

**Exploring constructs of capacity in learning disability contexts: power,
protection and institutional practices**

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ABSTRACT

The Mental Capacity Act (2005) is a legislative framework designed to promote autonomy and support those who may struggle to make decisions for themselves. Previous research suggests that the implementation of the Mental Capacity Act raises a number of challenges for professionals (McVey, 2013; Walji, Fletcher & Weatherhead, 2014) and that applying the Act in learning disability settings may be particularly complex (Brown & Marchant, 2013). The concepts of 'capacity' and 'learning disability' draw on knowledge across legal, philosophical and psychiatric discourses, which may imply different practices for professionals.

Semi-structured interviews were completed with eight professionals working in adult community learning disability services. A Foucauldian approach to discourse analysis was used to examine how capacity was constructed in professionals' accounts of their experiences implementing the Mental Capacity Act. The discourses and subject positions available to professionals and people with learning disabilities were considered.

Analysis of professionals' accounts suggested that 'legal' and 'rights' discourses of capacity were oriented to. Knowledge of capacity was constructed as being limited to professionals, with families and service users often in need of further information on the Mental Capacity Act. 'Legal' and 'rights' discourses enabled multiple subject positions for professionals and people with learning disabilities. These positions allowed for both restrictive and empowering practices. Promoting subject positions of 'personhood' appeared to allow for alternative understandings of capacity, in which decision-making is an interdependent rather than independent process.

This study suggests that capacity assessments are sites of tension between multiple discourses. Co-constructing meanings of capacity within services and across disciplines may allow for the development of best practice, and facilitate supported decision-making practices with people with learning disabilities.

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1. INTRODUCTION

“Mental capacity is not, as is commonly presented, an objective, scientific and naturally occurring phenomenon. Mental capacity is contingent on social and political contexts, as are the disciplines, professions and practices which play a dominant role in assessing capacity” (UN Committee on the Rights of Persons with Disabilities, 2014, para 14).

Medical and empowerment discourses are currently drawn on to construct mental capacity within legislation in England and Wales. However, new constructions of capacity in the global legal and academic literatures draw on alternative understandings of autonomy and decision-making, which emphasise the relational nature of capacity. This chapter will explore how the current and emerging discourses of capacity may overlap with discourses of learning disability, particularly in the context of mental capacity assessments within learning disability services. The rationale for this study will then be presented, and the main research questions outlined.

1.1 Literature Search

The literature search for the papers discussed in this chapter was conducted using both publication databases (PubMed, PsycINFO, PsycArticles) and ‘grey’ literature searches such as the use of Google Scholar, and hand searching the references of relevant papers. Key search terms included “mental capacity”, “mental capacity act”, “learning disability”, “intellectual disability”, “discourse” and “discourse analysis”.

1.2 Terminology

People with learning disabilities have historically been labelled by others (Sinason, 1992) and their voices have been marginalised both within services and the academic literature. A full deconstruction of the term ‘learning disability’

is not within the scope of this chapter, however the historical context and controversies surrounding the term (see Carlson, 2005; Schalock, 2011; Simpson, 2011 for further discussion) are important in taking a critical approach to the ideas presented in the clinical and academic literature in this field.

In line with clinical practice in the United Kingdom (UK), the terms 'learning disability' and 'people with learning disabilities' will be used throughout this thesis, using the British Psychological Society construction of learning disability as a significant level of cognitive impairment (an IQ of 70 or below) and significant difficulties with adaptive living skills, both present before the age of 18 (BPS, 2001).

Rapley (2004) argues that 'intellectual disability' is constructed through the process of interaction, and that the psy-professions (Rose, 1998) have a significant stake in the perseveration of this idea, in so far as it allows them to take up positions of power. In using the term 'learning disability' I am aware that I could be understood as aligning myself with a medical model of disability that promotes divisive classificatory practices in the lives of people with this label. I hope to balance the use of this term with a critical approach towards the literature and policy surrounding learning disability and capacity.

1.3 Defining Mental Capacity: The Role of Legislation

1.3.1 Defining mental capacity prior to the Mental Capacity Act

Prior to the introduction of the Mental Capacity Act (2005) (hereafter known as MCA), there was no legal process surrounding the substitute decision-making that often took place in clinical practice with people who struggled to make decisions for themselves (Clough, 2015). English common law included ethical principles assuming the right of individuals to self-determination, which is making their own decisions about matters that affect their life, irrespective of their reasons for making those choices. However, academics and clinicians alike proposed that this right to self-determination was only meaningful if people had the capacity to make the decision and were given the freedom to do so without coercion (Bellhouse *et al*, 2001).

Due to inadequacies in English common law around the processes for substitute decision-making for those perceived to lack capacity, and following legal and governmental consultations going back as far as 1989, a draft Mental Incapacity Bill was submitted to UK government in 2003 (House of Commons, 2003), following the recommendations set out by the Law Commission report in 1995. The key principle of the Bill was to provide a single definition of (in)capacity and to enshrine in statute a best interests process to be followed if a person was unable to make a specific decision for themselves at a specific time. The draft Bill outlined the principles that were then formalised by the passing of the MCA in 2005.

Case law (*Re MB [1997]*) suggests that capacity was understood as involving the ability to understand and retain information, and to 'weigh that information in the balance' to arrive at a choice. This is similar to the definition outlined in the MCA, but had not yet been enshrined in statute. However, the Foundation for Learning Disabilities report (Myron *et al*, 2008) on preparing for the implementation of the MCA notes that historically there had been no specific guidance on how capacity was to be assessed in practice. Although a shift towards a functional approach prior to the MCA was acknowledged in some professional groups such as psychology and psychiatry, it was also noted that there was little evidence as to how capacity was being assessed by professionals and carers in other settings. They concluded that "a whole range of factors including perceptions of a person's illness or disability, desired or perceived outcomes, perceptions of risk or issues of control and power could and would be involved" (Myron *et al*, 2008, p.7).

A lack of a single definition of (in)capacity, and a reliance on status and outcome based approaches to assessing capacity (see section 1.3.2 below) meant that prior to the MCA, capacity could be globally assumed or questioned, with unwise decisions or the presence of difficulties such as mental health problems or a learning disability being seen as evidence of a person's inability to make decisions for themselves. This understanding of capacity positioned professionals as experts, and may have made it easier for paternalistic practices to be deployed.

1.3.2 Constructing and assessing capacity within the MCA

Historically there had been three approaches to understanding capacity – outcome, status and functional approaches (Thornton, 2011). These tend to have been used independently of one another and each has implications for how capacity may be assessed. Outcome based approaches have linked capacity to rationality, and the perceived risks/benefits of the decision made. This could be understood as enabling paternalism about what the ‘right’ decision may look like in any particular situation (Gibson, 2015). As such, an outcome-based approach to assessing capacity was rejected by the Law Commission (1995).

Status based approaches to assessing capacity associate capacity with the possession of certain characteristics (Gibson, 2015), such as gender, race or disability. Status approaches construct capacity as a global, binary characteristic; this obscures the multiple contextual factors that affect decision-making, and does not allow for capacity being decision-specific.

Functional based approaches to assessing capacity propose that it is the decision-making process, rather than a person’s ‘status’ or the ‘wisdom’ of the decision made that is important in establishing someone’s ability to make a decision. This allows the assessment process to be more individualised and for a “complex threshold” (Gibson, 2015, p.232) to be established before someone can be judged as lacking capacity. The MCA combines status and functional approaches to assessing capacity, evolving explicitly from concerns about the potential misuse of outcome and status approaches by themselves.

Within the MCA, mental capacity is defined as the ability to make a specific decision at a specific time. There are five key principles underlying the MCA:

- A person must be assumed to have capacity unless it is established that they lack capacity
- A person must not be treated as unable to make a decision unless all practicable steps to help them do so have been taken without success
- A person is not to be treated as unable to make a decision merely because they makes an unwise decision
- 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 their best interests
- Before the act is done, or the decision 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

Mental Capacity Act 2005: Part 1 (1).

The MCA takes a process based approach under which a capacity assessment is only warranted in cases where “an impairment of, or disturbance in the functioning of, the mind or brain” (MCA 2005, s2. (1)) may be affecting the person's decision-making ability. The person's decision-making processes are then assessed according to a four stage functional test, which establishes their ability to:

- Understand information relevant to the decision
- Retain that information
- Weigh up that information
- Communicate their decision

If assessed as not having capacity, a ‘best interests’ process is undertaken, in which the wishes, beliefs and values of the person lacking capacity are considered. Along with the views of important people within their support network, the best course of action in relation to the decision is agreed (Department of Constitutional Affairs, 2007).

1.3.3 Mental capacity and a medical discourse

In foregrounding the presence of an “an impairment of, or disturbance in the functioning of, the mind or brain” (MCA 2005, s2. (1)), the MCA draws on a medical model and liberal theories of the self, which are atomistic and individualistic, ignoring the “web of relationships” (Clough, 2015, p.19) in which people exist and make decisions. Although the MCA applies to any adult over the age of 16 who may struggle to make their own decisions, it is commonly used in psychiatric (Owen *et al*, 2009), learning disability (Willner *et al*, 2012), older adult (Harding, 2012) and brain injury settings (Owen *et al*, 2015). These are settings in which a medical model of disability is often drawn on, wherein deficits are positioned within the individual being assessed, and a high value is placed on rationality. In this way, the MCA constructs capacity as a cognitive ‘ability’ exercised by an individual, which can be objectively measured in a value neutral process by professionals. This may unwittingly obscure alternative understandings of capacity that acknowledge the contextual factors that impact on people’s ability to make decisions.

Under the MCA, professionals are therefore often positioned as ‘experts’ and have the power to make decisions that have a material impact on the lives and bodies of those assessed as lacking capacity. Given this, the processes undertaken by professionals must be able to withstand scrutiny, and a thorough analysis of the accounts professionals give about their practice in relation to the MCA may provide information about the discourses and positions that professionals operate from in assessing capacity.

1.3.4 Mental capacity and a discourse of rights

In the context of a move towards rights based discourses in the field of disability, the UN Convention of the Rights of People with Disabilities (UN CRPD, 2007) was ratified by the UK in 2009. This signalled the intention of the UK government to take steps towards complying with the articles set out by the CRPD.

The UN CRPD aims to set out and protect the rights of people with disabilities internationally, to ensure that they receive equal rights to people without disabilities. The UN CRPD draws on eight guiding principles:

- Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
- Non-discrimination
- Full and effective participation and inclusion in society
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- Equality of opportunity
- Accessibility
- Equality between men and women
- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

Martin and colleagues (2014) argue that the MCA definition of mental incapacity violates Article 5 of the UNCRPD (2007), which prohibits discrimination against people with disabilities, and that its 'best interests' decision-making framework violates Article 12, which grants people with disabilities the right to exercise equal legal capacity. This suggests that both conceptual shifts in our understanding of mental capacity and practical shifts in our approach to assessing and supporting decision-making abilities are required.

The definition of mental capacity offered by the UN CRPD (2014, para 14) proposes that consideration of relational, social and political contexts may provide an alternative avenue for understanding and assessing mental capacity. A theoretical framework for this will be considered below, and alternatives to current assessment processes will be considered in section 1.5.

1.4 An Alternative Understanding of Capacity: A Relational Approach

The co-ordinated management of meaning (CMM) approach (Cronen, Pearce & Changsheng, 1989) will be used here to provide a theoretical framework for developing an alternative understanding of capacity, as it allows for

consideration of relational, social and political contexts as well as individual factors. The hierarchy model within CMM proposes that there are an “indeterminate number of levels of context” (Forbat & Service, 2005, p.418) which impact on the development of meaning, which emerges through interaction. A consideration of all the contexts affecting capacity is not possible here, but a brief consideration of some of the relationship, self-concept and cultural factors will illustrate the need to move beyond a medical discourse of capacity. Using CMM as a theoretical framework for understanding capacity may have implications for clinical practice, as research suggests that using a CMM approach can promote person-centred care in complex situations (Forbat & Service, 2005).

1.4.1 Self-concept factors

Intrapersonal factors such as the impact of cognitive impairments, particularly difficulties with executive functioning (Edge *et al*, 2015; Willner *et al*, 2010) may well affect capacity. However, critics have argued we need to go beyond a cognitive understanding of capacity in order to make sense of how people make decisions.

Our experiences of making decisions, looking after ourselves and being looked after, and coping with change, will impact how able we are to make choices and express these. Brown (2011) argues that our emotional experiences will also impact our motivation and our openness to influence. The emotional valence of the decisions we are faced with therefore needs to be taken into account and is often overlooked in capacity assessments (Mackenzie & Watts, 2011; Moorhead & Turkington, 2002).

Anecdotes from clinical practice suggest that value systems and strong preferences can persist despite cognitive impairments (Karel *et al*, 2010; Owen *et al*, 2009) and may be important factors in our decision-making processes (Banner, 2012; Banner & Szmulker, 2013). Gibson (2015) argues that values and beliefs may be implicitly oriented to within capacity assessments through consideration of how these factors may impact on the ability to ‘use and weigh’ information. He calls for further transparency in the significance given to the

values and beliefs of both the person being assessed and the criteria that professionals are using to make this assessment.

McDaid and Delaney (2011) found that people who have experienced mental health treatment constructed relational factors as having a more significant impact on their ability to make decisions than cognitive factors such as medication side effects or being given inaccessible information.

1.4.2 Relationship factors

Participants in McDaid and Delaney's (2011) study reported that a lack of trust in the information provider, and a perceived lack of empathy from information providers towards their distress impacted on their capacity. This reflects research that suggests people make choices about their lives in the context of "decision communities" (Martin & Hickerson, 2013).

The role of professionals in people's decision communities needs to be acknowledged, coupled with transparency about the values that professionals bring to their roles as assessors of capacity (Banner, 2012; Banner & Szmulker, 2013; Gibson, 2015). Higgs (2004) notes that the differences between personal and professional accounts of capacity may mean that important meanings and themes are missed: "not only may the values be different, but the values to society may be different: the patient's story may be completely obliterated by the professional discourse" (p.310)

1.4.3 Cultural context

As section 1.3 illustrates the legal frameworks of the MCA and the UN CRPD foreground the ways in which capacity can be understood. Professionals are also legally bound to uphold a duty of care, in which the protection of an individual from harm takes precedence.

The framework of the MCA links a lack of capacity with ideas of vulnerability, in which vulnerability is understood as a characteristic of the individual lacking capacity that requires protecting against. Clough (2015) draws on a range of

alternative theories of vulnerability (Dunn, Clare & Holland, 2008; Fineman, 2008; Mackenzie, Rodgers & Dodds, 2014) which collectively offer an understanding of vulnerability as an essential aspect of being human, affected by external factors such as legal, social and political practices.

This can include unintended consequences of structural level practices designed to reduce vulnerability, but which inadvertently exacerbate it or generate new vulnerabilities (Mackenzie, Dodds & Rogers, 2014). For example, it could be argued the normalisation agenda reduced people with learning disabilities' exposure to exclusionary practices; however, in doing so, it may also have generated new vulnerabilities in the form of increased exposure to hate crimes in the community (Scope, 2008).

Dunn, Clare and Holland (2008) emphasise the importance of acknowledging the relationship between vulnerability and the internal and external resources a person has to draw on. This alternative understanding of vulnerability would suggest that interventions focus on building individual and structural resources in order to facilitate decision-making capacity.

1.4.5 A relational approach to capacity

Clough (2015) proposes that a relational approach to capacity is required, which recognises interdependence rather than emphasising independence –an approach that is beginning to receive wider consideration in the literature (Martin & Hickerson, 2013; McDaid & Delaney, 2011; O'Connor, 2010).

As part of this interdependence Clough (2015) argues that the role of the state in providing contexts in which people are supported to develop their capacities and capabilities needs to be attended to. For people with learning disabilities, the role of the state in supporting inclusion and the development of capabilities has been outlined in the *Valuing People* policies (see section 1.6.3 for further discussion). However, the possibility of taking up alternative discourses of vulnerability and autonomy to apply a relational model of capacity may be complicated by a turn towards neoliberalism in UK health and social care policy

(Bell & Green, 2016) which privileges liberal concepts of independence and rationality.

1.5 Alternative Approaches To Assessing Capacity

There is a dearth of research looking at alternative ways to assess capacity in practice. None of the studies into the challenges of using the MCA in practice have considered how professionals construct 'capacity' or what contextual factors may impact on their use of particular definitions of capacity in practice.

Critics of the approach to assessing capacity outlined in the MCA call for capacity assessments to take more account of a person's ways of meaning making, suggesting that people can have 'practical rationality', which is based on their knowledge and experience of being in the world, and having a sense of belonging. When this sense of belonging or orientation is disturbed, this can affect their ability to decide and act on their choices (Benaroyo and Widdershoven, 2004).

Breden and Vollmann (2004) propose that the MacArthur Capacity Assessment Tool (MacCAT-T; Appelbaum, Grisso & Hill-Fotouhi, 1997) be adapted to include non-cognitive, qualitative factors and suggest that Kelly's (2003) personal psychology approach could be one avenue for exploring meaning making.

O'Connor (2010) provides suggestions for ways in which a relational lens can be applied to the assessment of capacity for older adults with a diagnosis of dementia, which merits further research in practice, whilst Karel and colleagues (2010), and Banner (2012) consider the ways in which values can be incorporated into the assessment process.

We have seen that medical and rights discourses have been dominant in the way that capacity has been constructed. Alternative understandings of autonomy and vulnerability may allow for a new relational model of capacity. This chapter will now turn to considering the discourses present in learning disability contexts.

1.6 Discourses And Power in Learning Disability Contexts

Despite what may appear to be recent changes in the way discourses and power have been deployed in learning disability settings (Department of Health, 2001, 2009b), there remains a complex interplay between political, institutional and legal discourses in the way that people with learning disabilities are understood and responded to by services, and by society.

Foucault (1978) explains that discourse “can be both an instrument and an effect of power, but also a hindrance, a stumbling block, a point of resistance and a starting point for an opposing ideology” (p100-101). Discourses can therefore open up and close down multiple possible courses of action, and are related to the exercise of power. A discourse provides a “set of possible statements about a given area, and organizes and gives structure to the manner in which a particular topic, object, process is to be talked about” (Kress, 1985, p.7). In this way, discourses can be understood as a set of common assumptions – they are often so taken for granted that they remain obscured or implied, without being made explicit (Cheek, 2004). These set of assumptions, or shared ideas, can be identified in texts, speech and wider social structures (Lupton, 1992).

Discourses can be deployed in ways which have an impact on what can be known, spoken about and done towards others. In this way discourse and power are inextricably linked. Power relations are enacted “whenever the actions of one person affect the field of possible actions of another” (Hamlin & Oakes, 2008, p.49), and become one-sided when possibilities for resistance are limited or removed. Power relations can therefore have a material impact on the opportunities available to others, which is often reflected in the institutional practices of services that support people with learning disabilities (Jingree, 2014). Consideration of the ways in which legal and institutional constructions of people with learning disabilities have developed over time may illustrate the ways in which discourses and power are deployed in the lives of people with learning disabilities.

1.6.1 Constructing learning disability: the role of the institution

In the early 19th century, institutions for the ‘feeble-minded’ were established, which allowed for new forms of knowledge about idiocy and feeble-mindedness to emerge. This knowledge was extended with the development of IQ testing, which heralded a new classification of idiocy – the moron (Carlson, 2005). Although these historical developments appear to represent shifts in understanding, Carlson argues that three dialectics exist across the conceptualisations of learning disability over time – quantitative and qualitative definitions, static and dynamic definitions, and learning disability as visible and invisible.

Under quantitative definitions of idiocy and feeble-mindedness, the difference was of degree or intensity – in contrast, qualitative definitions understood ‘idiots’ as being a separate kind, less than human. These definitions had implications for how people could or should be treated, and how scientific practices were used to classify them. In static definitions of feeble-mindedness, people were understood to be incapable of change or development – institutions therefore provided a space in which society could be protected from “idiots” and “moral imbeciles” (Carlson, 2005, p.141). Under dynamic definitions, the feeble-minded were amenable to training (rather than education), and this allowed the institutions to make their inmates productive. Through the development of the IQ test, feeble-mindedness became more visible outside of the asylum – tests were carried out in hospitals, prisons and schools, helping to identify “morons” who may have previously been unnoticed.

Although the terminology used to describe what is now commonly referred to as learning disability changed over time, institutions that segregated people with learning disabilities remained the primary sites of support until the implementation of the Community Care Act in 1992. The implementation of this Act called for the closure of institutions, and for people with learning disabilities to be supported within their local community. This illustrates the ways in which ‘expert’ knowledge can enable different practices, such as segregation or inclusion, that impact the bodies and lives of people with learning disabilities.

1.6.2 The normalisation agenda

The principles of normalisation (Nirje, 1985) and social role valorisation (Wolfensberger, 1972) preceded the move towards deinstitutionalisation in the UK. These ideologies emphasised the rights of people with learning disabilities to have an 'ordinary life' like anyone else. In the UK, these principles were embodied through O'Brien and Lyle's (1989) five service accomplishments of choice, competence, community presence, respect and participation.

The principles of normalisation have faced significant criticism for being 'paternalistic' and 'apolitical' (Foley, 2016), and requiring people with learning disabilities to conform to social norms. Foley (2016) argues that "if the normal/alternative binary is deployed to make a substantive point regarding the types of subject positions people with intellectual disability should aspire to, then surely the criteria used to categorise the distinctions in question should be clearly stated" (p.6), a practice he suggests is lacking on both sides of the debate. Despite this lack of clarity, the principles of normalisation continue to play a significant role in learning disability service design and ethos (Hamlin & Oakes, 2008).

1.6.3 Discourses in learning disability settings in the wake of normalisation

"As the exercise of government is embodied in the wielding of power, examination of the rhetoric of government is illuminative precisely because this discourse does not merely represent, but is the exercise of power. The rhetoric of government defines the nature of the 'social realities' the psy-complex is empowered to regulate, and acts as legitimation of action on the part of those authorised to dispose resources on its part" (Rapley & Ridgway, 1998, p.457)

Rapley and Ridgway (1998) propose that the community care movement draws on both the ideology of normalisation *and* corporate and managerialist

discourses. In order for the government to successfully deploy this discourse, “it is necessary to transform the construction of ‘the mentally handicapped’ into one recognising ‘individuals’ – people who are capable of being consumers” (Rapley and Ridgway, 1998, p.461).

In adopting a consumerist approach people with learning disabilities become capable of ‘independence’ and ‘control’, and in need of ‘quality care’. This is reflected in the use of the construct of ‘quality of life’ as a criterion by which services assess the standards of the support they are offering for people with learning disabilities (McVilly & Rawlinson, 1998; Schalock, 2005). Rapley and Ridgway’s (1998) analysis suggests that as professionals aligned with the psy-complex¹ we need to be mindful that constructs such as ‘quality of life’ may not only support people with learning disabilities to express their needs, but also deploy discourses that meet the needs of the political right.

More recently, government policy (Department of Health, 2001, 2009b) for supporting people with learning disabilities promotes a ‘rights’ discourse, which emphasises the importance of independence, choice and empowerment. The discourses within the *Valuing People* policies (Department of Health, 2001, 2009b) aim to oppose the paternalism inherent in previous institutional practices towards people with learning disabilities, and move towards promoting a social model of disability (Oliver, 1996), in which the barriers imposed by society are acknowledged and reduced.

Burton and Kagan (2006) argue that as a policy statement *Valuing People* constructs social inclusion as an individualistic process, based on neoliberal ideologies, rather than on working to build local communities and cultures. Instead of removing barriers, “the practice is one of adapting disabled people to the few openings that there are” (Burton and Kagan, 2006, p.309). Drinkwater (2005) proposes that *Valuing People* can be analysed “as a strategy of power, the objective of which is the making of good citizens” (p.232) - an extension of the use of power over life. These ideas are further taken up Byrne (no date)

¹ The psy-complex is the group of professionals dealing with the psyche – psychology, psychiatry, psychoanalysts, psychiatric nursing and social work. These professions are understood to regulate the practices of individuals, made ‘subjects’ (Rose, 1998).

who proposes that *Valuing People Now* frames “ideal citizenship as an independent individual in paid employment” (p.6), and uses a human rights discourse to legitimise this as a valued goal for people with learning disabilities. This has the potential to position people with learning disabilities as “deviant and deficient” (Byrne, no date, p.7) if they fail to achieve the goals for them set out in policy – which is often the case, particularly in relation to employment (Humber, 2014; Parker Harris, Owen & Gould, 2012; Redley & Weinberg, 2007).

Hamlin and Oakes (2008) suggest discourses of protection, power, humanity and rights continue to underlie the ethos of learning disability services and enable institutions to engage in a range of practices, including supported and substitute decision-making.

1.6.3.1 A discourse of protection

Historically, people with learning disabilities have been characterised both as needing protection, given their vulnerability, but also as people whom society needs protecting *from*, due to being ‘dangerous’ and ‘defective’ (Carlson, 2005; Hamlin and Oakes, 2008).

The concept of vulnerability is implicit within discourses of protection, but it is not always clear what is being referred to when the construct of vulnerability is deployed. Staff working in learning disability settings can struggle to offer a clear definition of the term vulnerability, with some equating vulnerability with risk, some understanding the two as separate, or as ends of the same spectrum (Parley, 2010). Vulnerability can be understood as both an individual quality or characteristic, and a factor of a person’s social and environmental context. Drawing on research from Clare and Murphy (2001), Parley (2010) notes “the vulnerability of people with intellectual disabilities is often based as much on the imbalance of power in relationships with others as in their individual characteristics” (p.267).

Discourses of vulnerability and protection appear to remain present in learning disability services, particularly in relation to issues of sexuality and parenthood

(Clough, 2015). Hamlin and Oakes (2008) suggest that although people with learning disabilities may no longer be constructed as a danger to society, the practices of services suggest that judgements are made about the value of different human lives. This is reflected, for example, in the inequalities in healthcare experienced by people with learning disabilities (Emerson, 2012; Department of Health, 2013a, 2013b) and their experiences of the criminal justice system (Department of Health, 2009a).

The discourse of protection positions professionals as responsible for ensuring the safety of not only people with learning disabilities, but also the general public. People with learning disabilities are positioned as needing care and protection, and this may justify services taking actions which limit the possible ways of being and doing for people with learning disabilities. These discourses can also be drawn on by people with learning disabilities themselves; in a study exploring women with learning disabilities' experiences, Scior (2003) interviewed a woman in her mid-30s who had undergone sterilisation following "intense pressure from non-disabled others" (p.790). Scior argues that "by attributing a motive of 'protection' to those invested with power over her body, Helen's sense of anger and outrage are subverted" (2003, p. 790). This suggests that discourses of protection may affect the range of responses people with learning disabilities' feel able to display when actions are suggested in their 'best interests'. The subject positions and subjective experiences enabled by a discourse of protection may be particularly important to bear in mind, as this appears to be a discourse that is also drawn on in constructing capacity (see section 1.4).

1.6.3.2 A discourse of power

The discourse of power in institutions for people with learning disabilities was "without question one of the most pervasive" (Hamlin & Oakes, 2008, p.49). In the institution power was exercised through a medical hierarchy that gave staff control over people with learning disabilities' movements, finances, activities and bodies. In current services, power may be exercised through the opportunities afforded to people to make their own decisions, which can be overridden in 'best interests' processes. The provision of information and

documentation of the lives of people with learning disabilities by professionals can also be understood as a deployment of power.

Barnes and colleagues (1999) suggest that in fact, normalisation “does not challenge the legitimacy of the professional role in the lives of disabled people, but guarantees its continued authority” (p.74). Discourses of power in learning disability settings position professionals as expert examiners, who work in “environment[s] of examination in the Foucault sense” (McIntosh, 2002, p.73), in which they assess the strengths and capabilities of people with learning disabilities, using neoliberal ideas of what it means to have ‘quality of life’ (Rapley & Ridgway, 1998) and to be a ‘good citizen’ (Drinkwater, 2005).

As ‘experts’, professionals often have power over the choices offered to people with learning disabilities, which can be limited to a “complex web of set frameworks” (Hamlin and Oakes, 2008, p. 52). This constrained set of choices is often recognised by professionals in learning disability settings as one of the dilemmas faced in their practice, particularly when considering mental capacity (Jingree, 2014; Brown and Marchant, 2011, 2013).

People with learning disabilities can therefore find themselves in positions where it is difficult to offer resistance, and where attempts to do so, such as refusals or expressions of anger or disagreement, are constructed as ‘challenging behaviour’ (Drinkwater, 2005; Finlay, Antaki & Walton, 2008; Nunkoosing & Haydon-Laurelut, 2011).

1.6.3.3 A discourse of humanity

Goffman (1961) argues that people in institutions were dehumanised through segregation and distancing practices such as taking away their clothing, cutting their hair and changing or removing their name. Although these practices would be challenged in current learning disability services, McIntosh (2002) suggests that “once the body is inscribed through classification, then depersonalisation becomes a matter of course” (p. 66). In order to counter this, a discourse of humanity in current learning disability services can be seen to be emphasising the personhood of people with learning disabilities. Within such an approach the

wishes and preferences of people with learning disabilities are prioritised and given weight and respect.

This is reflected in the personalisation agenda within health and social care services more broadly, and in the focus on person-centred planning within learning disability services specifically (Tarulli & Sales, 2009). How the MCA can be used to support people who lack capacity to engage with the personalisation agenda, such as the use of direct payments, is beginning to receive attention in the literature (Jepson *et al*, 2015). The interaction between the MCA and person-centred approaches requires further consideration, as Dunn (2013) has spoken about a tension between person-centred practice and decision-centred practice in learning disability services, where shared decision-making models may be in place that cannot be easily captured under the principles of the MCA

1.6.3.4 A discourse of rights

“A ‘right’, by definition, is concerned with agency, with the ability of an individual to make judgements and engage unimpeded in activities intimately associated with personal volition and an understanding of possibilities. Therefore... rights cannot be used to empower people whose very participation in a legal framework renders them powerless” (Young and Quibell, 2000, p. 753).

Fyson and Cromby (2013) propose that the permissive rights afforded by recent changes to policy are prioritised over protective rights for people with learning disabilities, and that this leads to service development based on neoliberal conceptualisations of welfare and personhood. They propose a more nuanced, relational understanding of personhood be adopted to ensure the “health, well-being, and safety of individuals whose capacities as rational, choosing agents may be limited, both by their inherent characteristics and by the social structures that surround them” (p1170). This parallels the relational approach to capacity proposed by Clough (2015).

Young and Quibell (2000) go further and suggest that rights based strategies in and of themselves may not be sufficient to address the social, material and legal inequities experienced by people with learning disabilities. They argue that in order to be able to exercise their rights, people with learning disabilities “need to be in an empowered position” (p. 753), which can be facilitated through communities sharing narratives and working towards understanding one another and the ways their stories intermingle. These narratives need to acknowledge social and cultural contexts and how these can promote or limit real choice for people with learning disabilities depending on the “intelligible alternatives” (Young and Quibell, 2000, p. 759) available. Young and Quibell argue that intelligible alternatives “can be provided only by a culture, that is, by an unseen host of collaborators. Culture is necessary to make rational choice possible. It is the condition of freedom” (Midgley, 1978, p. 317).

It could be argued that the self-advocacy movement contributes to the development of a culture in which people with learning disabilities can be empowered to share their stories and exercise their rights. Self-advocacy groups aim to promote self-empowerment and resilience (Goodley, 2005) and can be formed both within and independently of services (Buchanan & Walmsley, 2006). The self-advocacy movement also promotes people with learning disabilities being involved in research, and contributing to the knowledge that is developed ‘about’ them (Williams, 2011).

People with learning disabilities’ experiences of self-advocacy groups suggests that they can provide contexts in which group members can learn from each other, have the opportunity to speak up and ask questions, develop confidence and challenge others (Clarke, Camilleri & Goding, 2015). This parallels research into the life stories of leaders within the self-advocacy movement who spoke about self-advocacy groups offering opportunities for resistance, social justice and personal transformation (Caldwell, 2011). This suggests that the self-advocacy movement has the potential to engender change within individuals and within systems – allowing the personal to become political and the political to become personal.

1.7 Mental Capacity In Learning Disability Settings

1.7.1 Mental Capacity and Learning Disability Prior to the MCA

Prior to the implementation of the MCA, it was possible for professionals to use status or outcome based approaches to understanding and assessing capacity. This may have meant that at times negative assumptions were made about the ability of people with learning disabilities' to play an active part in making decisions about their own lives. A paper by Ellis (1992) suggests that assumptions about people with learning disabilities' level of knowledge, ability to communicate and 'denial of their disability' (p.7) may impact the opportunities that people with learning disabilities were given to decide for themselves.

Research into decision-making for people with learning disabilities prior to the implementation of the MCA in 2007 tended to focus on capacity to consent, particularly around healthcare interventions (Wong *et al*, 2000) and consent to sexual relationships (Murphy & O'Callaghan, 2004). Jenkinson (1993) suggested that decision-making for people with learning disabilities be contextualised within the broader decision-making literature, and that the impact of who has power over what choices are offered to people with learning disabilities be considered. The relationship between power, choice and decision-making capacity was also acknowledged in other research prior to the introduction of the MCA (Smyth & Bell, 2006).

1.7.2 Multiple Discourses and Institutional Practice: The Example of Mental Capacity Assessments

An investigation by the House of Lords (2014) into the practical application of the MCA identified an "attitudinal barrier to implementation" (p.40), whereby assessments were based on perceptions of risk and seen as a way of 'protecting' vulnerable adults rather than being used to facilitate decision-making. Conversely, concerns were also raised that the presumption of capacity was used to justify poor care or a lack of intervention from services. This is congruent with the discourses of protection and rights that we have seen are

often drawn on in learning disability services. The results of the House of Lords report suggest that drawing on discourses of protection and rights in relation to mental capacity allow for certain practices in relation to assessment practices.

The MCA proposes that objective, value neutral assessments of capacity can be undertaken. Research into complex cases (Brown & Marchant, 2011, 2013; Dunn, 2013) and professionals' experiences of implementing the MCA (Dunn, Clare & Holland, 2010; McDonald, 2010; McVey, 2013; Newby, Anderson & Todd, 2011; Walji, Fletcher & Weatherhead 2014) suggest there are significant challenges in the assessment process, including considering environmental and relational factors, managing perceived professional and emotional risks, and dilemmas around how to approach the assessment process.

In the move from deinstitutionalisation, normalisation and social role valorisation agendas (Wolfensberger, 1972) have emphasised people with learning disabilities being afforded equal citizenship - that is, rights, choices and inclusion. These discourses of rights, choice and empowerment are also reflected in professionals' accounts of working with people with learning disabilities (Jingree, 2014).

Within these accounts interpretive repertoires of 'duty of care', 'safety' and 'normalisation' were often drawn upon to talk about situations in which professionals withheld or granted choice, or assumed responsibility for people they were supporting (Jingree, 2014). Jingree (2014) found that people with learning disabilities were often constructed as lacking capacity, which allowed professionals to normalise the limited choices they offered.

This suggests that MCA assessments may be an institutional practice where multiple discourses need to be negotiated, and this is borne out in how professionals talk about their experiences of implementing the Act.

There is currently no quantitative data available on the number of MCA assessments carried out in learning disability services in the UK per year, however there is a burgeoning literature on applying the MCA in learning disability settings (Brown & Marchant, 2013; Craig, Nagi & Hutchinson, 2007;

Edge et al, 2015; McVey, 2013; Willner et al, 2011) which suggests the MCA is particularly pertinent for professionals working with people with learning disabilities.

McVey (2013) interviewed professionals working in a learning disability service about their experiences of implementing the MCA, and found that they understood the task as being part of a process of 'safeguarding' people with a learning disability. Using the Act in practice was discussed in terms of professional risks, such as a fear of being incompetent, or facing legal challenges; and emotional risks, such as sitting with feelings of anxiety, sadness and anger about the process. These risks were managed via the use of safety strategies such as peer support and ensuring that their actions were justifiable.

McVey (2013) speculated that a number of factors might impact professionals' experiences of these risks and the use of safety strategies, including the significance of the decision to be made, staff perceptions' of themselves as "professional helpers" (p.85) and managing competing demands as a professional. Professionals in learning disability contexts may therefore be caught between a number of subject positions, including facilitator and advocate (within 'rights' and 'empowerment' discourses), and responsible protector (within 'power' and 'protection' discourses).

1.7.3 Practice Gaps and Challenges in Implementing the Mental Capacity Act

1.7.3.1 Knowledge of the MCA

Willner and colleagues (2011) used structured interviews and vignettes to explore professionals' knowledge and understanding of mental capacity issues. The professionals were all based in community learning disability teams, and 33 out of the 40 professionals involved in the study reported having experienced situations that raised questions about a person's mental capacity. The results suggested that there were a number of gaps in professionals' knowledge, including:

- Whose responsibility it was to undertake capacity assessments
- Whether the outcome of the decision needs to be considered in assessing capacity
- The importance of considering severity of disability *and* the complexity of the decision to be made
- Identifying that a single decision maker needs to be decided upon in best interests decisions
- A lack of information about the scope of the Mental Capacity Act – it does not extend to personal relationships

The study has obvious limitations, in so far as professionals were asked to base their decisions on what to do in each scenario having been given very little information, and that response to vignettes may not reflect how professionals would respond in a real life situation. However, the results of this study are congruent with the House of Lords scrutiny report (2014) which found that there was a lack of awareness of the MCA and how to implement it across a range of health and social care settings. This suggests that there are barriers to implementing MCA training in practice, and that mental capacity issues may still not be clearly understood ‘on the ground’.

1.7.3.2 Adapting the assessment process in learning disability settings

Drawing on their experience of professionals’ uncertainty in implementing the MCA in learning disability settings, Skinner and colleagues (2010) outline a multi-disciplinary, structured approach to assessing mental capacity, involving an initial screening assessment to gain a sense of the person’s ability to understand and retain information, before offering more detailed information at a ‘higher’ level. For people who ‘pass’ the screening assessment, a multi-disciplinary approach is then used to assess capacity in more detail. This mirrors the legalistic approach to capacity assessment outlined by McDonald (2010) and the proposed pathway does not identify how differences of opinion within the multi-disciplinary team might be managed or thought about.

Edge and colleagues (2015) explored how the Montreal Cognitive Assessment (a 10 minute, 30 point screening test designed to detect Mild Cognitive

Impairment) could be adapted to act as a screening test for mental capacity assessments in people with learning disabilities. The adapted version of the scale, termed the 'MoCA-LD' used Clock Drawing, Trail Making, Copy Cylinder, Working Memory, Naming, Digit Span and Orientation tasks to explore participants' ability to understand, retain and communicate information. They found that participants who scored lower on the MoCA-LD were more likely to have lower scores on a measure of executive functioning. Previous studies have found 'weighing up' abilities were associated with executive functioning more than with IQ for people with learning disabilities (Willner et al, 2010). Edge and colleagues suggest that the MoCA-LD may provide a way to screen for the presence of decision-making abilities, but note that it should not be used to confirm their absence. Further research into the sensitivity and specificity of the MoCA-LD and its relationship to other mental capacity assessment tools is required in order to establish ecological validity.

1.7.3.3 Experiences of the assessment process

Looking at social workers' experiences of using the Act with older people, McDonald (2010) found that approaches to capacity assessments could be largely grouped into a legalistic approach, an actuarial approach, and a rights based approach. A legalistic approach understands capacity assessments under the MCA as a morally neutral, rules-based process. An actuarial approach understands the process as a "sub-set of risk assessments" (McDonald, 2010, p.9) and related to a duty of care towards clients. Finally a rights based approach to capacity assessment acknowledges the interpretative nature of the assessment process and uses advocacy to support people to make decisions. McDonald (2010) noted that social workers' ability to take up different assessment approaches was often affected by the circumstances of the case, their level of experience, and their work environment. This suggests that the assessment process is open to influence from a variety of factors, and may therefore not be neutral.

This was also reflected in research completed by Walji and colleagues (2014), who explored the experiences of implementing the MCA of seven clinical psychologists from a range of settings, including learning disability services,

older adult services and acquired brain injury services. Participants identified expressed a need for training that explored the clinical applications of the MCA in more detail, including guidance on the functional and ethical aspects of implementation. Some clinicians commented on the lack of congruence between their perceived professional values and the values inherent in the MCA assessment process, particularly in relation to taking an 'expert' position within best interests meetings. They also reflected on the power dynamics inherent in both the assessment and best interests process. This suggests that a discourse of power may be present within capacity assessments, which may overlap with discourses of power already implicit in learning disability contexts.

Walji and colleagues (2014) mapped the themes from their interviews onto, a framework of safety and uncertainty, with clinicians' moving towards a position of safe uncertainty (Mason, 1993) as they became more confident and competent (drawing on Newby *et al*, 2011). This move towards safe uncertainty allowed clinicians to move from legalistic and actuarial approaches to assessing capacity to a rights based approach (drawing on the work of McDonald, 2010).

1.8 Research Rationale

Capacity and learning disability are interdisciplinary concepts that draw on knowledge across philosophical, legal, psychiatric and psychological discourses (Carlson, 2005; Owen *et al*, 2009). How these concepts interact has not been well explored. The legal frameworks around the assessment of mental capacity imply certain practices for professionals involved in assessment, however research into implementing the MCA in practice identifies significant challenges involved in this process.

There is currently no research that explores how professionals in learning disability contexts construct capacity, what factors affect this and how different concepts of capacity may allow for different professional and institutional practices. Exploring the relationship between discourse and power in this context may allow for professionals to take up different practices when conducting capacity assessments in learning disability settings.

1.9 Aims Of The Current Study

This study is particularly interested in how capacity is constructed in learning disability contexts due to historical, social and institutional discourses around rights, power and protection that imply certain ways of relating to people with learning disabilities. Mental capacity assessments also appear to be an area of clinical practice where professionals have to manage multiple discourses. This study will explore how professionals' constructions of capacity invite certain practices and subject positions in response, and what the implications of this might be for clinical practice.

Research questions:

- In what contexts do certain behaviours or situations become problematised as issues of capacity?
- What discourses are drawn on in constructing capacity?
- What do these discourses of capacity allow or limit professionals to do in terms of their practice, particularly in relation to the Mental Capacity Act?
- What subject positions are available within the discourses of capacity that professionals construct?
- In what ways might these subject positions be taken up and resisted?

2. METHODOLOGY

This chapter outlines the epistemological position taken in this research study, and the rationale for adopting a discourse analytic approach to data analysis. The recruitment procedure and interview process are presented and discussed, as are the ethical considerations involved in undertaking this research. The Foucauldian approach to discourse analysis is discussed in more detail. Finally, this chapter also considers the role of reflexivity in relation to this research.

2.1 Epistemological Position

This research is undertaken from a critical realist social constructionist position, which can be understood as being ontologically realist but epistemologically relativist (Harper, 2011). This means that there is assumed to be a material 'reality' in which the research takes place and which participants and the researcher may orient to, but that knowledge of this reality is constructed through interaction. This research is therefore not considered to be 'objective' or capable of uncovering 'truths' about the realities in which participants find themselves.

2.1.1 Critical realism

Critical realism proposes that language is the medium through which we construct our social realities, and that "meaning is made in interaction" (Sims-Schouten, Riley & Willig, 2007, p.102). However, it acknowledges that our construction of meaning is also affected by material structures, which offer certain possibilities and limitations on the language we use. For example, the availability of financial resources and appropriate childcare might affect the way women talk about motherhood (Sims-Schouten, Riley & Willig, 2007).

Given this, a critical realist would argue that in order to understand meaning and discourses we need to take account of material 'extra-discursive' factors, such as social inequalities and disempowerment. This is particularly important in the context of research relating to people with learning disabilities, who struggle to gain equal access to resources including healthcare (Emerson,

2012) and employment (Humber, 2014) and may find themselves in disempowered positions as victims of abuse (Scope, 2008) and as subjects of assessment and interventions from services (Goodley, 2005). Craig and Bigby (2015) propose that a critical realist approach to researching social work practice with people with learning disabilities may provide a way of developing evidence based practice without disavowing the complexity involved in this work.

2.1.2 Social constructionism

Social constructionism is concerned with the process of how 'knowledge' is constructed – it takes a critical approach towards taken for granted ways of understanding the world (Burr, 2003). A social constructionist epistemological position holds that the categories and concepts we use to describe the world are culturally and historically specific, and that these categories and concepts are constructed through language and interactions (Burr, 2003).

Radical social constructionism proposes that there can be no 'truth claims', as there are always multiple possible perspectives. A radical position is rejected by this research, and instead a moderate social constructionist position is taken up, which references "a (discursive) reality outside the original text" (Willig, 2013, p.79).

Social constructionist research has allowed researchers to 'denaturise' taken-for-granted knowledge in the fields of psychiatric diagnosis and mental distress (Georgaca, 2013) and learning disability (Rapley, 2004; Carlson, 2005). The social model of disability (Oliver, 1996) takes up a social constructionist position, which acknowledges the structural barriers to inclusion instead of locating the 'disability' within the individual. This enables professionals to take a different approach to working with people with learning disabilities that shifts the focus onto social rather than individual difficulties (Clegg, 1993).

2.1.3 Critical realist social constructionism: taking an ethical position?

In taking a realist ontological position that assumes the existence of certain material and structural 'realities', certain 'truth claims' cannot be challenged (Willig, 2013). Whilst this is problematic in some aspects, a pure social constructionist approach means that no moral or political positions are available. A critical realist position offers a more ethical way of approaching research (Sims-Schouten, Riley & Willig, 2007) for this study, as the context of the social inequalities experienced by people with learning disabilities can be taken into account. This is particularly important in the context of undertaking research relevant to people with learning disabilities, who have often been positioned as powerless and incompetent by 'expert' others (Carlson, 2005).

It has been argued that a critical realist social constructionist position can lead to selective relativism and inconsistency (Harper, 2011) in documenting how, when and why decisions were made during the research process, including the construction of the 'problem' and the way in which this is analysed. In attempting to take up a more ethical position in relation to this study, I have used researcher reflexivity (see section 2.5) in the hopes of being more aware of the influences and roles that may have contributed to the research process.

2.2 Methodological Position

This study takes a discourse analytic approach to professionals' talk about mental capacity in learning disability contexts - it goes beyond discursive psychology and conversation analysis approaches by paying attention to more than just speech acts and the orientations of people within talk. Linking together discourse and practice enables an ethical approach to research that acknowledges participants' lived experience, whilst going beyond a phenomenological approach. This allows for exploration of the positions that might be taken up and resisted by both professionals and people with learning disabilities. A discourse analytic approach acknowledges the power of people with learning disabilities to take up 'active' positions in negotiating their interactions with others (Dozorenko, Roberts & Bishop, 2015) and construct knowledge about themselves (Williams, 2011).

2.2.1 Critical realist discourse analysis

A critical realist approach to discourse analysis aims to examine the 'extra-discursive' factors that provide a structure for the discourses that people are (un)able to draw on in their talk. Sims-Schouten and colleagues (2007) propose a systematic approach to considering 'extra-discursive' factors, which examines embodiment, institutional power and materiality. Following this the 'text' is then analysed at multiple levels – paying attention to the action orientation of participants' talk (see section 2.2.2 below) as well as times at which extra-discursive factors are acknowledged.

Critical discourse analysis can be understood as a tool through which emancipatory research can be conducted (Luke, 2002). In order to achieve this critical discourse needs to document forms of discourse that use power productively, as well as critiquing ideologies and discourses that are problematic (Luke, 2002).

2.2.2 A Foucauldian approach to discourse analysis

Arribas-Ayllon and Walkerdine (2007) propose that there is no such thing as 'Foucauldian discourse analysis' in so much as there is no one way to 'do' discourse analysis according to Foucault, and no single set of tools or techniques to use. Instead, Foucault presented a range of ideas, which can be applied in discourse analysis (see section 2.4.2) depending on the aims of the research being undertaken. This section considers the general principles underlying Foucault's interest in discourse analysis that guide the approach taken in this study.

Foucault aimed to explore the relationship between scientific disciplines and social practices, and in doing so, illustrate how power and knowledge are related to the ways in which human beings are made subjects (Rabinow, 1991). Foucault was interested in the processes by which humans can be made subjects through specific forms of knowledge, the processes through which power can make us subjects that both act upon others and are acted upon, and

the processes through which we acknowledge ourselves as subjects and govern ourselves (Yates, Dyson & Hiles, 2008). In understanding how power works Foucault proposes that we are then in a position to respond to political violence that would otherwise have remained obscure (Rabinow, 1991). In this way a Foucauldian approach to discourse analysis is well aligned with a social justice agenda within research.

This study draws on the approach to Foucauldian discourse analysis outlined by Willig (2013), and acknowledges that this is only one possible way of approaching analysis. Although the stages are presented sequentially, the process of analysis was iterative rather than linear.

Stage 1: Identifying discursive constructions

The first step requires identifying 'the discursive object' and the different ways this is constructed in the text. This includes implicit and explicit references to the discursive object, as well as attending to what was not said. The discursive objects in this study were 'capacity' and 'learning disability'.

Stage 2: Identifying discourses

This stage examines the similarities and differences between the various constructions of the discursive object, and locates these constructions within wider discourses, for example a 'biomedical' or 'moral' discourse. Although I often oriented to wider discourses that had been identified in the relevant literature (see Chapter One), I was conscious of having power over what I constructed as a 'wider' discourse.

Stage 3: Exploring action orientation

Exploring the action orientation of different discourses involves looking at how and when discourses are used within the text. Asking questions such as 'what is the function of this discourse?' and 'what does this discourse allow or limit?' facilitates this stage of the analysis. For example, it may be that drawing on a certain discourse allows for the assignment of responsibility, or the justification of certain practices.

Stage 4: Identifying subject positions

Discourses open up or close down different subject positions. Willig (2013) explains that subject positions “offer discursive locations from which to speak and act rather than prescribing a particular part to be acted out” (p. 387). The subject positions offered by particular discourses can be both taken up and resisted which may have implications for people’s subjective experiences.

Stage 5: Considering opportunities for practice

A Foucauldian approach to discourse analysis seeks to explore the opportunities for action that follow on from the discourses that have been identified. As with discourses and subject positions, these can be productive as well as restrictive – there will be actions that are opened up whilst others may be closed down.

Stage 6: Considering subjectivity

Discourses make available certain subject positions and possible ways of practising; this suggests certain ways-of-being are also opened up or closed down for people. Asking what can be thought, felt and experienced from different subject positions allows for consideration of what social and psychological ‘realities’ are possible given different discourses. This is the most speculative stage of the analysis, and therefore carefully framed in terms of possibilities rather than being prescriptive or fatalistic.

2.2.3 Integrating a micro and macro approach to analysing discourse – drawing on discursive psychology

A social constructionist approach to discourse analysis allows for a focus on both micro levels of discourse, in which language is used within ‘local’ interactions between people to create certain realities and possibilities for action, and macro levels of discourse, in which the relationship between language and institutional practices is made explicit, where it may previously have remained opaque (Burr, 2003; Jorgensen & Phillips, 2002). In order to better explore the micro level of discourse that was deployed in professionals’ talk, I drew on ideas from within discursive psychology to explore how people organised their talk in order to construct certain social realities or identities. By

paying attention to rhetorical strategies (Edwards & Potter, 1992; Potter, 1996) this enabled me to consider how professionals were able to reproduce or resist certain discourses within the context of their talk. Identifying how and when linguistic tools and rhetorical devices were used also allowed me to consider what implications this might have on how 'factual' the accounts that were being given were made to appear (Jorgensen & Phillips, 2002). This enabled me to consider the 'action orientation' of the talk of participants, that is the function of different aspects of the discourses that were constructed, as suggested in Willig's (2013) description of Foucauldian discourse analysis (please see section 2.2.2 above).

2.2.4 Bringing a Foucauldian lens to learning disability research

A small body of the qualitative learning disability literature has drawn on a discourse analysis approach (Jingree, 2009, 2014; Scior, 2003; Whittuck, 2009). Learning disability research drawing specifically on a Foucauldian approach to discourse analysis has been limited (Devonshire, 2014; Drinkwater, 2005; Wilson, 2007), and has focused on how people with learning disabilities construct their identity within a family context, how they construct interpersonal relationships and how they are constructed as productive individuals in supported living contexts. More theoretical applications of Foucault's ideas have explored how the concept of 'learning disability' has been constructed, identified discourses in learning disability policies, and analysed the practices of learning disability services and professionals (Carlson, 2005; Danforth, 2000; Gilbert, 2003; Hamlin & Oakes, 2008; McIntosh, 2002; Shaw, 2009; Yates, Dyson & Hiles, 2008).

Carlson notes that as an object of knowledge "mental retardation...has never had a permanent residence in any one field; it has been, and continues to be, an object of medical, psychological, pedagogical, moral, humanitarian and political discourse" (p.148). In the intersection of these fields, there are tensions within dominant discourses around power, protection, rights and humanity (Hamlin & Oakes, 2008). These tensions may be understood as problematic for both professionals and people with learning disabilities (McIntosh, 2002; Scior, 2003) as they may be productive of subject positions that imply limited

opportunities for action. In drawing on a Foucauldian approach to explore how the concept of mental capacity might be constructed within a learning disability context, it is hoped that this study may produce knowledge about how professionals “understand, act out, and resolve” (Hacking, 2002, cited in Carlson, 2005, p.147) these tensions in relation to the practice of mental capacity assessments.

2.2.5 Limitations of a critical realist Foucauldian approach

In attempting to explore the relationship between discourses and material reality issues arise about the primacy of either discourse or materiality, or whether the two exist interdependently. This has implications for the interpretations we can make about where power originates, is produced, enacted and maintained (Willig, 2013) and will need careful consideration in the process of analysis and discussion.

As the sole researcher on this study, I exercised power over what the focus of the research was, how data would be collected and from whom, and how the data would be analysed. It is hoped that Chapter One provides a transparent rationale for the ‘what’ of this study; section 2.3 outlines the ‘how’ and the ‘who’ of data collection; section 2.4 outlines the ‘how’ of the data analysis.

Throughout this process I took up the position of a reflexive researcher (see section 2.5) and used thesis supervision, a reflexive journal and discussion with peers to make sense of the contexts and contingencies that influenced my engagement with the research process. Chapter Four provides further analysis of the strengths and limitations of the current study.

2.3 ‘Choosing A Corpus Of Statements’: Data Collection

Arribas-Ayllon and Walkerdine (2007) note that discourse analysis *selects* objects or texts that illustrate “the practices on the basis of which certain problematizations are formed” (p.101). In order to explore how the concept of capacity is problematized in learning disability settings this research uses speech data from semi-structured interviews with professionals working in learning disability services who have undertaken mental capacity assessments.

2.3.1 Sample Selection

Participants are clinical psychologists, learning disability nurses and a social worker (see Table 1 below for participants' demographic information) currently working in community learning disability teams in London. Purposive sampling was used in order to try and reflect the multi-disciplinary nature of learning disability services, and to extend previous research exploring experiences of implementing the Mental Capacity Act, which has primarily focused on one professional group (McDonald, 2010; McVey, 2013; Walji, Fletcher & Weatherhead, 2014). In interviewing participants from different professional backgrounds this research hopes to pay attention to both continuities and discontinuities in how capacity is problematized through discursive practices across institutional spaces (Arribas-Ayllon and Walkerdine, 2007).

In a Foucauldian approach to discourse analysis there is no specific guide to sample size. The current study aimed to recruit between nine and twelve participants, on the basis of evidence to suggest that a minimum of six participants may be sufficient to achieve data saturation (Morse, 1994). Due to difficulties with recruitment and a delay in receiving ethical approval, interviews were conducted with eight participants.

Table 1: Participant demographics information

Thesis interview	Job role	Gender	Age	Ethnicity	Number of years in LD services	Length of interview
1	Clinical psychologist	Female	35	White British	6.5	72 minutes
2	Clinical psychologist	Female	Not given	White British	Not given	60 minutes
3	Learning disability nurse	Female	42	White British	18	61 minutes
4	Social worker	Female	49	Black British	2	47 minutes
5	Clinical psychologist	Female	41	White Other	11	50 minutes
6	Clinical psychologist	Male	50	White Other	28	45 minutes
7	Learning disability nurse	Male	Not given	White British	20	40 minutes
8	Learning disability nurse	Female	27	White British	10	60 minutes

2.3.2 Recruiting Participants

Team managers of learning disability services across five London boroughs were contacted via email (see Appendix A for email template), and given a copy of the participant information sheet (see Appendix B). Following agreement from the team managers, this initial email was distributed to the wider team to advertise the study to potential participants. Interested parties were invited to contact the researcher directly, thus ‘opting in’ to taking part in the study. Arrangements were then made to interview participants at a date, time and location convenient to them. Prior to interview participants were emailed a brief demographics questionnaire that captured information about their experience of

working in learning disability settings and in conducting mental capacity assessments (Appendix C).

2.3.3 Developing An Interview Guide

Although a Foucauldian approach to discourse analysis can be conducted on any kind of 'text', including unstructured speech, a semi-structured interview schedule (see Appendix D) was developed through discussion with my thesis supervisor in order to facilitate the interview process. Interview questions were developed based on the existing literature (McVey, 2013; Walji, Fletcher & Weatherhead, 2014) and holding in mind the aims of the research to pay attention to extra-discursive factors, wider discourses and the subject positions and possible ways-of-being these provide. The ecological validity of the questions was established through conducting a pilot interview with my second supervisor, a clinical psychologist in an adult community learning disabilities team.

Broadly speaking the interview aimed to explore:

- professionals' understanding of the concept of capacity
- professionals' experience of and role within mental capacity assessments
- the impact of the assessment process on professionals and people with learning disabilities
- the impact of the assessment process on the relationship between people with learning disabilities, professionals, and the wider system

2.3.4 The Interview Process

Participants were given a copy of the information sheet immediately prior to being interviewed. They were also given the opportunity to ask any questions about the research as a whole or about the interview process itself. Participants signed a consent form (Appendix E), which outlined how the interview data would be used and stored.

Interviews were conducted in a private room at the work location of the participant in order to minimise the amount of time that professionals were asked to take away from their clinical practice. Interviews were conducted following the semi-structured interview schedule, with the researcher asking follow-up questions and prompts based on the content of participants' answers. Interviews lasted an average of 48 minutes (mode: 60 minutes; range: 40 to 72 minutes). All interviews were audio-recorded using a dictaphone. Following the interview, participants were debriefed about their experiences of taking part in the interview process.

2.3.5 Ethical Considerations

2.3.5.1 Privileging the professional over the personal

In choosing to conduct this research with professionals working with learning disabilities rather than people with learning disabilities themselves, I was aware of contributing to a body of literature in which the voices of people with learning disabilities remain largely unheard (Goodley, 1996; Scior, 2003).

The self-advocacy movement and a turn towards participatory research have provided spaces in which people with learning disabilities are able to negotiate their identities (Clarke, Camilleri & Goding, 2015; Goodley, 2005). In spite of this, it is argued that people with learning disabilities' identities are still frequently constructed by others rather than themselves (Rapley, 2004). Capacity assessments can be seen as another method through which their abilities and experiences are constructed. Professionals often have power over how and when concerns about capacity are raised (Brown & Marchant, 2011, 2013) and in this way capacity assessments may represent sites of practice in which people with learning disabilities are 'done to' rather than 'done with'.

I considered alternative research designs during the development phase of this study, including the possibility of recording and analysing in-vivo mental capacity assessments, or interviewing people with learning disabilities about their experiences of being assessed under the MCA as well as the professionals conducting the assessment. In opting not to pursue those

possible avenues of research I have privileged the 'professional' position over that the 'personal' position for people with learning disabilities, which raises questions about who this research is for and what it aims to achieve.

Yates and colleagues (2008) note that "it should be recognised that care staff also exist within relationships of power, subjectivity and self-government, and an understanding of the forces that shape their identities and actions might also be helpful" (p.256). In addition McIntosh (2002) suggests that professionals "are linked to the space of social identity and can become marginalised in the way that the client group themselves are, and this is a final contingent in the discourse" (p.78). The turn to neoliberalism within health and social care systems requires that both professionals and service users regulate their actions in order to take up the positions of 'health care provider' and 'consumer' on offer (Speed, 2011).

It is my hope that in exploring how professionals' construct the concept of capacity this will enable links to be made between clinical practice, wider discourses and extra-discursive factors. In making these links I hope this will enable professionals to be more aware of the subject positions and practices available to them when drawing upon different discourses of capacity and learning disability. It may be that this knowledge allows for the identification of points of possible resistance and discontinuity available to them within MCA assessments. This in turn impacts on the possibilities that can be imagined and realised for their clients.

2.3.5.2 Ethical approval and potential risk to participants

Ethical approval was sought and received from the University of East London Research Ethics Committee (see Appendix F). Additionally ethical approval was sought and received from the Health Research Authority (Appendix G) given the recruitment of National Health Service (NHS) staff as participants.

No risks for participants were anticipated, however it was acknowledged that the process of being interviewed might have lead professionals to feel as though normative judgements were being made about their practice in relation

to undertaking MCA assessments. This was held in mind throughout the research process:

- during the development of the interview schedule - by emphasising the intention to understand the participants' personal experiences of capacity assessments
- in the interview process itself - through taking a position of curiosity
- during debriefing -through exploring with participants how they had experienced the interview and acknowledging, where appropriate, questions or themes that may have felt challenging or uncomfortable to think about.

2.4 Transcription and Data Analysis

2.4.1 Transcription

All interviews were transcribed verbatim, using a simplified transcription framework (Malson, 1998; see Appendix H for a table of transcription conventions). A simplified transcription process was used to allow for analysis of the text at a macro level, including wider discourses and practices, as well as micro level analysis of the talk, including the use of rhetorical devices (Potter, 1996) and what these enabled in terms of the action orientation of the discourses that were drawn upon.

2.4.2 Using a 'tool box' of Foucauldian ideas

As outlined in section 2.2.2 above, there is no single way to approach a Foucauldian discourse analysis. Instead Foucault's body of work presents a range of ideas to be drawn upon, which he presents as a 'tool box' (Foucault, 1974, p.523). In thinking about how this 'tool box' could be applied to the current research I drew on the following ideas to help me throw into relief what discourses and practices were being oriented to in the interview data.

Power/knowledge

For Foucault, power and knowledge are relational and inextricably linked. He proposes that “power produces knowledge...there is no power relation without the correlative constitution of a field of knowledge, nor any knowledge that does not presuppose and constitute at the same time power relations” (Foucault, 1975).

Technologies of power

Technologies of power are institutional techniques that govern conduct from a distance, for example legislation.

Technologies of the self

Technologies of the self are the practices through which individuals regulate their own conduct. These often provide ways of assigning meaning and value to our practices.

Both technologies of power and technologies of the self “come together around the objectification of the body” (Rabinow, 1991, p.17), where the aim is to make bodies ‘docile’ – bodies that are “subjected, used, transformed and improved” (Foucault, 1977). Foucault notes that a “body becomes useful only if it is both a productive body and a subjected body” (Foucault, 1977).

Bio-Power

Bio-Power can be seen as an example of technologies of power, specifically linking “the domains of medicine and politics through the concerted usage of the human body” (McIntosh, 2002, p.74).

Surveillance

Foucault was particularly interested in the social disciplines and mechanisms that enabled “the observations of others, supervision and recording of movements” (McIntosh, 2002, p. 72). Foucault noted that methods of surveillance often follow from a “theory of duality” (McIntosh, 2002, p.72) in which binary divisions are made between categories, such as mad/sane, and then linked with identity and the need for social regulation. The concepts of capacity/incapacity can be considered a binary division. Surveillance can be

both explicit, visible and external, as in the institutions set up for the 'feeble-minded' (Carlson, 2005), and invisible and internal. The technologies of surveillance can also be implied within policy and practices.

2.4.3 The analytic process

In analysing the data I incorporated the above ideas into the broader analytic stages outlined in section 2.2.2 as part of the following process.

2.4.3.1 Coding the interviews

I began the process of analysis by reading through my interview transcripts thoroughly twice, in order to immerse myself in the data. On my third read-through of my transcripts I began my coding by paying attention to the ways in which capacity was directly or indirectly spoken about, and what discourses these constructions appeared to draw on. I was also interested in how people with learning disabilities were being constructed in relation to their ability to make decisions.

I then identified the subject positions that appeared to be available to both professionals and people with learning disabilities given the discourses of capacity that were drawn on. Following this I paid particular attention to the practices that were constructed, particularly in relation to undertaking capacity assessments. The final stage of analysis involved coding examples where subjectivity was oriented to, in particular in relation to how the emotional impact of the assessment process was constructed. These different stages of analysis – discourse, subject position, practices and subjectivity were indicated using different coloured highlighters (see Appendix I for a worked example).

Across all these stages of analysis I paid attention to the rhetorical devices (Potter, 1996) in professionals' talk and asked myself what function these speech acts enabled or closed down at that point in the interview, and in analysing the data at a later date. For example, in being vague, did this allow the professional to resist an 'expert' position? How might this vagueness impact my ability to interpret the claims that were being made? How did I respond to

this vagueness as the interviewer – did I feel able to ask for clarification, or did I take-for-granted the claims that were being made?

2.4.3.2 Constructing a narrative – the writing up process

In attempting to write up the findings of my analysis, I was struck by the richness of the data I had, and was conscious of not being able to attend to all of the pertinent themes given the word count available to me. I initially attempted to construct a narrative around the stages of analysis, however I struggled to make this fit in a coherent way (see Appendix J for mind maps). I revisited my Foucauldian ‘tool box’ and thought about what had struck me most during the transcription and analysis process, and the concepts of power and knowledge seemed most salient. Using these as orienting concepts allowed me to develop a coherent narrative about how professionals constructed capacity, and what this allowed for in terms of subject positions, practices and subjectivity (see Appendix J for mind maps).

2.5 Reflexivity

In undertaking this study it has been important to acknowledge that research itself is a discursive construction (Willig, 2013). In my role as researcher I am conscious of being a co-author of the ‘knowledge’ that has been produced in this study rather than an objective ‘expert’ who is able to discover ‘truths’ in what has been said. It is therefore important for me to be aware of the assumptions, values and contexts that influence the positions I have taken during this research process.

Having worked in learning disability settings prior to and during training, I was struck by the challenges and dilemmas my colleagues faced in undertaking MCA assessments. This piqued my interest in thinking about how capacity might be constructed in relation to people with learning disabilities. However I was aware of having had limited experience of having to conduct MCA assessments myself, and that I would be interviewing people who may have significant experience of both working in learning disability services and in completing MCA assessments. As a trainee clinical psychologist I was mindful

of interviewing professionals of both a similar and different professional background to my own, and how this might impact on the assumptions I held about their understanding of capacity in learning disability settings.

As a trainee clinical psychologist at the University of East London I was aware of being influenced by my teaching in critical approaches to psychology and taken for granted 'knowledge' and that this might mean I was more likely to align myself with a critical position towards the MCA rather than acknowledging the opportunities and value that might be available within different constructions of capacity and different ways of 'doing' MCA assessments. I often found myself asking why I might be drawn to particular themes, papers, and extracts in thinking about the questions I asked in my interviews, and during the process of data analysis. Acknowledging when I was aligning myself with a critical position, for example in being initially drawn to examples of the restrictive practices enabled by the MCA, allowed me to consider what I may be obscuring, and what the value of taking up certain positions or ideas might be, as well as the limitations of these.

2.5.1 Using a research journal

I have used a research journal (Finlay & Gough, 2003) throughout this process to help me reflect on both the content and process of conducting research, and to make sense of how my own personal and professional contexts might impact my thought processes and actions as a researcher. After interviews I used the journal to make a note of what struck me from the conversations I had just had with people, including possible themes and what thoughts or feelings this evoked in me, both at the time and in hindsight. I also used the journal during the process of analysis and write up (see Appendix K for an extract from my research journal).

3. ANALYSIS AND DISCUSSION

This chapter will outline the main research findings, the author's interpretations of these, and the implications of these interpretations. Extracts from the interview data will be used to illustrate how capacity is constructed in the talk of learning disability professionals. Consideration will then be given to the subject positions, practices and subjectivity enabled and limited by these discourses of capacity.

In line with the critical realist social constructionist epistemological position taken in this research, the interpretations outlined offer only one of many possible readings of the data. A reflexive narrative of the steps taken as part of choosing and interpreting the extracts considered below can be found in chapter 4, section 4.3. The analysis of the extracts presented will go on to explore how the interpretations described relate to the literature on mental capacity and people with learning disabilities.

In attempting to make sense of the interview data, two Foucauldian concepts were particularly oriented to: knowledge and power. The concept of the "knowledge-power nexus" (Foucault, 1997, p.53) suggests that we need to understand the connections between knowledge and power in order to understand how certain "regimes of truth" are accepted within specific historical and cultural contexts. Foucault (1997) suggests that power and knowledge cannot therefore be studied separately, however the two will be separated in this analysis. This separation is artificial and allows for clarity and an exploration of the relationship between them – their interdependence will be acknowledged throughout.

3.1 Capacity and Knowledge: What, When, How And By Whom?

3.1.1 The 'what' of capacity: within and outside 'professional' knowledge

3.1.1.1 Professional knowledge: Qualified and unqualified

Extract 1: Participant 8, Learning disability nurse, lines 233-253

P8: I know that a few nurses in the nursing team have got a lot of cases where um the Mental Capacity Act isn't, isn't everyday practice, people don't know really what it is, and that's in a lot of care homes. So I think as qualified professionals we are good at using the Mental Capacity Act, but in homes I don't think they really implement it as much as we would. Yeah I suppose a good example is you know the everyday things like um people aren't given the choice about which outfit to wear

NR: Mmm

P8: And um that's a really important decision to make, um, but staff choose the clothes for people. Um so

NR: Do you have a sense of kind of what gets in the way of them offering that choice?

P8: Um I think it's a number of things. I think, I think it's lack of awareness of capacity and um, I think that um, my experience is with unqualified staff, carers um they want to care, and their understanding of caring is 'let's do things for people to make their life better', which is lovely and they have really kind hearts. But actually what we want to do is we want to support the person with a learning disability to do that skill, rather than do it for them.

Here qualified professionals are constructed as being more knowledgeable about the Mental Capacity Act, which allows them to implement the Act as part of '*everyday practice*'. The knowledge of qualified professionals is contrasted to that of '*people... in a lot of care homes*', who do not '*implement it as much as we would*', where 'we' is used to refer to qualified professionals. It is implied that

'unqualified' staff working in care homes are both less knowledgeable about the MCA and less able to use it in their day-to-day practice.

A *'good example'* of how the MCA can be used in *'everyday'* practice is in people being given choice in which outfit to wear. Unqualified staff members are positioned as the decision makers about what clothes people with learning disabilities wear, and this practice is justified through drawing on a discourse of caring as *'do[ing] things for people to make their lives better'*. The practice of *'doing for'* is contrasted with the *'professional'* position – *'but actually what we want to do is...'* – which is constructed as supporting the development of independence by enabling people with learning disabilities to do things for themselves.

Research into support workers' understanding and implementation of the MCA in practice suggests that they give moral accounts of their substitute decision making on behalf of people with learning disabilities, drawing on their own values and life experiences (Dunn, Clare & Holland, 2010). This complements some of the accounts given by professionals in this study of how their values impact upon their implementation of the MCA (see section 3.1.3.4).

From a *'qualified'* and *'knowledgeable'* subject position, professionals are enabled to engage in practices such as giving people choices, and supporting them to develop skills. This could be understood as promoting an *'autonomous'* subject position for people with learning disabilities, where autonomy is constructed as *"emancipation from others"* (Tarulli & Sales, 2009, p115). In this understanding of autonomy *'the other'* (in this case, professionals) is a potential source of constraint or barrier to full independence, rather than being seen as a source of dialogue or relationship through which autonomy is realised. In contrast, a discourse of autonomy as a *"relational, dialogical accomplishment"* (Tarulli & Sales, 2009, p.115) may go further to acknowledge the interdependence that we all experience by virtue of being social beings (Clough, 2015), and that may be particularly resonant for people with learning disabilities, who often live within complex networks of support.

The positioning of qualified professionals as having more knowledge about the MCA and its implementation is extended in the extracts below, by orienting to the learning disability field as a site of specialist knowledge of the MCA. This jars with previous research that suggests that (qualified) professionals in the learning disability field do not always have a 'full' understanding of the MCA (Willner *et al*, 2011) or how to implement it in practice.

3.1.1.2 *The expertise of the learning disability field*

Nearly all the professionals interviewed oriented to working in the learning disability field as leading to a more in-depth understanding of the MCA.

Extract 2: Participant 8, Learning disability nurse, lines 115-121

P8: I think the Mental Capacity Act is so complex and um I think working with people with learning disabilities we are able to understand the complexities of the Mental Capacity Act and um how to use the Mental Capacity Act at its best. Um but a lot of people don't have a full understanding of the Mental Capacity Act and how important it is to support people's independence and lives

Here the MCA is constructed as '*so complex*' and experience of working with people with learning disabilities is oriented to as a practice that enables understanding of these complexities and '*how to use the Mental Capacity Act at its best*'. This implies both specialised knowledge – 'expertise' – and best practice that may not be held by other professional groups. This is further emphasised by going on to say '*a lot of people don't have a full understanding*' of the MCA, which implies that a '*full*' understanding of the MCA is both possible and achieved by professionals working in learning disability fields. The use of the rhetorical device of vagueness in saying '*a lot of people*' makes it difficult to challenge this claim, whilst also serving to establish the specialist knowledge of learning disability professionals, who it is implied do have a 'full' understanding of the MCA.

A full understanding of the MCA is constructed as allowing for knowledge and practices that '*support people's independence and lives*'. This constructs use of the MCA within a rights discourse for people with learning disabilities, in which choice, inclusion and independence are emphasised. The practice of using the MCA to support independence allows for the subject position of 'independent' for people with learning disabilities, and opens up positions of 'facilitator' and 'advocate' for professionals.

Extract 3: Participant 5, Clinical psychologist, lines 36 -54

P5: I think the other thing is you know capacity is one of those things that I think in learning disabilities we, we tend to understand maybe a bit more because we have to we come across it so much more. Um and it's something that actually you know people need to think about um quite clearly um for people with learning disabilities but also you know, people in health settings or particularly in older age, so yeah it's quite an important area.

NR: And what, what is it about learning disability settings that you think sort of gives you maybe a better understanding of um than people working in different settings, say kind health or

P5: You mean a better um in terms of capacity?

NR: Yeah in terms of capacity

P5: Well I think partly because we have to deal with the issue of capacity much more frequently, so we have to think about it. But also um I think we do we think a lot more about um you know how things are said, how things are expressed, how um how do people get to understand maybe you know some concepts and ideas that are actually quite complicated

Here capacity is constructed as something that is '*come across...so much more*' in working with people with learning disabilities than in working in other settings such as health or old age. This is repeated later in the extract, when capacity is constructed as an '*issue*' that has to be dealt with '*much more frequently*'. The repetition of '*so much more*' and '*much more*' emphasises the frequency with which capacity is thought about in learning disability settings.

This positions people with learning disabilities as being more likely to have issues with capacity, whilst also positioning learning disability professionals as having the knowledge and understanding to be able to identify and think about these issues compared to other professionals. However, a number of professionals oriented to their knowledge of the MCA being bound to what is set out in the Act itself, and that they may not be up to date with the most recent case law around the using the MCA in practice (participant 2, lines 795-797; participant 3, lines 749-752).

Thinking about capacity more invites practices of considering how things are 'said' and 'expressed' and how people come to understand 'complicated' concepts and ideas. This parallels the talk of other professionals in this study, which emphasised the importance of thinking about communication when assessing capacity in people with learning disabilities (see section 3.1.3.3). This could be understood as drawing on a discourse of people with learning disabilities as qualitatively different (Carlson, 2005) to people without a learning disability diagnosis, however it also acknowledges the embodied experiences of living with cognitive impairments (Clough, 2015). Drawing on a discourse of qualitative difference might allow for different practices to be enacted, such as adapting communication, in order to minimise the disabling impact of interactions (Rapley, 2004).

3.1.1.3 Families' and service user knowledge

Families and service users were constructed as not holding knowledge about the MCA or what was meant by the term 'capacity'. This was sometimes constructed as a source of conflict, difficulty or distress for family members.

Extract 4: Participant 1, Clinical psychologist, lines 1040-1057

P1: Yeah, and families don't – although I think maybe agree with the moral ethos of that person having a right, um the world of capacity is so different and it's such a transition from how things were when their child was a child, whereas now they're an adult and there's been this transition it's been a technical one because

their age has and suddenly they're 18 you know, but as of last week nothing was different

NR: Mmm

P1: So nothing's actually changed qualitatively, but suddenly the law has changed

NR: Mhmm

P1: Around them, how services relate to them, how services engage with their views as parents, that's all changed without that really having been explained. It's a massive transition at that point and families, unless they're particularly um well connected um to the kind of LD professional world leg- you know legislation around all of that, um that happens without them knowing

Here the right to make decisions is constructed as a '*moral ethos*' which families agree with, but which may not fit with their lived reality of their loved one's ability to make their own decisions. '*The world of capacity*' is constructed as '*so different*' to families' experience of decision-making. The move from '*child*' to '*adult*' subject position for people with learning disabilities is the source of this change in worlds, but this is constructed as a '*technical*' transition rather than due to '*qualitative*' changes in a person's capacity. This technical transition suggests that people with learning disabilities may be understood within an 'eternal child' discourse (Wolfensberger, 1975), and this was alluded to in the talk of other professionals in the context of capacity assessment – '*we are the adults at the table*' (participant 4, social worker, lines 533-534).

The law governing capacity, that is the MCA, is a technology of power here, which changes '*around*' parents, and impacts the way services '*relate to them*' and '*engage with their views as parents*'. A legal discourse of capacity positions professionals and services as 'experts' who have access to knowledge and power, in contrast to families who are not given explanations about the changes to the law, and as such as positioned as passive subjects. In order to gain knowledge of these changes, families are constructed as needing to be '*particularly um well connected um to the kind of LD professional world*'. Without this knowledge, services change the way they engage with parents' views,

without explanation or consent, illustrating how power and knowledge can be both productive and repressive.

The productive and repressive implications of power and knowledge were also demonstrated in professionals' accounts of making decisions about whether to undertake a capacity assessment, and the contexts in which capacity was called into question – these will be turned to next.

3.1.2 The 'when' of capacity: to raise concerns or to assume (in)capacity

Research exploring professionals' experiences of implementing the MCA has found that the process involves a number of decisions, that are often intertwined, including whether a capacity assessment is required, what decision the question of capacity is in relation to, and whether or not the person has demonstrated that they have the capacity to make that decision at that point in time (McVey, 2013; Walji, Fletcher & Weatherhead, 2014). This was reflected in the accounts given by the learning disability professionals in this study, who constructed these decisions as complex.

In the examples given in this study, questions of capacity were sometimes raised by the professionals themselves, at times by other professionals from within their team, and at times by professionals from within other parts of the system. None of the professionals gave examples of families or service users requesting capacity assessments, although at times families were constructed as holding strong views on whether their loved one was able to make the decision for themselves or not.

The following extracts will illustrate the contexts in which capacity were globally assumed or questioned (section 3.1.2.1) and the contexts in which specific questions of capacity were raised and assessments of capacity were undertaken (section 3.1.2.2).

3.1.2.1 Assuming (in)capacity

Nearly all the professionals spoke about how the principle of assuming capacity was something that others struggled to hold onto when thinking about people with learning disabilities. At times this was constructed as a societal view (participant 3, line 433), whilst at others it was constructed as a '*common assumption*' that was particularly held by the medical profession (participant 7, lines 415-419; participant 8, lines 367-374), but also by other professionals, including people working in the learning disability field:

Extract 5: Participant 3, Learning disability nurse, lines 271-288

P3: it's still down to us as services to keep reinforcing what what is meant by capacity

NR: Mmm

P3: Now I was in a meeting just last not last week but the week before with our colleagues here in housing who keep asking me and other professionals for an assessment to prove someone's got capacity, and we keep saying 'well there is no assessment because you assume everyone's got capacity' and so the assessment is about proving they don't have capacity, not proving they do have capacity. And that's from our colleagues here and we feel like we're on groundhog day 'cause every time we meet we have the same conversation. And I think it's because, well I know it's because, this person is making unwise decisions, engaging in anti-social behaviour, and people really struggle that someone with learning disabilities and mental health problems is putting themselves in a situation where they're at at risk. Um and, and people really struggle that that they've got capacity to do that

In line with previous extracts, learning disability services are constructed as knowledgeable about what is meant by capacity, and positioned as responsible for reinforcing this to others. The detail of '*not last week but the week before*' contextualises the example given, making it seem more accurate, and emphasises the proximity of the event. The '*colleagues from housing*' are positioned as misunderstanding the MCA, in asking for an assessment to '*prove*

someone's got capacity. The speaker and her colleagues are in turn positioned as educators, who inform their housing colleagues of the principle that everyone is assumed to have capacity. This principle appears difficult for others to hold in mind as *'every time we meet we have the same conversation'*. Initially the speaker offers a tentative, opinion-based explanation for this difficulty – *'I think it's because'*, but quickly reasserts her explanation as being knowledge based – *'well I know it's because'*. This makes her proceeding claim difficult to dispute.

The difficulty in assuming capacity is associated with the person with a learning disability making unwise decisions and engaging in *'anti-social behaviour'*. These actions are *'putting themselves in a situation where they're at risk'*. Although not explicitly stated, this constructs capacity as the ability to make wise decisions, which are not perceived as risky. The conflation of capacity and issues of risk was raised in other professionals' accounts (participant 1, lines 400-401; participant 6, lines 102-106), and was highlighted by the House of Lords' (2014) review of the implementation of the MCA as an area of concern.

In this extract, the tension in assuming capacity when someone is behaving in a risky way is constructed as a *'struggle'* for professionals. Research suggests that a tension between duty of care and promoting autonomy is a common difficulty that professionals working with people with learning disabilities have to navigate (Fyson & Kitson, 2007; Hawkins, Redley & Holland, 2011; Jingree, 2014). It was not clear from professionals' accounts in this study how this tension was managed in practice.

The verbs *'making'*, *'engaging'* and *'putting'* imply intention and position people with learning disabilities as active participants in risky situations. It is not clear from the account given here whether the person with a learning disability is assumed to have knowledge of these risks, or whether they are unaware of them. Irrespective, the practice of *'engaging in risky behaviour'* constructs people with learning disabilities as vulnerable. Situating people with learning disabilities within a protection discourse enables paternalistic practices, including using the MCA to raise questions about their decision-making abilities.

This assumed intentionality was also demonstrated in an example given by another professional talking about times when people *do* assume capacity for people with learning disabilities.

Extract 6: Participant 8, Learning disability nurse, lines 71-85

P8: I've got a man at the moment on my caseload, he's fascinating, he's got autism and a learning disability, um very very challenging to work with, quite aggressive. Um and he looks totally normal, um and that's, he's um a young guy, he's 30, he's black, and um he's um a bit of a lad. And he's very easily mistaken for, I don't like using the word normal, but normal you know, and he's been arrested so many times 'cause he looks suspicious. And 'cause of his autism he takes a long time, for example if he goes food shopping, he takes a very long time to choose a loaf of bread. Um and he gets in trouble with the law all the time and um there's, he has had a lot of staff changeover because of his, he's very challenging to support. Um and staff always say to me um 'oh he knows exactly what he's doing' um 'oh he should be arrested, you know, take him away'.

A young man with autism and learning disability is constructed in multiple ways that could be understood as conflicting – he is '*fascinating*' and '*very, very challenging*'; he looks '*suspicious*' and is '*a bit of lad*'. He is also described as young, black and '*easily mistaken...for normal*'. This draws on a discourse of people with learning disabilities as being different from the established norm, and that this difference is visibly notable (Carlson, 2005). The practices that construct the young man as different from the norm include taking a long time to choose a loaf of bread. The young man has been arrested '*so many times 'cause he looks suspicious*', and it is then repeated that he '*gets in trouble with the law all the time*'. '*Gets in trouble*' constructs the young man as an active participant in this situation rather than as someone who may be discriminated against by the police. In being constructed as young, black and male, this may illustrate the impact of intersectionality for people with

learning disabilities, particularly in the context of perceived criminal behaviour, where discourses of age, race and gender are dominant (Jackson, 2006).

In getting into trouble with the law this may construct the young man as deviant in some way, and this draws on discourses of people with learning disabilities as criminal delinquents and deviants (Carlson, 2005; Lundberg & Simonsen, 2015). This discourse of people with learning disabilities suggests intentional disregard of social norms, and makes punishment an acceptable practice in response. In this way society is constructed as needing protection 'from' people with learning disabilities (Carlson, 2005; Hamlin & Oakes, 2008) and justifies their removal and exclusion from the community.

A morally deviant discourse is implicitly drawn on by staff when they claim that he '*knows exactly what he's doing*' and should be taken away. In knowing exactly what he was doing this constructs the young man as understanding the consequences of his actions, and therefore in part, demonstrating capacity. If we assume capacity this also implies that a person is then responsible for their actions. This link between capacity and taking responsibility was also suggested in other professionals' accounts (participant 5, lines 387-390; participant 6, lines 40-43).

3.1.2.2 Raising concerns: making decisions about bodies, daily living and relationships

Professionals shared one or more examples of capacity assessments they had been involved in. The issues around which concerns were raised about whether people with learning disabilities had the capacity to decide for themselves included:

- Having a contraceptive implant removed (participant 5)
- Choosing where to live (participant 4, participant 6, participant 8)
- Consent to medical investigations/procedures (participant 6, participant 7, participant 8)

- Deciding to cut contact with family members and the possibility of undue influence (participant 2)
- Engagement with services and the involvement of family (participant 1)
- Consent to marriage (participant 2)
- Managing finances (participant 3, participant 4, participant 8)
- Consent to sex (participant 3)

These issues are congruent with research into decision-making in people with learning disabilities since the publication of the UN CRPD (Werner, 2012).

3.1.2.2.1 Decisions in the context of personal choice

Many of the capacity assessments given as examples were initiated following people with learning disabilities expressing the intent to make certain decisions in relation to their bodies or their relationships, for example refusing to have a check-up at the dentist (participant 7), or requesting to stop using contraception:

Extract 7: Participant 5, Clinical psychologist, lines 168-178

P5: Um well it was one of a, a young woman who had uh she had an incredibly difficult traumatic um background and um childhood. Um and now she was 20 and she was in a relationship with um someone who historically had been quite abusive to her and um she, he'd actually been imprisoned for being, for being aggressive towards her so for, for actually um yeah um I think the charge had been GBH [grievous bodily harm] and he'd been in prison and he was due to come out of prison. And she wanted to have her contraceptive implant removed because she wanted to get pregnant and she wanted to have a baby with him

The speaker uses detail to provide context for the decision the young woman wanted to make regarding her contraceptive implant. A subject position of victim is enabled by drawing on a trauma discourse – '*she had an incredibly difficult traumatic...background and childhood*' – and given further weight in the speaker's talk by orienting to her recent experiences of abuse and aggression

from her partner. Taking up a subject position of victim may imply limited opportunities for control and self-expression – this could be understood as being resisted by the young woman, who asserts her right over her body by making choices about having her contraceptive implant removed in order to achieve her goal of getting pregnant.

3.1.2.2.2 *Decisions in the context of external factors*

A number of the capacity assessments focused on decisions that had been suggested by others, or came about as the result of external factors, for example an older man developing dementia and struggling to manage his finances, or concerns that a young woman was going to be involved in a forced marriage. Another example given was when families want to make changes to a loved one's care, such as their accommodation:

Extract 8: Participant 4, Social worker, lines 153-156

P4: we know the parents doesn't want him at home anymore. Not because he's done something wrong but there's so many challenging behaviours and they think it'd be best if he moves out

In this case the possibility of moving out is raised by the parents rather than the person with a learning disability. The capacity assessment then focuses on the young man's ability to decide where he wants to live, given the available options. The speaker emphasises that the young man hasn't '*done something wrong*' but rather that '*challenging behaviours*' are behind the parents' wish for him to move out. Drawing on a psychological discourse of challenging behaviours implies potential risk to others, which legitimates the control of the body in terms of the spaces where the young man will be accepted and 'managed'.

The examples of capacity assessments given by professionals in this study speak to wider difficulties people with learning disabilities experience in being given the opportunity to exercise their human rights to life, sexual expression and personal relationships (Owen & Griffiths, 2009). These demonstrate the use

of bio-power (Foucault, 1978), a specific example of a technology of power, whereby bodies are made docile. The challenges faced by people with learning disabilities in having power over their bodies, both in terms of what happens to them and the spaces they are permitted to occupy, are reflected in debates in the literature regarding the limits of neoliberal citizenship for those with a label of intellectual disability (Ignagni *et al*, 2016; Redley & Weinberg, 2007).

3.1.3 The 'how' of capacity: assessing mental capacity in people with learning disabilities

3.1.3.1 'Formal' versus 'everyday' assessments

Many of the professionals distinguished between 'formal' capacity assessments and other ways of assessing capacity, that required less in-depth or less standardised assessments (participant 1, participants 6-8).

Extract 9: Participant 2, Clinical psychologist, lines 184-198

P2: I think sorry bluh to me there's almost two different types of capacity assessments so there's

NR: Mhmm

P2: The very kind of formal um can you do a you know we need to a capacity assessment around this um and then there's the kind of everyday can someone consent to an assessment and those sorts of things. And I think in some ways they're sort of slightly separate in my head so when I'm thinking about a kind of more formal assessment I'll do things like talk to the team or colleagues about what the sort of questions, you know these are the sorts of questions I was thinking about asking the sort of things I think people need to know, are there any other things that I've missed or any other things so there's just a bit of kind of protection really.

This extract suggests that constructing a capacity assessment as either '*formal*' or '*everyday*' implies different sets of practices for professionals. '*Formal*' assessments of capacity invite practices such as checking your ideas with other

team members, to ensure '*protection*' and that nothing has been missed out. It is implied that '*everyday*' assessments required less protection. Drawing on a discourse of capacity as a '*formal*' process therefore allows for '*technologies of the self*' (Foucault, 1988) to be applied, in which professionals regulate their own practice. This suggests a sense of being monitored, which was oriented to by a number of professionals (see section 3.2.1).

'*Everyday*' assessments were constructed as being in relation to '*consent to an assessment*' or '*consent to a referral*' (participant 7, lines 374-378), and still involved following the principles of the Act (participant 7, lines 383-387) but were not as time consuming or long-winded. Other practices might involve assessing capacity "*by the fact that they stayed in the room with you, they engaged with your questions and that was ok, it was the same as before*" (participant 1, lines 1292-1294).

In contrast, '*formal*' assessments were constructed as being triggered by decisions that had significant consequences, such as moving house, managing finances, or consent to marriage or sexual relationships – "*I guess in that sense it's almost a kind of risk management thing, I suppose the greater the consequence in a way you're saying potentially the greater the potential risks to the person or the people around them. Um so I think, I think that it tends to be the marker for it*" (participant 6, lines 102-106). Formal capacity assessments invite an assessment of the level of risk management that is required and allows for the subject positions of '*at risk*' for both people with learning disabilities and the people around them, and subject positions of '*assessor*' and '*protector*' for professionals. This distinction between formal and everyday capacity assessments has been acknowledged in previous research into the use of the MCA in learning disability settings (McVey, 2013), where '*formal*' assessments were associated with a "*need for intervention*" (McVey, 2013, p.70). Drawing on a discourse of risk also lends weight to previous research which proposes that professionals often take up legal or actuarial approaches to capacity assessments, which rely on rules-based practice and assessments of risk (McDonald, 2010).

3.1.3.2 Asking the 'right' questions

In order to assess capacity, a number of questions need to be clarified. Firstly, the decision at hand needs to be identified – this is not always easy to do, as decisions can often be cumulative or interlinked (Brown & Marchant, 2011, 2013). For example, in assessing a young woman's capacity to decide to have their contraceptive implant removed, it was important to separate this decision out from the young woman's potential ability to parent, or her capacity to make decisions about her relationships (participant 5, lines 186-195). Clarity was valued by nearly all the participants in order to get at the '*nub*' (participant 1, line 613) of what is being asked.

Extract 10: Participant 2, Clinical psychologist, lines 335-340

P2: ...that's what I think capacity assessments really are about is um how do you make sense of this situation and are you sure that people are really understanding and I think you know we're really good at not just taking things at face value but digging a bit deeper and asking the right questions

Capacity assessments are constructed as being about making sense of situations, and ensuring people '*really understand*', creating a subject position for professionals as an 'assessor' of understanding. This is enabled through practices of '*not just taking things at face value*' and '*asking the right questions*'. In constructing the possibility of '*right*' questions, this implies that someone's 'true' level of understanding can be accurately assessed, and that we cannot accept people with learning disabilities' responses at '*face value*'. Other professionals also spoke about needing to check out what is said by people with learning disabilities as they may be "parroting back to you" (participant 3, lines 404-405) rather than demonstrating actual understanding. This is congruent with the literature on acquiescence and communication in people with learning disabilities (Sigelman *et al*, 1980; 1981). Communication was seen as both a barrier and a tool in being able to assess capacity for people with learning disabilities – difficulties in communication during the assessment process were constructed as having a possible impact on the subjectivity of

people with learning disabilities, including experiences of confusion – ‘*it’s not fair to put him through this because he started looking confused*’ (participant 4, lines 89-90) – and distress – ‘*he became quite distressed around the talking, whether it was because...we were taking it away from him or whether he just didn’t understand I don’t, I’m not too sure*’ (participant 3, lines 559-562).

3.1.3.3 Adapting communication

Extract 11: Participant 3, Learning disability nurse, lines 351-363

P3: but for me it’s about providing the information in a way they understand, making sure I can get the information from them in a way we both understand, but it’s about being able to break some stuff down to be able to assess whether they can weigh things up, and sometimes you’ve just got to be a little bit inventive in how you do that. Um it’s not just you speak to them and say this is it, sometimes you’ve got to use a bit of role-play or you use objects of reference, or you know, there are other ways of doing it, and I think we’re probably better at doing it ‘cause we’ve got more time

NR: Mmm

P3: And it’s what, what we do on a day-to-day basis.

Adapting communication is constructed as ‘*providing information in a way they understand*’ and ‘*being able to break stuff down*’. Communicating effectively requires professionals to be ‘*inventive*’ and go beyond simply using speech, including using role-play or ‘objects of reference’ (Ockleford, 2002) as aids. The need to understand communication as more than just language was acknowledged in other accounts, including the importance of “interpreting...emotional reactions” (participant 6, line 289). Learning disability professionals are constructed as ‘*better*’ communicators as they have ‘*more time*’ and it forms part of their everyday practice. The practice of adapting communication allows for professionals to take up subject positions as both ‘facilitators’ of capacity and ‘experts’ in adapting communication. The challenges of assessing capacity in the context of communication barriers is a topic which is starting to receive more attention in the academic literature

(Pachet, Allan & Erskine, 2012) and may provide new forms of knowledge that open up new ways of practising for professionals.

As a process that involves 'interpreting' multiple aspects of communication, and making multiple decisions, many professionals oriented to the potential for bias in assessing capacity, which will be considered in more detail below.

3.1.3.4 Acknowledging the potential for bias

The MCA constructs capacity within a medical model (Clough, 2015), which implies that objective assessment of capacity is both possible and desirable. In contrast to this, a number of professionals oriented to "*the degree of subjectivity and uh some degree of cultural value bias in what you assume to be the things that somebody needs to understand in order to make those decisions*" (participant 6, lines 409-412).

Extract 12: Participant 5, Clinical psychologist, lines 468-477

P5: Well I think, particularly with a dilemma like this one, or a question like this one, um I think there's a large part about where you have to be you really have to believe in each person's worth and ability um to, to have ideas about their own future and to have ideas about their own self. Um and the worth of each person as an individual and um and to be able to put one's own kind of moral decisions to the side um and to say 'this is kind of about this person's decision' and sort of not the decisions I would necessarily make. And I think being able to be quite tolerant um of different ideas and opinions

The psychologist in this extract had been talking about their involvement in a capacity assessment looking at a young woman's ability to decide to have her contraceptive implant removed (see section 3.1.2.2.1). The decision about whether or not the young woman has capacity is constructed as a '*dilemma*' implying a choice between two unfavourable alternatives. In order to manage this dilemma, it is important for professionals to believe in '*each person's worth*'

and their ability to have ideas about '*their own future and...their own self*'. This draws on discourses of rights, personhood and autonomy, and positions people with learning disabilities as individuals capable of self-determination. These discourses invite professionals to take up practices that '*put one's own kind of moral decisions to the side*' and to prioritise the person's decision-making context rather than their own. It is implied that that this requires '*being quite tolerant of um different ideas and opinions*'.

Other professionals constructed the subjectivity in assessing capacity as a 'greyness' (participant 1, line 1125; participant 6, line 424) that needed to be acknowledged. In doing so, some professionals constructed the outcome of capacity assessments as representing an opinion rather than knowledge (participant 3, line 306; participant 6, line 434).

The dilemmas described by professionals here speak to what Banner (2012) describes as an "ethically oriented dimension of capacity" (p.1039) in which clinicians are invited to make "intrinsically normative judgement[s]" (p.1040). In making these judgements, professionals may be considered to be taking up the subject position of 'interpreter' (participant 6, line 289) – this invites practices of acknowledgement: acknowledgement that "the process of interpretation involves a dialogic encounter" (Banner & Szmulker, 2013, p.384), and acknowledgement of the influences of the clinician's own perspective, including the beliefs, values and emotions that may be factors in the assessment process (Banner, 2012).

3.2 Capacity and Power: Institutional, Professional and Personal Power

3.2.1 Institutional power and the legal gaze

Capacity was frequently constructed within a legal discourse, where the MCA was a technology of power that could be used to influence the actions of others – "*it gives us a bit of legislation to be able to say 'you can't do that'*" (participant 3, lines 130-131) – but that also resulted in technologies of the self, as professionals found themselves under the surveillance of the legal gaze and under pressure to be seen to be implementing the MCA in the 'right' way.

Extract 13: Participant 2, Clinical psychologist, lines 239-256

NR: Mmm and you, you talked earlier about when you're sharing those questions with the team there being a sense of protection I think was the word that you used

P2: Mmm, mmm

NR: Can you say a bit more about that?

P2: Um yeah I guess just thinking about obviously you my hope is and it goes back to your kind of first question that, you know, that we do things that are best for the clients but of course um all of our all of our decisions are up for um challenge

NR: Mmm

P2: And it's those times um where you want to kind of make sure that you've really um made the best decisions you can for people and and so if they are challenged, which people should be able to do, they're robust enough to stand up if you have to go to court and defend them. And it's that sort of protection I guess, about showing that you haven't done it casually, you know that you've you've thought carefully and conscientiously about um the person's life that you're influencing

Learning disability professionals are constructed as doing '*the best for the clients*' but that these decisions are '*up for challenge*'. Professionals therefore become the subject of scrutiny and assessment, which invites '*protection*' practices that demonstrate capacity assessments have been carried out '*carefully and conscientiously*'. Decisions about capacity are constructed as needing to be '*robust enough*' to '*defend them*' in court. Indeed, a number of professionals spoke about capacity assessments that had lead to legal cases being brought to the Court of Protection (participant 2, participant 3, participant 4). Being under legal scrutiny could have implications for the subjective experience of professionals in feeling criticised and under pressure, leading them to look for certainty in their practice.

Professionals constructed the power to scrutinise as not only being held by the courts, but also by other institutions such as the Care Quality Commission (CQC) and NHS Trusts. The knowledge and power available to these institutions may affect the discourses available to professionals for understanding capacity and implementing the MCA.

Extract 14: Participant 1, Clinical Psychologist, lines 210-232

P1: I guess maybe's that why definition comes first because that's where there's so much emphasis from

NR: Mhmm

P1: Various different trusts from various different bodies about being very very clear around people's capacity to consent to things so I think in some ways it does go quite hand in hand with a lot of legislation

NR: Mhmm

P1: A lot of expectations around um various different groups of people having a vested interest in capacity so from Trusts from social services from clients to families so it feels like yeah I guess definition comes in probably maybe that's why I was a little bit stumped because it feels like quite a broad question

NR: Yeah

P1: Yet but in my mind it feels like it's about a definition

NR: Yeah

P1: Um but I think that's probably because there is so much that comes through around you know pressure from the CQC from Trusts everybody to make sure you're documenting things as well

In response to a question exploring what the term capacity meant to them, the psychologist in this extract oriented to the MCA definition of capacity, and had constructed it as '*tricky*' (line 196) to think about capacity outside of the legal definition. In this extract, this position is justified by the pressure on professionals '*from various different trusts from various different bodies*' to be '*very very clear around people's capacity to consent*'. This is explicitly linked to the status of the MCA as '*legislation*'. Other professionals also oriented to the

legal definition of capacity in response to this question (participant 3, participants 5-7) and appeared keen to demonstrate their knowledge of the Act – ‘*Do you want me to expand on that or does that seem?*’ (participant 7, line 69). This suggests that professionals may interpret questions about the meaning of capacity to represent an ‘examination’² in the Foucauldian sense, which makes it possible to qualify, to classify and to punish by making individuals visible (Foucault, 1977) – the (in)correct response to the question may be seen as making their practice more or less visible and open to further scrutiny by the interviewer.

The legal discourse of capacity invites specific knowledge of capacity, and the power of this discourse is implied through the term ‘*vested interest*’. Capacity is constructed as not only in the interests of institutions - ‘*Trusts and social services*’ - but also of individuals – ‘*clients to families*’. Later in the extract, the gaze of the CQC and ‘*everybody*’ is oriented to, with a focus on how issues of capacity are documented. The use of the word ‘*everybody*’ can be understood as an extreme case formulation which emphasises the extent to which professionals might feel their practice is being observed and judged in relation to understanding and assessing capacity. This has parallels with Foucault’s concept of the panopticon (1977), in which an experience of constant surveillance is created, thus negating the need for external control of an individual’s conduct. This can be seen as operating on both the conduct of learning disability professionals and people with learning disabilities themselves.

Professionals managed this sense of constant surveillance by engaging in further practices that provided ‘protection’ for them. These included doing joint assessments, using supervision, and checking out with colleagues whether they were asking the ‘right’ questions. Documentation of the steps they had taken was also constructed as an important practice, and one participant oriented to using an audit tool (participant 2, lines 201, 214) to ‘check’ their practice in relation to capacity assessments.

² A combination of hierarchical observations and normalizing judgments (Rabinow, 1991, p.188).

3.2.2 Professional power and multiple subject positions

3.2.2.1 *The power of the expert*

Extract 15: Participant 2, Clinical psychologist, lines 293-306

P2: So the family had such a bad relationship with the team that they asked me to go in um and do the assessment kind of as an independent and I guess that's why it stuck in my mind because it was al-, it was as close to being a level of expert witness if you like

NR: Mmm

P2: As I've ever got, um it wouldn't be my idea of a good time, um so yeah it was kind of one that I was kind of very careful with

NR: Mhmm. And how did you find being put in that role I spose as the expert outsider?

P2: I didn't like it. Um it's really interesting so uh I didn't come into learning disability to restrict people, um and I don't really like being in a position to make decisions about people's lives, I don't it doesn't sit naturally with me

In this example the subject positions available for the psychologist are '*independent*' and '*expert witness*'. As the interviewer I then position the psychologist as an '*expert outsider*'. This subject position is taken up, but also resisted through the subjective experience it allows – '*I didn't like it... I didn't come into learning disability to restrict people*'. An '*expert*' position is implied as enabling restrictive practices in relation to people with learning disabilities. Repetition is used to emphasise the subjective experience of disliking being '*in a position to make decisions about people's lives*' – this can be understood as resisting exercising the potential repressive power afforded by taking up an expert position. The power of the expert position was managed differently by other professionals – doing joint assessments for example allowed for '*shared opinions*' (participant 8, line 313) and a system of '*checks and balances*' (participant 6, line 629), suggesting a desire to distribute the power and responsibility of the assessment process.

Power was also exercised by professionals in taking up alternative subject positions alongside and in contrast to that of 'expert' and 'independent' – the positions of advocate and facilitator will be explored further below.

3.2.2.2 *The power of the advocate*

Many of the professionals spoke about being drawn to working in the learning disability field as they wanted to work with people who '*lack a voice*' (participant 1, clinical psychologist, line 34), and who can't '*advocate for themselves um as much as other people can*' (participant 5, clinical psychologist, line 15).

One professional spoke of '*really using psychology um to help people who don't have many people to advocate for themselves*' (participant 2, clinical psychologist, lines 26-27), whilst another described how they used the Mental Capacity Act '*all the time with my work um to make sure that people really have a choice and a voice, in a way that they understand*' (participant 8, learning disability nurse, lines 65-67).

An area that required taking up a subject position of advocate for two professionals interviewed (participant 7, lines 415-428; participant 8, lines 321-330) was around Do Not Resuscitate (DNR) orders being given to people with learning disabilities in hospital settings without consulting the individual, or completing a capacity assessment.

Extract 16: Participant 7, Learning disability nurse, lines 434-459

NR: And in those situations did those doctors or those consultants were they able to say what led them to not discussing it or making that decision?

P7: Yeah I mean what, the first time I came across it four years ago and um I uh, yeah I, the consultant phoned me up and said that I erm wasn't happy actually with me challenging it um they said that the quality of life that person if they was to come back would be poor because they've already got a poor quality of life and it would be worse. Um and that it wouldn't be fair on the

parents to have to look after somebody who they had come round they may be even more disabled than they already were. So it was not, not a great opinion, but not a you know, not medically valid either really so. Um and or um with the other person it was the idea that they might be better off dead anyway because their quality of life was not good, so in a way that's a sort of judgement on somebody's worth isn't it. So both those ones I had to judge, uh had to challenge.

NR: How did you find that process of challenging?

P7: Uh it's quite difficult 'cause you've got somebody's who quite intimidating and powerful with the first, the second one wasn't so bad, but the first one had this guy really having a go at me on the phone and uh I've had my kind of mental capacity stuff out in front of me and saying 'well this is law, you can't do this, technically you could be taken to court' and that's when they backed down. 'Cause I was trying to argue that quality of life for somebody can't be judged like that and wasn't getting anywhere.

Providing details such as the timing of the event – '*four years ago*' – adds weight to the claims being made, which position the consultant as being unhappy with being challenged about his decision to give a DNR order. A quality of life discourse is drawn on to justify this decision, constructing the person with learning disabilities as already having '*a poor quality of life*' which would be made '*worse*' if they were resuscitated. A discourse of fairness was also drawn on, in which the parents of the person of a learning disability were positioned as having to look after someone who might be '*even more disabled*' if they were to be resuscitated.

These discourses construct people with learning disabilities as less worthy of life-saving intervention due to their disability, and position them as a 'burden' to those who support them; this parallels discourses in the academic literature about family burden (Robinson *et al*, 2015). This discourse is emphasised further in the second example given, where it is assumed by the consultant that the person with a learning disability '*might be better off dead anyway*'. Drawing on quality of life discourses and subject positions of 'burdens' allows for

discriminatory practices against people with learning disabilities, in which DNR orders are given without consultation to the individual, and the MCA is overlooked.

In this extract an advocate or 'challenger' position is taken up in order to resist the quality of life discourse - '*quality of life for somebody can't be judged like that*'. However, it is only when a legal discourse is oriented to - '*technically you could be taken to court*' - that the consultant changes their practice and backs down. The subjective experience of the advocate position is of being confronted with hostility - '*this guy really having a go at me*' - and the difficulties of disagreeing with someone in a position of power. Here, again, the power of the legal gaze has a material impact on the practice of professionals.

Discourses of quality of life are frequently used as an evaluative benchmark for learning disability services (McVilly & Rawlinson, 1998; Schalock, 2005; Verdugo, Schalock, Keith & Stancliffe, 2005) and as a factor in medical decision making for people with learning disabilities (Bekkema *et al*, 2014), however what is understood by the term 'quality of life' is multi-faceted and often contested. Bekkema and colleagues (2014) found that 'quality of life' was the main factor that was considered in decisions around whether to initiate "potentially burdensome medical interventions" (p.204) in end of life care for people with learning disabilities. Here, quality of life was associated with maintaining mobility, minimising pain and suffering and promoting comfort and dignity.

In this extract the quality of life discourse is constructed as a '*judgement on somebody's worth*', where the life of the person with a learning disability is being explicitly devalued by the medical professional. This mirrors historical and current challenges faced by people with learning disabilities in asserting their right to life (Owen & Griffiths, 2009). Watson and Griffiths (2009) propose that the "life of the person with a disability is a value that is calculated against the economic factors of costly medical treatment and the societal estimation of who is most deserving of scarce resources" (p.94). Right to life and equal access to healthcare continues to be an area of significant discrimination for people with learning disabilities as evidenced by recent inquiries into the premature deaths

of people with learning disabilities in hospital settings, often linked to a failure to use the MCA appropriately (Heslop *et al*, 2014; Mazars, 2015).

3.2.2.3 *The power of the facilitator*

Extract 17: Participant 5, Clinical psychologist, lines 75 – 96

P5: But you know it's basically just that ability to be able to, to think through options and, and to kind of think about you know what what the options are and make a choice based, based on those options. Um you know and how do you facilitate that process. So you know to me it's not it's not only about that kind of question 'do they or don't they capacity?' but to me ideally it's about, it's about a process and how can one facilitate that process of capacity. Because you know, you kind of think of any you know maybe complex legal, financial, or medical decision, and would I necessarily you know, would I or you necessarily have the capacity to make those decisions, maybe not because we don't have all the information, so we actually have to go through a process of acquiring that information

NR: Mhmm

P5: Maybe into getting it simplified into terms and languages that we can understand without you know neurological training or, you know, a med- detailed medical training or financial training or whatever, to get it to a level where we can understand it to to make a decision you know. And we do those things all the time, about you know buying houses, getting mortgages, um deciding to have surgery or not etcetera. And you know it shouldn't be much different for, for our clients

A legal discourse of capacity is oriented to here by giving part of the MCA definition of capacity – '*it's basically just that ability to... think through options... and make a choice based...on those options*'. In contrast to previous extracts where the legal discourse has allowed for 'expert' and 'scrutinised' subject positions to be taken up, in this extract the subject position of 'facilitator' is taken

up, whereby professionals hold responsibility for enabling '*that process of capacity*'. In constructing capacity as a '*process*', the speaker draws on their own personal sense of decision-making around '*complex*' issues and invites the interviewer to do likewise, making the claim difficult to challenge – '*would I necessarily you know, would I or you necessarily have the capacity to make those decisions, maybe not*'. This constructs people with learning disabilities as being 'like us' and suggests a shared experience of struggling to make complex decisions.

Taking up the subject position of facilitator enables exploring our own experiences of decision-making, and emphasises the importance of having '*all the information...simplified into terms and languages that we can understand*'. This process of seeking support to get all the information is constructed as something that '*we*' do '*all the time*' around issues such as buying a house and deciding whether or not to have surgery. The use of '*we*' assumes shared experience between the speaker and the interviewer, which is later complemented by claims about the decision-making process for people with learning disabilities - '*it shouldn't be much different for our clients*'. The use of '*our*' here again implies a shared experience between the speaker and interviewer, although it may also be referring to the learning disability team. In stating that it '*shouldn't*' be a different process for people with learning disabilities, this positions them as entitled to the same right to support to decision-making as '*us*' but suggests that this opportunity may not always be provided. This draws on a rights discourse, which emphasises equal access to resources and support (Hamlin & Oakes, 2008; UN CRPD, 2007).

In accepting decision-making as a facilitated process that requires support, this constructs capacity as being influenced by factors outside individual, cognitive factors and lends weight to proposed models of supported decision making rather than substitute decision making (Davidson *et al*, 2015; Carney, 2014; Richardson, 2012). A facilitator position enables taking a 'one down' approach (Anger & Hawkins, 2000) that recognises that as social beings we do not make decisions in a social vacuum, and are all open to influence, in ways that can both promote and inhibit our ability to make choices about our lives (Brown, 2011; Martin & Hickerson, 2013). In constructing capacity as a shared,

developmental process, this allows for possibilities of new knowledge about capacity, and suggests a social model of capacity could be accepted (Clough, 2015).

3.2.3 Personal power for people with learning disabilities

3.2.3.1 The power of personhood

In the extracts considered thus far, the subject positions available for people with learning disabilities have suggested that they occupy disempowered positions such as ‘burden’, ‘in need of protection’ and ‘incompetent’. However, many professionals also drew on a rights discourse, which emphasised choice, inclusion and empowerment for people with learning disabilities, and constructed the use of the MCA as a practice that promoted alternative subject positions for people with learning disabilities.

Extract 18: Participant 8, Learning disability nurse, lines 143 – 158

P8: Um there was a lady who um, again she’s one of those people that comes across as being very borderline learning disabilities, um and people thought she had capacity to make a lot of decisions and actually when we did um like more assessments, it turns out that she actually has a moderate learning disability and a lot of her language is very fluffy language, it doesn’t have any meaning, and um she consents to things that she doesn’t actually mean to consent to. She gets herself in a lot of trouble and um but actually by using the Mental Capacity Act we um she was able to say, make a lot of decisions. So we did loads of posters about her life and her world, and um you know that was her life from her point of view and her eyes, and then from that she wrote all of her own care plans – she was moving house – she wrote all of her own care plans. And then she designed a training package for staff about her world and um, yeah it was just really really helpful

Here the subject position of ‘having capacity’ is made available for the young woman in question by virtue of ‘*coming across as being very borderline learning*

disabilities'. The subject position of 'having capacity' was then called into question by '*more assessments*', which found that the young woman had 'a moderate learning disability' and her use of '*fluffy language [that] doesn't have any meaning*'. This renders the ability to make decisions as possible only in relation to someone's level of learning disability, which has been noted in previous research (McVey, 2013) and was alluded to in other professionals accounts (participant 6, lines 399-402). This divisive practice of categorisation allows for the exclusion of people with certain 'degrees' of learning disability – "usually in a spatial sense, but always in a social one" (Rabinow, 1991, p.8). In this context, people with a label of severe or profound learning disability may be more likely to be assumed to lack capacity and so have decisions about their lives made on their behalf, which is congruent with emerging research (Watson, 2016).

The practice of '*using the Mental Capacity Act*' allowed for the young woman to be positioned as '*able to make a lot of decisions*' and to demonstrate personhood through making posters '*about her life...from her point of view and her eyes*'. In taking up a position of personhood, this allowed the young woman to exercise power and knowledge to produce new 'truths' about herself – '*she wrote all of her own care plans. And then she designed a training package for staff about her world*'. If the documentation of mental capacity assessments can be seen to "capture and fix" (Rabinow, 1991, p. 201) both professionals and people with learning disabilities in a potentially restrictive fashion, this represents an example of the productive power of "turning real lives into writing" (Rabinow, 1991, p.203) in which the voice of the person with a learning disability is privileged over that of professional opinion.

Facilitating this taking up of the position of personhood was spoken about by other professionals, and contrasted with the subject position of 'learning disabled' and therefore 'Other' that is often made available for people with learning disabilities.

Extract 19: Participant 3, Learning disability nurse, lines 154-158

P3: I think what we have to work really hard in doing is bringing that person and that quality of life they have to the capacity and if needed the best interests process. So you you make them a person because I think they become a learning disability rather than a whole person.

Notions of 'the person' and 'quality of life' are constructed as essential to the '*capacity...process*'. Here professionals are tasked with the responsibility of bringing personhood to the process, rather than this being something that could be achieved by the person with a learning disability – '*you make them a person*'. The power of the learning disability label is constructed as inhibiting knowledge of '*a whole person*'.

The dialectic between 'learning disability' and 'whole person' presented in this extract reflects debates within the literature regarding what constitutes personhood – in particular whether we are 'people' by virtue of being human and therefore have an 'ethical status' worthy of respect, or whether personhood is dependent on our ability to think rationally and retain a sense of ourselves over time (Dewing, 2008; Kitwood, 1997).

Discourses of personhood invite subject positions of 'person' or 'human being' for people with learning disabilities. In cases where capacity assessments were constructed as facilitating personhood, this appeared to have a positive impact on the subjective experience of people with learning disabilities:

Extract 20: Participant 6, Clinical psychologist, lines 505-507

P6: I think he found it an engaging experience um and because I enjoyed meeting him um he brought out the playful me

Extract 21: Participant 2, Clinical psychologist, lines 595-603

P2: So it's interesting, because my fear is that it's a very disempowering process. Um but actually when I think um back to the case I was talking about with the family actually she felt very empowered

NR: How did she let you know that?

P2: So she was extremely vocal, I got a little card to say thank you, um and she was very happy um with the outcome of the decision um and said you know it it's the first time anyone's sort of listened to me

3.2.3.2 The power of resistance

People with learning disabilities were also constructed as exercising power through resistance – this could be through refusing to engage in the assessment process and as such resisting subjectification, or at other times demonstrating resistance through their interactions with professionals during the process of assessment.

Extract 22: Participant 2, Clinical psychologist, lines 749-763

P2: I mean this was another example of like needing a really clear question, has she got the capacity live on her own? I mean sort of what's the decision at that point? Um 'cause you're really asking has she got the ability, is that an occupational therapy we need to do a formal assessment of her can she cook can she, or is it more about is she making good decisions? Yeah. Um. And so eventually we kind of broke down a series of questions and one of them has she got the ability or you know the capacity to decide whether she wants care or not, because she would tell her carers to piss off. Um and she refused to have the assessment. What do you do? Um and you know good for her in some ways, because I think we possibly would have found that she didn't have capacity but it was

impossible to find out because she wouldn't engage in the assessment and so sort of that was that.

The use of rhetorical questions at the start of the extract – *'I mean sort of what's the decision at that point?'* allows the speaker to provide her own answer – *'you're really asking has she got the ability'*. This establishes that capacity is often conflated with ability – a lay use of the term 'capacity', rather than the legal definition provided with the MCA. Clarity is therefore required not only about the question being asked, but the definition of capacity being used.

A moral discourse is drawn on when the speaker wonders whether it is the person's daily living skills that are being questioned or her ability to make *'good decisions'*. In being *'really clear'* about the question being asked, this practice allowed for exploration of whether the young woman had capacity to make decisions about *'whether she wants care or not'*. This allows the young woman to take up or resist the subject position of 'needing care'. The young woman resists this position through a number of practices; firstly through refusing support – *'she would tell her carers to piss off'* -and secondly through refusing the capacity assessment. This implies a subjective experience of anger and hostility for the young woman.

Resisting the subject position of 'needing care' is constructed as *'good for her'* as she avoids becoming subjectified as someone that lacks capacity to make decisions about her care. Resistance through lack of engagement with services was described by a number of professionals as a feared potential outcome of classifying someone as lacking capacity (participant 1, lines 1100-1103; participant 2, lines 76-729; participant 6, lines 598-599). Other professionals spoke about how the person with a learning disability had demonstrated resistance through the ways in which they engaged with the assessment – *"um she kind of came out quite, you know, um yeah quite feisty and ready for a battle"* (participant 5, lines 358-360).

Acts of resistance by people with learning disabilities are often constructed as 'challenging behaviour' (Drinkwater, 2005; Finlay, Antaki & Walton, 2008;

Nunkoosing & Haydon-Laurelut, 2011) that require modification or intervention. It may be that through these small acts of resistance (Wade, 1997; Van Hove *et al*, 2012) people with learning disabilities are orienting to what is of value them – this is particularly important to think about in the context of capacity assessments where *‘the whole point about capacity is that it is about you know making sure that the service user is at the centre of what’s being done, whether they’ve got capacity or not’* (participant 3, lines 108-110).

4. WIDER DISCUSSION, IMPLICATIONS AND EVALUATION

4.1 Revisiting Research Aims

This research aimed to explore the contexts in which capacity was problematized for people with learning disabilities, what discourses of capacity were drawn on and the subject positions these enabled or limited for professionals and people with learning disabilities. It also sought to consider how these different subject positions might be taken up or resisted by professionals and people with learning disabilities. Although not an explicit research question, identifying the different subject positions available also allowed for consideration of subjectivity – that is, different ways of doing and being - for both professionals and people with learning disabilities. From the accounts given by the participants in this study, the findings from this study mapped onto the research questions as outlined below.

4.1.1 Problematizing capacity

- Professionals spoke about how capacity was often not assumed in contexts where people with learning disabilities were perceived to be making ‘unwise’ decisions or acting in ways that might put them at risk
- Questions about capacity were often related to issues where people with learning disabilities were making decisions about their bodies, their relationships and where they lived

4.1.2 Discourses of capacity

- Capacity was understood within ‘legal’ and ‘rights’ discourses, which enabled professionals to take up ‘expert’, ‘advocate’ and ‘facilitator’ subject positions
- The availability of different discourses and subject positions may be influenced by the contexts of professionals, for example being involved in legal proceedings or under pressure from service targets or external inspection – these contexts appeared to make it more likely that professionals would draw upon a ‘legal’ discourse of capacity

- Capacity assessments are often sites of tension between protection and empowerment discourses

4.1.3 Subject positions

- The Mental Capacity Act can be understood as a ‘technology of power’ which allows for both professionals and people with learning disabilities to be constructed as the subjects of assessment and scrutiny
Professionals can experience capacity assessments as uncomfortable and may resist taking up an ‘expert’ position, and strive to take up ‘facilitator’ positions
- People with learning disabilities may experience capacity assessments as both empowering and distressing, and use the assessment process as a way to resist subject positions of incompetent and take up positions of personhood

4.1.4 Implications for subjectivity

- Knowledge of capacity within a legal discourse is constructed as limited to professionals, and inaccessible to families and people with learning disabilities without education from others
- Professionals working in learning disability settings engage in ‘technologies of the self’ – that is, actions that regulate their practice - in order to implement the Mental Capacity Act. This may involve both a search for certainty (asking the ‘right’ questions) and acknowledging uncertainty and subjectivity

4.1.5 Opportunities and constraints for professional practice

- Drawing on a legal discourse and taking up an ‘expert’ subject position appeared to allow for professionals engaging in ‘protective’ practices including joint working and searching for certainty
- Drawing on a rights discourse of capacity and taking up ‘facilitator’ and ‘advocate’ position appeared to allow professionals to understand

capacity as a developmental process and enable more flexibility in their practice

4.2 Wider Discussion and Implications

In Chapter One the CMM (Cronen, Pearce & Changsheng, 1989) approach was used to outline an alternative way of understanding mental capacity. The CMM framework will now be used to structure a wider discussion of the key findings of this study and their implications for clinical practice, and further research that might scaffold this.

Taking a mental capacity assessment to represent an 'episode' within the CMM model, then the findings of this study have implications at the level of relationship, self-concept and culture, where 'culture' exists at both a service level and wider social and political level. There is not space within this chapter to consider the wider social and political culture, but this may have an impact on the practices that services are able to put in place, and would be worthy of further research.

4.2.1 Meaning and Action in Relationships

4.2.1.1 Multi-disciplinary teams, multiple relationships

The current study attempted to capture the multi-disciplinary nature of capacity assessments within learning disability teams. In choosing a sample on the basis of previous research into issues of capacity (McDonald, 2010; McVey, 2013; Waljii, Fletcher and Weatherhead, 2014) this led to a focus on recruiting clinical psychologists, learning disability nurses and social workers. However, in the course of interviewing professionals and analysing their accounts, the role that occupational therapists, speech and language therapists, psychiatrists, and physiotherapists can play in assessing capacity was highlighted. Their experiences of implementing the MCA would be worthy of future study to consider whether similar or different discourses of capacity are available to them, and what subject positions these might allow.

Additionally, given the potential discrepancies between ‘qualified’ professionals’ understanding of the MCA and the knowledge of frontline staff such as support workers, it would be worthwhile to build on previous research exploring how support workers and other care home staff use the MCA in practice (Dunn, Clare & Holland, 2010). Gough and Kerlin (2012) suggest that more tailored and innovative approaches to MCA training in older adult care homes needs to be offered. Although this research would need to be extended to learning disability settings, this suggests a role for learning disability MDTs to work with local services to develop engaging ways of delivering training about the MCA.

4.2.1.2 Supported decision-making

A move towards a relational model of capacity (Clough, 2015) and implementing the UN CRPD (2007) requires that professionals engage in supported decision-making rather than substitute decision-making wherever possible (Richardson, 2012). Supported decision-making is conceptualised as providing people with appropriate assistance and support so that they are able to make decisions for themselves, rather than having another person appointed to make decisions on their behalf, as happens in substitute decision-making, such as the ‘best interests’ process under the MCA.

Although there is a burgeoning academic literature on models of supported decision-making, there are currently few studies exploring the implementation and impact of supported decision-making in practice (Browning, Bigby & Douglas, 2014; Davidson *et al*, 2015). It may therefore be of value to explore what supported decision-making could look like in practice, both for professionals in learning disability settings and people with learning disabilities. Watson (2016) emphasises the importance of supported decision-making practices being extended to people with severe and profound learning disabilities and found that the responsiveness of the supporter was fundamental to ensuring that the person with a learning disability’s will and preferences were acknowledged and given meaning. In turn, supporters’ level of responsiveness was associated with positive beliefs about the ability of people with severe cognitive impairments to lead a self-directed life – negative beliefs were associated with lower levels of responsiveness. This suggests that supported

decision-making practices may be facilitated by reducing stigma in relation to people with learning disabilities (Werner, 2015), and promoting discourses of personhood.

4.2.2 Meaning and Action in Self-Concepts

4.2.2.1 The role of 'advocate' and 'facilitator' – for professionals, families and people with learning disabilities

The subject position of advocate allowed professionals to challenge discriminatory practices or failures to adhere to the MCA. In promoting a discourse of personhood this allowed for people with learning disabilities to be seen as 'human beings' rather than 'labels'. A number of professionals spoke about the potential positive impact of involving people with learning disabilities in training about the MCA, and of supporting them to share their experiences of decision-making, in order to encourage other professionals to put people with learning disabilities at the centre of the process.

Research suggests that peer- and self-advocacy movements can provide new possibilities for making connections with others, negotiating identity and promoting organisational change within learning disability services (Friedman, Arnold, Owen & Sandman, 2014; Miller, 2015; Power, Bartlett & Hall, in press). In supporting self-advocacy practices professionals may therefore enable increased recognition of the personhood and rights of people with learning disabilities both within professional settings and local communities. In this way collaborative working between professionals and self-advocacy groups can take steps towards implementing the UN CRPD (Mittler, 2015).

In taking up subject positions of 'facilitator' professionals oriented to a relational understanding of capacity, in which our decision-making abilities are impacted by environmental and social factors as well as individual ones (UN CRPD, 2007). In order to support the development of capacity with in a relational context, it will be important for those around people with learning disabilities to be aware of the legal context in which decision-making is constructed under the

MCA. This will enable families and carers to more easily take up subject positions of 'facilitator' and 'advocate'.

In this study professionals oriented to families and service users being largely unaware of the MCA and its implications. Professionals in learning disability settings are well placed to share their knowledge of the MCA and in doing so, enable others to exercise power in raising issues of capacity and engage in supported decision-making. Suggestions from professionals in this study included offering training to families, and involving service users in the training process to allow them to share their experiences of being assessed under the MCA. This would be in line with the Government response (HM Government, 2014) to the House of Lords (2014) MCA scrutiny report, which proposes "all implementation partners...plan their own MCA awareness raising strategies" (p.16).

4.2.3 Meaning and Action in Culture

4.2.3.1 Culture within services

In order for there to be a shared understanding of how the 'episode' of capacity assessments might be undertaken, what the purpose of these are, and what subject positions might be available within these, there needs to be dialogue. Many of the professionals in this study oriented to the utility and value of sharing ideas, questions and concerns about implementing the MCA with their colleagues. This appeared to be on an informal basis, or within the context of conducting a joint assessment with another colleague.

Providing a dedicated space for discussion of capacity issues could be a worthwhile investment for teams, and would appear justified given the apparent frequency with which questions of capacity arise within learning disability services. Reflective practice groups may provide one such avenue for the consideration of capacity issues, and there is evidence to suggest that they help staff to manage the emotional impact of challenging work (Dawber, 2013a, 2013b; Pearson, 2015).

4.2.3.2 Culture between services

Although professionals in the learning disability field were constructed as having a certain level of 'expertise' in relation to understanding mental capacity, it is by no means the only field in which the MCA is used on a frequent basis. It may therefore be useful to establish a shared understanding of mental capacity across disciplines as well as within learning disability services.

A number of professionals oriented to their knowledge of capacity being limited by access to up-to-date information on case law. Although the value of guidance on capacity assessments from organisations such as the Royal College of Psychiatrists and the British Psychological Society was acknowledged, improved collaboration with other disciplines that also take up positions of power and knowledge in relation to capacity could prove useful. Research from the disciplines of philosophy, law, public policy and psychiatry (Banner, 2013; Banner & Szmulker, 2012; Martin *et al*, 2014; Owen *et al*, 2009) may be useful in understanding what is meant by 'capacity' and how this can be facilitated in practice.

Issues of capacity are also receiving attention from professionals working with older adults (Harding, 2012; Hinsliff-Smith *et al*, 2015; Shah *et al*, 2010) and with people affected by brain injuries (Acquired Brain Injury and Mental Capacity Act Interest Group, 2014; Mackenzie, Lincoln & Newby, 2008; Owen *et al*, 2015; Pachet, Allan & Erskine, 2012). This may facilitate the development of alternative perspectives on capacity from professionals and service users who are also making sense of decision-making in the context of cognitive impairments and interdependent networks of support. Setting up virtual and physical forums through which professionals in these fields can share resources, ask questions, and discuss examples of 'best practice' would be a fruitful avenue for the development of new knowledge and practices in relation the MCA; the Essex Autonomy Project (<http://autonomy.essex.ac.uk/research>) is an example of the value of an interdisciplinary approach to questions of autonomy.

4.3 Critical Evaluation of Research

Drawing on Spencer and Ritchie's (2012) guiding principles for evaluating qualitative research, I will consider the credibility, contribution and rigour of this study. I will then consider the limitations of the study, before turning to future areas of research.

4.3.1 Credibility

Spencer and Ritchie (2012) propose that credibility is concerned with the plausibility and defensibility of the research findings. In order to hone the interpretation of my analyses, I met with peers who were also using Foucauldian ideas as part of their data analysis to discuss my interpretations of my data and to consider alternative perspectives. I also discussed my interpretations in thesis supervision and how these might fit (or not) with findings in the relevant literature.

It is hoped that these processes helped me not to become wedded to my ideas, and to be curious about what subjugated stories I might need to pay attention to in my analysis. For example, given the medical model of capacity drawn on in the MCA I had expected more accounts of how capacity assessments illustrated the 'deficits' of people with learning disabilities. However, there were a number of accounts that suggested that capacity assessments provided opportunities for engagement, demonstration of knowledge and taking up positions of personhood, which I was able to explore by taking a position of curiosity towards my data.

4.3.2 Contribution

The contribution of research is established through its value and relevance to policy, practice and the lives of the individuals who took part (Spencer & Ritchie, 2012). In chapter Two, part of the rationale for undertaking this project was a hope that it might provide a space in which professionals could reflect on their experiences of undertaking capacity assessments and consider some of the opportunities and challenges inherent in this process. This was oriented to by a

number of professionals at the end of their interviews (participant 8, lines 819-822):

Extract 23: Participant 2, Clinical psychologist, lines 876-880

P2: Yeah it's good. It does make me think about we should really tighten up on that, and maybe there's a piece of work we could do, project about that. So yeah it's good for helping me think about things that we need to tighten up on and maybe do a bit differently. So it's helpful, thank you.

This lends support to the potential value of providing a reflective space for professionals to make sense of their knowledge and practice in relation to implementing the MCA with people with learning disabilities.

Spencer and Ritchie (2012) also suggest that the contribution of research can be considered through whether inferential generalisation (Lincoln & Guba, 1985) – that is, generalisation across contexts - is possible given the data. The results of this study are primarily based on the accounts of clinical psychologists and learning disability nurses - only one social worker was recruited – and reflect issues raised in other research with clinical psychologists (Walji, Fletcher & Weatherhead, 2014) and learning disability nurses (McVey, 2013) exploring the implementation of the MCA.

The sample of this study is likely to limit the ability to generalise the findings to other professional groups, as other members of a learning disability multi-disciplinary team may work in ways that allow them to draw on different discourses of capacity and take up different subject positions. However, many of the professionals in this study used the pronoun 'we' to orient to their experience of working within a team context, and spoke of the importance of discussing capacity issues with colleagues. This suggests that constructs of capacity may be negotiated at a systemic level within learning disability teams.

The use of the MCA is not limited to learning disability services, and although extending the findings to work with other client groups should be undertaken cautiously, the findings here may be of use in settings where professionals are working to support people with cognitive impairments, such as older people with a diagnosis of dementia or people affected by brain injuries. This is supported by evidence to suggest that discourses of autonomy and personhood are prevalent in these contexts as well as in learning disability settings (Harding, 2012; O'Connor, 2010).

4.3.3 Rigour

In operating within a critical realist social constructionist epistemology and taking a reflexive position in relation to my role as research, I acknowledged that this project could not be undertaken from a position of neutrality. Keeping a reflexive diary (see Appendix K) has allowed me to document the decisions I made during the process of data collection, data analysis and the writing up of this research, as well as my relationship to the work. Section 4.4 outlines how I considered knowledge and power during the interview and analysis process, whilst Chapter Two and Appendix I give further details of how I analysed my data.

4.4 Reflexive Review

4.4.1 Power and Knowledge in the Interview Process

I was aware of oscillating between the position of 'interviewer' and a more 'therapeutic' mode in terms of how I responded to the professionals I was interviewing. This enabled me to draw on the experience and knowledge I have of more therapeutic conversations with others as a trainee clinical psychologist. The 'interviewer' position felt unfamiliar and uncertain to me - many of my reflexive diary entries reflect concerns about whether I had done a 'good enough' job as interviewer. In taking up a more 'therapeutic' position I noticed I oriented to understanding the participant's experience of the assessment process, whereas taking up the 'interviewer' position allowed me to hold in mind more easily the macro focus of the study.

Although I often felt I had less power and knowledge to draw on than my participants, the opposite was sometimes suggested in the ways the professionals related to me during the interviews. For example, one professional oriented to not having to go into detail about what capacity meant to them, as they assumed I had prior knowledge of the legal definition of capacity and what this implied.

At other times the responses of professionals suggested that I may be perceived as holding a position of power, in which the interview was used as an 'examination' of their knowledge of the MCA and their implementation of this in practice. I attempted to manage this dynamic by engaging in 'active interviewing' (Holstein & Gubrium, 1997), which allowed me to be flexible in the questions I asked and invite interviewees to share their own topics of interest. However, as author of the interview schedule and in the role of 'interviewer' I am conscious of having exercised power over what was discussed and how. This showed me the power of being in a position to ask questions, and that the mere act of doing so may position others in certain ways, even if asking the question was in the hopes of enabling multiple or alternative subject positions.

In one interview I also found myself taking up the position of 'interviewee' – one professional was interested in how I intended to use the findings of my research. I found myself wanting to take up the position of 'advocate' and to both demonstrate my knowledge and acknowledge its limitations.

4.4.2 Power and Knowledge in the Process of Analysis

During analysis I was conscious of my knowledge of Foucauldian ideas being 'in development', which often led to me feeling uncomfortable and incompetent. Holding in mind that this was a 'normal' part of the analytic process allowed me to move forward in exploring my own interpretations of the interviews. At times I found myself concerned that I was either being too descriptive in my coding or that I was making interpretative inferences that moved too far beyond the 'talk' – at these times I found it useful to ask myself how my ideas related to the Foucauldian concepts I had in my 'toolbox', and to

share dilemmas within thesis supervision and with peers who were also using Foucauldian ideas.

I was mindful of taking up too critical a stance in relation to the MCA and current constructions of capacity that aligned with a medical model, and attempted to balance this by identifying extracts that did not 'fit' with this critical view, where the value and utility of the MCA was implicitly or explicitly oriented to. I found it useful to hold onto the Foucauldian idea that power can be productive as well as oppressive, and attempted to think about how this might be enacted across the interview process, the analysis process and the write up, in terms of what could and could not be spoken or written about.

4.4.3 Epistemology and Methodology

The epistemological and methodological position of this research allowed for the construct of capacity in learning disability settings to be understood within the context of historical and social discourses about people with learning disabilities, and acknowledged the impact of recent shifts in law and policy to emphasise the importance of 'rights' and 'empowerment'. The critical realist position enabled acknowledgement of the material impact of decisions around capacity, as well as the lived realities of supporting decision-making in the context of cognitive impairment.

4.5 Limitations Of The Current Study

The current project has focused on how learning disability professionals construct capacity and what this might allow or limit for ways of doing and being for both professionals and people with learning disabilities. As noted in the methodology (see Chapter Two), this privileges the professional position over that of people with learning disabilities.

This is problematic for a number of reasons, primarily in obscuring the voices of people with learning disabilities in the process of assessing and demonstrating mental capacity. In addition, the interviews in this study provide post-hoc accounts of the mental capacity assessment process, and may therefore not be

reliable. The responses of professionals at various points suggested that they experienced the interview as an 'examination' and therefore they may have felt the need to engage in impression management strategies to demonstrate a 'good enough' knowledge and application of the MCA.

If meanings are constructed through interaction, an exploration of the in-vivo interactions between professionals and people with learning disabilities is required to capture the processes through which 'capacity' and 'incapacity' are constructed. Examples of ethnographic research that capture day-to-day interactions in the lives of people with learning disabilities (Finlay, Antaki & Walton, 2008; Jingree, Finlay & Antaki, 2006) suggest that this may be a useful avenue for exploring decision-making practices and capacity assessments between professionals and people with learning disabilities.

4.6 Suggestions for Future Research

There appears to be a dearth of research into how people with learning disabilities experience mental capacity assessments, and limited research into their experiences of being supported to make decisions (Jingree, 2009). Members of a local self-advocacy group for people with learning disabilities met with members the House of Lords review committee on the implementation the MCA to talk about their experiences of decision-making (House of Lords, 2014). People had a variety of experiences of decision-making, with some preferring to make decisions themselves, whilst others spoke about wanting support because they worried about 'getting it wrong'. They spoke about making decisions about a range of topics including going on holiday, deciding to have surgery, and asking for support to look after their child. However, not everyone was consulted about decisions that had been made about their lives. Participatory action research (Bibgy & Frawley, 2010) may be a promising avenue through which these issues might be taken up, although ethical and practical considerations such as obtaining informed consent and how to meaningfully engage people with learning disabilities as co-researchers require careful navigation (Coons & Watson, 2013).

An ethnographic approach would allow for in-vivo observations of the ways in which capacity assessments are carried out in practice. Using this approach, Emmett and colleagues (2013) explored how capacity assessments regarding discharge decisions about where to live were carried out with older adults in hospital who had a diagnosis of dementia. They found that the standards outlined in the MCA were not strictly adhered to in practice in acute settings, and suggested that more specific legal guidance was required in this context. A similar approach might allow for exploration of how capacity assessments are carried out across different contexts in relation to people with learning disabilities – for example in inpatient, community or residential settings.

It may be that through participatory and ethnographic research alternative understandings of choice, empowerment and capacity can be developed, contributing to the construction of new knowledge about how people with learning disabilities navigate decision-making in their lives. This could further enable changing perspectives on what it means to have a label of ‘learning disability’ (Dorozenko, Roberts & Bishop, 2015).

4.7 Conclusions

This study considered how professionals in learning disability contexts construct ‘capacity’ and what this allowed or limited them to do in terms of their clinical practice, particularly in relation to the MCA.

In drawing on a legal discourse to construct capacity, this allowed for professionals to take up ‘expert’ positions from which they could ‘document’ and make decisions about the lives of people with learning disabilities. However, a legal discourse also allowed for professionals to take up an ‘advocate’ subject position, from which they could challenge discriminatory practices of others, and from which people with learning disabilities were understood as being supported to have a voice.

Capacity was also constructed within a ‘rights’ discourse, which enabled subject positions of facilitator for professionals and promotion of personhood for people with learning disabilities. This mirrors research that highlights the tensions of

balancing 'protection' and 'empowerment' that are often experienced by professionals working with people with learning disabilities (Dunn, Clare & Holland, 2010; Fyson & Kitson, 2007; Jingree, 2014; Nunkoosing & Haydon-Laurelut, 2013).

A relational model of capacity, drawing on discourses of autonomy and vulnerability that acknowledge that decision-making is an interdependent rather than independent process, may help professionals navigate these tensions. This allows for both professionals and others to take up the role of 'facilitator' and to consider supported decision-making practices that allow people with learning disabilities to resist subject positions of 'incompetent' that may accompany the label 'lacking capacity'.

Further research needs to privilege the experience of people with learning disabilities and explore how they make decisions and experience mental capacity assessments. In the meantime, improving the knowledge of the MCA for families and service users and providing a reflective space for professionals to discuss capacity assessments may provide ways for new knowledge of capacity to be developed in practice.

5. REFERENCES

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6. APPENDICES

Appendix A – Email template

To The Manager of the Service

My name is Natalie Read and I am a trainee clinical psychologist at the University of East London. As part of my course I will be completing a doctoral level piece of research, and my thesis is exploring how professionals working in learning disability settings understand the concept of capacity and how this impacts their practice. I would be grateful if you could forward this on to the members of your team to see whether they would be interested in taking part in interviews with me about this aspect of their work.

Please find attached a copy of my participant information sheet which contains further information about the research and what the process would involve for people who may be interested in taking part.

The study has received ethical approval from the University of East London.

If you have any questions about my research, please do not hesitate to contact me.

Best wishes

Natalie Read
Trainee Clinical Psychologist
University of East London



Appendix B – Participant information sheet

UNIVERSITY OF EAST LONDON

School of Psychology
Stratford Campus
Water Lane
London E15 4LZ

The Principal Investigator(s) – Natalie Read

Email: u1331809@uel.ac.uk

Telephone: xxxxxxxxx

Consent to Participate in a Research Study

The purpose of this letter is to provide you with the information that you need to consider in deciding whether to participate a research study. The study is being conducted as part of my doctorate in Clinical Psychology at the University of East London.

Project Title

Exploring how professionals in learning disability contexts understand the concept of capacity

Project Description

Professionals working in learning disability settings are often asked to complete capacity assessments under the Mental Capacity Act (2005). Research into the implementation of the Act suggests that professionals encounter a number of challenges in completing capacity assessments. The current study is interested in finding out how professionals understand the concept of capacity, what factors might influence this, and what this means for how professionals use the concept of capacity in their practice.

The proposed research project would like to gain the views of clinical psychologists, social workers and nurses to find out more about how they understand the concept of capacity and use this in their practice. Interviews are expected to last approximately an hour, although you may want to talk more or less than this.

It is hoped that the information gathered as part of this research project can be used in future to support professionals in learning disability settings to reflect on the concept of capacity and the process of conducting capacity assessments.

It is not anticipated that you will be exposed to any hazards or risks as part of the proposed study, however, it may be that you find the experience of being interviewed uncomfortable. I will be making all efforts to ensure that the interviews feel like a safe space in which professionals can talk about their understanding of capacity, and what may impact on how they apply the concept in practice.

I will contact participants who express an interest in taking part in the project to give them the opportunity to ask any questions they may have about the process before arranging to interview them.

Confidentiality of the Data

Consent forms that contain identifying information will be kept securely in a locked filing cabinet.

Interviews will be audio recorded using a Dictaphone, and following the interview the recordings will be transcribed in full by the researcher. Audio recordings and transcripts will be stored anonymously and all identifiable information will be changed or removed as appropriate. Excerpts from the transcripts will be used anonymously as part of the thesis write up and may be used in future journal publications.

Audio recordings and transcripts will be deleted 5 years after completion of the project write up.

Location

In order to minimise the amount of time professionals are being asked to take out of their clinical practice to be involved in the project, interviews will be conducted in an appropriate setting at professionals' place of work wherever possible. If this cannot be arranged, you will be invited to be interviewed at the University of East London Stratford Campus, Water Lane, London E15 4LZ.

Disclaimer

You are not obliged to take part in this study and should not feel coerced. You are free to withdraw at any time. Should you choose to withdraw from the study you may do so without disadvantage to yourself and without any obligation to give a reason. If you withdraw your participation after March 2016, I reserve the right to use your anonymised data in the write up of my thesis and any future journal publications

Please feel free to ask me any questions. If you are happy to continue you will be asked to sign a consent form prior to your participation. Please retain this invitation letter for reference.

If you have any questions or concerns about how the study has been conducted, please contact the study's supervisor [Dr XXXXX, School of Psychology, University of East London, Water Lane, London E15 4LZ. 0208 223 4411; XXXXX@uel.ac.uk.]

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr. XXXXX, School of Psychology, University of East London, Water Lane, London E15 4LZ.

(Tel: 020 8223 4493. Email: xxxxx@uel.ac.uk)

Thank you in anticipation.

Yours sincerely,

Natalie Read

Trainee Clinical Psychologist, University of East London
December 2015

Appendix C – Background information questionnaire

Name:

Age:

Gender:

Ethnicity:

Job title:

How long have you been working in your current service for?

How long have you been working in learning disability settings for?

How many Mental Capacity Act assessments have you been involved in?

Which of the following decisions have you undertaken Mental Capacity Act assessments in relation to?

- Finances
- Changes in accommodation – who to live with and where
- Consent to medical treatment
- Understanding a tenancy agreement
- Other

If 'other' please tell us more about the decision the assessment was in relation to:

What training have you received in relation to the Mental Capacity Act?

	<p>7. Were there any particular frameworks, experiences or training that you drew on to help you think about assessing their capacity?</p> <p>Prompts: How did your ideas about capacity from your personal/professional life impact or not impact the process? I'm interested in hearing whether you think ideas about capacity in people with learning disabilities affected the process.</p> <p>If struggling to remember- in retrospect is there anything that springs to mind now?</p>
<ul style="list-style-type: none"> What do these understandings of capacity and incapacity allow or limit them to do in terms of their practice, particularly in relation to the Mental Capacity Act? 	<p>8. How able did you feel to connect your knowledge and understanding of capacity to your practice?</p> <p>Prompts: What made applying this understanding of capacity easier or more difficult? - structure, content, process, guidance</p>
<ul style="list-style-type: none"> What subject positions are available for professionals and for people with learning disabilities within assessments of capacity? In what ways might professionals and people with learning disabilities take up and resist these positions? 	<p>Impact on the person with a learning disability:</p> <p>It's been really useful to hear about your experiences of the assessment process. I'd like to explore what the process might have been like for the person being assessed.</p> <p>9. What impact did the assessment process have on the person's day to day life?</p> <p>Areas to explore/prompt for: (Depending on the decision the assessment was in relation to) Accommodation, independence, relationships with others, finances</p> <p>10. How do you think the person with a learning disability understood the process of being assessed under the mental capacity act?</p>

	<p>Impact on the professional:</p> <p>11. What impact did the assessment process have on you?</p> <p>Prompts: Were there any consequences for you as a person/professional/team/service? How happy were you with the structure, content, process of the assessment?</p>
<ul style="list-style-type: none"> How might these subject positions shape the relationship between professionals and people with learning disabilities? 	<p>12. How did the assessment process impact on your relationship with the person with a learning disability?</p> <p>Prompts: Impact on engagement with you individually/the team/services</p>
	<p>13. Based on your experiences do you have any ideas on how professionals could be supported to understand the term capacity?</p> <p>14. Do you have any thoughts on how capacity assessments could be improved?</p>

Open ended responses or prompts

- Tell me more about....
- You said X, Y, Z. I'm interested in hearing more about your views on Z
- What did you mean when you said Y?
- We've been talking about.... Now I'd like to move on to talking about....

Appendix E – Participant Consent Form

UNIVERSITY OF EAST LONDON

Consent to participate in a research study:

Exploring how professionals in learning disability contexts understand the concept of capacity

Please tick the boxes and sign below to confirm the following:

1. I have the read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

2. I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher(s) involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.

3. I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. I also understand that should I withdraw after March 2016, the researcher reserves the right to use my anonymous data in the write-up of the study and in any further analysis that may be conducted by the researcher.

When completed, one copy will be given to the participant, and one copy will be kept by the researcher.

Name of Participant	Date	Signature

Name of Person taking consent	Date	Signature

Appendix F – University of East London Ethical Approval

1st February 2016

Dear Natalie

Project Title:	Exploring Constructions of Capacity in Learning Disability Contexts: Power, Protection and Institutional Practices
Researcher(s):	Natalie Read
Principal Investigator:	Natalie Read

I am writing to confirm that the application for the aforementioned NHS research study reference **187436** has received UREC ethical approval and is sponsored by the University of East London.

The lapse date for ethical approval for this study is **1st February 2020**. If you require UREC approval beyond this date you must submit satisfactory evidence from the NHS confirming that your study has current HRA ethical approval and provide a reason why UREC approval should be extended.

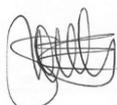
Please note as a condition of your sponsorship by the University of East London your research must be conducted in accordance with HRA regulations and any requirements specified as part of your HRA ethical approval.

Please confirm that you will conduct your study in accordance with the consent given by the HRA Research Ethics Committee by emailing researchethics@uel.ac.uk.

Please ensure you retain this approval letter, as in the future you may be asked to provide proof of ethical approval.

With the Committee's best wishes for the success of this project.

Yours sincerely,



XXXXXXXXXXXX
Research Integrity and Ethics Manager
For and on behalf of
XXXXXXXXXXXX
University Research Ethics Committee (UREC)
Research Ethics
Email: researchethics@uel.ac.uk

Appendix G – Ethical approval letter from the Health Research Authority

5 January 2016

Dear Miss Read

Study title:	Exploring Constructions of Capacity in Learning Disability Contexts: Power, Protection and Institutional Practices
IRAS project ID:	187436
Sponsor	University of East London

I am pleased to confirm that the above study has been given **HRA Approval**, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Scope

HRA Approval provides an approval for research involving NHS patients or staff in England. Organisations listed in your application are not obliged to undertake this study; arrangements for organisations to confirm their capacity and capability to undertake the study, where formal confirmation is required, are detailed in *Appendix B Summary of HRA assessment (Participating NHS Organisations, Capacity and Capability and Agreement sections)*.

If your study involves participating organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

Participating NHS Organisations in England

The HRA has determined that participating NHS organisations in England do not need to formally confirm their capacity and capability to undertake their role in this research, because study procedures (staff interviews) will be carried out by the study team. It is expected that these organisations will become participating NHS organisations 35 days after the date of issue of this letter (no later than 9th February 2016) if they have not already confirmed participation, unless justification can be provided to the sponsor and the HRA as to why the organisation cannot participate, or the organisation requests additional time to confirm. Further details are given in *Appendix B - Summary of HRA*

assessment.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. This is the case even where some or all participating NHS organisations in England are not required to provide formal confirmation of capacity and capability, as the HRA expects the organisations' research management functions to confirm by email to the CI and sponsor that the research may proceed in advance of the no-objection deadline (where one is given). Contact details and further information about working with the research management function for each organisation can be accessed from <http://www.hra.nhs.uk/hra-approval>.

For guidance on how you and the sponsor should work with participating NHS organisations in England, please see *Appendix B (Participating NHS Organisations, Capacity and Capability and Agreement sections)*.

After HRA Approval

The attached document "*After HRA Approval – guidance for sponsors and investigators*" gives detailed guidance on reporting requirements for studies with HRA Approval, including:

- Working with organisations hosting the research
- Registration of Research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics and is updated in the light of changes in reporting requirements or procedures.

New Participating Organisations

Plans to include any new participating organisations in the study in addition to those listed in the application should be notified to the HRA as an amendment. The study should not start at the new participating organisation until:

- For Clinical Trials of Investigational Medicinal Products (CTIMPS), the HRA has acknowledged that the amendment has been received by the Research Ethics Service.
- For NHS organisations in England, the organisation has confirmed capacity and capability, where required to do so, in line with the guidance provided by the HRA in the HRA categorisation email for the amendment.
- For NHS organisations in Northern Ireland, Scotland or Wales, management permission has been obtained.
- For non-NHS organisations, management permission has been obtained and SSA has been obtained from the REC where necessary.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of Documents reviewed during HRA assessment
- B – Summary of HRA Assessment

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please email the HRA at hra.approval@nhs.net. Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

Your IRAS project ID is **187436**. Please quote this on all correspondence.

Yours sincerely

XXXXXXXXX

Senior Assessor

Email: hra.approval@nhs.net

Appendix H – Transcription conventions

(.) indicates a pause

(???) indicates a portion of the recording that was inaudible

(laughter) indicates laughter

very – underlining indicates emphasis

[] are used to explain acronyms used by the participants

Punctuation has been included in the transcripts in order to aid the ease of reading.

Appendix I – Worked example of data coding

Policy vs. legislation

█ - discursive construction
█ - subject positions
█ - practices
█ - subjectivity? not powerful?

135 NR Mmm

136 P3 That's what I mean. I think Valuing People's a great

137 document, Valuing People Now's a great document, it raises but

138 it's not a legislative document that that you can draw people to

139 and make people do, um where the Mental Capacity Act is. And

140 mental health have lots of things that you know you can make

141 them do and I think that's probably because you've got the

142 Mental Health Act you know. So I think in that, in that point of

143 view, especially when decisions are made around health

144 interventions, um, and I'd like to think on most occasions people

145 do make the best interests to not give if things because it's not in

146 their best interests, it doesn't matter if they've got a learning

147 disability or not. But there are, but I think, no I know what

148 happens is that staff outside the learning disability field see a

149 person that is really, really disabled and are unable to think that

150 they have a quality of life. And I think that's for a number of

151 reasons, you know it could be because they are very busy, they

152 don't know anybody with learning disabilities, they're just thinking

153 about their own experience and how they would feel if they were

154 in that person's shoes, um and I think what we have to work

155 really hard in doing is is bringing that person and that quality of

156 life they have to the capacity and if needed the best interests

157 process. So you you make them a person because I think they

158 become a learning disability rather than a whole person.

159 NR Mmm

160 P3 And we've had lots of, lots of um cases of that. That doesn't

161 mean to say it's changed the best interest outcome, but I think it

162 makes people reflect more about what their decision is, um and I

163 think that's really good. And without the new legislation we

164 wouldn't have been able to raise the profile as much as we have.

165 I mean there's still a long way to go, um, but also as well I mean I

166 think the Capacity Act, I think it's a great bit of legislation, like

167 everything it needs tweaking you know but overall, but families

168 find it really really difficult. And and I think that's twofold – people

Valuing People + Valuing People Now
 not legislative - doesn't enforce action
 Legislation as 'making them do' things - who are 'them'? Professionals, service users, families?
 move from opinion to stating a fact
 Quality of life discourse affects decisions around health interventions
 Need to bring quality of life and personhood into capacity assessment process - hard work
 MCA as raising profile of person over diagnosis?
 Families find MCA really difficult

Diagnosis vs. person

169 find the transition from child to adulthood difficult anyway, that
 170 there's always making the decisions and then no longer
 171 NR Mhmm
 172 P3 But now we have this bit of legislation as well, it's even harder.
 173 I think they will really really struggle, and I don't think there's
 174 been enough done with families um around it. Um so and that
 175 can be really tricky, working with with families within that,
 176 especially when there's a fundamental disagreement about
 177 what's in their best interests
 178 NR Mmm
 179 P3 Um and while there's really nice kinds of processes, I think
 180 when you're talking about should they have a hip operation or
 181 shouldn't they you know that's fairly concrete and the outcome.
 182 When you're talking about something that's a little bit more
 183 nebulous um like something within social care you know they
 184 haven't got capacity about their money um but they if you give
 185 them a fiver they can go to the shop but their parents go 'no
 186 they'll lose it' or 'they'll get mugged' then that can make it
 187 tricky
 188 NR Mmm
 189 P3 That paternalism protectiveness, that must be really really
 190 difficult for parents. But on the other hand in trying to use the Act
 191 to do that, I don't think enough's been done with the parents for
 192 them to understand
 193 NR Mmm so there are some. Yeah there's quite a lot in what you
 194 just said. So something capacity and the process of assessing
 195 that or identifying what the decision is that
 196 P3 Or the questions and what the decision is
 197 NR Mmm. That as a process making people more than just a
 198 learning disability, thinking about their quality of life and them as
 199 a person. And that being something that can be quite useful in
 200 helping professionals to reflect, but then maybe being a separate
 201 set of difficulties when thinking about explaining the capacity or
 202 the process to families and that feeling quite tricky at times

NCA makes transition harder for families

There can be fundamental disagreements about best interests

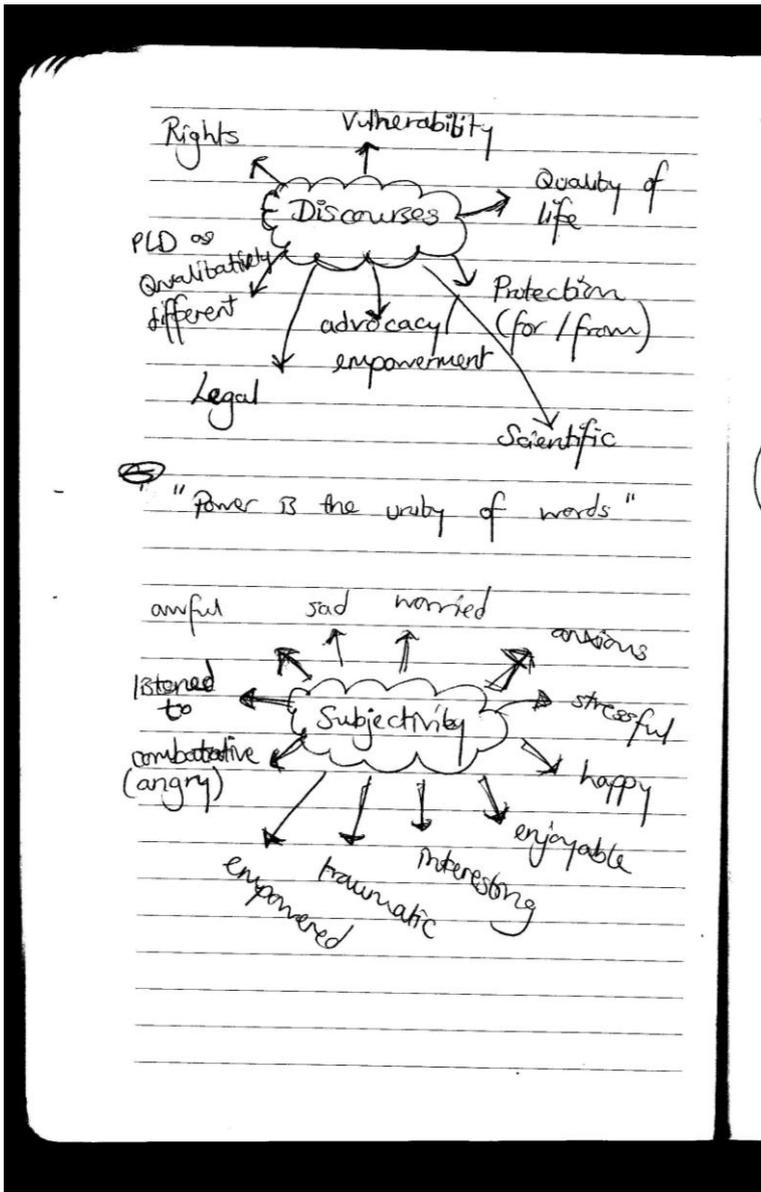
Concrete decisions around health; social care decisions as 'nebulous'

Macro to micro level decisions

Parental concern / anxiety

Discourse of protection / paternalism
 SP - 'really difficult' for parents.
 What does this mean for PLD? What does it allow / shut down?

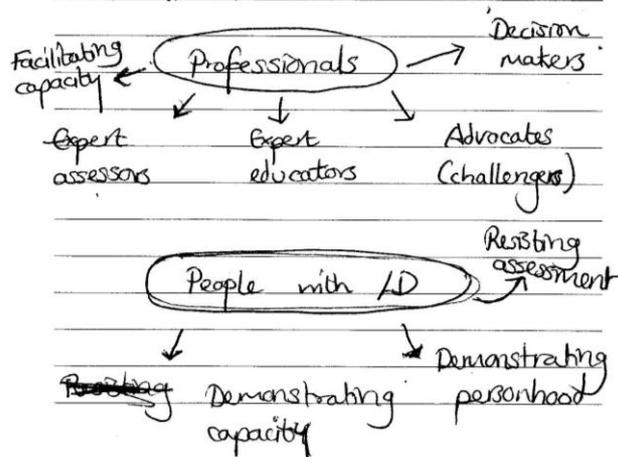
Appendix J – Mind maps used to aid write up

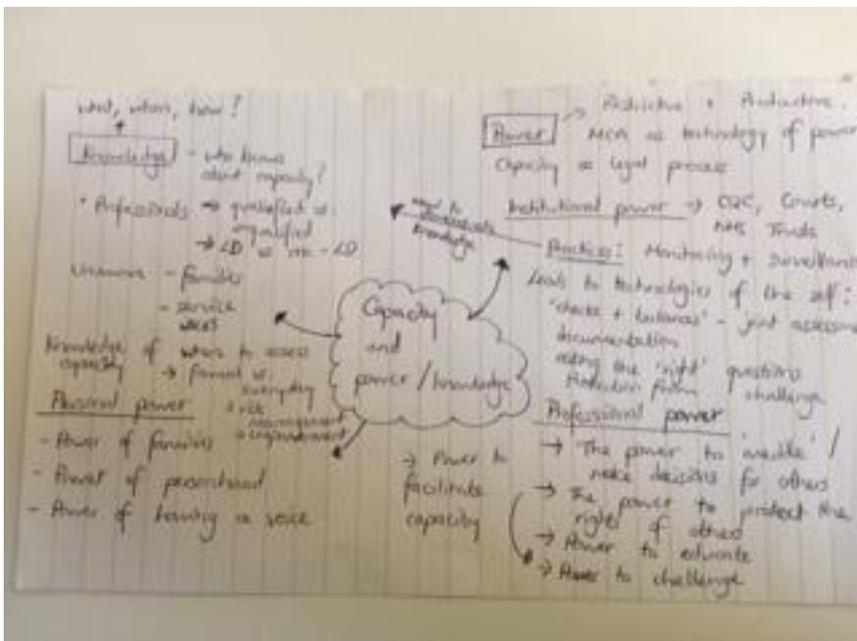
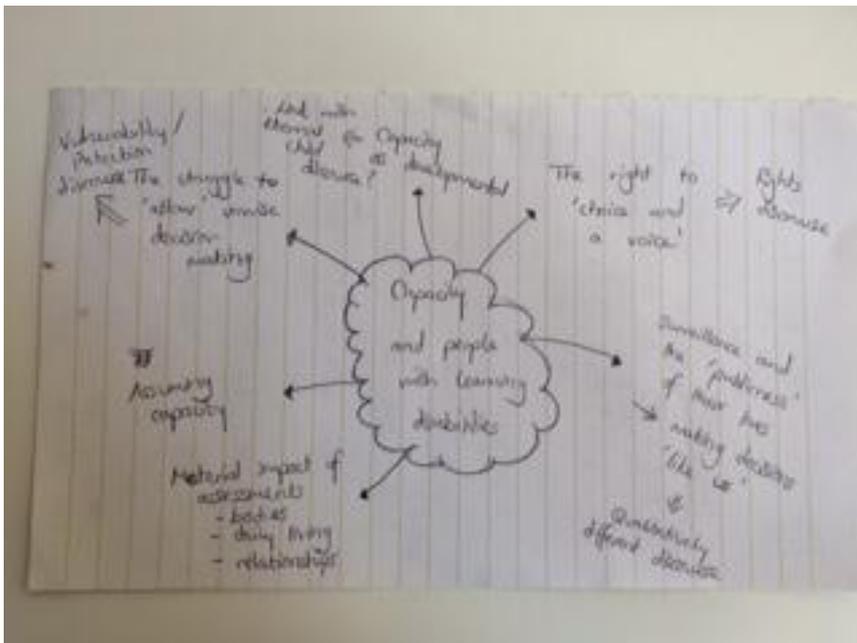


Leads to technology of the self
 → regulation of own
 behaviour for professionals
 ↘ ↓ ↓ ↓
 supervision joint audit checking
 assessment tools with colleagues
 'checks + balances'

Documentation of capacity assessments
 → 'the examination'? Interview
 as an exam / test?
 ↓

particularly evident in response to
 question on what capacity means
 to them





Appendix K – Extract from research journal

Notes on thesis interview 2

Another interview where I felt that I missed the opportunity to follow up on certain themes – I was particularly struck by ‘R’s use of the phrase ‘officer of social control’ but did not ask more about what she meant by this, or how this might relate to what she felt able to do or not do in her role as assessor/lead psychologist in the team. I think I may have chosen not to follow up on this as it fits with some assumptions I might hold about the potential use of the Mental Capacity Act in a restrictive way. What would it have been like to ask for exceptions – are there times when using the Act does not feel like taking up the role of officer of social control? This might be worth holding in mind when looking at the transcript for analysis, particularly in contrast to her ‘fears’ that the process is disempowering, but that in the example she gave, the young woman being assessed thanked her and said she felt listened to.

‘R’ spoke more about how psychology training might specifically fit with the role of assessor in the capacity act – I wonder how this might compare with other professionals, and how much psychology training might impact how the role of assessor is ‘done’ – the examples she gave suggested using skills in assessment and formulation – ‘asking the right questions’.

I was also struck by the theme of ‘protection’ across the interview – both for professionals and for people with learning disabilities. It will be useful to think about how this relates to power and Foucault.