Social Work perspectives on Mental Capacity Act decision making in the context of practice with people with young onset dementia

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Thesis submitted for the Degree of Doctor of Philosophy

Royal Holloway University of London

December 2023

Declaration of Authorship

I, Stefan Brown hereby declare that this dissertation and the work presented in it is entirely my own. Where I have consulted the work of others, this is clearly stated.

Signed: ________________

Date: 20/12/2023

Acknowledgements

I would like to express my gratitude to the many people whose contributions have been instrumental in the process of undertaking and completing this thesis. It has been a privilege and an honour to have had your support and encouragement as I have worked on these studies.

I would like to acknowledge all my supervisors, Professor Tony Evans, Professor Frank Keating, Professor Anna Gupta and Dr Jane Marriot for their excellent guidance and input throughout all the stages of this doctoral work. Particular thanks to Professor Frank Keating whose wisdom, encouragement and willingness to talk through my ideas has been invaluable. Thank you to Dr Jane Marriot for your sharp attention to detail which often encouraged me to dig deeper. To Rachel Gristwood who proofread my work, thank you for your timely feedback.

I would like to acknowledge the participants of the research study who gave up their time to contribute to the research study. Your willingness to share your practice insights during the challenges of the Covid 19 pandemic was remarkable.

To my amazing family who I am indebted to for their love, patience and sacrifice throughout the duration of this work. Jackie, you have been my constant anchor and support throughout the good and the challenging times. Jessie, Daniel and Ruth you have been and continue to be my motivation and I thank you for affording me the space over many long days, late nights and early mornings. To my wider family and friends who all have had a part in listening to my ideas, encouraging me and offering many acts of kindness, which went a long way.

To my colleagues in the Social Work subject group and the wider Department of Law and Criminology, thank you all for the many supportive conversations and thoughts you’ve shared with me. These have mattered and were often timely.

Abstract

The Mental Capacity Act 2005 (MCA) in England and Wales provides a legal framework for those who lack capacity to make decisions. Social workers use the MCA to assess mental capacity and make Best Interests decisions in their practice. Little is known about how social workers use the MCA in their day-to-day practice to make decisions. Drawing on the findings of a qualitative research study using grounded theory, this thesis explores how social workers use the MCA to make decisions in the context of their practice with people who have young onset dementia (YOD).

The study examined the perspectives of 17 social workers based in adult social care settings, carrying out MCA assessments and Best Interests decision making with people who have YOD. The findings from the research study reveal how social workers use the MCA to make decisions. Highlighted in the findings is a typology of the approaches social workers use in their MCA decision making, consisting of procedural, medicalised, creative, shared, positive risk and rights-based approaches. The findings also reveal the processes that social workers engage in as part of their MCA decision making, the contextual factors which shape social worker decision making and the nature of collaborative practice between social workers and other professionals, family members, carers and community organisations. The conclusions of this thesis highlight the complex nature of MCA decision making for social workers in their practice with people with YOD as well as recognising the importance of social worker cognisance with risk issues and promoting the rights of people as part of their MCA work.

Key words: MCA decision making, Best Interests, Social work practice, Young onset dementia, social constructivism, rights.

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Glossary of terms

CA	Care Act 2014
CRPD	United Nations Convention on the Rights of Persons with Disability
DH	Department of Health (or Department of Health and Social Care)
DoLS	Deprivation of Liberty Safeguards
EA	Equality Act 2010
ECHR	European Convention of Human Rights
ECtHR	European Court of Human Rights
HRA	Human Rights Act 1998
LA	Local authority
LOD	Late onset dementia
MCA	Mental Capacity 2005
MHA	Mental Health Act 1983/2007
MCAA	Mental Capacity Amendment Act 2019
NICE	National Institute for Health and Social Care Excellence
SALT	Speech and language therapist
SCIE	Social Care Institute for Excellence
YOD	Young onset dementia

Chapter 1: Introduction

1.1. Background

This thesis presents an in-depth exploration of social work mental capacity decision-making and dementia. It is firmly anchored in bringing to light core issues for social work practice when using the Mental Capacity Act 2005 (MCA). By way of introduction, these key topics will be defined, and key areas of focus highlighted and considered.

Work for this research study originated with my own practice observations around how social workers understand the rights and needs of adults with dementia. These observations occurred in the 1990s and into the early 2000s when I worked as a social worker in adult community mental health services. I made further observations about how social workers explore decision-making as my practice increasingly involved using legal frameworks such as the MCA and the Mental Health Act 1983/2007 (MHA) and their influence on decision-making.

Alongside practice observations, my own first-hand experiences have influenced my thinking and interest in this area. My father experienced dementia which led to a gradual but profound decline in his overall health and wellbeing. Tracking the onset of his dementia led to questions about whether the onset was before age 65 or after. This led to more questions regarding the nature of Young Onset Dementia (YOD) and how it is recognised and addressed in professional and institutional settings. The writing contained in this research study does not detail my own experiences of having a family member with dementia, although it does attempt to include reflections on how my experiences in practice and wider life might have played a role in the research process and analysis of the findings of the study exploring the perspectives of social workers.

1.2. Research questions

The work outlined is based on core research questions. In exploring social work practice, YOD and MCA decision making the following research question was developed:

How do social workers use the MCA in assessment and decision-making in the context of practice with people who have YOD?

Within the research question, there are two sub-questions which will be explored. The sub-questions are:

> What are the different ways in which social workers can use the MCA to make decisions for people with young-onset dementia?
>
> How do social workers understand YOD as part of MCA decision making?
>
> What are the implications for social workers in using the MCA in their decision-making?

1.3. Aims and objectives

This research study aims to explore social work practice decision-making to inform social work theory, policy, and practice. Specifically, the aims are to gain a better understanding of how social workers make decisions using the MCA for people who have dementia. The aims are further articulated in the objectives. The objectives are:

a) To gain a better understanding of how social workers make decisions for people with dementia when using the MCA 2005
b) To review existing knowledge around social work decision-making in relation to mental capacity and dementia in younger people
c) To explore the frameworks for understanding how social workers engage in assessment and decision-making for people with YOD.

1.4. Importance of the topic to social work

Social workers are a professional group whose role includes intentional and unique interactions with people to support their welfare needs across their lifespan. As a profession social work seeks to promote the wellbeing and flourishing of people across all life stages. Social work practice with adults has evolved significantly since the National Assistance Act of 1948 created a legal duty for local authorities to provide accommodation and support to older people and adults with disabilities under sections 21 and 29 (Bottery, 2023). Social work as a profession became further established through the Social Services Act of 1970 which saw the creation of local authority social services, a single body responsible for the planning of home care, residential accommodation and social work support (Thane, 2009). The Chronically Sick and Disabled Persons Act 1970 furthered the role of social work with adults by requiring local authorities to publicise and take responsibility for the welfare arrangements and housing of all disabled people within their area. These welfare arrangements included home care services, access to day services as well as assistance with travel to these services. (Haves, 2020; Thane, 2009). These early developments formed the foundation for adult social care for people with a range of social care needs.

Today, social work practice with adults covers a wide range of groups and addresses many complex needs. Social work linked to people with YOD falls primarily within the domain of adult social care although the needs of people with YOD straddles both health and social care services (Royal College of Psychiatrists, 2018). Social workers who engage with YOD can be based in local authorities or NHS trusts or be in voluntary or private organisations providing social care-based input. The key concerns for social work with YOD include providing care and support in a person-centred way (Manthorpe and Samsi, 2016), implementing the legal framework of the Care Act 2014 and the Care and Support statutory guidance (Scourfield, 2023) and offering relevant support to people with YOD.

The contribution that social work decision-making with people who have dementia makes to the broader practice of social work is argued to be one of significant value (Scourfield, 2023). In exploring decision making I seek to illuminate this social work field by exploring key ideas that shape and support social workers decision-making when they use the legal tool of the MCA. The MCA is widely used by social workers working with adults (SCIE, 2014) and assessments carried out under the MCA have a direct impact on people’s ability to retain autonomy over their lives (Jayes et al., 2019). As much of social work practice now operates within a multi-disciplinary field the study examines arguments that the social work practice domain is highly influenced by both medical and legal approaches. Further to this, the work seeks to understand what approaches and perspectives might be conducive for social work models of decision-making and how they might support practice with people with dementia. There is a specific focus on dementia affecting the lives of people below the age of 65, or what has been termed YOD. In focusing on YOD, I seek to explore assumptions about social work practice with younger people who have dementia, eliciting whether there are specific areas of need and support that have been suggested in the wider literature around YOD (Carter, 2022; de Vugt and Carter, 2022).

1.5. Definition of terms

1.5.1. Mental capacity

Mental capacity refers to the ability to make decisions. Having mental capacity encompasses being able to make one's own decisions (DOH, 2009). Mental capacity has direct application when applied to decision-making and consent to actions conducted by a person or actions that will impact a person. In England and Wales, mental capacity has been formalised within the law under the Mental Capacity Act 2005, which will be referred to as the MCA forthwith. The MCA applies to all people aged 16 years upwards. Before the MCA was implemented in 2007, approaches to understanding and determining a person's ability to make decisions were partly covered by common law arrangements and the common law arrangement consisted of a doctrine of necessity (Elliot, 2013). Chapter Two of this study provides a more detailed exploration of the MCA including a discussion of the relevant areas for assessment and decision making. The MCA principles assume that people have capacity unless it has been established that they lack capacity (MCA, 2005).

1.5.2. Decision making

For this study, decision-making forms part of the theoretical framework and thus will be explored in greater detail in Chapter Four. From a social work point of view, decision-making refers to ideas based on the reasoning and judgements made by social worker professionals (Bergeron, 1999). The decision-making process in this work seeks to draw a focus on what social workers do in their decision-making, alongside considering the decisions made by service users themselves, although the primary interest is social work professional decision-making with acknowledgement of its interconnection with decisions made by service users, carers and other parties.

1.5.3. Decision making and social work

Social workers in all fields make decisions as part of their practice. Decision making processes for social workers are shaped by legal, ethical and professional regulatory requirements (Feldon, 2017). Focusing on ethical and professional regulatory requirements, social workers in England are currently required to register with Social Work England to practise. For Northern Ireland, Scotland, and Wales there are specific bodies that register those practising within their domains. As a regulatory body, Social Work England set out professional standards which registrants are expected to follow. These Professional Standards include reference to decision-making under Standard 3 in which registrants are expected to:

> "Be accountable for the quality of practice and the decisions I make." (Standard 3, Social Work England, 2023, Page 6)

The Social Work England professional standards go into further detail in Standard 3.2 by requiring social workers to:

> "Use information from a range of appropriate sources, including supervision, to inform assessments, to analyse risk, and to make a professional decision" (Social Work England, 2023, page 7).

The standards as a regulatory requirement for all social workers provide a threshold for safe and effective practice (Social Work England, 2023) but lack detailed practice guidance on how social work decision-making should operate in specific settings such as with people with dementia. Chapter Four, which sets out the theoretical frameworks, provides a detailed discussion of decision-making.

1.5.4. Dementia

Dementia is an umbrella term used to refer to a collection of illnesses in a person, characterised by cognitive decline that affects daily living activities (Moore and Jones, 2012). Dementia has been referred to as an illness which leads to a progressive decline in the mental functioning of a person (Marshall & Tibbs, 2006; Alzheimer's Society, 2023). As a condition that affects functioning, dementia is often mistakenly linked to being an inevitable part of later life, which is not the case and has been challenged by several commentators (Couzner et al., 2022; Moore and Jones, 2012). Dementia is, however, more prevalent in later life (Dementia Research UK, 2023) and the likelihood of developing dementia doubles every five years (NHS, 2023).

1.5.5. Young-onset dementia (YOD)

The term YOD is referred to the presence of dementia in the pre-65 age band (Alzheimer's Society 2016; Hayo et al., 2018). The Alzheimer's Society (2023) consider that evidence of symptoms before age 65 is enough to classify a person as experiencing YOD. There is a lack of consensus around the upper age of the categorisation for YOD being 60 or 65 (Ash, 2014). There is even less consensus about whether there is a lower age banding (Koopmans and Rosness, 2014) and some literature such as van Veen et al. (2022) notes the lower age band is 30, while for others, there is no lower age band, as there is recognition that dementia as a broad term representing a range of presentations can affect any age group (Koopmans and Rosness, 2014). The nomenclature of dementia present in people below the age of 65 lacks consensus, and a variety of terms are used to refer to dementia found in people before age 65 such as working age dementia, early onset dementia, younger onset dementia and early age dementia (Koopmans and Rosness, 2014). Lesser-used terms include pre-senile dementia and adult-onset dementia (van Veet et al. 2022). I have chosen to use the term YOD which is a commonly used term in the literature to refer to dementia within the pre-sixty-five age group. Throughout the work, both dementia and YOD are used interchangeably, although it should be recognised that YOD is dementia, with an age demarcation (Koopmans and Rosness, 2014; Rosser et al., 2010). Within this study, the term dementia will be used to refer to all people with dementia regardless of age. YOD is the term used to refer specifically to people who are known to have dementia and are between the ages of 18 and 65 years.

1.6. Outline of the thesis

The writing presents an in-depth look at social work practice linked to the MCA with a specific focus on the social work practice context of work with people who have been identified as having YOD. The interest of this research study is how social workers engage in MCA decision-making and an exploration of the salient issues. As a way to explore MCA decision making I selected to focus on YOD practice which is a less significant area of social work practice but is a growing area (Scourfield, 2023). The work is outlined in nine chapters which guide the reader through how social workers engage with MCA decision-making and how they do this in the context of their practice with people who are known to have YOD.

Chapter One, the Introduction, outlines the aims and the core objectives, as well as articulating the initial research question. In the introductory chapter, key terms such as mental capacity, YOD, dementia and decision-making are defined to confirm how they have been used throughout the study. The Introduction provides an overview of the key foci of social work decision-making, mental capacity and (YOD) which are outlined in greater detail in chapters Two, Three and Four.

Chapter Two sets out the legal and policy context for the MCA, offering a focused exploration of key legislative frameworks linked to mental capacity decision making. The chapter incorporates a critical discussion of specific legislative areas including the MCA, the Care Act 2014 (CA), The Equality Act (EA), The Human Rights Act 1998 (HA) and the United Nations Convention on the Rights of Persons with Disability 2006 (CRPD).

Chapter Three provides an exploration of dementia and the key discussions and approaches found in dementia. Included here are critical discussions on medical, psychological, social and citizenship approaches to dementia. The chapter also details a discussion of the policy context for working with people who have dementia as well as the role of social workers in working with people who have dementia including those with YOD.

The theoretical frameworks used throughout the work are articulated in Chapter Four. The primary theoretical ideas drawn on in the chapter are social constructivism and decision-making theory. These theoretical ideas are outlined, discussed and analysed in relation to their relevance to the research study and to social work practice.

Chapter Five provides a detailed look at literature linked to social work, MCA and YOD in the form of a literature review. The chapter begins with an explanation of how the literature review was conducted and the process undertaken to retrieve the literature. The core focus of this chapter is an appraisal of literature linked to social work, YOD and MCA decision-making. Here, key issues that arise in the literature are highlighted and discussed and there is a discussion of the gaps in the literature linked to social work practice with people who have YOD.

Chapter Six details the research methodology used in preparing the study. Starting with the research epistemology, the chapter discusses why social constructivism is relevant to research and how it was used to inform the research process. The chapter then goes on to explain how a grounded theory approach was used in the design and collection of data. The methodology chapter includes a discussion of how the research study was affected by the Covid-19 pandemic and how this led to changes having to be made to the study.

Chapter Seven outlines the findings of the study. The findings have been arranged into five thematic categories which emerged through the analysis of the interviews with participants and are further broken down into themes which were coded using a grounded theory approach. The findings reveal the first-hand descriptive insights shared by participants in the research study.

Chapter Eight details the discussion of the findings from the research study. This chapter draws attention to the novel insights around the perspectives of social workers in their MCA work with people who have YOD. As well as discussing my findings this chapter considers the key messages from the literature and how the perspectives of social workers in their MCA decision-making with people who have YOD can be better understood.

The conclusions from my research exploring social worker MCA decision-making are articulated in Chapter Nine. This chapter discusses the key contributions the research makes to knowledge in social work practice as well as a discussion of the implications this work has for social work practice and wider MCA policy and practice. The limitations of the research study are outlined in the conclusion chapter as well as important recommendations for future areas of exploration in terms of research around mental capacity, YOD and social work practice.

Throughout the thesis literature and findings are presented in tables and figures. These have been embedded within the chapters and numbered numerically to make them distinguishable. For example, Table 1 in Chapter 2, outlines the Best Interests decision making. Across the study, abbreviations have been used for frequently used terms, for example, Mental Capacity Act which is abbreviated as MCA. Abbreviations have been listed alphabetically in a glossary of terms and there is a full reference list and appendices outlining key documents used in the planning and execution of the study.

Chapter 2: Legal and Policy context for mental capacity decision making

2.1. Introduction

This chapter provides a detailed and critical exploration of the legal context of mental capacity decision making. The purpose of this chapter is to first explore through a critical lens how the MCA as a statute operates concerning decision making with some attention given to its application to people with dementia. The chapter initially looks at the key areas of the MCA linked to decision making such as MCA assessment and Best Interests' decision making but explores important concepts like autonomy and deprivation of liberty which have shaped discussions about MCA work over the past 15 years. The chapter then goes on to consider related legal frameworks that have shaped MCA practice including the Care Act 2014 (CA), the Equality Act 2010 (EA), the Human Rights Act 1998 (HRA) and the Convention on Rights for Persons with Disabilities (CRPD) 2006 and how they relate to decisions embedded in the MCA.

2.2. The Mental Capacity Act 2005 (MCA)

The MCA is primarily about the rights of people related to making decisions (Graham and Cowley, 2015). It outlines a detailed legal framework for when steps can be taken to engage in decision-making on someone else's behalf as well as what these steps should be. Its implementation into practice on the 1st of October 2007 represented a significant effort to codify how to understand when a person is unable to make a decision and how the decisions can be made (Graham and Cowley, 2015). The MCA is accompanied by the MCA Code of Practice (2007), which has statutory force, requiring a list of people to follow its guidance, including social workers. Much of the MCA focus is on outlining a legal framework for people who cannot make decisions, due to lacking the mental capacity. The MCA includes restrictive elements like the Deprivation of Liberty Safeguards (DoLS), and these will be explored later in this chapter.

The Law Commission (1995) noted that the need for mental capacity policy and procedures came about due to medical, demographic and social changes in society including an increasing proportion of older people in society, medical advances enabling people with mental impairments being able to live longer and community care reforms that meant increasing numbers of people receiving care in community settings, such as care homes, supported accommodation rather than institutional settings. Additionally, there were concerns raised by professionals and service user groups that people were falling through the net in terms of care and decision making (Spencer-Lane, 2009). Further reasons for a need for a statute to address decision-making came about due to the case of *F v West Berkshire HA [199] 2 AC (1)* brought to attention the legal limitations in decision making. F was a 36-year-old woman with a learning disability living in a hospital for adults with learning disability, who developed a sexual relationship with a male resident of the hospital. Doctors held the view that (F) would not be able to cope with pregnancy and childbirth and it was therefore in her best interests to be sterilised. The case drew public interest to the lack of ability of the courts or any other person to make a medical decision on behalf of a person without capacity (Law Commission, 1995). The judgement noted that the common law doctrine of necessity could be relied on as a defence for action by doctors in determining and providing treatment to people deemed unable to make decisions (Elliot, 2013).

The doctrine of necessity as a practice enabled doctors to provide care and treatment to people without their consent, once they had determined that the person was unable to make a decision for themselves (Elliot, 2013). Treatment would be given to a person who was deemed unable to decide for themselves based on evidence that they (doctors) believed it to be reasonably necessary and proportionate to protect the person or others from the immediate risk of significant harm (Elliot, 2013). The doctrine of necessity approach was criticised by welfare groups for leading to too many inconsistent decisions being made by medical professionals (Szerletics, 2012) and was limited in that it did not cover all decisions. For example, decisions relating to residence (Szerletics, 2012). Efforts to address these flaws saw Lord Makay in 1988 request the Law Commission to investigate and report on all areas of the law that relate to decisions about personal and financial matters for people who were believed to be unable to decide for themselves (House of Commons, 1998). Throughout the 1990s the Law Commission carried out research exploring existing case law on incapacity and consultation with the public and various disability and professional bodies to explore options to address the existing legal mechanism which was referred to as “complex, inflexible and piecemeal.” (Law Commission, 1995 p2). The Law Commission’s 1995 report, titled *Mental Incapacity*, outlined a detailed legal framework to address the significant gaps in procedures and processes of decision-making for adults who lacked the ability to make decisions. The report recommended specific legislation to address the everyday circumstances of those who lack capacity (House of Lords/ House of Commons, 2003). It took several years and numerous amendments to the report before the draft Mental Incapacity Bill was put before Parliament and eventually enacted into law (House of Lords, House of Commons, 2003; Spencer-Lane, 2009).

Mental capacity refers to a person’s ability to make their own decisions and if this ability is hindered because of some impairment of the mind or brain the MCA ensures the individual remains involved in any decision-making process and that decisions are based upon their best interests. The term brain here refers to the physical organ located in the human head and the mind refers to reasoning, thinking and mental processes.

Central to the MCA are five statutory principles found in Section 1 of the Act. These principles are:

1. A person must be assumed to have capacity unless it is established that he lacks capacity.
2. 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.
3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person’s rights and freedom of action.

(MCA, s.1 (1-5)).

The five principles of the MCA set out core values and considerations to be followed when using the MCA. The principles are universal to the application of the MCA. They form a starting point for understanding mental capacity in given situations and how professionals such as social workers may be involved or become co-opted into decision making situations.

2.2.1. Assessment under the MCA

Mental capacity within the MCA is regarded as an 'individual property' in that it refers to a person having capacity rather than persons (Kong and e-Keene, 2019). The MCA asserts the assumption that all people have the mental capacity to make decisions for themselves (Department for Constitutional Affairs, 2007). This is crucial to the idea of assessing mental capacity because assessment under the MCA must be justified based on reasonable doubt that a person may no longer have capacity to make a specific decision at a specific time (Kong and Ruck-Keene, 2019). The notion of reasonable doubt forms what can be referred to as the trigger for an MCA assessment to be commenced. The MCA Code of Practice in commenting on when to assess mental capacity notes that:

> "It is important to carry out an assessment when a person's capacity is in doubt. It is also important that the person who does an assessment can justify their conclusions" (Department of Constitutional Affairs, 2007, para. 4.43).

Although the MCA assumes everyone has the capacity to make decisions, it also sets out criteria for determining whether a person is considered unable to make a decision. These criteria include what is referred to as a diagnostic test (Ruck-Keene et al., 2023b; Taylor, 2016), although it does not necessarily include reference to a diagnosis. The criteria for determining whether a person has capacity is outlined in Section 2(1) of the MCA:

> "A person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain" (S.2(1) MCA 2005).

Alongside the ‘diagnostic assessment’ the MCA outlines another aspect of the assessment of capacity under Section 3. This section outlines that the mental capacity to make decisions involves the ability:

(a) to understand the information relevant to the decision,

(b) to retain that information,

(c) to use or weigh that information as part of the process of making the decision, or

(d) to communicate his decision (whether by talking, using sign language or any other means.

(S.3(1) of the MCA 2005).

Together sections two and three of the MCA form what the MCA Code of Practice refers to as the two-stage assessment process (Department of Constitutional Affairs, 2007). The guidance given by the MCA Code of Practice (2007) regarding the two-stage assessment process, has been identified as flawed with suggestions that the guidance should be withdrawn from the MCA Code of Practice (Ruck-Keene et al., 2023b). A key concern about the guidance is that by starting with stage one, assessing whether there is an impairment, it could lead to a tick box and potentially a discriminatory approach to assessing capacity where it can be subconsciously easier to move to stage two, once stage one criteria have been met (Ruck-Keene et al., 2023b). Case law derived from *A Local Authority v JB* [2021] UKSC 52 recognised this problem and indicated that MCA assessments should first consider whether a person can make a decision (Ruck-Keene et al., 2023a) i.e., start with exploring stage two. The MCA Code of Practice has not yet been amended to reflect this change of emphasis (Ruck-Keene et al., 2023b), although the practice has changed by emphasising that there needs to be a relationship between Section 2 and Section 3, or what is referred to as the causative nexus (Kong and Ruck-Keene, 2019). The causative nexus as a part of the MCA assessment process requires that there needs to be a direct link between the finding of an inability to be able to understand, retain, weigh up, or communicate a decision and the person experiencing an impairment of or disturbance in the functioning of the mind or brain (Kong and Ruck-Keene, 2019). Once it has been found that a person cannot make a decision then it should be explored whether this is because of an impairment or disturbance in the functioning of the mind or brain. The direct link between the two aspects should be evidenced in the recording of the assessment (Kong and Ruck-Keene, 2019). Assessment under the MCA is noted as decision and time-specific, meaning that an assessment of a person’s capacity should be made in relation to a decision at the time the specific decision needs to be made (Department of Constitutional Affairs, 2007; Bartlett, 2020; SCIE, 2014a).

2.2.2. Decision making and the MCA

According to the Care Quality Commission around two million people are directly affected by the MCA which includes people with YOD (CQC, 2023). With the enactment of the MCA, its use in decision-making became a core part of the day-to-day practice for social workers who work with people who cannot make decisions for themselves (Bogg and Chamberlain, 2015). For social workers using the MCA, assessment and decision-making takes place in a variety of settings, including nursing and residential care homes, hospitals, supported living arrangements or people’s own homes. Decision-making using the MCA 2005 has similarities with decision-making in other areas of social work practice.

The purpose of the MCA is to uphold the rights and freedoms of all people regardless of whether they have capacity to make decisions or not. In seeking to achieve this, people who have been identified through assessment as lacking capacity to make decisions, are to be supported to make decisions wherever possible (see Principle 2 of the MCA). In the event of a person being unable to make a decision, despite being given practical support to make a decision, the MCA sets out the process for making decisions (Principle 4 of the MCA) which is known as the Best Interests approach.

Best interests’ decision making is detailed under Section 4 of the MCA and represents a form of substituted decision making. The MCA does not define Best Interests and this has been considered to be intentional due to the broad scope of settings and circumstances where decision making can occur (SCIE, 2009). Principles noted in the MCA Code of Practice and MCA Section 4 set out what has been described as a Best Interests’ checklist or things that should be considered in deciding what the person’s best interests are. Table 1 outlines the considerations that need to be taken into account when exploring Best Interests as part of MCA work. These have been categorised into columns denoting how the MCA indicates who should be included in Best Interests' decision making, what should be excluded from Best Interests' decision making and who can be consulted as part of the Best Interests' decision making process. Section 4(3)(a) of the MCA stipulates that a Best Interests' decision making process must check whether the person will at some point regain capacity to ascertain whether the person will be able to make a decision at some point themselves. This supports the overall aim of the MCA which regards that the person is best placed to make decisions for themselves. Furthermore, Section 4(4) requires encouragement for the involvement and participation of the person who is deemed to lack capacity to make a decision (Department of Constitutional Affairs, 2007). Involvement of the person and their views in Best Interests decision making was noted in the Supreme Court case in *Aintree v James* [2013] UKSC 67 where judges emphasised the purpose of Best Interests decision making considering the matter from the person's point of view (Ruck-Keene et al., 2013).

Table 1. Best interests' checklist table. Adapted from the MCA Code of Practice (2007)

What needs to be considered in Best Interests' decision making?	**What Best Interests' decision making cannot be based on**	**Who can be consulted regarding Best Interests'?**
The person's past and present wishes and feelings (including written statements made by the person when they had capacity). The person's beliefs and values that would be likely to influence his decision if he had capacity. The views of anyone named by the person as someone to be consulted on the matter; anyone engaged in caring for	Decisions cannot be made based on the person's age, appearance, condition or aspects of the person's behaviour. A decision cannot be made for another person in relation to consenting to marriage or a civil partnership; consenting to have sexual relations; consenting to a	Anyone who is named by the person as someone to be consulted on the matter. Anyone who is engaged in caring for the person or interested in their welfare. Relatives, friends and others who take an interest in the person's welfare. Donees of a lasting power of attorney.

the person or interested in his welfare; views of one of a lasting power of attorney granted by the person; views of deputy appointed for the person by the court of protection. Important factors the person would want to be considered in making the decision. All circumstances of the case. Whether the person is likely to regain capacity.	decree of divorce on the basis of two years' separation; consenting to the dissolution of a civil partnership; consenting to a child being placed for adoption or the making of an adoption order; discharging parental responsibility for a child or giving consent under the Human Fertilisation and Embryology Act 1990. A decision concerning life-sustaining treatment motivated to bring about the person's death.	Deputies appointed by the Court of Protection. Independent Mental Capacity Advocate (IMCA) where the person does not have an appropriate person to provide support or where there are safeguarding matters.

From Table 1 it can be seen that the MCA does not stipulate who should be a decision maker in the Best Interests process although the MCA Code of Practice suggests that:

> "For most day-to-day actions or decisions, the decision-maker will be the carer most directly involved with the person at the time." (Department of Constitutional Affairs, 2007, p.69).

In situations in which a person has a current Lasting Power of Attorney or where the Court of Protection has appointed a Deputy, these are identified as decision-makers (Department of Constitutional Affairs, 2007). The MCA Code of Practice also recognises that there may need to be multidisciplinary team involvement in Best Interests' decision making. The other notable location of decision making under the MCA is through the court system and in particular the Court of Protection. The Court of Protection is a specialist court created under the MCA to hear matters specific to mental capacity. The Court of Protection's decision-making powers are defined under sections 12 – 16 of the MCA. The Court of Protection holds decision making powers where it has established that a person lacks the capacity to make a decision and can act to appoint a deputy to make decisions (Ruck-Keene et al., 2019). While the majority of the Court of Protection's decision making relates to personal property and affairs (Ruck-Keene et al., 2019), there is a growing number of health and welfare cases, brought to the Court of Protection highlighting the increasing volume of litigation in mental capacity matters (Ruck-Keene et al., 2019), confirmed by Family Court statistics that show a significant increase in Court of Protection cases linked between 2008, soon after the new Court of Protection was established and 2016 (Series et al., 2017). This also highlights that there's been an increase in mental capacity decision making within legal settings, rather than in everyday settings like a person's home.

One other way in which decision making can occur under the MCA is the involvement of the Independent Mental Capacity Advocate (IMCA). The MCA includes the statutory right to be supported and represented by an IMCA in certain circumstances (Gordon, 2015). The IMCA role can be instructed when a person lacks capacity to make a decision and has no family or friends or appropriate support (Dixon, 2023; Boyle, 2008) or where it is not practicable to consult with family and friends of the person. In March 2008, local authorities were given powers to involve IMCAs in adult safeguarding processes (Redley et al., 2011). The IMCA role has been posited as a positive step towards supporting the interests of people who lack capacity to engage in decision making (Redley et al., 2011). However, in a review by Gordon (2015) evidence was presented that the IMCA service may be underused within MCA work and it can be argued that there is scope for greater promotion of advocacy for people who lack capacity to make decisions.

As a framework for supporting adults in decision making where they are unable to make decisions for themselves the MCA 2005 can be argued as strengthening rights (Manthorpe et al., 2008, Mackenzie & Rogers, 2013; Boyle, 2008) and enhancing the legal options available to people who lack capacity to make decisions and their families (Kong and Ruck-Keene, 2019). Prior to the implementation of the MCA the options available to challenge the decision-making of professionals were shaped by organisational complaint processes or through judicial review (Carpenter et al., 2014). Furthermore, the MCA has been credited for bolstering rights in the form of recognising that it endorses the autonomy of those who lack capacity to make decisions for themselves, by giving legal pathways to contest decision making (CQC, 2022). These legal pathways refer to the establishment of a new Court of Protection under the MCA creating a process for those who lack capacity to have access to legal hearings of their contestation of decision making. However, access to the Court of Protection is not entirely free and is subject to means testing of income for most matters with the exception of deprivation of liberty cases (Kong and Ruck-Keene, 2019). This raises questions related to the adequacy of access to justice for people who lack capacity to make decisions and their families.

2.2.3. The MCA's approach to capacity assessment and decision making

Assessment using the MCA involves making decisions. Decisions are made regarding whether a person has a condition that represents an impairment of the mind or brain, and decisions are made in relation to the four areas found in Section 3 of the MCA. In MCA assessment there is an emphasis on the cognitive abilities of the person being assessed (Kong and Ruck-Keene, 2019: Craigie et al., 2019) leading to the suggestion that the MCA in the assessment process largely follows a cognitive approach (MacKenzie and Rogers, 2013). This approach relies on a person having cognitive abilities to understand the information being communicated to them in the assessment, retain the information and weigh the information (MacKenzie and Rogers, 2013) as well as being able to articulate their mental capabilities for decision making. Using a cognitive approach has both benefits and drawbacks in a MCA assessment. Exploring the person's cognitive ability by exploring whether they can retain, weigh up and understand the information can enable the assessor to understand a person's thought processes, memory and attention (Craigie et al., 2019). The drawbacks are that a cognitive approach may be reductionist, missing vital aspects of a person's decision-making framework such as their accountability to other people in the process of making a decision (MacKenzie and Rogers, 2013).

Alongside a cognitive approach, the MCA relates to a functional approach to addressing issues of capacity (Series, 2011). A functional approach as part of the assessment of capacity focuses on what a person can and cannot do (Kong and Ruck-Keene, 2019) and was noted as the preferred approach by The Law Commission's Report to Parliament in 1995, entitled Mental Incapacity*,* which noted the preference for adopting a functional approach above an outcome-based approach in mental capacity law (Law Commission, 1995). However, functional approaches have been criticised in that once the threshold has been established that the person meets the criteria for lacking capacity then no further questions are asked (Series, 2011) and assumptions that people with specific disabilities like dementia will lack capacity (Dhanda, 2007). More recent discussions have noted that undue influence may be an area that has been overlooked in the use of functional tests for capacity (Murray, 2017; Ayrio et al., 2023). The functional approach to capacity can be contrasted with outcome-based approaches which base the focus on the consequences of the decisions that a person will make and puts forward that where a person makes decisions in stark contrast to conventional wisdom, this presents evidence of an inability to make a decision (Series, 2011).

Outcome-based approaches depend on justifying a decision being made for a person who lacks capacity to prevent significant harm to the person. Outcome-based approaches can be noted as limiting individual preferences (Bartlett, 2012). Despite these limitations, evidence from The Law Commission in its report, Law Reform for Mentally Incapacitated Adults (1995) noted before the MCA that many medical practitioners or doctors tended to employ an outcome-based approach (Law Commission, 1995) and over 25 years since the Law Commission's review the practice of focusing on outcomes as part of MCA assessment has been found to prevail today. This was evident in the findings of Williams et al. (2012b) who, in their study on decision-making using the MCA, found a minority of practitioners would often base Best Interests' decisions on whether an individual has the mental capacity to make a decision, rather than on the suitability of the decision.

Status approaches to capacity are based on the recognition of a qualifying factor such as age or diagnosis of dementia as the basis for a person to be defined as lacking capacity. A status approach, where adopted, can lead to significant numbers of people being unnecessarily defined as lacking capacity without a thorough exploration of the issues (Banner and

Szmukler, 2013). This then can lead to an in or out approach to mental capacity issues (Browning et al., 2014), based on whether a person meets a particular set of qualifying characteristics, without understanding what the person can or cannot accomplish, which potentially strips them of any sense of agency in the MCA process. A status approach is found in the first stage of the MCA assessment process which requires a qualifying 'diagnostic' threshold to be met, i.e., an impairment of or disturbance in the functioning of the mind or brain. The requirement to evidence a medical diagnostic threshold as part of mental capacity assessment points towards the prominence of the medical model in determining mental capacity (Clough, 2015). The MCA then, can be argued to embed a hybrid approach (Murray, 2017), consisting of both a functional and status approach to mental capacity decision making. For practitioners using the MCA awareness of the strengths and limitations of both functional and status approaches can be beneficial to help increase the involvement of the person and avoid bias (Murray, 2017). Bias can be found in the use of status approaches. For example, Clough (2015) in her comments based on reviewing the recorded transcript discussion between Mostyn J and Counsel for the Official Solicitor, in the case of *Re AA* [2012] EWHC 4378 (COP) highlights concerns that people with a diagnosed mental disorder could be assumed to also lack mental capacity. Practitioners should also hold a recognition of the link between both elements referred to as the causal nexus (Kong and Ruck-Keene, 2019), which links both aspects of MCA assessment, i.e., the inability to make a decision (functional) because of an impairment of the mind or brain.

These explorations have recognised that functional, outcome and status approaches are all evident in the MCA and therefore shape practice where the MCA is used, but their emphasis can overlook the importance of family and carers, who know the person being assessed well. The involvement of family and carers in MCA assessment and decision making highlights a relational approach to decision making (Murray, 2017) and emphasises that assessment and decision making may be made in conjunction with family members or carers with who the person has been found to have an interdependent relationship with (MacKenzie and Rogers, 2013). Within the MCA the views of family members and carers are often drawn on under s(4) MCA, Best Interests decisions, however, a more comprehensive approach of involving family members and carers has been stressed by the Nuffield Council of Bioethics (2009) which notes that adults with dementia “rarely make decisions in isolation” (p.2)

2.2.4. MCA assessment and dementia

A key focus of the thesis is exploring mental capacity decision making in the context of practice with people with YOD. With regard to how the MCA applies to people with dementia it can be seen that, in line with the legal requirements of the MCA, people may carry out MCA assessments where there is reasonable doubt that a person with dementia is able to make a specific decision (Department of Constitutional Affairs, 2007). There are currently no legal rules that stipulate when an MCA assessment should take place for a person with dementia, although the MCA Code of Practice does include dementia in a list of conditions which may amount to an impairment of, or disturbance in the functioning of, the mind or brain (Department of Constitutional Affairs, 2007). The MCA Code of Practice (2007) also attempts to clarify discussions on who should assess capacity more generally, stating that:

> “For most day-to-day decisions, this will be the person caring for them at the time a decision must be made. For example, a care worker might need to assess if the person can agree to being bathed. Then a district nurse might assess if the person can consent to have a dressing changed” (Department of Constitutional Affairs, 2007, p.53).

The suggestion from the MCA Code of Practice is that carers, family members and support workers will make most day-to-day decisions for people with dementia and that social workers are likely to be involved in MCA assessments when there are more complex decisions being made. Examples given in the MCA Code of Practice of more complex decisions include decisions about where a person will live and the provision of care and treatment (Department of Constitutional Affairs, 2007). These tend to be the types of decisions that may arise for people with dementia, particularly in the later stages of the illness (Alzheimer’s Society, 2023). Although the Mental Capacity Act Code of Practice (2007) provides some fundamental guidance on conducting and recording capacity assessments, there is a lack of clarity about the way in which practitioners conduct MCA assessments of capacity to make a decision and how the process and outcomes of these assessments are being recorded (House of Lords, 2014). The MCA Code of Practice (2007) does not refer specifically to YOD, although it does refer to dementia and recognises the specific challenges that can arise when using the MCA when dementia is present (Department of Constitutional Affairs, 2007).

2.2.5. The MCA and autonomy

At the heart of MCA decision making is the principle of autonomy (Rapaport et al., 2009; Craigie, 2013). Lennard (2016) posits that the MCA aims to protect the autonomy of a person and avoid unnecessary paternalism. Autonomy as used in the MCA refers to the ability or right to decide one's course of action with freedom from interference from others (MacKenzie and Rogers, 2013). It holds similarities with the term agency, which refers to a person's ability to influence their actions and thoughts (Ritzer 2005). Like agency, autonomy enables individuals to make decisions rather than have decisions made for them. The autonomy to make decisions under the MCA is highlighted within Section 1(1) of the MCA which promotes the presumption of capacity. Although autonomy to make decisions is assumed in the MCA, where it is found not to be present, it is replaced by a supportive framework known as Best Interests, which aims to help a suitable decision to be made which upholds the autonomy of the person (Lennard, 2016).

Embedded within the definition of autonomy are the concepts of self-governance and self-determination (Mackenzie and Rogers, 2013). Self-governance can be understood in relation to a person's internal ability to decide the course of action, whereas self-determination draws emphasis on the external conditions which help to support a person's decision (Mackenzie and Rogers, 2013). In examining autonomy, as used within the MCA, the concept is employed narrowly (MacKenzie and Rogers, 2013). Looking at the areas of the MCA which emphasise autonomy, key parts are found in Principles 1 and 3 of the MCA. These principles, in emphasising autonomy, point toward the individual being able to make their own independent decision which suggests autonomy is conceptualised as a form of individual independence (Craigie, 2013; Harding, 2012). The suggestion in the MCA, then, is that a person is empowered to make a decision of their own choosing, independent of the control and influence of other people like health and social care practitioners (MacKenzie and Rogers, 2013). Although independence can be of great benefit to people, it can be argued that the term independence has been interpreted in welfare policy terms as self-reliance (Vernon and Qureshi, 2000). There are huge challenges with a conceptualisation of autonomy that suggests self-reliance, based on how cognitive decline affects a person's everyday activities and decision making (Craigie, 2013).

The conceptualisation of autonomy as independence suggests that the MCA relies on an individualistic approach to decision making which can in turn neglect the idea that decision making can also include interdependence. Interdependence here refers to decisions being made in reference to relationships with others or within a relational approach. Dhanda (2012) captures this in her critique of rights under guardianship approaches, noting that decisions are not made merely in isolation of others, but in reference to other people. For people with dementia, where memory related to decision making can be reduced, an interdependent component of decision making can be noted as important. However, in examining the MCA 2005 and the Code of Practice (2007) there is no discussion of interdependence in decision making (Craigie, 2013) which presents a notable disadvantage to people whose approach to decision making may include reference to others. It can be suggested, therefore, that a broader framework is needed which interprets autonomy more broadly than ideas of individual independence but includes relational aspects which have been found to shape decision making such as interdependence and accountability (Harding, 2012; MacKenzie and Rogers, 2013; Murray, 2017).

2.2.6. The MCA and Deprivation of Liberty

The next part of the examination of the MCA as a legal framework looks specifically at how the MCA deals with decision making in the deprivation of liberty for people who lack capacity to make decisions. In doing so, this section draws attention to the Human Rights Act 1998 (HRA). The importance of deprivation of liberty to dementia is borne out by government statistics in 2013 that showed 54% of all Deprivation of Liberty Safeguards

(DoLS) applications were for people with dementia (NHS Digital, 2023). The MCA 2005 has effected positive change by framing capacity as decision making on specific matters and strengthening the rights of people who are deemed to not have capacity through the provision of advocacy (Manthorpe et al., 2008; Kong and Ruck-Keene, 2019). However, using a broader welfare lens to scrutinise the MCA we see that it has meant rights have been limited and there remain key gaps, such as the Deprivation of Liberty in private settings, where rights are still not being fully protected. The original MCA (2005) legislation did not include provisions regarding the Deprivation of Liberty and the provisions known as the Deprivation of Liberty Safeguards were added via the MHA 2007 following the 2004 European Court of Human Rights (ECtHR) decision (Brindle, 2015). The case of *HL v UK* 45508/99 [2004] ECHR 471 also referred to as the "Bournewood case" is well known, relating to HL, a 48-year-old man with autism, who was admitted to Bournewood Hospital, in Surrey as an informal patient without consent being obtained or any legal process occurring (Godefroy, 2015). The key facts of the *HL v UK* 45508/99 [2004] ECHR 471 case were that HL lacked capacity to decide whether to remain in the hospital yet was kept in the hospital and was denied contact with his carers (Godefroy, 2015). HL was compliant with his care and this was used by the hospital trust to suggest that HL was not being deprived of his liberty. The outcome of the ECtHR highlighted the salience of what deprivation of liberty for people who lack capacity to consent to arrangements of admission to a hospital or a care home means. HL was deprived of his liberty and his human rights were breached, specifically under Articles 5(1) and (4) of the HRA (Godefroy, 2015). Furthermore, HL did not have any legal protection available at the time because he was not and could not be detained under the MHA (Godefroy, 2015).

Deprivation of Liberty as a term used within the MCA relates to situations in which people cannot consent to the arrangements under which they are being kept (Department of Constitutional Affairs, 2008). As evidenced in the *HL v UK* 45508/99 [2004] ECHR 471 deprivation of liberty links to Article 5(1) of the Human Rights Act 1998 which outlines a broader understanding of deprivation of liberty which states:

> "Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law". (Article 5(1) Human Rights Act, 1998).

Article 5(1) HRA outlines six different circumstances in which liberty can be lawfully restricted and includes reference to people of "unsound mind" which relates to people who lack capacity to make a decision (Godefroy, 2015). Section 64(5) MCA confirms that the MCA adopts the same meaning of deprivation of a person's liberty as found in Article 5(1) of the HRA. What is helpful to note is that the right to liberty is recognised as a limited right (Brindle, 2015) meaning that in given circumstances this right can be restricted. In MCA where deprivation of liberty is seen as necessary to protect a person from harm, the decision to restrict liberty follows a procedural process laid out under Schedule 1A of the MCA. *HL v UK* 45508/99 [2004] ECHR 471 also related to Article 5(4) HRA which states that:

> "Everyone who is deprived of his liberty by arrest or detention shall be entitled to take proceedings by which the lawfulness of his detention shall be decided speedily by a court and his release ordered if the detention is not lawful." (Article 5 (4) Human Rights Act, 1998).

The Article 5(4) HRA rights of people who lack capacity to make decisions are affected when they are not given access to legal proceedings to challenge decisions to admit or retain them in a hospital or place of residence (Godefroy, 2015).

The efforts to ensure that Article 5(1) and (4) HRA rights were upheld for people in care homes or hospital settings led to the UK government drafting up the Deprivation of Liberty Safeguards((DoLS) (Godefroy, 2015). However, an obvious gap in the plans meant people who were not in residential care or nursing homes or hospitals did not receive the same protections under the MCA (Godefroy, 2015). These relate to people whose care is not funded or provided by a public body like a local authority or NHS trust (Brown, 2015). Examples of people who are not covered by the DoLS arrangements are people in their own homes and in community settings that are not nursing or residential care homes. In these cases there was an expectation that a person or a representative for the person would apply to the Court of Protection for a Deprivation of Liberty order (Ruck-Keene et al., 2023a). However, where a deprivation of liberty comes to the attention of a local authority, there is a positive duty for the authority to raise the matter before the Court of Protection (Schwehr, 2016). The requirement to apply to the Court of Protection for a Deprivation of Liberty order has been criticised for being a timely process in which time a person may continue to be subject to deprivation of liberty while they await the court process (Schwehr, 2016).

2.2.7. The Deprivation of Liberty Safeguards (DoLS)

Following the *HL v UK* 45508/99 [2004] ECHR 471 *c*ase the UK government produced the DoLS (Ministry of Justice, 2008). The Deprivation of Liberty Safeguards came into force in April 2009 and outlined a decision making process for determining whether a person was deprived of their liberty. This process rested on deciding whether the intensity or degree of a restriction of liberty amounted to a deprivation of liberty (Brown et al., 2015; Godefroy, 2015). The DoLS code of practice outlined a set of guiding factors which were based on details found in cases presented to the European Court of Human Rights including the *HL v UK* 45508/99 [2004] ECHR 471 case (Ministry of Justice, 2008). These guiding factors included:

- Restraint is used, including sedation, to admit a person to an institution when that person is resisting admission.
- Staff exercise complete and effective control over the care and movement of a person for a significant period.
- Staff exercise control over assessments, treatment, contacts, and residence.
- A decision has been taken by the institution that the person will not be released into the care of others, or permitted to live elsewhere unless the staff in the institution consider it appropriate.
- A request by carers for a person to be discharged to their care is refused.
- The person is unable to maintain social contacts because of restrictions placed on their access to other people.
- The person loses autonomy because they are under continuous supervision and control.

(Para. 2.5, Ministry of Justice, 2008).

Under the DoLS, local authorities were required to put in place a system of identifying whether people in nursing or residential care homes and hospitals were being deprived of their liberty. Determining whether someone met the DoLS threshold involved conducting six assessments which examined age, mental capacity, mental health, eligibility, no refusal (linked to Lasting Power of Attorney or Court appointed deputies) and Best Interests' (Ministry of Justice, 2008). The DoLS received significant criticism from practitioners for the lack of a statutory definition of deprivation of liberty which often meant the assessment of deprivation of liberty was based on interpretation of the guiding factors by practitioners or courts (Godefroy, 2015). Harsher criticism of the DoLS came from the House of Lords Select Committee on the Mental Capacity Act 2005 report entitled Mental Capacity Act 2005: Post-Legislative Scrutiny (2014). The report concluded that the DoLS were not fit for purpose as they were:

> "Poorly drafted, overly complex and bear no relationship to the language and ethos of the Mental Capacity Act" (House of Lords, 2014, p.7).

In practice the DoLS represented a new bureaucracy that was complex (Godefroy, 2015). The new bureaucracy of DoLS was found to be poorly understood by staff which led to poor practice (CGC, 2020). Furthermore, there were failures to consider how the new processes might affect those on the receiving end of the assessment and whose wishes the MCA seeks to promote (Carpenter et al., 2014). A noted deficit in DoLS was that it offered protections only to those people who were admitted to a hospital or a nursing or residential care home as settings that have a public duty to follow the requirements of the HRA (SCIE, 2017). This meant an unknown number of people residing in their own homes or private settings and supported care settings did not meet the requirements for the DoLS (SCIE, 2017). Amendments to DoLS came through case law, in particular one case that formed a decision of the UK Supreme Court in 2014*. P (by his litigation friend the Official Solicitor) v Cheshire West and Chester Council and Anor* [2014] UKSC 19 *and P and Q (by their litigation friend, the Official Solicitor) (Appellants) v Surrey County Council (Respondent*) [2014] UKSC 19, known as the '*Cheshire West case'* (Godefroy, 2015), outlined a clear definition of deprivation of liberty based on a test, referred to as the 'acid test' of whether someone is deprived of their liberty and requiring authorisation under the DoLS. This test set out three areas to be established for a person to be deprived of their liberty.

Is the person subject to continuous care and supervision?

Is the person free to leave (whether they initiate attempts to leave or not)?

Does the person lack capacity to consent to the arrangements?

(Godefroy, 2015, p.136).

As a piece of case law, the Cheshire West case shaped how deprivation of liberty decision making operated, leading to a sharp increase in DoLS applications for people living in nursing and residential care homes, who met the three criteria of the acid test (Spencer-Lane, 2023a; Ruck-Keene, 2023b). Since the Cheshire West judgement, there has been a year-on-year increase in the number of DoLS assessment requests made to local authorities (Spencer-Lane, 2023b). In 2022/23 there were over 300,000 DOLS applications made compared with just under 12,000 in 2012/13 (NHS Digital, 2023), the year prior to the Cheshire West case. The significant increase in the number of DoLS applications uncovered a widespread backlog of DoLS assessment requests (Law Commission, 2017; NHS Digital, 2023). The backlog represents significant delay in the process of decision making for people who lack the capacity to make decisions. In 2021/22 there were 124,145 incomplete DoLS assessment requests known to local authorities (Spencer-Lane, 2023). The backlog has persisted and increased partly because local authorities do not have adequate staff resources to clear the outstanding applications and the additional cost of directing resources to clear their backlogs would mean cutting essential services (Ruck-Keene, 2019). Crucially, concerns have been raised that the backlog of DoLS assessment requests means that people whose care circumstances mean they are left without any safeguards under the law and are being failed by local authorities who are unable to fulfil their statutory duties to examine and remedy where a deprivation of liberty may be occurring (Spencer-Lane, 2023a).

2.2.8. The Mental Capacity Amendment Act 2019 (MCAA)

In April 2019, the MCAA became a statute. The amendment to the MCA originated from critical feedback on the implementation of the MCA (Ruck-Keene, 2023a) including the influential House of Lords Select Committee report which made 39 recommendations for change including that the DoLS were not fit for purpose (House of Lords, 2014; Fanning, 2016). These criticisms formed the impetus for the Law Commission to set about reforming the MCA principally in the area of Deprivation of Liberty. The Law Commission's 2017 report findings on the MCA and deprivation of liberty noted that the DoLS arrangements were found to be "overly technical and legalised" (Law Commission, 2017. p37), lacked meaning for people who fall under the arrangements and also their families and "were not designed to deal with the increased numbers of people considered deprived of their liberty following Cheshire West" (Law Commission, 2017. p37). The UK Government in response to the Law Commission's report set out the MCAA which outlined plans for a set of Liberty Protection Safeguards (LPS). The LPS aimed to protect people from the age of 16 and above who lack capacity to give consent to their arrangements and need to be deprived of their liberty in order to receive their care or treatment (Spencer-Lane, 2023a) bringing 16 and 17-year-olds within a lawful system of deprivation of liberty (Webster, 2023). This represents a change from the current DoLS age criteria which is 18. Another part of the proposed plans within the LPS are to enable people to be deprived of their liberty in any setting, which will enable deprivation of liberty in supported living settings, people's own homes and while a person is being transferred between places. These plans aim to provide a more simplified system that operates in a range of settings (SCIE, 2017). A key aspect of the MCAA, the LPS include a system to ensure that people who do not object to their care arrangements would not need to undergo the six detailed assessments but instead go through a lighter, less bureaucratic assessment regime (Spencer-Lane, 2023). This planned change has significant implications for the decision making process and would lead to greater attention being placed on health and social care practitioners and wider family and friends to make a judgement of whether a person lacks capacity. Other changes noted in the LPS included introducing a duty to consult families and others who are involved in caring for a person, prior to a deprivation of liberty occurring (Spencer-Lane, 2023b). Within health and social care practice the LPS as part of the MCAA were suggested to be an improvement on the DoLS arrangements (Spencer-Lane, 2023b) providing a better balance of supporting individual human rights and avoiding the bureaucracy of DoLS (Law Commission, 2017). The MCAA and the LPS plans have been described as more comprehensive and connected to the MCA (Spencer-Lane, 2023) and have been noted as drawing attention to the core aspects of the MCA, which are about clear evidence-based mental capacity assessments and Best Interests decision making (Webster, 2023).

The MCAA was due to be implemented initially in 2019, but this did not occur as the government wanted to ensure successful implementation by setting out implementation and practice guidance plans (Spencer-Lane, 2023). There were further promises from the government of implementations, but these too failed to materialise despite a widespread consultation of the draft code of practice for the Liberty Protection Safeguards (LPS) in 2022. In April 2023, the Department of Health and Social Care released a statement confirming that there be a delay to the LPS beyond the life of the current parliament (Department of Health and Social Care, 2023). The cumulative effect of the MCAA not being implemented has led to uncertainty and disillusionment for those who use the MCA, but, more importantly, anger and frustration from people who may fall under these provisions and advocate for their rights (Alzheimer's Society, 2023).

The current position of the MCAA is uncertain and at the time of writing there is not a clear timeline for its implementation (Spencer-Lane, 2023). The result is that the non-implementation of the LPS via the MCAA has led to the existing framework of the DoLS continuing. The numbers of DoLS continue to rise (NHS Digital, 2023) and as noted earlier in this section, a significant proportion of people who are assessed under DoLS have dementia. Therefore, the delays in implementing change have weakened the rights and protections for people with dementia (Alzheimer's Society, 2023). Dementia Rights groups such as the Alzheimer's Society described this as a significant concern for people who do not have full protection under the current MCA's DoLS arrangements (Alzheimer's Society, 2023).

2.2.9. Summary of the MCA

In summary, the MCA outlines ways in which the rights of people to make decisions can be upheld, as well as outlining a framework for decision making when a person has been 'assessed' to be unable to make decisions. Discussion of the approaches to MCA decision making has drawn attention to functional and status approaches. It has been argued that the MCA made progress in offering greater rights for people who lack capacity including those with dementia, through clear principles, assessment processes and opportunities for making advanced decisions. However, from a broader rights perspective, the MCA continues to have gaps in securing the full rights of people (Brown, 2015), as noted in relation to confinement to nursing or residential care homes and Deprivation of Liberty. The Deprivation of Liberty Safeguards have been noted as a weak part of the MCA in that it does not uphold the full rights of people who are deprived of their liberty (Webster, 2023; Fanning, 2016). For social workers, the MCA, along with the Code of Practice, is often presented as a normative tool for practitioners to practically follow (Brown, 2015; Kong and Ruck-Keene, 2019). But through closer examination it is recognised that perspectives and theories shape the MCA and there are assumptions about forms of autonomy and the rights of people embedded within the MCA and as noted in relation to DoLS and substitute decision making, these can be argued as falling short of a rights-based approach (Bartlett, 2012). Finally, it has been shown that MCA practice is dynamic and changing and continues to be shaped by case law.

2.3. The Care Act 2014 (CA)

The CA created a single legislative framework for adult social care, which was implemented in April 2015 and represented several years of drafting and consultation via the Law Commission and Parliament (Feldon, 2017). As a single piece of legislation the CA replaced numerous Acts of Parliament linked to the care and support of older people or people with disability on the grounds that the legislative framework before April 2015 was outdated, inadequate and sometimes incomprehensible (Law Commission, 2011). Amongst the legislation that the CA replaced was the National Assistance Act 1948. The National Assistance Act of 1948 aimed to offer welfare assistance to people who were not making National Insurance contributions and who the Act defined as ‘without resource’ (Health Foundation, 2013) which included the welfare of people who were blind, deaf, or disabled by illness or injury (Health Foundation, 2013).

The importance of mentioning the National Assistance Act 1948 here is twofold. Firstly, as primary legislation it established local authority responsibility to provide care and support for adults with care and support needs which included older people and people with a disability, although the words used in the National Assistance Act are outdated and point towards an institutional model of care and support (Spencer-Lane, 2009). The second reason is that the National Assistance Act set up the divisions between the NHS, free at the point of use and social care, which is ‘means tested,’ that continue today (Bottery, 2023). The implementation of the CA brought in a new focus for social care, one not focused on deficit or institutionalisation, but one focused on wellbeing and personalisation (Feldon, 2017; Braye and Preston-Shoot, 2020).

The main provisions of the CA include the responsibilities of local authorities under Sections 1 to 7 which address well-being, preventing the need for care and support, the promotion of integration of care and support with health, provision of information and advice, promoting diversity and quality and cooperation in the provision of services (Evans and Harvey, 2022). The requirement for preventing the need for care and support, under Section 2 of the CA, was new for local authorities and represented a change in focus for social work (Feldon, 2017). Tew et al. (2019) in their research looking at the implementation of prevention requirements of the Care Act 2014, suggest that these have stimulated positive initiatives such as strengths-based practice approaches and provided an emphasis on building community capacity and activating family and community resources. However, financial pressures and the lack of sustained funding were cited by Tew et al. (2019) as challenges to social workers effectively using the new powers created under the Act.. For people with dementia and their families, the concept of prevention, as embedded in Section 2 of the CA, can be argued as opening the potential for new opportunities for support and assistance (Tew et al., 2019). For example, identifying and signposting positive ways to increase social, cognitive and physical activities which are seen as important measures to help in the prevention of dementia (Livingston et al., 2020).

Sections 9 to 13 of the CA outline the legal guidelines for assessment and eligibility and Sections 18 to 30 of the CA expand on the duties of local authorities to meet the care and support needs of individuals and their carers (Evans and Harvey, 2022). Within this part of the CA, Section 28 outlines Personal Budgets, which have been seen as a way of enabling people with dementia to design or co-produce their own care support plan (Evans and

Harvey, 2022; Scourfield, 2023). The use of Personal Budgets as a way of funding the provision of social care for people presented opportunities for enhancing the rights of people with dementia and their families, although in practice this has been found to be fraught with challenges such as a lack of information about how Personal Budgets work, a lack of community support services to assist people wishing to use them and concerns about financial exploitation (Manthorpe et al., 2013; Moore and Jones, 2011).

Other areas of the CA that are relevant for people who cannot make decisions due to lacking capacity include Sections 42 to 47, which outline the legal framework for safeguarding adults, giving duties to local authorities regarding adults who are at risk of abuse. As part of the CA's safeguarding approach six key principles are outlined and defined: Empowerment, Proportionality, Prevention, Protection, Partnership and Accountability set the approach to how safeguarding matters should be addressed. In addition to this, following a review safeguarding processes incorporated a personalised approach, known as Making Safeguarding Personal, which emphasises an outcome-based approach (Johnson and Boland, 2019). The outcome approach can be argued as rebalancing a focus of safeguarding away from the safeguarding organisation to the person(s) at the centre of the safeguarding enquiry (Spencer-Lane, 2020). The result of the new approach to safeguarding has led to an increase in safeguarding enquiries (Johnson and Boland, 2019) and safeguarding inquiries under the current system continue to increase (NHS, Digital, 2023c). The new safeguarding framework under the CA replaced the previous guidelines under the No Secrets: Guidance on Protecting Vulnerable Adults in Care (Department of Health, 2000), which was evaluated as inadequate by the Law Commission and led to a recommendation that the use of the term 'vulnerable adults' in the guidance was inappropriate due to its negative use and potentially stigmatising construction of those at risk of abuse (Johnson and Boland, 2019). Other criticisms of the No Secrets guidance were that as a policy for England and Wales, it was unevenly implemented across different regions, leading to failings in safeguarding (Spencer-Lane, 2020) those at risk. The new framework brought greater confidence that the rights of adults at risk are better protected than they have been in the past, which has relevance for people who lack capacity to make decisions for themselves and for those who have dementia, considering research evidence suggesting higher numbers of people with dementia experience abuse and neglect (Dixon et al., 2022). Safeguarding continues to be closely associated with mental capacity work and a number of studies have noted its importance. For example, Braye and Preston-Shoot (2017) in their analysis of the content of 27 safeguarding adult reviews commissioned and completed by London Safeguarding Adult Boards, highlight that mental capacity was noted as a theme in 21 out of the 27 reports.

In summary, the CA is a significant legal policy as it spans all adult social care groups, and it is highly relevant to the lives of people who fall under the MCA. As a statute which implemented the government's personalisation initiative, the CA was hailed as a major improvement in the arrangements of the care and support of adults, giving a more clearly defined approach to adult social care practice. However, the CA does not provide definitive actions that social workers should carry out (Spencer-Lane, 2020) and this was left to the Care and Support Statutory Guidance (Department of Health, 2016b), which was intended to be used as a practical guide for health and social care staff in terms of using the CA in practice. The Care and Support Statutory Guidance is a detailed practice manual for professionals to use on a day-to-day basis which Feldon (2023) notes should be followed unless there are cogent reasons to depart from it.

2.4. The Equality Act 2010 (EA)

The EA is a UK statute, outlining a legal framework for protecting the rights of people against direct and indirect discrimination. Section 4 of the EA identifies nine characteristics, known as protected characteristics which embed the rights of people with any of the characteristics to be protected under the law against discrimination. It cannot be assumed that all people who fall under the provisions of the MCA, i.e., people who lack capacity to make decisions, will have a protected characteristic, although people who have dementia are legally protected under the EA as meeting the criteria for disability (Alzheimer's Society, 2019). Despite this, there is evidence that not all people with dementia self-identify as having a disability (Thomas and Miligan, 2018; Shakespeare et al., 2019) and some see themselves as experiencing a medical condition (Alzheimer's Society, 2019). As outlined in more detail in Chapter Three, people with dementia including younger people with dementia experience discrimination in society including access to social care services, transport and housing (Milne, 2020; Keating, 2017; Alzheimer's Society, 2019).

Key issues linked to the EA include the public sector duty of equality under section 149 of the act. This duty requires public authorities or organisations carrying public functions to have due regard to:

> "eliminate unlawful discrimination, harassment, victimisation and any other unlawful conduct prohibited by the act, advance equality of opportunity between people who share and people who do not share a relevant protected characteristic and foster good relations between people who share and people who do not share a relevant protected". (s.149 EA 2010).

A weakness in the public sector equality duty has been highlighted as the requirements only indicate for public authorities to have 'due regard', a term that is not outlined in detail in the EA (Pyper, 2022). This has led the courts through case law to try and bring greater clarification. In the case of *Stuart Bracking & Ors v Secretary of State for Work and Pensions* [2013] EWCA Civ 1345, Lord Justice McCombe stated that due regard should include public bodies taking a:

> "conscious approach" and the duty must be exercised "in substance, with rigour and with an open mind" *Stuart Bracking & Ors v Secretary of State for Work and Pensions* [2013] EWCA Civ 1345, [60-61].

Despite these attempts to clarify the substance of the public sector duty through case law there remains a lack of consistency concerning what the public duty means in practice (Pyper, 2020). Furthermore, the EA has been noted as falling short of requiring organisations to take proactive action to stop discrimination (House of Lords, 2016). This was the findings from the House of Lords Select Committee on the Equality Act 2010 and Disability Report in 2016 concluded that there was a lack of proactive steps being taken to protect people with disability from discrimination, for example in the area of providing accessible transport for people to attend medical appointments (House of Lords, 2016). The finding led to a recommendation by the House of Lords Select Committee to strengthen the EA to require bodies to address discriminatory practices (House of Lords, 2016).

As well as a public sector duty towards equality the EA also outlines a duty on public bodies to make reasonable adjustments for people with a disability under section 20 of the act. Reasonable adjustments in employment have been noted as relevant for people with dementia, because increasingly people with dementia may still be actively working at the point of diagnosis (Alzheimer's Society, 2019). The All- Party Parliamentary Group on Dementia in their investigation of the links between dementia and disability found that many employers have been unaware of how to respond in line with the EA to people with a recent diagnosis of dementia (Alzheimer's Society, 2019). In summary, the EA codifies the prohibition of discrimination in which people with dementia are recognised as a protected group under the act. The EA outlines obligations for public authorities to positively pursue equality and make reasonable adjustments. Despite this, weaknesses have been exposed in the EA regarding the extent to which public bodies are compelled to promote equality, which has raised questions about the rights of people with dementia under the EA (Alzheimer's Society, 2019).

2.5. Human Rights Act 1998 (HRA)

Earlier in this chapter the HRA was discussed in relation to deprivation of liberty. The HRA is a statute outlining the rights and freedoms of everyone in the UK, enforceable in the UK courts (Brammer, 2020). As a core part of UK law, the HRA aligns with the European Convention on Human Rights and Fundamental Freedoms (ECHR) which is an international treaty signed by 47 states in the Council of Europe (Brammer, 2020; Sabbagh and Korgaonkar, 2022). Relevant Articles of the HRA in the day-to-day use of the MCA include Article 3, the right not to be tortured or treated in an inhuman or degrading way Article 5, the right to liberty and security and Article 8. Having already examined Article 5 of the HRA in relation to deprivation of liberty this section will focus on Article 8 of the HRA.

Article 8 of the HRA sets out that:

> "Everyone has the right to respect for his private and family life, his home and his correspondence". (Article 8(1) HRA 1998)

Article 8 of the HRA rights are considered important to prevent arbitrary interference in personal life (Hassiem and Yusef, 2019; Brammer, 2020) and personal autonomy to decide how to live their personal life. However, the right to private and family life is a qualified right and this can be breached in instances where it is found to be reasonable and proportionate to do so (Brammer, 2020). For people who lack capacity to make decisions, attention has been drawn to the importance of ensuring that their Article 8 rights to private and family life are not overlooked. Overlooking or minimising the Article 8 rights to private and family life can occur where emphasis is placed on Best Interests without considering the wider human rights implications of decisions made using s(4) of the MCA. For example, in the case of moving a person from their home to a hospital or residential care setting the emphasis can be solely on what is believed to be the Best Interests of the person, following the Best Interest checklists with little or no attention paid to the wider human rights implications of moving a person to a residential care setting (Hassiem and Yusef, 2019). While the decision to move or protect can found to be in the person's Best Interests under the MCA, it can fail to fully take account of the person's rights under Article 8 of the HRA. This has been brought to light in several cases relating to mental capacity that have been brought before the Court of Protection (Hassiem and Yusef, 2019) and was the finding in *the LB Hillingdon v Steven Neary* [2011] EWHC 1377 (COP) case, where Steven Neary, a young man with autism and learning disability was found to be unlawfully deprived of his liberty (Henderson, 2011). Judge Peter Jackson found that the local authority's poor communication around its intentions to keep Steven at a staffed support unit against the wishes of his father breached not only Steven Neary's Article 5 rights to liberty but also his Article 8 rights to family life. In this case, Best Interests decision making appeared to overlook the views of Steven and his father as was noted that there was no mention of the disadvantages of Steven remaining at the staffed unit for a prolonged period or the discussion of the strong bond he had with his father (Henderson, 2011). As a result, aspects of both Article 5 and Article 8 of the HRA were found to be breached in this case, highlighting the equal importance given to rights to liberty and private and family life. The Steven Neary case has relevance to mental capacity decision making as it drew attention to the need for MCA decision-making to go beyond the intention to protect (Hasseim and Yusef, 2019) which while it is important can lead to overlooking other rights as noted above. Since the Steven Neary case, the Court of Protection has emphasised that determining Best Interests should give greater attention to the wishes and views of the person who lacks capacity (Kong and Ruch-Keene, 2019).

Having explored the relationship between the MCA and the HRA it can be posited that like other areas of law, MCA law and policy is shaped by the HRA. Practitioners in using the MCA as a decision making framework need to be cognisant with the human rights implications of decisions (Brammer, 2020) which should lead practitioners to consider the principles of necessity and proportionality linked to Best Interest decision making (Ruck-Keene, 2020).

2.6. United Nations Convention on the Rights of Persons with Disabilities 2006 (CRPD)

Moving from domestic legal frameworks to international frameworks, this chapter now focuses on the CRPD. The CRPD is an international treaty authored by the United Nations in 2006. Across the world 164 countries are signatories to the policy. The UK is a signatory and ratified the CRPD policy in 2009 (UN, 2006). The CRPD has been described as a “tool for achieving domestic social change” (Crowther, 2016, p.1) with the aim to outline the human rights of those with disabilities (UN, 2006). This is achieved by encouraging countries to remove barriers faced by people with disability and reforming policies, practices and legal codes that discriminate against persons with disability (Crowther, 2016), as well as to address the financial and practice support needs of people with disability (Crowther, 2016). The CRPD came about because of the global recognition that disability was not sufficiently incorporated into the existing human rights framework (Crowther, 2016). The convention draws from a social model of disability perspective (Shakespeare et al., 2019), recognising disability as part of the human experience rather than being a deficit. Dementia as a condition affecting the social experiences of people has been argued to fall under the scope of disability. Shakespeare et al. (2019) for example, note various societal barriers faced by people with dementia are similar to those faced by people with other disabilities. For example, the prescribed disengagement following diagnosis, the social isolation encountered by people with dementia (Shakespeare et al. 2019), as well as the experience of stigma and discrimination both of which the CRPD seeks to address. In making the case for dementia to be fully recognised as a disability Shakespeare et al (2019) draw attention to the Dementia Alliance International's focus on Human Rights based approaches which encourage the participation of people with dementia, which they see as aligned to the wider disability motto of 'Nothing about us, without us'.

The eight principles of the CRPD point towards the core ideas of bringing about equality and respect for people with disability. Article 1 of the treaty recognises that people with disabilities will include a range of needs including physical, mental, intellectual or sensory impairments (UN, 2006) with the aim to promote:

> "full and effective participation in society on an equal basis with others" (UN, 2006. Article 1).

Alongside Article 1, Article 5(2) requires states to prohibit discrimination based on disability and provide legal protection against discrimination. The CRPD has 50 Articles related to the rights of persons with disabilities. This chapter does not seek to examine all 50 articles but will focus on two key articles that are relevant to mental capacity. The key articles covered here include Article 5, Articles 12 and 14 of the CRPD.

Article 12(1) of the CRPD addresses equal recognition before the law for persons with disabilities. Equal recognition before the law enshrines the right to enjoy legal capacity in Article 12(2) (Crowther, 2016). Legal capacity has been noted as differing from mental capacity in that legal capacity refers to the ability to hold and exercise rights and duties as a legal status (Martin et al., 2014), whereas mental capacity is about the ability to make decisions (Ruck-Keene et al., 2023a). It is important to note here that mental capacity and disability are not the same thing and the majority of people with disabilities will have the capacity to make decisions (Martin et al., 2014). The aim of the CRPD in outlining the right to legal capacity looked to promote meaningful participation in society for people with disabilities (Ruck-Keene et al., 2023a). This purpose led the CRPD committee, made up of a panel of experts, academics and people with disabilities (Bartlett, 2020; Ruck-Keene et al., 2023a), to criticise the MCA's inclusion of substitute decision making under Section 4 of the MCA which it saw as conflicting with the right to legal capacity (Donnelly, 2016; Crowther, 2016; Ruck-Keene et al., 2023a) for people with identified disabilities. The committee's argument is that substitute decision making under section 4 of the MCA occurs once an assessment of capacity has evidenced that a person cannot make a decision and a Best Interests decision is made by a decision maker (Ruck-Keene et al., 2023a; Bartlett, 2020) and this does not fit with the human rights-based model of disability of the CRPD (Martin et al., 2014). Based on opposition to substitute forms of decision the CRPD committee subsequently requested that the practice of Best Interests' decision making once a person has been found to lack capacity be ceased and replaced by supported decision making processes such as advocacy (Donnelly, 2016; Crowther, 2016). Specifically, the committee noted the need to replace the Best Interests paradigm with a 'will and preferences' approach as outlined in Article 12(4) of the CRPD (Martin et al., 2014). However, the UK government to date has not carried out the requirements of the CRPD (Bartlett, 2020) and the CRPD committee's recommendations did not receive universal support. Martin et al. (2014) concluded that while there is evidence of incompatibility between the CRPD and the MCA s (4), this should be remedied by greater safeguards to promote the will and preferences of the person in MCA Best Interest decision making. Bartlett (2020) acknowledged that if the CRPD committee recommendations to replace substitute decision making with supported decision making were fully implemented it would improve the rights of people with disability who lack capacity, but also noted that there are significant barriers to this as the current legal system would need a major cultural shift (Bartlett, 2020). Finally, it can be highlighted that since the CRPD committee raised their objections to substitute decision making within section 4 of the MCA, there has been a shift in decision making towards promoting the wishes and feelings of the person as a primary consideration (Brown, 2023; Ruch-Keene et al., 2023), as well as a stronger emphasis on finding appropriate ways to support a person to make a decision (Ruch-Keene et al., 2023).

The other area of the CRPD of relevance in this chapter is Article 14. Article 14 enshrines that the existence of a disability shall in no case justify a deprivation of liberty (Article 14(1)(b), 2006). The aim of Article 14 (1) (b) is to ensure that people with disabilities enjoy the same freedoms as all people (Dixon et al., 2022). This holds huge significance for people with dementia who as noted earlier, the CRPD includes in reference to its definition of groups that fall under its provisions. Article 14 (1) (b) differs from and goes beyond the provisions of the European Convention of Human Rights (ECHR) Article 5 (1) (e) which allows for the lawful deprivation of people of 'unsound mind' (Harding, 2021) which includes people with dementia (Harding, 2021). In 2017, The CRPD committee sought to clarify Article 14 (1) (b) by issuing guidance indicating that the exclusion of deprivation of liberty includes actual or perceived impairment even if additional factors or criteria are also used to justify the deprivation of liberty like a perceived danger to themselves or others (Harding, 2021). The guidance given by the CRPD committee was opposed by the ECtHR which acknowledged that impairment does not justify a deprivation of liberty but contended that there are occasions when deprivation of liberty can be justified as necessary and proportionate in the interests of the person or others from harm (Harding, 2021; Ruck-Keene, 2023). The incompatibility between CRPD Article 14 (1) (b) and the ECHR Article 5 (1) (e) has resulted in attempts to bring the MCA DoLS closer to the CRPD position to avoid arbitrary deprivation of liberty based primarily on the presence of dementia but there's been little progress to date (Harding, 2021). The incompatibility poses significant challenges to the current arrangements for DoLS under the MCA (Harding, 2021) which involves people being deprived of their liberty, primarily in nursing and residential care homes, on the grounds that they lack capacity to consent to the arrangements (Flynn, 2018). In summary, the CRPD can be seen as offering alternative perspectives on mental capacity decision making to what has been interpreted in the MCA.

2.7. Conclusion

This chapter has explored the legal and policy frameworks linked to MCA decision making. It has drawn attention to the key law that connects with the MCA and discussed some key issues that emerge when the MCA is explored more closely. In concluding this section on legal frameworks for MCA decision making it is helpful to summarise the key issues discussed. The legal frameworks linked to MCA decision making include the MCA, the CA, the EA, the HRA and the CRPD. The discussions about the MCA and related legislation has noted that the MCA as the main legislative framework for capacity assessment and decision making has been lauded in literature by some as bolstering the rights of people who lack capacity (Manthorpe et al., 200he8; Banner and Szmukler, 2013). This has been seen in how the MCA emphasises the centrality of enabling the person to make decisions where possible (Manthorpe et al., 2008) and promotes the autonomy of the person (Lennard, 2016). However, with closer examination and analysis, it has been found that the MCA embeds legal and to some extent medical ideas about how to address the needs and decisions related to people who fall under its provisions (Case, 2016).

The legal frameworks linked to the MCA have helped to highlight that there is a mis match of values and perspectives, found in the MCA, which both empowers and creates barriers for people who lack capacity (Boyle, 2011). For example, the MCA offers a supportive framework for decision-making in promoting advocacy but under the DoLS, rights are undermined in two ways. Firstly, those who do not meet the DoLS criteria of being in a care home or hospital do not have the same protections as those who do meet the criteria and secondly, due to the significant backlog of DoLS applications, which means there can be delays in legalising a deprivation of liberty. The CA stands out as a legal framework that is particularly supportive of person-centred and holistic well-being approaches which have been found to be of benefit to a range of groups with specific needs (Bartlett, 2022). By drawing on the CRPD as an international policy premised on a social model of disability, a wide range of issues linked to disability, gaps and inconsistencies are identified in the MCA, particularly regarding how the rights of people who cannot make a decision are protected, suggesting there are deficits in the MCA in supporting the rights of people (Harding, 2021).

The discussion in this chapter informs that in practice mental capacity decision-making is shaped by a range of factors including legal perspectives, medical perspectives and policy developments. Wider rights-based legislation like the HRA and the CRPD have played a pivotal role in shaping our understanding of how MCA decision-making can be both supportive and limiting. Having explored the legal and policy areas for the MCA the next chapter looks to explore dementia and specifically consider key approaches for understanding and working with dementia.

Chapter 3: Exploring Dementia

3.0. Introduction

This chapter provides a critical examination of dementia including YOD. The chapter starts by exploring key themes linked to dementia as well as different approaches to dementia. A summary of key areas of focus for social workers in their practice with people with dementia is explored. The second part of the chapter examines the policy context of dementia. Within this part of the chapter there’s a discussion of key policies such as the National Dementia Strategy 2009 and the Prime Ministers Dementia Challenge on Dementia 2020.

3.1. Prevalence of dementia

Globally more than 55 million people currently live with dementia (WHO, 2023a). Across the UK, current estimations indicate that there are 944, 000 people identified as having dementia (Alzheimer’s Research UK, 2023b). Future predictions suggest the number will reach more than a million by 2030 and that future cases of dementia are likely to reach one in three for those born in 2015 (Alzheimer’s Research UK, 2023b). Public attention regarding dementia has grown in many societies as the number of people who have a diagnosis of dementia has grown (Burns, 2016). In terms of YOD, the global prevalence is 119 per 100,000 persons (Hendricks et al., 2021). In the United Kingdom, research by Carter et al. (2022) revealed that 7.5% of people with dementia had symptoms before age 65, thus meeting the criteria to be included in a categorisation for YOD. This has led to a 2022 estimate of 70,800 people living with YOD in the UK (Ford, 2022; Carter et al., 2022; Dementia UK, 2023a). This is the highest recorded number of people with YOD in the history of statistics being collected. It has been possible to provide more accurate figures on the number of people with YOD because of the Department of Health and Social Care requirements for General Practitioner practices to electronically report data on dementia to NHS Digital. The increase in the prevalence of YOD may be down to more systematic and standardised ways of collecting data by NHS Digital and better General Practitioners’ data collection systems (Carter et al., 2022).

3.1.1. Common sub-types of dementia

Dementia has been described as a syndrome due to its wide range of causes and symptoms (Penn and Rosser, 2022). There are believed to be many different sub-types of dementia (Alzheimer’s Society, 2023) and some estimations note more than 100 different types (Dementia UK, 2023b). Some of the common subtypes of dementia are noted below.

3.1.2. Alzheimer's disease

Alzheimer’s disease (AD) is a brain disorder in which there is a decline in memory and cognitive functioning which is believed to be primarily caused by the build-up in the brain of two proteins, called amyloid and tau. Alzheimer’s Research UK (2023a) notes that AD is the most common form of dementia in all age groups, affecting six out of every 10 people who have a diagnosis of dementia. In relation to YOD, AD accounts for around one in three cases of YOD (Alzheimer’s Research UK, 2023c). AD in people below the age of 65 years is often found to be of an atypical type linked to visual and verbal difficulties or a familial type linked to genetic mutations which run in family genealogies. (Alzheimer’s Society, 2023). Penn and Rosser (2022) note that younger people with AD are less likely to have co-morbid problems such as heart disease and kidney failure, which would require additional treatment.

3.1.3. Vascular dementia

As a subtype of dementia vascular dementia refers to the damage that occurs to the brain when there is an interruption or reduction through the narrowing of blood vessels carrying oxygen to the brain (Penn and Rosser, 2022). Vascular dementia can be caused by a stroke or multi-infarct (Alzheimer’s UK, 2023a). Vascular dementia is the second most common form of dementia after Alzheimer’s disease and in relation to people below age 65 is linked to exposure to risk factors.

3.1.4. Dementia with Lewy bodies (DLB)

Dementia with Lewy bodies is characterised by the presence of cortical Lewy bodies, which are found in the brain. Dementia with Lewy bodies was first discovered in 1961, by a

German physician (Alzheimer’s Research UK, 2023a) who gave his name to the condition. Dementia with Lewy Bodies may also include features of Parkinson’s disease such as stiffness and tremors and the illness shares similar characteristics to Parkinson’s. Dementia with Lewy bodies is more commonly diagnosed in later life, although in people below age 65 years, it is more frequently linked to genetic causes (Penn and Rosser, 2022).

3.1.5. Mixed dementia

Refers to the presence of more than one type of dementia. Mixed dementia is quite common and includes combinations such as AD and vascular dementia (Dementia UK, 2023b).

3.1.6. Learning disabilities, Downs Syndrome and dementia

People who have learning disabilities have an increased likelihood of developing dementia (Dementia UK, 2023b). The likelihood of dementia is particularly pronounced for people who have Downs Syndrome, where current evidence suggests up to two-thirds of people who have a diagnosis of Downs Syndrome will develop a form of dementia before the age of 60 (Dementia Research UK, 2023). Despite this, there is a small amount of literature linked to dementia in people with learning disabilities including Downs Syndrome and even less literature exploring YOD (Dementia Research UK, 2023).

3.1.7. Parkinson’s disease dementia

Parkinson’s disease refers to a condition where a loss of nerve cells in the brain affects movement (Dementia UK, 2023b). Parkinson's is often characterised by shaking or tremors, involuntary movement and stiffness in muscles and can be associated with depression. Some people with Parkinson’s develop memory problems and difficulties making decisions which lead to a form similar to Lewy body dementia.

3.1.8. Frontotemporal dementia (FTD)

FTD is used to refer to a spectrum of non-Alzheimer's dementias. It is linked to damage to the lobes in the front and side of the brain (Dementia, UK, 2023b). What the collection of FTDs have in common is evidence of a disturbance in interpersonal behaviour, language communication and language comprehension linked to deterioration of the frontal lobe or the temporal lobe (Dementia UK, 2023b; Penn and Rosser, 2022). FTD is most diagnosed in people aged 45 – 65 years, indicating that it is a common type of YOD.

3.1.9. Mild cognitive impairment (MCI)

Mild cognitive impairment is a term used to refer to the experience of memory and thinking problems (Alzheimer's Research UK, 2023a). MCI is not a type of dementia, although it can indicate the very early stages of dementia and has been recognised by neurologists as part of the early symptoms of YOD (Rosser et al.,2010).

3.1.10. Huntington's disease

Huntington's disease is a rare genetic condition which affects movement, learning and cognition (Dementia UK, 2023b). Huntington's disease is primarily inherited (Alzheimer's Society, 2023) and progressive memory decline is believed to be the cause of dementia found in some people with the condition. Huntington's disease has been included in this list of dementias because the onset of the condition tends to be between the ages of 30 and 50 years (Alzheimer's Society, 2023).

3.1.11. Other types of dementia

Alcohol-related dementia

Dementia in people below the age of 65 is evident with non-degenerative illnesses that severely affect cognitive functioning. Included within this categorisation is alcohol-related dementia or dementia-related to excessive alcohol use (Kvello-Alme, 2021). In relation to alcohol dementia, Wernicke-Korsakoff's syndrome is a common diagnosis which includes severe cognitive decline that can be reversed with the withdrawal of excessive alcohol use.

Alcohol-related dementia makes up around 10% of the population of people with YOD (Dementia UK, 2023b).

3.1.12. Rare dementias

Posterior Cortical Atrophy (PCA)

This type of dementia relates to damage to the area of the brain that helps with making sense of what the eye sees. This leads to difficulties with vision and the perception of what is seen (Alzheimer's Research UK, 2023a). According to the Alzheimer's Society PCA tends to be identified in people aged in their mid-fifties and early sixties.

3.1.13. Creutzfeldt-Jakob disease.

Creutzfeldt- Jakob's disease (CJD) is a condition named after two German neuropathologists, Alfons Maria Jakob, and Hans Gerhardt Creutzfeldt (Dementia UK, 2023b). The condition is characterised by a deterioration in memory and intellect, a change in personality and a deterioration of mobility. The condition is noted to be caused by infectious proteins called prions which multiply in the brain, causing severe damage (NHS, 2023a). The Alzheimer's Society (2023) notes that this sub-type of dementia progresses more rapidly than any other dementia type. Although it is a rare form of dementia, CJD in its familial (inherited) and variant forms is more likely to be found in people below the age of 65 (Penn and Rosser, 2023).

3.1.14. Limbic-predominant age-related TDP-43 encephalopathy (LATE)

Limbic-predominant age-related TDP-43 encephalopathy (LATE) is a recently characterised type of dementia (Dementia Research UK, 2023). Like other forms of brain disorders, such as Alzheimer's disease, LATE causes problems with memory and thinking but has different underlying causes.

The types of dementia outlined above confirm that there is a broad range of conditions and illnesses which grouped all come under the umbrella of dementia. The range of conditions noted here suggests that there is a lot of variation in dementia presentations, which indicates that there needs to be a range of health and social care responses to dementia, depending on the form it takes. Many of the types of dementia noted above can be experienced by people before the age of 65, confirming that dementia is not a condition only linked to later life (Rabanal et al., 2018). The outline of the different types of dementia is relevant for this study as it acknowledges that a range of dementias can occur before later life when dementia is believed to be much more common. Furthermore, this summary of the types confirms all dementia is not the same and does not affect those with the lived experience of dementia in similar ways (Penn and Rosser, 2022; Hayo et al., 2018). Some types may require greater or lesser levels of health and social care input and this study seeks to explore what might be the issues for social work practice collaborating with people who are identified with dementia before the age of 65.

3.2. A brief history of dementia

The term dementia is believed to have its root in the Latin word *demens,* which means *without mind* (Ahmed et al. 2021; Ash 2014). The early writing attributed to dementia was found in the works of Greco-Roman philosophers Pythagoras, Hippocrates, Plato, Aristotle, Cicero, and Galen whose writings included reference to cognitive decline which they all linked to being an inevitable consequence of ageing (Berchtold and Cotman, 1998). These Greco-Roman texts offered little help to the person or their carers as at the time the belief was that dementia was so closely linked to the ageing process that it was not seen as a matter that could be addressed (Berchtold and Cotman, 1998). Between these early periods and the so-called ‘discovery’ of dementia by Alois Alzheimer in 1906, dementia was understood and responded to in a variety of ways. For example, in the medieval period, people with dementia were deemed as being ‘childlike and out of control’ (Ahmad, et al., 2014). Throughout this period research or scholarly enquiry into any brain or developmental condition was dramatically limited due to the dominance of religious perspectives (Berchtold and Cotman, 1998). The religious perspectives propagated by the Church classified dementia and many other related mental health conditions as punishment from

God linked to sinful behaviour (Ahmad, et al., 2014). Throughout the medieval period and right up until the 19th century, there were few variations in perspectives linked to dementia, in part because of the dominance of religious perspectives that rejected the study of illness outside of their worldview and also due to the persistent belief that is that dementia was a natural part of ageing (Berchtold and Cotman, 1998). Practices in the 1800s followed an institutional approach to dementia that saw people with dementia incarcerated in prisons or ‘lunatic asylums’ often under harsh treatment/care conditions (Dementia UK, 2023b). Many people with dementia were considered to be ‘insane’ (Andrews, 2017) linked to a loss of mental faculties, encapsulating dementia within the broader medical field of psychiatry. The relationship between dementia and mental health persists today and many services for people with dementia fall under the umbrella of psychiatric services, linking back to traditional medical ideas that both dementia and mental ill health are changes in brain functioning (Regan, 2016).

In 1906, a German psychiatrist, Alois Alzheimer conducted a post-mortem examination on a patient where he found what came to be known as amyloid plaques and tangles which are now known to be the key properties of Alzheimer’s disease (Ahmed et al. 2021). This was seen as a breakthrough in understanding dementia (Ahmed et al. 2021) and the condition Alzheimer’s disease was named after Alois. What was most interesting from Alzheimer’s work was that the examination was carried out on a patient, August Deter, who was 51 years old (Berchtold and Cotman, 1998). Alzheimer’s findings led him to refer to what he termed pre-senile dementia or what today is referred to as YOD (Ash, 2014).

The term pre-senile dementia was historically commonly used within medical and legal fields. Pre-senile dementia was contrasted with the term senile dementia which was categorised as dementia in later life and is referred to in this research study as LOD. Both pre-senile dementia, senile dementia are pejorative terms which negatively describe the experience of dementia and contribute to the stigma for people who have dementia. Both terms are no longer used to refer to dementia, although the terms are evident in the literature up until around 2010 (Ash, 2014; Rosser et al., 2010).

3.3. YOD and age

Age is a principal factor in the YOD discourse. The terminology used to describe dementia occurring in people before reaching older age has historically been unclear with ambiguity around the common terms used to refer to this grouping (Koopman and Rosness, 2014; van de Veen et al., 2022). The term YOD and other similar terms such as early onset dementia, younger onset dementia, earlier life dementia or working age dementia*,* imply a difference based on the age or life stage. The nomenclature of dementia at a younger age requires scrutiny around what exactly is being referred to and the questions raised by the age-based categorisation referred to as YOD are important. Historically, the categorisations of YOD and LOD were drawn from health care systems which separated general psychiatric care and old age psychiatric care (Tolhurst et al., 2014). These categorisations persist today in healthcare practice and have incorporated YOD which sits within the older persons' psychiatry (Tolhurst et al., 2014). The inclusion of dementia care and support within old age psychiatry has led to questions of whether people with YOD are best served under this system (Carter et al., 2022). Focusing on terminology, the word ‘young’ in YOD may itself be misleading when for example, comparing a 64-year-old person with dementia to a person aged 25 with dementia (Koopmans and Rosness, 2014). Secondly, the classification of YOD is linked to those who have a diagnosis of dementia before age 65. Carter et al. (2022) note that the details on the number of people with YOD were drawn from the UK NHS Recorded Dementia Diagnosis data, but this data fails to acknowledge those who have received a diagnosis before age 65 but have since transitioned beyond age 65 years with dementia. An accurate picture of those who have dementia which arose before age 65, is not easy to capture. Some studies have identified that on average it takes 4.7 years for a diagnosis to be achieved for YOD (van de Veen et al., 2022; O’Malley et al., 2019), which casts further doubt on how YOD has been understood. A further deficit in the conceptualisation of YOD is whether current estimations of people with YOD account for dementia in children. Studies by O’Malley et al., (2019) and van de Veen et al., (2022) have explored the nomenclature of YOD, recognising that the term YOD links primarily to biological aetiologies and this might partly explain why the definition of YOD retains so much ambiguity.

Looking further at age as part of the concept of YOD, Ash (2014) notes that the cut-off age for YOD is 60 years, although many UK studies use the cut-off age of 65 years. Setting the distinction between YOD and LOD at the age of 60 or 65 has been referred to as an arbitrary calculation (Ash, 2014; Tolhurst, 2016). Rossor et al. (2010), in their review of YOD, remind us that the definition of dementia, linked to symptoms and onset before age 65 years is not biologically significant, but more linked to modern societal or sociological definitions of what is believed to be working age and retirement. Working age has historically and politically been determined to be up to 65 years linked to the male retirement age and state pension age until the Pensions Acts of 2011 and 2014 amended the state pension age (Thane, 2011). Since this time the UK and many other countries have increased the retirement age beyond 65 years (Thane, 2011). Furthermore, a notable concern with the terms mentioned to refer to YOD is that the age range that they refer to is very broad (Koopmans and Rosness, 2014) and there may be more notable differences among people over 65 years who have dementia than between people under 65 years with dementia (Koopmans and Rosness, 2014). Therefore, in trying to define YOD, it is salient to recognise that understanding dementia is conceptually linked to ideas about ageing and disability (Sandburg and Ward, 2023). Following on from this point it can be postulated that YOD is linked to dominant medical ideas about the life course and what has been biomedically defined as later life or old age.

Other factors relating to age include evidence of the prevalence of dementia increasing as people grow older (Carter et al., 2022; Alzheimer's Society, 2023) which has led to conclusions that age is the biggest risk factor for the likelihood of dementia developing (Alzheimer's UK, 2023a). Within the categorisations of YOD and LOD, there are socio-cultural beliefs about processes of ageing which also have a political influence. On a cultural level, the idea of dementia relates to societal fears of ageing (Sandburg and Ward, 2023), which are perpetuated in cultural institutions such as the media and literature. What is remarkable is how beliefs about ageing align across many societies, and the way older age is framed as decline (de Vugt and Carter, 2022). These ageist assumptions link closely to ideas that like age, dementia including YOD, is socially constructed, as it has a fixed social meaning shaped by culture (Johfre and Saperstein, 2023) and formed from ideas that become embedded in thinking and practice over time (Tolhurst et al., 2014). How dementia is perceived and responded to is shaped by the social and cultural context (Sandburg and Ward, 2023). A helpful example is the historical belief that dementia was linked to divine judgment. In today's terms, socio-cultural representations of dementia influence social workers who, engage with dementia, provide services and support for people with dementia (Parker, 2021). Furthermore, the experiences of people with dementia, their families and carers are shaped by media and policy decisions on what services and support (Parker, 2021). The social construction of YOD becomes even more evident in recognising that the chronological age at 65 years has been categorised as LOD, rather than attempting to pinpoint the age of onset as an indicator for whether the person has YOD or not (van de Veen et al., 2023).

Having noted that YOD is a socially constructed term based on outdated ideas linked to retirement, rather than biologically significant factors, it should be emphasised that YOD shares many of the same characteristics of LOD, such as the decline in a person's cognitive functioning which may include memory loss, poor judgement and a loss of language and motor skills (de Vugt and Carter, 2022; Ash, 2014). There are, however, differences which have been noted. These differences include younger people with dementia being more likely to have rarer types of dementia (Burns et al., 2017), a tendency for a faster progression of the illness and more behavioural challenges (de Vugt and Carter, 2022). The Alzheimer's Society (2023) states that younger people with dementia are less likely to have problems with movement. In terms of overall health those who experience dementia earlier in their lives often face multiple health complications (Young Dementia UK, 2022c) across their life course. Rabanal et al. (2018) note evidence that people who experience YOD are more likely to have a longer period leading up to diagnosis and delays in connecting their presenting problems to dementia. Linked to this point studies have noted that people who have YOD tend to wait longer for a diagnosis (Carter et al, 2018; Burns et al. 2017) and once diagnosed are subject to unclear pathways to accessing care (Rodda and Carter, 2016; de Vugt & Carter, 2022) and have higher care costs (Van de Veen et al., 2022). These factors have been linked to the stigma associated with the experience of dementia in people below the age of 65 (Carter et al., 2022). In terms of support and services younger people with dementia may experience greater difficulties finding suitable community and residential services due to mainstream dementia care services being aimed primarily at older adults (Rabanal et al., 2018; Ramluggun and Ogo, 2014).

3.4. Dementia and disability

Drawing on the ideas of disability studies, dementia can be seen as being subject to social barriers linked to institutional and collective practices as well as individual attitudes and activities that lead to marginalisation (Thomas and Milligan, 2015). Within the definitions of the UK's Equality Act 2010 (EA) people who have dementia are legally seen as having a disability, as they have a physical or mental impairment and this impairment in most cases has substantial and long-term negative effects on the ability to carry out day to day activities (EA 2010). At an international level, the Convention of Rights of Persons with Disability Committee (CRPD committee), which monitors the implementation of the United Nations Convention on the Rights of Persons with Disability (CRPD) consider dementia to be protected and included under the 33 articles of the CRPD, highlighting that dementia is a major cause of disability and dependency (Crowther, 2016). The legal recognition of dementia as a disability provides a foundation for supporting the rights of people with dementia. Evidence from the All-Party Parliamentary Group on Dementia indicates people with dementia face significant disadvantages in the areas of employment, social protection, social care, transport, housing and community life (Alzheimer's Society, 2019). However, not all people with dementia wish to be identified as having a disability (Shakespeare et al., 2019), with some people with dementia preferring to avoid another label that can add stigma (Shakespeare et al., 2019; Alzheimer's Society, 2019). There are positives in recognising the link between dementia and disability. Acknowledging dementia as a disability highlights the wider societal systems that work to subdue people with dementia. For example, the economic system that highlights the value of people linked to their ability to engage in employment means that people who have dementia become excluded or marginalised as they often have no option to engage in employment (Thomas and Miligan, 2015; Gilliard et al., 2005). Critical disability studies emphasise the social construction of disability the relationship between impairment, a person's response to impairment, and the social environment (Goodley, 2013) has benefits in drawing attention to the wider factors that affect the lives of people with dementia. Disability studies have also helped to reveal the role of cultural institutions in maintaining the marginalisation of people with disability. With dementia, this can be seen where greater value is placed on youth and beauty in media, literature and art and brings to the fore the need for changes not only at an individual level but also at a cultural and societal level (Scourfield, 2023). The discourse of disability then helps to recognise that people with dementia can experience dual discrimination in the form of age and disability negatively affecting their lives (Scourfield, 2023). Dual discrimination leads to greater levels of marginalisation, stigmatisation and isolation (Scourfield, 2023). For younger people with dementia, there is evidence of multiple and complex forms of marginalisation linked to age, such as poor integration of younger people with dementia into mainstream dementia services (Carter et al., 2018; Gilliard et al., 2005). This represents another less-known aspect of the dual discrimination that people with dementia can experience. More recent or second-wave disability studies have been useful in drawing a focus on psychosocial perspectives on disability (Shakespeare et al., 2019). These approaches can be considered useful for understanding dementia as they promote the experiences of people with dementia, recognising emotions and the person's own experience as a core aspect of the dementia discourse.

3.5. YOD and gender

For this study, ‘sex’ is used to refer to biologically determined characteristics of men and women and is differentiated from ‘gender’ which refers to characteristics of what it means to be a woman or a man that is socially constructed including norms and values (WHO, 2023c). The incidence of AD in women is two times higher than that of men (Sourial et al., 2020; Beam et al., 2018). The reasons for the differences are not fully known, although there are suggestions that the reasons relate to evidence that women tend to live longer than men (Beam et al., 2018). Risk factors are also relevant to understanding the sex differences in dementia. Women with dementia tend to have lower educational attainment (Sourial, et al., 2020; Rocca et al., 2014). Women who have caring responsibilities are twice as likely to be diagnosed with depression which is also a risk factor for dementia (Milne, 2020b; Sourial et al., 2020). In terms of YOD, studies have found that there is no conclusive evidence that the gender differences evident in AD appear in people with YOD (Peeters et al., 2022), although a review of sex differences in YOD found that there are greater risks of YOD in women than men. This suggests that there are gendered aspects to YOD, and the wider social inequalities faced by women in society contribute to the experience of YOD. Milne (2020b) highlights that women are invisible in the wider dementia discourse, and it can be postulated that this is likely to be the case with women who have dementia at a younger age.

3.6. Summary of the exploration of the terminology of dementia

Having explored YOD as part of the wider discourse of dementia it can be suggested that YOD is a socially constructed term which has been shaped by cultural perceptions of age and there are questions about the usefulness of the term YOD as it can contribute to a binary using age to demarcate a condition which is experienced differently across the life course. This research study has selected to specifically focus on YOD due to its relative obscurity within the dementia discourse, despite the significant period of life span that it relates to (Koopmans and Rosness, 2014). Thus, exploring YOD may provide useful insights into social worker decision making connected to the experience of dementia. Within this study, YOD is a term used to refer to adults right up until age 65. Within this wide age range, it is accepted that there may be a range of presentations and concerns, including people who have genetic and/or lifestyle factors that have shaped their experience of YOD. The next section of this chapter considers different approaches to understanding dementia, looking at dementia across the lifespan concerning YOD in specific places.

3.7. Approaches and perspectives to understanding dementia

So far, the explorations into the dementia discourse led to the recognition that dementia is shaped by historical, social, cultural and medical ideas (Sandberg and Ward, 2023). Therefore, a useful way of understanding dementia is to consider the different approaches and their contribution to the dementia discourse. In this next section medical, psychological, and social approaches to dementia will be critically evaluated in terms of their contribution to understanding YOD dementia.

3.7.1. Bio-medical paradigm and approaches to dementia and YOD

The biomedical paradigm also referred to as the biomedical approach constructs dementia as a neuro-degenerative disease of the brain characterised by irreversible deterioration of cognitive function and associated behavioural changes. Biomedical approaches dominated the understanding of dementia right up until the 1990s and continue to have a considerable influence on the dementia discourse (Milne, 2020a; Sandburg and Ward, 2023; Tolhurst, 2014). Biomedical ideas are impairment-focused and concentrate on efforts to alleviate dementia and treat the symptoms of the illness and have promoted the cause-effect relationship (Harding and Palfrey, 1997). The biomedical approach through its emphasis on dementia as an impairment contributes to the personal tragedy discourse of dementia, which sees dementia in a negative light and contributes to the stigmatisation of people with dementia (Reed and Carson, 2017). Significant international attention is given to biomedical approaches to dementia, with large amounts of funding for research, and medical-based interventions to alleviate symptoms of dementia (Keating, 2017; Harding and Palfrey, 1997). A fundamental weakness of the biomedical approach to dementia is that it focuses on individual impairment in the person, which often means all challenges and problems experienced are linked to the impairment (Milne, 2020a). This process referred to as medicalisation empowers medical experts who define dementia and make decisions about treatment and care (Harding and Palfrey, 1997; Milne, 2020). Within the biomedical paradigm dementia is identified as a group of symptoms, such as mood changes and memory loss (Dementia Research UK, 2023), which are observed to be present when brain impairment occurs. YOD does not attract a separate medical definition, as it is defined as dementia manifesting itself within a different life stage (Koopmans and Rosness, 2014). Under the biomedical approach, YOD is classified using medical criteria within the Diagnostic and Statistical Manual of Mental Disorders (DSM) and also the International Classification of Diseases (ICD), the latter being used within the UK. The ICD version 11 classifies one specific type of dementia as early onset, namely AD with early onset under code 6D80.0.

The description given to early onset Alzheimer’s Disease is:

> “Dementia due to Alzheimer's disease in which symptoms emerge before the age of 65 years. It is relatively rare, representing less than 5% of all cases, and may be genetically determined (autosomal dominant Alzheimer's disease).

> Clinical presentation may be similar to cases with later onset, but progression of cognitive deficits may be more rapid." (WHO, 2019/2021: Accessed 17.07.23).

3.7.2. Critique of biomedical approaches

The approach to classifying dementia, as overseen by The World Health Organization (WHO) highlights the weakness of a biomedical approach. In 2016, ahead of the publication of the ICD 11th version, the WHO proposed changes to the categorisation of dementia (WHO, 2023d). The changes involved moving the categorisation of dementia from its current Chapter Six descriptions under *Mental and behavioural disorders* to the Chapter Eight descriptions of *Diseases of the nervous systems* (Gaebel et al., 2018). These proposed changes to the ICD under the planned 11th version created controversy within the international medical community. Medical communities highlighted a range of arguments for retaining the existing categorisations of dementia including, for economic reasons, concerns about a need for a biopsychological approach to the treatment and care of dementia, the major role of psychiatry in dementia treatment and care and concerns around behavioural symptoms that do not fit with neurology (Gaebel et al., 2018; Sathyanarayana et al., 2017). As a result of these arguments, the categorisation of dementia was retained under chapter eight (Sathyanarayana et al., 2017). The failed attempts to change the categorisation of dementia highlight two points. The first point is that the medical classification of dementia includes subjective elements, rather than purely scientific elements, which some have argued it to be (Gaebel et al., 2018). The second point is that medical categorisations of dementia are shaped by a wide range of factors including economic issues, the social circumstances of people with dementia and the perspectives of professionals and contextual factors which were part of the arguments put forward by those who opposed the change. A further deficit in biomedical approaches is related to the voice of the person with dementia which is argued to be secondary to the perspective of the expert or medical clinician.

Biomedical approaches have drawn on pharmacology to support treatment for dementia and in particular address behavioural aspects that are associated with dementia (Scourfield, 2023). In particular the use of antipsychotic medication to address behavioural and psychological symptoms has been noted as an area of deep concern and criticism, particularly as anti-psychotics were not designed to address dementia but to treat psychosis (NICE, 2018a) and are known to include unpleasant side effects. Overall, biomedical approaches still dominate the dementia discourse (Milne, 2020a) but have been exposed as limited in terms of explaining dementia as they lack reference to the experience of dementia (Tolhurst, 2016).

3.7.3. Psychosocial approaches to dementia

Psychosocial approaches to dementia draw attention to the psychological, emotional and subjective responses to the experience of dementia as well as acknowledging the wider context in which a person experiences dementia (Pipon-Young et al., 2012). Thomas Kitwood's work in the 1990s highlighted the need to move away from medical and psychological approaches to dementia which he believed would lead to treating people with dementia as victims (Pipon-Young et al., 2012). His work on dementia has been noted as pivotal to understanding a psycho-social approach to dementia (Thomas and Miligan, 2015), helping to reveal how psycho-social approaches can promote dignity and self-esteem (Williams et al., 2014). Kitwood (1997) notes the importance of what became termed as 'personhood' in his work on dementia, which is a complex term relating to the unique characteristics and attributes of a person (Dewing, 2008; SCIE, 2013). Kitwood recognised how people with dementia are viewed and treated can indicate a complete loss of identity, or what is referred to as a body with physical care needs (Harding and Palfrey, 1997). Personhood as outlined by Kitwood includes the attributes that contribute to a person's status which include, recognition, trust and respect (SCIE, 2013). Together these attributes support a sense of wellbeing. Importantly for Kitwood, personhood is a status conferred on a person with dementia by another person in the context of a social relationship (Kitwood, 1997). By proposing personhood as central to collaborating with people who have dementia, Kitwood challenged the Cartesian dualistic views, suggesting mind and body operate separately (Harding and Palfrey, 1997). Loss of personhood for Kitwood did not amount to the reduction in cognitive abilities, which medical approaches purport, but Kitwood noted that this loss was a broader decline and eventual loss of identity or status through interactional and relational changes (Kitwood, 1997). A focus on relational ideas is central to personhood ideas and focuses attention on how the behaviour of other people is part of the construction of a dementia experience (Bartlett and O'Connor, 2007).

Kitwood's work encouraged a change of focus from medical approaches to providing care for a person with dementia as directed by professionals, to focusing more directly on the person, with greater attention to interpersonal care that affirms personhood (Fazio et al., 2018). For Kitwood this meant an emphasis on person-centred care (Kitwood, 1997). Person-centred care rejects the notion that care for people with dementia is only about protection and meeting basic needs (Marshall and Tibbs, 2006) and opposes practice that seeks to merely control or manage behaviour in an 'us' and 'them' way (Marshall and Tibbs, 2006). Instead, person-centred practice is based on an underlying philosophy of the unique identity of the person with dementia, who has a life history which should be engaged with and explored (Marshall and Tibbs, 2006) to improve their well-being, engagement, and quality of life.

Kitwood's research on people with dementia highlights that the processes that contribute to the erosion of people with dementia, which he named malignant social psychology (Moore and Jones, 2012). Malignant social psychology was an important finding for Kitwood in that it identified that people with dementia are undermined in terms of their social status through a variety of actions including de-personalisation, infantilisation, stigmatisation, disempowerment and mockery (Pipon-Young et al., 2012; Raineri and Cabiati, 2016). Through his work on malignant psychology, Kitwood then refused the negative constructions of dementia and the consequent responses that resulted, choosing instead to focus on relational responses to person-centred care (Keating, 2017; Raineri and Cabiati, 2016). Kitwood's work on malignant psychology led to an equation conceptualising dementia into five relatable factors which together point towards person-centred care for a person with dementia (Raineri and Cabiati, 2016).

Dementia = Neurological Impairment + Personality + Biography + Physical Health + Malignant Social Psychology (Raineri and Cabiati, 2016, p.1008).

Kitwood’s equation has been widely used in academia and practice but also has been critiqued for the lack of attention to the wider social structures that influence the experience of dementia (Sandburg and Ward, 2023). In summary, psycho-social approaches to dementia with an emphasis on person-centred practice highlight specific approaches such as the psycho-emotional aspects and life history work that are relevant to all people with dementia (Marshall and Tibbs, 2006).

3.7.4. The social model of disability and dementia

The social model of disability has been credited as originating from the work of the Union of the Physically Impaired Against Segregation (UPIAS) in the 1970s campaigned for improved conditions and recognition for people with a physical disability (Swain and French, 2008). It was the UPIAS that popularised a social definition of disability, a definition that detracted away from the individual focus of the impairment or disease to one focusing on the forms of discrimination that people with impairments experience (Oliver and Sapey, 2006). The social model of disability represents a clear contrast to the biomedical approach that suggests impairments represent abnormality (Thomas and Miligan, 2015) and offers a new paradigm that recognises society as disabling people with impairment (Oliver and Sapey, 2006) and the need to campaign for change. Crucially, the social model of disability holds that disability is a social construct (Palfrey and Harding, 1997), meaning there will be different experiences in different settings and cultures and as a model of how disability operates it helps to understand how discrimination and oppression impact people with dementia (Gillard et al., 2005; Bartlett and O’Connor, 2007). Social approaches to dementia align with the wider social models of disability in which there is an emphasis on empowerment rather than illness. Importantly, the social model draws attention to the structural and personal barriers created by society as well as the attitudes and responses to dementia from others which influence the experience of dementia. It highlights the need for people with disability to participate in decision making and recognition of their part in everyday life activities (Milne, 2020a).

3.7.5. Social approaches to dementia

Social approaches to dementia utilise the social model of disability as a way of critiquing forms of marginalisation experienced by those who have dementia. Like the social model of disability, the social approach to dementia situates dementia as a disability rather than a disease or illness (Hayo, et al., 2018; Oliver, 2013; Shakespeare et al., 2019). This is an important distinction as dementia has been framed by adherents to biomedical approaches as primarily a medical illness requiring a medical solution (Shakespeare et al., 2019). Social approaches to understanding dementia have been noted to have less exposure in the dementia discourse due to the medicalisation of dementia focused on the cause/effect relationship rather than the social experiences (Harding and Palfrey, 1997). Social approaches offer helpful contributions to the field in their focus on the experiences of the person and their environment (Keating, 2017) and highlighting the need to consider the sociocultural dimensions of dementia (Lyman, 1989) such as exploring cultural definitions of brain disease (Lyman, 1989). They build on the ideas found in the social model of disability by emphasising that there is a lack of attention paid to the social environmental factors that contribute to the experience of dementia (Moore and Jones, 2012). An example of how the social environment contributes to the experience of dementia is found in open space and community access limits that people with dementia can experience (Steele et al., 2020). Furthermore, it has been noted that people with dementia may have little control over their social environment which can lead to an elevated level of stress (Marshall and Tibbs, 2006). Although social approaches have progressed the discourse of dementia away from locating the problem in the person there are limitations in social approaches. For example, social approaches have been noted as shifting the focus of dementia from being about a medical disease to a problem with the person's environment (Bartlett and O'Connor, 2010).

In sharp contrast to medical approaches social approaches draw attention to the importance of a person's social circumstances, as contributing to the condition of dementia (Marshall and Tibbs, 2006), encouraging a critique of practices that over-medicalise dementia and obscure the wider social circumstances (Shakespeare et al., 2019) as well as helping to increase awareness of the health inequalities experienced by people with dementia (Reagan, 2016). Further to this, social approaches highlight the rights of people with dementia, centring the lived experience of dementia and promoting the voice of people with dementia (Marshall and Tibbs, 2006). Developments in social approaches to dementia have led to the recognition of relational approaches, which build on the external barriers and limitations imposed on people with dementia and draw attention to the social and psychological barriers linked to having dementia (Shakespeare et al., 2019). Relational approaches recognise that dementia experiences are situated within a context of human interactions and how these interactions are key for people with dementia. Relational approaches have been used to expose how people who have dementia develop coping strategies and communicate their needs (Bartlett and O'Connor, 2010).

3.7.6. Citizenship and rights-based approaches

In comparison to the medical, psychological and social approaches to dementia lesser-known ideas include citizenship and rights-based approaches to dementia. Citizenship approaches to dementia draw attention to the social rights of people within society, which include social inclusion, access to services and support and how people with dementia relate to systems of power in society (Bartlett, 2022). They consider the role of the person with dementia in society as well as their relationship to the state (Bartlett, 2022) in obtaining and benefiting from rights, responsibilities and services in society. Promoting the rights of people who have dementia enables a process of reciprocity to be engaged in (Marshall and Tibbs, 2006) in which the person can realise their citizenship through access to places and services. Importantly, citizenship approaches seek to challenge the notion that people who experience dementia are passive recipients who have little or no agency with which to contribute to the process (Marshall and Tibbs, 2006).

Traditional notions of citizenship have been recognised as potentially being restrictive and limiting for people with dementia (Bartlett, 2022). Active notions of citizenship suggest engagement in voting and civic life as demonstrations of citizen obligations, whereas passive citizens are those who do not engage in the political process. Both active and passive notions of citizenship have been argued to be detrimental for sections of society. For example, Lister (1997) notes that this is the case for women because they infer a sense of women being victims, having little or no agency with which to engage with public and private aspects of society, thus fulfilling their citizenship identity (Lister, 1997). A similar argument can be made about dementia and citizenship. Passive citizenship can construct those who experience YOD as victims lacking citizenship if they are not engaged in the wider political and social aspects of society, while active notions of citizenship can marginalise people with YOD as not fulfilling civic or citizenship duties such as voting when they may lack capacity to engage in such processes.

More recent contributions to citizenship approaches have helped to illuminate our understanding that citizenship goes beyond traditional ideas of civic participation to recognise relational aspects such as interactions in social settings (O'Connor et al., 2022) in what is now referred to as relational citizenship. Bartlett's work on relational citizenship has been particularly helpful in classifying citizenship as a social practice in which people with dementia are connected to the wider community and society through everyday activities such as shopping, eating in café and visiting coffee shops (Bartlett, 2022; O'Connor, et al., 2022). Citizenship approaches to dementia have been beneficial in highlighting the disjuncture between policies linked to dementia and what people experience in reality (Bartlett, 2022).

Rights-based approaches to dementia overlap with citizenship approaches as they concern themselves with the empowerment of the person with dementia, ensuring that their lived experience is valued and recognised within society (Bartlett, 2022). Central to rights-based approaches is the belief that dementia raises significant human rights issues (Shakespeare et al., 2019). Rights-based approaches emphasise the participation of people with dementia in the decision making process and for their voice to be held at the forefront of decision making. Alongside participation, they promote accountability from organisations to people with dementia for initiatives to support and uphold the rights of people with dementia as well as ensuring that practices and policies do not perpetuate discrimination. Importantly, rights-based approaches can empower those with dementia, which starts with an acknowledgement that people with dementia have a marginalised status in society, one that is affected by discrimination faced in everyday life (Thomas and Milligan, 2015). Finally, the main goal of rights-based approaches is to use domestic and international law and treaties as a tool for the promotion of the rights and needs of people with dementia (Crowther, 2016).

3.7. Biopsychosocial approaches to dementia

In more recent years literature has reflected a hybrid of approaches to dementia. The biopsychosocial approach as a hybrid approach emphasises biomedical, psychological and social approaches to dementia and is often credited with being a pragmatic tool used by practitioners in addressing dementia. Biopsychosocial approaches acknowledge the limitation of one singular approach to understanding and addressing dementia (Scourfield, 2023) and draw attention to the interaction of biomedical, psychological and social approaches to dementia. George Engel who has been credited with devising the approach in the late 1970s, highlighted the use of a biopsychosocial approach in general medicine as a way of remedying the weaknesses of the biomedical model (Scourfield, 2023) and a descriptive, practice-orientated tool for practitioners. Despite the appeal of biopsychosocial approaches in practice settings, the weakness of these ideas lies in the lack of evidence explaining how biological, psychological and social factors interact together in dementia. Furthermore, the lack of empirical rigour and detailed account of how these models work are noted deficits (Shakespeare et al., 2019). In the dementia discourse, biopsychosocial approaches connect with humanistic and person-centred as they embrace psychosocial ideas of dementia, which form a key consideration in the experience of dementia. The biopsychosocial approach has been credited with providing opportunities for greater interdisciplinary cooperation (Scourfield, 2023). NICE (2018a) in the publication *Dementia: assessment, management and support for people living with dementia and their carers*, notes the usefulness of biopsychosocial approaches to dementia for practitioners.

3.8. Dementia care

Reforms in health and social care in the late 20th century shifted the focus of care for people with dementia from institutional hospital settings to community settings (Scourfield, 2023). Institutional settings include hospitals and large residential care homes. Hospitals as a setting for dementia care were widely used until the later part of the 20th century (Ahmed et al., 2021). Examples included the use of workhouses, asylums, and county hospitals as places of confinement for people who were unable to care for themselves. The institutionalisation of people with dementia began to diminish in the early years of the twentieth century (Andrews, 2017) marked by medical discoveries around Alzheimer's disease and changing perceptions around the needs of people with dementia and saw a shift to the use of residential care homes and nursing homes (Andrews, 2017) which persists today. The decision to move a person with dementia to a care home or nursing home is usually made by the person and their family and carers but may include social workers to ensure that the setting will meet the person's needs (Scourfield, 2023). The use of care homes for people who have dementia is widespread and there has been some criticism that opting for care homes can limit independence, not enabling people who can continue to live in their own homes to do so, because of safety fears (Manthorpe et al., 2013). However, institutional settings, such as care homes and nursing homes, continue to have a pivotal role for people with dementia who need significant support and care (Scourfield, 2023). For people who have YOD, there are significantly fewer residential care homes places or nursing home provision (Hayo, et al., 2018; Rabanal et al., 2018) and this is believed to be mainly because of the expectation that based on age, there will be more family involvement in the care and support of the person (Mayrhofer et al., 2018). This can be a dangerous assumption about the capacities of families, friends, and other informal carers to offer the level of care required for someone with dementia in their mid-life stage. Health and social care services have been encouraged to support the use of direct payments and personal budgets to enable greater flexibility in meeting care needs (Scourfield, 2023).

Services for dementia care have historically been based in psychiatric services (Manthorpe and Iliffe, 2016) and most people who have YOD are treated under old age psychiatric services (Yeung et al. 2021). For the person who has YOD dementia a range of professionals can be potentially drawn into health and social care provision, including general practitioners (GPs), psychiatrists, neurologists, community nurses, speech and language therapists and social workers. This reflects the increase in the multidisciplinary approach that is being used in dementia care (Scourfield, 2023). At the initial stages of presenting with concerns around dementia, GPs and health care are normally the first services to be involved. Current service configurations around dementia beyond the primary care services may involve referral to a memory clinic (Scourfield, 2023). Memory clinics offer psychological testing and brain scans and the specialist input of a neurologist or psychiatrist who can diagnose dementia (Rabanal et al., 2018), although examinations have found that memory clinics are not widely available across the UK and they can be limited in supporting the emotional needs of people who receive a diagnosis of dementia (Carter et al., 2018; Xanthopoulou and McCabe, 2019).

National guidelines published by The National Institute of Clinical Excellence (NICE) and the Social Care Institute of Excellence (SCIE) have attempted to set out the best ways in which professionals working in care services should respond to YOD. Both NICE and SCIE as part of their aim to support knowledge and standards in health and social care, produced joint guidelines in 2007 which noted the need for specialist services for younger people with dementia which should include multidisciplinary services allied to existing dementia services, to meet their needs for assessment, diagnosis, and care (NICE, 2007). More recent publications such as *Dementia: assessment, management and support for people living with dementia and their carers (2018)* have set out evidence-based guidelines on how to provide care and support for people with dementia and their carers.

3.9. The role of social work with people who have dementia

Social worker roles and activities are constantly evolving and adapting. Societies change and respond to new developments and ideas, as does social work. Social work at its core looks to improve the lives of people who come into contact with their services (BASW, 2022). Social workers work across all ages and a varied range of human needs. The role of social work with dementia fits into the area of adult social care services, although there are likely to be overlapping areas, such as mental health social work and gerontological social work. Gerontological social work, although not widely referred to in social work, has important contributions to make to the discourse of dementia (Milne, 2020b). It offers a wider lens for social workers to understand dementia by drawing attention to the economic, social factors that connect to the experience of dementia (Ray et al., 2014). Drawing on gerontology gives social workers a stronger grounding in which to address the complexities of practice with dementia in settings where there are competing and contradictory themes like personalised care, consumerism and independence (Ray et al., 2014).

The role of social work with people who have dementia has in the past been found to be marginal (Marshall and Tibbs, 2006; Keating, 2017), due to ideas that people who have dementia are believed to be experiencing a 'medical illness', which needed to be 'treated' by medical clinicians (Keating, 2017). Although medical approaches form a significant part of care and support for people with dementia, greater attention to psychological and social aspects of dementia has seen social workers and other allied professionals take on greater roles in the care and support of people with dementia (Milne, 2020b; Scourfield, 2023). Examples of where social workers and other professionals are increasingly engaging with dementia include the psycho-social impact a diagnosis of dementia has on a person or the changes in family income when a person with dementia can no longer engage in full-time employment (Rabanal et al., 2018). The changes brought in by the Care Act 2014 (CA) led to a change of focus in practice from a marginal social work role concentrated on assessment and brokering services to one of increasingly drawing in social workers to more central activities of understanding the impact of the illness and working effectively with carers (Department of Health 2016b). This enhanced social work practice moves from reactive responses towards understanding how preventative approaches can support those in the initial stages of ill health, exploring alternative support services, highlighting strengths and abilities and arranging advocacy. Today, social workers engage with the complexities of practice linked to dementia in hospital and community settings (Scourfield, 2023) using an array of skills and knowledge including communication skills, assessment skills and skills related to care and support. Social workers in their practice with people who have dementia engage in signposting people to suitable services (Scourfield, 2023), alongside their assessment of need and eligibility for care support under the CA as well as monitoring and reviewing care services that have been put in place for people with dementia (Scourfield, 2023). Social workers are also involved in exploring issues of risk and harm through the safeguarding requirements (Bogg and Chamberlin, 2015). The role of social work includes assessing suitability for residential care when a person requires a significant level of care that cannot be provided in their own home. The process of deciding suitability and eligibility for residential or nursing care may include carrying out MCA assessments to ascertain whether the person can actively engage in the decision making process (SCIE, 2009a).

The remainder of this chapter will discuss key policy documents linked to dementia, commenting on how they have shaped organisations and practice with dementia across adult ages. The chapter focuses on policy derived in the last 40 years. Throughout this section of the chapter, it is acknowledged that a large proportion of policy linked to YOD is subsumed within the wider policy context of dementia. The chapter therefore includes policy that relates to dementia but recognises YOD as a sub-category, sometimes explicitly through mentioning YOD and other times implicitly through the use of terms like ‘all people with dementia.’ Selected policies regarding YOD then, will be drawn from the policy context of dementia, where it has been found that this relates specifically to YOD. The policy discussions consider the UK government’s 2009 Dementia Strategy, the Prime Ministers Dementia Challenge policies and policies driven by third-sector organisations linked to dementia.

3.10. Policy Frameworks

The next section of the chapter outlines the key policy framework linked to dementia. The term policy is not always well defined. In some settings policy is used to refer to guidance and legal requirements for organisations and in other instances, policy refers to government actions that affect whole populations (Alcock and Gregory, 2022). For this chapter, the term policy is aligned with ideas which consider policy to be “connected to notions of public and social issues and the solutions to these and the role of the state in providing these solutions” (Ward et al., 2016, p.45). Policy related to dementia across all ages, then, refers to government or organisation based solutions which shape the arrangements and delivery of services linked to people with dementia.

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The growing public consciousness of dementia has increased the focus on dementia as a policy issue in the UK (Downs, 2000). Looking over the last 40 years, the vast majority of policies linked to YOD are incorporated within the literature on dementia (de Vugt and Carter, 2022). The nomenclature of YOD differs depending on the setting and time of the policy, so terms such as YOD, early onset dementia and dementia in younger people are used (Koopmans and Rosness, 2014). Within the dementia policy context, it is quickly recognisable that YOD is mentioned sometimes as an appendage to policy discussions on dementia or it is often assumed that dementia will refer to all age groups experiencing dementia (Carter et al., 2016). This can be unsatisfactory for people with dementia, their families and carers and others who seek to progress the specific needs related to people who are identified as having dementia in younger life.

3.10.1. The National Dementia Strategy 2009

The National Dementia Strategy was launched in 2009 by the Labour government in 2007. The strategy represents a coordinated attempt to envision policy and practice around dementia. The strategy came about through the recognition of the growing number of people with dementia. Referred to as Living Well with Dementia this strategy sets out an ambitious statement of radical change that the government at the time saw as necessary to achieve three core requirements: firstly, to improve services, secondly, to increase awareness of dementia and finally to support better assessment (Department of Health, 2009). The National Dementia Strategy came at a time when the standards of health and social care services for people with dementia needed significant improvement (Iliffe, 2010) due to poor value for money stemming from a lack of investment from the government in response to the growing needs (Abdi and Burns, 2012). The strategy offered a vision for transforming dementia services, setting out seventeen objectives that at the time were believed to be able to deliver transformation, through a comprehensive strategy (Department of Health, 2009).

Once the National Dementia Strategy was published the Government highlighted several objectives or themes it believed to be key towards achieving the transformation and engaged in a sustained promotional drive of these objectives through NHS services and local authorities (Greaves and Jolly, 2010). These themes included reducing the stigma surrounding dementia, improving awareness of dementia and providing better education and training around dementia (MacDonald, 2010; Department of Health, 2009). The communication and promotion of the above-selected objectives achieved focused attention and raised the profile of dementia care (Greaves and Jolly, 2010) and increased the standard of care and support well above the levels that previous policy initiatives around dementia had done (Department of Health, 2010). As a result, The National Dementia Strategy (2009) was deemed by the government to be a success in achieving the objectives of increasing diagnosis rates (Department of Health, 2010) and reducing the use of antipsychotic medication for people with dementia (Greaves and Jolly, 2010). The policy achieved success arguably because it raised the profile of dementia, bringing greater public awareness and media attention to the issue of dementia that was already affecting increasing numbers of people across the UK (Iliffe, 2018). There were, however, gaps in the National Dementia Strategy. The strategy, in setting out the key objective of the importance of improving awareness of dementia, gave minimal attention to raising awareness of dementia within marginalised communities and in particular Black and Global Majority communities, where there was growing evidence of an increase in the prevalence and experience of dementia (Reagan, 2016). This reflected the tendency of policy to employ a one-size-fits-all approach to dementia, overlooking the range of types of dementia. Furthermore, the National Dementia Strategy, although it was labelled as a comprehensive policy, did not consider the need for collaborations involving families, carers and professionals who could work together (Greaves and Jolly, 2010) to achieve shared outcomes.

3.10.2. Prime Minister's Challenge on Dementia 2012 and 2020

Following on from The National Dementia Strategy the next government policy that tried to address dementia was The Prime Minister's Dementia Challenge (2012). This policy was developed under the coalition government led by David Cameron. The policy sets out the challenges posed by dementia which, at the time of publication, included a notable increase in public and political attention around dementia (Department of Health, 2012). A policy response to the challenge was to further raise standards of care and support for people living with dementia. The policy focussed on 3 areas: the first was to deliver improvements in health and care services for people with dementia through increased dementia diagnosis rates, offering financial rewards to hospitals providing good dementia care, offers of financial incentives for innovation, working with care home providers to provide high quality care and support and promoting information on local services for people with dementia. The second area that the Prime Minister's Challenge focused on was creating dementia-friendly communities which included an aim of having twenty towns and cities which are 'dementia friendly,' encouraging national commercial organisations to support dementia initiatives. Dementia-friendly communities became a salient part of efforts to address the marginalisation of people with dementia in UK society and for people with YOD, dementia-friendly communities have been posited as one of the successful ways that dementia policy has addressed the specific needs of this group (Rabanal et al., 2018). The third area that the policy focused on was facilitating better research. This was to be done by more than doubling funding for research, announcing investments in brain scanning, an increase in social science research and creating greater opportunities for people with dementia to participate in research. Like its predecessor, the National Dementia Strategy (2009), the Prime Minister's Dementia Challenge received approval and endorsement by health and social care organisations for its progressive ambitions for dementia care and support (Rodgers, 2021). A major challenge that influenced the Prime Minister's Dementia Challenge policy was that it was launched amid the government's austerity policy from 2010 onwards which led to cuts in the budgets of various government departments and consequently saw negative effects on health and social care services (Rodgers, 2021) including cuts to services for people with dementia. Here it can be pointed out that this was counterproductive to the policy aims. In 2015, a legacy policy was published, entitled The Prime Minister’s Challenge 2020. This policy was equally as ambitious as the 2012 policy (Department of Health, 2015a) with the plan to further expand on the plans outlined in the 2012 policy. The 2015 policy indicated that the 2012 Prime Minister’s Challenge had successfully met the plan to make England:

> “The best country in the world for dementia care and support and for people with dementia, their carers and families to live; and the best place in the world to undertake research into dementia and other neurodegenerative diseases” (Department of Health, 2015a, p.3).

Unlike the National Dementia Strategy (2009) where there was little mention of YOD, the 2012 and 2015 Prime Ministers’ Challenges on Dementia both mention dementia in younger people, highlighting the need for awareness of the needs of this cohort (Department of Health, 2015a).

3.10.3. Prime Minister’s Challenge on Dementia 2020: Implementation Plan

Directly linked to the Prime Minister’s Challenge on Dementia (2020) was the Prime Minister’s Challenge on Dementia 2020 implementation plan. The implementation plan provided an emphasis on improving access to data to enable clearer information to be made available on the prevalence of dementia at national and local levels, providing valuable information to commissioners and service providers at a local and national level and using this data to inform the commissioning and planning of dementia services so that more people with dementia receive a timely diagnosis and appropriate post-diagnosis support. These changes saw a collection of data on people with dementia at GP practice level which was published each month by the NHS.

Across the UK there has been increasing recognition of the need for better coordination and planning regarding dementia care (Scourfield, 2023). In tandem with the government’s devolution process, the home nations published equivalent dementia strategies. A

Dementia Action Plan for Wales 2018 – 2022 was published by the Welsh Government (Scourfield, 2023). In Northern Ireland, the Department of Health published Improving Dementia Services in 2011. The Scottish Government published Scotland's Dementia Strategy in 2017 (Scourfield, 2023) and the more recent, New Dementia Strategy for Scotland: Everyone's Story (Scottish Government, 2023). The dementia strategies of the home nations, along with other devolved welfare arrangements, saw convergent and divergent approaches to addressing dementia at a policy level. For example, Scottish devolution led to a policy of free personal care to adults over the age of 65 years, positively affecting people with dementia.

3.10.4. National Institute for Health and Care Excellence (NICE)

Government policy on dementia has been delegated to and implemented via non-departmental organisations. The National Institute for Health and Care Excellence (NICE) is an example of an executive body outside of direct government leadership having a pivotal role in the development of policy. NICE is directly sponsored by the Department of Health and Social Care (NICE, 2023). As an organisation holding responsibility for disseminating and implementing policy NICE has objectives which look to inform people and care services of up to date information and best practice (NICE, 2023). The NICE guidance, Dementia: assessment, management and support for people living with dementia and their carers (2018a), represents a comprehensive set of recommendations and guidelines covering diagnosis, assessment and decision making involving people with dementia. While this is not direct policy from the government, nor legally binding, the guidelines provide an authoritative document on professional responses to dementia (NICE, 2018a). Aspects of the 2018 Dementia NICE guidelines that apply to this study are shared decision making between health and social care professionals and patients, which indicates a desire to put people at the centre of care and treatment decisions.

3.10.5. Third sector organisations' Involvement in the policy context

The Westminster Government has recognised the role that third-sector organisations play in the provision of support and care for people with dementia (Department of Health, 2009) and provided funding and encouragement for charities and third-sector organisations to have a role in the provision of services for people with dementia but also to contribute to the policy process, for example in giving evidence to Health Select committees and the All Party Parliamentary Group on Dementia (APPG). Many third-sector organisations have important contributions to dementia research policy and practice (Mayrhofer et al., 2018; Alzheimer's Society, 2016). The Dementia Empowerment Engagement Project (DEEP) which created a network of groups of people with dementia across the UK seeking to improve dementia services has been posited as a positive development for people with YOD (Rabanal et al., 2018; Mayrhofer et al., 2021). The emergence of the National Dementia Action Alliance in 2010 was one example of national and local third-sector organisations coming together to seek to transform the experiences of people with dementia and shape policy (Regan, 2016). On a national level, the National Dementia Action Alliance lobbied parliament for greater rights and resources for people with dementia and their carers (Regan, 2016). On a local level alliance structures drew together a wide range of community services including fire and rescue services, police forces, retailers, local authorities, transport providers, charities, community groups, businesses, care providers, health trusts, and people living with dementia and their carers (Regan, 2016). Local committees signed up to the National Dementia Declaration, which was an implementation of the Prime Minister's challenge on dementia launch of dementia communities' initiative. Organisations with a specific focus on YOD include the Young Dementia Network, which in 2022 authored a document *Young onset dementia pathway: Diagnosis and support for people with YOD and their families* (Young Dementia Network, 2022b). The report set out recommendations from the steering group of the Young Dementia Network. The document outlines several steps that government, commissioners and practitioners should consider in designing and delivering dementia services for people who have YOD. These include arrangements to think about the specific needs of people with YOD in the design of services, steps to ensure timely diagnosis of dementia and clearer referral routes to specialist services, specific workers who are 'key workers' who have knowledge, training and experience of YOD, and better collaborative working between clinicians, social services and charitable organisations for the person with YOD and their families (Young Dementia Network, 2022a).

3.11. Conclusion

The chapter has provided an overview of dementia with a discussion of different perspectives and approaches that confirm dementia and specifically YOD has historically been shaped by a range of perspectives including biomedical perspectives which are more dominant than others. These perspectives continue to shape how dementia is understood but also have importance in the way that dementia is responded to by health and social care professionals and the services where they practice. The chapter has noted that the biopsychosocial approach to dementia has in recent times been promoted as an approach that best addresses the realities of dementia, but this is not without criticism. The chapter has considered the role of social work with people who have dementia, recognising that there is a growing role for social workers in working with people with dementia.

The latter part of the chapter explored dementia policy and highlights that there have been similar messages over the last 25 years and these messages include that there is a need for greater public and professional awareness of dementia (Department of Health, 2015b), greater attention is needed to understand how dementia affects the lives of people who have been identified with the condition, an understanding the position of carers and families of people with dementia and the need for further research into dementia (Department of Health, 2015b). What this chapter has drawn attention to is the paucity of policy specifically looking at dementia in people mid-life. Most policy focus is broadly on dementia, with assumptions of dementia affecting people in later life, which is the most prevalent group of people affected by dementia (Rossor et al., 2010). There are limited policies drawing attention to YOD and the reasons for the lack of attention to YOD in policy discussions, including the prevalence of YOD being seen as less significant, due to historically low numbers of people with YOD (Carter et al., 2022; Department of Health, 2015b). However, questions can be asked about the systems of recording dementia prevalence which are currently reliant on GP-collected data, which may not capture the prevalence of dementia in younger people (Carter et al., 2022). Finally, the policy context for dementia is subject to regional variations across the UK and even within the regions of the UK. Devolved governance has seen divergent paths being taken by the UK home nations in relation to dementia policy. This further obscures the policy context of dementia and evidences a lack of a joined-up government vision for dementia that can be carried across all areas of the UK.

Chapter 4: Theoretical framework: social constructivism and decision making

4.1. Introduction

This chapter outlines the theoretical positions found throughout my research study. It includes two conceptual areas which together make up the theoretical framework for this research study. These are social constructivism and decision making. Social constructivism will be explored first and this chapter will examine the main tenets of social constructivism and key issues related to social work, dementia and mental capacity. The second theoretical construct, decision making is outlined and there is a discussion of several aspects of decision making theory that are relevant to the research study. The concluding section of this chapter offers a discussion of the relevance of social constructivism and decision making to this research and how these theoretical ideas will be used.

4.2. What is social constructivism

Social constructivism relates to the idea that people produce knowledge through their social practices and organisations (Young and Collins, 2004) and through individual cognitive processes (Teater, 2010). It focuses on everyday activities (Boahen, 2004) and social interactions for defining knowledge and social reality. The premise for social constructivism enquiry confronts science-based ideas which suggest that truth is independent and therefore can be sought and captured (Şahin, 2006). As a theory then, social constructivism engages a critical understanding of facts and how facts relate to actions (Parton and O'Byrne, 2000a). The work of Berger and Luckmann (1966) is seen as central to social constructivist ideas (Young and Collins, 2004). Through their research based on a macro level, they espouse the idea that knowledge held is socially constructed including our understanding of reality (Berger and Luckmann, 1966) and these ideas help to reveal that some realities are assumed and privileged above others. Key aspects of Berger and Luckmann's work include the focus on the use of language as a driver for understanding reality and maintaining the privileged ideas of reality (Berger and Luckmann, 1966) and the meaning given to experiences which are seen as powerful in the making of knowledge (Parton and O'Byrne, 2000a).

Other theorists who have contributed to social constructivism include Erving Goffman (1956). Goffman (1956) theorised that people are actors on a social stage of life, asserting that meaning arises from interactions in which a key role is played by language and cultural knowledge (Martinez-Brawley, 2019; Harding and Palfrey, 1997). Goffman goes on to suggest that "self" can be understood as a social product in relation to its social context (Goffman, 1956, cited in Martinez-Brawley, 2019). This infers the importance of social interactions as part of the process of creating meaning from events. While Goffman's contributions to social constructivism provide a helpful description using dramaturgic analysis of what can occur in making sense of social interactions, his ideas on social constructivism are limited in that they are not based on research evidence and they focus on a micro level (Harding and Palfrey, 1997). Another theorist who contributed ideas to social constructivism is Lev Vygotsky. Vygotsky's ideas are built on the work of Jean Piaget, who posited that learning occurs as part of responses to what occurs in the external environment (Akpan et al., 2020). Vygotsky added to these ideas by indicating that culture and language are key components of learning and cognitive development (Akpan et al., 2020). Vygotsky saw learning and development as occurring using cultural transition tools, which are principally language and symbols. Vygotsky's ideas helped to connect learning and development beyond an individual cognition to one recognising the wider processes.

Drawing these contributors together, a central aspect which helps to define social constructivism includes the inference of knowledge as being historically and culturally specific (Young and Collins, 2004). Social constructivism is found in several disciplines, including literary studies, psychology, philosophy, and sociology (Parton, 2003; Young and Colin, 2004). As a critical theory, social constructivism challenges commonly held ideas about knowing (Fook, 2016) and what professionals do based on their knowledge (Parton and O'Bryne 2000b). Social constructivism has been used as a theoretical basis in research studies. Boahen (2004) for example, notes the usefulness of social constructivist theory in supporting a framework for critically exploring concepts such as mental capacity and dementia. Constructivist theory provides a platform for deconstructing practice and uncovering assumptions (Parton and O'Bryne, 2000b). This approach fits with the intention of this research to explore and understand MCA decision making by social workers.

4.2.1. Social constructivism and its terminology

When exploring the literature on social constructivism it is noticeable that there exists a level of ambiguity linked to the terminology in that there are a range of terms used. Furthermore, the terms are used interchangeably and sometimes may refer to the same thing (Young and Collin, 2006). The interchangeable use of terms related to social constructivism has been acknowledged by some such as Charmaz (2009), while others recognise that the terminology represents a range or collection of theories linked to the premise that reality is constructed (Wilson, et al., 2011; Parton and O'Bryne, 2000a). To ensure there is a clear understanding of what is being referred to throughout this study, it is helpful to clarify the use of the term. Social constructivism, as noted earlier in this chapter is used in this work to refer to the idea that people construct the realities in which they engage with. These realities are shaped by a range of dynamics including internal and social factors (Denicolo et al., 2019; Teater, 2010). Therefore, social constructivism will draw on both ideas linked to social factors that shape experiences and sense-making as well as internal or cognitive processes (Teater, 2010). This definition of social constructivism can be differentiated from social constructionism which refers to realities being constructed via relational, linguistic and social factors (Denicolo et al., 2019; Teater, 2010). Social constructionist emphasises that the social processes and the roles people adopt within groups are important to their understanding of reality (Denicolo et al., 2019).

4.2.2. Social constructivism and social work

Social constructivism when applied to social work acknowledges that practice is a collaborative activity, not only with people with lived experience of social work (Parton and O'Bryne 2000a) but also with other professionals. For this study, the importance of other professionals cannot be overlooked as the social work role and activities are intrinsically linked to that of other professionals in MCA assessment and decision making.

Martinez-Brawley (2020) affirms that social constructivism offers social work a rich theoretical platform with which to draw on diverse ways of understanding the world and reality (Martinez-Brawley, 2020). Despite its benefits, Martinez-Brawley (2020) posits that in the early 2000s social work academic circles were initially reluctant to engage with social constructivist philosophies in research, preferring approaches which were underpinned by positivism. This explains why social constructivism is often regarded as relatively a more recent approach within social work. Within the social constructivist framework meanings, language and understanding of categories like dementia and mental capacity are matters of negotiation rather than objective singular realities, meaning there is room for new ways of understanding them. A social constructivist epistemology seeks to reveal these multiple realities and understand their application within social work. Moreover, drawing on social constructivism draws attention to the importance of the historical and cultural contexts of social work decision making.

As a practice, social work seeks to improve the lives of people. From a social constructivist standpoint this aim is achieved in part by deconstructing traditions, exploring bias, exploring values and by drawing out new meanings through their identity (Parton, 2003). These identities are themselves seen as constructed and in their practice social workers are social actors who incorporate their identities in the activities they do in practice. Thus, social work identity takes centre stage within a social constructivist framework. This identity is shaped by interactions with others. Parton (2003) recognises this shaping occurs primarily with people with the lived experience of service users, while others like Martinez-Brawley (2020) consider that this occurs through the activities of practitioners. While the focus of this study is not to directly explore the experiences of people with dementia, the role of people with dementia in shaping meanings and ideas is recognised as a salient aspect of the social construction of realities. Social constructivism therefore serves to broaden the focus of practice from that of achieving outcomes to exploring the processes, through asking questions about how our knowledge of reality has come about (Parton, 2003).

4.2.3. Social constructivism and dementia

Following the discussion of social constructivism and social work, it is helpful to map out the conceptual links of this epistemology to dementia. There are different perspectives linked to dementia that form the basis of how it is understood and responded to. Positivist assumptions suggest dementia can be consistently revealed and tested, whereas social constructivist thinking contends that dementia is a condition defined within communities of meaning (Young and Collins, 2004). In wider society, dementia as a phenomenon is predominantly explained as a medical condition, although it can be understood in many ways (Harding and Palfrey, 1997).

Harding and Palfrey (1997) draw a rich understanding of how the condition known as dementia has become correlated with medical understanding of illness and disease and how this may be problematic. Social constructivism as a critical theory helps explore questions about the idea of dementia as a physical illness, similar to other conditions, in which the illness is consigned to physical reductionism in which the body is held as the location of disease without taking into account social and psychological explanations (Harding and Palfrey, 1997). Thus, the usefulness of social constructivism is that it facilitates exploration of the experience of dementia being societal as well as individual, noting the value in identifying the wider influences that might shape the experience of dementia.

Much of what is known about dementia is drawn from the meanings attached to the condition from people who have not experienced dementia (Ward and Sandburg, 2023). A further observation of how social constructivism may be of use is in the terminology associated with dementia. When investigating the term dementia, it is highly likely that these definitions were not created by people experiencing dementia but have largely been shaped by medico-legal professions. Further to this, the way in which we understand dementia has been shaped by socio-cultural and political contexts, which have different meanings in different social contexts (Bosco et al., 2019). For example, dementia in East Asian communities is commonly perceived as part of growing old (Hillman and Latimer, 2017). This sheds light on matters of power and dominance in dementia and how powerful groups and professions have been shaping the key concerns and agendas for the categorisations of YOD (Bosco et al., 2019).

4.2.4. Social constructivism and mental capacity

The historical and political context in which the MCA developed provides a rich source of understanding for this study. In summary, the context in which the MCA was developed draws out legal and professional factors which otherwise may not be revealed. These political and professional factors have seen attempts to increase the rights and legal protections for people who are viewed as vulnerable (Brindle, 2015) which includes much older people and people with mental health problems and learning disabilities. Making improvements in the rights of people who fall under the provisions of the MCA has been the political campaign for families and disability groups such as the Mental Health Foundation dating back to before the MCA became statute (Law Commission, 1995). Professional factors linked to the development of MCA practice have seen the influence of medico-legal perspectives in mental capacity policy and practice. For example, the dominance of psychiatry in expert witness testimony in mental capacity court of protection proceedings (Case, 2016) and the use of medical terms like ‘non-compliance’ (Case, 2016), as well as an increasing number of health and welfare cases being scheduled in the Court of Protection (Ruck-Keene et al., 2019).

Exploring social constructivism’s relationship to mental capacity, Munro (2013) elucidates that attempts to rationalise assessment and decision making using the MCA continually fail, explained in part by the inability to produce adequate tools which can be consistently applied across a range of circumstances. This is evident when considering how to assess capacity when there are fluctuations in a person’s awareness and engagement. This has raised several ethical considerations such as how an assessor can fully capture a person’s differing states of capacity and awareness during the assessment process. The failure to rationalise assessment and decision making reveals that rather than being a property of the mind, mental capacity assessment and decision making under the MCA are properties of the social world (Munro, 2013). Reality then, in terms of mental capacity assessment and decision making is less certain and includes social understanding rather than only measurable cognitive thinking.

Linking the theory of social constructivism to the phenomenon of mental capacity is necessary within this work to support a clearer understanding of the social and political processes in which mental capacity and decision making evolve. Social constructivism confers an understanding of mental capacity to be defined culturally and set at this time in history. Evidence of these ideas can be drawn upon when comparing international and even regional processes for determining whether a person has capacity to make decisions or not. An example of this is found when looking within the United Kingdom, where there currently remain different legal and practice frameworks for understanding and responding to matters of mental capacity within the different home nations of England, Wales, Scotland, and Northern Ireland. England and Wales enacted the MCA in 2007. Scotland’s capacity law follows the Adults with Capacity (Scotland) Act 2000. Northern Ireland in 2017, operationalised the Mental Capacity Act (Northern Ireland) 2016. Across the three nations there are similarities in capacity law but key differences as well. The details of these differences are not key to the discussion of mental capacity in this chapter but do remind us that mental capacity practice can be operationalised in different ways linked to how law and policy are being interpreted.

Social constructivism provides an alternative position to scientific positivism, which holds that knowledge is reality and can be discovered as a value-free activity (Bosco et al., 2019). This is rejected as a premise for undertaking academic enquiry in favour of understanding social phenomena as constructed or framed through subjective meanings and ideas of people (Parton and O’Byrne, 2000a). In relation to this study the relevant people of interest are social workers, whose practices are made by their social worlds, which in turn shape their practices (Harding and Palfrey, 1997; Parton and O’Byrne, 2000a). These ideas are important in MCA work where there is a strong medico-legal basis for practice (Munro, 2013) which shapes social workers using the MCA. Understanding social processes within their cultural and historical context can be supportive of social work values and in particular values which aim to uphold the rights and needs of people who use their services.

4.2.5. Summary of social constructivism

This section of the chapter has outlined the concept of social constructivism, its application to social work and dementia with some reference to YOD. As a part of the conceptual framework, social constructivism offers a theoretical tool for understanding how mental capacity influences the practices and activities of social workers, including when working with those who experience dementia. Although the focus of this study is on YOD, discussion of social constructivism has looked at dementia as a whole.

It has been noted that some authors have considered constructivist approaches, emphasising the individual cognitive processes, which are considered central to the construction of knowledge (Young and Collins, 2004), or social constructionist approaches which emphasise social processes. My research chooses to focus more on the social constructivist position which locates both individual mental processes and social processes as central to the construction of meaning (Young and Collins, 2004). It considers that social constructivism contributes towards broadening thinking around theory building and dimensions of practice, in the case of this study social work practice using the MCA. Throughout the study, discussions about social work practice, social constructivism have been drawn on to explore and sometimes challenge assumptions and ways of knowing.

4.3. Decision making theory

Decision making theory forms a central part of the conceptual framework for exploring mental capacity decision making. Decision making remains a central concern within social work practice and helps draw attention to the questions of why professionals do what they do (Garro, 1998). The terminology used alongside decision making includes words such as judgement, risk, and professional discretion. These terms are used interchangeably in the discussion of decision making as part of the conceptual framework for this study. Ideas around decision making theory are drawn from vast fields including psychology, sociology, economics and public administration. The interdisciplinary nature of decision making theory provides an interesting lens within which to explore it, particularly as it is shaped by the discipline within which it is being drawn. For this conceptual framework greater attention is given to how decision making operates within health and social care settings, with a focus on decision making in social work practice.

There are a range of ways to explore and understand decision making in social work practice, partly because it is not always clear how practitioners make decisions (Bergeron 1999). Decision making relates to the reasoning and judgements made by professionals in exercising judgements. It helps to understand a range of matters. Decision making is core to a range of disciplines and professions – psychologists, doctors, nurses, economists and social workers.

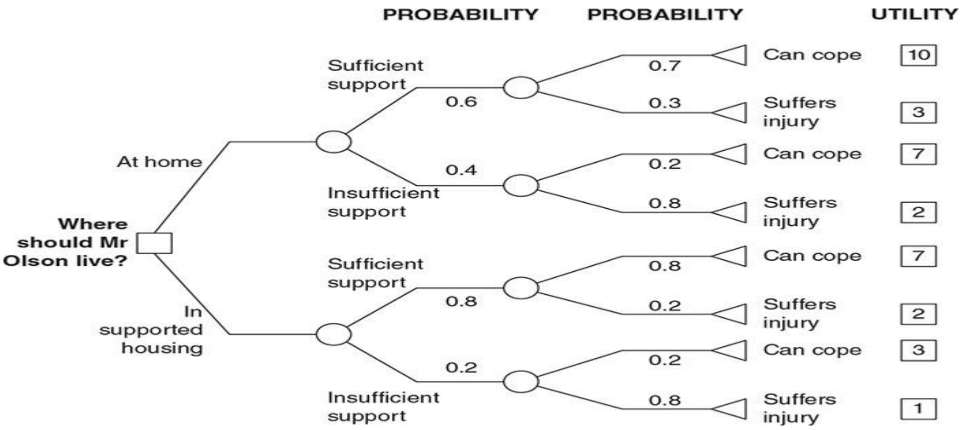
Psychological perspectives have made contributions to decision making which inform that there are multiple systems of decision making present in the brain or mind (Ferrin, 2017). Notably two systems have been revealed and these are known as system one: responsible for intuitive, "gut based" and quick decisive decision making and system two: where there is more reasoned, rational and reflective decision making (Ferrin, 2017). These ideas have been used in part to attempt to explain why despite there being rational-based approaches to decision making, these are not always followed. However, understanding the presence of different "systems" involved in the process of decision making does not give us a detailed understanding of why rational and intuitive systems are used and what the broader environmental factors are that contribute to intuitive and rational-based decision making.

4.3.1. Models and approaches to decision making

Decision making has been understood in terms of models or approaches. Quantitative approaches have drawn on concepts such as Game theory, which is used by economists and political scientists to understand decision making. Game theory is premised on anticipating action and like other probabilistic approaches to decision making it attempts to suggest decision making is optimised to achieve the best outcome (Lukens et al., 2013). Qualitative approaches differ from quantitative approaches to decision making in that they draw on the subjective, highlighting psychological factors and contextual factors (Taylor, 2012). Heuristics are a popular form of qualitative decision making, referred to as mental shortcuts, which help to enlighten our understanding of decision making through their acknowledgement of the presence of bias in the process of decision making. Heuristics enable decisions to be moulded within routine thinking (Lukens et al., 2013) rather than by a systematic process. As a result, heuristics have been described as a fast and frugal approach to human decision making (Viale, 2020) in that they enable good enough decisions to be made without having all the complex components and calculations (Taylor, 2012). Heuristics, however, have a weakness in that they rely on limited information and may miss vital contributions to the decision making process. This can be crucial in social work decision making in which minor details can influence the course of action taken, an example being a person's current wishes may be shaped by their earlier experiences, which may not be readily known, but this detail will be significant if making a decision on the person's behalf.

Decision making trees offer a rational approach to decision making and are commonly used in health and social care settings. Decision making trees refer to diagrammatic maps that outline decisions, consequences and outcomes (Hood, 2018). They offer practitioners an easy to interpret, visual layout that can be shared with others. However, they can become quite unwieldy and complicated when there are many decisions options and consequences with regard to the decision (Hood, 2018), which makes them less attractive in practice situations.

Figure 1. Example of a decision tree (Hood, 2018)



4.3.2. Decision making theory and social work

The role of decision making in social work has been given increasing attention in recent years (Taylor, 2010; Helm, 2011; Saltiel, 2012). Decision making has become an area of focus not only for social work practice but increasingly it is an area which social work research seeks to explore (Gambrill, 2005). Decision making ideas are found in academic writing on social work practice with children and their families and adults. Taylor (2010) outlines four types of decision making which are prevalent in social work practice. These are: supporting service users and their families in making decisions; the decisions related to care planning or intervention where different courses of action are possible; making judgments about the threshold for intervention (an example being safeguarding) and finally, judgments about eligibility for services. Taylor's (2010) outline of types of decision making are useful as a starting point for understanding decision making within social work practice, but in the current complexity of social work practice they provide a limited understanding of the breadth of decision making engaged in by social workers in practice settings.

Other ideas around social work decision making theory have drawn attention to analytic and intuitive decision making ideas (Taylor, 2012). Both these ideas help detail the usefulness of decision making in social work practice with adults. Analytic models attempt to find a step by step approach to arrive at a decision. Studies have drawn attention to the accuracy and benefits of rational decision making (Taylor, 2012), but there are considerable limitations linked to their application within health and social care settings. For example, the restrictiveness of time to make decisions, the presence of emotions in making decisions and the influence of the organisation.

Intuitive approaches in social work concern the use of practitioner perceptions in decision making and are considered to be skills-focused ways for social workers to make decisions (Taylor, 2012). Studies noting the importance of intuition in decision making draw attention to key elements which support the skill of intuition being used effectively. Klein (1998) identified four key components of intuition: practice, gathering experience, feedback and reflection. Studies noting the importance of intuition have been found in children and families’ practice. Munro (2011), for example, recognises intuition as a component of child protection work and furthermore emphasises critical thinking as a core skill for decision making (Munro, 2011). The Department of Education funded research report by Kirkman et al. (2014), investigated social work decision making within local authorities. Kirkman’s research noted several key aspects of social work decision making and included a range of behavioural factors that impacted social work decision making. Their findings suggest that social workers are most likely to rely on intuitive decision making because of time and work pressures (Kirkman et al., 2014) and the information provided to social workers is often not of high quality and therefore leads to additional time being spent on decision making. This fits with ideas that social workers often make decisions based on limited information (Lukens, et al., 2013).

An alternative to intuitive approaches to decision making in social work is the theory of Bounded rationality. Bounded rationality as an approach incorporates the limitations of rational approaches, i.e., the need to have detailed information, but it rejects the sense of intuition as being the main component of decision making. Bounded rationality draws on the ideas of Herbert Simon, who incorporates the concept of satisficing, a term which draws together the words satisfy and suffice and suggests decision makers will choose the approach likely to be the most successful within the limitations of time and resources (Hood, 2018; Lukens et al., 2013). Bounded rationality, like intuitive approaches applied to social work practice, implies that practitioners’ approach to decision making is from a pragmatic stance and they will make decisions linked to the resources available at the given time. Resources here refer to limits on the time social workers have in which they must engage with decisions, with only limited information often available to make decisions and constraints on funding which limit decision choices. Bounded rationality ideas have much resonance with social work practitioners, who under the pressures of limited resources, indicate decision making is challenging (Taylor, 2012). They are useful for social workers in that they draw focus on decision making being shaped by the decision maker and the environment in which the decision is being made (Taylor, 2012). By highlighting the role of the decision maker, the role of social workers in decision making processes is brought to the foreground rather than obscured as secondary to the technical aspects of decision making.

Despite the appeal of intuitive approaches to decision making the challenge in using them is to understand how legal frameworks such as the MCA influence social workers in using intuitive approaches to make decisions. This discussion is explored further when looking at decision making and mental capacity.

4.3.3. Actuarial approaches

Actuarial approaches to decision making are often linked to risk, and how risk is understood and responded to (Taylor, 2017). These approaches have tended to be referred to as judgement tools or risk assessments and are used to predict the potential for harm and manage risk. Actuarial approaches are more commonly used within clinical settings where it is accepted that there is risk in specific clinical populations, but the level of risk is unknown (Taylor, 2012). They use sizeable data sets of information containing a range of behaviours that are being assessed (Hardy, 2017). Alongside data sets, statistical algorithms are used to predict potential risk outcomes (Taylor, 2017). In relation to social work, Hardy (2017) notes actuarial approaches commonly involve inputting "static and dynamic variables, history and context, into a software programme, which results in a percentage score" (p.397). The resulting data is then categorised into bandings which detail the level of risk or likelihood of harm (Hardy, 2017). During the 1990s and 2000s actuarial approaches were popular within mental health settings, where risk assessment was a central focus (Hardy, 2017). In these settings actuarial approaches were promoted as providing accurate unbiased guidelines on which decisions about risk could be made (Hardy, 2017). The main benefits of actuarial approaches to decision making are their predictive capacity to indicate the probability of an event occurring, which makes them attractive in settings where the potential for the risk of harm needs to be understood. In social work terms actuarial tools have been useful in predicting the risk of neglect or physical or sexual abuse (Mendoza et al., 2016) and risk of harm to self or others. They are less suited to day to day decision making scenarios where risk is less of a concern and as Hardy (2017) acknowledges, actuarial tools "lack specificity" making them less effective when working with individuals (p.397).

4.3.4. Unstructured and structured clinical decision making

Both structured and unstructured clinical judgement approaches to decision making are useful to review in relation to social work decision making. Unstructured clinical judgments refer to clinical judgments made based on clinical knowledge (Mendoza et al., 2016). Practice knowledge, experience and intuition are relied on as resources for unstructured clinical judgement (Mendoza et al. 2016). Social workers in using unstructured clinical judgement to formulate decisions will tend to draw to decisions based on practice experience or a gut feeling. The drawbacks of unstructured clinical decision making are well noted as being subjective (Hardy, 2017), with potential for inconsistency (Mendoza et al., 2016), but from a positive angle it recognises the value placed on practitioner wisdom and the relationship between the practitioner and the person subject to the decision. Structured clinical decision making differs from unstructured clinical decision making in that it combines individual clinical judgement with actuarial tools for understanding decision making and risk. They can be referred to as integrated approaches to decision making which use evidence-based tools alongside the intuitive skills of practitioners (Mendoza et al., 2016). The appeal of structured clinical decision making tools lies in the lack of total reliance on actuarial approaches or individual clinical judgement as the remedy to decision making challenges.

4.3.5. Decision making and professionalism

Decision making has been linked to what professionals do in their practice. In relation to social work, professionalism has a varied conceptualisation. Ideas of professionalism in social work are far from unified, and a wide spectrum of ideas and notions of professionalism persist (Webb, 2017). These range from traditional elitist ideas of distant experts to command knowledge and expertise (Wilson et al., 2011) and conceptualisation of professionalism linked to ethics and accountability (Thompson, 2016). Wilson et al. (2011) recognise the limitations of the traditional view of professionalism to social work's core approach of relational intervention. Regardless of the conceptualisation of professionalism, it is recognised as a necessity for social workers and their identity.

A core component of professionalism within social work is believed to be freedom of decision making (Evans and Hardy, 2017). While autonomy of decision making is not always readily recognised in practice, it is something that remains valued by practitioners (Thompson, 2016). However, professionalism does not always serve to grant greater flexibility to social workers, as arguments around the pervasiveness of neoliberalism confirm autonomy can contract.

Exploring the relationship between professionalism and decision making further, the intertwined nature of professionalism and decision making means that one will have an impact on the other. Alongside professionalism it is also useful to look at this in relation to professional discretion. Professional discretion in social work recognises that social workers operate within a bureaucratic system that prescribes how they conduct their work activities but also has significant freedom in how they work. Evans and Harris (2004) posit that professional discretion is nebulous, providing a range of professional freedoms for social workers in different forms for different purposes.

4.3.6. Decision making and managerialism

The broader organisational context of professional decision making should not be ignored as it forms a key shaper for how decision making occurs. Since the 1990s social work has undergone a range of structural transformations which significantly impacted the role of social workers. These are collectively referred to as new public management or managerialism and were introduced within public services including social services under a neoliberal political backdrop during the 1990s onwards. The changes included all or some of the following: the use of indicators to apply with a focus on performance, the belief that managers were necessary to ensure the social work services achieve targets and service users being seen as consumers with rights (Heffernan, 2005; Harris, 2008).

The impact of managerialism on social work practice and how it is practised can be argued as being significant in the past 20 years (Taylor and Whittaker, 2018; Kirkpatrick, 2006). Managerialism and marketisation of social work practice occurred following the introduction of purchaser-provider splits, increasing management functions such as that of budgetary control (Kirkpatrick, 2006), greater focus on cutting costs and achieving output targets, increased attention given to managerial concerns as opposed to workers and service users being reconfigured as customers or even consumers (Harris, 2008). Of relevance here is that managerialism was perceived as something done *to* social work staff, rather than done *with* (Harris, 2008). This is relevant in as much as the changing landscape of managerialism was not always agreed upon and was on occasion resisted and challenged by social workers (Harlow et al., 2012).

Managerialism is believed to have had a direct impact on social work (Harris, 2008) and therefore it can be surmised that there is some influence on social work decision making. This is despite much of the guidance and theory around decision making failing to discuss the political/ideological dimension of decision making. What can be argued is the need for social work decision making processes to have greater acknowledgement and analysis of the political and organisational components which influence them.

4.3.7. Decision making and emotions

More recent literature on decision making has recognised the role of emotions. The place of emotions in decision making is not a new concept but has historically been under-researched (Brown, 2011). In mental capacity work emotions have been found to be influential in decision making (Brown, 2011). Breden and Vollman (2004), for example, discuss that models that try to assess capacity can miss the complexity of decision making, overlooking what they consider to be key aspects of values and emotions. Brown (2011) in her literature exploring the role of emotions in MCA decision making notes that there is a lack of attention on emotions, mood or changeability in the MCA or the MCA Code of Practice. She suggests account should be taken of the person's decision-making history, their mood, their emotional stability, and the relational context as a way of acknowledging the complexity of MCA decision making (Brown, 2011).

4.3.8. Decision making theory and mental capacity

Mental capacity is an area of practice which draws on decision making across a range of groups who use health and social care services including older people, people with learning disabilities and people with cognitive impairment (Davies et al., 2011). For all adults who are found to be unable to make decisions for themselves, the MCA is the principal legislative framework used to inform decision making. The MCA sets out how professionals and carers can make decisions when required under the Act. Section 1 (5) outlines the legal principle of how decision making should occur where a person is found to lack capacity, stating:

> "An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests". (MCA 2005, 1(5)).

Before the assessment of capacity decision making occurs at several points. The decision to assess capacity is seen as a pivotal one in that this decision triggers the statutory assessment of capacity as outlined in Sections 2 and 3 of the MCA. The MCA Code of Practice indicates that this threshold is reached where there is reasonable doubt (Department of Constitutional Affairs, 2007) that the person can make a decision. The notion of reasonable doubt can be vague, and this has been argued as setting a low threshold when embarking on an MCA assessment (Graham and Cowley, 2016). The second point at which decision making occurs is within the actual MCA assessment process. In the process of establishing whether a person lacks capacity because of an impairment or disturbance in the functioning of the mind or brain the assessor will complete what is termed the functional test.

Once it is established that a person lacks capacity to make a decision, this principle stipulates that a Best Interests process should be followed. Building on the principle set out in Section 1(5) of the MCA details of what should be and should not be part of a Best Interests' decision making process is outlined in Section 4 of the MCA. These guidelines are referred to as the Best Interests' Checklist in the MCA Code of Practice (The Department for Constitutional Affairs, 2007) and form a salient guide to health and social care professionals, carers, family members and friends in decision making for matters where it has been established that the person lacks capacity to make a decision. Table 1 in Chapter Two outlined S.4 of the MCA, Best Interests' decision making checklists.

The MCA Code of Practice (2007) points out that while the MCA covers a wide range of decisions, there are some decisions which the Act does not cover (The Department for Constitutional Affairs, 2007). These include what are termed "personal decisions and cover decisions relating to marriage, civil partnership, divorce, sexual relationships, adoption and voting" (Department of Constitutional Affairs, 2007). Under the MCA others are prevented from making Best Interests decisions linked to the above areas, as these are seen as personal decisions which link to individual rights (Ruck-Keene et al., 2019). Looking further at the legal requirements outlined in the MCA and the MCA Code of Practice it can be argued that much of the mental capacity decision making is shaped by unstructured or structured clinical judgements, as opposed to legally directed decisions (Banner, 2012). Common decisions such as what someone will eat or where someone will live, tend to be made involving those who are closely connected with the person who lacks capacity (Department of Constitutional Affairs, 2007). Professionals are often involved in decision making where there are medical, social, or financial decisions such as an admission to a hospital or moving a person to a residential care home (Department of Constitutional Affairs, 2007). These decisions are often more complex and require professional knowledge of the potential options. Clinical decision making has been seen to be a trusted form of decision making in the MCA (Banner, 2012; Ruck-Keene et al., 2019). Case (2016) notes in their analysis of 66 cases referred to the Court of Protection that most experts called to provide evidence around capacity matters were doctors, reminding that the expert opinion of medical practitioners is valued within legal cases linked to MCA decision making (Ruck-Keene et al., 2019).

4.3.9. MCA and participation in decision making

A core aspect of social work practice is to involve people who lack capacity to make a decision in the process of decision making (Wilson et al., 2011) and support their autonomy. The MCA Code of Practice notes that the person making a decision should: "do whatever is possible to permit and encourage the person to take part, or to improve their ability to take part, in making the decision" (Department of Constitutional Affairs, 2007. p.65). However, involving the person in decision making can be challenging (Banner and Szmukler, 2013) as this may not always bring greater clarity as to what the person might decide, particularly in cases where there is a significant cognitive decline (Banner and Szmukler, 2013).

4.3.10. MCA supported and substituted decision making

Decision making for people unable to make decisions for themselves has been demarcated into two categories; substitute decision making and supported decision making. Substitute decision making refers to decisions made by a practitioner or clinician, a legal body such as the Court of Protection, a family member, a carer, or a friend when a person is deemed unable to make a decision for themselves (Devi et al., 2011). Under the MCA, substitute decision making can occur in several ways. Firstly, substitute decision making is found in the Best Interests decision making process under Section 4 of the MCA (Department of Constitutional Affairs, 2007). However, the Best Interests process ensures that the person making the decision considers several factors including the person's wishes and views and the views of people connected to the person. This provides an important distinction from other forms of substitute decision making which confer full decision making rights on others (Davidson et al., 2016a). Substitute decision making is also evident in Court of Protection appointed Deputy appointments under S.16 of the MCA and court decisions made by judges in the Court of Protection (Crowther, 2016). Lasting Power of Attorney is a form of substitute decision making, which differs in that it is invoked by the person at a time when they have capacity to decide. Outside of the MCA, substitute decision making more commonly occurs in compulsory mental health detention and the use of Guardianship (Davidson et al., 2016a). On some occasions, the power (right) to make a decision has been granted to another by the person who is unable to make the decision or by a legal authority such as the Court of Protection in the UK context. This is the case when considering aspects of the MCA which empower people to make advanced decisions (S.24 MCA).

Supported decision making confers that a person will be given assistance in making their own decision (Spencer-Lane, 2016) and presents a more inclusive way of supporting vulnerable people (Davidson et al., 2016a). The Department of Health (2007) publication, Independence, Choice and Risk guidance, highlights a policy for practitioners to encourage individuals to make their own decisions where possible and to receive support to do so. The MCA promotes and encourages a supportive decision making approach through its emphasis on taking practicable steps to help a person to make a decision (Spencer-Lane, 2016; Graham and Cowley, 2015). International legal codes also emphasise the importance of supported decision making. The CRPD indicates that states should put in place appropriate arrangements to provide access by persons with disabilities to the support they may require in exercising their legal capacity (Devi et al., 2011).

Supportive and substitute decision making represent two different approaches to decision making for people who cannot make decisions for themselves, but the differences between these approaches in practice are obscured (Davidson et. al., 2016a) The effectiveness of substitute decision making regimes has been questioned for a variety of reasons including, abuse by empowered decision makers, neglect of understanding the wishes of the person, (Carney, 2012). The debate as between the use of substitute and supported decision making in MCA work has been highlighted by the CRPD, which strongly advocates for supported decision making, suggesting that substitute decision making should be replaced by a supported decision making model (Crowther, 2016; Taylor, 2017). In its endorsement of supportive decision making the CRPD criticised the use of decision making approaches that do not empower people with disabilities to engage in decision making, recommending an end to substitute decision making practices in UK health and social care settings (Crowther, 2016; Devi et al., 2020). Despite this, some studies highlight how substitute decision making can become common practice in certain settings, such as residential care homes (Dunn et al., 2010) and the Court of Protection processes (Devi et al., 2011). This highlights a disconnect between legal and policy encouragement for supportive decision making and what happens in practice (Devi et al., 2011).

4.3.11. Person-centred approaches in MCA decision making

Decision making has often been seen as a professional activity but also draws attention to mental capacity decision making grounded in person-centred approaches (Manthorpe et al., 2014; Case, 2016). Person-centred approaches place the person at the centre of the decision emphasising their wishes as a core part of the decision to be made. These can be contrasted with paternalistic approaches, which place primary emphasis on organisational and professional knowledge as the basis for decision making (Banner and Szmukler, 2013). Paternalistic approaches to decision making are often found in historical accounts of decision making (Banner and Szmukler, 2013) and were noted as commonplace prior to the MCA where there was less scrutiny of ensuring the consent of people who could not make decisions due to incapacity (Series, 2011). Part of the intention of the MCA was to promote autonomy and thus address paternalistic practices which limited decision making (Series, 2011). By using person-centred approaches, social workers endeavour to explore a person's perceptions of themselves and their problems (Teater, 2010) and select an approach that has values which are congruent with their own professional values.

4.3.12. Summary on decision making

Having set out and explored some of the terrain of decision making it is helpful to highlight how the areas covered will be of relevance to this research. This study is anchored within the descriptive realm of MCA decision making, as it looks to explore and shed light on what social workers actually do in terms of mental capacity decision making. While rational approaches to decision making might clarify how to best make decisions (Taylor, 2010) this does not support the primary focus of this study. The focus is firmly linked to understanding social work decision making to build a clearer picture of ways in which decision making occurs.

As a conceptual aspect of this work, there are assumptions that decision making is seen in the light of analytic and intuitive approaches. In this study intuitive approaches to social work decision making will be explored and analysed both in the research study and the analysis of the findings. However, recognition of the clinical dimensions of decision making is also relevant to this work as social work decision making in mental health and mental capacity work has been understood as being linked to clinical decisions (Jayes et al., 2022). Furthermore, clinical decisions may hold further insights into social worker decision making, particularly when social workers make decisions collaboratively with other professionals, such as psychiatrists, doctors and nurses who have clinical training.

4.4. Conclusion

This chapter has explored social constructivism and decision making as conceptual ideas that have shaped initial thinking and planning around the research study. Both theoretical ideas have relevance to the aims and objectives of the study. Social constructivism as a theoretical framework has been applied to the research methodology, where constructivist research paradigms are examined and used as part of the research design for the study. Decision making will be used within this work in reference to the relational aspects. Relational aspects of mental capacity decision making stand out as relevant to this study, as they emphasise how decision making can be best aligned with a person's values ideas and wishes (Banner and Szmukler, 2013). Examination of relational aspects of decision making will be considered in the literature review. Both social constructivism and decision making theoretical ideas are drawn on in Chapter Eight, the discussion of the findings and in Chapter Nine, the conclusions.

Chapter 5: Literature Review

5.1. Introduction

The literature review as a part of this thesis supports the process of clarifying the parameters of the research by exploring the state of existing research on the topic. This literature review aims to address one of the objectives outlined in the introduction, specifically, to review existing knowledge around social work decision making in relation to mental capacity and dementia in younger age people. The chapter begins with an outline of the initial questions that informed the literature review process and then goes on to outline the search strategy used to identify literature, as well as the data extraction approach to select materials for inclusion in the literature review. The review of the literature is broken into three distinct sections based on the initial questions and was identified as a suitable way to identify relevant literature in the overlapping areas of the MCA, social work and YOD. The findings from the literature review identified from these three areas are organised in terms of discussion of the prominent themes. Following this, the chapter includes a discussion of methodological issues found across the literature noting the methodological strengths and limitations of the research found. The chapter concludes by outlining the key messages from the literature review that are relevant for the research study.

5.2. Starting the literature review

There are many ways to undertake a literature review (Bryman, 2016). For this study, it was beneficial to conduct a literature review to help to identify the ideas and themes found in the literature on the subjects of mental capacity and decision making. Furthermore, it was necessary to have a grasp of the quality and strength of evidence in these areas (Booth, et al., 2016). The literature review was driven by core questions, including “What is the past research in the area of mental capacity and social work?” and “What are the key debates concerning mental capacity decision making?”

At the outset of exploring the literature there was a cognisance of the broad scope covered by topics of mental capacity decision making social work and YOD. These topics relate to a wide range of foci for practice and research and based on this awareness there was a desire to understand the relationship between these phenomena. A thematic approach was taken to synthesising the literature drawn out of the search which involved continual perusal of the findings of the studies drawn out at the data extraction stage, then the material was categorised into descriptive themes, followed by identification of the analytical themes which were used as thematic headings in the final write up (Bryman, 2016).

5.3. Literature review questions

The first step taken to develop the literature review was to clarify the underlying purpose of the review and to ensure the process of the review aligns with the research question. The following questions were identified to inform the literature review and give a clearer focus for the literature review:

What is known about MCA decision making and social work?

What is known about YOD and decision making?

What is known about social work and YOD?

5.4. Definition of terms

The definitions of the terms YOD, mental capacity and decision making have already been outlined in Chapter One of this study. The definitions of these terms have helped to recognise the subjectivities around how these terms have been used and continue to be used. For example, YOD has been found to refer to dementia prior to age 65 in some instances and age 60 in others. Awareness of these subjectivities helped to shape the literature review process and were taken into account in the literature search strategy which is detailed below.

5.5. The search strategy

The literature review was initially conducted between February 2018 and March 2018 and repeated in April 2023 to identify any new literature that had emerged in the period since the initial review. The following databases were used in the search. PsycINFO, PubMed, ScienceDirect, Web of Science, Scopus, Social Care Online, Academic Search Complete (via Senate House) and the Cochrane Library. Peer-reviewed studies from selected journals were used to support the literature search. The following journals were used: Ageing, Dementia, Ageing and Society, the Journal of Dementia Care and the International Journal of Dementia Care and Gerontology. Grey literature was drawn from Google Scholar and Government websites such as the Department of Health and Social Care. To try to capture relevant literature a broad range of key terms were used including Boolean searches. For the literature search on decision making and YOD the following search terms were used:

decision making, decisions, young onset dementia, younger onset dementia, early onset dementia, working life dementia, young onset or early onset AND dementia AND NOT elderly or older, dementia pre-65 years. Young-onset Alzheimer's or "vascular dementia" or "frontotemporal dementia" or ''acquired brain injury'' or ''Lewy body'' and ''cognitive impairment''.

For the literature search related to mental capacity decision making and social work the following search terms were used:

social work, social workers, social care professionals, mental capacity, mental capacity act, mental capacity decision making, decision making, social work and mental capacity AND NOT mental health.

For the literature search related to YOD and social work the following search terms were used:

young onset dementia, younger onset dementia, early onset dementia, earlier onset dementia, working life dementia, dementia pre-65 years, young onset dementia or "early onset dementia" AND dementia AND NOT ''elderly'' or ''older'', "younger onset Alzheimer's'' or "vascular dementia'' or ''frontotemporal dementia'' or ''acquired brain injury'' or ''Lewy body'' and ''cognitive impairment''.

The criteria for inclusion and exclusion of studies differed for each of the three literature searches. The inclusion and exclusion criteria are set out in Table 2.

Table 2. Inclusion and exclusion criteria in the literature searches

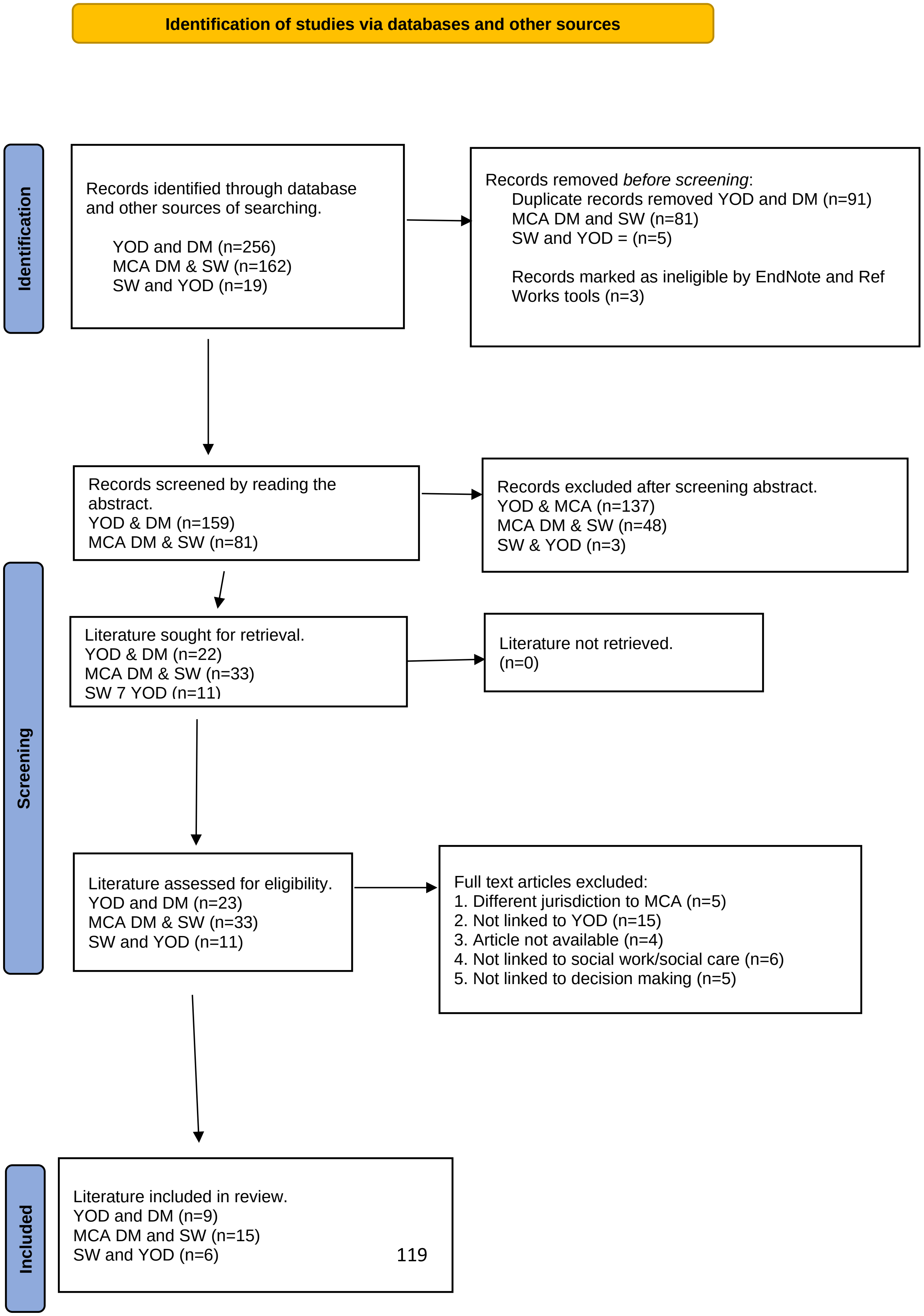
Literature search	**Inclusion criteria**	**Exclusion criteria**
Literature search on decision making and YOD	Studies published in the English language Studies related to the diagnosis of dementia before age 65 years	Studies that are not related to YOD Studies not related to cognitive decline
Literature search on mental capacity decision making and social work	Studies published in the English language Studies published since 2007	Studies that do not relate to the MCA 2005 Studies that are not related to decision making Studies not including social work or social care
Literature search on social work and YOD	Studies published in the English language	Studies not published in the English language

5.6. The Data extraction approach

Booth et al, (2016) note that “extracting data is key to demonstrating that you have followed a systematic approach” (p218). Therefore, as part of seeking to achieve a robust review of the literature a data extraction approach was taken to ensure the literature found corresponded to the review questions. The process of extracting data included selecting studies after reading the abstract of the study and then adding studies of interest were added to an EndNote database. The details of the selected studies were transferred to a data extraction table. For the data extraction tables see Appendices One, Two, Three and Four. The process of identification, screening and selection of studies has been detailed in a Prisma flow chart, Figure 2. Duplicate records of studies were removed during the initial phase and any literature that was not able to be retrieved were excluded. Literature was excluded from the review for four main reasons. Firstly, literature in the MCA decision making search that did not address mental capacity within the England and Wales context were excluded. The second reason for exclusion was where literature was not linked to YOD. This proved challenging as many studies use dementia as a generic term and do not always specify whether there is an age focus. Literature not related to social work or social care was excluded from the search looking at YOD and social work and in the YOD and decision making search, studies not linked to decision making were excluded.

As noted in the introduction to this chapter, the literature review has been separated into three distinct sections in line with how the literature search was carried out. The three sections are: decision making and YOD, mental capacity decision making and social work and social work and YOD. The reasons for delineating the literature into three areas are based on the recognition that they are within themselves quite broad areas of enquiry; there are overlaps between each literature review search. Each literature review search area was then analysed, identifying key themes drawn from the literature search.

Figure 2 PRISMA flow diagram for identification of studies for the literature review



Literature review findings

5.7. Methodological issues

This section of the literature chapter draws observations on the methodologies used in the studies that have been appraised as part of the literature review. The purpose of reviewing the methodologies is to evaluate the strengths and reliability of the literature found.

Most studies followed a qualitative research design from the literature search on decision making and YOD. However, this is not surprising as the topic under discussion indicates that a deeper understanding of the experiences of people and professionals was needed. A range of methods were used including systematic reviews, interviews, ethnographic approaches and focus groups. The sample size varied from 8 to over 600. From the studies extracted from the mental capacity decision making and social work literature search there were a mixture of quantitative and qualitative studies. The quantitative studies unsurprisingly included larger samples. For example, Ariyo et al. (2021) had a sample of 611. The literature search linked to social work practice and YOD identified a small number of studies and within these studies mixed methods approaches were used. The methods used included a Delphi study (Couzner et al., 2022; Clerk et al., 2018) a case study (Regan, 2016), a quantitative analysis of cases (Chemali et al., 2012) and documentary research (Manthorpe (2014). The sample sizes tended smaller, apart from Chemali et al. (2012) which had a sample size of 85 as part of their quantitative study.

In the Decision making and YOD and the Social Work and YOD literature reviews, the literature identifying dementia in people below age 65 years was targeted. The literature found many of the studies defined YOD as being dementia found in ages below 65 years, although this was not universal. Pipon-Young et al. (2012) for example, included in their sample, people between the ages of 60 and 67 years who had a diagnosis of dementia before their 65th birthday. Not all of the studies used the term YOD, and some studies like Chemali et al. (2012) used the term Early Onset Dementia. Other studies like Manthorpe and Samsi, (2013); and Rodda and Carter, (2016) omitted age references and some studies appear to cover both YOD and LOD dementia (Livingston, *et al.* 2010).

From the findings of the literature searches, the terminology used to describe decision making is wide-ranging. Decision making as a search term did not always lead to results, however, when terms like involvement and assessment were applied a richer array of studies highlighting decision making appeared. This supports the notion that decision making refers to a broad range of phenomena often linked to choices and outcomes.

5.8. Decision making and YOD

Looking firstly at the findings from the literature review linked to the search on decision making and YOD this section outlines the key themes drawn out from the literature search. Nine studies were identified and included in the review that explored decision making and YOD. The themes include material drawn from grey literature.

There is a recognisable body of literature which explores the phenomena of dementia. This literature is growing and covers a range of topics and themes including, treatments, diagnosis, care and support, relational matters, services for people with YOD and the experiences and needs of families and carers. Less is known about the experiences of people in younger age groups who have dementia (Greenwood and Smith, 2016) and dementia services tend to focus on LOD, due to its greater prevalence in people over the age of 65 (Greenwood and Smith, 2016); Clemerson et al., 2014). Care pathways for people with YOD have been found to be less clear and the provision of services is recognised to be variable across the UK (Rayment and Kurvilla, 2015), which informs that there is a lack of unifying policy and guidance on care and support for people with YOD. Furthermore, decision making for people with dementia at a policy level often involves a range of key actors including clinicians, political actors and commissioning managers (Alzheimer’s Society, 2016)

5.8.1. Family and carer involvement in decision making

Studies exploring YOD and LOD recognise the key role that family and relational support systems play in the care post-diagnosis (Rabanal et al., 2018; SCIE, 2011; Stamou et al., 2022; Manthorpe, 2014). It remains evident that these support systems are likely to have a central role in the decision-making processes when YOD dementia has been recognised. Family support is often evident throughout the early and into the later stages for people with YOD (Rayment and Kurvilla, 2015). Still there is limited research on the role families play in support following a diagnosis (Greenwood and Smith, 2016). The impact of YOD dementia on family decisions was noted in Svanberg et al.'s (2010) systematic literature reviews drawing on 26 studies around YOD. Svanberg et al. (2010) confirm the family as key following the diagnosis of dementia, but mainly focus on the needs of families rather than the challenge a diagnosis might bring for decision making. This, like other studies (Greenwood and Smith, 2016; Clemerson, et al., 2014) recognises the poor provision of services for people who have been identified as having YOD.

Focusing on how family members contribute to decision making as a form of "support" evidence emerges from a range of research highlighting that family carers actively support decision making for people with YOD (Lai et al., 2019; Boyle, 2013). Livingston et al., (2010), in their study, Making decisions for people with dementia who lack capacity, draws attention to the unrecognised ways in which family carers contribute to "difficult" decision making for a relative with dementia. The study drew on the experiences of approximately 40 family carers using focus groups and interviews. The findings reveal that there are identifiable obstacles family carers face in decision making suggesting that these obstacles are a source of guilt, with conflict impacting the emotions and coping strategies within families where there is a diagnosis of dementia (Livingston, et al., 2010). The study is valuable to understanding family involvement in decision making when YOD is present, although its focus on "difficult" decisions may not accurately inform the scope of decision making. A limitation of the Livingston et al., (2010) study is that it looked at dementia in a range of ages rather than solely focusing on YOD, so the findings may be more applicable across all people with dementia. Studies that explore family involvement in decision making highlight that families remain essential in the processes connected to decision making for people with YOD. This was an aspect in Lai et al. (2019) who recognised that decision making for people with YOD is an interdependent process involving people with dementia and their close family members. Their study focused on future decision making around advanced care planning and found that decision making is more individualised to families with a lack of a recognisable approach.

5.8.2. Social factors in decision making

Alongside these individual or personal factors, the literature shows that there is evidence of social factors which influence decision making. Social factors as found in the literature reviewed refers to the social circumstances of people with dementia and their families rather than factors relating to what is happening in their bodies. Social factors include issues around housing, employment and family size but also refer to matters that can affect how people with dementia live, such as stigma, discrimination and access to services. While studies have recognised the impact of dementia on the person there is growing awareness of a need to gain a better understanding of the social circumstances and the social impacts that are associated with YOD (Manthorpe and Iliffe, 2016; Manthorpe, 2014; Greenwood and Smith, 2016).

In exploring social factors Greenwood and Smith (2016) in their systematic review of literature on younger age people with dementia, highlighted challenges which they found to be unique to this group. Greenwood and Smith's (2016) study draws attention to access and engagement in society which facilitates decision making. Their findings point out that stigma, social isolation and social exclusion are often overlooked, but remain central to addressing the negative impact that dementia has on engagement in activities. The impact of stigma for those who experience YOD has been noted by other studies and literature. Roach, et al., (2014a) noted stigmas as a significant theme in evaluating the subjective experiences of people with YOD and their families and Ramluggun and Ogo (2016) highlight the impact stigma has regarding younger persons with dementia's withdrawal from common activities such as attending social clubs or going out for meals. The significance of stigma has been noted in wider factors which influence and potentially hinder decision making.

The relevance of social factors has also been brought to light by Clemerson et al. (2014) who examined the views of eight people with young-onset Alzheimer’s disease and found that for the participants, the social context mattered in understanding ways of coping with the condition. Although Clemson et al. (2014) was a small study, it does illuminate understanding of dementia, offering a different perspective on how dementia impacts a person’s life beyond the difficulty of diagnosis and how to remedy it (de Vugt and Droes, 2017). The study conclusions make the important point that change across the whole society is a key solution to addressing the marginalisation and stigma experienced by those with YOD, although this too is a limitation of their work, as little clarity is given to how societal change can be achieved. Further support for the relevance of social factors in YOD and decision making is found in Boyle and Warren’s (2013), two-year Economic and Social Research Council qualitative study examining the social processes of everyday decision making by people with dementia. Boyle and Warren’s (2013) study explored an understanding of how dementia impacts everyday processes. Although their study was not specifically focused on YOD, it does include people diagnosed with dementia before the age of 65 years, hence its inclusion in this review. In relation to decision making Boyle and Warren’s (2013) findings emphasise social factors such as the gender impact on key decision making processes for couples where dementia arises. Further to this, Boyle and Warren (2013) draw on the example of financial decision making to reveal how gender has a distinct role in decision making, leading to their conclusion of the need to look beyond cognitive factors in dementia to recognise the social factors embedded in decision making for those with dementia.

Included in the theme of social factors is that of employment. The condition of dementia before the age of 65 can lead to a disturbance in employment, friendships, hobbies and social activities. (SCIE, 2011). Understanding the impact that dementia has on activity has been explored to understand the experiences of younger people post-diagnosis. Pipon-Young, et al.’s (2012) detailed action research study of people’s experience of dementia recognised the difficulty associated with loss of employment for those who are diagnosed during their working age. Employment support however was a minor theme in Pipon-Young's study and little is known about the younger age people with dementia who have employment support needs. The Royal College of Psychiatrists, (2006) in their report on services for younger people with dementia and their carers*,* outline employment decisions as a pivotal issue, recommending that practices are developed to support people with dementia who have to give up employment. Although The Royal College of Psychiatrists (2006) had no recognisable empirical work linked to their report it does draw on previous studies that emphasise employment as a factor in YOD.

5.8.3. Personal and individual factors in decision making

YOD impacts all aspects of a person's wellbeing and there is often a need for increased care and support to be provided to the person as the condition progresses (Young Dementia Network, 2022b). Individual factors associated with YOD and decision-making focus on the impact of the condition, drawing attention to how the person makes adjustments and copes with stress and the psychological aspects related to the condition. As well as affecting their overall well-being, YOD has a lasting impact on a person's psychological and emotional well-being (Rayment and Kurvilla, 2015). It leads to diminished coping abilities and the stress of diagnosis and coming to terms with the condition profoundly affects wellbeing. Cosgrove and Williams (2004), in their report to the Alzheimer's Society focusing on services for people who have YOD, discuss individualised approaches. For Cosgrove and Williams (2004) an individualised approach refers to the need for greater personalisation, emphasising the centrality of the person in decision making. Some studies recognise that diagnosis of YOD also impacts identity and how self-identity shapes the person's perspective (Boyle, 2013). Clemerson et al. (2014) make the point that the changes in identity and sense of self, following a diagnosis of dementia in younger age people, lead to a sense of loss for the person. This loss and change are considered to impact decisions related to engaging in new activities, although further evidence may be required to support this assertion.

5.8.4. Involvement of people with YOD in decision making

Across health and social care services there have been significant developments in the involvement of people who use these services. Early attempts have focused on patient councils and separate forums for “patients,” “service users” or “clients”. The widely recognised work of Arnstein (1969) outlines a progressive ladder of involvement for people with lived experience, ranging from non-involvement in decision making to full control. More specifically, in dementia services the involvement of people with dementia has been linked to furthering their social recovery (Pipon-Young et al., 2012). The involvement of people with dementia in their care is noted by several studies such as Clemerson et al. (2014) and Pipon-Young et al. (2012), although there is a lesser mention of involvement in decision making processes in these studies.

International studies identify that decision making is impacted by cognitive and physical decline. Even so, the benefits resulting from involving people with dementia in decision making have been noted in studies exploring LOD dementia (Boyle, 2013). This, however, is less clear when exploring YOD. Several studies have explored the views of people who have YOD or their carers and made recommendations for greater involvement in decision making (Pipon-Young et al., 2012; Roach et al., 2012, Livingston, et al., 2010), yet they fall short of charting what involvement in decision making looks like. Carter et al. (2018) draw attention to the need for increased supported decision making. This identifies a gap in the literature around YOD and decision making.

5.8.5. Professional decision making and YOD

Professional input for people who have YOD usually begins at diagnosis. Current evidence suggests that the time taken to achieve a diagnosis for younger age people with dementia is longer than it is for those being diagnosed later in life (Rodda and Carter, 2016). These lengthier time scales for diagnosis are problematic for the person and their family (Carter et al., 2018). Therefore, the role of professional decision making in the early stages of the impact of YOD is likely to be crucial and often vital to the person and their family. Once a person has received a diagnosis indicating YOD, some suggest that difficulties in professional support persist. For example, the Royal College of Psychiatrists (2006) highlights that there is a lack of post-diagnosis multidisciplinary services for those with YOD. The suggestions of the Royal College of Psychiatrists have been echoed in studies such as Stamou et al. (2022), Rabanal et al. (2018) and Clemerson et al. (2014) all of which noted the lack of coordination between professionals and services for people who have YOD. Rayment and Kurvilla (2015) in exploring the challenges faced by younger age people with dementia noted that the lack of specialised services and professionals has led GPs to be unsure who to refer people with YOD to. Similar findings are noted by Rodda and Carter (2016) in their survey of professionals' support for people with YOD. Rodda and Carter (2016) draw attention to the variability of services and professionals involved in YOD, stating that some professionals lack the opportunity to participate in multi-professional case discussions. Some studies recognise the lack of a multi-disciplinary team presence in the care and support of people with YOD (Ramluggun and Ogo, 2016), while others highlight the lack of the presence of social work within care decisions for people with YOD (Manthorpe, 2014).

Studies such as that of Livingston, et al. (2010) which sought to highlight the difficult decisions made by family carers, also managed to draw attention to the role of professional support to family carers in their role in making decisions for their relatives with dementia. For Livingstone et al. (2010) the involvement of professionals assisted families by offering emotional support and relieving them of the weight of decision making. However, this draws attention to the difficulty that can arise in obtaining the consent of a person to involve family carers in decision making. Alongside supporting families to make decisions professionals and other family members were seen as important sources of practical and emotional support for family carers.

5.9. Mental Capacity decision making and social work themes

This next section of the literature review focuses on the themes drawn from the literature search around MCA decision making and social work. A total of 15 studies were included in this review of the literature. Themes have been drawn from the studies and grey literature that was found by the literature search. Since the implementation of the MCA in 2007, it has had a significant impact on professional behaviour in health and social care settings. In the early stages, following the implementation of the MCA it was indicated that it would empower the rights of people who were deemed to not be able to make decisions for themselves (Manthorpe et al., 2009; Mac Kenzie and Rogers, 2013; Boyle, 2008). Further to this, the MCA has been argued as representing a re-balance against what can be seen as paternalistic practice particularly in health and social care (Brown, 2015). Social work practitioners like other professional areas have had to absorb and implement the changes that have come about following the implementation of the MCA 2005.

5.9.1. Best Interests decision making

Several studies highlighted the impact of Best Interest decision making found under s.4 of the MCA on the decision-making process. Many of these studies recognise the role of professionals in decision making within the use of s.4 of the MCA. Williams, et al. (2012a) carried out a study commissioned by the Mental Health Foundation. Their study used surveys and interviews with a significant number of professionals which included social care workers. Their study was at the time the most extensive study of its kind, with more than 450 participants, in a collection of online surveys, telephone interviews and face-to-face interviews, drawn across four areas in England. Although the primary purpose of the study was to explore how best interest decisions were being made following the implementation of the MCA (Williams et al. 2012a), its findings shed light on a range of issues relevant to social work practice using the MCA. Of great significance, the study recognised professional perceptions that there has been an increase in decision making for professionals following the implementation of the MCA. Linked to this finding, the study asserts that professionals appear to have been empowered in their decision making. Similar findings were recognised by Manthorpe and Samsi (2016b) in their qualitative study of decision making in care homes, from which they concluded that the MCA 2005 through Best Interest decision making appeared to contribute to supporting the legal knowledge of practitioners (Manthorpe and Samsi, 2016b).

The findings by Williams et al. (2012a) and Manthorpe and Samsi, (2016b) can be contrasted with studies highlighting a more complex picture around Best Interests and decision making. These studies note that the MCA has had limited success in promoting the rights of people who lack capacity to make decisions for themselves. Boyle (2013), for example, found this to be the case with dementia patients and their carers. In their research, Boyle (2013) explored the communication and decision-making abilities of spousal couples where dementia was a factor. The research highlighted that MCA decision making was a complex activity which did not always follow a sequence. The findings noted that rather than promoting decision making, the MCA was found to reinforce gendered assumptions through the practitioner's assumptions about male spouses managing finances and spending. Murrell and McCalla *(*2016) consider the complexity of understanding decision making under the MCA 2005, specifying the variety of ways in which provisions of the MCA offer opportunities to make decisions.

5.9.2. MCA supported and substituted decision making

The literature recognises that the MCA contains two forms of decision making; substitute and supported decision making. Supported decision making refers to the support and assistance given to a person to make a decision, whereas substitute decision making infers that a person makes a decision on behalf of another, who is deemed incapable of making the decision (Devi et al., 2011). The MCA expanded the use of supported decision making or what is sometimes referred to as “assisted decision making” where the MCA is used but also continues to endorse aspects of substitute decision making such as the roles of a Best Interests decision maker or a Court appointed deputy. Supported decision making within the MCA is seen as important as it helps to maintain the autonomy of the person by identifying assistance for the person to remain engaged in decision making. In the literature both supported and substitute decision making are noted. Dunn et al. (2010) explored substitute decision making with social care support workers in residential care homes, finding that substitute decision making was justified by the support workers and helped the residents to live a good life, although support workers interpreted substitute decision making within a moral framework of their care for the person, believing that this would result in “better” outcomes for the person subject to the substitute decision making. Dunn et al. (2010) went on to suggest that there was a need for further training around Best Interests indicating that greater attention could have been paid to supportive decision making approaches.

Closely linked to supported decision making are ways in which the MCA can be used to involve people. There has been an emerging discourse around the involvement of people who use services and decision making (Graham and Cowley, 2015). Fundamental to the MCA is the belief that a person should make decisions whenever possible as endorsed by the MCA Code of Practice (Department of Constitutional Affairs, 2007). Several studies included in the review consider the importance of involvement in MCA capacity decision making.

5.9.3. Advanced decision planning, Lasting Power of Attorney and delegated decision making

The MCA outlined new pathways which support decision making. These include advanced decision making, which refers to decisions made by a person at a time when they have capacity to make a decision to be able to refuse treatment at a time when they lack capacity (Department of Constitutional Affairs, 2007). Some of the new decision-making opportunities outlined within the MCA such as Lasting Powers of Attorney already existed in other forms. For example, Enduring Power of Attorney existed prior to the MCA but was updated by the MCA. These have become important sources of decision making within the MCA, increasing options for people to have their wishes recognised in situations where they are unable to make a decision. Studies included in the review note that the MCA has enabled new ways of decision making. For example, Manthorpe and Samsi (2016b) recognise the contribution of advanced planning to general decision making in their qualitative study on the use of the MCA in care homes. They found the use of advanced planning had become more commonly used in practice in relation to care home residents. Other studies such as Jepson et al. (2016) note the lack of awareness around Lasting Power of Attorney and advanced decisions for staff. These studies say little about the role of social work in using advanced decision making.

5.9.4. MCA Assessment and decision making

The MCA has drawn a greater focus on the assessment skills practitioners need when determining whether a person can make a decision. The MCA assessment process involves decision making and this has been evidenced in the literature (Ariyo et al., 2021). It has been noted that MCA assessment is a regular activity for social workers. Ariyo et al. (2021) for example, confirmed that professionals such as social workers can commonly engage in over twenty-five MCA assessments per year and notes that professional confidence in using the MCA appears to be growing. Many studies recognise that assessment of capacity involves decision making and it is often not straightforward. Murrell and McCalla, (2016) explored how MCA assessments are carried out in practice in their qualitative study of five social workers in a local government county. Their study noted that participants spoke about the complexity of assessing capacity and the salience of knowledge and confidence (Murrell and McCalla, 2016). Decision making within MCA assessments was found to be difficult for a range of reasons that included fluctuations of capacity, a lack of information and the competing demands of social workers. Similar findings were noted by Emmet et al. (2013) in a study exploring hospital discharge for people with dementia and Jayes et al. (2020) in their study exploring health and social care workers MCA assessments. Jayes et al. (2020) found that MCA assessment practices of health and social care workers have wide variations, with some workers not always following legal requirements of the MCA by using the two-stage assessment process. Their findings highlighted that health and social care professionals could benefit from further resources and aids to support their decision making.

Murrell and McCalla’s (2016) study of social workers' use of the MCA notes that the assessment of mental capacity can be conflated with the assessment of Best Interests by social workers. This conflation of assessment of capacity and Best Interest decision making which are different aspects of the MCA, suggests that professionals adapt the provisions of the law using their own discretion. Exploring this further the conflation can pose a problem in that the assessment of capacity under Section 2 and Section 3, of the MCA could be subject to pre-determined ideas about a person's best interests. Murrell and McCalla are not alone in recognising this problem. Jayes, et al. (2020) in their review of several studies draw attention to formal processes not always being used. McDonald (2010) notes that predetermined Best Interests decisions was a finding in relation to residential care admission, suggesting that this is relevant not only to social workers but probably to other professionals as well. Williams, et al. (2012a) cited as one of their key themes, the conflation of capacity and best interests being an unforeseen practice development which is influential in decision making under the MCA. This finding which has been noted as occurring in several studies raises concerns about whether the MCA is being used properly by professionals in their decision making (Jayes et al. 2020).

Recent research on MCA assessment has drawn attention to the more complex matters in MCA assessment. Ariyo et.al. (2021) in their research study exploring the experiences of professionals identified issues of interpersonal undue influence in MCA assessment carried out by professionals including social workers   Undue influence in MCA decision making refers to situations in which a person who lacks capacity to make a decision receives support in decision making when the support is not appropriate (Craige, 2023). Ariyo et al. (2021) noted that professionals hold concerns about undue influence in their mental capacity work but had little or no resources on how to address it.

5.9.5. Risk and decision making

The MCA has drawn a greater focus on the autonomy of people who receive health and social care services. However, focusing on autonomy can overlook the wider trends in health and social care practice which include an increasing focus on addressing risk (Koubel and Bungay, 2012). Social work literature has sought to draw attention to understanding risk as an aspect of the assessment process (Koubel and Bungay, 2012), so it is not too surprising that risk appears prominent in the literature exploring mental capacity and decision making. Williams, et al. (2012b) found that professionals believe that risk is core to the process of assessment and decision making and in some cases was the basis of decision making. Wilner et al. (2011), as part of their study looking at professionals within community learning disability teams noted a lack of awareness from different practitioners, including social workers, on risk issues. The lack of awareness of risk was linked specifically to the community learning disability setting. Clerk et al. (2018) in their study explored risk issues in MCA decision making, highlighting how risk in mental capacity work can be seen as an ethical issue. They explored how mental capacity can be linked to ethical theories of consequentialism and deontology. McDonald (2010) in her study of social work decision making and approaches to risk draws attention to the different ways in which risk can be understood when using the MCA. McDonald's (2010) research looking at the perspectives of social workers in carrying out MCA assessments with older people with dementia recognised the need for a critical approach to risk assessment (McDonald, 2010). The study informs that risk can be oversimplified which can lead to overlooking the rights to be treated with respect and equal concern for people with dementia.

5.9.6. Advocacy

The MCA 2005 introduced several new roles such as advocacy the role of the Independent Mental Capacity Advocate (IMCA) found in Sections 35-36 of the MCA 2005). Advocacy is increasingly being seen as a key aspect of support available to people who fall under the provisions of the MCA, where there are significant decisions to be made. Some studies recognise the role of the IMCA as a source of advocacy in supporting decision making (Dunn et al., 2010; Manthorpe et al., 2009; McDonald, 2010; Williams et al., 2014). The IMCA role is appraised as valuable but lacking promotion and awareness within social work. Furthermore, the literature notes that people who could benefit from IMCA support are often not aware of the assistance they can receive. Some of the literature found highlights the need for greater advocacy, even outside of the formal role of the IMCA (Murrell and McCalla, 2016).

5.9.7. Training and the MCA

Many of the studies included in the review draw conclusions indicating more training is required by social workers on the provisions of the MCA (Jayes et al., 2020; Wilner et al., 2011; Williams et al., 2014; Murrell and McCalla, 2016). Wilner et al. (2011), from their study of professionals in learning disability teams, highlighted the importance of training to fill the gaps that professionals held in how to identify whether a person has capacity or not. Manthorpe et al. (2009) in their study exploring the experiences of people with learning disability and their carers highlight the limited awareness of the MCA that existed at the time and the need for professionals to provide training to people who fall under the MCA as well as to their carers.

5.10. YOD and social work practice

Exploring the literature linked to social work practice and YOD brings together two quite different topic areas. Literature on social work practice and YOD is limited and much of the literature exploring social work and YOD is subsumed within studies that explore a range of health care and social care professionals and their practice with YOD. Only one of the studies involved direct contact with social workers, confirming that little research data is looking at social work and YOD. Couzner et al., 2022), detail an international Delphi study conducted online with a range of health and social care experts including social workers, to establish consensus around what professionals need to know about YOD. Only one social worker was involved in the study out of a total sample of 19 (Couzner et al., 2022) which suggests that there are limited messages for social workers from this study. Furthermore, there were no specific findings identified by the authors that relate to social work. Couzner et al.’s (2022) study highlights the importance of multidisciplinary working and the importance of care and support services, such as social work, as part of the need for comprehensive YOD care (Couzner et al., 2022).

5.10.1. Accessing social work services

Out of the studies found, three studies referred to issues of access to social work services. Reagan (2016) outlines research carried out in the form of a case study involving a Pakistani Muslim man, diagnosed with YOD in his early fifties. The study provides an in-depth exploration of the motivations and experiences of the participant drawing attention to the cultural and religious aspects of dementia. Reagan’s (2016) study highlights that barriers to dementia health and social care services exist for Black and Global Majority groups (referred to as underrepresented groups) in the UK and there can be a lack of awareness from within these groups as to what services are available. The barriers to services and lack of awareness were pointed out as contributing to negative experiences. Stigma was identified as a theme that helped to explain the underrepresentation of Black and Global Majority people accessing dementia services (Reagan, 2016). In addition to racial background, religion and being aged under 65 years with a diagnosis of a rare dementia type were noted as barriers to accessing health and social care services.

Access to social work services was a key finding for Chemali et al.,(2012). Their study involved a review of the medical records of 85 patients at a memory disorder unit where assessment for YOD was being carried out (Chemali et al., 2012). Lack of access to social work services as well as financial support and employment support was a noted finding from their study, which asserted that this deprivation had an impact on the person and family network, although these challenges may also be present for people who receive a diagnosis in later life (Chemali et al., 2012). The study asserts a need for social work assessment to be integrated into the care plans of those undergoing assessment for YOD diagnosis (Chemali et al., 2012). Manthorpe (2014) carried out historical documentary research drawing findings from a book written by a social worker who worked with people recovering from neuro-syphilis related dementia in the 1940s and early 1950s. The research offers a novel documentary analysis of a social worker’s case notes in the post-war years and can be appraised for highlighting how social workers operating during a specific period engaged with people experiencing a rare type of dementia. Manthorpe (2014) notes that following the diagnosis of dementia at a younger age, many of the patients had changed roles. The study highlights the usefulness of this type of historical research for contemporary social work to help “build on its legacies” (Manthorpe, 2014 p.1108). Manthorpe (2014) notes access to social work support was linked to institutional care within the hospital setting. The involvement of a social worker included providing information about the hospital care, and the welfare system including housing support and children’s support services for people who were all in the early stages of developing dementia (Manthorpe, 2014). From these studies, the theme of access to social work input appears to hold some importance for people with YOD. The studies provide indications that there may be needs and issues that are relevant for social work intervention, although from the appraisal of three studies, this suggestion cannot be generalised without wider evidence.

5.10.2. Exploring social circumstances

Social work practice interacts with people in their social environment, so social circumstances are key to the interventions of social workers. The social circumstances of those experiencing YOD were a theme found by Manthorpe (2014). Referring to the social circumstances evident at the time, Manthorpe's study identifies overcrowding, poor housing, and multigenerational family environments as a set of challenges that the social worker sought to address. Manthorpe (2014) linked the findings from her documentary research to contemporary themes in social work such as continuity of care and help in addressing financial difficulties reinforcing peer and group support systems as a way of addressing the needs arising out of the social circumstances of those with dementia. Social circumstances were relevant to Reagan's (2016) study. Reagan (2016) found that isolation was a negative outcome of losing confidence and hiding the experience of dementia from those in the wider religious and cultural community.

5.10.3. Family support

Reagan (2016) and Manthorpe (2014) highlight linkages between social work and family support. Reagan notes that family support can be a difficult issue for people with YOD and highlights the perspective of a person with YOD not wanting to "burden" family members and being part of the reasoning involved in deciding to access social care services. Reagan's (2016) finding is in contrast to wider YOD research, which tends to draw attention to the salience of family support for people with YOD (Clemerson et al.,2014; Roach et al., 2012; Roach et al., 2014a; Manthorpe et al., 2013). Manthorpe (2014) draws attention to social work practice including recognition of the wishes and needs of family carers as well as exploring stresses and providing advocacy. Although based on historical documentary research Manthorpe (2014) recognises how this finding holds similarities to wider social work practice in the present day.

In summary, the literature search on YOD and Social Work revealed that there is a paucity of literature exploring these topics. Of the literature found, the studies were small-scale or had low numbers of participants. The themes that arose from the literature draw attention to access issues within social work organisations as well as providing limited insights into areas that social work practitioners may come across when working with YOD.

5.11. Summary of findings and themes

This literature review has drawn together key strands of research and knowledge relating to YOD, decision making, mental capacity and social work. From the literature review it can be concluded that there is a growing body of evidence exploring YOD, scoping a range of fields of inquiry. The literature acknowledges that the experience of people with YOD has many similarities with that of dementia in later life, but there are also differences (Manthorpe, 2014; Greenwood and Smith, 2016; Reed, et al., 2011). These differences include both medical and social aspects. Medical differences include greater evidence of rare forms of dementia for those with YOD (Reagan, 2016; SCIE,2020a).

The findings from the literature on YOD and decision making raise salient themes linked to the decision making process, as well as the involvement of family members and people with YOD in decision making. Studies such as that by Clemerson et al. (2014), emphasise the need to raise awareness of YOD and highlight the need for supportive services and studies such as that by Greenwood and Smith (2016), have drawn attention to the experiences and the voice of people with YOD.

Several studies recognise the importance of the involvement of people with YOD in their care and their involvement in decision making (Livingstone et al., 2010; Pipon-Young et al., 2012; Roach et al., 2012). The link between the involvement of people with YOD in their care and their decision making is interesting and should lead to greater efforts to centre YOD care and plans based on the person with YOD rather than the professional. However, there may be a dichotomy between theoretical discussion of involvement in decision making and research evidence of this involvement, which several studies highlight by recommending that greater efforts are made to involve people with YOD in decision making (Pipon-Young et al. 2012; Roach et al. 2012).

The role families and carers play in YOD decision making has been explored and discussed in a number of studies, often highlighting the challenges faced by families, who may or may not be carers. The findings and discussions from studies such as Clemerson et al. (2014) suggest family caring roles are central to decision making. This aligns with evidence drawn from charities and voluntary organisations that are strong campaigners for the voices of families to be heard in commissioning and policy discussions (Young Dementia Network, 2022b; Dementia Alliance 2016). However, the findings of this literature review indicate that families and carers do sometimes feel misunderstood (Livingston et al. 2010; Clemerson et al., 2014). Misunderstandings around carers' roles and wishes contribute to the process of decision making and studies recognised this can lead to feelings of detachment from the decision making processes. Several studies recognise the impact of the diagnosis on the person, their family and all who are seen as key to decision making (Williams et al., 2012b; Boyle, 2013; Reagan, 2016). Diagnosis remains a key juncture for people with YOD and is often the gateway to professional support and services.

Social factors relating to YOD provide rich and interesting material when explored through the lens of decision making. Recognition that changes in employment, the presence of stigma and social isolation influence the identity of the person (Greenwood and Smith, 2016; Boyle, 2013) and in turn impact decision making is a key finding from the literature explored. Historically, dementia studies have tended to be medically dominated with less attention given to the social aspects of YOD, but there is potentially much to be gained from understanding the social factors involved in decision making for people with YOD. As highlighted in the review, social factors draw attention to the barriers which people with YOD face (Greenwood and Smith, 2016).

5.12. Gaps in the literature

The literature review illustrates that there is a small but growing research base on YOD. The second round of literature searches carried out in 2023 confirms this as more studies for potential inclusion in the literature review were found in the 2023 literature search. There are, however, notable gaps in the literature especially in relation to social work and YOD. Manthorpe (2014) recognises this in her documentary research noting the 'rarity' of discussion about social work within the dementia discourse. Sparse literature was found in relation to social work practice and YOD and little evidence of the perspectives of social workers. The review highlights that despite in use for over 15 years, the MCA is not so prominent in the literature exploring decision making for people who are unable to make their own decisions. This is also true of mental capacity in relation to YOD literature.

5.13. Limitations of the literature review

Carrying out literature reviews involves a range of skills involving analysing, summarising, and appraising literature. As a novice researcher the author is aware that there may be limitations in the work compared to a more experienced researcher. This literature was carried out by a single researcher who led the process of collecting and analysing data and writing up findings without the benefit of comparing findings with other researchers. Carrying out a literature review with three distinct topic areas - mental capacity, YOD and social work, meant that there was some level of overlap in the studies found. For example, Manthorpe and Samsi (2013) could be categorised in both decision making and YOD and social work and YOD. Completing a literature review involves the subjective processes of identifying relevant search terms and selecting databases in which to carry out the research. Specific databases were used and these were drawn from available databases in the university's online library system and from identifying databases used in studies exploring similar topic areas.

Reflections on the literature review process highlight that this was an extensive task carried out in two relatively distant periods. The amount of literature available in the first phase in

2018 was quite limited and by the time of the second search, there was a greater amount of literature available. This was particularly true in the case of literature linked to MCA decision making and social work. This reflects the growing research and literature generated within the four to five year time span.

5.14. Conclusion

This literature review set out to answer the following questions:

What is known about MCA decision making and social work?
What is known about YOD and decision making?
What is known about social work and YOD?

The literature searches yielded a large number of results initially, but the data extraction process whittled down numbers of relevant material to double figures. The literature on decision making is broad and applies to a wide range of settings. Concerning mental capacity, decision making and social work, the literature draws on a wide range of themes, exploring the ways in which social workers can engage in decision making. There is little literature that considers mental capacity decision making in relation to people with YOD. Similarly, there was limited literature exploring social work practice with people with YOD.

The review covered a broad range of literature addressing it in three parts with the overlapping focus being decision making. In setting out to retrieve the relevant literature there were prominent themes. The themes from the literature point to the involvement of people with YOD in decision making processes and the role of families in decision making (Clemerson et al., 2014). Many of the studies included in this review note that while YOD has a significant impact on social functioning there is not always a strong link to its effect on decision making (Roach et al., 2012; Clemerson et al., 2014). There is little evidence around the actions and interventions of social workers linked to YOD practice. This may be linked to the relative obscurity of YOD, which affects just over 70,000 people in the UK compared to a total population of 850, 000 people with dementia (Carter et al., 2022; Dementia UK, 2023a). Linked to this point is evidence of the significant numbers of people with YOD who are undiagnosed (Clemerson et al., 2014), who are less likely to come to the attention of social work services. Furthermore, YOD care and support tends to be a health-focused practice involving doctors, occupational therapists and Admiral Nurses (Scourfield, 2023).

The contribution of the literature review to the overall research study is that it has helped to bring a clearer focus onto areas of inquiry. From evaluating the literature, it can be concluded that while a lot is known about the use of the MCA, less is known about whether there are distinguishable ways in which the use of the MCA in day day-to-day practice and in particular, how social workers, are using it to make decisions. Much of the evidence found on mental capacity practice and decision making is drawn from a medical perspective and highlights overarching medical themes. Key observations from the literature indicate that literature on the use of the MCA tends to focus on medical professionals or broad categorisations of health and social care professionals and there is less of an understanding of the key issues for specific practitioners such as social workers (Manthorpe et al., 2013; Jayes et al. 2020). This limits understanding of the contributions that social workers make to mental capacity decision making and is the impetus for developing a research study to understand social worker perspectives of mental capacity decision making.

Finally, the literature review has highlighted that not much is known about social work practice with regard to YOD. Practice with people who have YOD mental capacity is dominated by health professionals (Mayrhofer et al., 2021; Reagan, 2016). As a result of these findings there is an interest in gaining a better understanding of the role of social workers role in their practice with people with YOD and this being linked to MCA practice.

Chapter 6: Methodology

6.1. Introduction

This chapter outlines the methodological approach used in the research study. It begins by outlining the research question and objectives of the research and how these are connected to the findings in the Literature Review in Chapter Five and informed by the theoretical frameworks discussed in Chapter Four. The chapter begins with a discussion of the underlying research philosophy that shaped the study, exploring the ontological position of interpretivism the research process followed in completing the research including a discussion of ethical issues and the methods selected and then a discussion of the process used to analyse the data collected.

6.2. The research question

Following on from the Literature Review attention was drawn to understanding a social work perspective in MCA assessment and Best Interests decision making. The findings from exploring existing literature in the areas of mental capacity decision making, decision making and YOD and social work highlight the absence of social work perspectives linked to assessment and decision making when using the MCA. Social work perspectives on using the MCA consider the distinguishable ways in which social workers complete mental capacity work linked to their professional skills and values (Godefroy, 2015). It was found that there is an increasing amount of literature on understanding the experience of YOD (SCIE, 2020b; Rabanal et al., 2018), including responses by professionals and the inclusion of family members and carers in responding to and supporting those with YOD (Greenwood and Smith, 2016), but within this little attention has been given to the role of social workers. More specifically literature on the MCA does include reference to decision making (SCIE, 2020a), but with scant attention to how specific professionals such as social workers engage in decision making with specific groups. People with YOD as a specific group who may be assessed under the MCA during or following diagnosis had little presence in the literature. The lack of presence in literature raised my curiosity on whether social workers in their MCA work engage with people with YOD in similar ways to people with LOD or in different ways. This led to the impetus to design a study to gain a better understanding of the issues that social workers face in their practice with people who have YOD.

Based on the insights gained from the literature review I developed a research question to explore MCA decision making. The research question in this study was: How do social workers use the MCA in assessment and decision making in the context of practice with people who have YOD? Within the research question, there are three sub-questions. The sub-questions are:

> What are the different ways in which social workers can use the MCA to make decisions for people with YOD?
>
> How do social workers understand YOD in their MCA decision making practice?
>
> What are the implications for social workers in using the MCA in their decision making?

Connected to the research questions several objectives for the research study were set out to guide the design of the study, the data collection, and the analysis. The objectives were:

To gain a better understanding of how social workers make decisions for people with YOD using the MCA.

To review existing knowledge around social work decision making in relation to MCA work and with people with YOD

To explore frameworks for understanding how social workers engage in assessment and decision making for people with YOD.

6.3. The ontological and epistemological position

An awareness of the broader context of a research study aims to ensure the research is theoretically grounded (Williams and May 1996). The underlying philosophy of research can be discussed in relation to what are known as research paradigms (Bryman, 2016). Denicolo et al.(2016) discuss different research paradigms including post-positivist and constructivist. Historically, quantitative research has aligned to the epistemology of positivism (Bryman 2016). Positivist paradigms have been used to explain behaviour and in terms of decision making could be used to support attempts to generalise observations about professional decision making in mental capacity through deductive approaches, potentially using quantifiable tools to achieve this (Denicolo et al., 2016). This can be helpful where research is predicated to find facts and knowledge, although does raise questions in relation to exploring subjective experiences and the meanings that can be attributed to them (Denicolo et al., 2016).

A key aspect that shaped the methodology of this thesis was to explore what research paradigm would be suitable for the examination of social reality and experiences (Lee, 1991) in the form of social workers' mental capacity decision making. This examination began with exploring positivist approaches. In social research positivism offers a logical and testable epistemology for research (Bryman, 2016), based on beliefs about the existence of social facts and rules as well as the presumption that the methods used in natural sciences are suitable for social research (Denicola et al., 2016; Rodwell, 1998). Using a positivist research approach could involve designing a study to test whether social workers use the MCA to make decisions in similar ways to other professionals. However, positivism has been noted to have weaknesses when exploring human activity, specifically in its limitation on making generalisations about subjective emotional responses and how they might be conceptualised (Bryman, 2016) and beliefs that the researcher can maintain an objective distant position from the subject of the research (Rodwell, 1998). Denicolo et al. (2016) note that positivist research infers that social facts can be observed and objectively understood. Based on these observations about research epistemology, I made the decision to employ an interpretivist approach in developing the research study. Interpretivist approaches to research rest on the belief that phenomena being explored have subjective meaning requiring close scrutiny of the researcher (Denicolo et al., 2016; Bryman, 2016). In the case of exploring decision making, it relies on the notion that decision making sits within a set of ideas which are observable and can be interpreted as part of the research process.

Rather than making many generalisations about observations made from research, at the outset, this study sought to contribute to the process of building the theory of decision making with a specific focus on mental capacity. The foundations of the methodological approach for this study recognised that research is engagement with perceived knowledge (Lincoln et al., 2011; Charmaz, 2014) and therefore this makes it difficult to hold a distant stance on what is being explored (Mills et al., 2006). Based on recognising the need to understand the topic from the perspective of social workers, the research study sought to not only explain the decision making of social workers but also to understand how they go about making decisions. Core to this is the belief that people are subjects in their own right, with dynamic and variable meanings (Lee, 1991). The rejection of a positivist paradigm supports the move to avoid an objectivist methodology based on finding an objective view of reality (Rodwell, 1998), which will reveal the “right” answers to different research questions (Lee, 1991) and the belief that knowledge is created via the research process only (Fox, 2008). From this position, positivistic epistemologies cannot draw out the interconnectedness of social processes and research or what can be termed recognition of both the subject and the object in research (Mills et al., 2006; Kellner, 1990). Moving away from a positivistic epistemology then opens opportunities to minimise the distance between the researcher and the subject (Denzin and Lincoln, 2017; Lincoln et al., 2011) by engaging with alternative methodologies to form a multifaceted approach. These alternative methodologies can incorporate critical theory as a viable tool, which can be used to unearth the power differentials embedded within data (Lincoln et al., 2011). Epistemologically, the aim of selecting a methodology is to understand social work decision making through engaging in in-depth observation using research involving people and then interpreting their observations to find meanings.

The ontological position of research refers to the beliefs about the nature of phenomena and entities (Lincoln and Guba, 1985). For this thesis, the methodology is based on a recognition of subjective, rather than objective realities (Denicolo et al., 2016; Rodwell, 1998). Subjective realities recognise that realities are explicitly linked to people and created experientially (Deniolco et al., 2016). Alongside the subjective the thesis aligns with a relativist ontological perspective to understand the realities of MCA decision making as defined by social workers, which in this study were individual social workers. Within relativist research designs ideas about reality norms need to be understood as relative to particular settings and cultures (Mills et al., 2006). Therefore, relativism is relevant to this research philosophy because the experiences of social workers practising in community settings are perceived to be important towards recognising the realities of mental capacity decision making within everyday practice.

6.4. Social constructivism and research

In chapter Four social constructivism was outlined including its main foci and how it would be used within this thesis. One of the ways in which social constructivism has contributed to this thesis is in terms of the development of the research methodology. Constructivism in research holds that knowledge is constructed from human experience (Charmaz, 2009). It can be further defined as a research approach that includes flexibility and embraces alternative ways of understanding the world (Rodwell, 1998) and a recognition that knowledge is inseparable from the person in the specific context (Fox, 2008). The research study has been designed with the premise that knowledge is a social and historical product (Miles et al., 2014) and because of this, meanings are central to understanding what is observed. One way to navigate through the subjective and phenomenological is through a framework of constructivist research. Central to constructivist research is the aim to understand the lived experience of the subject, from the perspective of the subject (Denicolo et al., 2016). In the case of this research the subject is social workers. A constructivist research paradigm premises that social objects do not have their own objective existence (Harding and Palfrey, 1997), but rather are subject to interpretation. It holds that any observation of the phenomena in the social world is dependent on the meaning attributed to the phenomena (Williams and May, 1996).

Thus, this research study aimed to use an inductive approach to find better ways of theorising decision making when using the MCA. Inductive approaches aim to understand observations from specific phenomena and to explore if the observations can be theorised with broader applications (Lee, 1991). The starting point for inductive approaches involves planning and carrying out research free from preconceived categories or theories (Rodwell, 1998). To do this the interpretative process and meanings attributed to data will be important, as will be the use of self or reflexivity as a researcher. These areas are discussed further in this chapter under section 6.11.

6.5. The Research Strategy

The study is premised on a qualitative research strategy. Qualitative research strategies are at the core of much social work research (Smith, 2009). Qualitative approaches highlight the meanings and attempt to understand the perspectives of those being researched. Further to this, using a qualitative approach aims to build thinking and theory on the subjective experiences of social workers using the MCA in their decision making. The approach used for this thesis was exploratory, recognising that the Literature Review has already revealed that little is known about mental capacity decision making for social work practitioners when they work with people with YOD. This tells us that constructing a quasi-experimental study would be less feasible at this stage because of the lack of prerequisite understanding of the population being examined.

Although a quantitative approach could be useful for exploring impact and extent, this would not be sufficient for scrutinising the specific issues in this thesis. Taylor (2016) informs us that decision making involves language and emotional responses, both of which are vague and often challenging to quantify. Research methodology is recognised to be a part of the research process and involves the application of recognised methods to support the steps and judgements (Williams and May 1996). For this thesis the methodology used evolved through a process of recognising key phenomena through the reading around YOD and reading about the research processes.

6.6. Study design

The study was designed to carry out an in-depth exploration of social worker decision making within the confines of their MCA practice. The design encapsulated an exploratory approach to gain a better understanding of how social workers make decisions in the context of their practice with people who have YOD. The design involved carrying out qualitative interviews of social work practitioners, analysing the data from the transcripts using a grounded theory approach and highlighting key theoretical codes and themes in the findings.

Following on from the Literature Review in Chapter Five, it was noted that many of the studies employed a qualitative exploratory research strategy. Exploratory research has been indicated as being most helpful when there is not a lot of existing knowledge about the phenomenon being researched (Bryman, 2016). Some studies noted in the Literature Review employed a case study approach drawing participants from single or multiple teams. Other research designs that have been noted in the Literature Review include mixed methods combining both qualitative and quantitative study designs. Common among these designs was a two-phase study approach with the first phase being quantitative followed by a qualitative study. The quantitative designs for these studies tended to include the use of questionnaires. Survey research design is noted to be helpful when trying to collect data from a larger sample (Ariyo et al., 2021). Qualitative aspects that followed often used semi-structured interviews or an ethnographic method to delve further into the research phenomena. Although useful, the collection of quantitative data was not considered necessary for a study of this size as the focus was to explore the perspectives of social workers in the context of their practice.

Recognising previous studies, this research study wanted to understand social work decision making in the specific context of practice with people who experience young onset dementia and from this identify theoretical conclusions from the findings. Akesson et al. (2018) note that identifying theory as part of a research study can support a social work researcher to construct new insights and move beyond existing interpretations of data. So, the aim here was to adopt a design that would enable new insights to be found. Alongside this a specific focus was placed on engaging with social workers who were the main source of data collection. This led to selecting an exploratory qualitative research design approach to attempt to unearth the perspectives that social workers have of mental capacity decision making. To achieve the “unearthing” of ideas and theories linked to social work decision making a grounded theory method was selected.

6.6.1. Grounded theory

This section examines the use of grounded theory as a methodology within the study. Grounded theory was originally developed by Glaser and Strauss in the 1960s. Their key studies, Awareness of Dying (1965), Discovery of Grounded Theory (1967) and Time for Dying (1968) highlight the emergence of grounded theory as a research methodology and are still in use today (Flick, 2018). These early versions of grounded theory were novel and encouraged new methodologies of qualitative research (Reiger, 2019). Central to grounded theory methodology is the idea that theory can be discovered or generated in empirical research (Akesson et al., 2018; Flick, 2018). As a research methodology grounded theory emphasises systematic analysis of data through induction, an idea that can be referred to as founded on the belief that the relevant findings and discoveries are in the data, which the researcher must discover (Flick, 2018).

6.6.2. Versions of grounded theory

Glaser and Strauss's approach to grounding theory in empirical research has been referred to as Classic Grounded Theory. Classic grounded theory highlights the centrality of discovering theory through the methodological approach (Akesson et al., 2017). Their early versions of grounded theory were novel but received criticism for being overly rigid in their approach to data analysis (Rieger, 2019) and for assuming that the researcher can objectively understand the subject being studied (Charmaz, 2009). Over time Glaser and Strauss' ideas were adapted and refined by other researchers and given greater approval (Flick, 2018).

The second version of grounded theory has been referred to as the 'Straussian' grounded theory (Rieger, 2019). Named after Anselm Strauss and developed in collaboration with Juliet Corbin in the 1990s this version brought new emphases to grounded theory with a focus on more systematic coding practices, such as axial coding, which uses deductive (pre-determined) processes (Flick, 2018). This differs from classic grounded theory which relies on inductive (emergent) coding processes. Strauss and Corbin's grounded theory also draws on the interpretations and meanings which arise in research, either via the researcher or the participants. This is allied to the sociological theory of symbolic interactionism, in which meanings and ideas contribute to the construction of realities in society (Charmaz, 2014). The Straussian version of grounded theory holds to the idea that theory is developed as a product of the methodology (Akesson et al., 2018).

A third version of grounded theory is constructivist grounded theory which theory builds on the original work of Glaser and Strauss (1967), holding the key tenets of the approach, which posits that a grounded theory approach provides a systematic method to collect and analyse data to enable the development of theory (Charmaz, 2012). One way in which constructivist grounded theory differs from classic grounded theory and the Straussian version is in its suggestion that the methodology is used in the development of substantive theory (Akesson et al., 2018). Substantive theory refers to theories that explain or interpret phenomena (Chun et al., 2019) and for Charmaz, substantive theory is seen as a mid-range theory (Charmaz, 2012). More recent versions of grounded theory have been acknowledged and draw on feminist adaptions of the methodology (feminist grounded theory) or a focus on power (transformational grounded theory (Akesson et al., 2018).

6.6.3. Constructivist grounded theory

Within the different types of grounded theory noted, this study selected a grounded theory approach for several reasons. Firstly, grounded theory is being used to unearth the layers of meaning beneath the construction of ideas found in the data. It holds to the core ideas of Glaser and Strauss (1967) and Strauss and Corbin (1997), that theory and concepts are earthed in the data that has been collected. Under this selected approach researchers typically identify categories which further on can be integrated into theory.

As part of the development of the research approach for this thesis an understanding of the limitations of Glaser's and Strauss's development of grounded theory was important to consider. These limitations lie in the open-ended nature of the theory (Flick, 2018), which can prove challenging when trying to understand the end of the process (Rieger, 2019). For this reason, a more nuanced, conceptually strong approach to grounded theory was sought for this study. Charmaz (2008) in her reconstruction of grounded theory reviewed the emergence of the approach, acknowledging the streams and contributions of Strauss, Glaser and Corbin, but drawing closer emphasis on relativism. Key assumptions within a constructivist grounded theory approach involve the acceptance of multiple realities, a rejection of objectivist approaches to understanding data but embracing the process and the product of research within its context (Charmaz, 2014). Charmaz's (2012) grounded theory research is conceptually tied to social constructivist research and the premise of this is that new ideas and thinking are earthed in the data rather than only in existing literature. This means that there will be an ongoing process of examining the data.

A second reason for adopting a grounded theory approach is that a further component of Charmaz's grounded theory approach is the acknowledgement of the researcher's voice (Ramalho et al. 2015). Acknowledging the researcher's voice confers that a researcher's active engagement in the construction of knowledge as a product of the research (Charmaz, 2014). This means that the researcher is recognised as not being passive or silent throughout the research process. This was an important consideration for this study in that the study relates to a subject area in which the researcher has had some practice experience.

6.7. The research process

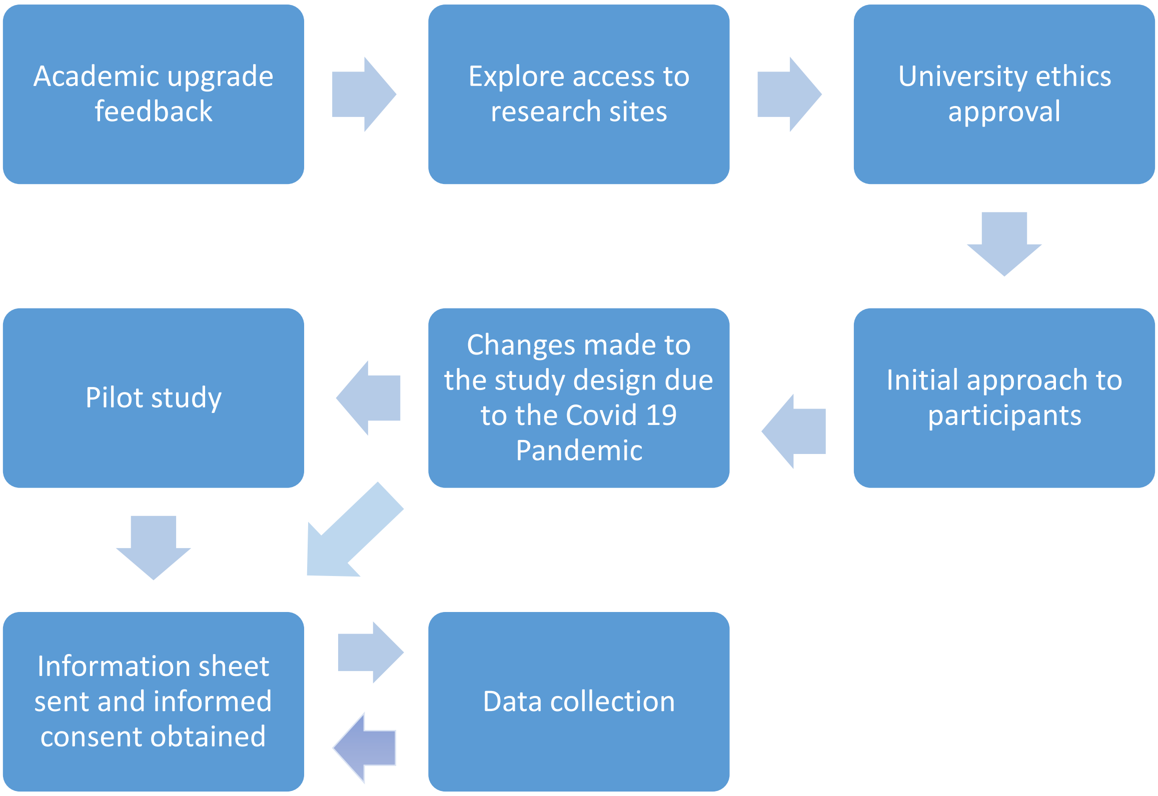
This section outlines the steps taken to carry out the research study following the upgrade. It includes information on the ethical approval, the selection of methods used, how sampling was carried out and details of the changes made to the methodology.

6.7.1. Ethical approval

A key part of the ethical rigour of this study was to ensure ethical approval is applied for and obtained, prior to the study beginning. An application for ethical approval was made to the Royal Holloway University London's Ethics Board in 2019, with a detailed application outlining the study plan and location of the study. See Appendix Six, Ethical Approval Document 1. The ethical approval process involved a detailed description of the study plans including the outline of the study and the location plans, submitting these plans, and responding to any questions raised by the University Research Ethics Committee. Ethical approval for the study was granted on 3rd June 2019.

There were delays in receiving responses from research sites and an update of the ethical approval was submitted when it became clear that it would not be possible to carry out the study as planned. The timing of the request for changes to the ethical approval for the study coincided with the onset of the Coronavirus outbreak in early 2020 which also led to additional delays in collecting data. Please see Appendix Five for details of the updated ethical approval documents. Figure 3 illustrates the process of obtaining ethical approval and carrying out the research.

Figure 3. Flow diagram of the ethical approval and research process



6.7.2. Ethical considerations for the research

Ethical considerations arise in different stages of research (Bryman, 2016) and concern a broad array of guidelines, practices and considerations. Having outlined the research plan it was appropriate to ensure the research would be ethically sound and that ethical considerations were taken into account in all aspects of the plans including the identification of sites of study, the selection process and access to participants and the analysis of data. Ethical considerations are often seen as a procedural aspect of a research study; they require careful planning and reflection by researchers.

Diener and Crandall (1978) highlight ethical principles in research noting that attention ought to be paid to whether harm, lack of informed consent, invasion of privacy or deception is involved. Key ethical considerations for this study included ensuring anonymity and privacy for participants in the study. These ideas were helpful tools for assessing the ethical strength of the research study at the initial stage. At the outset there were discussions with supervisors to ensure the questions in the information sheet and consent form were clear and did not leave any ambiguity for participants.

6.7.3. Mental capacity and ethical issues

Research that relates to mental capacity ought to explore ethical considerations. While this study does not seek to engage directly with people who lack capacity, the MCA and MCA Code of Practice (2007) research guidelines were useful reference points for upholding high standards in research ethics. Sections 30 - 34 of the MCA detail legal guidelines governing the involvement of people who may lack capacity to consent within research. These sections note the distinction of intrusive research which refers to research that would be unlawful if it was carried out “on or in relation to a person who had capacity to consent to it, but without his consent” (MCA, 2005, Section 30(2)). While this research study did not directly involve contact with participants who lack mental capacity to make decisions, mental capacity is a central focus of the study. As part of collecting data the researcher was aware that participants could discuss their practice with people who lack mental capacity, so further scrutiny was sought. The MCA Code of Practice Paragraph 11.7 provides guidance on the instances where research conducted around the issue of mental capacity does not require the consent of individuals. This includes research involving data that has been anonymised and cannot be traced back to the individual (Department of Constitutional Affairs, 2007). This research study fits into this categorisation, as the collection of data does not seek to identify individual perspectives or circumstances; but rather explore the processes that social workers were engaged in.

6.7.4. Other ethical issues

In research, ethical issues often omit to recognise the importance of respect and transparency. For this study, the principles of respect for participants' perspectives and expressions as well as the transparency of the research process were central, as the responses and views drawn from participants will inform thinking about decision making. Respect and consideration for participants was especially linked to the timing of when the research was carried out. The data was collected during the Coronavirus pandemic (2021-2022) when many professionals experienced additional challenges and restrictions in their work. Foley and Foster (2022) note that reporting adverse impacts of the pressured work settings increased for social workers during the Covid-19 pandemic. Taking into account the difficult circumstances of social workers throughout the data collection stage was therefore important. All contact with participants was online and a flexible approach was employed to ensure social workers were participating in the study at a time that was suitable for them. Most of the participants opted to take part at the end of their working day or in the evening.

6.7.5. Informed consent

Ahead of carrying out the research study the informed consent of all participants was required. All participants were contacted by email and sent an information sheet which gave an outline of the study and its purpose together with a consent form. Participants were asked to read the information sheet and complete the consent form prior to the interview, at the point when they indicated an interest in taking part in the study. See Appendix Four for an example of the Consent form sent out to potential participants. Completed consent forms were collected either prior to the interview or on the day of the interview. The consent forms were stored in a passworded electronic file. Participants were informed of the option to withdraw from the study at any stage or have their information removed from the study. Ways that participants were informed of withdrawal from the study included sending an email to the researcher or the research supervisor.

6.7.6. Confidentiality

A commitment to confidentiality in social research can be understood including ensuring sensitive information is held and not shared beyond its intended use (Hammersley and Traianou, 2012). Handling data with attention to confidentiality included storing gathered data securely using password-protected or encrypted online files for storage. The participants were also reassured ahead of the interview that their information would not be used as part of the doctorate thesis and any information shared would not be identifiable. See also anonymity in the next section for further details.

Exploring the perspectives of social workers can raise concerns that information may be used negatively. For example, to criticise individual social worker's practice. It was important to reassure participants that their data was being handled appropriately, would be anonymised, and used for the research study only. Prior to the collection of data participants were informed in the information sheet that their data would be handled confidentially. Details of the handling of participant data were repeated verbally prior to the beginning of the interviews to ensure participants were clear about confidentiality and to offer them an opportunity to ask any questions about confidentiality.

The interviews were recorded on Zoom. Consent was obtained from participants to carry out the interviews on Zoom and also to record the interviews. Consent was obtained by writing to participants explaining the interview process and also in a verbal discussion prior to the interview. Before the interview a verbal explanation of the purpose of recording and how the recording would be used was shared with all participants. This was done to reassure participants that the recording of interviews would not be used beyond the transcription of the interview. The recorded interviews were uploaded to a password-protected file. The information sheet informed participants that the recorded interviews were destroyed once the transcription had been completed. Participant transcripts were anonymised and then saved in a password-protected Word document.

6.7.7. Anonymity

The study was designed to elicit the perspectives of social workers around their decision making using the MCA. Within the design there was no plan to draw attention to individual participants in terms of evaluating their practice, so it was essential to ensure that data collected could not be traced to an individual participant.

Maintaining the anonymity of individual social workers and the team they worked in was an important part of the research process. The names of participants were removed from notes and transcripts at the earliest possible time and saved versions were anonymised. In practice this happened during the transcription stage when recorded interviews were transcribed to word-processed documents. Once interviews were transcribed, names were removed and an anonymous indexing system was adopted to ensure that individual participants could not be identified. The data was then read and coded. Thematic codes and themes derived were written into the findings of the study.

The selection of methods for the research study links to the findings from the review of the literature. Murrell and McCalla (2016) in their qualitative study which sought to understand how decisions are made using the MCA, used semi-structured interviews to gather the views of social workers. Murrell and McCalla's study was small, which enabled more in-depth responses from participants could be gathered. Pipon-Young et al. (2012) in their study exploring the experiences of younger people with dementia report a phased methodology, initially consisting of interviews followed by a discussion of findings and a final phase of action research. This methodology enabled greater triangulation of the data. These studies and their methodologies were found to be influential in the Literature Review and helped to shape the methods.

6.8.1. Methods

Using an exploratory qualitative research approach for this research study opened up the opportunity for different methods to be used to collect data. The methods selected for the study are outlined and discussed below.

6.8.2. Interviews

The data collection method used within this research was semi-structured interviews which are a flexible way of gathering data from participants (Flick, 2018). Interviews are a popular way of gathering data in social work research, as they enable researchers to collect large amounts of data from a selection of participants. The primary purpose for employing interviews as a method of data collection was to hear first-hand the experiences and meanings that social workers attribute to decision making. Using semi-structured interviews was specific to the aim of ensuring that there was sufficient flexibility to hear what participants perceived as important contributions to understanding mental capacity decision making.

Semi-structured interviews as a method use open-ended questions which invite participants to explore their ideas that they believe are important. Within a semi-structured interview method participants were able to elaborate and talk beyond the questions being asked to share their thinking. Using interviews informed by grounded theory built on the notion of co-constructing research with participants by recognising the role the participant plays in shaping the questions as well as sharing their answers, for example, within the topic guide including questions that ask, “Are there any issues that you think are important to add here.” Co-construction was further reinforced through the use of a pilot study, where participants who took part in the pilot study were given feedback on the questions that they were asked.

6.8.3. The topic guide

The approach and attitude in carrying out interviews in a grounded theory methodology has been described as a gentle conversation (Flick, 2018). For this study, the gentle conversation metaphor helped construct the topic guide for the interviews, taking into account the participants' perspectives, and developing ways to encourage them to share their practice experience.

Designing questions for interviews took a developmental approach. Unlike in a structured interview or questionnaire, drawing up a defined list of questions that had to be followed was not necessary. However, within semi-structured interviews there needed to be a shape to the interview. It was decided that a topic guide would be developed to support the idea of learning how to obtain data and ask questions (Charmaz, 2014). Practically, a draft topic guide was drawn up initially, which was amended following further scrutiny and discussion with supervisors. The second draft topic guide was used as part of the pilot study. Details of the pilot study are included below. Following the pilot study further changes were made to the topic guide. These changes involved adding more signposting in the topic guide to help participants to be able to respond more easily to questions drawing on their practice. An example of the amendments to the topic guide included ensuring questions were open-ended to support sharing more in-depth responses about their MCA work with people with YOD.

6.8.4. Observation ethnography

The use of observation was included in the initial research plans. Observation as a research method was planned to support the development of interview questions and follow-up interviews. Bryman (2016) notes that there are different approaches to using observation as a research method, including participant observation and ethnographic observation. For this study, the initial choice was to use participant observation. The rationale for using participant observation in this study was to learn about what social workers do in their day-to-day practice. However, as noted later in this chapter, participant observation was not possible, and changes were made to the research study design. For further details of the changes please see section 6.8.7. for the methodological changes.

6.8.5. Documentary analysis

The final method to be used is documents. Documents come in the form of primary and secondary sources and are useful for understanding organisational, professional, and governmental thinking on social phenomena being studied. Within research the gathering of documents can reveal the social practices of organisations (Coffey, 2013) and may hold insight into the decision making of social workers. Documents can come in the form of public records and personal documents available in physical form or online (Bryman, 2016). The exploration of historic documents may also be of use to understand current practices. Documents were explored as part of the Literature Review and are detailed in Chapter Five.

6.8.6. Location and timing

Working out the location of the research was influenced by several factors. Prior to identifying participants questions were asked whether there is any evidence that the location in which the research is drawn could have a significant impact on the study. Having carried out a Literature Review of social work decision making in young onset dementia there were not any notable regional factors highlighted. However, this is not to say that they do not exist. A further consideration in terms of location for the research was accessibility and availability for the researcher. Once the decision was made to carry out the interviews online, there was a change in approach to thinking about location. Accessibility issues after moving interviews online concentrated more on how suitable using Zoom as a platform for capturing the views of social workers would be. Moving online supported accessibility by enabling a wider pool of social workers to be reached and included in the sample.

6.8.7. Methodological changes

The research was initially planned to take place in late 2019 and early 2020. At this time there were delays in obtaining access to participants. Several local authorities were approached, one responded positively and three said they would get back to me but never did despite further efforts. These responses were unexpected and time was taken to reassess the research plans. Between January 2020 and March 2020 there was a growing unease internationally regarding the emerging severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) also known as coronavirus, leading to restrictions on travel and interaction. The initial responses and concerns linked to the early stages of what became an international pandemic, harmed my attempts to plan to collect data for the research study. Wider evidence noted that social research was affected by the public health advice given to people to self-isolate when they had travelled to an affected area or had influenza symptoms. On the 20th of March 2020, there was a national lockdown in the UK because of the growing coronavirus outbreak. As noted elsewhere in this thesis, the Covid 19 pandemic caused significant disruption to the plans to collect data. This unfortunately led to methodological changes to the thesis based on my inability to continue to collect data in a way that I had planned to. These changes were initially discussed with supervisors and ethical approval was sought for the changes. Changes were made in March 2020 to two areas of the research plan and ethical approval was sought and granted for the changes.

The first area where changes were made was the plans to complete ethnographic work with social workers in their day-to-day practice. These plans were stopped. An assessment was made of the possibility of completing ethnographic work and there were discussions with one organisation that had initially agreed to be part of the research, who confirmed that it would not be possible to carry out ethnographic work during the Covid-19 pandemic. The second area where changes were made relates to the interviews. Interviews had been planned to be face-to-face. Through consultation with supervisors it was agreed that face-to-face interviews should be changed to online interviews.

6.8.8. Sampling approach

Selecting a sampling method is a core aspect of the research strategy. The study used a purposive sampling approach to identify participants for the study. Qualitative sampling lends itself to purposive sampling (Bryman, 2016). Purposive sampling recognises that the target population for the research will be small and draws on flexibility to enable variety in the sample selected. The goal of using a purposive sample approach is to ensure that participants are selected in line with the aims of the research question (Bryman, 2016). A useful aspect of purposive sampling is the opportunity to use a contingent approach to sampling that recognises the evolution of sampling criteria as the research progresses (Bryman 2016).

As the study took an exploratory form it was unclear initially what the ideal sample size should be. The size of a sample for a research study can vary quite significantly. Drawing on existing research of a similar nature, Murrell and McCalla's (2016) study on decision making was a small sample size of 5. In contrast, Livingston et al. (2010) in their study on carers and young onset dementia had a sizeable sample of 43 for focus groups and 46 for interviews. At the outset there was a plan to conduct up to 15 interviews with social workers to understand MCA assessment and decision making better.

6.8.9. Selection of participants

A summary of the research plan, including information sheets and consent forms were sent out to a national social work organisation and local authorities in the London area. London had been originally selected as the area where the fieldwork would take place when it had been planned that the interviews would be carried out in person. This was for accessibility to participants. Due to the decision to change to online interviews, it was no longer necessary for interviews to take place in a proximal area, so contact was made with social workers across England. This was carried out via a snowball approach, involving contacting social workers with an interest and asking for further interested social workers. Once participants responded to the initial information sheet they were contacted by email or telephone.

6.8.10. Profile of the participants

Including the pilot interviews the research study involved a total of 19 participants. All the participants were social workers and currently engaged in social work practice. All participants were social workers practising in the area of adult social care. The range of areas of practice are presented in Table 3 together with other pertinent data.

Table 3. Table of participants' details

Participant number	Male or female	Team	Length of time in practice (in years)	Region where practising
1	Male	Early intervention team	Not disclosed	London
2	Male	Community adults' team	2.5	North West England
3	Female	Community adults' team	8	South West England
4	Female	Adults with a Learning disability	9	Midlands
5	Female	Mental health discharge	2	Oxford
6	Female	Mental health	10	Suffolk
7	Male	Adults general	2	London
8	Female	Adult general	3	London
9	Female	Adult general	20	London
10	Female	Adults general	3	London
11	Female	Adults with learning disability	1	London
12	Female	Adults general	7	London
13	Female	Adults general	12	South West England
14	Female	Adults general	5	South West England
15	Female	Adults with Learning disability and generic adults team	Not disclosed	South West England
16	Female	Older adults' team	2	South West England
17	Female	Adults general	5	South West England

All participants confirmed that they were practising social workers at the beginning of the interviews. All but one of the participants were practising social workers at the time of the interview. One non-practising social worker was in the process of returning to practice, following a career break.

Three of the participants described that they were involved in senior or middle management roles such as a senior social worker or team leader. Participants were not asked to provide information about any additional qualifications or responsibilities in practice prior to or during the interview because this was not part of the aims of the study. However, some participants chose to speak about their additional qualifications. For example, one participant noted that they worked as a Best Interests Assessor under the Deprivation of Liberty Safeguards and another noted that they had completed the fast-track mental health social work training programme, Think Ahead.

6.8.11. Location of participants

As noted in section 6.8.8 on sampling the study used a purposive sample and engaged with a snowballing approach to generate further potential participants. Using a snowball approach to identify participants meant that some participants worked in similar teams and locations in adult social care services. The participants were not aware of who else had agreed to be interviewed at the time of their interview. A third of the participants were based in London. More than 70 per cent of participants were based in the south of England. At the time of interviewing all but one of the participants worked for a local authority or NHS Trust.

6.8.12. Demographic information of the participants

Age profiles were not collected as part of the interview process. In hindsight an understanding of the age profile of participants may have helped elucidate if age had any bearing on decision making practices. The majority of participants were women and this gender divide is not unusual in social work practice and broadly reflected the gender division of the social work practice profession. Most participants (14) identified themselves as women and three identified as men. Most of the participants shared their self-identified gender during the interview.

6.8.13. Conduct of the interviews

The interviews for the research study were carried out between February 2021 and November 2022. The wide gap in the period for the collection of data occurred for several reasons. Firstly, there were delays in obtaining access to participants. Once the initial contacts had been made it took some time for individuals to respond. The second reason for the prolonged time taken to gather data was due to the Covid 19 pandemic. The Coronavirus outbreak began to have an impact on a global scale from January 2020 and by March 2020 led to the first of several national lockdowns in the UK, affecting all face-to-face activities. A lot of research activities involving face-to-face meetings came to a halt during the early stages of the Covid 19 pandemic. This led to a pause in the plan to gather data and a re-evaluation of the methodology. Further details are provided in the methodological changes section 6.8.7.

6.8.14. Online interviews

The interviews all took place online, rather than in person, using the online platform of Zoom. Zoom is an online communications video, audio, phone, and chat service that has been available for public use since 2013 (Oliffe, et al., 2021). In terms of its uses Zoom is widely available via a website platform, which people with access to the internet and a device that supports video and audio communication, can use freely. While Zoom has been embraced as a communication tool for work and social purposes, it has more recently drawn interest in its use as a qualitative research tool, in the form of interviews (Oliffe, et al., 2021). The use of online platforms such as Zoom increased significantly during the Covid 19 pandemic when many governments and organisations imposed social distancing restrictions and limitations on movements (Thunberg & Arnell, 2021). Although the use of online tools such as Zoom is not new to qualitative research, the challenges for face-to-face communications raised by the Covid 19 pandemic of 2020 – 2021 led to more research being carried out via Zoom and other similar online communication platforms.

Using online communication platforms as a research method has both benefits and limitations. Oliffe et al. (2021) in reviewing many studies that used online platforms to collect data, found that platforms such as Zoom can increase the reach of research to a greater number of participants. Thunberg and Arnell's (2021) study of digital interviews online noted that online interviews are different from in-person interviews and non-verbal information can be missed.

Once the decision had been made to conduct the interviews online a new information sheet was drawn up to reflect the changes to the research plan. Participants were emailed the information sheet and consent form prior to the interview. Interviews were only carried out once the consent form had been returned. Prior to the interview there was a further conversation with the participant to confirm that they were aware of the purpose of the interview and happy to proceed. The online interviews were recorded with permission from participants to assist with transcription.

6.8.15. The pilot study

In advance of collecting data a pilot study was used. A pilot study can be described as a feasibility study carried out prior to data collection. In relation to qualitative interviews, Bryman (2016) notes that pilot studies enable researchers to confirm how adequate the instructions to participants are, but also support researchers to understand the flow and sequence (order) of the questions being asked.

Conducting a pilot study in this research offered the opportunity to explore the topic guide and ensure whether the instructions given to participants were suitable and adequate (Bryman, 2016). Furthermore, as changes were made to the research plan, with the interviews moving online via Zoom rather than face-to-face, the pilot study offered an opportunity to test out the use of Zoom as a platform for carrying out the interviews.

Practising the use of online interviewing in a pilot study was helpful to minimise errors in data collection. The pilot study was carried out in August 2020. Two participants were selected for the pilot study. The two participants were amongst the initial responders to the request for participants and were notified that they would be taking part in the pilot study of the research. The benefit of carrying out two pilot interviews for this study was to provide greater confidence in how the topic guide could be used in the semi-structured interviews. In practice I was able to look at the sequence of questions and the terminology used. Changes were made to the topic guide in relation to the question about the link between YOD and MCA assessments. The pilot study revealed that further clarity was needed on particular aspects of the semi-structured interview plan.

The pilot study was helpful in relation to me as the researcher in understanding the process of interviewing using Zoom. While I was familiar with holding meetings on Zoom or MS Teams, this was the first time I had carried out research on Zoom using semi-structured interviews. My reflections from the pilot interview revealed that I needed to give greater attention to comments made by participants. The pilot interviews highlighted the need to repeat or re-phrase questions when interviewing online. This was not an expected finding from the pilot interviews.

6.9. Transcription

The transcription of recorded interviews took place soon after the interviews occurred. The recorded interviews were transcribed verbatim using Otter.ai, an online technology company that offers speech-to-text transcription via artificial intelligence. Otter.ai as a tool for transcribing interviews has grown in popularity in a short space of time, in part because of its low cost for transcription. A year’s subscription with Otter.ai was taken out to ensure that all required aspects of the package would be available when transcribing the interviews. For example, the opportunity to edit the initial transcription was an important part of the process and this was not available in the free trial version of Otter.ai.

The use of Otter.ai to transcribe the recorded interviews was swift, although it was not without its challenges. One challenge found with using Otter.ai to transcribe the Zoom interviews was that the accuracy of the artificial intelligence application to translate speech from the interviews was variable. Some words were not transcribed correctly. To ameliorate the inaccuracies, line-by-line checking of the transcripts was carried out to check for any missing words or errors in words.

6.10. Procedure used in analysing the data

The purpose of data analysis in this study was to draw out meaning from the collected data. A key aspect of drawing meaning from the collected data is to uncover complexity (Miles et al., 2014).

In practical terms the analysis occurred across 12 months concurrent with when the interviews were carried out. The interviews were recorded with the permission of the participants and alongside this the recording notes were taken during the interviews. From the recorded interview and notes the data collected was labelled using a pen and clustered into similar groupings. These groupings were given codes or labels and then a process of further scrutiny took place. As the data was looked through repeatedly and the emergence of similar themes were noted. In line with Charmaz's (2009) constructivist approach to grounded theory this process occurred throughout the data collection period.

6.10.1. Coding

Coding has been described as a key part of the analysis of data in a qualitative study. In grounded theory, coding is an important link between the data collection phases of the study and the theorising of findings, supporting the "leap from concrete events and descriptions of them to theoretical insights and theoretical possibilities"(Charmaz, 2014, p137). Practically, coding relates to labelling individual segments of data which will eventually lead to the development of categories (Charmaz, 2014). Charmaz (2014) identifies key stages in a constructivist grounded theory approach to coding, distinguishing her approach and other similar grounded theory coding approaches such as those of Glaser and Strauss (1967) and Strauss and Corbin (1997). In constructing the codes attention was given to the language and meanings attributed to the words used in participant responses. There were 2 main stages of coding as noted below.

6.10.2. Initial coding

Once the data had been collected and transcribed the first stage coding process involved initial coding. Initial coding consists of labelling parts of data with words that reflect actions (Charmaz, 2014). Initial coding can create potential pathways for further analysis (Charmaz, 2014) when the codes are revisited. The initial coding phase was a swift process which identified provisional labels (codes) based on the data. Remaining open to participant responses and what was happening in the data was a key consideration in the initial coding phase. To facilitate open coding each transcript was coded on a line-by-line basis. These provisional codes were amended as further transcripts were available for coding. As part of the initial coding, Invivo codes, which is coding based on the participant's own words were used to capture what was happening in the data and explore potential assumptions (Manning, 2017).

6.10.3. Focused coding

Following the initial coding, the next phase for coding the data involved focused coding. Focussed coding draws on the most significant and or frequent codes to explore whether they offer analytic direction with the data (Flick, 2018). It is used as a way of moving from initial codes to more defined analytical material in the research process (Charmaz, 2014). Focussed coding took place when initial codes had been framed and there was evidence of specific codes occurring more frequently within the analysis. Focussed coding helped to draw attention to categories or units of meaning and clusters of ideas and to ensure that these were not my own biases as the researcher. Appendix nine outlines a part of the coding framework table.

6.10.4. Memo writing

Memo writing can be described as an intermediate step between the process of collecting data and writing up final drafts of the findings, which “capture thoughts and comparisons” (Charmaz, 2014, p.162). As an activity, memo writing involves noting down key thinking that occurs prior to, during and following data collection. This thinking can be linked to the researcher’s reflections and tacit links between the data can be collected. The importance of memo writing within research is that it facilitates the movement from collected data to data that has been formed into theoretical categories (Charmaz, 2014). Memo writing helps to connect the research to existing knowledge around the emerging theory. Memo writing as an aspect of grounded theory was used throughout the coding, categorising, and writing up processes. A key benefit of memo writing for this study was to support the exploration of the “ implicit, unstated, and condensed meanings”(Charmaz, 2014, p.180).

For this study, memo writing occurred throughout the collection of data, although there were three key points at which memos were used for this study. The first use of memos occurred directly following the interviews to highlight interesting or notable responses from participants. Memos were also recorded at the stage of transcription when particular responses were noticed by the researcher and to note whether these would be followed up in future interviews. Finally, memos were recorded when data was added to the NVivo software for further analysis. Practically, memo writing following transcription was captured in handwritten notes recorded following interviews and after transcribing. Handwritten notes were chosen as the preferred way of capturing memos because they helped to more easily track how ideas and codes emerged.

Jasper (2005) notes how journaling such as writing memos enhances rigour in qualitative research through the use of reflexivity. As a part of the research process noting thoughts, initial responses and emotions and then revisiting them helped to make sense of how I discovered codes, categories and themes. In relation to bias, constructing memos was helpful and enabled me as the researcher to see the progress of the findings which emerged over the time period of the research study.

6.10.5. Generating themes

Themes were generated after focused codes had been identified. The themes were developed in tandem with the coding process, although the development of themes during coding helped to bring the coding process to a conclusion as the themes confirmed that the coding had led to a meaningful understanding (Braun and Clarke, 2021). The generation of themes in the research study is an adaption within a grounded theory approach, drawing on the thematic analysis approach of Braun and Clarke (2021). The inclusion of developing themes is an adaptation that other studies have noted as useful in the process of using a grounded theory approach. For example, Davidson et al. (2023) note the development of themes and sub-themes through memo writing. The benefit of using thematic analysis for this study was to support the focus on meaning and context of the research study while also acknowledging the pivotal role of the research in the research process (Denicolo et al., 2019).

6.10.6. Computer-aided qualitative analysis (CAQDAS) - NVivo

The analysis of the data was supported by the use of NVivo. NVivo is a computer-aided qualitative analysis software (CAQDAS) which provides a structured and manageable way of organising qualitative data for analysis (Alston and Bowles, 2013). It supports the ability to work with large amounts of data (St John and Johnson, 2000) and supports the organisation of data. NVivo provided a tool to support breaking text data from the transcripts into smaller more manageable units (Bringer et al., 2006). Using NVivo for this study also accelerated the categorising of data (Silver, 2016) by visually being able to see transcripts and codes that had been generated. This supported the categorising of codes. Using Braun and Clarke’s (2021) thematic analysis approach thematic analysis was carried out once initial codes had been found. This was an adaption of the Braun and Clarke model (2021).

Despite the benefits of computer-aided software analysis, there were criticisms which I needed to be aware of. For example, St John and Johnstone, (2000) note that using computer-aided tools can lead to analysis becoming quantitative. To avoid this NVivo was used once the data had been transcribed with an aim to complement the grounded theory approach once some analysis had already occurred. As a novice to NVivo I completed an online training course on NVivo to become aware of all its features. The interview transcripts were entered into NVivo and saved. The codes generated from the initial coding were also entered into NVivo. Having the transcripts available online supported focused coding to happen more smoothly. Both the codes from the initial coding and the focused coding were combined into one coding framework. The coding framework was the basis on which themes were developed.

6.10.7. Theoretical saturation

Theoretical saturation refers to the point at which categories and themes are complete and gathering further data no longer draws out new codes (Charmaz, 2014). Confirming theoretical saturation is not without its challenges. Glaser (1998) cited in Flick (2018) noted that it was unnecessary to continue to gather data beyond the sample size, while Charmaz (2014) considered that coding can be an ongoing activity until the researcher senses that no new data arises from the research. Dey (1999, p.257) notes that saturation can be an “unfortunate metaphor” because it suggests that no further data can be added, which in a sense is unlikely because data can always be added to (Dey, 1999). To help navigate to find the place at which data collection ceases, Dey (1999) uses the term “theoretical sufficiency” to describe how grounded theory research can arrive at a place where categories and themes are clearly formed, but it is recognised that there is potential for further analysis. Recognising that there are challenges drawing on theoretical saturation as a reliable process for confirming the completion of data collection, this study opted to use theoretical sufficiency as a grounded way of confirming data collection completion. Theoretical sufficiency was confirmed when there was evidence of no new codes and categories arising from the interviews conducted.

6.11. Reflexivity and the role of the researcher

In qualitative exploratory research the researcher does not stand outside of the study but remains connected and immersed in the study (Mills et al., 2006; Bryman, 2016), not only through methodological tools such as interviews, but also through the activity of constructing, exploring and analysing data (Denicolo et al., 2016). Furthermore, it is recognised within constructivist research that there's an implicit link between the researcher and the subject (Ramalho et al., 2015) and therefore they cannot be understood in isolation from each other. Producing knowledge through social work research is a collaborative process, in which the role of the researcher is seen to be pivotal (Smith, 2009). The relationship between the researcher and the research has been explored by many studies (Bryman, 2016, Palaganas et al., 2017), highlighting that it should not be overlooked.

As the researcher for this doctoral thesis, I was the lead person in the design, data collection and analysis of the data. Being a solitary researcher for this study, self-awareness is a necessity to understand the relationship with the research, which is also referred to as reflexivity. The nature of reflexivity in social work research includes an awareness of one's own values and theoretical perspectives (White, 1997) and a willingness to examine these (Taylor and White, 2001). Similarly, constructivist ideas in exploring social phenomena highlights that the researcher is likely to be "close" to the research (Charmaz, 2008), supporting the importance of the researcher recognising their presence and influence throughout the research data collection. Closeness to the research although positive, can mean that the researcher is less aware of their assumptions and ideas and how these influence the research process.

Drawing on the theory of reflexivity, Bourdieu whose research spanned the 1990s and 2000s, from his extensive fieldwork, identified epistemic reflexivity as a requirement for research when there is a close connection or association between participant and researcher (Bourdieu and Wacquant, 1998 cited in Larsen, 2016). Epistemic reflexivity is concerned with researchers paying attention to their disciplinary pre-suppositions and ways of knowing (Gray, 2013). It confers that at all stages researchers will scrutinise their preconceived theories and ideas linked to the phenomenon being explored. Wacquant, drawing on Bourdieu's epistemic reflexivity uses the term "self-criticism" to describe the processes that research needs to engage with post-data collection (Bourdieu and Wacquant, 1998, cited in Larsen, 2016). Self-criticism suggests that the researcher will ask questions about their own role and influence throughout the research process.

Considering epistemic ideas throughout this research study it was useful for me to hold a reflexive awareness of my own assumptions, my preferred theories, ways of practising and how these influence the research being carried out (Becker et al., 2012; Fook, 2002). The epistemological and ontological premise of this study acknowledges that there are subjective interpretations which are important ingredients to arriving at the meanings and conclusions that have been drawn within this study. These subjective interpretations were scrutinised through discussion with supervisors and feedback given from presentations on the research plans.

6.11.1. Personal reflexivity

Personal reflexivity acknowledges the imposition of the researcher's status, personal ideas, interests and values at all stages in the research process and therefore requires open acknowledgement of how the research may be influenced by the researcher. Self-scrutiny can be used as a helpful tool within the research process. The task of this study was to embrace the overlap between the researcher and the subject and include scrutiny of the researcher's role as part of the research plan.

At the outset of this research study an acknowledgement of my interest and thoughts about the topic matter was noted in a research diary. As a qualified social worker who worked as a social work practitioner using the MCA, I have a personal interest and closeness to the topic. As noted in Chapter One of the thesis, my own family experience of dementia was an influential factor in the selection of the topic and became an area for reflection throughout the research study, particularly in relation to the curiosity about how the data might support or contradict my own experiences. Exploring the assumptions that the researcher holds about the decision making of social workers in this area was important. These assumptions are not always immediately apparent and required ongoing scrutiny.

Prior to collecting data, I considered how my own ideas and thoughts on mental capacity assessment and decision making might have had an influence. I re-looked at my own practice experiences of working with dementia and mental capacity practice and the initial thoughts I had on these in a reflective diary. Consciously selecting a constructivist research strategy informed me that an aspect of the research study would be to open me up to different ways of understanding mental capacity decision making which might be different to my ideas (Denicolo et al., 2016). This was initially unsettling for me and I would put this down to a reliance on my past experience of practice and study of decision making in MCA practice. I was helped when I reminded myself that part of the research strategy is to become aware of how decision making is constructed by others. Throughout the data collection the memos were used to note down thoughts, responses, and reflections of the data. The use of memos formed a useful reference point throughout the research process. During the writing up of the findings and discussion of the findings I found it helpful to add further reflections on how the data I was making sense of contrasted with my own practice experiences. Some of the reflections I recorded highlighted my uncomfortableness and ambivalence with the data that had been generated from the research, revealing that there were preconceived ideas of what might emerge from the data.

My identity as a black male social worker and academic also led to reflections throughout the research process. These reflections highlighted my curiosity about how I would be perceived as a researcher exploring mental capacity and dementia. All of the interviews were carried out using Zoom and participants had their personal computer cameras on, so they could see me and I could see them. I introduced myself to interview participants as a PhD researcher and social worker. There were few interviews where issues of culture and race were raised and I wondered whether this linked to an assumption that race was not a prominent matter in decision making and mental capacity practice for social workers. In preparing the interview schedule I had not consciously thought about race and culture, so at the time of the interviews, it was not a matter in the foreground of my attention. I did perceive that my past practice experience as a social worker with people with dementia assisted in the participants talking more freely about their experiences as they used terminology common to social work without taking steps to explain these terms. For example, participants spoke about duty and referral processes which I was able to understand. As a fairly inexperienced researcher I had questions about whether my research study would be robust and acknowledged by participants. These thoughts were further reinforced when there were significant delays in identifying participants for the study. These reflections were mulled over and sometimes raised in meetings with my supervisors. Drawing these reflections together highlighted that reflexivity had salience in the construction and execution of the research study, and as noted by (Fook, 2002) helped to understand the gap between theory and practice.

6.12. Conclusion

This chapter has presented a theoretical road map of the design and execution of the research. It builds on epistemological premises for the research and outlines how this shaped the direction of the research plans. The centrality of a grounded theory approach to the methodology has been outlined. The chapter confirms that the methodological approach used was non-linear in process and was subject to changes in response to wider events that were outside of the control of the researcher. These events saw adaptions to the methodology, which were discussed and verified with supervisors and relevant organisations. Important to the methodology is the recognition of my role as the researcher and how reflexivity helped to examine my role within the research.

Chapter 7: Findings

7.1. Introduction

The findings chapter outlines the rich contributions from the participant interviews that formed the core of the fieldwork research. The findings in this chapter are arranged in thematic categories and themes informed by the grounded theory approach used to collect data. To illuminate the themes anonymised verbatim quotes of participant responses within the semi-structured interviews are used. Throughout the chapter, the term mental capacity or MCA work is used to refer to the activities that participants engaged in when using the MCA. The term MCA assessment is used to refer specifically to MCA assessments, i.e., the formal assessment process found in s(2) and s(3) of the MCA. The other term commonly used is Best Interests decision making which refers to activity carried out in line with s(4) MCA.

The findings link to the research question: How do social workers use the MCA to assess and make decisions in the context of their practice with people with YOD? Across this chapter, there is firstly a description and explanation of each of the thematic category that emerged in the analysis and their significance to the study. This is followed by an outline of the theme that emerged from the analysis linked to the wider thematic category.

7.2. Thematic categories and themes

Table 4 below outlines the thematic categories and themes that emerged within the categories.

Table 4. Thematic categories and themes

Thematic category	Themes
Social worker understanding and awareness of working with YOD in MCA work)	Understanding YOD Importance of diagnosis in working with YOD Age and YOD Stigma and YOD
Social worker MCA assessment and decision-making processes	Social worker awareness of the MCA Getting to know the person in MCA work Communication and person-centred skills in MCA work Person-centred approaches in MCA assessment and decision-making Using tools in MCA assessment and decision-making
The context of social worker MCA assessment and decision making	Covid 19 and MCA decision making Settings for MCA decision-making Time constraints on MCA decision-making
Social worker collaboration in MCA assessment and decision making	Collaborative work with professionals Collaborative work with families and carers Collaborative work with community organisations
A typology of social worker MCA decision making	Procedural approaches to MCA decision making Medicalised approaches to MCA decision-making Shared approaches to MCA decision-making Positive risk approaches to MCA decision-making Creative approaches to MCA decision-making Rights-based approaches to MCA decision-making

7.3. Thematic Category 1: Understanding of YOD in MCA work

The first thematic category identified was social worker understanding and awareness of YOD. This refers to ways in which YOD was talked about by participants in the study, revealing their practical understanding of YOD. This goes beyond what they know about YOD regarding mental capacity work to consider their general understanding of YOD and experiences working with YOD. During the interviews, participants were prompted to share their understanding of YOD, including a detailed discussion of their thoughts about YOD. The thematic category reveals a variety of views about the nature of YOD and responses to it. The theme recognises that participants held differentiated ideas of YOD. These ideas include understanding what YOD is, who is affected by YOD, the role of diagnosis in YOD and how YOD relates to LOD.

7.3.1. Theme: Understanding YOD

Participants shared their understanding of YOD in a range of ways. Some were able to give details about their understanding of YOD and were able to identify people who they worked with who have YOD and described the experience of assessing them using the MCA. Other participants spoke about an awareness of YOD but indicated little practice experience with YOD. These participants spoke about coming across YOD in their practice, but that it was not a central feature of their practice. Different terms were used to describe their understanding of the onset of dementia before the age 65. Some used YOD, others used early-onset dementia, and a few used working-age dementia.

Some participants had reported little or no practice experience working with people who have YOD. These participants found it more difficult to talk about YOD but engaged more fully in discussions about dementia in older people during the interviews. For these participants, the responses to questions asked about their MCA practice with people with YOD included a comparison based on their work with people who have dementia in later life.

Some asserted a clear understanding of what they thought the definition of YOD was and this is an example of the ability of some participants to speak about YOD in sophisticated ways. Moreover, some participants stated that they found the discussion of definitions of YOD quite useful in terms of their clarifying own understanding of whether they had worked with people who have YOD. A noticeable finding concerning understanding YOD was that some participants shared their personal experiences of dementia as a way of talking about their understanding of YOD. This included referring to a family member, relative or friend.

Table 5 outlines the typology of social work practice with YOD. A typology can be described as a classification system to arrange different phenomena according to similarities and dissimilarities (Stapley et al., 2022) and has been noted as a useful way to gain a better understanding of the similarities and differences (McDonald, 2010). The table refers to different and distinct types of social worker understanding and engagement with YOD. The first type, Type 1, is referred to as dementia experienced and YOD inexperienced social worker who can be described as having an awareness of dementia in older age groups but lacking awareness and experience of working with people with YOD. Participants volunteered that they had little or no practice experience in working with YOD and tended to talk about dementia in broad terms with little reference to YOD as a specific category. The findings here highlight that these participants tended to want to talk about dementia linked to older age, despite being recruited for a study exploring YOD. They were comfortable discussing YOD and LOD together rather than talking about them as a separate age category. From their contributions, it was evident that these participants' experience in working with older people with dementia far outweighed their experience and understanding of working with YOD. The second type outlined in Table 5 identifies those who had YOD practice experience and less experience in working with people with LOD. Participants in this category typically indicated an understanding and awareness of YOD, but a lesser awareness of dementia in people over 65 years. They tended to work in specific services aimed at younger adults or in learning disability settings. They engaged in conversation about YOD and were able to draw on practice examples of YOD., for example, giving accounts of when they carried out MCA assessments with people who have YOD. The final types of social work practitioners outlined in Table 5, were those with experience in both YOD and LOD. These indicated a lot of awareness of YOD and substantial practice experience working with people who have LOD. These participants spoke fluently about their practice experience of working with YOD. They were able to reference their work and experiences in relation to YOD, and sharing their thoughts on YOD with confidence. A quote from a participant who was confident in talking about YOD and LOD is noted below.

> *“At the moment I think in the past couple of years we’ve had quite a younger generation being diagnosed with dementia. I remember working with them and learning lots.” Participant 11.*

Table 5. Types of Social Worker understanding and awareness of people with YOD

	Type 1: Dementia experienced but YOD inexperienced	Type 2: YOD experienced and inexperienced with dementia in older age	Type 3: YOD and older age dementia experienced
Awareness of YOD	Little awareness of YOD, little or no practice experience.	A good awareness of YOD and some direct practice experience. Limited experience of practice with people with dementia in later life	A good awareness and practice experience of YOD and LOD.
Area of Practice experience	LOD	YOD	Both

From the interviews, it was evident that most participants were able to articulate their understanding of YOD, although there were a variety of responses concerning what they understood YOD to be. Some participants talked about YOD being partly evidenced through diagnosis of dementia before the age of 65, via a medical professional but not all held this view. For example, one participant shared their understanding of YOD being linked to the early stages of the experience of dementia, rather than an age category. This is a significant finding and exemplifies that there were differentiated understandings about the nature of YOD and a variety of ways of understanding YOD. As a theme within the thematic category of understanding YOD in MCA practice, the table outlined in Table 5 helps by giving greater clarity of the levels of understanding and engagement in talking about YOD.

7.3.2. Theme: Diagnosis and categories of YOD

In discussions about their understanding of YOD, participants spoke about the diagnosis of YOD, as being relevant to their practice. This is of relevance to these findings because social workers are not usually directly involved in the processes of diagnosis of YOD. Diagnoses are usually made by medical professionals like GPs., neurologists and psychiatrists. Concerning the diagnosis of YOD, participants spoke about the specific types of dementia, with which they were familiar. They volunteered to talk about the different types unprompted and some spoke in detail giving examples of their practice experience working with a person with the specific type of dementia. The different types of dementia that were noted included, vascular dementia, Alzheimer’s, alcohol-related dementia, Lewy body syndrome and Korsakoff’s Syndrome.

> *“Yeah. Onset dementia is where someone has memory issues, starting to forget about things and then they’ve been diagnosed by a medical professional with onset dementia, which could be anything ranging from Alzheimer’s dementia, or vascular or Lewy body or any of the dementia types.” Participant 9.*

Discussions around Korsakoff’s type of YOD came up frequently in discussions on types of YOD. Korsakoff’s was noted as a form of YOD which participants had come across in their practice, although one participant saw the inclusion of Korsakoff's as a form of dementia as incorrect and went further to suggest that categorising Korsakoff's as dementia represents a misuse of resources, based on their belief that Korsakoff's should not be responded to as a form of dementia.

> *"And having Korsakoff's and needing care, when you are in your late 50s or 60s, it's not what I call on early onset dementia. That I do know. I may be wrong. But for me, it's two different things." Participant 8.*

The above quote from a participant represents a perspective, suggesting that Korsakoff's should not be regarded as the same as YOD. The object of the interview was not to debate the perspectives shared by participants, so the interview moved on, although on reflection it was interesting to think about why a participant had decided that Korsakoff's should not be seen as YOD.

Participants spoke about diagnosis of YOD and this was linked to their understanding of what YOD is and how it affects the lives of those who experience dementia. This included awareness of the length of time it can take for a diagnosis to be made.

> *"Let's be honest, people could be living with dementia for quite some time without a diagnosis." Participant 16.*

There were suggestions that diagnosis can be a challenging aspect of their work with people who have YOD. Participants were familiar with evidence indicating there can often be longer waits for people with YOD to obtain a diagnosis. Linking diagnosis to their practice, comments were made about how an absence of diagnosis presents a barrier for those with YOD receiving social care input.

The 186onversatins of diagnosis were relevant to how participants engage in MCA assessment. For example, participants were cognisant of the two stages involved in MCA assessment and how diagnosis links to understanding whether a person has an impairment of or disturbance in the functioning of the mind or brain. Misdiagnosis was noted as a challenge linked to completing the two-stage assessment of capacity, in particular about working out if the person has an impairment in the functioning of the mind or brain. Misdiagnosis here is used to refer to instances where YOD was misdiagnosed as acute mental ill health or being referred to as a long-term mental health problem. Several participants shared their practice experiences where a person with YOD was misdiagnosed as having mental health problems. In these instances, misdiagnosis was perceived as problematic because it seemed to create further delays in the process of accessing social care support.

The diagnosis was linked to discussions around learning disability and YOD. Some participants spoke about their substantial experience in practice with adults with learning disabilities, acknowledging that there is a higher prevalence of YOD for people with learning disabilities and that dementia can occur in adults with learning disabilities at an earlier age in their lives. Concerning learning disabilities and YOD, participants' suggestions indicated that social workers who work primarily with adults with learning disabilities may have greater experience in working with YOD.

> *"I think possibly workers in learning disability services might have maybe more contact with early onset dementia when considering when we work with individuals with Down syndrome." Participant 13.*

7.3.3. Theme: YOD and age

Age emerged as a salient aspect of how participants made sense of YOD. Many participants spoke about YOD being linked to people below the age of 65 years.

> *" And I had a client that she was, she was still in her 50s. And I think the youngest we had at the time, she was 32, alone parent with a couple of children". Participant 8.*

Some explained that their understanding of YOD and age issues in dementia developed through their practice experiences while others linked it to policy, either in their organisation or at a national level as a key to understanding YOD.

> *"I've only come across probably a handful of cases where dementia, the person has been within the ages of 50 to 55." Participant 17.*

Throughout the interviews participant discussions of YOD overlapped with discussion of LOD. This finding raised curiosity and prompted questions to clarify whether they were referring to LOD or YOD dementia in their responses. Many participants mentioned that their practice was with people who have YOD and people who have LOD, justifying the overlapping way in which they spoke about YOD. It was noticeable that during the interviews participants referred to dementia in a generic sense, often without confirming whether they were referring to YOD or LOD. This raised questions for me about how participants viewed YOD.

The language used to discuss YOD and LOD, was often the same, with generic terms like adults with dementia, younger adults with dementia and LOD being used in conversations about both YOD and dementia in older people, which may suggest that some participants were content to draw together or conflate YOD and LOD as one singular categorisation of dementia.

Participants drew comparisons between their practice experience with people with YOD and people with LOD, which was initially surprising. These comparisons were unprompted and illustrated how participants understood YOD. The comparisons made by participants between people with YOD and LOD included their perspectives on the differences between people with YOD to process information, level of support, involvement of professionals and awareness of family members. These differences will be discussed in turn.

There was a perception that people with YOD have a greater ability to process information than people with LOD. The belief was justified by participants in highlighting that their practice experience of people with YOD was with those who have less advanced stage dementia and were likely to be more engaged and responsive to questions.

> *" I've practised mostly with people who have younger onset dementia, they still will be more capable of processing information." Participant 15.*

Concerning levels of support from professionals and services, participants indicated that levels of support were more likely to be greater for people with dementia in later life, based on dementia being more common in later life. However, participants recognised that assumptions about the level of support and needs should not be made based on the person's age. Here, it was acknowledged that a more individualised approach was helpful in practice, as shown in the quote below.

> *"I'm always going to tailor the process to that individual's needs, whether they have early onset, or whether they have sort of advanced in their late 90s" Participant 14.*

Alongside contrasting the support available to people who have YOD participants spoke of varying levels of professional involvement in their work with people who have YOD. There were divergent views about the involvement of professionals between participants with some stating that professional involvement was greater with LOD because of greater awareness about LOD as well as more services being available for people with LOD, whereas others drew observations that professional involvement was often more responsive to people with YOD.

Contrasting LOD with YOD was a common way in which participants talked about their own experiences of working with YOD. Participants found the comparison and contrasts of YOD and LOD helpful in their attempts to talk about YOD. Many noted that there were little or no differences between how they practised with people who have YOD and people who have LOD. However, there were instances where participants recognised that YOD was seen differently as highlighted in the quote below.

> *"Yeah, I think so. I think there are differences in expectation, and I think they come from maybe from an ageist place, I think there is a kind of general sense that people who are older, dementia is inevitable, an inevitable thing, this is going to come." Participant 3.*

7.3.4. Theme: YOD and stigma

The final theme outlined within this thematic category is stigma. Contributions from participants noting the stigma experienced by people with YOD were prominent in the interviews. Many of the conversations where stigma was discussed emerged from participants' contributions and discussions about the negative experiences faced by people with YOD. In some cases, participants shared their first-hand accounts of the negative events experienced by people with YOD with whom they have worked.

Participants recognised that people with YOD experience inequality and discrimination through stigma and were keen to talk about this. Stigma was recognised by participants as being linked to diagnosis. They noted that receiving a diagnosis of dementia could contribute to stigma and this would affect the experiences of the person to engage with services.

> *"I think as I mentioned before, I think stigma is a big one. And thinking about how the potential stigma attached to that diagnosis that the person may have*

> *and how that may affect their presentation and the answers they give and their engagement with you." Participant 14.*

The experience of stigma was noted as central to an understanding of the experience of YOD. Participants spoke about stigma in different ways. This included the stigma they believed those with YOD can experience, after receiving a diagnosis of YOD. Participants recognised that the stigma attached to the status of having YOD affected their MCA work. For example, they found people with YOD would not want to talk about dementia or minimise how dementia affected their lives. This was identified by participants as due to the stigma that a person holds about their status as having dementia at a young age. From the findings, there was also a discussion of stigma linked to YOD, deriving from others, including other professionals, which is often referred to in the literature as societal stigma (Nguyen and Li, 2020).

> *"There's still a strong paternalism around people who are deemed to be lacking capacity, particularly people with dementia. I think there's often an infantilization of people who have cognitive impairment with dementia" Participant 3.*

The above quote from a participant recognises what are termed 'paternalistic responses' towards people with YOD links to wider societal stigma and prejudice. The above quote was also related to professionals who work with people with dementia and the participant revealing how professionals can infantilise people with YOD, creating a stigma. Participants shared that there were challenging conversations with family members and carers which relate to stigma. The challenging conversations with family members related to parts of MCA work where it was evident to participants that family members struggled to come to terms with the diagnosis of dementia or that the person with dementia would require greater care than they had anticipated.

Summarising the thematic category of understanding YOD, it has been found that there is a rich insight into how social workers make sense of YOD in their practice. The themes highlight that the term YOD is embedded with many ideas about diagnosis, age, and stigma. Interpreting understanding of YOD from the participants can helpfully be categorised into a typology of understanding YOD. The typology of understanding YOD will be discussed further in the discussion chapter.

7.4. Thematic category: The process of MCA assessment and decision-making

A finding that emerged related to MCA assessment with people who have YOD was a process that comprised of a set of activities. This formed a thematic category highlighting the process of MCA decision-making. The process of MCA assessment and decision-making is made up of core activities which participants described as central to their practice in MCA assessment and Best Interests decision-making. Social workers appeared to engage in both formal and informal processes as part of their MCA assessment and decision-making. Formal processes refer to participants' use of conversation to assess whether the legal threshold for the person lacking capacity has been met. An example of this is a participant asking questions linked to the two-stage MCA test to form an opinion on whether the person has decision making capacity. Informal processes refer to skills and approaches used by participants in assessment and decision-making processes, such as communication and rapport building.

7.4.1. Theme: Knowledge and Awareness of the MCA

Concerning MCA assessment and decision making all the participants in the study were able to articulate how they used the MCA as part of their practice. MCA assessments and Best Interests decision-making were recognised by participants as a core activity in using the MCA in practice. Participants shared how they carry out MCA assessments when working with people who have YOD. This included how they use the MCA principles to guide and lead their practice and how the two-stage assessment process is used to assess mental capacity. Across interviews, participants spoke confidently about the legal aspects of MCA assessments and decision-making. Below is an example of how a participant explained the need to follow the MCA assessment process.

> *"I've got a gentleman at the moment and it's quite interesting, he hasn't got a diagnosis of dementia, because he's been refusing to engage with the memory assessment team. So, in a way, we've kind of hit a bit of a stumbling block, because like I said, on the capacity assessment [document] you need to be saying kind of, if there's a reason why you're looking at capacity…And you've, as the law says, you've got to assume capacity." Participant 16.*

Participants reported that they had an understanding and awareness of the Best Interests processes outlined in the MCA and the MCA Code of Practice (2007). Discussions drew responses from participants about how they carried out Best Interests decision-making and also what supported their Best Interests decision-making. There were examples of participants

> *" I have been asked to be in a best interest meeting with somebody I have not seen or not met and I don't know if the person has capacity. And suddenly there is not a mental capacity assessment available at the meeting. And when I am in our best interest meeting and I am like, wait a minute, I am not feeling confident about talking about this person. Even there is information on the system is not enough for me because it's not giving me an idea of what I'm dealing with and that you are asking me to be part of some group who are going to decide about what is the best one this person." Participant 18.*

Participants stated that there was a mismatch in how they understood Best Interests processes and what happens in practice. They noted that Best Interests decision-making ordinarily happens after an assessment of capacity but not always. Some participants saw Best Interests decision-making as occurring at the same time or ahead of an MCA assessment. Conversations about Best interests' decision-making occurring ahead of MCA assessment was an area that participants wanted to talk about. One participant in their discussion of this practice described their observations as 'like working backwards' in the MCA process. The occurrence of Best Interests decision-making happening before the MCA assessment has been noted by Williams et al. (2012a) who termed this as the Concertina effect. The Concertina Effect was not the term that participants used, but many recognised that they had seen or been part of a practice where decision-making had been considered ahead of the MCA assessment.

> *"A best interest meeting where you haven't done a capacity assessment where you haven't spoken to the person, so you don't know what their wishes and feelings are. Anyway. So, it's basically just some health professionals gathering around a table and deciding what they're going to do to someone. Yeah, yeah. And I think it's, it's easy to get away with that, at least in the short term."*
> *Participant 4.*

Where Best Interests decision-making happens before capacity assessment participants acknowledged that this did not follow the legal process of the MCA, which starts with the assumption of a person having the capacity to make decisions for themselves, until an MCA assessment has occurred, evidencing that they cannot make a specific decision for themselves. In line with the MCA Code of Practice, the Best Interest decision-making process should follow assessment. For some participants not following the legal process was perceived as problematic and one participant described their experience of seeing this happen in practice as irritating. In discussions about Best Interests being engaged before ascertaining capacity, some participants indicated that they challenged other professionals, noting that they saw it as part of their role to ask questions or challenge, particularly where professionals engaged in what appeared to be Best Interest Decision making and there was no evidence of an MCA assessment.

> *" I remember seeing a care plan in a care home. And it was like a care plan around night needs. I don't remember how it was exactly written but it said that the person can't decide about their bedtime or something like that. And I'm like, what do you mean, she, what do you mean, they can't decide when they want to go to sleep? Like, I don't understand. Tell me how you assessed them because I don't understand." Participant 19.*

The ability to challenge others appeared to come from a position of knowing the MCA sections linked to assessment and Best Interests, the MCA principles and the code of practice guidance. Participants spoke about challenging others with confidence that they are doing the right thing regarding following the law and for the person with YOD. Participants were able to talk about their awareness of what they believed their roles and responsibilities were in using the MCA.

There was a divergent view where participants did not perceive decision making prior to assessment as a negative activity. Not all participants commented that engaging in decision-making prior to assessment was a negative. In these discussions, it was noted that they were likely to engage in Best Interests decision-making before a formal MCA assessment when it was clear to them that the person would be found to lack the capacity to make a decision. Other participants noted that MCA assessment and Best Interests decision-making work was not always straightforward or linear and it was common to have conversations about decisions ahead of the MCA assessment process as part of the response to the complexity of the work. Other explanations that were offered were that there are often time pressures to complete MCA decision-making as quickly as possible, so decision making would happen in tandem with assessment. Other views suggested that the process of MCA assessment and Best Interests decision-making would often overlap as one participant stated:

> *"So, you are sort of forced to make decisions as quickly as possible. And you sort of frame it as in people's best interests." Participant 7.*

The above quotation is an example where a participant explained how they rationalised making a Best Interest decision as part of their MCA assessment because of what they referred to as time constraints. However, the participant did not see it as problematic.

In summary, then, awareness of the MCA was central to how participants engaged in the process of MCA decision making and being clear about the legal requirements in some cases led to questioning others involved in the MCA decision-making process.

7.4.2. Theme: Getting to know the person and building a rapport as a part of the assessment

Getting to know the person with YOD as an initial part of the MCA assessment and gathering information was discussed by many participants. There was a broad acknowledgement that there can be challenges in carrying out MCA assessment with people who have YOD and participants and getting to know the person was one of the techniques used by participants. The quote below provides an example of the importance of initial discussions with a person during a MCA assessment.

> *"I mean, that's huge, hugely important for me. It's not always practical, I guess, I'm thinking about real-world social work. For example, if you're on duty one day, and there's a need to do a capacity assessment and you've not met this person. There are still steps you can take to get to know what's important to the person in relation to the decision in question. So, you know, talk to well talk to the person gain their wishes, understand their history, their backgrounds. familiarise yourself with the file." Participant 14.*

Participants were able to share in detail how they went about getting to know the person and drawing out information from people with YOD when assessing their mental capacity. Getting to know the person with YOD was also described as building a rapport. This process was seen as vital in MCA assessment and was supported by how participants spoke about how they used information from their initial conversations. In many cases the initial conversations which aimed to build a rapport with people who have YOD seem to serve as a foundation before exploring mental capacity in their work with people with YOD as the following quote shows:

> *"As a social worker, that's always been the kind of most important element which is about kind of getting to know your client, your service user, however, you choose to use the label. But just getting to know something about them gives you some kind of commonality in some ways, some human interaction. So that's, that's what I like to kind of do. I like to try and if I've got the luxury of time, I'd like to try and be able to engage in a bit more of a, I should say, less directed, less structured, real conversation, something real for me to start with. It helps I think, for people to feel a little bit more comfortable." Participant 3.*

The sense of importance attached to the initial conversations of getting to know the person with YOD was highlighted by participants in the context of recognising that MCA work can be complex for the person and their families. Terms like creating a 'safe environment' and 'finding as much about the person' suggest that this was a well-considered aspect of the work with people with YOD during MCA assessment.

> *"So, what I guess I'm getting at is I think what's important is building a rapport with someone, for them to let down the guard a little bit. And then, for me, it's about having a conversation, gaining a bit of information through that conversation, and then feeling comfortable enough for you to kind of ask more probing questions." Participant 16.*

The above quote is an example of the suggestion from participants that the MCA assessment process is more than a formal statutory process which includes gathering information to ascertain whether the person has capacity. It also includes a therapeutic dimension that recognises the circumstances of the person who is being assessed and seeking to bring reassurance and support. Linked to these suggestions some participants said that before a MCA assessment, they would find out details about the person, to support their conversations with the person. This was described in one case as trying to understand the 'wider context' of the person, which can be used to know what sorts of questions to ask as part of the MCA assessment.

Participants reported that getting to know the person with YOD conversations was not viewed as being separate from their assessment of capacity, but rather as a necessary part of the MCA assessment. These conversations were explained by participants as being helpful towards gathering background information which helped in building the rationale for whether the person had the capacity to make a decision. In this way, initial conversations of getting to know the person could make MCA assessments more straightforward and it was suggested that this had benefits for both the participant and the person with YOD being assessed under the MCA.

> *"..if you can talk in a real and meaningful way, and a way that kind of where people feel like they've had some value." Participant 3.*

Conversations with participants about building a rapport with a person with YOD as part of a MCA assessment and decision-making process were viewed as positive and described as highly valued aspects of their MCA work with people with YOD. With the social work process of MCA decision making these aspects were seen as supporting other aspects such as Best Interests decision making and understanding wider care needs.

7.4.3. Theme: Person-centred approaches in MCA assessment and decision-making

As well as building a rapport with the person in the process of assessment and decision-making using the MCA the findings reveal wider skills used by participants in their practice. For example, participants highlighted communication skills like listening and reflecting on what has been said. Within the repertoire of skills discussed in the interviews, the findings showed that person-centred approaches were commonly spoken about. Person-centred approaches were described as core to social work practice with people with YOD. Participants described themselves as interested in understanding the person and wanting to represent the person’s views through finding out information that was relevant for the person with YOD.

Person-centred approaches as defined by participants included starting with the person’s perspective on what had happened to them. This would often involve listening to and exploring what the person wanted to talk about within the assessment of mental capacity alongside explaining the purpose of their involvement. Starting with the person’s understanding of what happened to them was seen by participants as particularly useful in the MCA assessment process with suggestions that helped to open up conversations. Participants outlined that their person-centred approach included not making assumptions based on the person having a diagnosis of dementia and whether they might or might not have mental capacity.

> *“The social work role is basically to support regardless of, you know, not to make any assumptions basically, of that person’s capacity. And, you know, use your use the laws that are in place to assess that person’s capacity, the needs, look at what that person wants from us.” Participant 5.*

7.4.4. Theme: Use of tools and aids in MCA assessment and decision-making

The use of practice aids and tools brings to light that participants were able to talk in detail about what they did as part of their MCA assessment with people with YOD. As part of their descriptions, participants spoke about what has been termed practice tools to assist them in their assessment of capacity. The term ‘tools’ is used here to refer to resources that social workers would use to support the assessment of capacity and the process of decision-making in mental capacity work.

Many participants shared their experiences of using tools in MCA work. Not all participants used the word tools. Some used the word ‘resources,’ others used the words like ’aids.’ Tools were spoken about in regard to specific impairments, such as tools that can be used during an assessment with a person who has a hearing impairment or a visual impairment. Examples given here were picture tools for people with hearing impairment or using basic sign language. There was an acknowledgement that tools needed to be sensitive to the specific needs of people with YOD, recognising that written information or photos might not be of use if the person’s memory had declined. Participants spoke positively about using tools to assist their MCA work and in particular decision making by helping to understand the person’s views and wishes more clearly.

Many of the participants in the study were able to speak about tools for assessment and decision-making where finances were a significant part of the mental capacity work, suggesting that discussions regarding finances are frequent topics for social workers in their MCA assessment and decision-making with people who have YOD. There was a common reference to the use of fake money as a practical tool to support the assessment of capacity with people with YOD.

> *“Yeah, well, I’ll probably, well, if they’ve got a purse or money in it, we’ll use that. If it’s to do with a bill or an invoice, you know, I have one of those. I’ll show it to them and ask them to explain it to me and see if they can relate that to them.” Participant 15.*

Whilst using tools to support MCA assessment were perceived as beneficial, there were some suggestions that they are not always helpful.

> *“But also, I have used picture tools as well, which I’ve had two different responses to very different responses from that one person that just looked at*

> *me kind of blankly and thought that I was being sort of patronising in a way, I guess because I was using tools that you may use with a child is how she saw it". Participant 7.*

The quote above reminds us that in assessing capacity for people with YOD, there may not be a need for additional support through the use of tools and highlights that assumptions can be made about how cognition and engagement have been affected by the condition the person experiences.

Participants spoke about the use of tools for a range of purposes in their MCA assessment decision making. Tools were used to help clarify information already discussed within MCA assessment processes. For example, a participant after describing options about moving to residential care homes, showed a photograph of a range of residential care homes to the person being assessed. Participants recognised that tools helped communicate more complex information such as details about financial decisions. Finally, participants used tools to triangulate information read in case files and shared by family members and carers. In most cases, participants said they were able to identify suitable tools to support their MCA work.

In summary, participants communicated that the MCA assessment and decision-making process was central to their work with YOD and described how they went about their assessment work. Of key importance in MCA assessment is what has been described as having a conversation where participants would try to get to know the person being assessed as well as using person-centred approaches. These skills describe how participants went about their assessment work with people with YOD. A key support for their MCA assessment and Best Interests decision making was the use of tools and aids which were often helpful for supporting communicating complex or abstract ideas with a person who has YOD.

7.5. Thematic category: Context to MCA assessment and decision making

The context of MCA assessment and decision-making emerged as a thematic category in this study and this relates to the many conversations where the importance of contextual factors in MCA work was spoken about in the interviews. Participants spoke about MCA assessments taking place in people's own homes, in care homes, and in hospitals and the importance of setting as well as the amount of time afforded to carry out assessments.

7.5.1. Theme: Covid 19 as a contextual issue

The most commonly discussed issue was that of Covid 19. This can be partly explained due to the interviews taking place at a time of significant disruption due to the Covid 19 pandemic. Participants noted that there was a huge disruption to their practice generally and the specificity of their MCA work with people who have YOD. MCA assessments and decision-making meetings were moved online in line with the government guidance. In the interviews there was frequent reference from participants about restrictions on face-to-face contact, the requirements to follow social distancing guidance, wear face masks and use other forms of PPE in their day-to-day practice.

Participants noted how carrying out MCA assessment and Best Interests decision-making were more challenging than before the pandemic. These were described as additional to the day-to-day challenges in MCA work with people who have YOD. In discussing how the Covid 19 pandemic affected practice some participants spoke about requirements to work from home, which prevented them from meeting with people face to face and led to MCA assessment taking place over the telephone or online.

Interview conversations linked to Covid 19 and how it influenced how MCA assessments were completed raised an array of challenges. These challenges included the barriers to getting to know the person finding out information about the person and having meaningful contact with families and carers. The Covid 19 pandemic and the restrictions imposed during the pandemic meant that participants were less able to do what they described as rapport building and understanding the person's context through face-to-face conversations. The inability to meet face-to-face with people with YOD was noted to be a barrier to the positive aspects of MCA work.

> *"And again, as I've kind of alluded to throughout this, it's all about the communication building that rapport having a mask on your face is going to end potentially being two meters apart or wearing everything else PPE is going to impact and that rapport building." Participant 16.*

Some participants were able to articulate quite clearly the effect that the Covid 19 restrictions had on how they went about completing MCA assessments for people who have YOD. One example below shows that participants were very aware of the limitations that online or telephone assessment had on their MCA work.

> *"There are things that we consider within our assessment not only what I can hear the client saying but the body language, the expressions, there are things that we pick up by being with the person." Participant 10.*

As well as noting limitations participants shared ways in which they tried to overcome the challenges to their MCA work created by the Covid 19 pandemic. Common responses included embracing online platforms such as Zoom and MS Teams to complete assessments or using telephone interviews to carry out the MCA assessment but involving another person like a care home manager or relative who can be with the person being assessed. They would initially ask the question, then ask the care home manager to repeat the question directly to the person. This example demonstrates that the participants still attempted to find ways to engage in meaningful ways as part of their MCA assessment despite the barriers created during the pandemic. Participants reported that they did not always like having to find alternative ways to carry out MCA assessments but recognised the need to find a way to complete MCA work within the limitations imposed during the Covid 19 pandemic.

A salient finding from the conversations on how Covid 19 affected MCA assessment and decision-making relates to how participants perceived the responses of organisations in which they worked. Participants acknowledged the restrictions such as not being able to carry out face-to-face assessments imposed during the pandemic as a *de facto* part of how their practice changed. However, participants raised that within their organisational management structures the changes imposed became a preferred approach for carrying out assessments. Participants noted that senior staff and managers saw online or telephone MCA assessments as a more efficient way of carrying out MCA work.

> *"So, our managers do encourage us to do it over the phone. I don't like it…. Some of us are happy to just sit at the desk with our phone call and do it all like that. And some are still kind of, you know, trying to squeeze those visits and see people in person." Participant 19.*

The above quote highlights a perspective that senior staff and managers actively encouraged participants to complete assessments online or over the telephone which contrasts with what participants said they saw as the benefits of face-to-face interactions with people with YOD.

7.5.2. Theme: Settings for MCA decision-making

Participants spoke about the places where they did their MCA work and made decisions. These included people's own homes, care homes, hospitals, offices, online or over the telephone. Most participants identified that their MCA assessments happened in a set place and stated their preference for carrying out MCA assessment in the person's natural environment and would often like to visit the person at their home. However, it was acknowledged that they did not always have much control over the setting where their decision-making occurred. For example, participants noted that Covid 19 meant that many MCA assessments took place online or over the telephone because of the restrictions imposed on face-to-face work and visits during periods of the pandemic. Participants noted that where MCA assessments happened in a care home setting this benefited their decision making. It was noted that care homes offered opportunities for there to be conversations with staff around the person's needs, which was described as beneficial.

From reading the transcripts there was little discussion about whether they had different experiences in the settings where they carried out MCA work. Where differences were discussed, these were mainly related to Best Interests decisions taking place in hospital settings. In these cases, it was noted that staff in hospital settings tended to be less willing to discuss capacity issues and Best Interests decisions and more focused on confirming the next steps for the person. This was partly explained due to pressures to discharge people from the hospital.

> *"So yeah, but in the hospital, hospital discharge, it's very, very different. It challenges your beliefs and your social work values. And I've witnessed where you've had, effectively what would be a Care Act assessment, a capacity assessment and best interests are held within one hour with everybody sat around the table. I've had to weigh up there about what the intentions of the meeting was." Participant 7.*

The above participant indicated the pressure to arrive at a Best Interests decision within the hospital discharge meeting despite being uncomfortable with how the wider needs of the person with YOD were being overlooked.

Overall, the settings where MCA decision-making occurred tended to relate to places where participants most commonly worked and where the person with YOD lived or happened to be at the time of the assessment or the Best Interest decision meeting. However, as discussed in the section above the pandemic significantly influenced where decision-making occurred, resulting in more decision-making discussions happening online or over the telephone.

7.5.3. Theme: Time constraints

The time available for MCA work emerged as a theme in the conversations on MCA assessment and decision-making. Participants spoke frequently about limitations on their time to carry out MCA assessments and make Best Interests decisions. Time constraints were discussed in relation to completing the MCA assessment within an agreed frame, although there was no indication from participants that they had been given a set amount of time to complete their MCA assessment. Many shared that there was limited time to prepare for carrying out a MCA assessment. Preparation time for an MCA assessment was described as a time to read background information and time to speak with family members to find out more information about the person with YOD prior to the MCA assessment.

> *"Yeah. So, I think that kind of preparation is the key with any mental capacity assessment. And I think that that is something that professionals very often just don't have time for, and kind of skip and just go into it when I think that that's one of the key points. And if you don't do it right, your assessment is just not worth doing really. So yeah, the preparation, finding out information about the person." Participant 19.*

In discussions about Best Interests decision-making, participants noted that there are often time pressures to complete the MCA Best Interests decision-making process as quickly as possible, which would sometimes lead to an overlap between the MCA assessment and Best Interests decision-making processes. Other participants noted that Best Interests decision processes often involve multiple people and drawing together all parties or consulting with all parties involved was a factor in the difficulties linked to time.

> *“So, you are sort of forced to make decisions as quickly as possible. And you sort of frame it as in people’s best interests. Participant 7.*

7.6. Thematic category: Social work and collaborative decision-making

As a thematic category, collaborative decision-making illuminates the discussions with participants about how they assess and make decisions with other professionals. As part of the interviews, questions were asked about the experiences in assessment and decision-making in practice with people with YOD alongside other people. Participants shared that their mental capacity work was often collaborative rather than completed alone. To this extent, participants emphasised the importance of collaborating with other professionals in their MCA work. It emerged from the data that there were different types of collaboration, which were collaboration with professionals, collaborating with families and carers, and collaborating with community organisations.

7.6.1. Theme: Types of collaboration

The findings showed that participants were able to talk about how collaboration impacted their MCA work with people who have YOD. They were able to talk about their roles in collaborative working and contrast this with the roles of other professionals. Within these contributions, participants spoke in a normative sense of what collaboration *should* be like.

Table 6 outlines the different categories of participant collaboration and the different ways in which they collaborated. The table draws together the main ways in which participants interpreted their collaborative work when doing MCA work. Table 6 includes evidence of how often participants saw themselves as collaborating with others in their MCA work.

Table 6. Types of professional collaboration for social workers working with YOD.

Type of collaboration	Type 1: social work collaboration with other professionals	Type 2: Social worker collaboration with families and carers	Type 3: Social worker collaboration with community organisations
Frequency of collaboration	Regular	Regular	Infrequent

7.6.2. Theme: Collaborative practice with other professionals

Working alongside other professionals in MCA work was a common theme. Participants spoke about working with a range of different other professionals in assessing and decision-making with people with YOD. These included GPs, nurses, psychiatrists, occupational therapists, and psychologists. Participants used terms like multi-disciplinary team or multiagency work to describe the nature of the work they did alongside other professionals. Notably, all the participants were keen to talk about how they collaborated with other professionals in assessing mental capacity and Best Interest decision-making making and this was a topic that participants were able to talk about with fluidity, drawing attention to what they saw as the benefits and the challenges in working with other professionals.

Conversations with participants about collaborating with other professionals point towards collaboration being seen as a relevant part of their work with YOD. Not only did they see collaboration as relevant, but it was also framed as being positive for the person with YOD.

> *"I mean, I would always say, okay, maybe have a professional meeting, to basically try and see if we can, you know, have a mutual understanding? I think, to me best practices, it should be multi-agency and coordinated in a multi-agency way." Participant 6.*

Collaboration was affirmed as a positive and beneficial aspect of their work in assessing MCA. The responses from participants revealed that they wanted to collaborate with other professionals and value collaborative working. This was further evidenced by the positive comments linked to collaborative working.

Concerning collaborative working participants shared their accounts of the day-to-day experiences of collaborating with other professionals when using the MCA. These discussions highlighted that there were sometimes disagreements and differences between participants' perspectives and other professionals or what has been referred to as professional differences. Professional differences also refer to how participants contrasted their role with their understanding of the role of other professionals in collaborative mental capacity work. There was an awareness from participants that in collaborative working other professionals did not always incorporate a shared approach to MCA work. The quote below exemplifies how participants elaborated on professional differences.

> *"But I guess that's why the whole best interest decision is about everybody still sitting in the room and discussing it. Like everybody has a view. But I suppose everybody is coming from their own kind of angle, but hopefully, at the centre of it is the person that's being kept there. But I suppose every professional does come from their own kind of, yeah, from their own kind of angle, I guess." Participant 13.*

Conversations about professional differences included exploring what different professionals do in collaborative work. Of note here is that participants spoke confidently about what they believed the role of the social worker (their role) was in collaborative MCA work with people with YOD. This involved describing how they carried out assessments and decision-making. There were indications from participants that some professionals held different perspectives on MCA work with people with YOD. These different perspectives were noted to lead to MCA work being more challenging. One way that participants noted different perspectives was in how other professionals carried out MCA assessments. Approaches to drawing information from people with YOD during an MCA assessment and nurses asking too many irrelevant questions were shared as significant differences between participants and other professionals.

> *"A frustration for me is when if you're doing a kind of MDT capacity assessment jointly with other professionals. In my experience, particularly nurses like to ask a lot of questions to people about things like where are we now? What day is it? What time is it? Who's the Queen? This kind of bleeding the Montreal capacity cognitive assessment, into assessment of mental capacity? And if you don't*

> *know who the queen is, then of course, you can't understand a question about where you're going to live when you leave hospital, or what care and support you might need or how to manage your finances, which absolutely blows my mind." Participant 3.*

The quote above highlights that there were different perspectives on how MCA assessments should take place and how a particular type of assessment approach was questioned in terms of its usefulness. Similar comments were noted regarding Best Interests decision making where there was often a lack of discussion about the views of the person being assessed.

7.6.3. Theme: Collaborative practice with families and carers

Findings showed that MCA work can be multifaceted and involve a variety of people. Here the findings outline how participants spoke about their collaboration with family members and carers as part of the MCA work with people with YOD.

Participants gave accounts of how families were involved in MCA assessment and Best Interests decision-making. These two areas are discussed in more detail below. The term 'family' or 'families' was used a lot by participants. They appeared to use the term families in relation to spouses, partners, or relatives of the person with YOD. The term carer was not defined in the interviews although participants used the term frequently.

Participants gave descriptions were given of what it was like to collaborate with families and carers from a social work practitioner's perspective. Families and carers were described as being vital to understanding the person with YOD. Alongside discussions of practice where families and carers collaborated with participants there was acknowledgement of practice where there was no contact or collaboration with family members or carers. The examples shared indicated that in situations where there was little or no involvement and opportunity to collaborate with families or carers, this created a reliance on information stored in the case notes. Other discussions highlighted the use of advocates to ensure people with YOD were represented.

Within discussions about collaboration, participants noted that their Best Interests decision-making in using the MCA to assess the capacity of people with YOD was influenced by the wider families and carers of people with YOD. There were discussions from some of the participants suggesting that working alongside families was core to their use of the MCA with people with YOD. The quote below is an example of how a participant described how the daughter of a person with YOD participated in the MCA assessment helping to reassure her mother.

> *“And what was so good about that (assessment) is that she has a good supportive family system. That is the main thing that you know that they (daughter) say, ‘Oh, it's okay, Mom, you know, that's fine. Everybody forgets things you know, to say even I forget things.” Participant 12.*

The above quote gives evidence that there was an acknowledgement that family members were seen as collaborators in the MCA assessment process. Rather than working in isolation participants recognised the benefit of working in partnership with families and carers. Common ways participants described collaborative practice with families included eliciting information about the person being assessed, hearing the views of family members and carers, exploring Best Interests and problem-solving.

Within the conversations about collaborating with families and carers, discussions indicated that there should be more collaboration with families and carers. This view shared by some participants noted that collaborating with families and carers is core to MCA work and that it did not happen enough and linked to a perspective that collaborative practice with families and carers ought to have a therapeutic component, recognising the psychological, and emotional, and societal challenges for families and carers in supporting people with YOD. Here attention was drawn to what was seen as the specific needs of families, noting that families can be isolated and lack information about the MCA. Participants indicated the need for direct support for families as part of their collaborative MCA work and a suggestion that the social work role more generally should include supporting families and carers.

> *"I think the social work role could be very much around supporting the family, that psychological, emotional impact of having somebody with early onset dementia, the taboo that holds the lack of resources out there and support." Participant 17.*

Collaborating with families was largely referred to positively by participants, although there were examples given by participants of the drawbacks that can arise when collaborating with families. The quote below provides one example of how collaboration with families and carers was framed in a polarised way of either being good or bad.

> *"I think friends and family can either be really empowering and really important, for example, supporting that person to facilitate their wishes and their views…. And then there's others that will be very much like, but he's got dementia, she's got dementia, she needs to go into a care home, because of I know I've spoken to a lot of people and a lot of people have said, but they've got dementia, they need to go into care…. So, family and friends can either be really good or really bad." Participant 16.*

From the discussions participants indicated that they welcomed and valued collaborating with family members and carers of people with YOD, although they noted that this type of work requires time and attention.

7.6.4. Theme: Collaborative practice with community organisations

The final type of collaboration that emerged from the data is collaboration with community organisations. The discussions about community organisations with participants referred to a wide range of services found in local authorities, health NHS Trusts and third-sector organisations that provide care services, support services, respite support, advice, and advocacy to people with YOD and their families. Participants were aware of a range of community organisations that could be drawn on in their MCA work. This included transport services, advocacy support services, advice centres and support groups run in community centres or church halls and respite services that support people in their own homes. What came through clearly in the interviews with participants concerning community organisations was a recognition of the role that community organisations can have within MCA assessment and decision-making.

In the discussions about collaborating with community organisations, participants noted the value and contribution that people working in community organisations can make to MCA Best Interest decision-making. Within interviews, participants spoke about their own experiences of working alongside community services that support people with YOD and LOD. Participants shared that the take up of community organisations by people with YOD was good from their experience. Examples were given of people with YOD who had benefited from the involvement of community organisations. Advocacy was identified as a key support to their MCA work. Participants spoke about the beneficial role that advocacy can have in their MCA and how advocates can be collaborators. Advocacy services were described as outside of the participant's organisation and part of the wider community organisations that they draw on in MCA work. In MCA work advocacy participants described advocacy as either part of their role or a formal arrangement with an advocate working outside of their organisation. Some participants spoke about the role of the Independent Mental Capacity Advocate (IMCA) as a formal way of ensuring advocacy support for people with YOD.

> *“and then you have to be able to balance them all taking into account the person's best wishes, if there is and also you have to provide an advocate for when the person is not different that it's important to provide an independent advocate now, because in fact, sometimes family dynamics come in, you know, impair best interest for you, it can impair your ability to you know, to follow the herd.” Participant 11.*

Participants shared their perspectives on how people with YOD made use of services offered by community organisations. Participants believed that the take up of these services by people with YOD was from their experience quite good. The suggestion here highlights that participants who worked with people with YOD were actively engaged in using community organisations and some participants indicated that they found people with YOD who they had worked with, were more likely to engage with community services than older people with dementia.

> *"My experience is that younger people tend to take up some of those services, the service user tends to take up some of those counselling type supports with dementia more readily than an older person." Participant 3.*

As well as the benefits of collaborating with community organisations participants described what can be termed as limitations of collaborating with community organisations. They spoke about the sparsity of community services for people with YOD. Discussions about the dearth of community services highlighted that community support services for people with YOD appear to be less available in comparison to the community support services available for people with LOD. This was described as directly affecting practice and opportunities to collaborate with community organisations and access social support for people with YOD. Concerning MCA work the lack of community services is linked to the lack of discussion around Best Interests options and discussions. The difficulties experienced in identifying suitable community services for people with YOD were highlighted by participants as a concern. Here, the availability of community services for people with YOD was suggested as poor in contrast to community services for people with LOD.

> *"First, I think we're very lacking. We, I think we're incredibly lacking from the ages of sort of 25 to 65. When you reach a day centre, if you don't have a learning disability or something like that, or you might have a mental health, mental health condition, but we are so lacking in resources." Participant 17.*

> *"And I'm not sure there are. I mean, I don't know a lot about it, admittedly, but I'm not sure there are necessarily enough services support services for people with early onset dementia," Participant 14.*

In the first quote above, a participant refers to day services for people with YOD, noting the difficulty in finding day centres for people with YOD. This was linked to Best-interest decision-making options. The second quote below refers to the lack of community-based organisations for people with YOD. The second quote indicates that the paucity of community organisations for people with YOD was seen as problematic by participants in their Best Interests decision-making work. This was linked to limitations in the opportunities for participants to collaborate with community organisations.

The lack of collaboration with community organisations was seen as exacerbated by the Covid 19 pandemic. Some participants shared that they noticed community services closing during the Covid 19 pandemic, particularly during the periods when national and regional lockdowns were imposed. In these conversations, participants indicated that these services closed down because their funding sources were severely curtailed during the Covid 19 pandemic. Participants' evaluations of the changes that occurred during the Covid 19 pandemic were that their work with people with YOD was recognisably more challenging. An example given by a participant talked about the impact of the national and regional lockdowns on community organisations providing social network support to people with YOD. Participants here pointed to their experiences of community services and the organisations running them closing and not being available to continue to provide a social network resource to which they would refer people with YOD.

> *"So, I think that pre-Covid-19 pre-pandemic, we had loads of kind of voluntary run clubs, that would be appropriate for people with younger onset dementia, and kind of physically still able. Like a Memory Cafe or lunch clubs, where people can still get themselves to it by themselves, a family can help and they*

> *can eat their meal and use the toilet by themselves and kind of communicate. Then obviously everything closed down. And because it was voluntary run, they really struggled to start it again. And I think there are now some groups, but definitely not as many as we had before. And there is kind of less volunteers to do that social support. I think all the volunteers are now kind of supporting social services to keep the services running. So, it's hard, but it's definitely needed." Participant 19.*

In summary for this theme, a key finding is that participants valued the opportunity to collaborate with community organisations for people with YOD. While participants saw community organisations as holding key resources and a value in MCA work, attention was drawn to the challenges in collaborating with community resources which include the lack of available options for people with YOD.

7.7. Thematic category: Typology of MCA decision-making

As well as outlining the process involved in MCA decision making the findings draw attention to different ways in which participants made decisions in relation to their MCA work with people with YOD. These have been categorised into what can be defined as a typology of MCA decision-making. The typology of MCA decision-making includes six different approaches to MCA work. The six approaches have been identified as procedural, medicalised, creative, shared, positive risk and rights-based. These are discussed below.

7.7.1. MCA decision making as a procedural approach

Procedural approaches refers to decision-making that focuses on a particular process being followed. Participants who procedurally made MCA decisions tended to apply a legalistic approach to decision-making by emphasising following legal rules as the main driver for their decision-making. An example of participants following the legal rules was found in responses to discussions about the MCA assessment. These responses suggested that the MCA assessment comprised following the details of the law (MCA). Furthermore, a procedural approach was found to be one where participants saw MCA decision-making as linked to following a sequential set of steps or processes. The quote below provides an example of how a participant understood their decision-making procedurally by emphasising the use of legal rules.

> *"Or if it's somebody who I'm meeting because of a safeguarding then as the law requests, I will always, first of all, try to see if the person can make their own decision depending on the decision. After we just follow the law, it's quite simple in some ways, make sure it's the right time of the day. Make sure you don't assume because the person has a diagnosis of dementia that you will assume the person doesn't have capacity." Participant 8.*

Procedural approaches were also evident in Best Interests of decision-making. Within this type of decision making procedural approaches were used to ensure all aspects of the Best Interests checklist were completed. Furthermore, within the Best Interests process participants found the following procedure helped participants to question other professionals involved in Best Interests assessments where they missed key aspects of deciphering Best Interests.

> *"I try and stay as structured as I can when I'm looking at best interests, making sure that I've gone through that checklist in my mind. And I use the process as well to get to know the person's views. I know that it's part of the checklist, but I sort of personally use it as kind of the overriding thing, you know, Can we meet, meet this person's wishes? If not, can we incorporate them somehow? That type of thing?" Participant 14.*

Although the findings identify a procedural approach to MCA decision making it was found that there was some awareness of the drawbacks of using a procedural approach. Below is a quote highlighting a perspective that questioned the procedural approach in MCA work suggesting it can feel like a tick-box exercise.

> *"I think there is sometimes a feeling that the best interest process is just a tick box exercise. It's just a formality. So the way our organization, gears, this process is if you do need a formal decision maker, that it would have to be someone at my level or above." Participant 3.*

7.7.2. MCA decision-making as a creative approach

The second approach to decision-making is creative approaches to MCA decision-making. This approach to decision-making involves how participants used innovation in their MCA work to make decisions. Creativity or innovation in MCA decision-making includes professionals going beyond normal processes to achieve outcomes and results in their MCA work.

In paragraph 7.1. the use of tools and aids was noted as forming part of the process of MCA assessment for participants. The use of tools and aids can also be seen as part of a creative approach in their decision-making because participants expressed the need to develop their practice tools specifically to support MCA assessment and decision-making with people who have YOD. This was seen as a creative way to engage people with YOD in decision-making. The quote below is an example of a participant developing resources to engage a person with YOD and evidence of how it supported them.

> *"So, I've used tools like that. The thing is, what I do find is that I don't have a general go-to for those, you've ended up creating your own, off websites and Googling, which is not sufficient." Participant 7.*

Listening to participants describe their creativity and their discretion in assisting their MCA assessment and Best interest decision-making was encouraging but also led to questions about participant comments that tools they used in MCA work were not prescribed by their organisation or given support via a training organisation.

Participants spoke about resources being helpful in Best Interests decision-making work which can take place in formal meetings or less formal discussions. Here, participants shared that they used different resources to support their Best Interests decision-making.

> *"Currently, we've done pictures of each service that he's going to be able to have a choice to pick from, and every time he comes back from the service, he supported to write down his likes and dislikes. But photos and pictures are kind of quite big in terms of decision-making." Participant 13.*

The above quote notes that resources were supportive of the decision-making process. Other participants discussed the use of social media in their MCA assessment with people who have YOD. Social media was used as a way to explore social support services for people with YOD and was seen as an age-appropriate tool to support decision-making.

Another example of creative approaches to decision-making in MCA assessment and Best Interests work is how participants explained the use of language to support their practice. The use of language and in particular language skills like similes or analogies were referred to by some participants as a practice resource used during the MCA assessment. Here, participants spoke about the use of particular words and phrases, which they saw as support for MCA assessment.

> *"It could be anything, it could be phrases, like, it depends on the person. But yes, I would use tools. I would use like, say, talking about a recipe with someone, as a way to assess that person's capacity, for instance, asking about how to cook a meal, you know, to prepare and what ingredients. It could be money, we could like, say you could money how like, say how much you think it*

> *cost? Do you think it's too expensive? You know? Yeah, it could be anything really, I think that because at the end of the day is a conversation that we have, and most of the situations we assess are real-life situations. So, I think that it does make sense to use real-life examples." Participant 10.*

In the quote above the participant gives the example of talking about a recipe as a way of exploring capacity with a person with YOD. There were many examples where participants shared they had used creative approaches to support their MCA assessment and decision making evidencing this as a popular way in which participants went about their decision making.

7.7.3. MCA decision making as a shared approach

Participants collaborated with other professionals, families' carers, and community organisations in their MCA work. This has already been discussed earlier in this chapter. Emerging from the findings was a type of decision-making that veered towards making decisions alongside others which is referred to as a shared approach to decision making. A shared approach to decision-making draws attention to how decision-making was perceived by participants as a joint enterprise rather than an activity carried out solely by social workers. Shared approaches to decision making were evident in both the MCA assessment and Best Interests decision-making. In MCA assessment participants evidenced a collaborative approach through talking about the importance of joint assessment work.

A shared approach was particularly evident in Best Interests discussions. Participants recognised that best-interest decision-making was often carried out in discussion with other professionals. These processes were valued as being collaborative parts of the participant's MCA work involving a range of people including other professionals and family members. Within Best Interests decision making participants acknowledged that there can be complexity in decision-making and shared views that a shared approach was a suitable way to respond to the complexity that arises in Best Interests decision-making. In these discussions, participants shared the importance of all those involved in the Best Interests' decision-making to have a voice.

> *"I think, to me best practices, it should be multi-agency and coordinated in a multi-agency way… you can spend a lot of time negotiating as professionals whose job it is to hold in terms of who coordinates the decision being made, or, and really, for me, it's just about let's just call it the bureaucracy and get the decisions around the table of who, what each individual and the professional view is." Participant 6.*

Delving further into the shared approach to decision making the findings suggest that professionals in their commitment to shared working would confront other professionals where they believed a collaborative approach was not being followed. For example, participants spoke about challenging other professionals when Best Interests decision-making occurred ahead of the MCA assessment. Within discussions about collaborative working, this was described as problematic. Some participants indicated in their response to Best Interests being engaged before ascertaining capacity was to confront other professionals. Participants noted that they saw it as part of their role to ask questions of others, particularly where professionals engaged in what appeared to be Best Interest Decision making and there was no evidence of a MCA assessment.

> *" I remember seeing a care plan in a care home. And it was like a care plan around night needs. I don't remember how it was exactly written, but it said that the person can't decide about their bedtime or something like that. And I'm like, what do you mean, she, what do you mean, they can't decide when they want to go to sleep? Like, I don't understand. Tell me how you assessed them because I really don't understand." Participant 19.*

The ability to confront other professionals within a shared approach to Best Interests decision-making was linked to knowing the MCA assessment and Best Interests assessment process and confidence that they are doing the right thing for the person with YOD. Participants were able to talk about their awareness of the MCA and what their roles and responsibilities are.

7.7.4. MCA decision making as a medicalised approach

Medicalised approaches to decision-making refer to ways in which participants spoke about their MCA work linking their decision-making to the importance of medical approaches to working with people who have YOD. Within medicalised approaches, it was found that the role of clinicians in MCA work was promoted and medicalised ideas were held as more prominent than others for example, social work perspectives. One example is how participants emphasised the importance of medical assessment above other assessments in MCA work.

The rationale for participants engaging in medicalised approaches in their decision-making appeared to be linked to the settings in which they worked. Hospital settings were identified as focusing on medical issues in MCA assessment and Best Interests decision making and this would shape MCA work. One participant noted that the clinical environment focused on ensuring that food and medication were primary considerations. Hospital settings were also identified by participants as under pressure to free up beds and this affected MCA work.

> *“But you know, it's difficult because you've got the hospital that needs to free up the beds. And that's the kind of process used to get people discharged quickly. So, these are kinds of things that, that I've sort of grappled with, when I'm in discharge meetings,” Participant 15.*

Within the interviews, some participants indicated that medicalised approaches were followed because of the perceived status of medical perspectives. One participant spoke about a GP having more authority in MCA assessment as a reason for why medical ideas had greater standing in MCA work. For this participant challenging a GP's medical perspective was seen as difficult because of the status they attributed to the GP in MCA work. Participants recognised both medical and social approaches shaped decision-making and found that an appreciation of medical approaches in MCA work was helpful. An appreciation of medical approaches included drawing on the perspectives of GPs, doctors and nurses, while other participants referred to reading medical notes and the medical history as a way of forming a holistic understanding of the person. Not all participants shared the view that medicalised approaches were helpful. Some described medical perspectives as limiting and missing the holistic needs of people with YOD. In these discussions, participants highlighted their role in promoting social perspectives as crucial.

Medicalised approaches to decision-making were discussed as pragmatic approaches within MCA work with people with YOD in MCA. Participants' descriptions indicated that drawing on a medicalised approach supported exploring MCA issues with the person's wider health in mind and gaining a better sense of how dementia affected their lives. Linked to these assertions were suggestions that Best Interests decision-making should be led by medical professionals where it was deemed that the decision was linked to medical matters.

> *"My default is it's dependent on the context of the decision as to who should lead that best interest consultation. If it's a medical decision, I do believe it should be led by a medical professional. If in the first instance, it's a social care-specific decision. And I do feel quite strongly about that, in regard to it is a multi-agency process, but it should be, you know, depending on the context of the decision, it should be led appropriately by, you know, professionals respectively, in that field." Participant 6.*

7.7.5. MCA decision making as a positive risk approach

Positive risk approaches refer to how participants were aware of the risk issues and cognisant of positive risk approaches in their MCA decision-making. Risk emerged as a common theme across the findings, particularly concerning MCA work. was noted by many participants in discussions about MCA work.

Risk and risk assessment were discussed by participants as a regular aspect of their MCA decision-making with people with YOD. Participants recognised that where a person was found to lack the capacity to make a specific decision risk discussions were often more challenging because they became linked to Best Interests decisions. From the interviews, risk was spoken about in positive ways by participants and they used terms like exploring risk when doing MCA work with people who have YOD. Discussions about exploring risks in MCA work led to questions about how risk was understood by people with YOD. Responses from participants included suggestions for creating everyday scenarios for people to help to understand and explore risk. These examples included references to items in the person's immediate surroundings or references to events that the person can recall. The use of everyday examples to talk about risk seemed to be something of value to participants, particularly in terms of exploring unwise decisions.

As well as helping people with YOD to explore risk many participants spoke about their role in MCA decision-making involving positive risk approaches. Positive risk was the term used by different participants in the interviews and refers to activities where participants along with the person look at achieving agreed goals while acknowledging the areas of risk. Descriptions were given by participants of the social work role as being less risk-averse and more prepared to engage in positive risk-taking than other professionals. It often involved initial agreement around what the risks are and putting in place contingency plans should things go wrong. Being more prepared to engage in positive risk conversations was an area participants spoke about a lot.

> *"I think that the kind of social workers or kind of people working in social care are a bit more open to taking positive risks. And kind of assessing that and I want to say allowing people but allowing is just the wrong word. But, you know, supporting people to take that risk to obviously some extent, because we would*

> *be you know, liable. To some extent, we need to ensure people are safe as well." Participant 19.*

Alongside discussions about social workers taking a positive risk approach in MCA work participants contrasted their perceptions of positive risk approaches with other professionals who were described as being less willing to explore risk or what was termed as being more risk averse. Participants identified doctors and nurses as specifically adopting risk-averse approaches to MCA assessment and Best Interests' decision-making. Some participants shared practice examples to support their ideas. One example is a participant who noted that different professionals approached risk differently.

> *"how different professionals evaluate the risk is more about certain professionals being really risk averse and thinking all the social worker needs to do something. Like say, it is dangerous." Participant 10.*

The above quote exemplifies that there were firm beliefs about differences between social workers and other professionals in exploring risk. Participants viewed themselves as being willing to explore risk with the person and saw other professionals as taking a more risk-averse approach. Risk-averse approaches were seen as problematic by participants who highlighted their concern that the wider rights of a person could be overlooked if risk-averse approaches were followed.

Positive risk was discussed by participants as a way of supporting the person with YOD to achieve their wishes in Best Interests decision-making processes. Participants gave examples where they noted the views of people with YOD during MCA assessment and then explored the possibility of whether these wishes could be pursued in Best Interests decision-making processes. In this way, participants described their positive risk approach as promoting the wishes of the person within MCA decision-making. This was explained by several participants as the central motivation for taking a positive risk approach. However, it was also recognised that a positive risk approach can be complex. Some participants discussed that promoting the wishes of the person through a taking a positive risk approach had raised challenges for families and carers who held different perspectives to them. The differences in perspectives could lead to disagreements about Best Interests or refusal to proceed with a course of action. In these conversations, there was an acknowledgement of the need to support the wishes of the person while balancing the perspectives of others who may be affected by the decision.

As an approach to MCA decision making, positive risk emerged as one that many participants related to through their discussions of risk within the interviews. The popularity of positive risk approaches was related to wider aims of promoting the voice of the person and enabling greater autonomy in MCA work.

7.7.6. MCA decision making as a rights-based approach

A rights-based approach to MCA decision-making refers to how participants' embedded thinking and actions are linked to the rights of people with YOD within their MCA work. The term rights based used here relates to a focus on the human rights and social welfare rights of people with YOD. Human rights discussions tended to focus on the rights to autonomy, the right to make decisions and the right to be protected from harm which are all evident within the MCA or the MCA Code of Practice. In terms of social welfare rights participants spoke about ensuring people with YOD who they assessed had access to services that would ensure that their voices and wishes were clearly understood. One example of this is in emphasising the need for advocacy within MCA work, which a participant noted can be easily missed within the Best Interests decision-making process. In this conversation the benefit for the person to be aware of all options available to them within the decision making process was the motivation for discussing advocacy.

Conversations where rights-based approaches were discussed tended to be linked to their Best Interests decision-making practice, with less indication of rights being explored regarding MCA assessment. In the cases where decision-making was seen as relevant to the

MCA assessment, participants identified how rights were important when exploring unwise decisions. Participants indicated that although there are challenges for them when a person makes an unwise decision there is a need to support to person and their rights to make an unwise decision.

> *"And then I need to also consider what kind of support the person who will need to be able to make that decision. And, and then also, as part of it, if the person makes, you know, they might come up with something that might sound unwise to me. It doesn't mean they cannot make decisions; they can have the ability to make an unwise decision, which is well supported. And then from there, I need to also look, if they make the unwise decision, I need to consider what are some of the ways that I can provide support in helping them make that decision."*
>
> *Participant 9.*

In regard to Best Interests decisions, participants considered that part of making the Best Interests decision was to ensure that decisions were consistent with supporting the person's rights to receive services. Some participants identified their Best Interests' discussions could lead to identifying relevant services that support a person with YOD to live as independently as possible. There were discussions that Best Interests decision-making involves considering the person's human rights. For example, some participants spoke about ensuring that decisions linked to where a person should live reflected their rights for private and family life found in Article 8 of the HRA.

> *" We don't want to deprive somebody of the article 8 rights, just because we want to ensure their safety. You have to be able to balance that, with their best interest. It's important to take into account the person's right to life, right or association, and balanced within what their needs might be presented."*
>
> *Participant 11.*

The quote above highlights that Human Rights legislation (the Human Rights Act 1999) was a concrete way in which some participants understood their role in MCA decision making and confirms that rights-based approaches drew attention to wider issues for people with YOD in MCA decision making.

In summary, the typology of MCA decision-making draws together the main ways in which participants seemed to talk about how they engage in MCA decision-making in their work with people with YOD. The typology of MCA decision-making confirms that there were a range of approaches linked to both MCA assessment and Best Interest decision-making. As part of the process of identifying approaches to decision-making, there was no evidence that the approaches were exclusive to any particular participant. Instead, multiple approaches to decision-making were identified in some of the participant interviews.

7.8. Conclusion

The purpose of this chapter has been to provide a detailed examination of the main findings from the qualitative research study. The findings detail that social work MCA decision-making is multidimensional consisting of a range of issues captured in themes that emerged from the research study. The themes were clustered together in thematic categories which contribute to emerging theory around MCA assessment and decision making. The emerging theory found in the thematic category and themes draws attention to participants, who are social workers, understanding and awareness of working with people who have YOD. An understanding of YOD means being cognisant of the factors that make up the experience of the YOD, such as receiving a diagnosis, the contrasts between people with dementia in older age and young age as well as how stigma impacts the lives of people with YOD. The findings have drawn attention to knowledge of the MCA as contributing to the process of MCA assessment and decision-making for social workers. Knowledge of the MCA can lead to challenging others who are involved in MCA decision-making for social workers. Other processes to which the findings draw attention include person-centred approaches and the use of tools in MCA assessment and Best Interests decision making. Together these were found to contribute to participant decision making in their MCA work.

Contextual factors were found to be central to how participants engaged in MCA decision-making. Here it has been noted that significant events such as Covid 19 as well as how organisations responded to it influenced how MCA decision-making took place. The findings confirm collaboration is at the heart of MCA decision making and social workers collaborate in different ways with professionals, families, carers and organisations based in the community. Collaboration was noted as being a valuable and positive experience for the participants in their MCA work but can include quandaries for them. For example, some professionals hold vastly different perspectives in MCA assessment work to social workers or where there is an absence of community organisations to work with in achieving Best Interest decisions.

Finally, the finding draws attention to a typology of MCA decision-making. This typology indicates five novel approaches to MCA decision-making in the context of social work practice with people who have YOD. The five approaches that form the typology indicate that MCA decision-making happens in a variety of ways linked to both MCA assessment and Best-interest decision-making under the MCA.

Chapter 8: Discussion of the findings

8.1. Introduction

This thesis so far has been an exploration of MCA assessment and decision making with a specific focus on social workers working with people with YOD. At the very outset, the research questions, which are the focus of the doctoral work, were stated. The principal research question asked: How do social workers use the MCA in assessment and decision making in the context of practice with people who have YOD? Within the research question, three sub-questions were included. The sub-questions for the research study are: What are the different ways in which social workers can use the MCA to make decisions for people with YOD? How do social workers understand YOD in their MCA decision making practice? What are the implications for social workers in using the MCA in their decision making?

In Chapter One of this thesis, as well as outlining the research questions, the aims and objectives of the work were set out as were the definitions of mental capacity and YOD. Chapter Two set out the legal context for MCA assessment and decision making, drawing on related law and policy that has and continues to shape MCA decision making. Chapter Three discussed dementia and the different approaches to working with dementia highlighting that there is a lack of connection between policy and the experiences of people with YOD especially at a local level, meaning that needs at a local level are invisible within policy and commissioning discussions due to the relatively low numbers of people recognised as experiencing it. Additionally, Chapter Three introduced approaches to understanding and responding to dementia and YOD and an evaluation of the social work role in working with people who have dementia. Chapter Four considered relevant theoretical areas, drawing on ideas of social constructivism and decision-making, which helped to explain the subjective nature of decision-making for social workers. This was followed in Chapter Five by a detailed review of literature linked to MCA decision-making, social work and YOD, highlighting the sparsity of literature linked to social work practice and YOD and the very little data on how social workers use the MCA. Chapter Six outlined the research methodology for the study including how a grounded theory approach and selected methods were used to collect data.

Chapter Seven outlined the findings, thematic categories, and themes that emerged from the research study.

This chapter examines how the findings presented in Chapter Seven answer the research questions, as well as assessing how the findings relate to existing knowledge, literature and theory on MCA decision making. In line with a grounded theory approach the chapter explores the emerging theory from the findings (Charmaz, 2009) by noticing where there is divergence from existing literature as well as where there is convergence. The chapter also uses the conceptual idea of social constructivism discussed in Chapter Four to help bring meaning to the findings. Finally, the chapter includes a discussion of my reflections on the findings and how this contributes to the thesis. In terms of structure, this chapter firstly summarises the key findings from the analysis of data and then goes on to discuss the findings in relation to each of the research questions.

8.2. Summary of findings

The key findings from this study draw attention to social worker MCA decision making being multi-faceted. In the context of social work practice with people who have YOD MCA decision making was connected to different levels of understanding of YOD. Understanding YOD for participants encompassed several components. These components include an awareness of age, diagnosis and the issues that arise from delays in diagnosis and inequality and stigma experienced by people with YOD. The exploration of how participants engaged in MCA decision making confirms a typology of MCA decision making. Within the typology of MCA decision making, several approaches to decision making were identified. These include procedural, medicalised, creative, shared, positive risk and rights-based approaches. Each of the approaches draws attention to understanding perspectives that shape why participants use that particular approach in their decision making.

The study confirmed that MCA decision making includes key processes that relate to MCA assessment and Best Interests decision making which the participants commonly use in their MCA work. These processes were categorised as being both formal and informal. The formal processes point towards a clear knowledge of the MCA and that the rules and responsibilities embedded in the law are a crucial element of MCA work for the participants in the study, so much so that they thought it necessary to challenge other professionals who did not follow the MCA guidelines consistently. The informal processes found were: getting to know the person with YOD by developing a rapport, using person-centred approaches and using tools as part of the MCA assessment. Finally, the context in which decision making took place was identified as a significant factor in shaping social worker MCA decision making. Regarding the context it was recognised that participants carry out MCA work in different settings and MCA decision making was found to be affected by time constraints as well as the Covid-19 pandemic which led to changes in how participants went about their MCA decision making.

8.3. How do social workers understand YOD as part of their MCA decision making?

This section of the discussion explores the findings related to the above research question drawing together several themes that are outlined in the findings of the study. These include the key theme of understanding of YOD, which included several components such as identifying what YOD is, age-related and YOD matters, and an awareness of inequality and stigma experienced by people with YOD.

8.3.1. Understanding of YOD in MCA decision making

The findings of the research show that the participants' awareness and understanding of YOD were diverse, highlighting the lack of a shared understanding of YOD. A lack of a shared understanding of YOD has been noted by other studies such as Ottobani et al. (2021) who, in their study of the perspectives of health and social care professionals working with YOD, drew conclusions about the need to promote awareness of YOD among professionals working with YOD due to the significant lack of awareness. Couzner et al. (2022) in their study exploring what healthcare professionals need to know about YOD reported similar findings concerning a requirement to be familiar with the aetiology and identification of YOD. Although this research study differs in that it focused on a single profession, namely social work, it does align with the conclusions of Couzner et al. (2022) and Ottabani et al.

(2021) who recommended that health and social care professional practice needs to be familiar with what YOD is and how it affects the lives of people who receive a diagnosis.

My research study findings illustrate that the participants’ understanding of YOD is differentiated and will vary, suggesting that a clear and uniform understanding of YOD by the participants cannot be assumed. Looking more closely at the findings linked to awareness of YOD some participants were more comfortable talking about dementia in later life, rather than YOD when questions were directed around YOD. This may be understood as being due to a lack of experience and casework with people with YOD. Relating this to MCA practice these findings highlight that participants engage with practice with YOD from different starting points in terms of their recognition of YOD. The finding supports Haylo et al. (2018) who suggest that there is a general lack of awareness of YOD for health and social care workers, which includes social workers.

In making sense of the findings it is helpful to be reminded that YOD is an umbrella term used to refer to a range of conditions (Dementia UK, 2023a) and there remains a notable gap in awareness around YOD and how YOD affects the lives of people who receive a diagnosis compared to those who are diagnosed with dementia in later life (Rabanal et al., 2018; Mayrhofer et al., 2021; Spreadbury and Kipps, 2018; Young Dementia Network, 2022c). This research study confirms evidence in social work literature that there remain gaps in understanding that can affect assessment (Mayrhofer et al., 2021) and access to community services (Stamou et al., 2022a). Furthermore, literature does not always differentiate between YOD and LOD (de Vugt and Carter, 2022) and the nomenclature of dementia found in people under the age of 65 can be confusing (Koopmans and Rosness, 2014; Van Veen et al., 2022). This was evident in the findings of this study in which participants used a wide variety of words to describe YOD, such as early age, early onset, younger persons with dementia, early life dementia, YOD and early-stage dementia. This can be related to Carter et al. (2022) who confirms that YOD is often poorly understood and misdiagnosed.

8.3.2. Types of social work understanding of YOD

Looking further at the findings linked to participants' understanding, the differences in understanding of YOD were categorised and tabulated, detailing various types of social worker practice with YOD. The table is found in Chapter Seven, numbered as Table 5. The findings indicate that categorising and tabulating the participants' perspectives on what YOD is provides a helpful way to understand the different ways in which they conceptualise their understanding of YOD in MCA work. Table 5 supports the finding that there are differentiated ways of understanding YOD, which directly connect to how the participants engage with people who have YOD. It can be used to enhance awareness around MCA work with people with YOD, generating greater confidence in the MCA the assessment and decision-making process. Moreover, the table illuminates how the participants work with people with YOD, providing clarity regarding the commonalities and differences in practice with YOD.

MCA work requires professionals to use a range of skills and abilities (Jayes et al., 2020) and this is the case for MCA work with people who have YOD. An outline of understanding of YOD can be a useful starting point for social workers in their MCA work with people who have YOD. Therefore, the emergence of the different types of participant awareness from the findings has practical application for social workers working with people with YOD. Using the table as a resource, social workers can assess their existing capability for working with YOD. However, the table is not a comprehensive indicator of awareness of YOD and the limitations need to be acknowledged. The table of understanding YOD may be limited in terms of the lack of detailed analysis of existing knowledge that participants possess around YOD, nor does it require social workers to add details. Therefore, the table could form a tool for initiating further discussion about YOD, prompting further enquiry into practice with people who have YOD.

8.3.3. YOD and age

Age emerged as a relevant factor for the participants of the study in their understanding of YOD. The findings pointed out that the participants have perceptions of what YOD means linked to age factors. Many of the participants compared and contrasted their practice experiences with people who have YOD with that of people who have LOD and there were suggestions that people with YOD may be able to engage more in their MCA work. What is useful to draw on here is that participants’ understandings of YOD and people who have YOD are shaped by medical, cultural, social, and individual factors (Marshall and Tibbs, 2006). In relation to age, the participants who work with people who have YOD may be seen as engaging in the social construction of YOD through their practice experience of it. Social constructivist theory informs that realities are constructed and reinforced through culture, society, and language (Şhahin, 2006). Social workers build their understanding of YOD through their experience of working with people who have YOD. Therefore, it can be suggested here that participants’ constructions of YOD are shaped by their practice experiences with people who have LOD as well as people who have YOD. Many of the participants in this study tended to practice with people who have YOD and also those who have LOD. This links to the reconfiguration of adult social care services in the 2000s, which saw a move to integrated social care teams for all adults above age 18, rather than separate older adult teams (Green and Clarke, 2016). This move has been referred to as mainstreaming adult social care (Payne, 2012) and was partly a response to removing age thresholds under the Equality Act 2010 which required public services not to discriminate in the provision of health and social care services (Regan, 2016). Mainstreaming has been noted as having economic benefits as well as encouraging integration and solidarity in practice across adult age ranges but has meant that social workers practice across a wide range of age groups requiring a knowledge of how to meet needs across different life stages.

Age is relevant to understanding YOD because dementia is shaped by age classifications (Rossor et al., 2010). In Chapter Two of this thesis, it was noted that the term dementia is shaped by historically constructed ideas about the human life course, particularly in relation to what is old age and what happens during old age (Rossor et al., 2010). These social constructions include the idea that dementia is a condition affecting people in their old age (Harris, 2004; Tolhurst et al., 2014) with less attention given to the presence of dementia in people not having reached older age. Age-based constructions of dementia have been found to be grounded in innate biological ideas about ageing and economic activity (Clemerson et al., 2014) including what happens during the process of ageing and what older people can physically do and the activities they want to engage in. Chapter Three discusses how the discourse of dementia has primarily been linked to age and being in older age, which can exclude the experience of younger people with dementia.

This research study illuminates participants' insights of age and people who have YOD. The overlapping way in which YOD and LOD were discussed by participants provides evidence that there is a tendency to see dementia as a condition inextricably linked to ageing and older people where the discourses of dementia and ageing become entangled (McParland et al., 2017). Tolhurst (2014) noted that age-based factors are a central aspect of understanding the experience of YOD, shaping the experience people have of the condition. The findings support the idea of conceptualising dementia, including YOD, as a matter across the life course rather than predominantly framing dementia as occurring in later life (Tolhurst, 2016). What can be noted is that age-based classifications of dementia in younger people and dementia in later life fail to consider the complexities that can be found across the life course (Tolhurst, 2014). For example, not all people wish to retire at the age of 65 years and want to be less active on reaching retirement age. Similarly, some people with dementia will live fairly independent lives regardless of their age. Furthermore, classifications based on YOD occurring before age 65 have been used to suggest that the experience of YOD is vastly different to LOD. These findings connect with the idea that people who have YOD have a different form of dementia (Tolhurst, 2016). The suggestion of YOD as different is divisive as it places YOD and those with LOD within a binary perspective. In the study, some of the participants tended to practice with both people who have YOD and LOD and recognised the dangers of a YOD and LOD binary as they talked in terms of taking an individualised approach to working with people with dementia. The individualised approach taken by participants in their practice can be seen as pointing towards a life course approach to understanding and working with YOD, which avoids assuming the experience of dementia based on fixed ages-based notions (Milne, 2020b) but emphasises the social, historical, and individualised contexts in which people experience dementia (Symonds et al., 2022).

8.3.4. YOD and stigma

Inequality emerged as a central theme in the experiences of people with YOD (Rabanal et al., 2018) and is a key issue for social workers to be aware of. In the study, participants, as part of the process of assessing mental capacity drew on their awareness of the wider social context of the lives of people with YOD including how these inequalities may affect their lives. Participants in the study were firmly aware that people with YOD and their families experience inequalities and as a response, they try to accommodate this in their MCA work by exploring wider issues and advocating for them to receive additional support.

The findings confirm that stigma is one of the aspects linked to the experience of YOD. The interview discussions indicated that the participants understood stigma as being evident in the experience of dementia and gave examples of observing this in their practice. This supports the suggestion that inequality and stigma are noted themes within the dementia discourse (Rabanal et al., 2018; Harper et al., 2019; Nguyen and Li, 2020; SCIE, 2023a) and the experience of dementia at any age will reflect social divisions linked to disability, gender, social class, sexuality, and race (Milne, 2020a). Within the literature on YOD, there are gaps in understanding how professionals respond to the inequalities that people with YOD experience (Rabanal et al., 2018). Some studies such as Milenaar et al., (2016) and Carter et al. (2018) recognise the disadvantages experienced by people with YOD in terms of receiving support from secondary care services. In 2022, the Young Dementia Network published Good Practice in Young Onset Dementia, which noted that people in their mid-life stage with dementia often find it difficult to access dementia services (2022c). As a result, requests for greater age-related services to reduce the inequalities have been made (Mayrhofer et al., 2018; Young Dementia Network, 2022c; Oyebode et al., 2023). Rabanal et al. (2018) noted that traditional dementia support services like reminiscence-based activities may focus on an era which younger people with dementia may not be familiar with due to their age. The participants in this research study shared similar views that amongst the services available to support the care needs of people with dementia, there appears to be a lack of services that address the needs of people with YOD.

Stigma was highlighted as a key concern for participants in their MCA assessment and decision making in the findings. Participants perceived that stigma was contributory to people who have YOD not accessing social care services, thus leading to delays in receiving a diagnosis of YOD. The literature on stigma can be drawn on to help make sense of these findings. The seminal work of Ervin Goffman (1956) defines stigma as a 'spoiled identity' and an attribute that is socially discrediting and harmful (Harper et al., 2019) and Link and Phelan (2001) cited in Evans (2018) highlight that stigma involves the process of labelling, stereotyping, alienation and loss of status. Three different forms of stigma were evident in the findings from the research study, which provide evidence that stigma is a key component to be taken into account in MCA assessment and decision making for the participants. Firstly, Hermann et al. (2018) and Nguyen and Li, (2020) remind us that for people who have dementia, the experience of stigma can be particularly marked due to perceived negative experiences and responses from wider society including health and social care professionals. Stigma is reinforced by the language and images surrounding dementia which instil fear and otherness of the condition (Manthorpe and Illife, 2016). This form of stigma is referred to as public stigma and can lead to delays in seeking help (Nguyen and Li, 2020). Public stigma in everyday practice leads to the second category of stigma for people with YOD known as self-stigma. Self-stigma is defined as internalised stigma, which occurs when negative stereotypes linked to prejudice become internalised by a person with dementia (Nguyen and Li, 2020). A third conceptualisation of stigma refers to stigma by association which has been identified as particularly significant for family members, carers and associates of people who have dementia (Harper, 2019). This form of stigma is highly relevant and requires attention (Werner and Heinik, 2008) due to the close ties families and carers can have with people with YOD. Therefore, social work efforts to understand stigma need to take into account the wider experiences of people with YOD and their relatives (Werner and Heinik, 2008). Other studies such as Rabanal et al. (2018) highlight that there is a link between awareness of YOD and reducing stigma. The study found that stigma awareness is salient for participants in their MCA work with people who have YOD.

8.3.6. Ageism and YOD

Connected to the findings on age the influence ageism has in social work practice with people who have YOD can be examined to obtain an improved appreciation of the experience of people with YOD in MCA work. Age has been stated as a factor in understanding how participants understood YOD, which links directly to their assessment and decision making processes using the MCA. Ageism is recognised as the discrimination experienced by people based on their age (Ayalon and Tesch-Römer, 2018). Milne (2020b), Evans (2018) and Higgs and Gilliard (2017) suggest that people who have dementia experience ageism which is a key concern for social work practice with people with dementia (Scourfield, 2023). More specifically, Milne (2011), for example highlights the lack of policy commitment to early intervention with people with dementia, linking this to discriminatory policy that invisibilises dementia. Concerning YOD Mayrhofer et al. (2018), Koopmans and Rossness (2014), and Oyebode et al. (2023) found that there is a lack of policy acknowledgement at the local commissioning level of how dementia can affect people below age 65. The findings in this study illustrate that participants shared how ageism might be an aspect of their MCA work, for example, the lack of community services suitable for people with YOD, limited participants' options for identifying appropriate support post-MCA assessment. This finding echoes existing research studies such as Rabanal et al. (2018) which recognised that in many cases the post-diagnosis care and support needs of people who have YOD were inadequately provided for, thus suggesting that there are disparities in the provision of support for people with YOD.

8.3.7. Intersectional approaches to understanding YOD

The findings draw attention to ageism, inequality and stigma as part of the experience of YOD. Within the participant discussions about inequalities comments identified that greater attention has been given to people with YOD linked to the idea that younger people should not experience dementia. One example noted that people who have YOD can be offered greater involvement in MCA assessments due to beliefs that they will be more engaged in an MCA assessment process than a person with LOD. Other perspectives highlighted that dementia is more inevitable for older people and a greater tragedy for younger people. These findings tell us that in relation to social work practice people with YOD may experience both oppression linked to their status of having dementia, as well as privilege linked to age related factors. Age therefore forms an important axis in YOD where both privilege and oppression co-exist (Hulko, 2009). In trying to make sense of the contrast of oppression and privilege drawn out from the findings, intersectionality provides a helpful theoretical lens through which to attempt to try to bring greater clarity. Intersectionality refers to a critical framework highlighting that oppression cannot be reduced to a singular form, but operates in multiple ways (Hulko, 2009). Intersectionality relates to the work of Kimberley Crenshaw (1989) who helped to explain it as a tool for interrogating the intersecting layers of oppression for black women. Bernard (2021), in her book *Intersectionality for social workers,* reminds us that:

> "Intersectional approaches can open up social work practice to new understandings of the complex linkages of multiple and intersecting systems of oppression that shape the lived experiences of diverse groups of service users" (p.2).

In relation to social work practice with people who have YOD, intersectionality reminds us of the fragmented nature of personal identities (Thomas and Miligan, 2018). It can be used as a framework to gain a better understanding of how interlocking oppressions present themselves in the everyday lives of people with YOD and then may support a more coherent picture of the experiences of people with YOD which can enrich their MCA work.

In summary, the evidence drawn from the findings and existing literature confirms that an understanding of YOD is vital to MCA assessment and decision making for participants. Examining what an understanding of YOD means revealed that theories of age and ageism, stigma and intersectionality are relevant for participants if they are to have a clear understanding of YOD. These are direct resources for participants in their MCA assessment and decision making and complement their wider practice. However, it is important to emphasise that the findings point to participants needing a robust understanding of the similarities and differences between YOD and LOD to support their MCA work.

8.4. How do social workers use the MCA in assessment and decision making in the context of practice with people who have YOD?

The findings revealed a typology of participant decision making consisting of different approaches used by participants in decision making with people who have YOD. The typology of social worker decision making provides evidence of how participants engaged in MCA decision making in their practice with people who have YOD. The five novel approaches to decision making, which are procedural, medicalised, creative, shared, positive risk and rights-based, indicate that there are multiple ways in which the participants use the MCA to make decisions. These approaches are discussed below in relation to their relevance to social work practice in MCA work.

8.4.1. Procedural approaches to MCA decision making

The first approach outlined in the findings was procedural approaches. This referred to participants following rules and procedures in their MCA decision making. This could involve careful attention being given to the legal aspects of the MCA in decision making or giving high value to the process or procedure in their MCA work. Williams et al. (2014), Murrell and McCalla (2016) and Beale et al. (2022) all previously noted the existence of similar approaches to the procedural approach in MCA decision making that this study has also found. McDonald (2010) in her study of social worker decision making elucidated what she termed legalistic types of decision making. Legalistic types of decision making refer to participants who sought certainty in their MCA practice instead of the accuracy of the approach to MCA decision making and also used guidelines to clarify whether a person had mental capacity or not (McDonald, 2010) and this has some similarities to the findings linked to procedural approaches in decision making as both have a focus on following a particular procedure. In this research study, the findings show evidence that participants followed a more legalistic approach to decision making although this was less pronounced than suggested by McDonald (2010). The differences between this study and McDonald's (2010) were that in this study participants did not see themselves as legal advisors or discuss legal processes outside of the MCA. The similarities between the findings from this study and

McDonald’s (2010) relate to the emphasis on following procedures in the process of making decisions. Participants in using procedural approaches followed the MCA assessment and Best Interests processes in a mechanical way, giving little room for exploration of the beliefs and values of the person being assessed or clinical judgements based on professional experience and wisdom. Banner (2023) posits that procedural approaches in MCA work rely on the logical relationship between inputs and outcomes and fail to fully take into account where there are complex and context-specific factors that shape decision making.

In Chapter 2 it was highlighted that the MCA promotes a procedural approach, evident in the functional test for MCA, so for many participants a procedural approach is likely to be seen as complying fully with the MCA assessment process. A procedural approach in MCA decision making confirms that for some of the participants’ certainty in their MCA decision making is important (McDonald, 2010). Using a procedural approach gives participants greater certainty in their decision making, although, as noted by Clough (2015), decision makers following procedural rules are given no impetus by the MCA guidelines such as the MCA Code of Practice (2007), to explore wider structural and social factors that might have a bearing on the person. There is some evidence from the study that procedural approaches are not always seen as adequate by participants, as at least one contributor noted in the MCA assessment that using a procedural approach can “feel like a tick box exercise.”

8.4.2. Medicalised approaches to MCA decision making

The second component of the typology of MCA decision making drawn from the findings was medicalised approaches to provide a decision making focus on medical ideas and in particular the perspectives of clinicians and the role of diagnosis in MCA decision making (Clough, 2015). Medical approaches connect to medicalisation which can be seen as the extension of medical ideas into other realms of people’s lives (Manthorpe and Iliffe, 2016). The findings confirm that some of the participants used a medicalised approach in their MCA decision making. Where participants discussed using medical approaches to MCA decision making this was characterised by them exploring wider health issues including diagnosis and using medical information to premise their decision making. Other examples of participants employing a medicalised approach were evidenced by some participants who saw medical professionals as having greater status in MCA work and so deferred to their responses.

In Chapter Two it was acknowledged that in the MCA assessment process, there is an emphasis on medical criteria in which assessors are required to evidence the impairment of the mind or brain (MCA, 2005) and in Chapter Three it was suggested that biomedical approaches dominate the discourse of dementia (Milne, 2020b; Manthorpe and Iliffe, 2016) shaping policy and practice (Milne, 2022b). Lyman (1989) argues that the adoption and widespread use of medical approaches can be argued as one of the ways of responding to their uncertainty surrounding dementia. Building on these ideas and the findings of the study, it can be posited that medical approaches shape and influence the decision making practice of participants when using the MCA to assess people who have YOD. Case (2016) adds further evidence to this argument by pointing out that medicalised approaches in MCA work can be reinforced through the use of clinical euphemisms in legal cases, such as the term “lacking insight”, which can be used to suggest an inability to make decisions.

Medical approaches to MCA decision making which are informed by the medical models of illness are one way that participants make MCA decisions, although it was evident from the findings that not all participants saw medical approaches as being helpful in their MCA assessment and Best Interests work and some indicated that their role was to take a non-medical approach to understanding mental capacity. Clough (2015) posited that medical approaches in MCA work have advantages. For example, they can give clarity about the “diagnostic” aspects of MCA assessment (Beale et al., 2023). However, a social constructivist analysis of medical approaches suggests that medical approaches in dementia relate to the exercise of power (Davis, 2004). Clough (2015) highlights that there has been a tendency for judges to rely on medical perspectives in mental capacity court cases over and above the perspectives of other professional experts. Connecting this argument to the findings of the study it was noted that participants rationalised following a medicalised approach in their MCA decision making based on beliefs that doctors held greater authority and in doing so, framed their MCA decision making based on medical evidence.

Medicalised approaches have been found to be dominant in MCA work (Boyle, 2008; Clough, 2015), although they present a one-dimensional way of understanding mental capacity issues (Clough, 2015) which can overlook the structural and institutional challenges which affect people who lack the capacity to make decisions. Therefore, in MCA work with people who have YOD and face social barriers such as stigma and unequal access as well as barriers to accessing post-diagnosis support (Giebel et al., 2021; Stamou et al., 2022a; Nwadiugwu, 2021), cognisance of the limitations of medical approaches is important. The findings on medicalised approaches tell us that participants rely on medical evidence in MCA decision making and this medical evidence does shape social worker decision making. However, the medicalisation in mental capacity decision making, like the medicalisation of wider health care, can be argued to be constructed, shaped not only by the dominance of medical professionals (Ballard and Elston, 2005) but also by perspectives of people who receive services, their families and carers as well as other professionals (Pereira Gray et al., 2016) who can be active and implicit in endorsing medicalised ideas within mental capacity issues.

8.4.3. Creative approaches to MCA decision making

The research study found that participants use creative approaches to MCA decision making in their practice with people who have YOD. A range of creative approaches were noted by the participants in the study, for example, using the description of a recipe to explore what mental capacity to make a decision means or using language skills such as analogies to support understanding. The creative approaches used by participants often involved finding ways to overcome barriers to MCA assessment or Best Interest decision making or to support and improve MCA work. Jayes et al.'s (2020) literature review of MCA decision making brought to light a range of studies that found professionals using creative approaches in their MCA work. They note a wide range of novel resources such as screening tools for cognitive communication and tools to support money skills. Similar to the messages from participants in this research study, Jayes et al. (2020) evaluated that creative resources in MCA decision making were used as a way of ensuring MCA work was compliant with guidelines or to ensure that the relevant details are collected with an MCA assessment.

The use of creative approaches in MCA decision making for participants can be seen as a response to the recognition that MCA assessments and Best Interests assessments are complex and can be challenging (Ballard, 2023; Brown, 2023). Furthermore, people with YOD are a heterogeneous group where there may be a range of needs, therefore participants in their MCA work will need to be flexible. The analysis of creative approaches tells us that they can be of great benefit to participants in their MCA work, although to date there is no evaluation of creative approaches to decision making in MCA work (Jayes et al., 2020), indicating that it is difficult to confirm whether participants could use them more widely.

8.4.4. Positive risk approaches to MCA decision making

Participants in the study discussed how they explored risk issues in positive ways as part of their MCA decision making. These positive discussions included exploring the person's perception of risk related to the decision and using this discussion to highlight the benefits of taking a positive risk approach. Within social work literature, risk is a concept that is widely discussed and debated (Stevenson and Taylor, 2017; Alfandari et al., 2023; Wilson et al., 2011). In the first few years after the MCA was implemented commentators such as McDonald (2010), Boyle (2008) and Rappaport et al. (2009) highlighted the risk discourse as a major component of social work practice using the MCA. McDonald (2010) in her study of dementia and decision making noted that approaches to risk in MCA work were seen as extensions to social worker risk assessment and Taylor (2016) posits that the MCA can be used as a risk management tool. Williams et al. (2012b) in their study of MCA decision making noted Best Interests processes were often triggered by changes which revealed issues of risk. This study confirms that participants were keen to talk about risk as part of their MCA decision making and found it to be one of the areas of their practice where they were able to draw on wider perspectives such as autonomy and rights for people with YOD. Participants recognised the key role risk has in their MCA work and used their professional judgment to understand risk.

An area where analysis of this study's data produced novel findings about risk was in terms of participant discussions about positive risk-taking within MCA work. Positive risk-taking can be understood as a type of decision making connected to risk that relies on professional judgement. Assessment of risk within a professional judgement approach to decision making draws on the skills of social workers as well as their understanding of the risk issues presented (Dixon, 2023). It enables practitioners to use intuition and interpersonal skills as part of understanding risk (Hardy, 2017). Positive risk-taking recognises the institutional disadvantages that people with dementia face in everyday situations (Thomas and Milligan, 2015) and seeks to counterbalance these by exploring and, where possible, endorsing the person's wishes (Blood and Wardle, 2018). Positive risk-taking emerged into the lexicon of health and social care at a similar time to developments around personalisation and greater involvement of people in their own care decisions (Blood and Wardle, 2018). It represents a change from paternalistic approaches to risk that emphasise protecting people with dementia from risks to recognising people are capable of understanding their own risk and making their own decisions (Willis et al., 2022; Blood and Wardle, 2018). Positive risk conversations recognise that people with dementia may have different perspectives about risk to that of professionals (Dixon et al., 2022). In MCA work, positive risk work has been linked to Best Interest decision making. Participants in this study recognised the need to explore positive risks in their Best Interests work as part of evidencing the views and wishes of the person and ensuring their involvement in MCA decision making.

Discourses of risk intersect with social constructivism which posits that powerful groups in society define what risk is and use the tools of language and information gathered to reinforce their ideas (Fanning, 2016; Hardy, 2017). In MCA practice, this can be seen as the tendency to adopt risk-averse approaches in Best Interest decision making under the guise of safety and use terminology that reinforces fear and avoidance of risk (Taylor, 2016). For example, risk within MCA work has been noted as being poorly defined and potentially stigmatising (Fanning, 2016) due to its tendency to be linked to adverse outcomes such as a deprivation of liberty or in cases where mental health is a noted concern, detention under the MHA. The opportunity to change negative constructions of risk in MCA can be achieved by changing the focus from one of harm and protection to exploring the person's strengths

(Blood and Wardle, 2018). Clarke (2011) in a study exploring risk assessment and dementia identifies that rather than solely focusing on outcomes, risk assessment is a process that can consist of several stages. The first stage for Clarke (2011) consists of understanding the person’s circumstances and the second stage of identifying risks, followed by assessing the impact and likelihood of risk. The fourth stage refers to risk enablement and planning or what can be termed as positive risk (SCIE, 2023b). This approach to risk can be argued as more balanced as it moves towards including the wishes and perspectives of the person and moves away from actuarial approaches to risk which focus on the likelihood of a negative event occurring. Willis et al. (2022) in their study connect positive risk approaches to ethical issues for social workers who are ambivalent about taking a risk-averse approach, which many participants in this study raised as a concern in their MCA work.

Positive risk as a theme in MCA work has been emphasised in case law, where in several cases Court of Protection judges have emphasised the importance of balancing the desire to protect a person who lacks the capacity to make a decision against the person’s wishes and views (Clough, 2018). The *Westminster City Council v Sykes* [2014] EWHC B9 (COP) case is an example in which exploring and ascertaining the Best Interests of the person led to a determination to make a positive risk decision and enable the person at the centre of the case, Manuela Sykes, to return home with home care support provided by the local authority, instead of continuing to deprive her of her liberty in a nursing home placement. In this case, District Judge Eldergill acknowledged that there was a significant risk that the home care support for Manuela Sykes would break down, but that safety was only one part of the consideration, and emphasised the importance of Manuela’s strong desire to remain independent using the term “If not now, then when?” *Westminster City Council v Sykes* [2014] EWHC B9 (COP) [10].

Munby J in his observations on *Local Authority X v MM & Anor* (No. 1) [2007] EWHC 2689, sums up why positive risk remains important in MCA work. Munby J noted that risk is ever present, stating:

> "The fact is that all life involves risk, and the young, the elderly and the vulnerable, are exposed to additional risks and to risks they are less well equipped than others to cope with." Local Authority X v MM & Anor (No. 1) [2007] EWHC 2689 [120].

Munby J comments in the *Local Authority X v MM & Anor* (No. 1) [2007] EWHC 2689 highlight the need to understand risk within the framework of Best Interests where the person's wishes, which may be less risk averse, are central to the understanding of Best Interests. In highlighting this, Munby J suggests that risk approaches should consider the wishes of the person:

> "The emphasis must be on sensible risk appraisal, not striving to avoid all risk, whatever the price, but instead seeking a proper balance and being willing to tolerate manageable or acceptable risks as the price appropriately to be paid to achieve some other good – in particular to achieve the vital good of the elderly or vulnerable person's happiness. What good is it making someone safer if it merely makes them miserable?" Local Authority X v MM & Anor (No. 1) [2007] EWHC 2689 [120].

Justice Munby's rhetorical question at the end of the above quote suggests that MCA decision making is not only a matter of protecting the person's safety but should take into account the overall well-being of the person and, importantly, the person's wishes, whether present or past. Positive risk therefore can have an empowering element which promotes a person's autonomy. For the participants in their MCA decision making, positive risk approaches appeared to offer a meaningful way in which to explore risk while holding to principles that value the views of people. It moved away from the tendency to make MCA work primarily about protection and carrying out risk assessment to avoid risk (McDonald, 2010; Taylor, 2016).

8.4.5. Shared approaches to MCA decision making

Within the typology of social work decision making participants valued shared approaches to decision making. Shared approaches involved participants making decisions alongside and in consultation with others. Shared approaches to decision making were seen in part as a response to the complexity of MCA work and are evident in other studies which endorse it as a part of MCA decision making, for example, Williams et al. (2014) found that in MCA Best Interests work joint decision making was based on democratic ideas and Jayes et al. (2020) found collaborative working between professionals was more likely to lead to assessments being person-centred and legally compliant. McDonald (2010) identified that MCA work where different agencies shared responsibility had a stronger likelihood of taking a legalistic approach to decision making. In another study, Dixon et al. (2022) suggest that people with dementia can benefit from shared decision making. Although there is no direct mention of shared approaches to decision making, the MCA Code of Practice (2007) gives guidance on decision making practices indicating in Para. 5.11 that there will be times when there will need to be joint working in MCA assessment and Para. 5.51 that decision makers must show they have thought carefully about who to speak to in the course of Best Interests (Department of Constitutional Affairs, 2007). This study confirms evidence that shared approaches to decision making are helpful and draws attention to participants using shared approaches within MCA assessment and Best Interest decision making processes to achieve outcomes that align with the person's wishes.

Shared approaches support ways in which participants involve the person in the decision making process (Boyle, 2008), which is important in light of literature that mentions that people with dementia are often marginalised in the decision making process (Boyle 2008; Greenwood and Smith, 2016; Murrell and McCalla, 2016). Findings from Jayes et al. (2020) affirm that in mental capacity decision making the involvement of people who lack capacity should occur routinely and Para. 5.21 of the MCA Code of Practice (2007) endorses that wherever possible the person who lacks capacity to make a decision should be involved in the decision making process (Department of Constitutional Affairs, 2007). Despite this, evidence from this research study suggests that shared approaches were mainly talked about in connection to MCA decision making with other professionals rather than people with YOD.

8.4.6. Rights-based approaches to MCA decision making

Rights-based approaches emerged as one of the ways in which participants engaged in MCA decision making. Rights-based approaches were drawn from the discussions with participants in which they emphasised the social welfare rights and human rights of people who have YOD. Participants used terms like freedoms and rights to articulate what they were trying to achieve in their MCA decision making. Rights-based approaches can be argued to shift the conceptualisation of dementia from an individual health matter to a wider societal concern by drawing attention to the gap between policy ideas and how they are implemented in practice (Bartlett, 2022). In this way, rights-based approaches are practice-orientated as they seek to actualise wider awareness into real opportunities for people with dementia (McDonald, 2010). This aligns well with the MCA which, as a tool for decision making, aims to improve the rights of people who lack capacity (Boyle, 2008). There are other studies that have recognised that social workers in their practice gravitate to rights based approaches. McDonald (2010) for example, notes that social workers in their assessments used human rights principles such as the right to privacy, rights to family life and the right to own and dispose of property. Willis et al. (2022) found that social workers practising in multi-disciplinary settings with older people make distinct contributions to joint working linked to their knowledge of human rights.

Within social work attention to rights-based approaches has concentrated on how to promote the human rights of people who come into contact with services (IFSW, 2016: Briskman and Peman, 2012). Human rights can be pointed out as constructions of universal human values which have been embedded in legal frameworks, in particular the HRA (1998) and the ECHR (1950) (Ife et al., 2022). These frameworks represent a focus on first generation human rights instruments, for example, the right to life, the right to vote, the right to freedom of movement and a fair trial (Ife et al., 2022; IFSW, 2016; ECHR, 1950). The first-generation rights set a foundation but they do not secure what are referred to as second and third-generation rights which draw attention to social, cultural and economic rights as well as collective rights (Ife et al., 2022; IFSW, 2016). Examples of second and third generation rights are the right to adequate health care, housing and social care and the right to development and self-determination (Ife et al., 2022; IFSW, 2016). Examining how participants engaged with human rights in this study, the analysis shows that in their MCA work focus they were more aligned to second and third generation human rights. Furthermore, participants used inductive or bottom-up approaches to understand rights, which rely on starting with the perspectives of people, rather than a top-down approach which draws from legislation such as HRA or ECHR (Ife et al., 2022). In adopting this approach to MCA decision making the participants chose to hear the personal accounts of people and then connect them to wider rights issues. In starting with the accounts of people with YOD this tells us that participants aligned to autonomy, dignity and self-determination approaches to supporting rights, as outlined in the International Federation of Social Worker's social work rights framework (IFSW, 2016). These approaches also align with the United Nations Convention on the Rights of Persons with Disabilities (CRPD) which encompasses principles that emphasise full and effective participation and inclusion in society (UN, 2016) and represent a progression in securing the rights of people with dementia (Dixon et al., 2022). Clough (2016) posits that the CRPD emphasises the need for positive action to protect and promote the enjoyment of human rights. The participants recognised people with YOD as a marginalised group and acknowledged that there is still work to be done to bring the rights of people with YOD on to a more equal standing with the rest of the population (Bosco et al., 2019).

Rights-based approaches in social work connect with the core values of social justice and social citizenship (Boyle, 2008; Brown, 2023). As noted in Chapter Three, social citizenship and rights-based approaches form alternative responses to the biomedical and psycho-social approaches in practice with people who have dementia. In the MCA social citizenship can be promoted through social workers involving advocates to support a person's inclusion in decision making. Instructing and collaborating with Independent Mental Capacity Advocates (IMCA) where appropriate within the MCA work is one such example of participants from this study promoting social citizenship in their MCA work. Other examples include the emphasis on inclusion in community activities run by community services such as respite services, community-based support groups and day centres. These examples point towards MCA work endorsing rights through relational citizenship, where people with dementia express their citizenship through interactions with others in social spaces (Bartlett, 2022).

8.5. What are the different ways in which social workers can use the MCA to make decisions for people with YOD?

This section examines how evidence drawn from the study's findings identifies the different ways that participants use the MCA to make decisions. The discussion in this section considers that MCA decision making consists of a set of processes that participants knowingly engaged with. These processes include knowledge and awareness of the MCA, getting to know the person, person-centred approaches and the use of tools in MCA work.

8.5.1. The process of MCA assessment

The Department of Health publication, *A manual for good social work practice: Supporting adults who have dementia* (2015b), outlines that assessment is not a one-off process in relation to dementia. The findings from this study align with this statement but also add different ways of understanding the assessment processes for people with YOD. From this study MCA assessment and decision making with people who have YOD were multi-faceted and sometimes complex. It involves the professionals engaging in both formal and informal processes which include using a range of skills and abilities, as well as working collaboratively with others to make decisions. There is much to be learned about how social workers engage in assessment and decision making using the MCA (Brown, 2023; Rapaport et al., 2009). The existing literature in this area is sparse and reliant on smaller qualitative studies (Jayes et al., 2020). The findings from this study evidence that social worker MCA assessment aims to achieve quality assessments that empower and promote the autonomy and dignity of people with YOD. This study has helped to illustrate that the processes involved in MCA assessment and decision making for participants can be valuable and reminds us that social work decision making is rarely an activity that occurs in isolation but is often linked to other events in the person’s life (Bogg and Chamberlain, 2015) and in the case of MCA decision making it is shaped by a knowledge of the MCA, person-centred approaches and building a rapport with the person who has YOD.

8.5.2. A knowledge of the MCA

From the findings there was evidence that the participants in their MCA work engage in both formal and informal processes. Within the formal processes drawn out in the analysis of data on the MCA, a key theme that emerged was for participants to have a knowledge of the MCA. In relation to knowledge of the MCA, some studies have highlighted that social workers have a variable awareness of the MCA and its provisions, for example, Murrell and McCalla's (2016) study of social workers found that there was knowledge of how to assess capacity but deficits in adherence to the overall principles of the MCA. Williams et al. (2014) noted awareness of the MCA was not strong among professionals. Rogers and Bright (2019) noted a lack of awareness of the complexity of the MCA in their study of MCA and DoLS practice. More recently, Ariyo et al. (2022) in their study exploring professional perspectives on using the MCA, suggested there is strong social worker confidence in assessing mental capacity. This research study's findings highlight that participants were competent in explaining the MCA assessment process and talking about how they use the MCA in practice, indicating confidence in using the MCA. Confidence was further evidenced by participants indicating that they would challenge others where they thought their practice was not compliant with the MCA. These findings diverge from the findings of Murrell and McCalla (2016) and Williams et al. (2014) and the divergence may be explained by looking at the timing of when the research was carried out. For example, both studies were carried out in the first five years after the implementation of the MCA in 2007, when the MCA was still considered quite new and social workers were still adjusting to its use in practice (Kong and Ruck-Keene, 2019). It was widely acknowledged that awareness of the MCA was poor in the early stages after its implementation (House of Lords, 2014; Aspinwall-Roberts et al., 2022; CQC, 2015; Scott et al., 2020). Moreover, the indication that the participants who shared their perspectives in the study possess a clear knowledge of the provisions of the MCA relates directly to their discussions about Sections 2 and 3 of the MCA, whereas other studies have referred to wider aspects of the MCA, such as matters of decisional capacity or executive functioning in their conclusions about social worker understanding of the MCA (Jayes et al., 2020).

Although there was an indication that participants in their MCA work with people with YOD have a good knowledge of MCA in relation to the decision making options available to them, there are other considerations to be noted around the MCA. For example, participants were not always alert to how to address practices where Best Interests decision making was engaged before an MCA assessment. Engaging in Best Interests decision making before the MCA assessment has been completed has been found in several previous studies such as Williams et al. (2014), McCalla and Murrell (2016) and Jayes et al. (2020). Williams et al. (2014) referred to the formulation of outcomes practitioners believe should be followed ahead of MCA assessments, such as the Concertina effect. Participants in this study indicated that they challenged other professionals where Best Interests decision making occurred before MCA assessment, but it was not evident for all participants in the study. For participants, confidence in using the MCA can be linked to ideas of legal literacy. Willis et al. (2022) highlight that social worker’s knowledge of the MCA and other statutory frameworks helped to influence multidisciplinary teamwork. Manthorpe and Samsi (2013) in their study found that social workers embraced and followed the MCA although they lacked a detailed understanding of the legal guidelines and could benefit from regular legal updates. Braye et al. (2011) in their scoping study of social work practice with people who self-neglect, drew attention to respondent concerns that a lack of legal literacy in MCA work can lead to less thorough MCA assessments. Braye and Preston-Shoot (2016) postulate that legal literacy for social workers consists of three main components. The first is having a sound knowledge of legal rules and understanding the relevance of legal rules to social work practice. Participants in my study appeared to have a good grasp of the main components of the MCA but were less confident in discussing associated legislation and guidance like the MCA Code of Practice. Secondly, legal literacy involves practitioners being able to engage in professional ethics within their day-to-day practice and thirdly incorporating human rights, equality and social justice into practice. While some of the participants in this study discussed human rights and ethical issues, there was not a strong thread covering these areas throughout all interviews. In relation to MCA decision making, legal literacy can be argued to help social workers move beyond knowing the MCA to exploring the broader ethical and rights issues, especially where there is limited practical guidance on how to apply the law in everyday practice (Braye and Preston-Shoot, 2016; Jayes et al., 2020).

8.5.3. Getting to know the person with YOD in MCA work

MCA assessment with people with dementia is often complex (Brown, 2023) and the findings of this research suggest that participants were attuned to this by engaging in the processes of getting to know people who have YOD and building a rapport with them within their MCA assessment work. From the study it was evident that participants engaged in asking questions to get to know people with YOD as part of their MCA work. The process of getting to know people was seen as a valuable aspect of the MCA assessment process and was not seen as a separate process. Informal processes like getting to know the person being assessed and rapport building are common among a range of professionals who use the MCA to assess capacity and many studies have noted the significant benefits these have for professionals and people being assessed (Jayes et al., 2020; Rabanal et al., 2018; Williams et al., 2014; Scott et al., 2020) such as reassuring the person who might find the MCA assessment process unsettling or helping to gain an informal impression of the person. Participants in the research studies referred to both of these examples, suggesting that, like other professionals carrying out MCA assessments, these social workers engage in getting to know the person as part of their MCA work.

Analysis of participants developing a rapport with people during MCA work provides consistent evidence that MCA work is linked to relationships. Within social work literature, rapport building is linked to relationship-based practice approaches which have been posited as a core facet of how social workers practise (Wilson et al., 2011). Relationship-based approaches, which are sometimes referred to as client-centred practice (Teater, 2010), refer to the use of self and relationship to make decisions along the way as well as how social workers engage with the complex issues for people in need linked to an underlying theory that guides thinking (Wilson et al., 2011). As a popular set of ideas relationship-based approaches have been found to encourage a supportive environment for people with YOD and their carers, particularly as a way of counterbalancing stigma faced by people with YOD (Nwadiugwu, 2021). The importance of relationship-based approaches has been noted to help in MCA work where there is currently no emphasis on recognising the impact of abuse and trauma and how that can affect decision making (Brown, 2023). In this way, getting to know the person can form a key approach in acknowledging the emotions as a necessary aspect of MCA work.

8.5.4. Person-centred approaches

A theme that emerged from the findings linked to social work processes in MCA work practice was that participants use person-centred approaches within their MCA assessment and Best Interests decision making. These findings align with other studies looking at MCA decision making. For example, Jayes et al. (2020) and Manthorpe and Samsi (2013b) both noted that person-centred approaches were evident in how practitioners carried out MCA assessments. Person-centred approaches relate to the original work of Carl Rogers' client-centred psychotherapy (Symonds, et al., 2020) which highlights person-centred care as central to understanding a person. Person-centred care has been noted as a value-based commitment by professionals including social workers (Manthorpe and Samsi, 2016a), that helps to strengthen interactions (Stamou et al., 2022b). Looking at mental capacity, person-centred care approaches have been noted as being intrinsic to the principles of the MCA (SCIE, 2017), and NICE (2018b) in their guidance on decision making and mental capacity approaches noted that:

> "Practitioners should take a personalised approach accounting for any reasonable adjustments and the wide range of factors that can have an impact on a person's ability to make decisions" (NICE, 2018b p.12)

Person-centred approaches in MCA work have been posited as valuable for professionals (Manthorpe and Samsi, 2016a) and in practice with people who have YOD, they enable social workers to work with those who have YOD as a whole person rather than someone with only physiological needs or cognitive deficit (Tolhurst, 2014). The participants of this research study believed that their practice with people who have YOD aligned to a person-centred approach, although they were not always able to articulate what a person-centred approach looked like in their MCA assessment and Best Interests decision making. Understanding person-centred approaches connects to Dowling et al.'s (2006) findings who posit that person-centred approaches in practice require more than asking a person what they think. The suggestion here is that the participants in this study were committed to person-centred approaches in terms of the philosophy of what person-centred approaches promote, i.e., creating conditions so a person can achieve their goals through the use of non-directive approaches (Symonds et al., 2020; Murphy et al., 2012), but less confident about what this means in practice. This has been noted in the literature, for example, Manthorpe and Samsi (2016a) draw conclusions that person centred approaches can run the risk of being too abstract and Symonds et al. (2020) found that in social care assessments person-centred approaches are often not clearly defined. Clarity about the tenets of person-centred approaches then may be of benefit for social workers in their MCA practice where there is a commitment to using person-centred approaches to support decision making.

Person-centred approaches are widely recognised and have links to Kitwood's (1997) theorisation of personhood. Kitwood’s work asserts achieving personhood is dependent on others and developing mutual trust and can also have positive impacts on staff satisfaction (Fazio et al., 2018; Manthorpe and Samsi, 2016a). This tells us that how social workers assess people using the MCA can contribute towards supporting personhood (Fazio et al., 2018). From the study, the participants indicated that they value person-centred approaches but did not link this to personhood, highlighting further that participants espouse the idea of person centred approaches in their practice without necessarily being familiar with all the components of involved in person centred approaches. While person-centred approaches were a positive part of how participants went about making decisions, there is evidence that person-centred approaches may hold challenges for them. Murphy et al. (2013) suggest that person-centred approaches are traditionally non-directive, which can be argued as difficult to attain in the context of MCA work because the purpose of a MCA assessment is for the professional to arrive at a decision that the person may or may not agree with, which conflicts with the philosophy of person-centred approaches.

8.5.5. Using tools as part of MCA assessment and decision making

In Chapter Seven it was stated that participants use tools and aids to support MCA assessment and Best Interests decision making. Tools and aids are used regularly to obtain information from the person with YOD during the MCA assessment or Best Interests decision making process. The study found that resources and tools were commonly used when supporting a person with YOD to understand information as part of the MCA assessment process. Examples of the tools that the participants used in their MCA work are pictures, storyboards, laptops or iPads with images, physical money or physically accompanying people to visits to care homes.

There was a rich discussion on the use of tools used for assessing people who have YOD in the study and the participants saw the use of tools as part and parcel of the MCA assessment process rather than separate from their MCA assessment. Using tools or resources to support the assessment of mental capacity and decision making is not new and has been identified in the literature on mental capacity. Ariyo et al. (2022) found that proformas and psychological tools such as the Montreal Cognitive Assessment, which detects cognitive impairment, were used in MCA work but not extensively. Lamot et al. (2013) in their review of the use of tools for assessing capacity found that there was a plethora of tools used by health professionals in MCA assessment. The NICE guidance document, *Decision making and mental capacity NG108* (NICE, 2018) comments on the lack of evidence of the effectiveness of tools used that are compliant with the MCA (NICE, 2018b). The document recommends health and social care organisations:

> "Identify or devise specific tools to help health and social care practitioners to assess where appropriate and necessary the mental capacity of people they are working with and audit the tools against adherence to the Mental Capacity Act Code of Practice" (NICE, 2018b, p.47).

The importance of the use of tools in MCA assessments has also arisen in case law deriving from the Court of Protection. In the case of *LBX v K, L, M* [2010] EWHC 2422, the judge, Justice Theis, commenting on the evidence drawn from an MCA assessment, noted:

> "The importance of using tangible resources, like drawings and pictures, to assess and improve the person's level of understanding" *LBX v K, L, M [2010]* EWHC 2422 [20].

The *LBX v K, L, M* [2010] EWHC 2422 case saw Justice Theis commend the social worker for their MCA assessment and in particular the use of tools to evidence capacity for the person. Justice Theis's comments illustrate that in practice the use of tools to support MCA decision making can make a difference and support the findings that suggest that tools are a part of the way that participants use the MCA to make decisions. From the analysis of this study, participants did not benefit from organisational involvement in the development of tools in MCA work. The lack of organisational guidance on using tools to support MCA assessment is therefore relevant to participants in their MCA decision making.

A wide range of tools exist that social workers can make use of as part of their MCA work with people who have dementia. Milne (2020b) highlights the importance of tools to measure the quality of life for people with dementia to capture their perspective. Tools like the Quality of Life in Alzheimer's Disease scale (QoL-AD) and Dementia Care Mapping have been evaluated as beneficial for capturing the perspective of the person with dementia and supporting person-centred practice and placing the person's perspective as central (Milne, 2011). While quality of life tools may not be directly linked to mental capacity they may help inform social workers of wider issues to be considered in their mental capacity work and can be used productively within MCA assessment and Best Interests work to inform best outcomes for the person. The use of tools and instruments like quality of life tools was not mentioned by the participants of this study, highlighting there is likely to be limited awareness of tools that can be used in MCA decision making. Furthermore, evidence from this study confirmed that participants appeared to identify tools intuitively, rather than based on following guidance. As noted in the NICE (2018b) Decision making and MCA report, there is likely to be a role for organisations that employ social workers, such as local authorities and NHS Trusts, to contribute to identifying and developing specific tools linked to MCA work with people with YOD, as well as guidance in using tools as part of MCA work.

8.5.7. Social work decision making and collaborative working

MCA decision making with people who have YOD is often complex and takes place in collaboration with others. To help understand the nature of MCA collaborative decision making with people with YOD different types of collaborative practice were identified within the findings. The three different types of collaborative practices identified for participants in their MCA assessment and decision making are: collaboration with other professionals, collaboration with families and carers and collaboration with community organisations. These types of collaboration are discussed below.

8.5.8. Collaborative working with professionals

Collaboration with other professionals was found to be a core part of their MCA assessment and Best Interests decision making work. From this study, the participants recognised the centrality of collaborative working as part of their MCA assessment and decision making practice and were able to articulate in detailed ways how collaborative working can benefit people with YOD. These findings concur with several studies that found that collaboration between professionals has a central role in MCA work (Murrell and McCalla, 2016; McDonald, 2010; Wilner et al., 2011; Williams et al., 2014; Ariyo et al., 2021). Collaborative practice is today a normative component of health and social care practice (Hood, 2018) and social workers in most areas of adult social care increasingly need to work with other agencies and professionals to effectively carry out their work. This has been found to be the case in MCA work as well (Manthorpe and Samsi, 2012b). The participants in this study indicated that they regularly work in partnership with a range of professionals including psychiatrists, GPs, psychologists, nurses, speech and language therapists and occupational therapists. However, collaborative practice in relation to people with YOD is under-researched (Ariyo et al., 2021) and this study draws attention to the perspectives of the participants in their collaborative work when using the MCA. The findings from this study show that participants collaborate with a range of health and social care professionals or workers in their practice with people with YOD and that this collaboration is welcomed by participants who recognise the benefits that come from shared MCA work.

In analysing collaboration with different professionals, it was found that professional differences occur in collaborative decision making. The professional differences involved participants recognising that there was no shared perspective in understanding capacity issues. The participants noted the lack of a shared perspective to present challenges and dissonance for them, where they wanted to collaborate with other professionals but recognised that the different perspectives would bring about challenges. Although the MCA Code of Practice notes that MCA assessments may require a multidisciplinary approach (Department of Constitutional Affairs, 2007) there is a lack of discussion about how to manage professional differences as part of MCA assessment and Best Interests decision making. The findings from participants suggest that awareness of professional differences holds importance within collaborative work.

What is noticeable here is that these tensions were not an indication that the participants were working collaboratively or even unwilling to work collaboratively but an indication of the challenges linked to collaborative working. Similar discussions are noted by McDonald (2010) who found that social workers have limited powers in their collaborative practice, suggesting that collaboration does not always lead to a shared decision. Bronstein (2003) in her model of interprofessional collaboration notes the salience of values and ethical guidelines for social workers to be balanced with wider team interests.

8.5.9. Collaborative working with families and carers

The analysis of participants' MCA decision making showed that there was a strong willingness to collaborate with and support family members and carers. Within the literature, there is a healthy awareness of the importance of collaborative practice with wider families or carers of people with YOD. Chirico et al. (2022) for example, highlights the key role that family members have in the day-to-day lives of those with YOD. Stamou (2021) and Mayrhofer et al. (2018) endorse collaborative partnerships with relatives and carers as valuable for people with YOD. The MCA Code of Practice encourages involving family and carers in Best Interests decision making (Department of Constitutional Affairs, 2007), although collaboration with family members and carers goes beyond the requirement to consult and evokes an approach of mutual working.

Chapter Two examined how the MCA emphasises an individual approach to decision making over more relational or interdependent ideas which specific literature has endorsed (Dhanda, 2012; Mackenzie, 2013). The participants in the study highlighted collaboration with family members, carers or other nominated persons as important to their decision making which contrasts with the underlying idea of the MCA which focuses on the views of the person (Taylor, 2016), suggesting participants held some awareness of decision making not only being an individual matter. What has been drawn out from this study is that collaborating with families and carers goes beyond the idea of consulting with them as part of the Best Interests decision making process to drawing them into all aspects of MCA decision making.

Participants described the importance of forming what can be termed collaborative alliances with family members and carers. Collaborative alliances were described as working to achieve mutual goals with family members and carers. They are not exclusive to just families and carers and may include anyone nominated by the person. The collaborative alliances for participants were part of their efforts to display a person-centred approach to working with a person and communicating warmth, care, interest and contributing to developing trust. These were particularly relevant in light of the barriers and stigma experienced by people who have YOD and their families and carers (Rabanal et al., 2018). Such alliances are important for social workers in MCA work, particularly where MCA decision making can have significant implications for a person who has been found to lack capacity.

8.5.10. Collaboration with community organisations

Collaboration with community organisations was recognised by participants as a necessary aspect of their MCA work with people who have YOD. Chapter 3 outlined policy linked to YOD and noted that charities and other voluntary organisations working with YOD have a crucial role in supporting the needs and rights of people with YOD (Mayrhofer et al., 2018). Several studies have drawn attention to evidence that community organisations have a pivotal role in offering support to people with YOD (Greenwood and Smith, 2016) and, in particular, post-diagnosis support (Mayrhofer et al., 2018; Stamou et al., 2022a; Oyebode et al., 2023). This was confirmed in the findings of this study in which participants recognised the resource that community services are to their own practice and also acknowledged the need to develop collaborative partnerships with community services in their MCA work. In MCA work social workers will often need to be aware of a range of services depending on the needs of the person (Scourfield, 2023; Manthorpe, 2014). In social work practice with those who have YOD, connecting with post-diagnostic community services can present complex challenges as many of these services are run by charities that tend to use volunteers (Mayrhofer et al., 2021). The participants in this study articulated their thoughts about the challenges, noting that some community support services for people who have YOD disappeared during the Covid-19 pandemic, which was problematic because it reduced the limited options available to them to identify suitable community resources.

Across social work practice with adults there is a recognition of the need to work in collaboration with community services, many of which are charities and non-profit organisations (Mayrhofer et al., 2021). Statutory policies in the form of The Care and Support Statutory Guidance (2016) endorse collaborative working in adult services. The perspectives of the participants in this study suggest that the gaps in the provision of community service for people with YOD mean further work at a strategic level is required to address the deficit (Oyebode et al., 2023; Mayrhofer et al., 2021). From this study, the importance of community services to those with YOD was further highlighted because the research was carried out during the height of the Covid 19 pandemic and at a time when the participants noted that people with YOD with whom they worked were most affected by the lockdown, including the suspension or closure of community services (Giebel et al., 2021) which increased isolation.

8.6. What are the implications for social workers in using the MCA in their decision making?

This section considers wider implications for participants when using the MCA in their decision making. The analysis of the factors that result in implications for participants begins with considering the context in which they made their MCA decision making, then moves to examine how Covid 19 impacted the participants in their MCA work and decision making. Finally, there is an exploration of time constraints in decision making by participants.

8.6.1. The context of MCA assessment and decision making with people who have YOD.

The practice of social work can be described as a mediating role between the individual and society (Parton, 2003). The context in which this mediation occurs is important and the findings from this research highlighted contextual factors play a pivotal role in MCA assessment and decision making for the participants. The findings indicate that participants engage in MCA assessment and decision making in a variety of settings which include residential care or nursing homes, people in their own homes or the homes of relatives or in hospitals. The list of settings drawn from the findings may not be complete as not all participants described the settings of their MCA decision making. Importantly, this study tells us that participants preferred engaging in MCA assessment and decision making face to face rather than virtually, over the telephone or in a socially distanced way. This is consistent with other studies such as Ariyo et al. (2022) and Giebel et al. (2021) who evidence the use of virtual assessments as part of MCA work. Several studies exploring MCA work highlight contextual factors and their significance in MCA assessment and decision making in the MCA assessment processes (Jayes et al., 2020; McDonald, 2010; Dunn et al., 2010).

MCA guidelines in the form of the MCA Code of Practice (2007) endorse that consideration should be made of the location and timing of MCA assessments (Department of Constitutional Affairs, 2007), although there is no comment about Best Interests decision making. A great amount of social work takes place in community settings including people’s homes, in cafés, and parks (Scourfied, 2023). The findings from the research study acknowledged that participants carry out MCA decision making in different settings. However, the analysis was not able to shed any further light on the settings for MCA decision making. This was in part due to the data being collected during a time when participants began carrying out MCA assessment and Best Interests processes virtually and as a result, discussed how they grappled with the changes to virtual MCA work.

8.6.2. The Covid 19 pandemic and MCA decision making

Of the contextual factors that have implications for social worker MCA decision making, the global pandemic caused by Covid 19 was the most significant. The Covid 19 pandemic was reported by the Health Foundation to have had significant implications for health and social care services and the lives of people who use health and social care services (Dunn et al., 2021). The UK nationwide lockdown required some older people and vulnerable groups to shield until early August 2021 (Giebel et al., 2021; Tuijt et al., 2021). At the time of writing, the understanding of the impact of the Covid 19 pandemic is still emerging (Giebel et al., 2021; Tuijt et al., 2021) and this study adds to the account of social work responses to events between March 2020 and July 2021. The participants in this study had a lot to say about how Covid 19 affected their practice and more specifically their MCA decision making. They shared detailed accounts of how they adapted their MCA practice in response to the restrictions that were imposed during the pandemic as well as services being suspended and having to carry out assessments in a socially distanced way or virtually.

People who have dementia including those with YOD were particularly affected during the pandemic. The Alzheimer’s Society (2020) in their report on the impact of the Covid 19 pandemic in the first half of 2020 noted that a higher proportion of people with dementia died during the early part of the pandemic, there was increased reports of isolation by people with dementia and their families, and health and social care services for people with dementia were in many cases put on hold. Dunn et al. (2021) in discussing the early impact of Covid 19 posited that the pandemic exposed underlying structural challenges in adult social care which they suggest points to the system being underfunded, understaffed and undervalued. Bannon et al. (2022) remind us that the pandemic created additional stressors for people with YOD, their families and professionals. In terms of social work practice, this study identified that during the Covid-19 pandemic, participants had to find new ways of working to complete MCA processes of assessment and decision making. These new ways of working included carrying out MCA assessments and Best Interests decision making via telephone or virtually, on doorsteps or in open spaces in a socially distanced way and finding ways to address the lack of access to people in care homes and hospitals. A study by Giebel et al. (2021) found professionals had to adapt to changes quickly and learn different ways of delivering care. Virtual MCA assessments were seen as part of the response of participants to the restrictions during the Covid 19 pandemic. However, there is evidence that services have continued to operate virtually following the lifting of restrictions, which may create further inequalities for people with dementia who struggle to access or use online or virtual resources (Giebel et al., 2021). With regard to social work practice, there is not enough evidence available to suggest whether the continued use of virtual MCA assessment has benefits.

In the early stages of the Covid 19 pandemic, the Government's response was to rush through amendments to legal frameworks that relate to decision making (Ruck-Keene, 2020b). These included the Coronavirus Act 2020, the Care Act Easement Policy and The Mental Capacity Act (2005) (MCA) and DoLS during the coronavirus (Covid 19) pandemic. Regarding MCA assessment and Best Interests decision making the key duties outlined in the MCA remained in place (Ruck-Keene, 2020b). The initiatives found in the new legal frameworks were aimed at supporting the NHS and local authorities which at the time were believed to be facing increased demand (Ruck-Keene, 2020b). The responses introduced by the Government and in particular the Care Act 2014 easement guidelines linked to assessment, care planning and reviews were not seen as helpful by participants, particularly regarding duties to protect and promote human rights (Dunn et al., 2021). In care home settings it was noted that the changes caused confusion among professionals about how they should engage with MCA issues (Kuylen et al., 2022). This study identifies that, for participants using the MCA, managerial responses encouraged the use of virtual MCA assessment through face-to-face assessments to ensure the MCA assessments were completed more swiftly, despite the challenges thrown up by restrictions on face-to-face communication. The response from the participants in this study to the encouragement to carry out MCA assessments more swiftly indicated that carrying out quality assessments of mental capacity involving people with YOD involves several steps that can take time. As noted earlier in this chapter these processes involve getting to know the person and working in a person-centred way to understand the personalised experience of YOD. Participants also stated their preference for face-to-face MCA work above virtual meetings.

The participants in this study were highly aware that the pandemic exacerbated inequalities and created new ones for people with YOD (Giebel et al. 2021). For example, some recognised that community services for people with YOD diminished significantly during the pandemic, leading to greater social isolation for people with YOD (Giebel et al., 2021). They were also cognisant of how it affected access to services and led to greater isolation for people with YOD and would eventually result in greater needs. As well as recognising how Covid 19 affected their practice the research study findings captured the perspectives of participants regarding how the Covid 19 pandemic affected their own health and wellbeing. The analysis of the findings of this study shows that participants' perspectives on the Covid 19 pandemic do not wholly align with studies that suggest social workers across adult and children’s services adapted to the changes during the pandemic with resilience in a time of uncertainty (Kingstone et al., 2022); instead, they resonate more with other studies that point to the devastating effect that the Covid 19 pandemic had on worker morale, health and wellbeing with increased workloads and increased vacancy rates (Foley and Foster, 2022).

8.6.3. Time constraints

Perspectives on MCA decision making include ideas about time constraints on completing MCA assessments. Participants saw time constraints as affecting their ability to build a rapport with the person who they were assessing or to gather background information for their MCA assessment or Best Interests decisions. The study highlighted that participants were under time pressure to complete MCA assessments and this pressure came from managers in their organisations. The findings indicate that participants wanted to spend greater time drawing together background information to support decision making to ensure the best decisions could be made with all relevant information available. The challenges of completing MCA assessments and decision making processes have been noted in other studies such as Murrell and McCalla (2016) and Williams et al. (2014), both of which found that time was a limiting factor for MCA assessments. Ayrio et al. (2021) found that professionals reported difficulties finding enough time to complete meaningful MCA assessments.

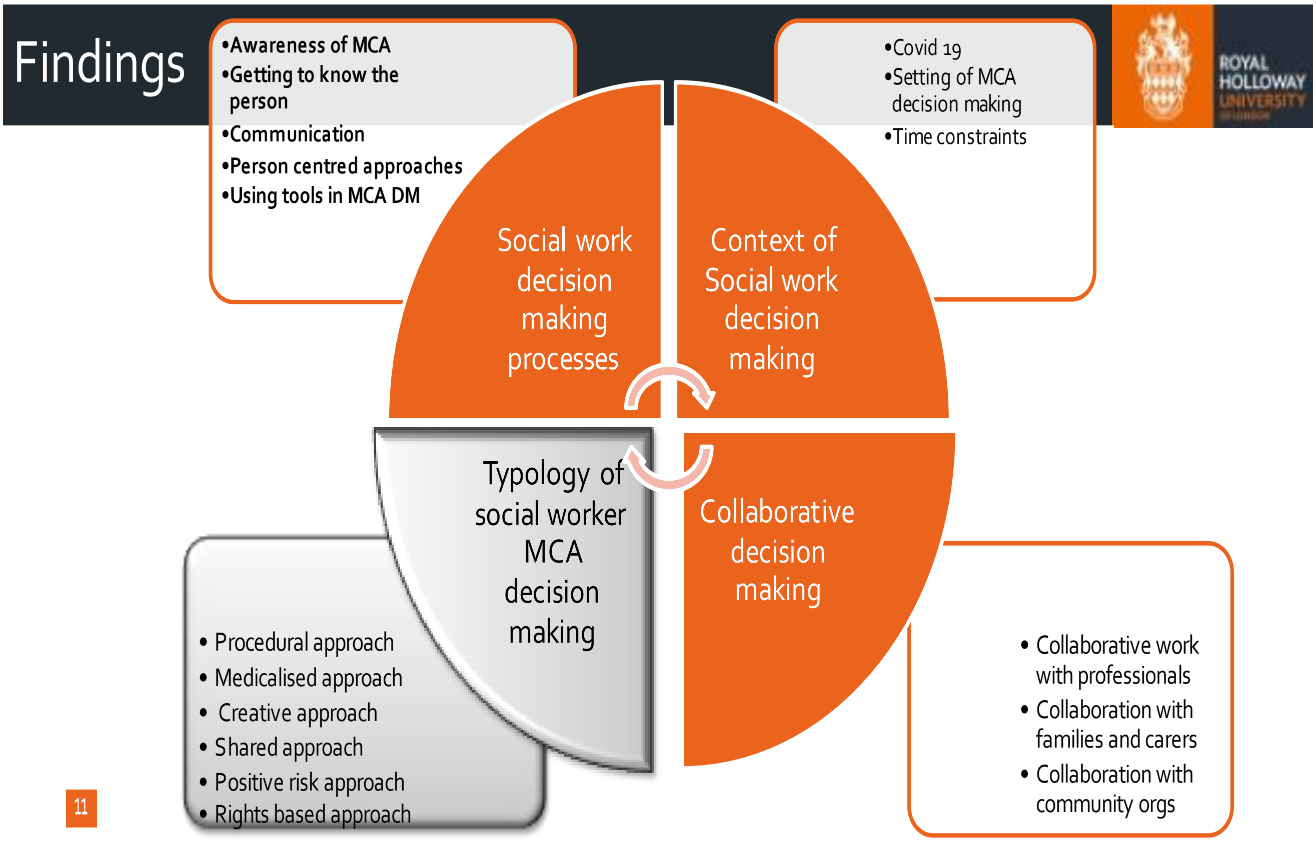
Social workers are increasingly being asked to practise within the context of organisational, political and financial challenges which lead to restrictions and capacity to carry out MCA work (Clough, 2015). Austerity and government cuts to welfare expenditure since 2010 have meant that adult social work practice takes place in an increasingly challenging organisational environment (Green and Clarke, 2019) which adds pressure on social workers to continue to do their work but with fewer resources (Brown, 2023). One of the resources that was found to have particular challenges for participants in MCA work with YOD is the resource of time (Scott et al., 2020).

Social work practitioners working in local adult services carrying out MCA work are not immune to the wider factors which influence practice (Manthorpe et al., 2013). Analysis of the findings highlights that practice was influenced by the wider organisational context in which participants carry out MCA assessments. Social work has been noted as being situated within settings influenced by the forces of managerialism (Webb, 2023). Managerialism here refers to the developments in public services that saw great amounts of attention given to organisational outcomes and outputs, and the processes to achieve them with managers put in place to ensure these are achieved. In social work settings managerialism has seen the promotion of technical rationality above professional skills and professional discretion (Evans and Harris, 2004). The pursuit of managerialism in social work organisations has been linked to wider neoliberal practices (Lawler, 2013) that intentionally cast social care services as best operating according to free market principles and include an uncritical emphasis on efficiency, cost saving measures and consumerism (Lawler, 2013; Alcock and Gregory, 2022). In adult social care teams, where most MCA work occurs, managerialism has been found to negatively affect social workers and the people whom they work with under the MCA (Manthorpe et al., 2013b). This research study's findings point out that managerialism can lead to pressure to increase work capacity and time-related targets (Jayes et al., 2020). The participants in this study suggested that they resisted pressures to meet time-related targets because they valued the time spent with people with YOD and they saw these processes as contributing to successful assessments. For people who are on the receiving end of MCA assessments, in this case those with YOD, managerialism can be argued at best to increase procedural rights but it fails to promote social citizenship rights (Boyle, 2008) which refer to access to services and inclusion in social activities (Bartlett, 2022).

8.7. Conclusion

This chapter has detailed and analysed the key messages from the research study exploring the participants' MCA decision making. The chapter has sought to do this by addressing each of the research questions outlined in Chapter One. In doing this the chapter has linked to evidence drawn from the earlier chapters including the Literature Review, the Legal and Policy Contexts chapter and the Conceptual Framework chapter, as well as drawing on wider literature related to MCA decision making. Incorporating all these ideas has brought attention to where the research study converges with existing research and literature as well as where there are differences. To help to visualise the key issues that the findings have drawn attention to Figure has been developed. Figure 8 displays four of the five main findings from the research study illustrating how they connect together to inform social worker decision making.

Figure 8: Findings of the research study



Findings

- Awareness of MCA
- Getting to know the person
- Communication
- Person centred approaches
- Using tools in MCA DM

Social work decision making processes

Context of Social work decision making

- Covid 19
- Setting of MCA decision making
- Time constraints

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Typology of social worker MCA decision making

- Procedural approach
- Medicalised approach
- Creative approach
- Shared approach
- Positive risk approach
- Rights based approach

Collaborative decision making

- Collaborative work with professionals
- Collaboration with families and carers
- Collaboration with community orgs

The findings affirm that MCA decision making is not a standalone activity for the participants in this study. It occurs within a social, economic and organisational context (Clough, 2015; Taylor, 2016). This was made apparent by participants in their discussion of time constraints on their MCA assessment and decision making and highlights how neoliberal managerialist policies have permeated adult social care services, shaping the everyday practice of MCA decision making for them. In the findings this came through most clearly in relation to time constraints on MCA decision making but can also be evident in relation to approaches to risk which is found in medical terminology which individualises YOD.

The chapter has connected the messages from the findings to existing literature on YOD. This relates to how YOD, like LOD, has been conceptualised as primarily an individual medical problem and contributes to the perpetuating marginalisation and stigmatisation, which participants were able to recognise as occurring in their MCA work. What has been noted here is that inequality has a definite bearing on the lives of people who have YOD (Giebel et al., 2021) and was found to be a real issue for participants in their decision making and wider MCA work and that theoretical tools like intersectionality can be helpful for participants in addressing the complexities of inequality and stigma. Within this chapter a typology of how participants use the MCA to make decisions has been examined. The different approaches that make up the typology reveal the complex nature of MCA decision making for social workers (Beale et al., 2022). These processes are multi-layered and are shaped by professional, legal and medical ideas. Analysis of the data from the study has drawn out new areas of scrutiny for participants in MCA decision making. The discussions around positive risk approaches within their MCA decision making are one example of an aspect of social worker MCA decision making not previously explored in research. Positive risk approaches present a different way for social workers to understand risk in their MCA decision making. Discussions linked to risk in MCA work have revealed that there can be a wider motivation to manage and alleviate harm to people (Blood and Wardle, 2018). The participants in this study were attentive to these themes and opted on occasion to pursue positive risk approaches to promote the autonomy of people with YOD.

Analysing the data from the study highlighted some surprises for me. These include the different levels of understanding that the participants had in relation to YOD as part of their MCA work. In preparing the semi-structured interviews it was assumed that all of the people participating in the study would have existing experience and awareness of YOD. The analysis identified that there was a variety of understandings of YOD including the idea that it relates to early-stage dementia. This may suggest that knowledge and awareness of YOD amongst social workers are likely to vary and cannot be assumed. This may also suggest that the messages from other studies such as Rabanal et al. (2018) and Ottaboni et al. (2022) that indicate a need for further training and awareness raising around what YOD is as well as the experience of YOD are also relevant for social workers. As well as unanticipated findings this chapter has explored findings that diverged from previous studies such as participants' knowledge of the law. Many studies noted that social workers have variable knowledge whereas this study noted the participants were confident in applying the MCA principles, the process of MCA assessment and Best Interests decision making guidelines. This may suggest that over the course of time and through training, social workers are becoming more familiar with the MCA.

Chapter 9: Conclusions

9.1. Introduction

This chapter brings the work to a conclusion by revisiting the initial aims and objectives and confirming how they have been achieved. A summary of the main findings are outlined and how these findings contribute to knowledge on social work practice and MCA work, as well as the insights the research study brings to light regarding social work practice with people who have YOD. To establish the contribution that the research study makes this chapter will discuss the implications the study has for social work practice and policy. Here suggestions are made on the practice responses that social workers can make in light of the research findings as well as suggestions for those involved in shaping MCA policy. As well as the clear strengths of the study a number of limitations are also identified. Lastly, based on the key messages from the study's findings there is a discussion of areas for future research.

At the outset my overall research question was: 'How do social workers use the MCA to assess and make decisions in the context of their practice with people with YOD?' I initially set out with the aim of exploring social work practice decision-making so as to better inform social work theory, policy, and practice. The aim was articulated further through objectives, which at the starting point of the work were:

To better understand how social workers make decisions for people with YOD using the MCA.

To review existing knowledge around social work decision making in relation to MCA work and with people with YOD.

To explore frameworks for understanding how social workers engage in assessment and decision making for people with YOD.

The process of completing this study included undertaking a literature review exploring MCA decision making and social work, YOD and decision making and social work practice and YOD. The literature review highlighted key messages drawn from existing research which provided the impetus for designing and carrying out the research study. Reviewing existing knowledge around social work decision making concerning MCA work and also examining literature related to social work with people with YOD found that few studies highlight ways in which social workers engage in decision making when they use the MCA, and where there are studies they tend to look across a range of professional groups. The review of literature about social work and YOD revealed similarly few studies noting the perspectives and practices of social workers with the cohort of people who have dementia. From this, an original research study was designed to explore how social workers use the MCA in assessment and decision making in the context of their practice with people with YOD.

The study adopted a qualitative grounded theory approach, using semi-structured interviews as a method to gain insights from social workers. A total of 17 social workers participated in the online Zoom-based interviews. Transcripts from the interviews were analysed using a grounded theory method drawing out novel themes which were outlined in Chapter Seven. These findings were analysed taking into account existing knowledge and literature in a discussion of social work mental capacity assessment and decision making and YOD. The study explored social work decision making drawing on the conceptual frameworks of social constructivism and decision making theory, which helped to draw attention to the meanings that social workers give to their practice using the MCA.

9.2. The main findings from the research study

The main findings from the research study are outlined below. The first finding to note is that social worker MCA decision making is multi-faceted. The ways that social workers make decisions using the MCA can be categorised within a typology which identifies a range of approaches in decision making that social workers in the study used as part of their MCA work with people who have YOD. These are ‘procedural’, ‘medicalised’, ‘creative’, ‘shared’, ‘positive risk’ and ‘rights-based’ approaches. Of the approaches that the research study highlighted, some are novel and evidence little or no discussion in other studies exploring mental capacity decision making. The approaches that were new and not found elsewhere are positive risk approaches and medicalised approaches.

Within MCA work with people who have YOD the importance of social workers' understanding of YOD alongside other types and subtypes of dementia has been highlighted. Like dementia at any age, YOD is complex because it sits at the intersection of age, disability and social citizenship in society (Tolhurst, 2016). From this study an understanding of YOD including the factors linked to age, diagnosis, inequality and the stigma experienced by people with YOD is suggested as being influential for social workers in their MCA decision making practice. Understanding and recognition of YOD can be constructed as a life course matter, where YOD is framed as dementia occurring within the mid-life stages of adulthood that holds many similarities to dementia in later adult life (Tolhurst, 2016) but also includes unique experiences and needs.

Social worker MCA assessment and decision making involves a set of processes. These processes are shaped by a knowledge of the MCA and include using person-centred and relationship-based approaches as well as the use of tools, such as photographs, physical money and brochures to support MCA assessment and Best Interests decision making. Social workers use various tools to maximise engagement in MCA decision making. Importantly for social workers, processes like person-centred and relationship-based approaches are supportive of maintaining the dignity, and wider rights of people with YOD.

Social worker assessment and decision making is shaped by their collaborative practice with other professionals, immediate or extended family members and carers and community organisations. My study has indicated that collaborative decision making in the context of MCA work can be complex, uncertain and challenging. However, the study has also evidenced that collaborative decision making is valued by social workers as providing necessary support to people with YOD, their families and carers as well as contributing to the individual's wider rights and social citizenship.

9.3. Contribution of the thesis

The MCA was implemented in April 2007 and has been promoted as a visionary piece of legislation for its time (House of Lords, 2014; Alghrani et al., 2016; Aspinwall-Roberts et al., 2022). The MCA principles and values have been adopted by a range of professionals including social workers (Iliffe et al., 2015) yet, despite this, the MCA has in the past been criticised as not being embedded into the everyday practice of health and social care professionals (House of Lords, 2014). This study confirms existing literature highlighting the complex nature of MCA decision making (Brown, 2023; Braye et al., 2011; Williams et al., 2012b; Scott et al., 2020), recognising that it is shaped by a mix of legal, medical and relational approaches (Clough, 2015). For social workers, the MCA is a core part of their practice with adults and is embedded into their pre- and post-qualifying training in line with the Professional Capabilities Framework (Beddow et al., 2015).

At the outset I set out to explore how practising social workers use the MCA to make decisions. The research highlights that social workers use the MCA in different ways to assess and make decisions in the context of working with people with YOD and makes important contributions to social work practice in the area of MCA work and practice with people with YOD. At the time of writing up this research study, there were few studies found that had explored how social workers engage in MCA decision making. In light of the context of a lack of research exploring social worker engagement in MCA decision making this study presents original data that contributes to knowledge about MCA decision making by social workers. Its focus on practice with people who have YOD has highlighted key challenges for social workers in MCA work when they work with people with dementia, a group of people with disability whose rights have historically been neglected (Dixon et al., 2022). The research makes five clear contributions to knowledge, as follows:

The first contribution to be noted here is that this work draws attention to distinct approaches that social workers use in their MCA work presented as a typology of MCA decision making in Chapter Eight. Within the typology new understandings about decision making have been added to the body of knowledge. These include positive risk approaches in MCA decision making with people who have YOD. Positive risk changes the focus of risk work from exploring deficits to considering strengths (Willis et al., 2022; Blood and Wardle, 2018) and as an approach in MCA decision making it offers social workers a way to explore risk in an empowering way (Dixon, 2023). Positive risk approaches were not found in other research studies on MCA decision making, although discussions of positive risk are noted in adult social care studies connected to safeguarding (Dixon, 2023) and integrated teams (Willis et al., 2022). Positive risk approaches therefore can be recognised as a viable aspect of MCA work and together with the other approaches noted in the summary of the findings, they highlight a message that decision making using the MCA is pivotal to maintaining the autonomy and independence of people with dementia (McDonald, 2010; Murrell and McCalla, 2016; Williams et al., 2014). The way in which social workers go about their MCA decision making is therefore of great significance to the social work profession and should continue to be examined to provide insights to support practice.

The second contribution made by this work relates to contextual issues in social work MCA decision making. The study illuminates how social workers went about using the MCA amidst the challenges caused by the Covid 19 pandemic, where huge strain and stress were felt within health and social care services and by people with dementia (Giebel et al., 2022; Kuylen et al., 2022). The research identifies an understanding of how social workers responded to the unanticipated changes during the Covid 19 pandemic. The public health response to Covid 19 included national and local lockdowns, the requirements for those believed to be at high risk to shield away until August 2020, social distancing and the use of personal protective equipment (PPE). These were all measures mandated or endorsed by government during the Covid 19 pandemic (Tuijt et al., 2021; Jayes et al., 2021; Giebel, et al., 2022; Ruck-Keene, 2020b). Of particular note and importance for social workers in this study was the change to virtual MCA work and the perspectives of how working virtually impacted their MCA decision making. In collecting the qualitative accounts of social workers this study therefore contributes to the small body of knowledge on virtual MCA decision making, informing social workers of the opportunities and challenges encountered when face to face MCA work is restricted. Virtual MCA practice appears to be continuing since the Covid 19 pandemic and the first-hand accounts of social workers tell us that virtual MCA decision making can be problematic. The insights from social workers about their practice during the Covid 19 pandemic sit alongside other studies that have drawn attention to how the Covid 19 pandemic changed professional practice, for example, Jayes et al. (2021), Giebel et al. (2021) and Tuijit et al. (2021). This study like others then provides evidence that contributes to the lessons to be learned from the responses to the pandemic, which are currently being examined by the UK Covid-19 Inquiry and can provide a blueprint for guidelines on responding in future pandemics.

The third contribution from this study can be seen in the processes social workers engage with in MCA decision making. The research findings draw attention to the core activities and skills social workers use when carrying out MCA assessments and making Best Interests decisions under the MCA and detail the perceptions and practices of social workers involved in supporting people with YOD in relation to mental capacity work. The different ways in which social workers go about MCA work have been illuminated, including how social workers in their MCA work develop a robust understanding of people, their strengths and abilities, and use person-centred and relational approaches in their mental capacity work. Together these findings form a robust guide to how social workers can engage in MCA decision making. They connect directly to findings and recommendations from the post-legislative scrutiny of the MCA carried out by the House of Lords Select Committee in 2014 that cited a lack of consistency in MCA assessment as a concern (House of Lords, 2014; Rogers and Bright, 2019) and the need for greater attention to the MCA and promoting best practice through raising awareness (House of Lords, 2014). Furthermore, analysis of the research study draws attention to the use of tools and resources by social workers to support their assessment and decision making. Within the Discussion Chapter, it was noted that there was a lack of guidance and evaluation of the tools used in MCA assessment and Best Interests decision making.

The fourth contribution relates to social work practice with people with YOD. Looking specifically at social work practice with people with YOD, the research study reveals the importance of social workers in their MCA work to understand YOD within the wider discourse of dementia. Aspects involved in understanding YOD include an awareness of the complexities of YOD linked to age, disability, and stigma. Analysis of these findings led to suggestions that intersectional approaches can be useful for examining the complexities of YOD and to gain a clearer awareness of how the interlocking systems of oppression which consist of both privilege and disadvantage affect practice with those who experience YOD.

This research study has drawn attention to YOD as a neglected discourse for social workers. As such it has been recognised that there is a complexity when exploring YOD that involves the overlapping discourses of ageing and dementia. It has been pointed out that a life course perspective is suitable for social workers in developing their understanding of YOD as it supports social workers in drawing attention to the individualised experiences, the wider social factors and interactive issues people who have dementia experience throughout their lives (Tolhurst, 2016) as part of their decision making and in turn avoids perpetuating the discriminatory and exclusionary practices linked to ageing and dementia that emphasise difference (Tolhurst, 2016). In this way, my research in exploring social work practice with YOD contributes positively to policy discussions on ageing and seeks to improve the experience of people with dementia across the whole life course as well as their family and carers. Therefore, the emphasis of this research study has not been to stress YOD as a category separate from LOD but to explore the relevance of understanding YOD in social work practice. The findings draw attention to key issues for social workers in their MCA work when working with people with YOD and the issues raised may also apply more widely to social work practice with people who have YOD, such as in terms of need and eligibility assessments under the CA and safeguarding processes under Section 42 of the CA.

Linked to the previous point is the need for greater attention to developing suitable services for people with YOD, especially at a local commissioning level (Mayrhofer et al., 2021; Carter et al., 2018). The invisibility of YOD in commissioning policy and practice discussions has been cited as contributing to the stigma attached to the experience of YOD and exacerbating the inequalities experienced by people who have YOD (Mayrhofer et al., 2018; Rabanal et al., 2018). Similarly, the lack of attention paid to post-diagnostic services for people with YOD has been highlighted as inadequate (Oyebode et al., 2023; Mayrhofer et al., 2021; Stamou et al., 2022a).

Finally, the contribution of this research to social work includes adding to the knowledge about collaborative practice for social workers within MCA work. Social workers as part of their MCA work collaborate with a range of professionals and also with family members, carers and with community organisations that meet the health and social care needs of people with YOD. The distinctiveness of collaborative practice for social workers in their MCA practice has been drawn out in this study. It has recognised that alongside the guidelines that encourage collaboration such as the MCA Code of Practice (2007), social workers are positive about collaboration as part of their practice, recognising the benefits for themselves and people with YOD they work with. This study has highlighted that social workers see collaborative working as offering many benefits but also challenges linked to professional differences. This therefore reinforces that social workers have a lot to offer with regard to collaborative working in their MCA work and they are able to draw on core skills of personal-centred approaches and relational approaches to work alongside others in their MCA work (Brown, 2023).

9.4. Implications for policy

Having outlined the contributions made by this research the focus turns to what these mean for social work policy and practice. Chapter Eight illuminates the key role social workers have in supporting the rights, autonomy and social citizenship of people with YOD. Gaps in MCA policy such as the backlog of DoLS assessments have revealed that the rights of people who have dementia and need residential care can be compromised (Clough, 2015; Harding, 2012). Current policy developments for the MCA include uncertainty around whether the plans for the LPS detailed in the 2019 Mental Capacity Amendment Act (MCAA) will be implemented. Government plans to implement the LPS by April 2022 were interrupted due to the impact of the Covid 19 pandemic (Spencer-Lane, 2023). On the 5 April 2023 the Department of Health and Social Care announced that the implementation of the LPS would be delayed beyond the life of the current parliament mandating that the existing DoLS system should continue to be used by health and social care services (Department of Health and Social Care, 2023). The delay in the LPS implementation has direct relevance to the wider MCA. One example of how the MCA is relevant is that part of the government's plans to implement the LPS involved amending the MCA Code of Practice (2007) to ensure it reflects the changes embedded in the MCAA (Spencer-Lane, 2023). The MCA Code of Practice (2007) in its current form is outdated and no longer relates to current MCA practice which over several years has been updated by case law (Ruck-Keene, 2023). The planned changes to the MCA Code of Practice included statements recognising social and psychological interests alongside medical interests but these and other changes to the MCA Code of Practice have since the announcement in April 2023 been placed on hold (Spencer-Lane, 2023) and it is unclear when a new MCA Code of Practice will be published by the government (Skowron, 2023). This tells us that for now there continue to be deficits and uncertainty in MCA policy which directly affect all those using the MCA, including social workers. The response to the delays has seen concerns raised that the human rights of people who fall under the provisions of the MCA will not be fully upheld until the planned updates to the MCA Code of Practice (2007) and LPS are made (BASW, 2023; Joint Committee on Human Rights, 2023). This study's findings remind us that, amidst the uncertainty around the implementation of the LPS and the updates to the MCA Code of Practice (2007), it remains important for MCA policy and practice to continue to seek ways to uphold the human rights of people who may lack capacity (Clough, 2015). MCA policy updates need to reflect the core principles of autonomy and the empowering of people which were at the heart of the MCA (Clough, 2015).

Within the study's findings it has been acknowledged that social workers frequently use the MCA to assess and make decisions (Ariyo et al., 2021). Insights from the findings can be beneficial to social workers and policy makers within health and social care organisations. The research study draws attention to the social workers' use of tools or resources as part of their MCA work. NICE's (2018b) has recommended a need for a clear identification of tools that support MCA assessment and decision making. This is endorsed by the discussions in this study that suggest that social workers can benefit from being able to put a name to resources they can use as part of the MCA work. Practically, this can be arranged at an organisational level, where the organisation provides guidelines around tools and resources that support MCA decision making that can be of great benefit to social workers. Chapter Eight of this research study confirms that evaluation of the use of tools can be useful for understanding which tools are effective in MCA work (Jayes et al., 2020) and a straightforward way to go about this is to collect the feedback of practitioners using the tools.

Moving to look at the implications connected to MCA work with people who have YOD, by 2030 more than one in five people in the UK will be over the age of 65 years (WHO, 2023a) and indications are that one in 11 people over 65 years currently have dementia (Alzheimer’s Research UK, 2023b). Recent research reveals that the number of people being identified as living with YOD is increasing (Hendrick et al., 2022; Carter et al., 2022). Chapter Three confirms that there is a lack of post-diagnosis community support services for people who have YOD (Oyebode et al., 2023; Carter et al., 2022; de Vugt and Carter, 2022; Stamou et al., 2022; Mayrhofer et al., 2021) and it has been found that the Covid 19 pandemic saw many volunteer-run community-based services close down due to a lack of staff and funding (Giebel et al., 2021). The provision of community services connects directly to Best Interests decision making where the presence of community services can bolster options for social workers in their decision making practice.

9.5. Implications for social work practice

Social work with people who have dementia is an emerging area of practice (Manthorpe, 2014; Scourfield, 2023) and, as greater attention is given to the experiences and needs of people with dementia of all ages, practice knowledge for social work will need to increase. Chapter Seven outlined that a key theme in social worker perspectives was the importance of understanding and awareness of YOD and how it affects the lives of people and the wider families and carers. Although awareness of younger people with dementia is growing (Rabanal et al., 2018) evidence from this research study confirms that there remains a notable lack of understanding of who is affected by YOD. For social work, an understanding of YOD is crucial in attempts to support the rights of people with YOD in their MCA assessment and decision making processes. From the findings of my study it can be suggested that social workers could benefit from training on understanding YOD in the context of their MCA work. This could be part of broader training in using the MCA when working with people with dementia. Included in such training should be detailed information about how structural inequalities and stigma can affect the lives of person with YOD and their family and carers. Training and development can be aligned to the practice experience of social workers. At the pre-qualifying level, the teaching of social work students could include education and skills training that raises their awareness of YOD which are the key skills linked to working with YOD. Post-qualifying training for social workers could explore YOD as part of the MCA assessment processes detailing the skills social workers need in assessment and Best Interests decision making. It is recognised that many studies exploring the use of the MCA have noted the need for social workers to engage in further training, for example, Scott et al. (2020), Manthorpe and Samsi (2013) and (2016b), Boyle, (2008), MacDonald (2010), Murrell and McCalla (2016), Jayes et al. (2020) and Brown (2023) all note the need for additional practitioner training linked to the MCA. As a response to the recurring messages for more training on the MCA, I suggest that training alone may not be enough to draw out the issues and it may be beneficial for social work practitioners to use line management or group supervision processes to explore the experiences of using the MCA in practice with people who have YOD.

A second area where the study raises implications for social workers is concerning rights based approaches. Rights-based approaches were discussed as a way in which social workers engage in decision making. The rights-based approach seeks to promote wider human, social and cultural rights of people within MCA work and correlates with the philosophy of autonomy which is at the core of the MCA (Clough, 2015). Practical ways in which social workers can promote rights-based approaches have been noted in Chapter Eight. These include the use of advocacy to ensure that the views and wishes of the person being assessed under the MCA are represented in decision making. However, in the MCA work the criteria for selecting an IMCA has been found to be narrow and the role of the IMCA has been found to be under used (Gordon, 2015; Dixon et al., 2022). Within rights-based approaches legal directives like the CRPD have been noted as a positive development which supports a social model (Clough, 2015; Brown, 2023). The perspectives of social workers in this study did not include any reference to the CRPD and although this does not suggest social workers are unaware of the CRPD, it does indicate that there may need to be a better grasp of the CRPD and its principles. The CRPD principles align well with social work values and ethics (Brown, 2023), so support the advancement of the social rights of people with dementia (Clough, 2015).

9.6. Strengths and limitations

All research has strengths and limitations in relation to its design and execution. This research study captured the first-hand accounts of social worker practitioners who use the MCA, then analysed them using a grounded theory approach which produced rich findings. The social workers shared their perspectives and experiences of MCA assessment and decision making which accounted for many hours of data collected, which is a strength of the study. However, the study relied on what social workers said during the interview rather than observing their decision making practice using the MCA, which arguably could have provided a different way to understand social worker decision making. The reasons for not including an element of observation within the study are discussed below.

The collection of data for this research study was affected by factors outside of my control as the researcher. The most influential of these was the Covid 19 pandemic between March 2020 and March 2022 when I was undertaking my fieldwork. As noted in earlier chapters, the Covid 19 pandemic caused significant disruption to health and social care services, including national and regional lockdowns, social distancing restrictions (Department of Health, 2021b) and periodic advice to work from home. It also caused substantial disruption to my research plans, requiring methodological agility to ensure data could still be collected in the time allocated. Chapter Five details that part of the original plan for exploring how social workers engage in MCA decision making was to include an ethnographic element. Ethnographic approaches have been credited as providing a useful account of everyday experiences and interactions (Smith, 2009). For this study it would have involved accompanying and observing social workers in their day-to-day environments discussing MCA assessments and decision making. This was a planned component of the research study, but it was not possible to carry it out due to the timing of fieldwork coinciding with the national lockdowns and restrictions which affected access to social workers, meaning that alternative ways of collecting data had to be considered.

The findings from this research study have been outlined as beneficial to social work practice and policy as well as to other professions working with YOD. It should, however, be noted that whilst the study produced rich data and valuable insights into the perspectives of social workers, the relatively small size of the sample, consisting of 17 social workers from specific regions of England may reduce the generalisability of the findings to all settings. Similar studies exploring social worker decision making carried out in different regions may be useful to clarify if there are regional differences.

The thesis engaged in a research study exploring the perspectives of social workers in the context of their practice with people who have YOD. Since its focus was on social work practice, the voice of people with the lived experience of YOD was not part of the research study. This may be argued to represent a limitation. There is emerging research and writing about dementia in which the voice of people with YOD is being foregrounded (Clemerson et al., 2014) and seen as vital to the development of the dementia discourse (Rabanal et al., 2018; Roach et al., 2008) but capturing the perspectives of people with lived experience was not an aim of this study. However, it is acknowledged that the involvement of people with YOD can offer many benefits to researchers and could be used to illuminate the practice and policy domains. This was a finding in Mayrhofer et al. (2020) in which people who have YOD were co-opted into the research to assess the authenticity of their research findings. Future research on social work decision making that includes the perspectives of people with lived experience and their families has the potential to draw out different perspectives.

9.7. Future research

The perspectives of social workers in the research study drew attention to the settings where social workers carried out their MCA decision making. The study did not focus on specific settings in relation to where social workers carried out MCA work. Some social workers spoke about their MCA work in care homes or people’s own homes but there was not enough data captured to evidence any findings on whether the setting of MCA assessment and decision-making holds any significance. The settings within which social work MCA decision making occurs have been posited in other studies as being useful for understanding how professional decision making is influenced, for example, Manthorpe and Samsi (2016b), (Murrell and McCalla (2016) and Jayes et al. (2020) all mention how the setting had a role in the way MCA practice is carried out. Going forward further examination exploring how settings influence social worker MCA decision making may reveal further ideas about the nature of social worker decisions as part of their MCA work.

Linked to settings where MCA decision making occurs is the wider context. Here the research identified how the Covid 19 pandemic affected MCA work. Within the discussions with social workers about MCA decision making the conversations related to how their decision making changed during the Covid 19 pandemic were of significant interest. Chapter Eight highlights that as a result of the Covid 19 pandemic practice across health and social care changed from face to face to virtual (Giebel et al., 2021). This study drew attention to the perspectives of social workers who indicated a preference for face to face MCA work. Evidence that virtual MCA work continues to happen after the Covid 19 pandemic (Jayes et al., 2020) suggests there may be other motivations for virtual MCA work continuing. Further research could explore instances where virtual MCA work is still happening and explore the usefulness of virtual work as a relatively new approach to practice for social workers using the MCA.

MCA decision making has been identified in this study as often being a collaborative activity. The study focused on one professional group in terms of its practice with YOD and it cannot be assumed that the same themes would arise in other professional groups. As part of the discourse about how social workers collaborate with other professionals a clearer awareness of the views of different professionals in collaborative MCA decision making could be of benefit. Looking forward future research needs to be carried out to enhance our understanding of the role and contributions of people with YOD in MCA decision making. This question has been beyond the scope of this study, although remains salient to fully grasp all dimensions of decision making for people with YOD.

9.8. Personal Reflections

In Chapter One, I shared my motivations for embarking on this exploration of MCA decision making, which highlighted my practice and personal experiences of dementia. Throughout the process of starting, carrying out the research study and writing up I have been able to reflect on my initial assumptions, which were shaped by my practice and personal experiences.

At the outset, there was an assumption about the awareness of social workers with regard to mental capacity work and dementia. This idea was based on social workers' knowledge and awareness about dementia across all ages being more developed and was perhaps based on my own distant social work practice experiences in using the MCA. It has been encouraging to design, lead and execute a study that has included exploring perspectives of social workers who are confident about their use of the MCA, as well as to hear the challenges that arise when undertaking MCA work with people who have YOD. The process of completing this research study has revealed clearly that dementia at any age brings significant challenges. These reflections have led me to appreciate the complexity found in MCA decision making processes. The research study has been a reminder that the MCA is embedded with a range of assumptions: medical, legal, structural, social and psychological and it is the awareness of these that influences decision making.

Bibliography

Abdi, Z. and Burns, A. (2012) ‘Championing of dementia in England’, *Alzheimer's research and therapy,* 4(5), *pp.36. doi: 10.1186/alzrt139.*

Abrams, R. C., Ansell, P., Breckman, R., Karlawish, J., Lachs, M., Holt-Knight, D., Needell, N., Rogers, G., & LoFaso, V. (2019) ‘The Interview for Decisional Abilities (IDA): A tool to assess the decisional capacity of abused and neglected older adults’, *Journal of Elder Abuse & Neglect, 31*(3)*, pp. 244–254. https://doi.org/10.1080/08946566.2019.1573392*

Ahmed, T.F., Ahmed, A. and Imtiaz, F. (2021) 'History in perspective: How Alzheimer's disease came to be where it is?', *Brain Research,* 1758, *pp. 147342. Doi 10.1016/j.brainres.2021.147342.*

Akesson, B., Braganza, M. and Root, J. (2018) ‘Is theory development essential for the social work dissertation?’, *Social Work Education, 37(2), pp. 209-222. Doi: 10.1080/02615479.2017.1391196*.

Akpan, V., Udodirim A.I., Ikechukwu B., Mampah, I. & Okoro, C. (2020) ‘Social constructivism: Implications for teaching and learning’, *British Journal of Education, 8(8), pp.49-56.*

Alcock, P. and Gregory, L. (2022) *Social Policy in Britain.* 5th edition. London: Bloomsbury

Alfandari, R., Taylor, B.J., Baginsky, M., Campbell, J., Helm, D., Killick, C., McCafferty, P., Mullineux, J., Shears, J., Sicora, A. and Whittaker, A. (2023) ‘Making Sense of Risk: Social Work at the Boundary between Care and Control’, *Health, Risk & Society, 25(1-2), pp. 75-92. Doi: 10.1080/13698575.2022.2147904.*

Alghrani, A., Case, P., & Fanning, J. (2016) ‘Editorial: The Mental Capacity Act 2005-Ten Years On’, *Medical law review, 24(3), pp.311–317. https://doi.org/10.1093/medlaw/fww032*

Alston, M. and Bowles, W. (2013) *Research for social workers. An introduction to methods.* 3rd Edition. London: Routledge.

Alzheimer’s Disease International (2016) *Dementia-friendly communities’ key principles*. London: Alzheimer’s Disease International. Available at: https://www.alzint.org/u/dfc-principles.pdf (Accessed: 19/09/2023).

Alzheimer’s Research UK (2023a) *Alzheimer's disease.* Available at: https://www.alzheimersresearchuk.org/dementia-information/types-of-dementia/alzheimers-disease/ (Accessed: 10/07/2023).

Alzheimer's Research, U.K. (2023b) *Statistics about dementia.* Available at: https://dementiastatistics.org/about-dementia/ (Accessed: 29/07/2023).

Alzheimer's Research, U.K. (2023c) *Young Onset Dementia.* Available at: https://www.alzheimersresearchuk.org/dementia-information/types-of-dementia/young-onset-dementia/ (Accessed: 19/06/2023).

Alzheimer’s Society (2016) *Dementia Report UK 2017*. [Online:] available at: https://www.alzheimers.org.uk/about-us/policy-and-influencing/dementia-uk-report (accessed March 2018)

Alzheimer’s Society (2019) *Hidden No More: Dementia and disability. All-party parliamentary group on dementia.* Available at: https://www.alzheimers.org.uk/about-us/policy-and-influencing/2019-appg-report (Accessed: (10/07/2023).

Alzheimer’s Society (2020) *Worst hit: dementia during coronavirus.* Available at: https://www.alzheimers.org.uk/sites/default/files/2020-09/Worst-hit-Dementia-during-coronavirus-report.pdf (Accessed: 01/12/2023).

Alzheimer's Society (2023) *What causes dementia?* Available at: https://www.alzheimers.org.uk/about-dementia/types-dementia/what-causes-young-onset-dementia (Accessed: 10/07/2023).

Andrews, E.S. (2017) ‘Institutionalising senile dementia in 19th-century Britain’, *Sociology of health & illness, 39(2), pp. 244-257.* doi: 10.1111/1467-9566.12452.

Ariyo, K., McWilliams, A., David, A.S. and Owen, G.S. (2021) ‘Experiences of assessing mental capacity in England and Wales: A large-scale survey of professionals [version 1; peer review: 2 approved]', *Wellcome Open Research,* 6(144) *doi: 10.12688/wellcomeopenres.16823.1.*

Ariyo, K., Kane, N.B., Owen, G.S. and Ruck Keene, A. (2023) ‘Interpersonal influences on decision-making capacity: a content analysis of court judgments’, *Medical Law Review, pp.1-30. doi: 10.1093/medlaw/fwad017.*

Arnstein, S. (1969) ‘A Ladder Of Citizen Participation’*, Journal of the American Institute of Planners, 35(4), pp. 216-224.* doi: 10.1080/01944366908977225

Ash, E.L. (2014) ‘What is Dementia?’, in Foster, C., Herring, J. and Doron, I. (eds.) *The Law and Ethics of Dementia*. 1st edition. London: Hart Publishing, pp. 3-14.

Aspinwall-Roberts, E., Fleming, V., Khatri, R., & Jones, P. A. (2022). ‘'They don't want them to have capacity': Multi-agency operationalisation of the Mental Capacity Act 2005 in England with adults who self-neglect, *Health & social care in the community, 30(6), e4395–e4404. https://doi.org/10.1111/hsc.13839*

Atkins, E.R., Bulsara, M.K. and Panegyres, P.K. (2012) ‘The natural history of early-onset dementia: the Artemis Project’, *British Medical Journal Open,* 2(5). doi: 10.1136/bmjopen-2012-001764.

Ayalon, L. and Tesch-Römer, C. (2018) *Contemporary Perspectives on Ageism*, Switzerland: Springer Open.

Baldwin, C. (2016) ‘Micro-citizenship, dementia, and long-term care’, *Dementia: The International Journal of Social Research and Practice, 15*(3*), pp.289-303.*

Ballard, K. and Elston, M.A. (2005) ‘Medicalisation: A Multi-Dimensional Concept’*, Social Theory & Health 3(3), pp. 228-241 doi: 10.1057/palgrave.sth.8700053*

Bannon, S.M., Wang, K.E., Grunberg, V.A., Dickerson, B.C. and Vranceanu, A.M. (2022) 'Couples' Experiences Managing Young-Onset Dementia Early in the COVID-19 Pandemic *Gerontologist', 62(8), pp. 1173-1184.*

Banner, N.F. (2012) 'Unreasonable reasons: normative judgements in the assessment of mental capacity,' *Journal of evaluation in Clinical Practice, 18(5), pp. 1038-1044. doi: 10.1111/j.1365-2753.2012.01914.x.*

Banner N. F. (2013). 'Can procedural and substantive elements of decision-making be reconciled in assessments of mental capacity?', *International Journal of Law in context, 9(1), pp.71–86. https://doi.org/10.1017/S1744552312000493*

Banner, N. and Szmukler, G. (2013) 'Radical Interpretation and the Assessment of Decision-Making Capacity,' *Journal of Applied Philosophy, 30(4), pp.379-394.*

Bartlett, P. (2012). 'The United Nations Convention on the Rights of Persons with Disabilities and Mental Health Law,' *The Modern Law Review 75(5), pp.752-778.*

Bartlett, P. (2020) 'At the Interface between paradigms: English Mental Capacity law and the CRPD,' *Frontiers in Psychiatry, 11(5) doi: 10.3389/fpsyt.2020.570735*

Bartlett, R. (2022) 'Inclusive (social) citizenship and persons with dementia', *Disability & Society,* 37(7), *pp. 1129-1145. doi: 10.1080/09687599.2021.1877115.*

Bartlett, R. and O'Connor, D. (2007) 'From personhood to citizenship: Broadening the lens for dementia practice and research', *Journal of Aging Studies,* 21(2), *pp. 107-118. doi: 10.1016/j.jaging.2006.09.002.*

Bartlett, R. and O'Connor, D. (2010) *Broadening the dementia debate: Towards social citizenship.* Bristol: Policy Press.

Beale, C., Lee-Davey, J., Lee, T. and Ruck Keene, A. (2023) 'Mental capacity in practice part 1: how do we really assess capacity?', *British Journal of Psychiatric Advances, pp. 1–9. doi: 10.1192/bja.2022.81.* Available at: https://www.cambridge.org/core/journals/bjpsych-advances/article/mental-capacity-in-practice-part-1-how-do-we-really-assess-capacity/45D8757359FB301730A813F170135E84 (Accessed: 08/08/2023).

Beam, C.R., Kaneshiro, C., Jang, J.Y., Reynolds, C.A., Pedersen, N.L. and Gatz, M. (2018) 'Differences Between Women and Men in Incidence Rates of Dementia and Alzheimer's Disease', *Journal of Alzheimer's disease: JAD,* 64(4), *pp. 1077-1083. doi: 10.3233/JAD-180141.*

Becker, S., Bryman, A., Ferguson, H., & Swift, R. (Eds.). (2012) *Understanding research for social policy and social work 2nd Edition. Themes, methods, and approaches*. Bristol: Bristol University Press. https://doi.org/10.2307/j.ctt1t892hf

Beddow, A., Cooper, M. and Morriss, L. (2015) *A CPD curriculum guide for social workers on the application of the Mental Capacity Act 2005*. Department of Health. Available at: https://assets.publishing.service.gov.uk/media/5a80ccb440f0b62305b8d36f/Pt2_Mental_Capacity_Learning_Accessible.pdf (Accessed: 03/12/2023).

Berchtold, N.C. and Cotman, C.W. (1998) 'Evolution in the Conceptualization of Dementia and Alzheimer's Disease: Greco-Roman Period to the 1960s', *Neurobiology of aging, 19(3), pp. 173-189. doi: 10.1016/S0197-4580(98)00052-9.*

Berger, P. and Luckmann, T. (1966) *The Social Construction of Reality: A Treatise in the Sociology of Knowledge*: New York: Doubleday & Company.

Bergeron, L. R. (1999) 'Decision-Making and Adult Protective Services Workers: Identifying Critical Factors', *Journal of Elder Abuse & Neglect, 10(3-4), pp.87-113, DOI: 10.1300/J084v10n03_05*

Bernard, C. (2021) *Intersectionality for Social Workers: A Practical Introduction to Theory and Practice.* Abingdon: Taylor and Francis.

Blood, I. and Wardle, S. (2018) *Positive risk and shared decision-making.* Social Care Wales. Available at: https://socialcare.wales/cms-assets/documents/Positive-risk-and-shared-decision-making.pdf (Accessed: 18/11/2023).

Boahen, G. (2013) *Ethnicity, learning disability, and the Mental Capacity Act 2005: a social constructionist ethnography of an integrated learning disability service.* PhD thesis submission. Faculty of Health and Social Care. Open University. Submitted 2013. Available at: https://oro.open.ac.uk/54718/ (Accessed: 10/03/2017).

Bogg, D. and Chamberlain, S. (2015) *Mental Capacity Act 2005 in practice: learning materials for adult social workers.* London: Great Britain. Department of Health.

Booth, A., Papaioannou, D. and Sutton, A. (2016) Systematic approaches to a successful literature review. Los Angeles: Sage.

Bosco, A., Schneider, J., Coleston-Shields, D.M., Higgs, P. and Orrell, M. (2019) 'The social construction of dementia: Systematic review and metacognitive model of enculturation', *Maturitas,* 120, *pp. 12-22. doi: 10.1016/j.maturitas.2018.11.009.*

Bottery, S. (2023) Why we should celebrate the birth of social care (but not too much), The Kings Fund, 8 May. Available at: https://www.kingsfund.org.uk/blog/2023/05/75-years-national-assistance-act (Accessed: 02/08/2023).

Bourdieu P, Wacquant L (1992*) An Invitation to Reflexive Sociology.* Cambridge: Polity Press.

Boyle, G. (2008) 'The Mental Capacity Act 2005: promoting the citizenship of people with dementia?', *Health & Social Care in the Community,* 16(5*), pp. 529-537. doi: 10.1111/j.1365-2524.2008.00775.x.*

Boyle, G. (2009) 'The Mental Capacity Act 2005 Deprivation of Liberty Safeguards and people with dementia: the implications for social care regulation*', Health and Social Care in the Community, 17(4), pp.415-422.*

Boyle, G. (2011) 'Early implementation of the Mental Capacity Act 2005 in health and social care', *Critical Social Policy,* 31(3), *pp.365-387. doi: 10.1177/0261018311398781.*

Boyle, G. and Warren, L. (2013) *The social process of everyday decision-making by people with dementia and their spouses.* Impact Report. ESRC. Available at: http://www.esrc.ac.uk/my-esrc/grants/RES-062-23-20 (Accessed: 10/02/2018).

Boyle, G. (2013) ‘Facilitating decision-making by people with dementia: is spousal support gendered?’, *Journal of Social Welfare and Family Law,* 35(2), *pp.227-243. doi: 10.1080/09649069.2013.800290.*

Brammer, A. (2020) *Social Work Law.* 5th edition. Harlow: Pearson

Brannelly, P. (2002) Rights and People with Dementia In Active Ageing: Myth or Reality? Proceedings of the British Society of Gerontology, Conference Available at http://epubs.surrey.ac.uk/id/eprint/828221 (Accessed 29/04/2018)

Braun, V. and Clarke, V. (2021) *Thematic analysis. A practice guide.* London: Sage

Braye, S., Orr, D. and Preston-Shoot, M. (2011) Self-neglect and adult safeguarding: findings from research. Adult Services SCIE Report 46. Available at: https://www.scie.org.uk/publications/reports/report46.asp (Accessed: 1/12/2023).

Braye, S. and Preston-Shoot, M. (2016*) Practising Social Work Law, 4th Edition*. London: Palgrave Macmillan.

Braye, S. and Preston-Shoot, M. (2017) *Learning from SARs: a report for the London Safeguarding Adults Board.* Available at: https://londonadass.org.uk/wp-content/uploads/2014/12/London-SARs-Report-Final-Version.pdf (Accessed: 15/12/2023)

Braye, S. and Preston-Shoot, M. (2020) *The Care Act 2014: Wellbeing in Practice,* 1st ed. London: Learning Matters.

Breden, T.M. and Vollmann, J. (2004) ‘The Cognitive Based Approach of Capacity Assessment in Psychiatry: A Philosophical Critique of the MacCAT-T’, *Health Care Analysis,* 12(4), *pp. 273-283. doi: 10.1007/s10728-004-6635-x.*

Brindle, N. (2015) ‘The Supreme Court and deprivation of liberty: where are we now?’, *British Journal of Psychiatric Advances, 21(6), pp.417-424. doi: 10.1192/apt.bp.114.014290.*

Bringer, J. D., Johnston, L. H., & Brackenridge, C. H. (2006) ‘Using Computer-Assisted Qualitative Data Analysis Software to Develop a Grounded Theory Project’, *Field Methods, 18(3), pp.245-266. https://doi.org/10.1177/1525822X06287602*

Brinkmann, S. and Kvale, S. (2023) *Doing Interviews.* Second edition. London: Sage Publications.

Briskman, L. and Penman, M.L.U. (2012) ‘Respecting Rights’, in Banks, S. and Nøhr, K. (eds) *Practising Social Work Ethics Around the World: Cases and Commentaries*, Abingdon. Routledge. pp.102-141.

British Association of Social Workers (2022) *What is social work?* Available at: https://new.basw.co.uk/about-social-work/what-social-work (Accessed: 10/05/2023).

British Association of Social Workers (2023) ‘BASW responds to decision to delay the introduction of liberty protection safeguards’, BLOG. 13 April 2023. Available at: https://www.basw.co.uk/media/news/2023/apr/basw-responds-decision-delay-introduction-liberty-protection-safeguards (Accessed: 10/12/2023).

Broders, K. and Wiersma, E.C. (2022) 'Creating change: the experiences of women living with young onset dementia', *Disability & Society,* 37(5), *pp.787-808. doi: 10.1080/09687599.2020.1848801.*

Bronstein, L.R. (2003) 'A model for interdisciplinary collaboration', *Social work, 48(3), pp.297-306. doi: 10.1093/sw/48.3.297.*

Brown, C. (2023) 'Towards a 'Social Model' of Mental Capacity for Social Work,*' The British Journal of Social Work,* bcad242, https://doi.org/10.1093/bjsw/bcad242

Brown, C., Johnstone, M., Ross, N. and Doll, K. (2022) 'Challenging the Constraints of Neoliberalism and Biomedicalism: Repositioning Social Work in Mental Health', *Qualitative Health Research, 32(5), pp. 771-787. doi: 10.1177/10497323211069681.*

Brown, R., Barber, P., Martin, D. (2015) *The Mental Capacity Act 2005.* Third edition. London: Learning Matters

Brown, H. (2011) The role of emotion in decision-making, *Journal of Adult Protection,* 13(4), *pp. 194-202.*

Brown, H. and Marchant, L. (2013) Using the Mental Capacity Act in complex cases, *Tizard Learning Disability Review*, 18(2), *pp. 60-69. doi: 10.1108/13595471311315074.*

Brown, J., Kirk-Wade, E., Baker, C. and Barber, S. (2021) *Coronavirus: A history of English lockdown laws.* London: House of Commons Library. Available at: https://commonslibrary.parliament.uk/research-briefings/cbp-9068/ (Accessed: 27/05/2023).

Brown, S. (2015) 'Mental Capacity and Social Policy', in Evans, T. and Keating, F. (eds.) *Policy and Social work*. London. SAGE Publications, *pp. 126- 133.*

Browning, M., Bigby, C. & Douglas, J. (2014) *Supportive decision-making understanding how its conceptual link to legal capacity is influencing the development of practice.* Research and Practice in Intellectual and Developmental Disabilities. Available at: http://dx.doi.org/10.1080/23297018.2014.902726. (Accessed April 2017)

Bryman, A. (2016) *Social research methods.* Oxford: Oxford University Press.

Burns, A. (2016) *Great strides are being made in dementia awareness.* Available at: https://www.england.nhs.uk/blog/alistair-burns-20/ (Accessed: 10/07/2023).

Burns, A., Carter, J. and Isaacs, J. (2017) Tackling the challenges of young onset dementia, BLOG 6 April. Available at: https://www.england.nhs.uk/blog/tackling-the-challenges-of-young-onset-dementia/ (Accessed: 29/04/2023).

Campbell, J., Brophy, L., Davidson, G. and O'Brien, A. (2018) 'Legal capacity and the mental health social worker role: an international comparison', *Journal of Social Work Practice, 32(2), pp. 139-152. doi: 10.1080/02650533.2018.1439458.*

Cantley, C. (2000) Early onset team proves a success, *Journal of Dementia Care,* 8(4*), pp. 10-11*.

Care Quality Commission (2015) Monitoring the use of the Mental Capacity Act Deprivation of Liberty Safeguards in 2013/14

Care Quality Commission (2020) *The state of health care and adult social care in England 2019/20.* London. Care Quality Commission. Available at: https://www.cqc.org.uk/publications/major-report/state-care-201920

Care Quality Commission (2022) *Working within the Mental Capacity Act during the coronavirus pandemic.* Available at: https://www.cqc.org.uk/guidance-providers/all-services/working-within-mental-capacity-act-during-coronavirus-pandemic#:~:text=It%20is%20recognised%20that%20during,and%20in%20upholding%20human%20rights. (Accessed: 19/05/2023).

Care Quality Commission (2023) *About the Mental Capacity Act*. Online: Available at: https://www.cqc.org.uk/help-advice/mental-health-capacity/about-mental-capacity-act (Accessed: 10/04/2023)

Carney, T. (2012) 'Guardianship, "Social" Citizenship and Theorising Substitute Decision-Making Law', *Beyond Elder law, 1(1), pp. 1-17.* Available at: https://doi.org/10.1007/978-3-642-25972-2_1 (Accessed: 03/02/2018)

Carpenter, J., Langan, J., Patsios, D. and Jepson, M. (2014) 'Deprivation of Liberty Safeguards: What determines the judgements of Best Interests Assessors? A factorial survey', *Journal of Social Work, 14(6), pp. 576-593. doi: 10.1177/1468017313504180.*

Carpenter, D. and Brownlee, K. (2017) Constructivism: A Conceptual Framework for Social Work Treatment, in Turner, F. (2017) (ed) *Social Work Treatment. Interlocking Theoretical Approaches.* New York: Oxford University Press

Carter, B. (2010) 'Human rights or social justice', *Journal of Law and Medicine, 18 (1), pp.143-155.*

Carter, J.E., Oyebode, J.R. and Koopmans, R.T.C.M. (2018) 'Young-onset dementia and the need for specialist care: a national and international perspective', *Aging & Mental Health,* 22(4), pp. 468-473. doi: 10.1080/13607863.2016.1257563.

Carter, J.E., Jackson, M. Gleisner, Z. and Verne, J. (2022) 'Prevalence of all cause young onset dementia and time lived with dementia: analysis of primary care health records', *Journal of Dementia Care,* 30(3), pp. 1-5. doi https://journalofdementiacare.co.uk/article/prevalence-of-all-cause-young-onset-dementia-and-time-lived-with-dementia-analysis-of-primary-care-health-records.

Case, P. (2016) 'Dangerous Liaisons? Psychiatry and Law in the Court of Protection—Expert Discourses of 'Insight' (and 'Compliance')', *Medical Law Review, 24(3), pp. 360–378.*

Centre for Ageing Better (2023) *State of Ageing 2023.* Available at: https://ageing-better.org.uk/sites/default/files/2023-12/The-State-of-Ageing-interactive-summary-2023-4.pdf (Accessed:10/12/2023).

Chang, J. (2017) 'Young onset dementia: the benefits of employment', *Journal of Dementia Care,* 25(2), pp. 30-31.

Chaplin, R. and Davidson, I. (2016) ‘What are the experiences of people with dementia in employment?’, *Dementia: the International Journal of Social Research and Practice,* 15(2*), pp. 147-161.*

Charmaz, K. (2008) Constructivism and the grounded theory method. In Holstein, J. A. and Gubrium, J.F. (eds) *Handbook of constructionist research*. New York: The Guilford Press.

Charmaz, K. (2009) Shifting the grounds: Constructivist grounded theory methods for the twenty-first century. In Morse, J., Stern, P., Corbin, J., Bowers, B., Charmaz, K., Clarke, A. (eds) *Developing grounded theory: The second generation.* California: Left coast press.

Charmaz, K. (2012) ‘The power and potential of grounded theory’, *Medical sociology online, 6(3), pp.2-15.* Available at: http://www.medicalsociologyonline.org/resources/Vol6Iss3/MSo-600x_The-Power-and-Potential-Grounded-Theory_Charmaz.pdf [Accessed 04 April 2018]

Charmaz, K. (2014) *Constructing grounded theory.* 2nd edition. London: SAGE.

Chaston, D., Pollard, N. and Jubb, D. (2004) 'Young onset dementia: a case for real empowerment', *Journal of Dementia Care,* 12(6), *pp. 24-25.*

Chemali, Z., Schamber, S., Tarbi, E., Acar, D. and Avila-Urizar, M. (2012) 'Diagnosing early onset dementia and then what? A frustrating system of aftercare resources', *International Journal of General Medicine,* 5, pp. 81-86. doi: 10.2147/IJGM.S26523.

Chirico, I., Ottoboni, G., Linarello, S., Ferriani, E., Marrocco, E. and Chattat, R. (2022) 'Family experience of young-onset dementia: the perspectives of spouses and children', *Aging & mental health,* 26(11), pp. 2243-2251. doi: 10.1080/13607863.2021.2008871.

Chun T., Y., Birks, M. and Francis, K. (2019) ‘Grounded theory research: A design framework for novice researchers’, *SAGE open medicine,* 7, *pp.2050312118822927. doi: 10.1177/2050312118822927.*

Clarke, C. (2011) *Learning Paper on Dementia and Risk.* Available at: https://www.genio.ie/system/files/publications/GENIO_DEMENTIA_RISK_LP.pdf (Accessed: 21/11/2023)

Clerk, G., Schaub, J., Hancock, D. and Martin, C. (2018) ‘A Delphi survey of practitioner’s understanding of mental capacity', *The Journal of Adult Protection, 20(5), pp. 174-186. doi: 10.1108/JAP-05-2018-0009.*

Clemerson, G., Walsh, S. and Isaac, C. (2014) ‘Towards living well with young onset dementia: an exploration of coping from the perspective of those diagnosed’, *Dementia: the International Journal of Social Research and Practice,* 13(4), *pp. 451-466. doi: https://doi.org/10.1177/1471301212474149.*

Clough, B.A. (2015) ‘People like that’: Realising the social model in mental capacity Jurisprudence’, *Medical Law Review, 23(1), pp. 53–80*. https://doi.org/10.1093/medlaw/fwu024

Clough, B.A. (2018) ‘New Legal Landscapes: (Re)Constructing the Boundaries of Mental Capacity Law’, *Medical law review, 26(2), pp. 246-275.* https://doi: 10.1093/medlaw/fwy012

Coffey, A. (2013) Analysing documents. In Flick, U. eds (2013) *The Sage handbook of research methods.* London: Sage. http://dx.doi.org/10.4135/9781446282243

Cooper, B. (2001) Constructivism in Social Work: Towards participative practice viability. *British Journal of Social Work, 31(2), pp.721-738.*

Cosgrove and Williams (2004) *Services for younger people with Alzheimer's disease and other dementias.* London: Alzheimer's Society.

Couzner, L., Day, S., Draper, B., Withall, A., Laver, K.E., Eccleston, C., Elliott, K., McInerney, F. and Cations, M. (2022) 'What do health professionals need to know about young onset dementia? An international Delphi consensus study', *BMC Health Services Research,* 22(14). Available at: https://doi.org/10.1186/s12913-021-07411-2 (Accessed: 10/01/2023).

Craigie, J. (2013) 'Capacity, value neutrality and the ability to consider the future'*, International Journal of Law in Context, 9 (1), pp.4-19.*

Craigie, J. (2021) 'Conceptualising 'Undue Influence' in Decision-Making Support for People with Mental Disabilities'*, Medical Law Review, 29(1), pp.48-79. doi: 10.1093/medlaw/fwaa041.*

Craigie, J., Bach, M., Gurbai, S., Kanter, A., Kim, S,. Lewis, O. and Morgan, G. (2019) 'Legal capacity, mental capacity and supported decision-making: Report from a panel event', *International Journal of Law Psychiatry, 62(2), pp.160-168. doi: 10.1016/j.ijlp.2018.09.006.*

Crenshaw, K. (1989) 'Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics', *University of Chicago Legal Forum,* 1989(1), *pp. 1-31.*

Crowther, N. (2016) *Harnessing the United Nations Convention on the Rights of Persons with Disabilities to improve the lives of persons with dementia*. Dementia Alliance International. Available at: https://dementiaexercise.com/wp-content/uploads/sites/2/2020/04/Harnessing-the-UN-convention-on-the-Rights-of-Persons-with-Disabilities.pdf

Davidson, G., Brophy, L. and Campbell, J. (2016a) 'Risk, Recovery and Capacity: Competing or Complementary Approaches to Mental Health Social Work', *Australian Social Work,* 69(2), *pp. 158-168. doi: 10.1080/0312407X.2015.1126752.*

Davidson, G., Brophy, L., Campbell, J., Farrell, S.J., Gooding, P. and O'Brien, A. (2016b) 'An international comparison of legal frameworks for supported and substitute decision-making in mental health services', *International Journal of Law and Psychiatry, 44, pp. 30-40. doi*: 10.1016/j.ijlp.2015.08.029.

Davies, M., Harries, P., Cairns, D., Stanley, D., Gilhooly, M., Gilhooly, K., Notley, E., Gilbert, A., Penhale, B., & Hennessy, C. (2011). 'Factors used in the detection of elder financial abuse: A judgement and decision-making study of social workers and their managers', *International Social Work, 54(3), pp. 404–420.* https://doi.org/10.1177/0020872810396256

Davis, D.H.J. (2004) 'Dementia: sociological and philosophical constructions'*, Social science & medicine, 58(2), pp. 369-378. doi: 10.1016/S0277-9536(03)00202-8.*

de Vugt, M. and Carter, J. (2022) *Understanding young onset dementia. Evaluation, needs and care.* 1st ed. Oxford: Routledge.

de Vugt, M. and Rose-Marie Dröes, R.M. (2017)' Social health in dementia. Towards a positive dementia discourse', *Aging & Mental Health, 21(1), pp.1-3, DOI: 10.1080/13607863.2016.1262822*

Dementia Alliance International (2016) *The Human Rights of People Living with Dementia: from Rhetoric to Reality.* Available at: https://dementiaallianceinternational.org/assets/2016/05/Human-Rights-for-People-Living-with-Dementia-Rhetoric-to-Reality (Accessed: 01/07/2023).

Dementia Research UK (2023) *About dementia*. Available at: https://demruk.org/about-dementia/ (Accessed: 10/08/2023).

Dementia UK (2023a) *Young onset dementia facts and figures.* Available at: https://www.dementiauk.org/about-dementia/young-onset-dementia/about-young-onset-dementia/facts-and-figures/ (Accessed: 25/03/2023).

Dementia, U.K. (2023b) *Dementia UK. Types of Dementia. Online:* Available at: https://www.dementiauk.org/about-dementia/types-of-dementia/#types (Accessed: 20/06/2023).

Denicolo, P., Long, T. and Bradley-Cole, K. (2016) *Constructivist approaches and research methods. A practical guide to exploring personal meanings.* London: Sage.

Department for Constitutional Affairs (2007) *Mental Capacity Act 2005: Code of Practice*. Available at*: https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice* (Accessed: 10/01/2021).

Department of Health (2000) *No Secrets: guidance on protecting vulnerable adults in care.* Available at: https://www.gov.uk/government/publications/no-secrets-guidance-on-protecting-vulnerable-adults-in-care (Accessed: 03/07/2023).

Department of Health (2007) *Independence, choice and risk. A guide to best practice in supported decision making.* Available at: https://webarchive.nationalarchives.gov.uk/ukgwa/+/www.dh.gov.uk/en/SocialCare/Socialcarereform/Managementofrisk/DH_079297 (Accessed: 01/04/2023).

Department of Health (2009) *Living well with Dementia: The National Dementia Strategy.* London: Department of Health. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf (Accessed: 10/07/2023).

Department of Health (2012) *Prime Minister's challenge on dementia. Delivering major improvements in dementia care and research by 2015.* London: Department of Health. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215101/dh_133176.pdf (Accessed:10/05/2023).

Department of Health (2015a) *Prime Minister's Challenge on Dementia 2020.* (2015) London: Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-dementia2020.pdf (Accessed: 29/04/2023).

Department of Health (2015b) *A manual for good social work practice. Supporting adults who have dementia.* London: Department of Health. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/467401/Office_Dementia_Practice_Guide_Accessible_pdf.pdf (Accessed: 29/04/2023).

Department of Health (2016a) *Prime ministers challenge on dementia 2020. Implementation plan.* London. Department of Health. Available at: https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020/prime-ministers-challenge-on-dementia-2020 (Accessed: 01/02/2018)

Department of Health and Social Care (2016b) *Care and Support Statutory guidance.* Available at: https://www.gov.uk/government/publications/care-act-statutory-guidance (Accessed: 03/04/2018)

Department of Health and Social Care (2021b) *The Mental Capacity Act (2005) (MCA) and deprivation of liberty safeguards (DoLS) during the coronavirus (COVID-19) pandemic.* Available at: https://www.gov.uk/government/publications/coronavirus-covid-19-looking-after-people-who-lack-mental-capacity/the-mental-capacity-act-2005-mca-and-deprivation-of-liberty-safeguards-dols-during-the-coronavirus-covid-19-pandemic (Accessed: 01/12/2023).

Department of Health and Social Care (2023) *Delay to the implementation of the LPS letter.* Available at: https://committees.parliament.uk/publications/39330/documents/193093/default/ (Accessed: 01/12/2023).

Devi, N., Prodinger, B., Pennycott, A., Sooben, R. and Bickenbach, J. (2020) 'Investigating Supported Decision-Making for Persons With Mild to Moderate Intellectual Disability Using Institutional Ethnography', *Journal of Policy & Practice in Intellectual Disabilities,* 17(2), pp. 143-156. doi: 10.1111/jppi.12314.

Devi, N., Bickenbach, J. and Stucki, G. (2011) 'Moving towards substituted or supported decision-making? Article 12 of the Convention on the Rights of Persons with Disabilities, *Alter, 5(4), pp. 249-264. doi: 10.1016/j.alter.2011.07.002.*

Dewing, J. (2008) 'Personhood and dementia: Revisiting Tom Kitwood's ideas'*, International Journal of Older People Nursing 3(1), pp.3- 13.*

Dey, I. (1999) *Grounding Grounded Theory: Guidelines for Qualitative Inquiry.* Bingley: Emerald Publishing.

Dezlin, N. and Lincoln, Y. (2017) *The Sage Handbook of Qualitative Research. 5th edition.* London: Sage.

Dhanda, A. (2007) 'Legal Capacity in the Disability Rights Convention: Stranglehold of the past or lodestar for the future?', *Syracuse Journal of International Law and Commerce, 34(2), pp. 429-462.*

Dhanda, A. (2012) ‘Constructing a new Human Rights lexicon: Convention on the Rights of Persons with Disabilities.’ *International Journal of Human Rights. 8.* [Online] Available at: http://www.surjournal.org/eng/conteudos/getArtigo8.php?artigo=8,artigo_dhanda.htm

Diener, E. and Crandall, R. (1978) *Ethics in social and behavioural research.* Chicago: University of Chicago.

Dixon, J. (2023) *Adult safeguarding observed: How social workers assess and manage risk and uncertainty.* Bristol: Policy Press.

Dixon J., Laing J, and Valentine C. (2020) ‘A human rights approach to advocacy for people with dementia: A review of current provision in England and Wales.’ *Dementia,19(2), pp.221-236.* doi:10.1177/1471301218770478

Dixon, J., Donnelly, S., Campbell, J. and Laing, J. (2022) 'Safeguarding People Living with Dementia: How Social Workers Can Use Supported Decision-Making Strategies to Support the Human Rights of Individuals during Adult Safeguarding Enquiries', *British Journal of Social Work,* 52(3), pp. 1307-1324. doi: 10.1093/bjsw/bcab119.

Donnelly, M. (2016) 'Best Interests in the Mental Capacity Act: Time to say Goodbye?'. *Medical Law Review, 24 (3), pp.318-332*

Dowling, S., Manthorpe, J. and Cowley, S. (2006) *Person-centred planning in social care. A scoping review.* York: Joseph Rowntree Foundation

Downs, M. (2000) ‘Dementia in a socio-cultural context: an idea whose time has come’, *Ageing and Society 20(3), pp. 369-375.*

Dunn, M., Clare, I. and Holland, A. (2010) ‘Living a’ life like ours': support workers' accounts of substitute decision-making in residential care homes for adults with intellectual disabilities’, *Journal of intellectual disability research, 54(2), pp. 144-160.*

Dunn, P., Allen, L., Grimm, F., Humphries, R. and Alderwick, H. (2021) *Adult social care and COVID-19 after the first wave: assessing the policy response in England.* The Health Foundation. Available at: https://www.health.org.uk/publications/reports/adult-social-care-and-covid-19-after-the-first-wave (Accessed on 16/11/2023).

Elliot, T.A. (2013) *Necessity or pragmatism?: The development and use of the justification of necessity in medical law*. PhD. Queen Mary's London.

Emmett, C., Poole, M., Bond, J. and Hughes, J.C. (2013) *Homeward bound or bound for a home? Assessing the capacity of dementia patients to make decisions about hospital discharge: Comparing practice with legal standards,* Oxford: Pergamon.

Evans, D. (2019) ‘An exploration of the impact of younger-onset dementia on employment’, *Dementia-international Journal of Social Research and Practice, 18(1), pp. 262-281. doi: 10.1177/1471301216668661.*

Evans, M. and Harvey, D. (2022) *Social work law applying the law in practice.* St Albans: Critical Publishing.

Evans, S.C. (2018) Ageing and dementia in Ayalon, L. and Tesch-Römer, C. (eds.) *Contemporary Perspectives on Ageism* Cham: Springer International Publishing. E-Book. Available at: https://doi.org/10.1007/978-3-319-73820-8

Evans, T. and Harris, J. (2004) 'Street-level bureaucracy, social work and the (exaggerated) death of discretion', *British Journal of Social Work, 34(6), pp.871-895. (doi:10.1093/bjsw/bch106).*

Evans, T. and Hardy, M. (2017) 'The ethics of practical reasoning—exploring the terrain', *European Journal of Social Work, 20(6), pp. 947-957. Doi: 10.1080/13691457.2016.1278524*

Evennett, H. (2022) *The Equality Act 2010: Impact on disabled people. House of Lords Library.* Available at: https://lordslibrary.parliament.uk/the-equality-act-2010-impact-on-disabled-people/ (Accessed: 10/12/2023).

Fanning, J. (2016) 'Continuities of risk in the era of the Mental Capacity Act'*, Medical law review 24(3), pp. 415-433. doi: 10.1093/medlaw/fww036.*

Fazio, S., Pace, D., Flinner, J. and Kallmyer, B. (2018) 'The Fundamentals of Person-Centered Care for Individuals With Dementia', *The Gerontologist,*58, (1), pp.S10-S19. https://doi.org/10.1093/geront/gnx122

Feldon, P. (2017) *The Social worker's guide to the Care Act 2014.* St Albans: Critical Publishing.

Feldon, P. (2023) *The Social worker's guide to the Care Act 2014. 2nd Edition.* St Albans: Critical Publishing.

Ferrin, A. (2017) 'Good Moral Judgment and Decision-Making Without Deliberation', *The Southern Journal of Philosophy, 55(1), pp.68-95. doi:10.1111/sjp.12210*

Fletcher, J.R. (2023) 'Regulating the disenfranchised: Reciprocity & resistance under the Mental Capacity Act', *Journal of Aging Studies,* 64, 101099. doi: 10.1016/j.jaging.2022.101099.

Flick, U. (2018) *Doing grounded theory.* London: Sage Publications.

Flynn, E. (2018) 'Disability, Deprivation of Liberty, and Human Rights Norms: Reconciling European and International Approaches', *International Journal of Mental Health, and Capacity Law, (22), pp. 75-101. doi: 10.19164/ijmhcl.v22i2.503.*

Foley, N. and Foster, D. (2022) *Impact of the Covid-19 pandemic on social work.* London: House of Commons Library. Available at: https://commonslibrary.parliament.uk/research-briefings/cdp-2022-0059/ (Accessed: 29/06/2023).

Fook, J. (2002). 'Theorizing from Practice. Towards an Inclusive Approach for Social Work Research', *Qualitative social work, 1(1), pp.79–95. https://doi.org/10.1177/147332500200100106*

Fook, J. (2016) *Social Work. A critical approach to practice.* London. Sage

Ford, H. and Megan, I. (2022) 'Estimated 70,800 adults living with young onset dementia in UK', *Nursing Times, Available at: https://www.nursingtimes.net/news/charities/estimated-*

70800-adults-living-with-young-onset-dementia-in-uk-16-09-2022/?gclid=CjwKCAjwmbqoBhAgEiwACIjzEPJFAzjPB9YD7awxRHBWRrFDRyiPmqtNqgr4LCkWP7ieHKIlRFeRdBoCTRUQAvD_BwE (Accessed: 10/08/2023).

Foster, C., Herring, J. and Doron, I. (2014) *The Law and Ethics of dementia.* Oxford: Hart Publishing.

Fox, N. (2008) Post positivism. Chapter in Givens, L. (ed) *The Sage Encyclopaedia of Qualitative Research Methods.* Thousand Oaks: Sage.

Gaebel, W., Jessen, F. and Kanba, S. (2018) 'Neurocognitive disorders in ICD-11: The debate and its outcome', *World Psychiatry: official journal of the World Psychiatric Association (WPA), 17(2), pp. 229-230. doi: 10.1002/wps.20534.*

Gambrill, E. (2005) Critical thinking in clinical practice: Improving the quality of judgments and decisions (2nd ed). New York: John Wiley.

Garro, C. (1998) 'On the Rationality of Decision-Making Studies: Part 1: Decision Models of Treatment Choice', *Medical Anthropology Quarterly 12(3), pp. 319-340.*

Giebel, C., Sutcliffe, C., Darlington-Pollock, F., Green, M.A., Akpan, A., Dickinson, J., Watson, J. and Gabbay, M. (2021) 'Health Inequities in the Care Pathways for People Living with Young- and Late-Onset Dementia: From Pre-COVID-19 to Early Pandemic', *International Journal of Environmental research and public health, 18(2), pp. 686. doi: 10.3390/ijerph18020686.*

Gillard, J., Means, R., Beattie, A., Daker-White, G. (2005) 'Dementia care in England and the social model of disability. Lessons and issues', *Dementia, 4(4), pp.571-586.*

Glaser, B. and Strauss, A. (1967) *The discovery of grounded theory.* London: New Brunswick books.

Godefroy, S. (2015) *Mental health and mental capacity law for social workers,* London: Sage

Goodley, D. (2013) Dis/entangling critical disability studies. *Disability & Society, 28(5), pp.631–644*.

Goffman, (1956) *The Presentation of Self in Everyday Life.* London: Penguin.

Gordon, A. (2015) *The Seventh Year of the Independent Mental Capacity (IMCA) Service. 1st April 2013 – 31st March 2014*. Department of Health. Available at: https://assets.publishing.service.gov.uk/media/5a747df1ed915d0e8bf18b8a/imca-report.pdf (Accessed: 10/12/2023).

Graham, M. and Cowley, J. (2015*) A practical guide to the Mental Capacity Act 2005. Putting the principles of the Act into practice.* London: Jessica Kingsley.

Gray, M. and Webb, S.A. (2013) *Social work theories and methods.* 2nd ed. London: Sage.

Great Britain (2007) *Independence, choice, and risk: A guide to best practice in supported decision making*. Department of Health. Available at: https://webarchive.nationalarchives.gov.uk/ukgwa/20130105035347/http:/www.dh.gov.uk

/prod_consum_dh/groups/dh_digitalassets/%40dh/%40en/documents/digitalasset/dh_074775.pdf

Greaves, I. and Jolley, D. (2010) 'National Dementia Strategy: well-intentioned--but how well founded and how well directed?', *The British Journal of General Practice: the Journal of the Royal College of General Practitioners, 60(572), pp. 193-198. doi: 10.3399/bjgp10X483553.*

Green, L. and Clarke, K. (2016) *Social Policy for social work.* Cambridge: Polity

Greenwood, N. and Smith, R., (2016) 'The experiences of people with young-onset dementia: A meta-ethnographic review of the qualitative literature', *Maturitas, 92, pp. 102-109. doi: 10.1016/j.maturitas.2016.07.019.*

Hammersley, M. and Traianou, A. (2012) *Ethics in qualitative research: controversies and controversies.* London: Sage.

Harding, N. and Palfry, C. (1997) *The social construction of dementia. Confused professionals?* London: Jessica Kingsley.

Harding, R. (2012) 'Legal constructions of dementia: discourses of autonomy at the margins of capacity', *Journal of Social Welfare and Family Law, 34(4), pp. 425-442*.

Harding, R. (2021) 'Safeguarding Freedom? Liberty Protection Safeguards, Social Justice and the Rule of Law,' *Current Legal Problems, 74,(1), pp. 329–359, https://doi.org/10.1093/clp/cuab011*

Hardy, M. (2017) 'In Defence of Actuarialism: Interrogating the Logic of Risk in Social Work Practice', *Journal of Social Work Practice, 31(4), pp.395-410. doi: 10.1080/02650533.2017.1394828.*

Hardy, S. and Joyce, T. (2009) 'The Mental Capacity Act: practicalities for health and social care professionals', *Advances in Mental Health and Learning Disabilities, 3(1), pp. 9-14.*

Harlow, E., Berg, E., Barry, J. and Chandler, J. (2012) 'Neoliberalism, Managerialism and the Reconfiguration of Social Work in Sweden and the United Kingdom', *Organisation, 20(4), pp.534 – 550.*

Harper, L., Dobbs, B.M., Stites, S.D., Sajatovic, M., Buckwalter, K.C. and Burgener, S.C. (2019) 'Stigma in dementia: It's time to talk about it: There's much you can do to address stigmatizing attitudes, beliefs, and behaviours', *Current Psychiatry,* 18(7) pp.16+. https://link.gale.com/apps/doc/A595143783/HRCA?u=anon~51869f9f&sid=googleScholar&xid=5a10886a

Harris, J. (2008) 'State social work. Constructing present moments in the past', *The British Journal of Social Work, 38(4), pp.662–679.*

Harris, P. B. (2004). 'The perspective of younger people with dementia is still an overlooked population'. *Social Work in Mental Health, 2(4), pp.17-36 doi: 10.1300/J200v02n04_02.*

Hassiem, F. and Yusef, A. (2019) 'Article 8: the forgotten right for older patients'. *Pavilion Health today.* Available at: https://pavilionhealthtoday.com/gm/article-8-the-forgotten-right-for-older-patients/ (Accessed: 01/10.2023)

Hayo, H., Ward, A. and Parkes, J. (2018) *Young onset dementia. A guide to recognition, diagnosis and supporting individuals with dementia and their families,* London: Jessica Kingsley.

Haves, E. (2020) *Fiftieth anniversary of the Chronically Sick and Disabled Persons Act 1970. House of Lords Library.* Available at: https://lordslibrary.parliament.uk/fiftieth-anniversary-of-the-chronically-sick-and-disabled-persons-act-1970/ (Accessed: 11/12/2023).

Health Foundation (2013) *The National Assistance Act 1948*. Available at: https://navigator.health.org.uk/theme/national-assistance-act-1948#:~:text=The%20Act%20established%20the%20National,lodging%20for%20'unsettled%20people'. (Accessed: 20/07/2023).

Heffernan, K. (2005) 'Social Work, New Public Management, and the Language of 'Service User', The *British Journal of Social Work, 36(1), pp.139–147, https://doi.org/10.1093/bjsw/bch328*

Helm, D. (2011) 'Judgements or Assumptions? The Role of Analysis in Assessing Children and Young People's Needs', *The British Journal of Social Work, 41(5), pp. 894-911. doi: 10.1093/bjsw/bcr096.*

Henderson, A. (2011) *A young autistic man, Magna Carta, human rights and unlawful detention. UK Human Rights Blog*. Online: https://ukhumanrightsblog.com/2011/06/16/a-young-autistic-man-magna-carta-human-rights-and-unlawful-detention/ (Accessed: 09/10/2023).

Hendriks, S., Peetoom, K., Bakker, C., van der Flier, W.M., Papma, J.M., Koopmans, R., Verhey, F.R.J., de Vugt, M., Köhler, S., and Young-Onset Dementia Epidemiology Study Group (2021) 'Global Prevalence of Young-Onset Dementia: A Systematic Review and Meta-analysis', *JAMA Neurology,* 78(9), *pp. 1080-1090. doi: 10.1001/jamaneurol.2021.2161.*

Herrmann, L.K., Welter, E., Leverenz, J., Lerner, A.J., Udelson, N., Kanetsky, C. and Sajatovic, M. (2018) 'A Systematic Review of Dementia-related Stigma Research: Can We Move the Stigma Dial?', *The American Journal of Geriatric Psychiatry: Official Journal of the American Association for Geriatric Psychiatry, 26(3), pp. 316-331. doi: 10.1016/j.jagp.2017.09.006.*

Higgs, P. and Gilleard, C. (2017) 'Ageing, dementia and the social mind: past, present and future perspectives'*, Sociology of health & illness, 39(2), pp. 175-181. doi: 10.1111/1467-9566.12536.*

Hillman, A. and Latimer, J. (2017) 'Cultural representations of dementia', *PLoS Medicine, 14(3), pp. e1002274. doi: 10.1371/journal.pmed.1002274.*

HM Government (2022) *Mental Capacity Act 2005 Code of Practice Including the Liberty Protection Safeguards Draft.* Available at: https://www.gov.uk/government/consultations/changes-to-the-mca-code-of-practice-and-implementation-of-the-lps/draft-mca-code-of-practice-summary (Accessed: 10/08/2023)

Hood, R. (2018) *Complexity in social work.* Los Angeles, California: Sage.

House of Lords, House of Commons Joint Committee on the Draft Mental Incapacity Bill (2003) *Draft Mental Incapacity Bill. Session 2002–03, Volume I. HL Paper 189-I. HC 1083-I.* London: The Stationary Office.

House of Lords (2014) *House of Lords Select Committee on the Mental Capacity Act 2005, Report of Session 2013–2014, Mental Capacity Act 2005: Post-Legislative Scrutiny.* London: TSO. Available at: https://publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/139.pdf (Accessed: 29/07/2023).

House of Lords (2016) *House of Lords Select Committee on the Equality Act 2010 and Disability Report of Session 2015–16. The Equality Act 2010: the impact on disabled people.* London: The Stationary Office. Available at: https://publications.parliament.uk/pa/ld201516/ldselect/ldeqact/117/117.pdf

Howe, E.G. (2006) 'Patients may benefit from postponing assessment of mental capacity', *Journal of Clinical Ethics, 17(2), pp. 99-109.*

Hubbard, R. (2018) 'Best Interests Assessor Role: An Opportunity or a 'Dead End' for Adult Social Workers?', *Practice (09503153), 30(2), pp. 83-98. doi: 10.1080/09503153.2017.1372738.*

Hulko, W. (2009) 'From 'not a big deal' to 'hellish': Experiences of older people with dementia', *Journal of Aging Studies, 23(3), pp. 131-144. doi: 10.1016/j.jaging.2007.11.002.*

Ife, J., Soldatic, K., & Briskman, L. (2022). *Human rights and social work: Towards rights-based practice.* Cambridge: Cambridge University Press.

Iliffe, S. (2010) 'National Dementia Strategy: a window of opportunity?: Commentary on the National Dementia Strategy: innovation or reiteration?', *The Psychiatrist, 34(7), pp. 294-297. doi: 10.1192/pb.bp.109.027094.*

Iliffe, S., Wilcock, J., Drennan, V., Goodman, C., Griffin, M., Knapp, M., Lowery, D., Manthorpe, J., Rait, G., & Warner, J. (2015). *Changing practice in dementia care in the community: developing and testing evidence-based interventions, from timely diagnosis to end of life* (EVIDEM). NIHR Journals Library. Available at: https://www.ncbi.nlm.nih.gov/books/NBK286152/ (Accessed 20/11/2023).

International Federation of Social workers (2016*) Towards a Social Work rights framework.* Available at: https://www.ifsw.org/towards-a-social-work-rights-framework/ (Accessed: 15/11/2023).

International Federation of Social Workers (2023) *Global definition of Social Work*. Available at: https://www.ifsw.org/what-is-social-work/global-definition-of-social-work/ (Accessed: 15/11/2023).

Jasper, M.A. (2005) 'Using reflective writing within research', *Journal of Research in Nursing, 10(3), pp. 247-260. doi: 10.1177'/174498710501000303.*

Jayes, M., Austin, L., and Brown, L.J.E. (2022) 'Supported decision-making and mental capacity assessment in care homes: a qualitative study', *Health and Social Care in the Community, 30(4), pp. e1061-e1069. doi: 10.1111/hsc.13512.*

Jayes, M. (2019) 'Improving Practice in Supported Decision-Making and Mental Capacity Assessment', *Logopedia e Comunicazione, 15(1), pp. 27-39. doi:https://doi.org/10.14605/LOG1511902.*

Jayes, M., Palmer, R., Enderby, P. and Sutton, A. (2020) 'How do health and social care professionals in England and Wales assess mental capacity? A literature review', *Disability & Rehabilitation, 42(19), pp. 2797-2808. doi: 10.1080/09638288.2019.1572793.*

Jayes, M., Borrett, S. and Bose, A. (2021) 'Mental capacity legislation and communication disability: A cross-sectional survey exploring the impact of the COVID-19 pandemic on the provision of specialist decision-making support by UK SLTs', *International Journal of Language & Communication Disorders. 57, pp.172–181. https://doi.org/10.1111/1460-6984.12685*

Jepson, M., Laybourne A., Williams V., Cyhlarova E., Williamson T., and Robotham D. (2016) 'Indirect payments: when the Mental Capacity Act interacts with the personalisation agenda', *Health & Social Care in the Community 24(5), pp.623-630.*

Johfre, S. and Saperstein, A. (2023) 'The Social Construction of Age: Concepts and Measurement', *Annual Review of Sociology, 49(1), pp.339-358. doi: 10.1146/annurev-soc-031021-121020.*

Johnson, K. and Boland, B. (2019) 'Adult safeguarding under the Care Act 2014', *British Journal of Psychiatry Bulletin 43(1), pp.38-42. doi: 10.1192/bjb.2018.71.*

Joint Committee on Human Rights (2023) Letter to the Minister of State for Social Care, Helen Whately. Available at: https://committees.parliament.uk/publications/40176/documents/196008/default/ (Accessed: 10/12/2023).

Kane, N.B., Keene, A.R., Owen, G.S. and Kim, S.Y.H. (2021) 'Applying decision-making capacity criteria in practice: A content analysis of court judgments', *PLoS ONE, 16(2), e0246521, Available at:* https://link.gale.com/apps/doc/A650856592/AONE?u=rho_ttda&sid=bookmark-AONE&xid=86ef22c0 (Accessed 25/11/2023).

Keating, F. (2017) 'Dementia: challenges for social work education in Europe', *European Journal of Social Work,* 20(3), *pp. 422-428. doi: 10.1080/13691457.2017.1314937*.

Kellner, D. (1990) 'Critical Theory and the Crisis of Social Theory,' *Sociological perspective 33(1), pp.11-33.* Available at: http://journals.sagepub.com/doi/abs/10.2307/1388975#articleCitationDownloadContainer (accessed 10 July 2018).

Kingston, D., Battsch, N. and Mittler, P. (2017) *Access to the United Nations Convention on the Rights of Persons with Disabilities by people living with dementia*, Online: Available at https://www.alzint.org/u/crpd-brief-alzheimer-associations.pdf: Dementia Alliance International. (Accessed: 10/02/2023).

Kingstone, T., Campbell, P., Andras, A., Nixon, K., Mallen, C., Dikomitis, L. (2021) 'Exploring the Impact of the First Wave of COVID-19 on Social Work Practice: A Qualitative Study in

England, UK', *The British Journal of Social Work, 52(4), pp. 2043-2062. doi: 10.1093/bjsw/bcab166.*

Kirkman, E. and Melrose, K. (2014) *Clinical Judgement and Decision-Making in Children's Social Work: An analysis of the 'front door' system. Research report*. London: Department of Education.

Kirkpatrick, I. (2006) 'Taking Stock of the New Managerialism in English Social Services', *Social Work & Society, Volume 4, Issue 1, 2006 [Online] available at: https://socwork.net/sws/article/view/173/564 (Accessed 26/01/2018).*

Kiteley, R. and Stogdon, C. (2014*) Literature reviews in social work*. Los Angeles, California: Sage.

Kitwood, T.M. (1997) *Dementia reconsidered: the person comes first.* Buckingham: Open University Press.

Klein, G. (1998). *Sources of Power: How People Make Decisions.* Cambridge: MIT Press.

Kong, C. and Ruch Keene, A. (2019) *Overcoming challenges in the Mental Capacity Act 2005. Practical guidance for working with complex issues.* London: Jessica Kingsley.

Kong, S.T. and Noone, C. and Quintana, A. and Pharoah, C. and Wills, D. and Shears, J. and Sildatke, K. and Roberts, W. and Thanki, V. and Stepanova, E. and Charnley, H. and Smith, R. and Banks, S. and Hawkes, S (2021) *Social Work During Covid-19: Learning for the Future Challenges, Best Practice and Professional Transformation.* BASW. Available at: https://durham-repository.worktribe.com/output/1604313/social-work-during-covid-19-learning-for-the-future-challenges-best-practice-and-professional-transformation (Accessed on 10/08/2023).

Koopmans, R. and Rosness, T. (2014) 'Young onset dementia – what does the name imply?', *International Psychogeriatrics, 26(12), pp. 1931-1933. doi: 10.1017/S1041610214001574.*

Koubel, G. and Bungay, H. (2012) *Rights, risks, and responsibilities.* Basingstoke: MacMillan.

Kuylen, M., Wyllie, A., Bhatt, V., Fitton, E., Michalowski, S., & Martin, W. (2022). 'COVID-19 and the Mental Capacity Act in care homes: Perspectives from capacity professionals', *Health & Social Care in the Community, 30(5), e3018–e3028. https://doi.org/10.1111/hsc.13747*

Kvello-Alme, M. (2021) *Young onset dementia in central Norway. Doctoral thesis*, Norway: Norwegian University of Science and Technology.

Lai, M., Yun-Hee, J., McKenzie, H. and Withall, A. (2019) 'How do people with young onset dementia and their family make decisions and plan for the future in relation to advance care planning, shared decision making, and supported decision making?'. *Alzheimer's & dementia: The Journal of the Alzheimer's Association, 15(7), pp.P548-P549*

Lamont, S., Jeon, Y. and Chiarella, M. (2013) 'Assessing patient capacity to consent to treatment: an integrative review of instruments and tools', *Journal of Clinical Nursing;* 22(17-18)*, pp. 2387-2403. doi: 10.1111/jocn.12215.*

Larsen, T.S. (2016) ‘Scrutinising the reflexive ethnography of Urban Outcasts’, *Urban Studies, 53(6), pp. 1099-1103. doi: 10.1177/0042098015613754.*

Lawler, J. (2013) Critical Management, *in Gray and Webb eds (2013) The new politics of social work.* Palgrave Macmillan: Basingstoke.

Law Commission (1995) *Mental incapacity.* Law Commission command number 231*. Item 9 of the Fourth Programme of Law Reform: Mentally Incapacitated Adults*. London. HMSO.

Law Commission (2011) *Adult Social Care. Law Commission number 326.* Available at https://cloud-platforme218f50a4812967ba1215eaecede923f.s3.amazonaws.com/uploads/sites/30/2015/03/lc326_adult_social_care.pdf (Accessed: 10/07/2023).

Law Commission (2017) *Mental Capacity and Deprivation of Liberty.* Law Commission Number 372. Available at: https://www.lawcom.gov.uk/app/uploads/2017/03/lc372_mental_capacity.pdf (Accessed: 29/09/2023).

Lee, A. (1991) ‘Integrating positivist and interpretivist approaches to organisational research’, *Organisational Science 4(2), pp.342-365.*

Lennard, C. (2016) ‘Fluctuating capacity and impulsiveness in acquired brain injury: the dilemma of “unwise” decisions under the Mental Capacity Act’, *The Journal of Adult Protection, 18(4), pp. 229-239. https://doi-org.ezproxy01.rhul.ac.uk/10.1108/JAP-11-2015-0035*

Lincoln, Y. S. and Guba, E. G. (1985) *Naturistic Inquiry,* California: Sage Publications.

Lincoln, Y. S., Lynham, S. A., & Guba, E. G. (2011). Paradigmatic controversies, contradictions, and emerging confluences, revisited, in Denzin, N., Lincoln. Y.S. (eds) *The Sage Handbook of qualitative research.* Thousand Oaks: Sage.

Lindsey, J. and O’Reardon, M. (2021) 'Social work expertise, best interests and the court of protection', *Journal of Adult Protection,* 23(6), *pp. 397-406. doi: 10.1108/JAP-06-2021-0020.*

Lister, R. (1997) *Citizenship: Feminist perspectives*. Houndmills: Macmillan.

Livingston, G., Leavey, G., Manela, M., Livingston, D., Rait, G., Sampson, E., Bavishi, S., Shahriyarmolki, K. and Cooper, C. (2010) ‘Making decisions for people with dementia who lack capacity: a qualitative study of family carers in the UK’, *British Medical Journal (18), pp. 341-494.*

Livingston, G., Huntley, J., Sommerlad, A., Ames, D., Ballard, C., Banerjee, S., Brayne, C., Burns, A., Cohen-Mansfield, J., Cooper, C., Costafreda, S.G., Dias, A., Fox, N., Gitlin, L.N., Howard, R., Kales, H.C., Kivimäki, M., Larson, E.B., Ogunniyi, A., Orgeta, V. and Ritchie, K. (2020) *Dementia prevention, intervention, and care: 2020 report of the Lancet Commission*, *Lancet 396,(10248), pp.413–46. https://doi.org/10.1016/S0140-6736(20)30367-6*

Lukens, J. M., Solomon, P., & Sorenson, S. B. (2013). ‘Shared decision making for clients with mental illness: A randomized factorial survey’*, Research on Social Work Practice, 23(6), pp.* 694-705. doi: 10.1177/1049731513489734.

Lynman, K. (1989) ‘Bringing the Social Back in A Critique of the Biomedicalization of Dementia’, *The Gerontological Society of America, 29(5), pp.597-605.*

McDonald, A. (2010) 'The Impact of the 2005 Mental Capacity Act on Social Workers' Decision Making and Approaches to the Assessment of Risk', *The British Journal of Social Work, 40(4), pp. 1229-1246. doi: 10.1093/bjsw/bcq021.*

MacKenzie, C., & Rogers, W. (2013). ‘Autonomy, vulnerability, and capacity: a philosophical appraisal of the Mental Capacity Act’, *International Journal of Law in Context, 9(1), pp.37-52.*

Manning, J. (2017). In Vivo Coding. In eds Matthes, J., Davis, C.S. and Potter, R.F. *The International Encyclopaedia of Communication Research Methods*. Available at: https://doi.org/10.1002/9781118901731.iecrm0270 (Accessed: 10/10/2023).

Manthorpe, J. (2014) ‘The dement in the community: Social work practice with people with dementia revisited’, *Dementia, 15(5), pp.1100-1111.*

Manthorpe, J. and Iliffe, S. (2016) *The dialectics of dementia.* London. Social Care Workforce Research Unit. Available at: https://daanow.org/wp-content/uploads/2016/07/The-dialectics-of-dementia.pdf (Accessed: 18/11/2023).

Manthorpe, J., Rapaport, J. and Stanley, N. (2008) 'The Mental Capacity Act 2005 and Its Influences on Social Work Practice: Debate and Synthesis', *Practice*, *20(3), pp. 151-162. doi: 10.1080/09503150802341384.*

Manthorpe, J., Rappaport, J. and Stanley, N. (2009). ‘Expertise and Experience: People with Experiences of Using Services and Carers' Views of the Mental Capacity Act 2005’*, British Journal of Social Work, 39(5), pp. 884-900*.

Manthorpe, J. and Samsi, K. (2012a) '‘Inherently Risky?’: Personal Budgets for People with Dementia and the Risks of Financial Abuse: Findings from an Interview-Based Study with Adult Safeguarding Coordinators', *The British Journal of Social Work, 43(5), pp. 889-903. doi: 10.1093/bjsw/bcs023.*

Manthorpe, J. and Samsi, K. (2012b) 'Mental capacity and dementia: a review. Part 1', *Journal of Dementia Care, 20(6), pp. 35-39.*

Manthorpe, J. and Samsi, K. (2013) 'Changing practice: adapting to the Mental Capacity Act 2005', *Social Care & Neurodisability, 4(3), pp. 124-133. doi: 10.1108/SCN-03-2013-0008.*

Manthorpe, J., Samsi, K. and Rapaport, J. (2013) ‘“Capacity Is Key”: Investigating New Legal Provisions in England and Wales for Adult Safeguarding’, *Journal of Elder Abuse & Neglect, 25(4), pp.355-373. DOI:10.1080/08946566.2013.770313.*

Manthorpe, J. and Samsi, K. (2016a) 'Person-centered dementia care: current perspectives', *Clinical interventions in the ageing;* 11, *pp. 1733-1740. doi: 10.2147/CIA.S104618.*

Manthorpe, J. and Samsi, K. (2016b). ‘Care homes and the Mental Capacity Act 2005: Changes in understanding and practice over time’, *Dementia-International Journal of Social Research and Practice, 15(4), pp.858-871.*

Manthorpe, J., Samsi, K. and Rapport, J. (2014) 'Dementia nurses’ experience of the Mental Capacity Act 2005: a follow-up study', *Dementia: the International Journal of Social Research and Practice, 13(1), pp.131-142.*

Manthorpe, J. & Tindall, L. (1997) 'Early onset dementia: A case of ill-timing?', *Journal of Mental Health, 6(3), pp. 237-250. Doi: 10.1080/09638239718770.*

Marshall, M. and Tibbs, M.A. (2006) *Social work and people with dementia: partnerships, practice, and persistence.* 2nd ed. Bristol: Policy.

Martin, W., Michalowski, S., Jütten, T. and Burch, M. (2014*) Achieving CRPD Compliance: Is the Mental Capacity Act of England and Wales compatible with the UN Convention on the Rights of Persons with Disability? If not, what next? Project Report*. Essex Autonomy Project, University of Essex, Colchester. Available at: https://repository.essex.ac.uk/13624/ (Accessed: 10/12/2023).

Martinez-Brawley, E.E. (2019) 'Changing Perspectives and Changing Goals. Constructivism in Social Work Re-Visited', *The British Journal of Social Work, 50(1), pp. 264-281. doi: 10.1093/bjsw/bcz112.*

Mathie, E., Antony, A., Kellett, A., Darlington, N., Buckner, S., Lafortune, L., Mayrhofer, A., Dickinson, A., Woodward, M. and Goodman, C. (2022) ‘Dementia-friendly communities: The involvement of people living with dementia’*, Dementia, 21(4), pp. 1250-1269. doi: 10.1177/14713012211073200.*

Mayrhofer, A., Mathie, E., McKeown, J., Bunn, F. and Goodman, C. (2018) 'Age-appropriate services for people diagnosed with young onset dementia (YOD): a systematic review', *Aging and mental health, 22(8), pp. 927-935. doi: 10.1080/13607863.2017.1334038.*

Mayrhofer, A.M., Mathie, E., McKeown, J., Goodman, C., Irvine, L., Hall, N. and Walker, M. (2020) 'Young onset dementia: public involvement in co-designing community-based support', *Dementia: The International Journal of Social Research and Practice, 19(4), pp. 1051-1066. doi: 10.1177/1471301218793463.*

Mayrhofer, A.M., Shora, S., Tibbs, M., Russell, S., Littlechild, B. and Goodman, C. (2021) 'Living with young onset dementia: reflections on recent developments, current discourse, and implications for policy and practice', *Ageing & Society, 41(11), pp.2437-2445. doi: 10.1017/S0144686X20000422.*

McCusker, P., Gillespie, L,. Davidson, G., Vicary, S. and Stone, K. (2022) ‘The United Nations Convention on the Rights of Persons with Disabilities and Social Work: Evidence for Impact?’, *International Journal of Environmental Research and Public Health, 20(20), 6927 Available at: https://www.mdpi.com/1660-4601/20/20/6927*

McGettrick, G. (2015) *Dementia, rights, and the social model of disability A new direction for policy and practice?* The Mental Health Foundation. Online. Available at: https://www.mentalhealth.org.uk/sites/default/files/2022-09/MHF-dementia-rights-policy-discussion.pdf

McParland, P., Kelly, F. and Innes, A. (2017) 'Dichotomising dementia: is there another way?', *Sociology of health & illness,* 39(2), *pp. 258-269. doi: 10.1111/1467-9566.12438.*

Mendoza, N.S., Rose, R.A., Geiger, J.M. and Cash, S.J. (2016) 'Risk assessment with actuarial and clinical methods: Measurement and evidence-based practice', *Child abuse & neglect,* 61, *pp.1-12. doi: 10.1016/j.chiabu.2016.09.004.*

Miles, M., Huberman, A., and Saldana J. (2014) *Qualitative data analysis. A methods sourcebook*. 3rd Edition. London: Sage.

Millenaar, J.K., Bakker, C., Koopmans, R.T.C.M., Verhey, F.R.J., Kurz, A. and de Vugt, M.E. (2016) 'The care needs and experiences with the use of services of people with young-onset dementia and their caregivers: a systematic review', *International journal of geriatric psychiatry, 31(12), pp. 1261-1276. doi: 10.1002/gps.4502.*

Mills, J., Bonner, A., & Francis, K. (2006). 'The Development of Constructivist Grounded Theory', *International Journal of Qualitative Methods, 5(1), pp.25-35.*

Milne, A. (2020a) 'Conceptualising dementia', in Milne, A. (ed.) *Mental Health in Later Life: Taking a Life Course Approach* Bristol: Policy Press,

Milne, A. (2020b) *Mental Health in Later Life: Taking a Life Course Approach.* Bristol: Policy Press.

Milne, A., Gearing, B., & Warner, J. (2007). An introduction to the mental health of older people: understanding the early stages of dementia. From http://www.scie.org.uk/publications/elearning/mentalhealth/index.asp

Milne, A., Guss, R. and Russ, A. (2014) 'Psycho-educational support for relatives of people with a recent diagnosis of mild to moderate dementia: An evaluation of a 'Course for Carers'', *Dementia, 13(6), pp.768-787. doi: 10.1177/1471301213485233.*

Ministry of Justice (2008*) Mental Capacity Act 2005: Deprivation of liberty safeguards - Code of Practice to supplement the main Mental Capacity Act 2005 Code of Practice*. London. The Stationary Office.

Moore, D., & Jones, K. (2011) 'Promoting self-directed support for people living with dementia: overcoming the challenges', *Social Care and Neurodisability, 2(2), pp.66-70.*

Moore, D. and Jones, K. (2012) *Social work and dementia.* London: Learning Matters.

Mueller, T., Haberstroh, J., Knebel, M., Oswald, F., Weygandt, M., Schröder, J., Markwort, S. and Pantel, J. (2015) 'Comparison of three different assessments of capacity to consent in dementia patients', *GeroPsych: The Journal of Gerontopsychology and Geriatric Psychiatry,* 28(1), *pp.21-29. doi: 10.1024/1662-9647/a000119.*

Munro, E. (2011) *The Munro Review of Child Protection: Final Report: A Child-Centred System, Cm 8062.* London: The Stationery Office.

Munro, N. (2013) The social construction of decision-making capacity. BLOG. 15th December 2013 Available at: https://mentalhealthandcapacitylaw.wordpress.com/2013/12/15/the-social-construction-of-decision-making-capacity/ (Accessed: 1/10/2017).

Murphy, D., Duggan, M. and Joseph, S. (2013) 'Relationship-Based Social Work and Its Compatibility with the Person-Centred Approach: Principled versus Instrumental

Perspectives', *British Journal of Social Work 43(4), pp.703–719.* *https://doi.org/10.1093/bjsw/bcs003*

Murrell, A. and McCalla, L. (2016) 'Assessing Decision-making Capacity: The Interpretation and Implementation of the Mental Capacity Act 2005 Amongst Social Care Professionals', *Practice. Social work in action, 28(1), pp.21-36.*

Murray, B.J. (2017) 'Mental Capacity: different models and their controversies', *British Journal of Psychiatry. Advances, 23(6), pp.366-374. doi:10.1192/apt.bp.116.016204*

National Health Service (NHS) (2013a*) Mental Capacity Act 2005, Deprivation of Liberty Safeguards Assessments, England - 2012-13, Annual report.* Available at: https://digital.nhs.uk/data-and-information/publications/statistical/mental-capacity-act-2005-deprivation-of-liberty-safeguards-assessments/mental-capacity-act-2005-deprivation-of-liberty-safeguards-assessments-england-2012-13-annual-report (Accessed: 20/08/2023)

National Health Service (NHS) (2013b*) Mental Capacity Act 2005, Deprivation of Liberty Safeguards, 2022-23.* Available at: https://digital.nhs.uk/data-and-information/publications/statistical/mental-capacity-act-2005-deprivation-of-liberty-safeguards-assessments/2022-23 (Accessed: 28/08/2023).

National Health Service (NHS) (2023a) *Dementia.* Available at: https://www.england.nhs.uk/mental-health/dementia/ (Accessed: 10/08/2023)

National Health Service (NHS) Digital (2023b) *Mental Capacity Act 2005, Deprivation of Liberty Safeguards, 2022-23.* Available at: https://digital.nhs.uk/data-and-information/publications/statistical/mental-capacity-act-2005-deprivation-of-liberty-safeguards-assessments/2022-23 (Accessed 22/09/2023)

National Health Service (NHS) Digital (2023c) *Safeguarding Adults England, 2022/23.* Available at: https://digital.nhs.uk/data-and-information/publications/statistical/safeguarding-adults (Accessed: 01/12/2023).

National Institute for Health and Social Care Excellence (2007) *Dementia: SCIE guide for supporting people with dementia and their carers in health and social care. National Clinical Guideline number 42.* London: British Psychological Society.

National Institute for Health and Social Care Excellence (2010) *Dementia: support in health and social care.* Available at: https://www.nice.org.uk/guidance/qs1 (Accessed: 23/04/2023).

National Institute for Health and Social Care Excellence NICE (2015) *Dementia, disability, and frailty in later life – mid-life approaches to delay or prevent onset NICE guideline [NG97].* Available at: https://www.nice.org.uk/guidance/ng97 (Accessed: 29/04/2023).

National Institute for Health and Social Care Excellence NICE (2019) *Dementia Quality standard [QS184].* London: NICE. Available at: https://www.nice.org.uk/guidance/qs184 (Accessed: 04/04/2023).

National Institute for Health and Social Care Excellence NICE (2018a) *Dementia: assessment, management and support for people living with dementia and their carers*. London: NICE

National Institute for Health and Social Care Excellence (2018b) *Decision-making and mental capacity. NICE guideline [NG108].* London: NICE. Available at: https://www.nice.org.uk/guidance/ng108 (Accessed: 25/05/2023).

National Institute for Health and Social Care Excellence (2023) *Our Charter.* Available at: https://www.nice.org.uk/about/who-we-are/our-charter (Accessed: 02/05/2023).

Nguyen, T. and Li, X. (2020) 'Understanding public stigma and self-stigma in the context of dementia: A systematic review of the global literature'*, Dementia, 19(2), pp. 148-181. doi: 10.1177/1471301218800122.*

Nwadiugwu, M. (2021) 'Early-onset dementia: key issues using a relationship-centred care approach', *Postgraduate medical journal,* 97(1151), *pp. 598-604. doi: 10.1136/postgradmedj-2020-138517.*

Nuffield Council on Bioethics (2009) *Dementia: Ethical Issues*. Nuffield Council on Bioethics. Available at: https://www.nuffieldbioethics.org/publications/dementia (Accessed: 10/11/2023).

O'Connor, D., Sakamoto, M., Seetharaman, K., Chaudhury, H. and Phinney, A. (2022) 'Conceptualizing citizenship in dementia: A scoping review of the literature', *Dementia,* 21(7), *pp.2310. doi: 10.1177/14713012221111014.*

O'Connor, D. (2010) 'Personhood and dementia: toward a relational framework for assessing decisional capacity', *Journal of Mental Health Training Education and Practice, 5(3), pp.22-30.*

Oliffe, J.L., Kelly, M.T., Gabriela, G.M. and Wellam F Yu, K. (2021) 'Zoom Interviews: Benefits and Concessions', *International Journal of Qualitative Methods,* 20, *pp.1-8*. Available at: https://doi.org/10.1177/16094069211053522 (Accessed: 10/02/2023).

Oliver, M. (2013) 'The social model of disability: thirty years on', *Disability & Society,* 28(7), *pp.1024-1026. doi: 10.1080/09687599.2013.818773.*

Oliver, M. and Sapey, B. (2006) *Social work with disabled people.* 3rd ed. Basingstoke: Palgrave Macmillan.

Ottoboni, G., Stamou, V., Chirico, I., Riso, L.D., Allione, L., Johannessen, A. and Chattat, R. (2021) 'Needs-appropriate services for people with young onset dementia: The perspectives of healthcare professionals', *Dementia,* 20(8), pp. 2725-2745. doi: 10.1177/14713012211009340.

Oyebode, J., La Fontaine, J., Stamou, V., O'Malley, M., Parkes, J., & Carter, J. (2023). 'Establishing and sustaining high-quality services for people with young onset dementia: The perspective of senior service providers and commissioners.' *International Psychogeriatrics, pp.1-10. https://doi.org/10.1017/S1041610223000443*

Palaganas, E.C., Sanchez, M.C., Molintas, M.V.P. and Caricativo, R.D. (2017) 'Reflexivity in qualitative research: A journey of learning', *Qualitative report, 22(2), pp. 426-438. doi: 10.46743/2160-3715/2017.2552.*

Parkin, E. and Baker, C. (2021) *Dementia: policy, services, and statistics. Briefing Paper.* House of Commons Library. Available at: https://researchbriefings.files.parliament.uk/documents/SN07007/SN07007.pdf (Accessed: 02/08/2023).

Parton, N. (2003) ‘Rethinking professional practice. The contributions of social constructionism and feminist ethics of care’, *British Journal of Social Work 33 (1), pp.1-16.*

Parton, N. and O’Bryne, P. (2000a) *Constructive Social Work: Towards a New Practice.* Basingstoke: Palgrave MacMillan.

Parton, N. and O'Byrne, P. (2000b) ‘What Do We Mean by Constructive Social Work?’, *Critical Social Work, 1(2). Available at: https://ojs.uwindsor.ca/index.php/csw/article/view/5605 (Accessed: 10/11/2022).*

Payne, M. (2012) *Citizenship social work with older people*. Bristol: Policy.

Pearl, J. (1999) 'Dementia does not discriminate', *Community Care,* (23), pp. 28-29.

Peeters, G., Katelekha, K., Lawlor, B. and Demnitz, N. (2022) 'Sex differences in the incidence and prevalence of young-onset Alzheimer's disease: A meta-analysis', *International journal of geriatric psychiatry, 37(1), pp.1-9. doi: 10.1002/gps.5612.*

Penn, D. and Rosser, M. (2022) Epidemiology and subtypes of dementia, in de Vugt, M. and Carter, J. (eds.) *Understanding Young onset dementia* Oxford: Routledge, pp. 177.

Pennington, C., Davey, K., Mullen, R.T., Coulthard, E., and Kehoe, P.G. (2018) 'Tools for testing decision-making capacity in dementia', *Age and Ageing*, 47(6), *pp. 778-784. doi: 10.1093/ageing/afy096.*

Pereira Gray, D., White, E., & Russell, G. (2016). ‘Medicalisation in the UK: changing dynamics, but still ongoing’, *Journal of the Royal Society of Medicine, 109(1), pp. 7–11.* https://doi.org/10.1177/0141076815600908

Phinney, A., Kelson, E., Baumbusch, J., O’Connor, D. and Purves, B. (2016) 'Walking in the neighbourhood: Performing social citizenship in dementia', *Dementia,* 15(3), pp. 381-394. doi: 10.1177/1471301216638180.

Pipon-Young, F., Lee, K. & Gus, R. (2012) 'I'm not all gone, I can still speak: the experiences of younger people with dementia. An action research study’, *Dementia: The International Journal of Social Research and Practice, 11(5), pp. 597-616.*

Pyper, D. (2022) *The Public Sector Equality Duty and Equality Impact Assessments. Briefing Paper Number 06591, 8 July 2020.* House of Commons Library. Available at: https://researchbriefings.files.parliament.uk/documents/SN06591/SN06591.pdf (Accessed: 10/12/2023).

Qureshi, H.A. and Züleyha Ünlü (2020) 'Beyond the Paradigm Conflicts: A Four-Step Coding Instrument for Grounded Theory', *International Journal of Qualitative Methods,* 19, *pp.1-10.* doi: 10.1177/1609406920928188.

Rabanal, L.I., Chatwin, J., Walker, A., O’Sullivan, M. and Williamson, T. (2018) 'Understanding the needs and experiences of people with young onset dementia: a qualitative study', *British Medical Journal Open, 8(10), pp. e021166. doi: 10.1136/bmjopen-2017-021166.*

Raineri, M.L. and Cabiati, E. (2016) 'Kitwood's thought and relational social work', *European Journal of Social Work, 19(6), pp. 1004-1020. doi: 10.1080/13691457.2015.1074549.*

Ramalho, R., Adams, P., Huggard, P. and Hoare, K. (2015) 'Literature Review and Constructivist Grounded Theory Methodology. Forum', *Qualitative social research, 16 (3).* Available at: http://www.qualitative-research.net/index.php/fqs/article/viewFile/2313/3877 Accessed 12th April 2018

Ramluggun, P. and Ogo, E. (2014) 'Young onset dementia service provision and its effect on service users and family members', *Mental Health Practice, 19(10), pp. 15-19. doi: 10.7748/mhp.2016.e1135.*

Rapaport, J., Manthorpe, J. and Stanley, N. (2009) 'Mental Health and Mental Capacity Law: some mutual concerns for social work practice', *Practice (09503153), 21(2), pp. 91-105. doi: 10.1080/09503150902807631.*

Ray, M., Milne, A., Beech, C., Phillips, J.E., Richards, S., Sullivan, M.P., Tanner, D. and Lloyd, L. (2014) 'Gerontological Social Work: Reflections on its Role, Purpose and Value', *The British Journal of Social Work, 45(4), pp. 1296-1312. doi: 10.1093/bjsw/bct195.*

Rayment, D. and Kuruvilla, T. (2015) 'Service provision for young-onset dementia in the UK', *Progress. Neurological. Psychiatry, 19(1), pp.28-30. doi:10.1002/pnp.391*

Redley, M., Clare, I. C. H., Dunn, M. C., Platten, M. and Holland, A. J. (2011). 'Introducing the Mental Capacity Advocate (IMCA) Service and the Reform of Adult Safeguarding Procedures', *The British Journal of Social Work, 41(6), pp.1058–1069. http://www.jstor.org/stable/43771493*

Reed, J. (2011) 'Services for younger people with dementia. Problems with differentiating needs on the basis of age', *Dementia. 1 (1), pp.95 -112.*

Reed, P.S. and Carson, J. (2017) 'Transcending Tragedy: Maintaining engagement and retaining selfhood of people living with dementia', *Innovation in ageing, 1, pp. 1116. doi: 10.1093/geroni/igx004.4086.*

Reagan, J.L. (2016) 'Ethnic minority, young onset, rare dementia type, depression: a case study of a Muslim male accessing UK dementia health and social care services', *Dementia: The International Journal of Social Research and Practice, 15(4), pp.702-720.*

Regan, M. (2016) *The interface between dementia and mental health: an evidence review*. London: Mental Health Foundation.

Rieger, K.L. (2019) 'Discriminating among grounded theory approaches', *Nursing Inquiry, 26(1), pp. e12261. doi: 10.1111/nin.12261.*

Ritzer, G. (2005) *Encyclopaedia of social theory.* London: Sage

Roach, P., Keady, J., Bee, P. and Hope, K. (2012) 'Subjective experiences of younger people with dementia and their families: implications for UK research, policy, and practice', *Reviews in Clinical Gerontology 18(2), pp.165–174.*

Roach, P. and Drummond, N. (2014a) ‘It's nice to have something to do': early-onset dementia and maintaining purposeful activity', *Journal of Psychiatric and Mental Health Nursing, 21(10), pp.889-895. doi: 10.1111/jpm.12154.*

Roach, P., Keady, J., Bee, P. and Williams, S. (2014b) ‘We can't keep going on like this': identifying family storylines in young onset dementia', *Ageing and Society*, 34(8), *pp.1397-1426. doi: 10.1017/S0144686X13000202.*

Rocca, W.A., Mielke, M.M., Vemuri, P., and Miller, V.M. (2014) 'Sex and gender differences in the causes of dementia: A narrative review', *Maturitas,* 79(2), *pp.196-201. doi: 10.1016/j.maturitas.2014.05.008.*

Rodda, J. and Carter, J. (2016) ‘A survey of UK services for younger people living with dementia’, *International Journal Geriatric Psychiatry, 31(1), pp.951–959.*

Rodgers, P.A. (2021) 'Designing Work with People Living with Dementia: Reflecting on a Decade of Research', *International Journal of Environmental Research and Public Health, 18(22), pp. 11742*. doi: 10.3390/ijerph182211742. doi: 10.3390/ijerph182211742.

Rodwell, M. (1998) *Social work constructivist research.* London: Routledge

Rogers, J. and Bright, L. (2019) ‘Assessments of mental capacity: upholding the rights of the vulnerable or the misleading comfort of pseudo-objectivity?'*, The Journal of Adult Protection, 21(2), pp. 74-84. doi: 10.1108/JAP-10-2018-0026.*

Rossor, M.N., Fox, N.C., Mummery, C.J., Schott, J.M. and Warren, J.D. (2010) 'The diagnosis of young-onset dementia', *The Lancet. Neurology,* 9(8), pp. 793-806. doi: 10.1016/S1474-4422(10)70159-9.

Royal College of Psychiatrists (2006) *Services for younger people with Alzheimer’s disease and other dementias. Council Report CR135.* London: Royal College of Psychiatrists.

Royal College of Psychiatrists (2018) *Young-onset dementia in mental health services. CR217: Recommendations for service provision.* London: Royal College of Psychiatrists.

Ruck-Keene, A., Stricklin-Coutinho, K. and Gilfillan, H. (2015) 'The role of the Court of Protection in safeguarding', *Journal of Adult Protection*, 17(6), *pp.380-390. doi: 10.1108/JAP-03-2015-0010*.

Ruck-Keene, A. Butler-Cole, V., Allen, N. (2013) *Mental capacity Act/ DoLs code of practice update*. 39 Essex Chambers. Available at: https://www.39essex.com/sites/default/files/2022-11/Mental-Capacity-Guidance-Note-Codes-of-Practice-Update-February-2022.pdf (Accessed: 11/11/2023).

Ruck Keene, A., Kane, N.B., Kim, S.Y.H. and Owen, G.S. (2019) ‘Taking capacity seriously? Ten years of mental capacity disputes before England's Court of Protection’*, International Journal of Law and Psychiatry, 62, pp. 56-76. doi:* 10.1016/j.ijlp.2018.11.005

Ruch Keene, A. (2020a) *What does Article 8 add to best interests? (clue – it definitely helps)* Available at: https://www.mentalcapacitylawandpolicy.org.uk/what-does-article-8-add-to-best-interests-clue-it-definitely-helps/ Accessed: 10/09/2023).

Ruck-Keene, A. (2020b) ‘Capacity in the time of Coronavirus’, *International Journal of Law and Psychiatry, 70, pp.101560. https://doi.org/10.1016/j.ijlp.2020.101560*

Ruck-Keene, A. (2023) ‘LPS on the shelf – what to do now’, Video. Available at: https://www.mentalcapacitylawandpolicy.org.uk/lps-on-the-shelf-what-to-do-now-video/ (Accessed: 10/09/2023).

Ruck-Keene, A., Kane, N.B., Kim, S.Y.H. and Owen, G.S. (2023a) 'Mental capacity—why look for a paradigm shift?', *Medical Law Review, pp. fwac052. doi: 10.1093/medlaw/fwac052.*

Ruck Keene, A., Butler-Cole, V., Allen, N., Lee, A., Kohn, N., Scott, K and Edwards, S. (2023b) *Carrying and recording capacity assessments.* 39 Essex Chambers. Available at: https://www.39essex.com/sites/default/files/2023-03/Mental%20Capacity%20Guidance%20Note%20Capacity%20Assessment%20March%202023.pdf (Accessed: 10/11/2023).

Sabbagh, M. and Korgaonkar, G. (2022) *Social work law, ethics and social policy.* London: Sage.

Samsi, K. and Manthorpe, J. (2011), ‘‘I live for today’: a qualitative study investigating older people’s attitudes to advance planning’, *Health & Social Care in the Community, 19(1), pp.52-59.*

Sandburg, L. and Ward, R. (2023) 'Introduction. Why critical dementia studies and why now?', in Sandburg, L. and Ward, R. (eds.) *Critical dementia studies. An introduction* Oxford: Routledge, pp. 1-13.

Saltiel, D. (2016). ‘Observing Front Line Decision Making in Child Protection*’, The British Journal of Social Work, 46(7), pp.2104–2119. http://www.jstor.org/stable/26363609*

Sathyanarayana Rao, T.S., Jacob, K.S., Shaji, K.S., Raju, M.S.V.K., Bhide, A.V., Rao, G.P., Saha, G. and Jagiwala, M. (2017) 'Dementia and the International Classification of Diseases-11 (Beta Version)', *Indian Journal of Psychiatry, 59(1), pp. 1-2.*

Schwehr B. (2016) ‘How to manage deprivations of liberty outside of the DoLS framework’, *Community Care*. Available at: https://www.communitycare.co.uk/2016/06/17/manage-deprivations-liberty-outside-dols-framework/ (Accessed: 10/10/2023)

Scourfield, P. (2023) *Social work practice with people with dementia*. London: Routledge.

Scott, J., Weatherhead, S., Daker-White, G., Manthorpe J. and Marsha Mawson M. (2020) ‘Practitioners’ experiences of the mental capacity act: a systematic review*’, Journal of Adult Protection, 22(4), pp. 227-244.*

Scottish Government (2023) *New dementia strategy for Scotland: Everyone's Story.* [Online] Available at: https://www.gov.scot/publications/new-dementia-strategy-scotland-everyones-story/ (Accessed: 1/09/2023)

Series, L. (2011) *Is the Mental Capacity Act 2005 too paternalistic*? BLOG. Available at https://thesmallplaces.wordpress.com/2011/08/24/is-the-mental-capacity-act-2005-too-paternalistic/ (Accessed 10/10/2023)

Series, L (2017) *Supported decision making under the Mental Capacity Act 2005*, Available at: https://aphasiaresearch.files.wordpress.com/2018/02/2017-12-06-ucl-lucy-series.pdf (Accessed:10/06/2019)

Series, L., Fennell, P., Doughty, J., Mercer, A. (2017) *Welfare cases in the Court of Protection: A statistical overview.* Available at: https://orca.cardiff.ac.uk/id/eprint/118054/1/Series%20Fennell%20Doughty%202017%20Statistical%20overview%20of%20CoP.pdf (Accessed: 22/09/2023)

Şahin, F. (2006) 'Implications of social constructionism for social work', *Asia Pacific Journal of Social Work and Development, 16(1), pp.57-65. doi: 10.1080/21650993.2006.9755992.*

Shakespeare, T., Zeilig, H. and Mittler, P. (2019) 'Rights in Mind: Thinking Differently About Dementia and Disability', *Dementia, 18(3), pp. 1075-1088. doi: 10.1177/1471301217701506.*

Shakespeare, T. (2021) 'Triple jeopardy: disabled people and the COVID-19 pandemic', *The Lancet, 397(10282), pp.1331-1333,doi link: https://doi.org/10.1016/S0140-6736(21)00625-5*

Sharp, S. and Cosgrove, C. (2006) 'Young onset survey: UK services updated', *Journal of Dementia Care, 14(4), pp. 14-15*.

Sicora, A. (2017) 'Reflective practice, risk and mistakes in social work practice', *Journal of Social Work Practice, 31(4), pp.491–502,* https://doi.org/10.1080/02650533.2017.1394823

Silver, C. (2016) Breaking down the boundaries between CAQDAS advocates and critics. Available at: https://www.fivelevelqda.com/article/9227-breaking-down-the-boundaries-between-caqdas-advocates-and-critics (*Accessed: 10/04/2018)*

Skowron, P. (2023) *Liberty Protection Safeguards implementation indefinitely delayed.* Research in Practice. Available at: https://www.researchinpractice.org.uk/all/news-views/2023/may/liberty-protection-safeguards-implementation-indefinitely-delayed/ (Accessed: 01/12/2023).

Smith, R. (2009) *Doing social work research.* Maidenhead: Open University press

Social Care Institute for Excellence. (2009) *Mental Capacity Act: Making 'best interests' decisions.* Available at: https://www.scie.org.uk/mca/practice/decision-making/making-best-interests-decisions (Accessed: April 2020).

Social Care Institute for Excellence (2011) *Living with young onset dementia.* Available at: https://www.scie.org.uk/dementia/symptoms/young-onset/living-with-young-onset-dementia-video.asp (Accessed: March 2020).

Social Care Institute for Excellence (2013) *Dementia Gateway: Knowing the person behind the dementia. What the research says.* Available at: https://www.scie.org.uk/dementia/after-diagnosis/knowing-the-person/files/knowing-the-person.pdf (Accessed: 05/05/2023).

Social Care Institute for Education. (2014a). *Mental Capacity Act: making sure the person is central to decision-making.* Available at: http://www.scie.org.uk/socialcaretv/video-player.asp?guid=c621ad85-8703-43b6-93e7-8be7fa6f4266 (Accessed: 29/01/2018).

Social Care Institute for Excellence. (2014b) *Early onset dementia: living at home with nursing support.* Available at: https://www.scie.org.uk/dementia/carers-of-people-with-dementia/supporting-carers/early-onset-living-at-home-with-nursing-support.asp (Accessed:21/04/2021).

Social Care Institute for Excellence (2017*) Deprivation of Liberty Safeguards: putting them into practice.* Available at: https://www.scie.org.uk/mca/dols/practice/care-home (Accessed: 05/11/2023).

Social Care Institute of Excellence (2020a) *Dementia Gateway: Young onset dementia. What the research says*. Available at: https://www.scie.org.uk/dementia/symptoms/young-onset/files/young-onset-dementia.pdf (Accessed: 10/08/2023).

Social Care Institute of Excellence (2020b) *Young onset dementia: Key issues.* Available at: https://www.scie.org.uk/dementia/symptoms/young-onset/key-issues.asp#:~:text=Younger%20people%20are%20more%20susceptible,)%20and%20HIV%2Drelated%20dementia. (Accessed: 02/08/2023).

Social Care Institute for Excellence (2023a) *Why early diagnosis of dementia is important.* Available at: https://www.scie.org.uk/dementia/symptoms/diagnosis/early-diagnosis.asp (Accessed on 17/08/2023)

Social Care Institute for Excellence (2023b) *Risk assessment process and key points to risk identification in virtual interaction.* Available at: https://www.scie.org.uk/care-providers/coronavirus-covid-19/social-workers/risk-identification#:~:text=information%20you%20have%3F-,SCIE%27s%20thoughts,or%20reduce%20the%20risk%3F (Accessed: 21/11/2023).

Social Work England (2023) *Social Work England Professional Standards.* Available at: https://www.socialworkengland.org.uk/standards/professional-standards/ (Accessed: 19/06/2023).

Sourial, N., Arsenault-Lapierre, G., Margo-Dermer, E., Henein, M. and Vedel, I. (2020) 'Sex differences in the management of persons with dementia following a subnational primary care policy intervention', *International Journal for Equity in Health, 19(1), pp. 175. doi 10.1186/s12939-020-01285-2.*

Spencer-Lane, T. (2009) 'Lost in a Legal Maze: Community Care Law and People with Mental Health Problems: The Law Commission's Review of Adult Social Care Law'*, Journal of Mental Health Law, (19), pp.139-148. doi https://doi.org/10.19164/ijmhcl.v0i19.250.*

Spencer-Lane, T. (2016) 'Mental capacity and deprivation of liberty: the Law Commission's consultation paper', *The Journal of Adult Protection, 17 (5), pp.331 – 334.*

Spencer-Lane, T. (2020) 'Overview of the Care 2014 (Chapter 2)', in Braye, S. and Preston-Shoot, M. (eds.) *The Care Act 2014. Wellbeing in Practice* London: Learning Matters, pp. 13.

Spencer-Lane, T. (2023a) '*Deprivation of liberty and the Mental Capacity Act – the way forward', Community Care. 5th April 2023.* Available at: https://www.communitycare.co.uk/2023/04/05/deprivation-of-liberty-and-the-mental-capacity-act-the-way-forward/ (Accessed: 28/08/2023).

Spencer-Lane, T. (2023b) ‘What now for deprivations of liberty*?’, Local Government Lawyer, July 2023.* Available at: https://www.localgovernmentlawyer.co.uk/adult-social-care/307-adult-care-features/54484-what-now-for-the-deprivation-of-liberty (Accessed: 01 October 2023).

Spreadbury, J.H. and Kipps, C.M. (2018) 'Understanding important issues in young-onset dementia care: the perspective of healthcare professionals', *Neurodegenerative Disease Management*, *8(1), pp. 37-47. doi: 10.2217/nmt-2017-0029.*

St John, W. and Johnson, P. (2000) ‘The Pros and Cons of Data Analysis Software for Qualitative Research’, *Journal of Nursing Scholarship, 32(4), pp.393-397.*

Stake, R. E. (2008). Qualitative case studies. In Denzin, N. and Lincoln, Y.S. (eds) *Strategies of qualitative inquiry* (pp. 119-149). California: Sage Publications.

Stalker, K., Davidson, J., MacDonald, C. and Innes, A. (2006) *A scoping study on the needs of and services to, younger disabled people including those with early onset dementia, in Scotland.* Edinburgh: Scottish Executive Social Research.

Stamou, V., La Fontaine, J., O'Malley, M., Jones, B., Gage, H., Parkes, J., Carter, J. and Oyebode, J. (2021) 'The nature of positive post-diagnostic support as experienced by people with young onset dementia', *Aging and Mental Health, 25(6), pp. 1125-1133. doi: 10.1080/13607863.2020.1727854.*

Stamou, V., La Fontaine, J., O'Malley, M., Jones, B., Parkes, J., Carter, J. and Oyebode, J.R. (2022a) 'Helpful post-diagnostic services for young onset dementia: Findings and recommendations from the Angela project', *Health & Social Care in the Community,* 30(1), pp. 142-153. doi: 10.1111/hsc.13383.

Stamou, V., Oyebode, J., La Fontaine, J., O'Malley, M., Parkes, J. and Carter, J. (2022b) 'Good practice in needs-based post-diagnostic support for people with young onset dementia: findings from the Angela Project’, *Ageing and Society,* doi: 10.1017/S0144686X22001362.

Standford, S. (2010) 'Speaking Back' to Fear: Responding to the Moral Dilemmas of Risk in Social Work Practice’, *British Journal of Social Work, 40 (4), pp. 1065-1080. https://doi.org/10.1093/bjsw/bcp156*

Stapley, E., Sally O’Keeffe and Midgley, N. (2022) 'Developing Typologies in Qualitative Research: The Use of Ideal-type Analysis', *International Journal of Qualitative Methods,* 21. Available at: https://doi.org/10.1177/16094069221100633 (Accessed: 02/02/2023).

Steele, L., Carr, R., Swaffer, K., Phillipson, L. and Fleming, R. (2020) 'Human Rights and the Confinement of People Living with Dementia in Care Homes', *Health and human rights, 22(1), pp.7-19.*

Stevenson, M. and Taylor, B. (2017) Risk Communication in Dementia Care: Professional Perspectives on Consequences, Likelihood, Words and Numbers’, *British Journal of Social Work, 47(7), pp.1940-1958.*

Strauss, A. and Corbin, J. (1997) *Grounded theory in practice*. London: Sage

Strauss, A. and Corbin, J. (1998) *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory.* California: Sage.

Svanberg, E., Spector, A. and Stott, J. (2010) The impact of young onset dementia on the family: a literature review. *International Psychogeriatric 23(3), pp. 356-71.*

Symonds, J., Miles, C., Steel, M., Porter, S. and Williams, V. (2020) 'Making person-centred assessments', *Journal of Social Work*, 20(4), pp. 431-447. doi: 10.1177/1468017319830593.

Szerletics, A. (2012) *Best interests decision-making under the Mental Capacity Act.* Available at: https://autonomy.essex.ac.uk/wp-content/uploads/2016/11/Best-Interests-Green-Paper-v3.0.pdf (Accessed: 10/01/2021).

Tanner, D. (2013) 'Identity, selfhood and dementia: messages for social work', *European Journal of Social Work, 16(2), pp. 155-170. doi: 10.1080/13691457.2011.611795.*

Taylor, B.J. (2010) *Professional decision making in social work.* Exeter: Learning Matters.

Taylor, B.J. (2012) 'Models for professional judgement in social work', *European Journal of Social Work, 15(4), pp. 546-562. doi: 10.1080/13691457.2012.702310.*

Taylor, B. (2017) *Decision making, assessment and risk in Social Work.* Sage: London

Taylor, B. and Whittaker, A. (2018) 'Professional judgement and decision making in social work', *Journal of Social Work Practice, 32(2), pp. 105-109.*

Taylor, C. and White, S. (2001) 'Knowledge, Truth and Reflexivity', *Journal of Social Work, 1(1), pp. 37-59. doi: 10.1177/146801730100100104.*

Taylor, H. (2016) 'What are 'Best Interests'? A critical evaluation of 'Best Interests' decision making in clinical practice.' *Medical Law Review, 24 (2), pp.176–205.* doi: 10.1093/medlaw/fww007

Teater, B. (2010) *An introduction to applying social work theories and methods.* Maidenhead: McGraw-Hill Open University Press.

Tew, J., Duggan, S., Carr, S., Ercolani, M., Glasby, J., Kinghorn, P., Miller, R., Newbigging, K., Tanner, D. and Afentou, N. (2019) *Implementing the Care Act: Building social resources to prevent, reduce or delay needs for care and support in adult social care in England.* University of Birmingham. Available at: https://www.birmingham.ac.uk/documents/college-social-sciences/social-policy/publications/implementing-the-care-act-2014.pdf (Accessed: 21/07/23).

Thane, P. (2009) *Memorandum by Professor Pat Thane (SC 47). History of Social Care in England.* London: Parliament. Available at: https://publications.parliament.uk/pa/cm200809/cmselect/cmhealth/1021/1021we49.htm (Accessed: 04/04/2023).

Thane, P. (2011), 'The experience of retirement in Britain, past and present', *Österreichischer Zeitung für Geschichtswischenschaft, 22(3), pp. 13-32. Available at:* http://www.univie.ac.at/oezg/ (Accessed:10/08/2022).

The Health Foundation (2023) *The National Assistance Act 1948.* Available at: https://navigator.health.org.uk/theme/national-assistance-act-1948 (Accessed: 29/07/2023).

The Law Commission (2010) *The Law Commission Consultation Paper No 192. Adult Social Care. A Consultation Paper.* London: The Law Commission. Available at: https://s3-eu-west-2.amazonaws.com/lawcoststorage11jsxou24uy7q/uploads/2015/03/cp192_Adult_Social_Care_consultation.pdf (Accessed: 20/06/2023).

Thomas, C. and Milligan, C. (2015) *How can and should UK society adjust to dementia?* London: Joseph Rowntree Foundation. Available at: https://www.jrf.org.uk/report/how-can-and-should-uk-society-adjust-dementia (Accessed: 14/07/23).

Thomas, C. and Milligan, C. (2018) 'Dementia, disability rights and disablism: understanding the social position of people living with dementia', *Disability & Society, 33(1), pp.115-131, DOI: 10.1080/09687599.2017.1379952*

Thompson, D. (2011) 'Younger onset dementia often ignored', *Social Policy Research Centre Newsletter, 109, pp.4-6*. Available at: https://www.unsw.edu.au/research/sprc/contact (Accessed: 14/01/2023).

Thompson, N. (2016) *Anti-discriminatory practice*. London: Palgrave

Thunberg, S. and Arnell, L. (2022) 'Pioneering the use of technologies in qualitative research – A research review of the use of digital interviews', *International Journal of Social Research Methodology*, 25(6), pp. 757-768. doi: 10.1080/13645579.2021.1935565.

Tindall, L., & Manthorpe, J. (1997). 'Early onset dementia: a case of ill-timing?', *Journal of Mental Health,* 6(3), pp. 237-249.

Tolhurst, E. (2016) 'The burgeoning interest in young onset dementia: redressing the balance or reinforcing ageism?', *Journal of Ageing in later life,* 10(2), pp. 9-29. doi https://doi.org/10.3384/ijal.1652-8670.16302.

Tolhurst, E., Bhattacharyya, S. and Kingston, P. (2014) 'Young onset dementia: the impact of emergent age-based factors upon personhood', *Dementia: The International Journal of Social Research and Practice,* 13(2), pp. 193-206.

Tuijt, R., Rait, G., Frost, R., Wilcock, J., Manthorpe, J. and Walters, K. (2021) 'Remote primary care consultations for people living with dementia during the COVID-19 pandemic: experiences of people living with dementia and their carers', *British Journal of General Practice 71 (709), e574-e582. DOI: 10.3399/BJGP.2020.1094* Available at: *https://bjgp.org/content/71/709/e574* (Accessed: 03/12/2023).

United Nations General Assembly (2006) *Convention on the Rights of Persons with Disabilities.* Available at: https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities (Accessed: 29/07/2023).

Van de Veen, D., Bakker, C., Peetoom, K., Pijnenburg, Y., Papma, J., PRECODE study group, de Vugt, M. and Koopmans, R. (2022) 'Provisional consensus on the nomenclature and operational definition of dementia at a young age, a Delphi study', *International journal of geriatric psychiatry, 37(3), pp. 1-11.* https://doi.org/10.1002/gps.5691.

van Vliet, D., de Vugt, M.E., Bakker, C., Koopmans, RT., and Verhey F.R. (2010) 'Impact of early onset dementia on caregivers: a review', *International Journal of geriatric psychiatry, 25(11), pp.1091-1100*.

Vernon, A. Qureshi, H. (2000) 'Community Care and independence: self-sufficiency or empowerment?', *Critical Social Policy, 20(2), pp.225 -276.*

Viale, R. (2020) *Routledge Handbook of Bounded Rationality.* London: Routledge

Ward, R., and Sandberg, L.J. (2023) *Critical dementia studies: an introduction.* Abingdon. Taylor & Francis.

Ward, S., Bagley, C., Lumby, J., Hamilton, T., Woods, P., & Roberts, A. (2016). 'What is 'policy' and what is 'policy response'? An illustrative study of the implementation of the Leadership Standards for Social Justice in Scotland, *Educational Management Administration & Leadership*, *44(1), pp.43-56.* https://doi.org/10.1177/1741143214558580.

Webb, S. (2017) *Professional Identity and Social Work.* Abingdon: Routledge

Webb, S. (2023) Social Work in a Risk Society, in Cree, V.E., & McCulloch, T. (Eds.) *Social Work: A Reader (2nd ed.).* Routledge: London.

Webster, C. (2023) 'What next for Liberty Protection Safeguards?' SCIE. Clare Webster Blog. 13th April 2023. Available at: https://www.scie.org.uk/mca/lps/blogs/what-next-lps (Accessed: 10/08/2023).

Werner, P. and Heinik, J. (2008) Stigma by association and Alzheimer's disease*, Aging & Mental Health, 12(1), pp.92-99.*

Werner, P., Vermeulen, P., Gorp, B., & Simonsen, P. (2022) From History to Intervention: A Sociocultural Analysis of Dementia Stigma. In M. Vandenbulcke, R. Dröes, & E. Schokkaert (Eds.), Dementia and Society (pp. 25-44). Cambridge: Cambridge University Press.

White, S. (1997) 'Beyond Retroduction? — Hermeneutics, Reflexivity and Social Work Practice', *The British Journal of Social Work*, *27(5), pp. 739-753. doi: 10.1093/oxfordjournals.bjsw.a011263*.

Williams, M. and May, T. (1996) *Introduction to the Philosophy of Social Research*. London: UCL Press

Williams, V., Boyle, G., Jepson, M., Swift, P., Williamson, T., and Heslop, P. (2014) 'Best interests' decisions: professional practices in health and social care', *Health and Social Care in the Community,* 22(1), *pp. 78-86.*

Williams, V., Boyle, G., Jepson, M., Swift, P., Williamson, T., and Heslop, P. (2012a) *Best interests decisions study Lay summary.* London: Mental Health Foundation.

Williams, V., Boyle, G., Jepson, M., Swift, P., Williamson, T., and Heslop, P. (2012b) *Making best interests decisions: People and processes.* London: Mental Health Foundation.

Willis, P., Lloyd, L., Hammond, J., Milne, A., Nelson-Becker, H., Perry, E., Ray, M., Richards, S. and Tanner, D. (2022) ‘Casting Light on the Distinctive Contribution of Social Work in Multi-disciplinary Teams for Older People’, *British Journal of Social Work 52(1), pp.480-497.*

Willner, P., Jenkins, R., Rees, P., Griffiths, V.J. and John, E. (2011) 'Knowledge of Mental Capacity Issues in Community Teams for Adults with Learning Disabilities', *Journal of Applied Research in intellectual disabilities,* 24(2), *pp. 159-171.*

Wilson, K., Ruch, G., Lymbery, M. and Cooper, A. (2011) *Social Work. An introduction to contemporary practice.* Second edition. Harlow: Pearson.

World Health Organisation (2019/2021) International Classification of Diseases, Eleventh Revision (ICD-11), Available at: https://icd.who.int/en/docs/ICD11-license.pdf (Accessed: 29/07/2023).

World Health Organisation (2023a) *Dementia. The facts.* Available at: https://www.who.int/newsroom/factsheets/detail/dementia#:~:text=Key%20facts,nearly%2010%20million%20new%20cases. (Accessed: 20/06/2023).

World Health Organisation (2023b) *Ageing and health.* Available at: https://www.who.int/news-room/fact-sheets/detail/ageing-and-health (Accessed: 29/07/2023).

World Health Organisation (2023c) *Gender and health.* Available at: https://www.who.int/health-topics/gender#tab=tab_1 (Accessed: 29/07/2023).

World Health Organisation (2023d) *International Classification of Diseases, Eleventh Revision (ICD-11), (WHO) 2022/2023. Online.* Available at: https://icd.who.int/browse11 (Accessed: 17/07/2023).

Yeung, M., MacFarland, K., Mlilo, V., Dean, N. and Underwood, B. R. (2021). ‘Patients with young-onset dementia in an older people's mental health service’, *British Journal Psychiatry Bulletin, 45(2), pp.81–86. https://doi.org/10.1192/bjb.2020.89*

Young, R. and Collins, A. (2004) ‘Introduction: Constructivism and social constructionism in the career field*’, Journal of Vocational Behaviour 64(6), pp.373–388.*

Young Dementia Network (2022a) *Supporting implementation of the NICE guideline for people with young onset dementia.* Dementia UK. Available at: https://www.youngdementianetwork.org/wp-content/uploads/2021/09/NICE-young-onset-dementia-guideline-FINAL.pdf (Accessed: 19/06/2023).

Young Dementia Network (2022b) *Young onset dementia pathway. Diagnosis and support for people with young onset dementia and their families.* Dementia UK. Available at: https://www.youngdementianetwork.org/wp-content/uploads/2022/03/Young-onset-dementia-pathway-03-2022-FINAL.pdf (Accessed: 19/05/2023).

Young Dementia Network (2022c) *Good Practice in young onset dementia. Improving diagnosis and support for younger people with dementia.* Dementia UK. Available at: https://www.youngdementianetwork.org/wp-content/uploads/2022/08/The-Angela-Project-Good-practice-in-young-onset-dementia_WEB_O8-22.pdf (Accessed: 19/06/2023).

Zhong, R., Sisti, D.A. and Karlawish, J.H.T. (2019) 'A pragmatist's guide to the assessment of decision-making capacity', *British Journal of Psychiatry*, 214(4), *pp. 183-185. doi: 10.1192/bjp.2019.17.*

List of statutes

Care Act 2014

Coronavirus Act 2000

Chronically Sick and Disabled Persons Act 1970

Equality Act 2010

Human Rights Act 1998

Mental Capacity Act 2005

Mental Capacity Amendment Act 2019

Mental Health Act 1983/2007

National Assistance Act 1948

The Convention for the Protection of Human Rights and Fundamental Freedoms 1950

United Nations Convention on Rights of Persons with Disabilities 2006

List of Cases

A Local Authority v JB [2021] UKSC 52

F v West Berkshire [1990] 2 AC

LB Hillingdon v Steven Neary [2011] EWHC 1377 (COP)

Local Authority X v MM & Anor (No. 1) (2007) EWHC 2689

HL v UK 45508/99 [2004] ECHR 471

P (by his litigation friend the Official Solicitor) v Cheshire West and Chester Council & Anor [2014] UKSC 19

The LBX v K, L, M [2010] EWHC 2422 (Fam)

Re AA [2012] EWHC 4378 (COP)

Stuart Bracking & Ors v Secretary of State for Work and Pensions [2013] EWCA Civ 1345

Westminster City Council v Sykes [2014] EWHC B9 (COP), [2014] MHLO 11

List of appendices

Appendix 1: Data extraction table: YOD and decision making

Authors year title	**Purpose of study (research question)**	**location**	**Sample**	**methodology**	**Findings and themes**	**Limitations**
Young, P. Fiona, Kritina,.M Jones, Guss, R. (2012) *I'm not all gone, I can still speak. The experiences of young people with dementia.*	Explore what are the experiences of younger people with dementia, what particular concerns or difficulties they encounter. What support has been beneficial to them and areas in need of change with the aim to develop an action plan.	NHS trust in England	A purposive sample was used of people between 60 – 67 with a diagnosis of dementia before 65th birthday. Phase 1, n=8 , Phases 2, n= 5 and phase 3, n= 3.	Qualitative design consisting of action research in three phases. The first phase involved interviews. Phases two and three involved action research and discussion of findings from phase 1.	Age of diagnosis of dementia and indication of shock at receiving a diagnosis in their 60's. Support of family and friends is pivotal. Social support from a variety of sources is a need. Shared social identity, focus on remaining strengths. Usefulness of information from people who have experienced dementia fosters hope and resilience. Age related difficulties include reaction to diagnosis. Maintaining a sense of self. The reaction of others to dementia. Keeping active and involved. Sharing a social identity. General areas of support	Smaller sample. Tended to be white females and may not represent a broad range of experiences of younger people with dementia. No employment issues as participants were not in employment and no childcare issues as none of the participants had dependent children.
Lai,M. Jeon,Y.H; McKenzie,H., and Withall,A. (2019)	Understand how people with YOD and their families make decisions about the	USA	14 people with YOD and 28 family members	Semi-structured interviews. Qualitative content analysis of the	Only a few of the participant engaged in any of the 3 approaches in decision making about the	Study relates to USA where policy differs slightly. Questions about how applicable the 3

Authors year title	**Purpose of study (research question)**	**location**	**Sample**	**methodology**	**Findings and themes**	**Limitations**
How do people with YOD and their families make decisions and plan for future in relation to advanced planning, shared decision making and supported decision making.	future in relation to the 3 key approaches.			interviews was carried out.	future. Implications for service delivery. Attention needed to the unique perceptions and experiences of decision making for people with YOD and their families	approaches are to people with YOD and their families.
Roach, P., Keady, J., bee, P., Hope, K. (2008) *Subjective experiences of younger people with dementia and their families: implications for UK research, policy and practice.*	Draw together available literature on the experience of younger people with dementia and highlight gaps in current evidence	UK	N/A	Literature based.	Little published research on experiences of those with YOD and their families. Need for early diagnosis. Recognising – diagnosis, stigma and positive outcomes, information providing. Relating – impact on the family, isolation, feelings of guilt, helplessness, loss and grief. Restructuring – relationships, strategy and coping, movement and adjustment	This was a literature based study, drawing together findings from previous studies. Earlier study. No formal measure of quality of the studies was used.
Rabanal et al. (2018). Understanding the	Aim to explore the experiences and needs of younger people	Northern England	14 people with dementia between the	Qualitative study. Semi structured Interviews carried out	3 superordinate themes: The process of diagnosis, The impact of living with	Smaller sample. Further analysis needed of the impact of interviewing with

Authors year title	**Purpose of study (research question)**	**location**	**Sample**	**methodology**	**Findings and themes**	**Limitations**
needs and experiences of people with young onset dementia: a qualitative study	living with dementia with an objective to identify services that may better fit their unique circumstances and needs and to understand the issues that impact on them		ages of 57 and 67 years Age at diagnosis ranged between 52 and 64.	with PWD and carers present. Analysis using Interpretative Phenomenological analysis.	YOD, the needs of people with YOD and living well with YOD.	carers present and whether the voice of the person was fully captured.
Greenwood, N. & Smith, R. (2016) The experiences of people with young onset dementia. A meta ethnographic review of qualitative literature	Synthesise and evaluate qualitative literature relating specifically to the experiences of people with YOD. Explored What are the experiences of young people diagnosed with YOD	UK but international research used in the literature viewed	Under 65 years	Meta ethnography database search experiences of 87 people noted. Preferred Reporting Items for Systematic Reviews and Meta-Analysis used. Meta ethnographic approach used to analyse the findings	People living with YOD face unique social challenges which are different to those of older people living with dementia and which result in an even greater negative impact on their lives. These include loss of employment, lack of understanding by other and contribute to social isolation. Interventions that facilitate peer support and allow people with YOD to engage in meaningful activity are helpful. Peer support can reduce the sense of medicalising the condition and social isolation. Diagnosis threatening to self, autonomy and	A literature based study which reviewed existing research. The study

Authors year title	Purpose of study (research question)	location	Sample	methodology	Findings and themes	Limitations
					identity. Challenges – made more difficult by a lack of understanding of others, and social isolation.	
Clemerson, G., Walsh, S. and Isaac, C. (2014) Towards living well with young onset dementia: An exploration of coping from the perspective of those diagnosed	To provide an exploration of the subjective experiences of young-onset Alzheimer's disease. To explore in depth the personal, social and psychological impact of living with the disease in younger life and the processes individuals go through in adjusting to and coping with these experiences	UK	8 participants (35 -65) known to a memory clinic with a diagnosis of AD	Semi-structured interviews were carried with participants. Data was analysed using Interpretative phenomenological analysis	AD is strongly situated in the life cycle and a person's social frame, which reflects the mid-life stage of human. Need to develop specialist services for younger people with dementia to help address the psychological feelings of difference and isolation. Societal understanding of YOD a crucial factor in reducing stigma and highlighting the needs. Disruption of the life-cycle- I'm too young, loss of adult competency, reviewing life expectations, Agency: powerlessness and loss of agency, regaining control	Focused on Alzheimer's and did not comment of other forms of dementia.
Rodda and Carter, J. (2016)	To understand the provision of services for diagnosis	UK	Online sample. Online Survey of 250 professionals	Quantitative study.	Chaotic pathways for people with YOD. Older peoples services likely to be responsible for	Study carried out online. Lack of discussion of the limitations of online research. Study did not

Authors year title	Purpose of study (research question)	location	Sample	methodology	Findings and themes	Limitations
A survey of UK services for younger people living with dementia	management and aftercare of YOD.		including psychiatrists 189, 33 non grade psychiatrists, 19 mental health nurses, 5 consultant neurologists, 2 psychologist and 2 OT's. 76 NHS Trusts across the UK.		diagnosing YOD. Diagnosis and care sometimes provided by adult mental health teams. A high percentage note no access to age appropriate dementia services post diagnosis. 65% of respondents agreed with the statement that YPD receive a timely diagnosis despite the lack of coordination. Average time to diagnosis from symptom onset is around four years Many people with YOD have no access to specialist clinicians focused on YOD. YOD absorbed into ageless generic mental health services. No access to age appropriate respite. Development of ageless services led to disbanding specialist dementia services for younger people.	have a wide take up. Some agencies did not respond to the survey.
Svanberg, E., Spector, A. and Stott, J. (2010) The	Exploring the experiences of younger people with	UK	Literature review	Narrative synthesis used. Studies focused on those with a	Difficulties with diagnosis, Impact on the family, age of person with dementia	Wide range of studies make it difficult to pinpoint key issues. Single

Authors year title	Purpose of study (research question)	location	Sample	methodology	Findings and themes	Limitations
impact of young onset dementia on the family: a literature review.	dementia and their families. Including the impact of a diagnosis of young onset dementia on the individual, the impact of a diagnosis on families			diagnosis of dementia under the age of 65 years, or their carers Studies concerned the individual experience of young onset dementia, caring experiences and implications for families; Studies written in English.	matters. Gender is a factor in carer outcomes. Few studies consider children., Need to form relationships with younger people with dementia in order to explore their experiences. Carers of younger people with dementia experience more negative outcomes than carers of older people with dementia.	researcher reviewed the literature. Use of a narrative synthesis may mean findings are more subjective and could be interpreted differently.
Stamou et al (2022) Helpful post-diagnostic services for young onset dementia. Findings and recommendations from the Angela Review	The study aimed to gather information about services that people with YOD and their family carers find helpful. The study sought to identify the core features of these services to inform service design, delivery and improvement.	England 14 NHS sites	Nationwide Survey carried out involving 233 respondents Purposive sample: Semi structured interviews: 8 with people with YOD, 14 with carers, 2 with dyads	Qualitative approach. Survey using SPSS 23 Interviews analysed using a qualitative analysis.	12 themes were captured and clustered into super-inordinate themes of 'Person-centredness', Functional consistency Organisational coherence, Key conclusions included the need for flexibility and a collaborative stance, age-appropriate services, and holistic, services need to provide for needs associated with rare dementias and be family-centred. The need for specialist services to be commissioned and	Lack of diversity in participants for the survey and interviews. Potential bias towards educated participants.

Authors year title	Purpose of study (research question)	location	Sample	methodology	Findings and themes	Limitations
					arrangements need to be stable over time to enable continuity	
Livingston, G., Leavey, G., Rait, G. Livingston, D., Sampson, E., Bavishi, S., Shahriyarmolki, K. & Cooper, C. (2010) Making decisions for people with dementia who lack capacity	Identify the common difficult decisions made by family carers on behalf of people Explore and identify what facilitates and are barriers to decision making. To use this information to assist in such decisions in future by making information available about barriers and how to overcome them	UK. Inner and outer London Health NHS NHS trusts. GP clinics, community clinics, memory clinics and specialist neurology clinics.	Carers people with dementia 43 for focus group and 46 for interview	Qualitative approach: Focus group and semi structured interviews. Analysis using coding frame and qualitative analysis computer package – Atlas	5 core problems of decision making: 1. Access to dementia related health care.2. making plans if they are too ill to care. 3. Care homes. 4. Legal/financial matters.5. Non dementia health care. Barriers to decision making include: patient denial of problem, rejection of help. Professional barriers: include not recognising the problem, late diagnosis, timing and quantity of information given. Confidentiality and data protection, bureaucracy and rigidity. Psychological barriers include: role conflict, carer guilt, family conflict, rigidity. Carer involvement in appointments.	Carers from a wide range of backgrounds. All participants were known to secondary services so may have missed people who do not see themselves as carers. Starting age of participants with dementia were 50

Appendix 2: Data extraction table: MCA decision making and Social Work

Authors, Year, study name	Purpose of the study	location	Sample	methodology	Themes	Findings and conclusions	Limitations
Ariyo, K., McWilliams, A., David, A. & Owen, G. (2021) Experiences of assessing mental capacity in England and Wales: A large-scale survey of professionals	Explore the experiences of assessing mental capacity across professional groups.	England and Wales	611. Made up of psychiatrists (10.1%), social workers (14.6%), nurses (7.5%), other Dr's (2%), clinical psychologists (4.9%), SALT (2.9%), solicitors 1.3%	Self-reporting questionnaire sent out to different professionals. Quantitative analysis using regression methods and thematic analysis for the qualitative data	how often capacity is assessed. where capacity assessment take place, self-ratings around competency and challenges linked to MCA assessment, use of psychological testing and concerns about undue influence.	+50% of professionals carry out 25 or more MCA assessments per year. Psychiatrists, nurses and social workers carry out MCA assessments most frequently. High rates of confidence reported by different professionals. Lower levels for psychiatrists. Most professional shared concerns about undue influence	The study used a qualitative analysis approach but some aspects of this are unclear. Smaller sample of social workers. Not a lot of qualitative data on social work.
Murrell and Mc Calla (2016) Assessing decision making capacity the interpretation and	Study aimed to explore and understand how the mental capacity is	Southwest England. Single county	5 social workers and one field work assessor in one county	Nonprobability, purposive sampling based on social workers using the MCA. 6	Knowledge in theory and confidence in using the MCA varies. Challenges in	A capacity assessment is only as good as the person who's doing it. Complexity of assessing MCA need	This was a smaller study which had an unclear strategy on how

Authors, Year, study name	Purpose of the study	location	Sample	methodology	Themes	Findings and conclusions	Limitations
implementation of the MCA amongst social care professionals	understood by social care workers with particular attention given to decision making			semi structured interviews. Material analysed using thematic analysis. Reflexivity noted as part of the approach	identifying relevant information. Tendency to merge capacity and Best Interests. Social care practitioners take on multiple roles. Competing demands for social care workers. MCA is valued amongst social care workers	for clarity in processes, how do service users perceive risk. Identifying the relevant information is challenging. Decision making can often be a complex process. There is an interdependent process of decision making and assessment in using the MCA. These are not always carried out sequentially and separately.	participants were recruited. The study occurred in the early years of the implementation of the MCA (2014).
Williams, Boyle, Jepson, Swift, Williamson and Heslop (2012) Making best interest decisions: people and processes. MH foundation	Explore and provide a picture of the main contexts and types of decisions being made using the best interests provision within the MCA.	England and Wales	4 areas in England. Health and social care and legal professions.	385 online surveys 68 telephone interviews 25 semi structured interviews	Risk and best interest decision making, multiple BI decisions, financial capacity. Confidence in BI decision making. Assessment of capacity, joint decision making, formal structures of mca, health care decision making, involvement of the	Assessment of capacity does not always precede best interest decision making. Joint assessment common, assessing capacity difficult, evidence of finding regaining capacity, blurred notion of capacity overlaps of capacity assessment and best	Unclear whether there was bias in selection process The analysis of data could have been outlined more clearly. Reflexivity of researchers was not noted in the study write up.

Authors, Year, study name	**Purpose of the study**	**location**	**Sample**	**methodology**	**Themes**	**Findings and conclusions**	**Limitations**
					person, formal and informal processes, lead decision maker, parameters of decision making, family disputes and decision making	interest, best interests not always formalised in a meeting, decision making. Lack of formal structures, lack of examples of involving people in decision making.	
Boyle, G. (2013) Facilitating decision-making by people with dementia: is spousal support gendered?	Explore the communication and decision-making abilities of people with dementia in everyday situations	UK Northern metropolitan town	21 married couples.	Qualitative: ethnography (participant observation) and interviews. Included assessment of capacity. Interviews adapted to the cognitive ability of participants	Gender perspective in the MCA. Gender differences in spousal support, financial decision making, and exclusion of spouses with dementia from decision making. Autonomy and rights.	Gender differences in spousal support. Gender influences whether there is involvement in financial decisions. Gendered assumptions impact mental capacity assessment. MCA assessment can reinforce gendered assumptions which potentially may lead to women being more likely to be deemed to lack capacity. Support strategies to involve spouses with dementia to be involved with decision	The study focussed on a specific settings (a northern town). Unclear whether this is representative of wider England and Wales. The study linked to assessment of capacity which can have an emotional impact on participants. This was partly acknowledged in the study.

Authors, Year, study name	**Purpose of the study**	**location**	**Sample**	**methodology**	**Themes**	**Findings and conclusions**	**Limitations**
						making varies according to gender.	
MacDonald, A. 2010 The impact of the MCA on social work decision making and approaches to assessment on risk	Explore the early impact of the Mental capacity act on decision making and recording in health and social care	UK	Purposive sample of social workers with older people	Document review, reading files and interviews with social workers. Focus group with Alzheimer's society including carers. Grounded theory approach	Diagnosis. Assessment of capacity. Unwise decisions. Best interest decision making. Types of decision making: Cognitive or legalistic, Recording, working across professional boundaries, risk, approaches to working with dementia (rights based, legalistic, actuarial),	Diagnosis of dementia deemed synonymous with lacking capacity. Awareness of a social construction of dementia in rights-based approaches. Actuarial approaches event Links to the wider risk society and culture which seeks to 'manage' risk.	The study used a small sample. It was carried out in the early stages of implementation of the MCA when there was limited awareness and training available.
Dunn, M. C., et al. (2010). "Living 'a life like ours': support workers' accounts of substitute decision-making in residential care homes for adults with intellectual disabilities.	Explore how the MCA interfaces with the practical and ethical dynamics of care and support in community-based support	UK	21 interviews with Support workers who work in one of 3 residential care homes for adults with intellectual disability	Qualitative, grounded theory analysis of 21 interviews with support workers working in residential care homes for adults with Intellectual disability. Observation of	Best interests, beliefs about benefits of substitute decision making, views on person centred planning, personal experience as a factor in substitute decision making. In contrast	There are discrepancies between the legal regulation of substitute decision-making and the ways that the support workers make sense of their work. This suggests further training around the MCA in the area of	From reading the study it's unclear what the status of support workers were and whether they were employees or agency staff. May suggest that status

Authors, Year, study name	Purpose of the study	location	Sample	methodology	Themes	Findings and conclusions	Limitations
	for adults with intellectual disability living in residential care homes.			the support workers care practices. Total of 176 hours.	to the narrow legal responsibilities placed upon them, it is argued that support workers interpret substitute decision-making within a broad moral account of their care role, orientating their support towards helping residents to live 'a life like ours'. In so doing, support workers describe how they draw on their own values and life experiences to shape the substitute decisions that they make on behalf of residents.	best interest decision making. Support workers believed following the care plans restricts daily living. Substitute decision making appeared to be used to support residents to live a good life.	makes a difference on responses in interviews.
Manthorpe, J., Rappaport and Samski, (2009). Expertise and Experience: People with Experiences of Using Services and	Explore people who have experiences of using services and carers of people who use services carers	England a range of settings (urban and shire counties)	10 participants, services users and carers supporting adults with learning disability, mental	Purposeful sample. Semi structured interviews. Thematic analysis was used.	Principles of the MCA, Best interests' knowledge about the condition is important. Advanced planning a good development.	Positive comments of the MCA. Supportive of best interest principles of the MCA. Advanced decisions within the MCA are seen to offer greater	The study included a small sample which meant the consultation was limited. Ethical approval

Authors, Year, study name	Purpose of the study	location	Sample	methodology	Themes	Findings and conclusions	Limitations
Carers' Views of the Mental Capacity Act 2005.	about the about the impact of the MCA on their lives and of those they support.		health problems and physical disability		Advocacy welcomed. Practitioners needing to adopt a holistic approach including communication and listening skills. Need to speak with people directly. Concerns about poor practice.	choice and empowerment. Lack of awareness around the MCA and need for professional to provide service users and carers with information. Training could be provided to those using services and their carers. Acknowledgment of the difficulty of balancing risks and safeguards.	not sought due to the nature of the study.
Manthorpe, J. and K. Samsi (2016). Care homes and the Mental Capacity Act 2005: Changes in understanding and practice over time."	Exploring support for older people with dementia living in care homes, and on findings from our follow-up investigation of care home staff's knowledge of and experiences with the MCA.	Southeast England	Purposeful sample of staff working in 5 different care homes at two time points (32 staff at Time 1 in 2008 and 27 staff at Time 2 in 2012. Sample included senior care staff and managers and care assistants	Semi structure Interviews: face to face and telephone. Thematic analysis	Staff knowledgeable about the MCA. Limited confidence of junior care staff in using the MCA. Manager were the most confident. Deference to senior staff in relation to decision making. Discussion and debate of moral and ethical issues related to decision making.	Staff in care homes tend to refer to seniors when specific decision making is required. Staff use the principles of the MCA in their work but are not always conscious of this. Care home staff in this study reported that advanced planning and pre-specifying preferences were more common among	From reading the article linked to the study it is unclear whether social workers were involved in the research.

Authors, Year, study name	Purpose of the study	location	Sample	methodology	Themes	Findings and conclusions	Limitations
					Legalising decision making.	new care home residents, especially those with dementia. Some homes incorporated principles of MCA better than others. Conflict and uncertainty in decision making evident despite provisions like advanced decisions. Some awareness of the protections offered by the MCA	
Manthorpe & Samsi (2013) Changing practice: adapting to the Mental Capacity Act 2005	Explore how social care staff experienced using the MCA following its implementation	England	3 phases. Initially interviews with 10 practitioners, 2nd phase interview with 9 and third phase interview with 15	Semi structured interviews	Legal clarity Early training	Fine grained judgement about the MCA Legal literacy important for social worker	Conducted in the London region. Staff turnover meant continuity of participants was not possible. Some interviews conducted by telephone.
Emmett, C, Poole, M., Bond, J. Hughes, J. (2013). Homeward	Look at ways of improving	North of England	Patients (n= 29 Family members (n= 28)	Ethnographic study and	Around half of the patients were assessed under MCA.	Findings note that practice in hospital settings is variable.	The location of the study was not disclosed.

Authors, Year, study name	**Purpose of the study**	**location**	**Sample**	**methodology**	**Themes**	**Findings and conclusions**	**Limitations**
bound or bound for a home? Assessing the capacity of dementia patients to make decisions about hospital discharge: Comparing practice with legal standards	assessments of capacity. and judgements about best interests in connection with people with dementia admitted to acute hospitals.		Professionals (n= 35)	qualitative interviews	Practice is variable.	Influenced by medical approaches.	The study linked only to inpatient experiences of the MCA.
Jepson, M., et al. (2016) Indirect payments: when the Mental Capacity Act interacts with the personalisation agenda.	Find out how Direct Payments is being administered for people who lack capacity. See how practitioners are bringing together the demands of personalisation in relation to people who lack capacity. Investigate current practice of DP for people	Local authorities in England mix of urban and rural	Social Workers (n=67) and recipients of indirect' payments (n=18)	Qualitative approach. Semi structured interviews. Participants were social work authorities in England in 2011-2012. Thematic analysis using coding	Contradiction between capacity and personalisation. Capacity to consent to direct payment and capacity to manage a DP. Informing 'suitable people' of the capacity assessment. DP and best interests. Deciding who a suitable person should be. Details of support plans Reviewing and monitoring DPs not always frequent enough.	Noted 5 decision-making points in the indirect payments process: The decision to take on an indirect payment, the assessment of mental capacity, the identification of a suitable person, the establishment of the care recipient's best interests and the decisions about how to execute the indirect payment. Most understand and follow the MCA although	There was a lack of analysis of methods and data collection approach Reflexivity was not included in the discussion

Authors, Year, study name	**Purpose of the study**	**location**	**Sample**	**methodology**	**Themes**	**Findings and conclusions**	**Limitations**
	who lack capacity					some confusion about consent.	
Willner, P., et al. (2011). Knowledge of Mental Capacity Issues in Community Teams for Adults with Learning Disabilities.	To evaluate the state of knowledge of mental capacity issues among health and social services professionals working in community. teams supporting people with learning disabilities	South Wales	40 professionals working in 10 MDT for people with LD. Community nurses, speech and language therapists, occupational therapists, physiotherapists and social workers	Quantitative approach. A structured interviews based on three scenarios, based on actual cases. The scenarios concerned a financial/legal issue, a health issue and a relationships issue, as well as a set of ten 'true/false' statements. Analysis was descriptive and used devised scoring sheet.	Gaps in knowledge, identifying capacity issues, whose responsibility, reluctance to decide, weighing up severity of disability and complexity of decision, assessing capacity, unwise decisions, failure to identify that a best interest decision is needed, the decision maker, consultation around best interest decisions, the least restrictive alternative, risk assessment, risk management,	There are some gaps in professional's knowledge of using the MCA. Where professionals are trained and have experience of MCA issues, knowledge is good. Interviews helped raise awareness of training needs. Performance of health and social services staff similar.	Focused on a specific area – South Wales. The scenarios provide limited interpretation of understanding of MCA
Jayes, M., Palmer, R. Endebry, P. (2019) How do health and social care professionals in England and Wales assess mental	A review of evidence of how health and social care professionals in England and	Literature review	None 20 studies included in the literature review	Systematic literature based on studies published between 2007 - 2018	preparing for assessment; capacity assessment processes; supported decision-making; interventions to	MCA assessment practice varies and is not always consistent with legal requirements, Interventions like training and practical	Focus mainly on 2 groups: adults with learning disability and adults with mental health needs.

Authors, Year, study name	**Purpose of the study**	**location**	**Sample**	**methodology**	**Themes**	**Findings and conclusions**	**Limitations**
capacity? A literature review	Wales assess mental capacity				facilitate or improve practice.	resources, flowcharts and checklists have been designed to help practitioners such as assessment flowcharts, checklists and documentation aids. But they would benefit from evaluation before they are implemented more widely.	Generalisability across groups is limited.
Clerk, G., Schaub, J., Hancock, D., Martin, C., (2018) A Delphi survey of practitioner's understanding of mental capacity	Explore the application of the MCA from a range of professionals	England and Wales	Range of practitioners initially 98. (49 nurses, 29 care assistants, 7 social workers, 2 physiotherapists, 4 GP's and nine professions not identified	Delphi study engaging practitioners and stakeholders in 2 rounds of scenario based questionnaires	Capacity to refuse treatment attracted divergent ideas. Unsure when to assess capacity. Lack of clarity around unwise decisions Consequentialist and deontological ethical judgements	Lack of consensus from practitioners when the use the MCA. Recommendations for review of the law for greater clarity.	Questions whether scenario based questionnaires mirrored real life or led to idealised answers. The study had a large initial take up but by the second round this number had whittled down. Not all professionals identified themselves.

Authors, Year, study name	Purpose of the study	location	Sample	methodology	Themes	Findings and conclusions	Limitations
Ratcliffe, D. and Chapman, M. (2016) Health and social care practitioners' experiences of assessing mental capacity in a community learning disability. team	Explore the challenges and barriers in undertaking MCA assessments amongst health and social care practitioners. The second aim was to identify. ways that practitioners can address the challenges.	North of England	N= 8 All staff based within a community learning disability team.	Qualitative semi structured interviews. Data was analysed using a thematic network analysis approach.	12 themes systemic barriers to assessment, capacity assessing as a challenging process, person-specific challenges, protective practices, and protection of a fundamental human right	Person specific barriers were noted.	This was a small study with limited generalisability. 2 social workers were participants in the study

Appendix 3: Data extraction table on YOD and Social work

Author, year and title	Purpose of study (research question)	location	Sample	methodology	Findings	Conclusions and themes	Limitations
Couzner et al. (2022). What do health professionals	Establish consensus around what health professional need to know about YOD	Australia	19 people on a panel of experts	An international Delphi study involving a ranged of disciplines	Consensus was drawn on themes that are important for health professionals to be	Findings are helpful in the design of care and support services for people with YOD and also education and training of health care	Lack of data capturing the experiences of participants due to Delphi study approach.

Author, year and title	Purpose of study (research question)	location	Sample	methodology	Findings	Conclusions and themes	Limitations
know about YOD?				including social work. A multistage method was used, where participants rank answers to an online survey with open ended questions Quantitative analysis was carried out on the collected data.	aware of in working with YOD. Themes drawing high consensus in the ratings included professional knowledge of YOD identification, diagnosis, treatment, and ongoing care.	professionals working with YOD.	
Chemali,Z.; Schamber,S.; Tarbi,Ec; Acar,D. and Avila-Urizar, M. (2012) *Diagnosing early onset dementia and then what? A frustrating system of aftercare resources.*	An investigation of the mechanisms of care given to people with early onset dementia.	New Zealand	85 participants who were patients of a dementia clinic.	Medical case review. Various statistical analysis tools were used. Mini mental state examination was used as a marker for inclusion	Patients receive extensive work, but this occurs while they are heavily medicated. They remained at home where they lacked access to age-appropriate care services. Social work support is available but does not tackle the lack of resources and	Alongside better awareness of YOD, recommends greater flexibility for greater roles for nursing social work. Greater policy level action needed to support the rights and needs of people with YOD.	Little involvement of social work in the study. Study relied on medical records which may be subject to some bias.

Author, year and title	Purpose of study (research question)	location	Sample	methodology	Findings	Conclusions and themes	Limitations
Manthorpe, J. (2016). *The dement in the community: social work practice with people with dementia revisited*	Explore historical account of young onset dementia and social work involvement	UK	None	Documentary research	Family care, continuity of care are important in YOD. YOD recognised as different. Rare for social work to be talked about with dementia. Social circumstances matter.	Social work, family care. Young onset dementia treated differentiation	Represents documentary research with a lot of interpretation of records.
Reagan, J.L. (2016) Ethnic minority, young onset, rare dementia type, depression: A case study of a Muslim male accessing UK dementia health and social care services	The study sought to understand How are people from ethnic and religious minorities are supported in UK dementia health and social care services and the motivations for a person from minority cultural and religious group to access UK dementia health and social care services.	UK. English city	Case study. 1 man with YOD and rare dementia	Case study of one participant investigation the contemporary phenomenon using biography, interviews and observation. Critical realist grounded theory used to analyse data.	Negative experiences of accessing services. Need for more education. Barriers to accessing health and social care services Religious needs overlooked.	Helpful to recognise the motivations of people using dementia services. Need to move from motivations linked to desperation to 'informed choice. Role of religious communities can be promoted to reduce stigma, self-isolation, and reduce the strain from health and social care services as well as improving the dementia care experience.	Little discussion of how gender, age and culture factors were explored.

Author, year and title	Purpose of study (research question)	location	Sample	methodology	Findings	Conclusions and themes	Limitations
Bentham, P. and LaFontain, J. (2005) Services for younger people with dementia	Discussion paper of the organisation of services for people with YOD	UK	None	None	None		Discussion paper of services. Social work only marginally noted in the paper.

Appendix 4: Data extraction table: Non empirical and grey material on MCA and YOD

Authors, Year	Document type	title	location	Findings	Themes	Limitations
Ramluggun,P Ogo, E. 2016 Young onset dementia service provision and its effect on service users	Peer reviewed article	Young onset dementia provision and its effect on service users and family members	UK	Importance of family involvement in working with YOD.	Impact on family, stigma, lack of awareness, overlooked, GP input with diagnosis, specialist support. Family involvement in decision making Interdisciplinary approach needed	Article fails to define which family members are commonly involved in decision making.

Authors, Year	Document type	title	location	Findings	Themes	Limitations
and family members,						
Cosgrove, C. & Williams, D. (2004)	Report on behalf of the Alzheimers society.	Services for younger people with Alzheimer's disease and other dementias	UK	Importance of coordination and liaison between dementia services for YOD and LOD is essential. Genetic factors important for YOD as is neurodegenerative disorder substance misuse, particularly alcohol misuse, has been identified as a cause of dementia in 10% of younger people. People with dementia should be involved in the planning of services whenever this is appropriate	Employment practices: Individualised approach for people with YOD	The article is quite dated and statistics used in the article are less relevant now.
Morgan, S. and N. Andrews (2016).	Conceptual paper	Positive risk-taking: from rhetoric to reality. Journal of Mental Health Training Education and Practice 11(2): 122-132.	UK	Based on professional experience of supporting people with dementia. Positive risk-taking can occur in a context of strengths-based, values-based and relationship-based working.	Health and social care practitioners face a range of challenges: Including positive risk taking. Mental capacity relevant when exploring positive risk taking	Unclear sources for ideas.

Authors, Year	Document type	title	location	Findings	Themes	Limitations
				Practical guidance for putting positive risk-taking into practice.		
Rayment, D. and T. Kuruvilla (2015)	Review article	Service provision for young-onset dementia in the UK." Progress in Neurology and Psychiatry 19(4): 28-30.	UK	Problems faced by younger people with dementia, the current state of care delivery in the country for young-onset dementia (YOD), guidelines for service provision and they suggest what could improve the availability of specialised YOD services in the UK. Wide variation across UK. Lack of specific services, poor coordination and commissioning of YOD services.	Need for better coordinated services for younger people with Dementia Current state of care services for younger people with dementia Variations across the UK	Limited reference made to access issues.
Department of health 2014	Guidance for practitioners	Department of health 2014 A manual for good social work practice supporting people with dementia	England	Various Social workers can use guidelines for practice		
Martin G. (2009) Recovery approach to the care of	Review article	Recovery approach to the care of people with dementia – decision making and best interest concerns	UK	Participation a key principle for working with dementia.	Dementia and decision making. Relevance of the Mental Capacity Act 2005.	

Authors, Year	Document type	title	location	Findings	Themes	Limitations
people with dementia: decision making and ‘best interests’ concerns					Applying a recovery approach to people with dementia. Looking for a model for change.	
Social Care Institute for Excellence November 2013	Information document	Dementia Gateway: Making decisions	England and Wales	Information and guidance on dementia and research on dementia Lack of research on social care workers, dementia and MCA. Assumptions can be made by staff based on negative stereo types Variation in following best interests. Professional uncertainty about legal responsibilities	Social care staff, care homes,	

Appendix 5: Consent form for participants

ROYAL HOLLOWAY UNIVERSITY OF LONDON

Consent Form

Name of study: Social work and mental capacity decision making.

Name of researcher: Stefan Brown

Please indicate I have read and understood the information sheet about this study	Yes/No
I have had the opportunity to ask questions	Yes/No
I have received satisfactory answers to any questions	Yes/No
I understand that I am free to withdraw from the study at any time, without giving a reason and that data will be destroyed	Yes/No
I agree to participate in this study	Yes/No
I understand that my data will be anonymously stored and used only for the duration of this project. It will be analysed anonymously and then destroyed.	Yes/No
I agree to be interviewed using an audio recording device	Yes/No
I understand that I am free to withdraw from this research project	Yes/No

Signed……………………….

Name ……………………….

Date ………………………..

NB: This Consent form will be stored separately from the responses you provide.

Your data will be processed in accordance with the Royal Holloway Data management policy, the Data Protection Act 2018. All information collected about you will be kept strictly confidential. Unless they are anonymised in our records, your data will be referred to by a unique participant number rather than by name. If you consent to be audio recorded, all recordings will be destroyed once they have been transcribed. Your data will only be seen by the research team and a professional academic transcription service. All electronic data will be stored on a password-protected computer file on a secure university laptop. All paper records will be stored in a locked filing cabinet within an office in Royal Holloway. Your consent information will be kept separately from your responses in order to minimise risk in the event of a data breach.

The lead researcher (Stefan Brown) will take responsibility for data destruction and all collected data will be destroyed on or before 1 year after completion of the research.

Appendix 6: Information sheet for participants

Research study Information Sheet

Royal Holloway University, School of Law and Social Sciences

Name of study: Social work and mental capacity decision making

Name of researcher and supervisor: *Stefan Brown, supervised by Frank Keating and Tony Evans*

This is a study exploring how social workers make decisions when using the Mental Capacity Act 2005. It focuses on how social workers make decisions specifically when working with people who are identified as having young or sometimes known as early onset dementia. Young onset dementia continues to increase in the UK, yet there are many unexplored aspects relating to how professionals understand the condition. Mental capacity practice is one of them.

Participating in the study will contribute to understanding social workers decision making using the mental capacity act and in particular with this vulnerable group.

The study aims to explore the experiences of social workers specifically to see they make decisions and what ideas support their decision making. Data collected from this study will be processed and used as part of a PhD thesis.

The study will consist of the following:

Interviews with 12 - 18 social workers

Participation in this study is entirely voluntary. All participants will remain anonymous and information collected will be anonymised when transcribed.

As a participant you can decide not to answer any questions if you prefer not to.

You are welcome to withdraw from this study at any point in time and your data will be destroyed.

The data will be collected through interviews either in person or online. Data collected from this study will be used for the analysis of this research. Data will be anonymised using pseudonyms.

Your data will be processed in accordance with the Data Protection Act 2018 and also the Royal Holloway Data management policy. All information collected about you will be kept strictly confidential. Data will be anonymised and your data will be referred to by a participant number rather than by name.

If you consent for the interview to be recorded, all recordings will be destroyed once they have been transcribed. Your data will only be seen by the researcher and a professional academic transcription service. All electronic data will be stored on a password-protected file.

All paper records will be stored in a locked filing cabinet within the Arts Building Royal Holloway University. Your consent information will be kept separately from your responses in order to minimise risk in the event of a data breach. The lead researcher will take responsibility for data destruction and all collected data will be destroyed on or before 1 year after completion of the research.

Signed consent is required for all participants. Your signed consent form will be stored separately from the responses you provide.

As the researcher I welcome any questions on the study or feedback you have on your participation in this study. You can contact either me on Stefan.brown@rhul.ac.uk or my supervisor, Frank Keating directly on frank.keating@rhul.ac.uk

Your involvement in this research study is entirely voluntary and it will not have any impact on any engagement you have with Royal Holloway University. You are able to withdraw from the study at any time, without giving a reason.

Please contact me if you wish to participate in the research. You can email me on Stefan.brown@rhul.ac.uk

If you are happy to participate in this study you will be asked to sign a consent form.

NB: You may retain this information sheet for reference and contact us with any queries.

Kind regards,

Stefan Brown

Appendix 7: Ethical approval document 1

Ethics Review Details

You have chosen to submit your project to the REC for review.

Name: Brown, Stefan

Email: Stefan.Brown@rhul.ac.uk

Title of research project or grant: Social Work mental capacity decision making with people with young onset dementia

Project type: Royal Holloway postgraduate research project

Department: Social Work

Academic supervisor: Frank Keating

Email address of Academic Supervisor: frank.keating@rhul.ac.uk

Funding Body Category: No external funder

Funding Body: None

Start date: 23/04/2019

End date: 25/11/2019

Design and Data

Does your study include any of the following?

Will it be necessary for participants to take part in the study without their knowledge and/or informed consent at the time?, No

Is there a risk that participants may be or become identifiable?, No

Is pain or discomfort likely to result from the study?, No

Could the study induce psychological stress or anxiety, or cause harm or negative consequences beyond the risks encountered in normal life?, No

Does this research require approval from the NHS?, No

If so what is the NHS Approval number,

Are drugs, placebos or other substances to be administered to the study participants, or will the study involve invasive, intrusive or potentially harmful procedures of any kind?, No

Will human tissue including blood, saliva, urine, faeces, sperm or eggs be collected or used in the project?, No

Will the research involve the use of administrative or secure data that requires permission from the appropriate authorities before use?, Yes

Will financial inducements (other than reasonable expenses and compensation for time) be offered to participants?, No

Is there a risk that any of the material, data, or outcomes to be used in this study has been derived from ethically-unsound procedures?, No

Requests will need to be made for documents which inform the process of decision making. These documents are not restricted under the Freedom of Information Act.

Risks to the Environment / Society

Will the conduct of the research pose risks to the environment, site, society, or artifacts?, No

Will the research be undertaken on private or government property without permission?, No

Will geological or sedimentological samples be removed without permission?, No

Will cultural or archaeological artifacts be removed without permission?, No

Risks to Researchers/Institution

Does your research present any of the following risks to researchers or to the institution?

Is there a possibility that the researcher could be placed in a vulnerable situation either emotionally or physically (e.g. by being alone with vulnerable, or potentially aggressive participants, by entering an unsafe environment, or by working in countries in which there is unrest)?, No

Is the topic of the research sensitive or controversial such that the researcher could be ethically or legally compromised (e.g. as a result of disclosures made during the research)?, No

Will the research involve the investigation or observation of illegal practices, or the participation in illegal practices?, No

Could any aspects of the research mean that the University has failed in its duty to care for researchers, participants, or the environment / society?, No

Is there any reputational risk concerning the source of your funding?, No

Is there any other ethical issue that may arise during the conduct of this study that could bring the institution into disrepute?, No

Declaration

By submitting this form, I declare that the questions above have been answered truthfully and to the best of my knowledge and belief, and that I take full responsibility for these responses. I undertake to observe ethical principles throughout the research project and to report any changes that affect the ethics of the project to the University Research Ethics Committee for review.

Certificate produced for user ID, UUJD124 Date: 09/02/2019 12:02

Signed by: Brown, Stefan Digital Signature: Stefan Brown

Certificate dated: 2/9/2019 2:02:10 PM.

Files uploaded: Ethical considerations for the proposed PhD fieldwork research.docx

Appendix 8: Ethics approval document 2: Confirmation of the changes to ethical approval

18th May 2023

Dear Stefan Brown,

I can confirm that project ID number 1439 entitled 'Mental capacity decision making with young onset dementia' was approved by the Research Ethics Committee via the full ethical review process on the 3rd of June 2019.

As a result of the pandemic, the Institution applied the measures below, to projects which had already begun data collection but then moved to remote participant interaction:

Unless the changes made to the way in which you interact with participants result in a substantial change to protocol, you will not need to submit a modification request. Simply update your recruitment documents to outline how you will remotely interact with participants and use this version moving forward. Any already active participants must be informed of the switch to remote interaction and be provided with the updated participant information sheet. It is important that you make clear to participants that if they no longer wish to participate owing to this change, or for any other reason, that they are free to withdraw at any point.*

As such you were not required to submit an amendment request to:

Change to online interviews from face to face interviews due to the pandemic, and remove ethnography data collection from the data collection methods.

I hope this is helpful in meeting the requirements for submission of your doctoral thesis.

Yours sincerely,

Professor Robert Jago

Research Ethics Lead

Appendix 9: Topic Guide for interviews

Topic guide: interview guide

This topic guide (also known as an interview guide) has been designed to support the collection of views during the interview stage of the research. The topic guide serves as a tool to help both the researcher and the participant

It has been designed in line with the research objectives

Purpose:

To explore social workers understanding of Young Onset Dementia and MCA decision making. **Topic or section of the interview**	Types of questions asked
Welcome and introductions	Tell me a bit about yourself, what you do, how long you have been
Young onset dementia	What is your understanding of YOD? Where does young onset dementia ‘fit’ with your practice?
Mental Capacity assessments	Tell me about how you go about carrying out a mental capacity assessment? What tools do you use when carrying out a mental capacity assessment – examples, decisional balance sheet, a formal proforma, visual aids? Tell me your experiences of making best interest decisions and what has been important to consider? Tell me what might be the differences in you as a social worker carrying out a mental capacity assessment and another professional like a doctor, a nurse a psychologist?
Links between YOD and MCA	In relation to your work with people who experience YOD dementia tell me about how you explore capacity issues?

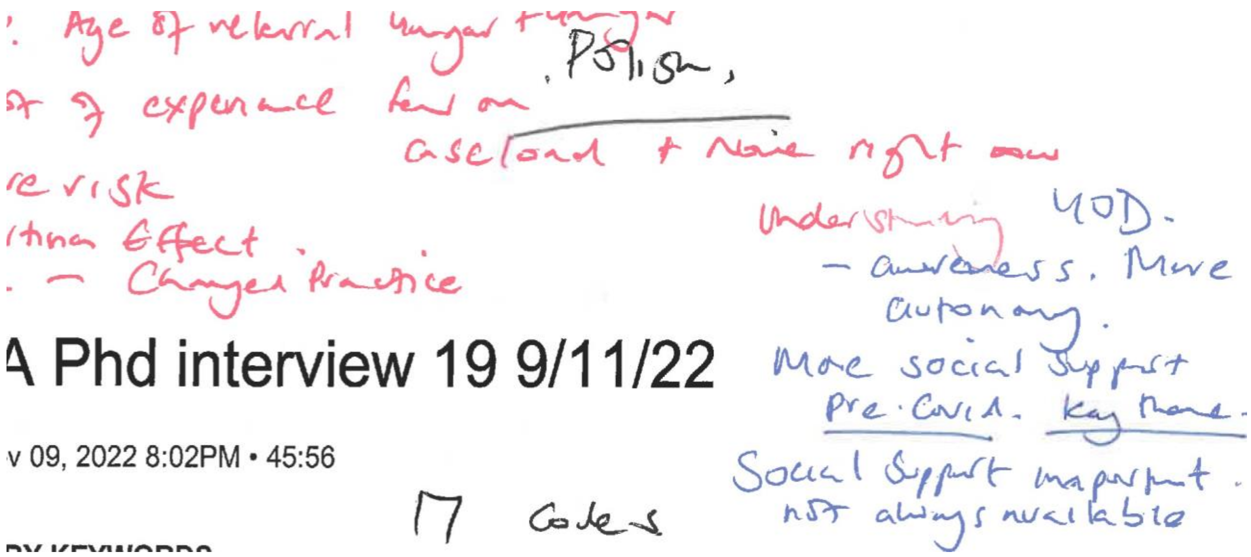
Appendix 10: Coding framework table

Initial code	Focussed code	Other issues into account (memo)
Advocacy support	Rights-based approaches MCA decision making	Not widely available
Age and YOD dementia	Understanding YOD	
Alternative assessments and YOD	Assessment process	
Assessing mental capacity	MCA assessment process	
Assumptions and YOD	Awareness of YOD	
Best interests' assessments	MCA decision making process	
Community support	Rights based approaches to MCA decision making	
Conversations as assessment	MCA decision making	
Covid	Context	
Definition of YOD	Awareness of YOD	
Diagnosis of YOD	Awareness of YOD	
Differences with YOD	Awareness of YOD	
Dignity and YOD	Awareness of YOD	
Disregarding Best interest	Decision making and collaboration	Common discussion for social workers. Linked to previous study
Family disputes	Collaborating with families	
Family history	Collaborating with families	
Family Support	Collaborating with families	
Family work	Collaborative MCA decision making	
Flexibility in MCA work Going beyond the law	Innovative approaches to MCA decision making	Dig a bit deeper into the data
Health professionals and MCA work	MCA decision making process	
Interprofessional practice	Collaborative practice	
Different ideas in MCA assessment	Creative approaches to MCA decision making	
Involving the person in assessment	MCA assessment	
Joint assessments	Collaborative practice	
Korsakoff's dementia	Specific conditions	
Learning disability and YOD	Diagnosis and MCA practice	
Legal processes and MCA	MCA decision making approaches – legalistic, procedural	
Little experience of YOD		
Masks and pandemic	MCA decision making process	

Medical ideas in MCA decision making	MCA decision making approaches - medical	
MCA assessment process	MCA decision making process	
Mis-diagnosis	Diagnosis and MCA work	
Multi-disciplinary assessment	Collaborative practice	
Not following Best interests	MCA assessment	
Observations as assessment	MCA assessment process	
Older people and dementia	Age and MCA decision making	
Pandemic and YOD	Context of MCA	
Paternalism	SW approaches to YOD	
Procedural/ legalistic	MCA decision making approach	
Personal experiences and YOD	Understanding YOD	
Physical health and mental health	Context	
Pre pandemic work	Context of MCA decision making	
Preparing for assessment	MCA decision making process	
Professional differences	Collaboration in MCA decision making	
Professional practices	Collaboration in MCA decision making	
Professional working	Collaboration in MCA decision making	
Questions and MCA work	SW process in decision making	
Restrictions on practice during COVID	Context of decision making	Significant discussion across data
Promoting the rights of people with YO	MCA decision making approaches – rights based	
Taking risks in MCA work	Positive approaches to risk in MCA decision making	Lots of participants spoke about positive risk taking
Risk adverse decision making	Risk and decision making	
Social context	SW perspectives	
Social isolation	SW perspectives	
Social networks	Collaboration and MCA decision making	
Social Perspectives	SW perspectives	
Social work role	Social awareness	
Stigma and YOD	Understanding YOD	
Stories	1st person accounts as decision making	
Support during covid	Context of MCA decision making	
timing of assessments	Context and MCA decision making	Time constraints discussed and linked to literature

Tools in MCA	MCA decision making process and creative approaches to decision making	Lots of conversation on tools
Training and MCA work	Training and MCA decision making	
Unmet needs Using interpreters	MCA decision making	Few conversations about interpreters
YOD and alcohol	Understanding YOD	
YOD treated differently	Understanding YOD	

Appendix 12: Transcript with some initial coding


: Age of referral younger [illegible]
. Polish,
of experience [illegible] on caseload + Naive [illegible]
e risk
tion Effect.
. – Changed Practice

A Phd interview 19 9/11/22

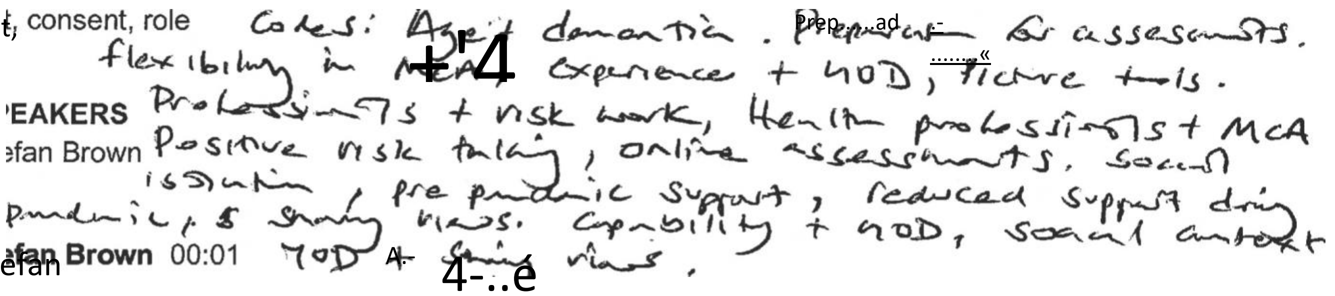
v 09, 2022 8:02PM • 45:56

17 Codes

Understanding YOD.
– awareness. More autonomy.
More social support Pre·Covid. Key theme.
Social support important. not always available

SUMMARY KEYWORDS people, assessment, capacity, dementia, decision, social worker, best interest, person, professionals, bit, younger onset, thinking, mental capacity, support, assessing, social, understand, mental capacity

act,


t, consent, role
EAKERS
efan Brown
efan Brown 00:01

Codes: Age of dementia. Preparation for assessments. flexibility in MCA, experience + YOD, picture tools. Professionals + risk work, Health professionals + MCA Positive risk taking, online assessments, social isolation, pre pandemic support, reduced support during pandemic, & sharing views. Capability + YOD, social context YOD + sharing views.

Stefan

There we go. Okay, good. So, thank you, really for agreeing to be interviewed? And just by way of introduction, can you tell me a bit about yourself and your role as a social work professional?

00:18

Yeah, so I qualified as a social worker in 2016. and I actually qualified in my home country, And when I moved to England in Oh, sorry, not I qualified 2014. And then I moved to England. And since 2017, I have been practicing as a social worker. So, I've been registered with HCPC at that time, and now social working Glen's. And I've been working in the same team, since I've started. So, I'm working for the local authority within the local kind of community team that works with adults, so anybody 18 Plus, the majority of people I work with, because of where we kind of based, our people over 65 years old. And most of them are experienced during experiencing some sort of cognitive impairment. Very often, it is a form of dementia. So as part of my role, I am completing assessments under the Care Act. And that very often kind of goes together with the mental capacity assessments under the Mental Capacity Act, when it comes to consent to any kind of care arrangements for them.

Stefan Brown 01:41

Brilliant, thank you. Yes. Yeah. So interesting work. So, it's overseen, it's an adult team, so that I didn't assume that 18 to whatever age, but you seem to work with mainly over 65.

0.51. Yeah, it's just the demographic and that in this area is such that a lot of people come to retire here. It's a lovely place.

Stefan Brown 02:04

Yeah. Okay. Would you say that dementia comes up a lot in your work?

Yeah, absolutely. Very often. Yeah. dementia

Stefan Brown 02:13

And hopefully, from the information sheet, you've seen that I'm quite interested in young onset dementia, or what's sometimes termed as early onset dementia? Could you tell me your understanding of it, and whether it comes into your work or toilet in your practice as a social worker?

02:31

Yeah. So, I mean, in terms of my understanding of it, I understand it as kind of, you know, the first stages of dementia when people are having some sort of when they are cognitive, maybe isn't that kind of advanced. And they are still very much able to function independently and make a lot of decision independently. However, they are starting to have more signs of forgetfulness, confusion, and so on. And I think that in our in my role, I don't get to meet that many people with the early onset, because normally they independent enough to just live their life. And mostly they come across our services, when they are much more advanced, but we do work. I do have experience with working with some people who are quite early in their kind of dementia journey. Unclear understan

Stefan Brown 03:40

Dementia. Okay. That's interesting. Yes. And one of the ways that I've looked at early onset dementia is or young onset dementia is this idea of dementia before age 65. Could you tell me your experience of this?

03:56 Younger + younger referrals

Yeah. I mean, I think in general, we we've not. So, I've been working on this thing for five and a half years now. And we see that the referrals we receiving the people are younger and younger, with sometimes with actually quite advanced dementia, considering their age. So, we do definitely get more referrals for younger people just kind of, you know, turning 60 and having already that that impairment.

Stefan Brown 04:24

Coll. Preparation key.

So, are you actively Can you think of cases where you worked, where you've got work with people will fit into that category?

04:33

Yeah. So, I don't work with anybody right now, who would fit in that category? But I have in the past.

Stefan Brown 04:41

Okay, that's really helpful. Thank you for that. Okay. So, I guess, other questions I'd like to ask you. So, you talked about your understanding of young onset dementia, and how it fits with your practice. Let's move on to talk a bit about mental capacity assessments in our I'm interested in the mental capacity assessments I've done them myself. Could you tell me about how you go about carrying out a mental capacity assessment? And I'm thinking specifically where there is dementia and potentially younger onset dementia?

05:15

Yeah. So, I think that kind of preparation is the key with any mental capacity assessment. And I think that that is something that professionals very often just don't have time for, and kind of skip and 'ust o into it when I think that that's one of the key points. And if I if you don't do it, right, your assessment is just not worth doing really. So yeah, the preparation, finding out information about the person. So, if we have any information on our system, just to have a bit of a background, so we know a little bit more about them, but also finding information from people who know them. So, it's not only kind of other professionals that work with them, like if they have carers or maybe if they're in a care home, but their family and friends who actually knew them before they started experiencing the signs of dementia, to know, to try to get to know how they perceive the world and how they understand things. Because the way that I understand things might be very different. And then if I'm not going to be able to assess how they they're understanding, if I don't know, how they normally do that. So yeah, I think the kind of preparation and finding out about how they normally kind of how they live their life, how they make their decisions in their life, what were their and beliefs. You know, what, what informed their decisions were, they're very quick to make decisions, or were they searching everything and taking days before they bought a new washing machine or something like that, that's very important for me to try to get to know them as a person, which is very difficult at times. And at times, it's hard to get that information, especially, you know, the decisions that normally we assess in capacity for or around care and potential change of accommodation. And those are things that people normally don't, don't talk about with their families. So that the families aren't, you know, they don't feel like they are able to contribute towards those-kinds-of-preparation. And time js another thing, because sometimes we you know, we are very busy, we have a huge waiting list, our managers want us to do things quickly. So, we are trying to do that prep as soon as possible with as many details as we can. So yeah, it is a challenge. But as I said, I think it's, you know, it's a first step to do it, you can just skip the next step. So yeah, that's kind of how I stopped them. And then I think another part is like finding the right time to do the assessment with the person the right time for the person. Making sure you know that they are aware that while we're going to talk

Duration

about that they are aware that somebody is coming, who I am making sure they are comfortable with me coming, you know, if it's their house, that they happy to have a stranger in their house that they've never met. before. You know, ideally, we would like I would like to see them over a couple of few visits. And not only one visit but again, being very realistic, that's not sometimes possible. Making sure is the right time of the day, they are not just about to have a meal, they're not just about to leave, and we have to ration and things like that. But also making sure that it's the right time of day in terms of like, I don't know, their confusion. Sometimes people are more confused in one part of the day, or they are always I don't know, have a nap and they wake up and they just need time to kind of come to it and stuff like that. So, ensuring that this is the right the best time for them that they are at their best. I think that that is important to always consider individuals capacity when they're at their best, because when I'm not at my best, I probably make decisions that could be questioned.

Stefan Brown 09:16

So, you spoke about time constraints. I'm interested just to take that theme forward a little bit if you don't mind. So, the idea of time constraints, are you is it? Is there a scheduled time that you have to do a capacity assessment?

Flexible in assessments
Lower risk YOD

And so, I think it all depends on the on the situation and on the decision. And I think I think probably for the group of people that we kind of discussing people with younger onset dementia, we have we are probably a bit more flexible with times because they're, you know, the needs are most likely lower and the risks are lower as well. But when we talk about people who have quite advanced dementia and are in a very unsafe situation, and I need to do, you know, I have to safeguard them, then things like that have to happen quickly. So, yeah, I think that depends on kind of where we are, what kind of decision it is, and what are the risks around it. Okay.

Stefan Brown 10:21

And do you think that's why you're making that decision? Or are you is it something that's mandated, or you have to be told, you've got to do this assessment at this time in this time?

10:33

I mean, to be fair, I think that in the kind of position that I am as a social worker, within my team, I'm kind of one of the most experienced, most more experienced social workers, I think that the managers are kind of trusting us enough to know that we are able to assess things like that, however, sometimes for whatever reasons that can come from the manager, because, you know, they feel that that has to be speed up for whatever reason, so Yeah,

experienced
Cadre

Stefan Brown 11:02 makes sense. Makes sense. Thank you for that. Just moving on a bit with thinking about mental capacity assessment and assessing capacity, just interested in do use tools? Probably not the best word to pick out. But do you use any specific tools or AIDS in your mental capacity assessments? And if so, which ones? And any thoughts on w, how you find using tools or aid in assessing capacity.

Tools: Sight + Hearing

So, I don't think if I could say that I use kind of any particular tools or aid, but sometimes I will be informed by the family or whoever knows the person best that there are some things that will, you know, that they always use to communicate. I mean, you know, that, I guess, for any communication for people who have sight or hearing impairments, there will be I don't know if that's the right equipment, I guess, rather than tools, but obviously, something like that will obviously have to be used to make sure that people can, can hear me and they are able to answer back to me. I do use pictures quite often, especially when we talk about kind of change of accommodation. And moving as to pictures o kind of properties. Why No, I'm just thinking about an example when the decision was around a lady moving closer to her daughter, so we would use pictures of her daughter. And actually, she didn't remember her daughter kind of from now she remembers she was in her mind. She was still a young girl. So, we will use the old pictures of her daughter. So that was Yeah, but I don't think I'm just trying to I don't think so. Again, so people with quite early onset of dementia, I don't think I've I would normally use tools.

Stefan Brown 12:59

Okay, that's really helpful. Okay. Yeah. And I'm just thinking a bit more about capacity assessments. And just tell me your thoughts on again, thinking specifically around younger onset dementia, how you go about making best interest decisions and things that you have to take into account when thinking about best interests where there are issues around dementia and younger onset dementia?

reflection

13:36

Yeah, so obviously, if the Capacity Assessment concludes that the person is unable to make the decision themselves, then kind of considering the best, best interests for them. And I would always start by checking if there isn’t anybody else who is legal able to make that decision• . So, through power of attorney or through deputyship, because then the decision is then the decision maker for that person. But if there isn't anybody like that, then I try to literally go through their, through their checklist from the Mental Capacity Act. So considering al} of those points, yeah, you know, things like, again, background information about the person, how they live their life and how they used to make decision what was important for them, what values they had absolutely consulting with people involved in their in their care s to be consulted, which that's that sometimes I think, is quite tricky, because obviously, they don't understand the concept of best interest as I think professional so they are giving their views but they're giving their views what they like would their fingers in the best interest, not what the person would fingers in their best interest. So That's often quite clashes with that, but at the end of the day is, you know, safety has to be considered and all of that as well. And I think I remember we had this kind of reflection reflective discussion with, with colleagues about what if somebody was, who would alive making really unwise decisions and putting themselves regularly at risk, because that's how they live lives like that. We as professionals would struggle to make a risky decision for them. Because that's not what we're we conflict around that. So Yeah, and I think in kind of, while considering best interest for the person is very important to have to see if the person had a conversation with their family about what they would like to happen. If that happened. And sadly, mostly people say, No, we never spoke about that. So, I now speak with my family very clearly. So, they know exactly what I would like for me to happen. By also considering advanced decisions to refuse treatment and any kind of, yeah, things like that. I'm just trying to think normally, when I do our best, and just I have a form in front of me that prompts me of all the things. Yeah, I think that this is kind of, yeah, the gist of it. And I am trying to kind of things like, you know, if the person was able to do it, what would they decide for themselves by is very often clashing with their safety aspect. Really?

Stefan Brown 16:45

Yes, yes. I can see that. Yeah, interesting. And just out of interest on some of we haven't done all these interviews already, one of the themes that's coming up, Julia, is this idea of some time, sometimes it becomes apparent that professionals or practitioners begin to engage in thinking about best interests before they've done assessments. And there's a there's a name given to this called the concertina effect. So, the idea that it's almost like the term we use putting the cart before the horse, yeah. engaged in thinking about what somebody should be doing what's best for the person, before you've really explored the capacity issue to see settings where it happens, you know, in hospitals, I imagine where they say, No, this person needs to go to a care home. That's not you know, and there's an assumption that they lack capacity, they can't make the decision themselves, before you've even assessed and

Health professionals

engaged in assessing capacity. Just wanting to hear your thoughts on that on whether that's something that you've seen, or you’re aware of, and what, what you've noted.

that you've seen, or you're aware of, and what what, what you've noted
18:04

Code Consent + Capacity Health - Code

Yeah, absolutely, I think that, sadly, is, is kind of happening very often. And I don't want to be kind of seen, like, I'm not trying to be working together with my health colleagues. But I do think it happens mostly with kind of in health settings by our health professionals, who I just think don't have that much of a practice and understanding of working under the Mental Capacity Act and doing the capacity assessments and the best interest decisions. And, and very often, you know, we kind of get, for example, a report. So, an ambulance crew was called out to a person. And the report says, we asked the person, what they it is, and they didn't know, therefore, they lacked capacity to make a decision of they should go to a hospital. And this is like two completely different things about what they it is today and what and if they should be taken to the hospital and, and people just think like, oh, they can't remember what I've told them two minutes ago, that means they lacked capacity. They put memory and capacity together. And it's not the same it is I understand, you know, it is connected to some extent about retaining the information, but it's about the right information. And there is all the weighing up of it and all of that. So definitely happens very, very often. And I think that I unconsciously probably I'm doing it as well. If I meet a person sometimes, and I'm, I'm going through the process of assessing the mental capacity, unconsciously already thinking, Oh! I think they lack capacity. I'm thinking best interest right away. I'm, I'm not going to kind of firmly implemented within my practice, but it’s and make sure that things are happening. We often have request from

I would say, mostly district nurses or hospital asking for our best interest mee Ing. And when I asked them, you know, what section? And you know, can you show me a capacity assessment? And they say, oh, no, we didn't do one, but it's obvious they lack capacity. And then there is another question because very often people just say they lack capacity, but they will not say what the decision is. And they just think that people can generally lack capacity, which there isn't a thing as a general lack of capacity.

— General Capacity Code.

Stefan Brown 20:46

I can remember going back I've been a social worker for quite a few years. And I remember when the capacity as well, even before the Capacity Act, we did use the term that's this person can't make decisions, or this person can’t consent. And what was often implied there, they can't consent for anything. You look back, and you think it's terrible practice to suggest that because somebody can't consent, whether they could say necessarily going a holiday, that means they can't consent what they have for breakfast. And unfortunately, I can remember those sorts of discussions happening, you know, it's been made that people can't give consent for anything, just because one area that they can't give consent for Yeah, I remember seeing a care plan in a care home. And it was like a care plan around night needs. I don't remember how it was exactly written by it said that the person doesn't have a capacity to decide about their bedtime or something like that. And I'm like, What do you mean, she, what do you mean,

they can't decide when they want to go to sleep. Like, I don't understand. Tell me how you assess them because I really don't understand. And they were just saying, you know, they Oh, they don't go to sleep until 1 pm was like, well, it doesn't mean that they lack capacity. That that's, you know, there's loads of other things that happened. But I don't think that you can, you know, make some capacity to that. So, yeah, yes, interesting.

Stefan Brown 22:19

So just to pick up on something you've mentioned around different professionals and health professionals, you've mentioned in what you said about Yeah, we're health professionals will often assume that somebody lacks capacity. Without assessing. We know that there are many different professionals involved in making decisions or judgments around capacity. Do you think there are professional differences? And I guess this is asking you to open up a bit more around? What do you think are the professional differences in terms of making decisions and assessing capacity? What would you say they are? Yeah,

S. Positive risk + SWk Professions

23:00 so I think that definitely like differences when it comes kind of around when it comes to risk. And I think that if somebody is making an unwise risky decision, that is for some, by some professional just seem us or they lack capacity, because why would they take that risk, and the same of making a best interest decision, I think that kind of social workers or kind of we are working in social care, are a bit more open to positive risk. and kind of assessing that and I want to say allowing people but allowing is just wrong word. But, you know, supporting people to take that risk to obviously some extent, because we would be you know, liable. To some extent, we need to ensure people are safe as well. But um, yeah, I think that this is the biggest thing that we are kind of saying, you know, well, they, for example, I worked with lady who was very comfortable in her own house and would often be in her own house without any clothes. So then when she had visitors, she would open the doors kind of hiding behind the doors. And then if she would let somebody and she would put something on, but a lot of professionals were saying, you know, it's a safeguarding she, she can't do it she lacks capacity and wag like, Why can't she be naked in her own a is wrong with like, and so it is about you know, they seen it as a risky behaviour who was comfortable in her own house with herself. You know that she locks the door covers the windows and does not

Stefan Brown 24:48 that's interesting example. Yes, thank you.

Safeguarding + capacity. Code.

24:51

I always remember because I remember when she opened the doors for me and I was a little bit shocked that she appeared that way.

Transcribed by https://otter.ai

Stefan Brown 24:58

Yeah, okay. and probably was going to touch on now and ask you to talk about it. Tell me about do you think COVID changed practice around assessing capacity and exploring capacity issues and can do it. Can you tell me a little bit about what your experiences of COVID and some extent we still have COVID around us? But uncertainty during the lockdown period, I guess, well, is what I'm referring to here. Yeah,

Covid + Capacity code

re phone Covid

25.25.yeah. No, it changed. Yeah, definitely changed and make a huge change. I didn't actually mention at the beginning, but I'm also a qualified best interest assessor. So, I'm doing a deprivation of liberty safeguards assessments. And I actually qualified as a best and just SSI thing, I got my certificate in April. So, in March covid started and in April, I got my qualification. And I suppose to how it works in my local authority, there is a six weekly router that you joined. So, I'm still working as a community social work. And every six weeks I'm doing an assessment under the dose. And I suppose to join the dose router. And I was terrified, because I thought how am I supposed to assess somebody's capacity when I can visit them and, and it's a new role, and I've never done it. So, I was very, very terrified. And, and I'm very thankful, because we have very, very supportive team, mental capacity team in our local authorities. So, they kind of encouraged me to join the router, I had a chance to view some assessments from my colleagues that started doing them in in COVID, any on my first capacity assessment on the, under the doors for the, for the BIA assessment I did over the phone, and it just felt wrong. It felt really wrong. And I definitely, you know, felt very stressed. And probably, if I could do it again, I will do it differently. But at that time, I did my best, I did a lot of preparation, probably much more than I do for face to face visits, which is interesting. And then it suddenly became a norm and doing it maybe over the phone we try not to we prefer to do it over camera to be able to see people that time that the camera didn't work. But yeah, we just kind of did the best out of the worst situation. And we very often reflected on it, that pre pandemic, if anybody would suggest that, you know, such about practice, we would never go for it. But I myself didn't have that experience. But I know a colleague who was assessing, or maybe that's not appropriate for the, for that study, but she was assessing a younger gentleman, he was actually he had learning disabilities, and he was able to engage with her through camera much better than face to face. Because that's, you know, that's his whole, his whole world kind of young people are very much into laptops, computers, social media, all of that. So, she actually visited him in person. And then they did have a camera and on camera, she got say much more out of him. So, I don't think it's very often but I'm sure there are some individuals that actually that improve things for them, which we would never even dreamed off. So yeah, and I think it also taught us to, you know, learn a bit more about the cues, you know, I think before you know, when you do face to face, you obviously look at their face or body language, facial expression " when you just have that image, you focus on it a little bit more than you normally would and probably make a little bit more notes of that, for your assessment, which will you wouldn't include in the past. So, I think it just, yeah, we just have to learn kind of new skills, how we can get more out of people and then also getting more information from the care home about, you know, the People's kind of behavior in general and things like that. So, it's relying and trusting other professionals that they understand things the way we are, if that makes sense. Preparation and Covid code.

Stefan Brown 29:22

You mentioned a bit earlier that you were terrified and you it wasn't something that you looked forward to doing why was that?

29:34

I think because it was of the pandemic and it was something new. Okay. Because obviously I just qualified as a best interest assessor and it's in the community now that those assessment is very

~~[illegible]~~
MCA

different than character assessment. The principles are very similar because we are considering capacity we're considering character needs and things like that, but it is something very, very different and it happened. As I said, you know, end of March we had locked down. And I just got, I think it was literally beginning of April that I've been told that I qualified as a BIA. And I suppose to start doing this new job when at that point, I didn't even know how to do the how to do my own job that I've been doing for the last four years, because everything changed then. And I thought, How am I going to start doing something completely new, which actually, after, you know, an assessment or two, I realize it's not that different than what I've been doing. It's a different form to fill in. But other than that capacity assessment is the same thing. So regardless, kind of where you're doing it, there are different decisions to be made on me.

Stefan Brown 30:38

Yeah. Okay. So, what I'd like to explore a bit further, as is just some of the links between younger people with dementia and capacity. And do you think there are differences when assessing capacity for people who are younger who have dementia? And if so, what do you think these differences might be?

30:59

So, do you mean differences between younger people with kind of younger onset and people with advanced dementia?

Stefan Brown 31:08

Yes, yes. Yeah. Yeah, the differences that might exist? Yes.

Conversations

Yeah. So, I think that you know, mostly with people who have younger onset dementia, they still will be more capable of processing information, then people were very advanced dementia, most likely now, they will be able to still express themselves to some extent, when people with advanced dementia, sometimes there is very little kind of literally coming out of the mouth, there are just some words that cannot be even understood. So, you know, the communication ability to understand both ways. Makes it definitely much makes the difference with the Capacity Assessment, because if I'm asking a question, I get nothing back. It's, it's really hard to, you know, continue. But obviously, if I can have a conversation, and if the person can actually understand, you know, who I am, and what are we talking about, and then I am here to try to understand how much you are able to understand of, you know, of your care needs. And what's happening, that's definitely make kind of gives me more to work with, I guess. Yeah, so I will probably say that, then the conversations are much longer, then with people who have quite advanced dementia around April engaged, and we are able to kind of, you know, explore things in a little bit more details, although obviously, you know, when, when we're doing capacity assessment: the bar isn't set too high. And there are some salient factors that needs to be understood. And every single detail does not have to be understood. But it definitely helps with, with, with being more confident about how much the person understands, actually. And also, I think it also helped with if people can kind of orientated and time, that helps as well, because, you know, we have a conversation about something here and now. But when I leave, Will they still be able to kind of

Capability

recognize what we spoke, spoke about and kind of applied the decision that they made, if they are able to make it to the next day or something like that?

Stefan Brown 33:32

Sure. That makes sense. Yes. And then just moving on to thinking about that next stage wants assessments done, where you're looking at best interests, if obviously, the person lacks capacity, do you think there are differences in exploring best interests where people have younger onset dementia versus those who have, we might say normal age or advanced age dementia?

33:57

I think that with people who have kind of younger onset dementia, they are potentially able to share a bit more views with us even though if they're not able to make that decision there. Yeah, they can tell you a little bit more what they would like to happen. (YOD

Share

Stefan Brown 34: 17

Sure, which should actually empower their voice in the best interest process? I would imagine.

Yeah,

5 34.•25 no, absolutely. Yeah. because, you know, it is, it is at the end of their life is that in the end of the day is their life and we are making a decision for somebody else's life. So, we do want it to be as close as possible to what they want to do So we do want to know what they would like. So, you know, we always try to keep that at the heart of the whole process. And it is definitely helpful with if that person can give us something, what some sort of use for us to work with it.

Process

Stefan Brown 34:57

That's really useful. Thank you for that. And I'm just moving on to another theme that I found really interested in exploring in these interviews is thinking about social support and family support. So, thinking about social support family support, so things like counselling support groups, what are your thoughts on how our social support issues? helpful or not helpful? What are your thoughts on the social supports? When thinking about capacity work when engaging in mental capacity work? So, what would you say the role of social support is, when you're having to explore capacity issues?

I'm not sure if I understand you mean, like, sorry, I'm not sure if I do mean, like, when you mentioned, like family, or could be counselling.

Stefan Brown 35:59 Groups for people who might have YOD? So, I guess what I'm thinking about is that often, as social workers were helping people to connect with social support beyond ourselves, and I'm probably just trying to get a sense on your understanding of social support and how it works and its usefulness for people where there are capacity issues, where there is dementia, young onset dementia.

36:29

Social Support

Okay, Okay. I think I know what you mean, if I'm, if I'm talking like off of the subject, just stop me. I mean, I think it kind of social support, social stimulation, social interactions, are mainly helpful for people to kind of, to help them cognitively. Because if people are just, you know, left by their own, and they do not have to use their brain in any capacity, then they're going to deteriorate very quickly. But if they are able to kind of interact and, and you know, just use their brain to have conversations with other people, and have that stimulation, that definitely kind of, you know, help them to, to remain focused, and to be I don't know, more orientated to time, kind of, you know, if they have a routine that every Monday they go to this grab this club, and on Wednesday, they're going there that I think has a really positive impact on people's cognitive abilities. +(clubs)

Stefan Brown 37:34

And I guess, in previous conversations I've had about social support. People been able to say their thoughts on how important but also, how available is social support? Any comments on the availability of social support and social resources, if you like, for people with dementia? Yeah,

37.•58 (pre-pandemic covid code) ↑ voluntary. yeah. So I think that pre COVID pre pandemic, that we had loads of kind of voluntary run clubs, that would be appropriate for people with young, younger onset dementia, and kind of physically still able, kind of like a Memory Cafe or lunch clubs, kind of where people can still get themselves to it by themselves, a family can help and they are able to eat their meal and use the toilet by themselves and kind of communicate those loads of it, then obviously, everything closed down. And because it was everything, voluntary run, they really struggle to start it again. And I think we are having kind of in the area that I'm working the are showing up some groups, but definitely not as many as we had before. And there is kind of less volunteers to do that social support. I think all the volunteers are now kind of supporting social services to keep the services running. So, it's, it's hard, but it's definitely needed. It's always a gap. Yeah, it's, yeah, we need more of them. There are some we used to have many more. (Reduction in Support code)

Stefan Brown 39:15

Yeah, it's interesting to note that that the pandemic has clearly affected the resources available for people and I guess, following on from that and thinking about what role do you think the social support play for people with younger onset dementia?

Community

39:34

I think they can. The role can be like really important, with you know, with things like staying in touch with your community, staying in touch with your peers and people who are experiencing similar kinds of difficulties in their life and sharing, you know, information or How to overcome that, or you know what to do, who to go to and what form to fill in to get a benefit, or even things like that. and yea , Just have to have a purpose in life to y go out because 'm meeting somebody and not just staying at home. So, I think they are essential .

people kind of find their group of people that they get on with, they will then you know, they will support each other if one of them deteriorates to something like that, that they will try to fill in the gaps between the services can do. And I think that places like that are keeping people kind of from deteriorating, they are keeping them running basically, they, they, they the stimulation, the sort of

Code (isolation + YOD.

simulation is so important in people's life. And I think that, you know, social isolation is such a dangerous thing. And it can impact on your cognition on your physical abilities on your mental health and can just cause you to deteriorate very quickly. So, if you do have that social support, it can make me I can mix wonders.

Stefan Brown41:16

Yeah, that's really helpful. Yes, yes. Thinking about social support being a core part of what people with younger onset dementia will need. Yeah. So, I guess that's most of the themes that I've wanted to talk about. I'm just trying to think if I want to. So just to recap on what we've looked at so far. J. So we've looked at your role and there's a specialism. So, you spoke talked about being a BIA, community, social worker, assessing Care Act care needs, generally, but using the capacitor quite a lot by the sounds of it. And then you've also spoken about your understanding of younger onset dementia, and there's been some exposure to it in your practice, but not a lot. Is that right?

42 : 04

Yeah, yeah, I think that's fair to say.

Stefan Brown 42:07

And then we talked about how you go about doing capacity assessments and the particular techniques, we spoke about tools as well, and tools that you might use. And then we also looked at this idea of the concertina effect, which I mentioned, you know, this, and then you spoke a bit about that, and, and gave examples of that. And alongside that, we explored ideas about professionals, differences, the differences that professionals might do, and looking at COVID, as well, which is interesting. I'm just trying to think, is there another question around COVID? I don't think there is, I think you covered that really well, in terms of getting me to think about, actually the links with COVID. And practice and how it changed practice, essentially. And then thinking about young onset dementia and capacity work, and how it might be different or similar to those without young onset dementia. And then I'm finally thinking about what social factors or social circumstances and social supports can be in place for people with onset dementia. So that's something we've covered more or less everything. Is there anything that you would like to add or say?

43:25

No, no, I don't think so. I know, nothing that kind of sprang to mind. I think your questions kind of got everything that I would normally be the kind of things about what I would say. So um, yeah, I think that's,

Stefan Brown 43:38 that's good. And, um, yes, I think in my mind, what the things you've said, Do chime with what has come up before in the interviews? And certainly, you know, I'm really interested in just hearing about your experience of COVID, for example, and just, it aligns with others. But you've given me a bit more to think about and to analyse, I guess, I've been thinking about how to change practice, because I think that's, that's an emerging theme for me. How COVID clearly changed practice for social workers. And social workers had to focus on a different set of skills.

44: 1 5

[ial context matter -Code.
in own home.

Yeah, I think one to add on that note is that I mean, like, for me as a social worker, that kind of social context going and seeing people and seeing their in their own house and seeing the whole picture of them. It's been always so important. And the best part for me, I don't like writing up the assessment that takes forever and filling In all those forms. But because we did it for you know, months and months, everything over the phone I think it's been seen that it's done quicker, if on the court is quicker than

3 driving somewhere and when you see them. So, our managers do encourage us-to-do-it over the phone. I don't like it. But I know that some people They prefer that and they do feel like they can achieve more for-people in general. because they don't waste that time on driving or things like that. So yeah, I think that's interesting that, yeah, some of us are happy to just sit at the desk with our phone call and do it all like that. And some are still kind of, you know, trying to squeeze those visits and, and see actually people in person.

Code. Critique of online assessments

Stefan Brown 45:25

Yeah. And I do wonder if there's a quality issue there around the quality of your assessment, if between doing it on the phone and doing it face to face, but that's another research study by the sounds. Well, the quality issues in in assessing over the phone or on Zoom versus face to face.

45:46

Yeah. Yeah.

Stefan Brown 45:48 Yeah. Interesting to look at that. Brilliant. Well, J, thank you very much for your time. I'm going to stop there.