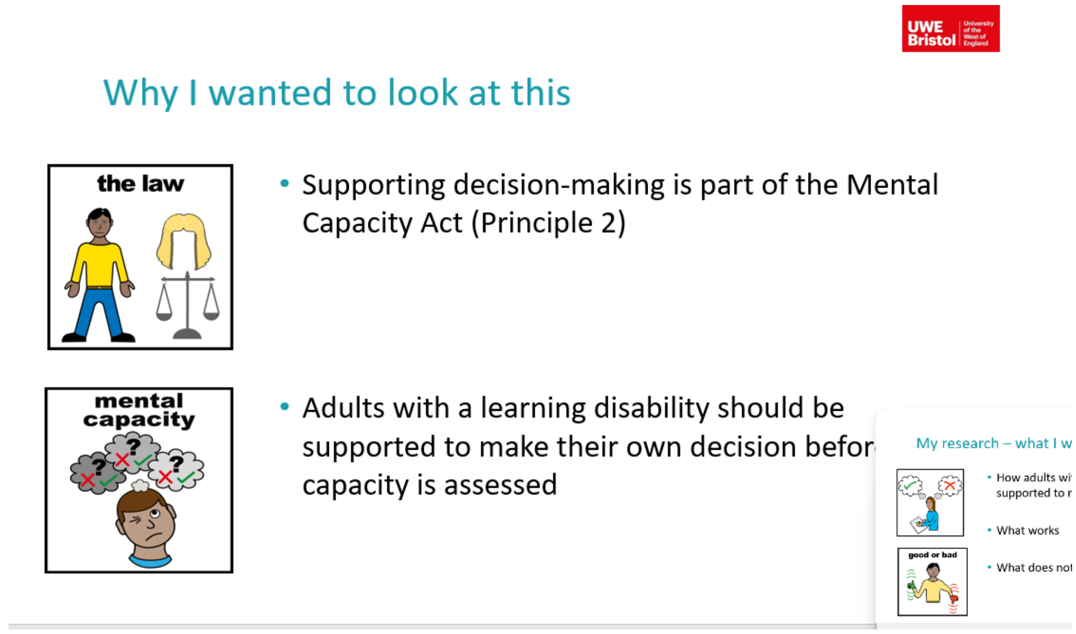


1. Talk about my research
2. Talk about what I have done so far
3. Ask you what you think



My research – what I wanted to find out

- How adults with a learning disability want to be supported to make their own **health** decisions
- What works
- What does not work

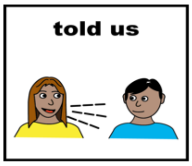


Why I wanted to look at this

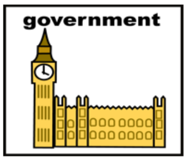
- Supporting decision-making is part of the Mental Capacity Act (Principle 2)
- Adults with a learning disability should be supported to make their own decision befor
capacity is assessed

My research – what I w
How adults wi
supported to r
What works
What does not
good or bad

When I started this research



- People told me they were not always supported to make their own **health** decisions



- The House of Lords said that ‘supported decision-making’ was “rare” in healthcare practice

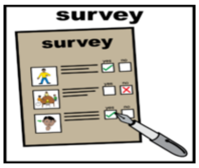
- Research said that people with a learning disability were not always supported to make their own decisions

An advisory group have helped me to make decisions about what to do and who to talk to

What I did

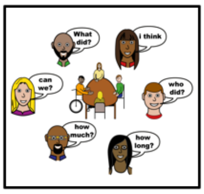
Interviews

- 7 adults with a learning disability
- 6 family members
- 16 healthcare staff



Survey

- 7 student learning disability nurses filled in a survey



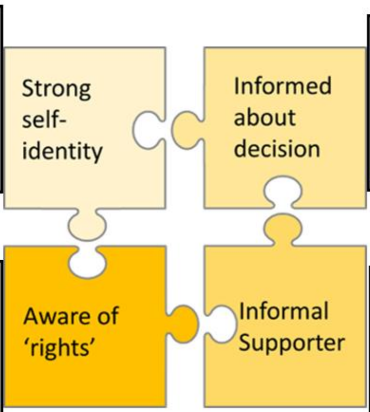
Focus groups

- With 12 adults who have a learning disability

- A total of 48 people have been involved

People have talked about lots of different health decisions

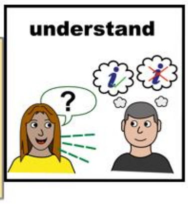
Adults with a learning disability

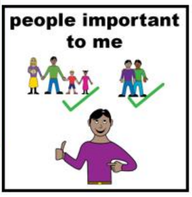

Strong self-identity

Informed about decision

Aware of ‘rights’

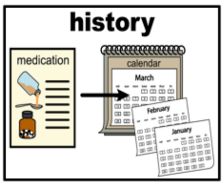
Informal Supporter



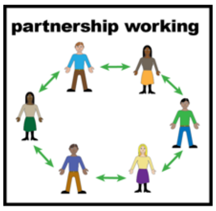


Family members

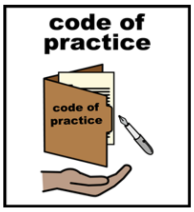
Family have expertise about the person



Understanding what has happened before is important



Working together is important but can be very difficult



Concerns that staff do not understand the Mental Capacity Act

Nurses and support workers

It is important to know the person

Understanding the person is at the heart of supported decision-making

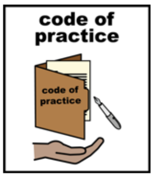
Let's make healthcare accessible to all people

Sometimes the staff do not understand the decision, which means they find it hard to provide support

Nurses and support workers continued

It doesn't always work first time.

Staff need to try lots of different approaches



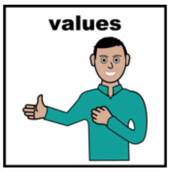
Staff should understand the MCA Code of Practice

Need respect for all people involved

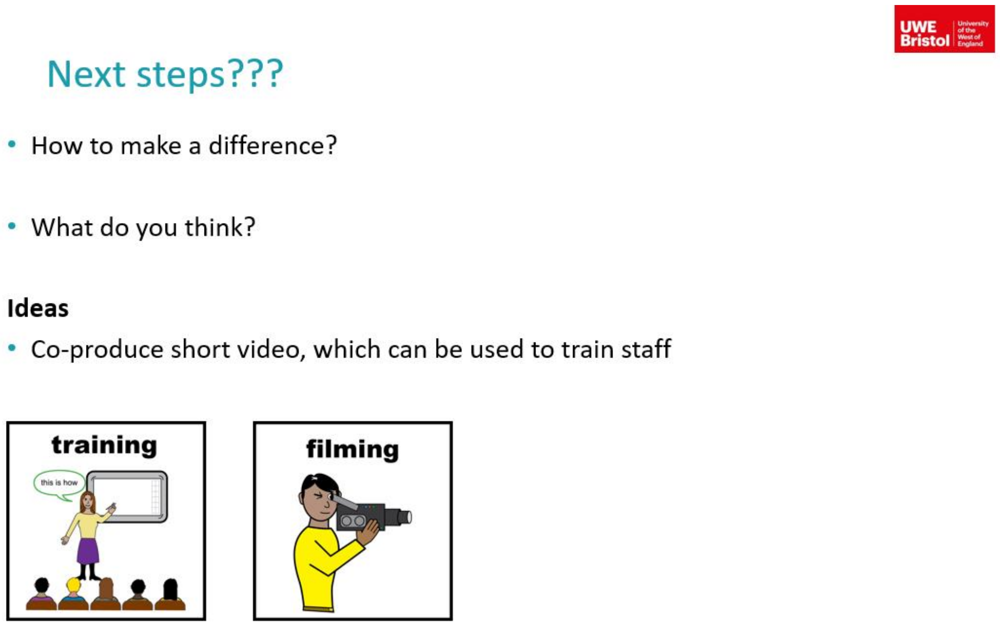
Focus groups

The support person helps **interpret** the health information

Knowing about health helps people to feel confident to make their own decisions



Doctors and nurses should be **prepared** for having a patient with a learning disability



Next steps???

- How to make a difference?
- What do you think?

Ideas

- Co-produce short video, which can be used to train staff

Thank you

APPENDIX TWENTY-SIX: Film Script

Film Script – 3rd draft

Title: ***Needs to be on screen***

Supporting adults with learning disabilities to make health decisions

(Principle 2 of the Mental Capacity Act)

Scene 1: Introduction: Film at Misfits Hub.

Red chairs in front of boards. Conversation around a table having a drink.

2 narrators – Actor 1 and Actor 2

Actor 1: People make decisions all the time but often need help to do so

Actor 2: Making health decisions can be tricky

Actor 1: This research tried to find out how people with learning disabilities want to be supported to make their own health decisions – in line with Principle 2 of the Mental Capacity Act.

Actor 2: 48 people talked to the researcher – 19 people with a learning disability, 6 family members, 16 healthcare staff and 7 student nurses.

Actor 1: We found that people with a learning disability want to make their own health decisions

Actor 2: We found evidence of good practice

Actor 1: Yes, some people are well supported to make their own health decisions

Actor 2: But not everyone has a good experience

Actor 1: This is what we found out

Scene 2: ***Film locations – Out and about, outside, garden, café, kitchen etc.***

Showing different lives/home settings

On screen: People with a learning disability know their decision-making rights

(voice over by Actor 2)

Actor 3 - Doctors and nurses cannot tell me what to do

Actor 4 - Making my own decisions makes me happy

Actor 5 - Making health decisions makes me feel really good about myself

Actor 6 - Before I wouldn't say boo to a goose but now they can't shut me up.

Actor 7 - But if I am not supported to make my own health decisions, I feel useless... I feel powerless... like it's my body but I've got no control over what happens to it.

Actor 8 - Why is it that because I've got a learning disability I haven't got the right to know about my health and my body?

Actor 4 - It's my body.

Actor 3 - Talk to me. Tell me about the decision that needs to be made.

Actor 5 - I think some doctors and nurses assume people with a learning disability can't speak for ourselves. They assume we can't make a decision. That's wrong.

Actor 6 - With support we can make our own health decisions.

Actor 7 - Don't make comments like, 'oh this person lacks capacity, so we'll just go ahead with that' – support the person to make their own decision.

Actor 8 - Everyone has a "voice" – It's the job of health staff to hear our "voice".

Actor 6 - If it's used properly, the Mental Capacity Act is a tool to maintain human rights

Actor 3 - Don't assess our capacity - help us to understand the decision.

Scene 3: ***Film at hospital ward - UWE medical ward***

Doctors – White coat (Actor 9). Scrubs (Actor 10)

On Screen: We often think we're doing the best for our patients... but it might not be what the patient wants (voice over by Actor 1)

Actor 2: This is what healthcare staff told us…

Staff 1 (Actor 10) - The most important thing is to really understand the person.

Staff 2 (Actor 9) - I had to be very careful about how I supported him to make a decision about changing his medication, I had to pace the information, so that I did not overload him with information all at once.

Staff 1 (Actor 10) - We put a little folder together about having the surgery so, at any point she could go and have a look at it, and speak to the staff who were supporting her on a daily basis.

Staff 2 (Actor 9) - The gentleman in question was absolutely petrified of going to any health appointments and so some of the work was around talking through and listening to his feelings and his worries and anxieties before we could talk about the procedure needed.

Staff 1 (Actor 10) - We could see how upset she became when we were talking about the procedure, and how she became so irate in her body movements, her volume, change of the tones of the sounds she was making, indicating her preference, her decision. And so we used videos to evidence that we could show that she was saying yes or no in her way.

Staff 2 (Actor 9) – Understand that whilst there might be conflict with family members, it's from a very caring, loving and often from a very fearful place. Respect family members' views and listen to what they say.

Staff 1 (Actor 10) - I don't expect to get it 100% right every single time but I'll learn from each experience and also talk to my peers for support, making sure that I've got somebody who I can go back to and ask advice from.

Staff 2 (Actor 9) – Supporting a person to make their own decision is very, very rewarding.

Staff 1 (Actor 10) - The outcome was very positive, it was brilliant, she now comes to the outpatient clinic without our support.

Scene 4: ***Film in the garden at UWE***

On Screen: If the person has a more severe learning disability and does not communicate using words (voice over by Actor 1)

Actor 2– This is what family members said…

Actor 11 - Remember that the family holds the history.

Actor 12 - Families often have the overview – they know what has worked and what has not worked before.

Actor 11 - It's really important for somebody who doesn't communicate using words, or understand the implications of a health procedure, that staff listen to those that know them best. It might be family members or it might be support staff.

Actor 12 - Ask the family – they have little gems of information that make it easier for everyone.

Actor 11 - It's about understanding that everyone has expertise that is needed to be brought to the table to get a good outcome.

Actor 12 - Family members are not difficult people, we want the best outcomes for our loved one.

Actor 11 - There are no quick fixes around people with learning disabilities and complex health needs, who have often have had a tough time before –

Actor 12: I often think that that's why they call us patients –

Actor 11 and Actor 12 together: work with us, not against us.

Scene 5: Misfits Hub

On Screen: Key messages for health staff to support decision-making (voice over by Actor 2)

Actor 10 (wearing scrubs, filmed at UWE in ward?) – As health professionals we should know what we are doing – we need to be prepared for our patient

Film locations? Out and about as before?

Actor 5 - Explain to me what the decision is.

Actor 6 - Sometimes I will bring my carer or family to an appointment.

Actor 7 - But remember to talk to me and not my carer

Actor 4 - It's my body.

Actor 8 - My carer is there just in case the doctor says something that I don't really understand, and the carer then can explain it in a way that I do.

Actor 3 - Be honest - I trust my doctor more when they are honest. Don't lie to me, prepare me for what might happen.

Actor 10 -(wearing scrubs, filmed at UWE in ward?) - If possible, give the person time - After the appointment, they might want time to talk about the decision with someone they choose - to see if they've got the right end of the stick –

Actor 3 - Because I might be wrong, so I'll double check if I've understood it right.

Actor 1 - Supporting decision making can be a process of trial and error – keep going until you find the right approach.

Scene 6: ***Film at Misfits Hub Same set up as first scene (two red chairs etc)***

Final take-away messages

Actor 2- Families are not difficult people, they want the best outcomes for their loved one. Work with them, not against them.

Actor 1 - Staff often think they're doing the best for their patients... but it might not be what the patient wants

Actor 2– *Making your own decision is not just awesome, it feels like you're being your own Prime Minister*

Actor 1 - Support us to make our own health decisions.